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Title	The meaning of environmental control systems (ECS) for people with spinal cord injury: An occupational therapist explores an intervention
Authors	Verdonck, Michèle Claire
Publication date	2012-05
Original Citation	Verdonck, M.C, 2012. The meaning of environmental control systems (ECS) for people with spinal cord injury: An occupational therapist explores an intervention. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
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Download date	2024-03-28 10:22:07
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The meaning of Environmental Control Systems (ECS) for people with Spinal Cord Injury: An occupational therapist explores an intervention

Michèle Verdonck

May 2012

This thesis is submitted for a PhD degree from
the National University of Ireland,
University College Cork,
School of Occupational Science and Occupational Therapy

Supervisors
Professor Gill Chard, Formerly Head of Department, Occupational Science and Occupational Therapy, University College Cork (UCC), Cork, Ireland
Dr Maeve Nolan, National Rehabilitation Hospital, Dublin, Ireland
Professor Fiona Gibbon, Head of School Clinical Therapies, Head of Department Speech and Hearing Sciences, UCC

DECLARATION

I declare that while registered for the Degree of Doctor of Philosophy [PhD] I have not been a registered candidate or enrolled student of any other award at another academic or professional institution.

This thesis is a record of work carried out by myself and has not been submitted for any other award. All sources of work have been acknowledged and/or referenced.

Name: Michèle Verdonck

Signature_____

Date _____

Abstract

The meaning of Environmental Control Systems (ECS) for people with Spinal Cord Injury: An occupational therapist explores an Intervention

Environmental control systems (ECS), also known as electronic aids to daily living (EADL), enable people with high cervical spinal cord injury (high SCI) to control and access everyday electronic devices in their environment such as navigating through television channels and using mobile phones. This access is an essential prerequisite to full participation in today's society. Despite the fact that ECS can enable people with high SCI to use these devices, many who could benefit from ECS do not have access to them in Ireland. This study explored a way to enable non-users of ECS to become users through the development of a generic ECS starter-pack by an occupational therapist.

A qualitative, person-centred approach was adopted that sought to explore an insider perspective on ECS use for people with high SCI living in Ireland. A phenomenological methodology was chosen in order to understand the first-hand experiences of users and to answer the primary research questions: what is it really like to live with ECS and what does it mean to live with ECS.

The study was conducted in three consecutive research phases. In Phase 1 fifteen people with high SCI met twice in four focus groups to discuss what they thought about ECS. Focus groups were video and audio recorded and transcribed verbatim. Thematic analysis (Krueger & Casey, 2000) influenced by the psychological phenomenological approach (Creswell, 1998; Langdridge, 2007) was used to yield rich practical and phenomenological findings. Phase 1 findings were arranged into three categories: *ECS Usage and utility* described the practicalities of obtaining and using ECS in Ireland, and highlighted the dissatisfaction of relying on commercial suppliers, the risks of non-use and the relationship of ECS with other assistive technology. *ECS Expectations* provided essential information for a starter-pack which needed to be reliable, simple, discreet, and (preferably) voice-controlled. The final category validated the need for ECS and their potential contribution to peoples' lives by facilitating autonomy, providing time alone and changing relationships.

An ECS starter-pack, or generic electronic assistive technology (GrEAT) pack was developed in Phase 2. It was informed by the findings from Phase 1, consultations with experts in the field and an internet search to identify suitable constituents. Short instructional videos and an information booklet were developed for inclusion in the GrEAT. Phase 2 culminated in a one-person, three-week pilot to evaluate and adjust the GrEAT based on the pilot participant's feedback.

Phase 3 involved a trial of the GrEAT by six people with high SCI in their own home for 8-weeks, followed by one in-depth interview with each person at the end of the trial. Data were analysed using Interpretative Phenomenological Analysis IPA (Smith, Larkin & Flowers, 2009) and aided by computer software ATLAS.ti and iMindmap. Findings revealed that although the experiences of each person were unique they shared an essential core of living with ECS. Themes of *Getting used to ECS* was described as both a *hassle* and *engaging*. The hassle involved challenging learned dependency and coping with frustrations both technical and service related while engagement yielded unexpected experiences such as good feelings and fun and enabled participants to *Take back a little of what they have lost* by both *doing* and *feeling* enabled. Doing encompassed engaging in everyday things like surfing television channels and making telephone calls, as well as being less physically dependent and able to enjoy being alone. Feelings associated with enablement provided by ECS use included pleasure, feeling safe when alone and reduction in neediness.

The findings of this study provide substantial insights into what it is like to live with ECS and the meanings attributed to that experience. The study has several practical real word implications including: ECS as an occupational therapy responsibility, acknowledging that ECS may be too much hassle for some and the viability of using an ECS starter-pack in high SCI rehabilitation and beyond.

Key Words: Environmental Control Systems (ECS), Environmental control units (ECU), Electronic Aids to Daily Living (EADL), rehabilitation, occupational therapy, Spinal Cord Injury, tetraplegia, quadriplegia, Assistive Technology, Electronic assistive technology, Interpretative Phenomenological Analysis, IPA, qualitative inquiry, insider perspective.

Acknowledgements

It is challenging to recall all those whose contributions during this doctoral journey were invaluable:

This study would never have been possible without the research participants. I thank them all for their sacrifices in attending groups, for welcoming me into their homes, and for their valuable and honest insights. I am grateful to those both in Ireland and Canada who allowed me to observe ECS in their own homes. I remember especially the five people involved in this study who have passed away since the start, and hope that their insights are adequate reflected in this study and that they may help to improve life for others in the future.

Conor, this work is yours by proxy (even if you claim to not understand what lies on these sheets of paper). Thank you for never doubting me, listening to me, showing interest, wiping tears, 'taking the mick' and looking after the children at those crucial moments. I am eternally grateful that this vocational interlude produced more than a dissertation. Brian and Claire both acted as co-researchers from the novel insider position during data collection, and may forever wonder what I was really doing in my office all that time.

My parents, Gail and Marcel, always stimulated my enquiring mind. I am grateful for their selfless sacrifices that always ensured that I have been able to pursue my academic interests. I know that it was frustrating for them to have been so far away when they wanted to help in so many ways. Nicole, who believed in her sister and provided helpful editorial comments. John and Claire, offered me a home close to the university whenever I needed it, showed a keen interest in my progress and often provided realistic insights in prioritising the tasks along the way.

While I may have claimed to be a single researcher I was never alone. I am eternally grateful to my formal and informal supervisors who read my work, provided feedback and challenged my thinking. Gill Chard, your pragmatic, yet balanced academic approach has suited me so well and I am pleased that we ended up together. You always made me feel like I was able to do this. Maeve Nolan, you have been there from the beginning as a colleague, and as a friend as a 'fellow sufferer'. I am eternally grateful that you agreed to supervise me and will forever

wonder how you found the time. Elizabeth Steggles, not only offered me academic and practical support but opened her home to me and has become a treasured friend. Susan Ryan lead me to UCC, supported my funding application despite my academic inexperience, and helped me plan this study.

Spinal Injuries Ireland have provided support throughout this study as consultants, helping with editing flyers and booklets, recruiting participants and publishing my work. Thanks to Colm Whooley, Christine Bradshaw, Noelle Daly, Siobhan O'Driscoll, Carmel Cunniffe and Joan Carthy.

I have also been supported along the way by a wide team of friends. Siobhán McMahon, helped with transcribing, editing, formatting and cheerleading. To all those who listened to my trials and tribulations: Lucie Bramich (neé Kirby), Cathy McCormack, Tina McGrath, and Rosie Gowran. My Phase 1 research team: Catherine Logan, Maeve Nolan, Pauline Moran, Marian Ward and Anne Marie Cassey, who also transcribed two of the focus groups. My colleagues who participated in the pilot focus group: Eleanor Little, Julie Flanagan, Ciara O'Flynn, Bridin Carey (neé Jones), Ciara Finlay, Mary Galvin, Orla Shannon and Shangdar Ronglo (neé Maring). Eileen Mooney and Susan McKinney who offered some editorial assistance. I have been supported by three successive occupational therapy head of departments: Nuala Tierney, Anne-Marie Langan and Lisa Held.

Finally, this study would never have been possible without the financial support of the Health Research Board, Ireland, from whom I received a HRB research fellowship for the Clinical Therapies (CTFP-06-15). Special thanks to Rebecca Beck who instigated and supported my application.

I appreciate the kindness and support of all of the above and many others not acknowledged here.

Dedication

Joey Hogan

RIP 16-09-2008

This thesis is dedicated to Joey Hogan whose untimely death meant that he could not be part of the study that he had inspired. Joey challenged me to see things from his perspective and his frank honesty made me realise that things, especially environmental control systems, were not as fabulous as I thought. He showed me that the most 'popular' devices may not be good enough and that improvements were needed. His strong views made me want to really understand what environmental control systems are like for people with high spinal cord injury in Ireland. Thank you Joey.

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LIST OF ABBREVIATIONS

ECS	Environmental Control Systems
SCI	Spinal Cord Injury
High SCI	high cervical Spinal Cord Injury
SII	Spinal Injuries Ireland
FG	Focus Group
AT	Assistive Technology
IR	Infra-red
IPA	Interpretative Phenomenological Analysis
QUEST	Quebec Users Evaluation of Satisfaction with Assistive Technology
PIADS	Psychosocial Impact of Assistive Devices Scale

Chapter 1: Orientation

1. Introduction

Imagine you are sitting in a bus on the way into town listening to your latest music playlist on your headphones and you look down at your telephone. You are thinking about checking the weather and then the rugby scores when your phone buzzes to signal a new email. It could be your brother in Australia, maybe you will be able to chat to him face to face on your laptop this weekend. Did he receive all the family photos you uploaded onto the internet yesterday? You remind yourself to send him a link to the video of the family party. The last time he called he told you about the latest crime investigation television series and you are looking forward to watching pre-recorded back-to-back episodes later tonight.

Music on demand, mobile phones, instant access to information (like sport and weather), email on-the-go, worldwide instant contact, live video conversations, sharing of photographs and video, recording and playing back television programmes, fifteen years ago these may have been considered futuristic activities but they are now taken for granted everyday occurrences.

Imagine again that you are sitting on a bus. The bus is an adapted minibus and you are seated in a powered wheelchair. Your mobile phone is attached to the wheelchair tray. You have no active movement in your arms. You know the phone offers so many opportunities but you are unable to access any of them without physical assistance. You will have to wait until the bus is stopped and your caregiver is able to navigate the phone for you. You will also need assistance to send emails and to set-up a video exchange. You can only watch pre-recorded television if someone sets it up for you. You are unable to fast forward through the advertisements or to rewind it when you miss something or change the channel to listen to the news.

We live in a technological age where many of our everyday actions involve technology. However, use of this technology, designed to make everyday life simpler or easier, is not possible for everyone. Living with a high cervical spinal cord injury (high SCI) and it's myriad of physical restrictions, limits or even prohibits access to such technology. One might expect technology to itself offer potential

solutions to the accessibility issues and physical restrictions imposed by spinal cord injury (SCI). While such things are indeed possible they are not yet an everyday reality for most people living with a high SCI in Ireland. Environmental control systems (ECS) in contrast are freely available and provide access to several everyday technologies including television and telephone for people with high SCI.

This study provides a comprehensive exploration of ECS by using a phenomenological lens to: examine the perceptions of such systems by users and non-users; develop an ECS starter-pack and explore the lived experience of living with that pack. The first two chapters introduce the context and scope of the study and Chapter 3 examines the existing ECS literature. The overarching methodology is introduced in Chapter 4 and an overview of the entire research design is presented in Chapter 5. The individual phases are then detailed in subsequent chapters. Phase 1: What do people with high SCI think of ECS? is presented in Chapters 6 and 7. Chapter 8 describes Phase 2 the development and piloting of the ECS starter-pack. Chapter 9 contains a description of the trial of the starter-pack explored through individual interview and the findings of Phase 3 are detailed in Chapter 10. The study is discussed in Chapter 11 and conclusions presented.

This first chapter presents an overview of the study and provides some context including an introduction to the background of the researcher (an occupational therapist) and the roots and origins of the study. It also introduces key concepts regarding living in the information age, SCI and occupational therapy, as well as an introduction to words, phrases and nomenclature used in the study. Section 2 orientates the reader to the origin of the study, section 3 introduces high SCI, section 4 introduces the occupational therapy lens through which the study was conducted and section 5 provides a summary of technical terminology applicable and associated with the study.

2. The origins of this study

I am a Caucasian African woman living in Ireland and working as an occupational therapist with a specialisation in SCI rehabilitation. My conceptualisation of the study process is akin to growing a tree, an occupation that requires time, care, patience and in which the fruits of that labour are unknown until they are harvested. This analogy seems appropriate to me because just as I am not a horticulturalist I am not an academic but the research process reflects my necessary transition from

clinician to academic. I consider the roots of the study to be African while its branches and fruits are Irish and the environment in which the study is cultivated is a technological biosphere.

2.1 African roots

> *I am an African.*
>
> *I owe my being to the hills and the valleys, the mountains and the glades, the rivers, the deserts, the trees, the flowers, the seas and the ever-changing seasons that define the face of our native land. My body has frozen in our frosts and in our latter day snows. It has thawed in the warmth of our sunshine and melted in the heat of the midday sun. The crack and the rumble of the summer thunders, lashed by startling lightning, have been a cause both of trembling and of hope.*
>
> *The fragrances of nature have been as pleasant to us as the sight of the wild blooms of the citizens of the veld. The dramatic shapes of the Drakensberg, the soil-coloured waters of the Lekoa, iGqili noThukela, and the sands of the Kgalagadi, have all been panels of the set on the natural stage on which we act out the foolish deeds of the theatre of our day…*
>
> *Today it feels good to be an African…*
>
> *I am an African…*
>
> *I am born of the peoples of the continent of Africa...*
>
> *Whoever we may be, whatever our immediate interest, however much we carry baggage from our past, however much we have been caught by the fashion of cynicism and loss of faith in the capacity of the people, let us err today and say - nothing can stop us now!*
>
> *(Thabo Mbeki, speech at the adoption of the Republic of South Africa Constitution Bill, 8 May 1996, Cape Town).*

I am an African born in a country where my colour provided me with the privilege of an education that enabled me to become an occupational therapist. Following graduation I worked for three years at [hospital], Khatlehong, Gauteng, South Africa, as an occupational therapist primarily in the SCI rehabilitation unit. The rehabilitation team there was therapist-led and consulted with a medical doctor only for medical (but not rehabilitation) advice. The spinal injury unit at [hospital] was infamous in the 1990s for its unusually high incidence of violent traumatic injury. Gun-shot injuries were the single greatest cause of SCI (36%) and stab injuries accounted for 20% (Hart & Williams, 1994). [Hospital] also saw several cases of Brown Sequard

injuries[1] resulting from gang warfare episodes during which bicycle spokes were stabbed directly into the spinal canal (Jackson, 1978). Despite the adverse circumstances surrounding rehabilitation at [hospital], or perhaps because of it, rehabilitation for me was epitomised by a *can do* approach encompassing creative solutions aimed at enabling patients to make the most of their lives. This *can do* attitude of the proud African I believe was shared by most of my patients.

One of my first patients was a man with a spinal cord injury at the fourth cervical level[2] whose upbeat attitude made no sense to me as a new occupational therapist. How could someone unable to move his arms, legs and trunk be positive? This man had developed such dexterous mouth movements that he was able to unwrap sweets in his mouth and remove chicken from the bone. For him rehabilitation at that time involved the provision of a manual simple wheelchair and education about his condition prior to discharging him home with little else.

I also vividly recall a 19 year old father of a new born. He was one of the first patients to challenge me as an occupational therapist. He was young and intelligent but was unable to lift his hand from his lap or touch his baby or his own face. Having been fortunate to have had access to a personal computer at home since I was 13, I was always eager to experiment with computer applications. Although computers were not a household item of technology for many South Africans in the late 90s, I knew then that the future for this 19 year old would have to include technology, including accessing a simple computer to enable occupation. His only access option was to use a thick stick held in his mouth and to type using a standard key board. He was quick to grasp simple word processing and the use of spread sheets. It was a starting point but not without problems. For example, how do you press control and p at the same time with a mouthstick? The answer today is simple using Windows accessibility options. The solution then was tedious and required me to contact people with high SCI living in the community in order to source a programme that would allow this simple task of using two keys at a time. The computer was so essential for this patient that we asked a local business to donate one of their old desktop computers and a printer. At discharge, I was able to visit his home and witness the very bulky mouthstick and old computer in action, as this young man wrote to his local housing authority to apply for suitable housing. At the

[1] Brown Sequard is a one sided incomplete spinal cord lesion resulting in severe motor and proprioceptive deficits on the side of the lesion with temperature and pin prick sensation deficits on the contralateral side (Roth, Park, Pang, Yarkony, & Lee, 1991).
[2] Injury at fourth cervical level results in paralysis of upper and lower limbs, with preserved shoulder shrug and neck movement.

time I had no concept of other technology that could be advantageous for patients with high cervical spinal cord injuries.

2.2 Irish branches

In 2001, I began working in SCI rehabilitation in Ireland with minimal knowledge of electronic assistive technology.[3] I was introduced to ECS[4] as a specialist therapeutic intervention. A small room in the occupational therapy department had been designated as an ECS demonstration room and had been equipped with a dated radio frequency (RF) system that included an electronic curtain rail, telephone and electrical door lock. The system required specialist installation and maintenance that had not been prioritised in a busy occupational therapy department and was therefore not functional. Several potentially useful electrical components were housed in a drawer. Furthermore, the room had been re-designated as a computer room with a single computer (the only computer in the occupational therapy department) with a head mouse.[5] One senior occupational therapist with some limited understanding of ECS was able to demonstrate two basic infra-red (IR) ECS that could operate a portable television and an IR telephone. I had no experience with any of these technologies nor did I receive training on their use or application. Patients with high SCI were referred to the experienced colleague who would demonstrate the ECS and then facilitate a short trial within a therapy session. There was no prolonged trials of equipment. In addition there were no ECS available on the wards where the need for them was greatest, given the common occurrence of long periods of bed rest.[6] Patients interested in purchasing equipment privately were referred to the two known suppliers in Ireland who then advised them on options for home use.[7] This was a problematic situation as the suppliers clearly had a direct conflict of interest as they stood to gain financially from recommendations and purchases. ECS were simply not a part of everyday occupational therapy life at the spinal injury centre.

My interest in ECS developed when the experienced senior occupational therapist took a leave of absence and, as the most senior occupational therapist in the SCI team, I was expected to adopt her ECS role. I learned how to programme two basic

[3] Discussed in section 5.2.
[4] Discussed in section 5.3
[5] Headmouse is a computer input device that allows navigation of a computer screen by tracking head movements.
[6] Bed rest is required when pressure areas developed, for respiratory complications and other medical conditions.
[7] Wheelchair prescription also followed a similar process involving the wheelchair supplier assisting a physiotherapist to make a wheelchair recommendation.

IR ECS controllers but continued to only incorporate ECS into therapy erratically as well as deferring to a supplier for assessment.

The incidence of high SCI was relatively low during my first years as an occupational therapist at [hospital] with only one or two patients a year. This trend has since changed with an increased proportion of those admitted for rehabilitation every year having sustained a high SCI. Statistics to support this are not available due to a patient record system that does not discriminate between anatomical level of injury (which is recorded) and functional severity of injury (which is not recorded).[8] Occupational therapy departmental statistics also failed to differentiate between high SCI and other tetraplegia with some functional upper limb use. This demographic shift towards increasing numbers of severe high level injuries could be attributed to improved motor vehicle accident survival rates (Cripps, Lee, Wing, Weerts, Mackay, & Brown, 2010). Ironically the change coincides or coincided with the Road Traffic Act 2002 (Office of the Attorney General, 2002) that introduced penalty points and claimed to be responsible for lowering road fatalities. The increased incidence of high SCI resulted in altered therapeutic demands in clinical practice. No longer could one senior occupational therapist treat all those with high SCI. The increased incidence required that all therapists[9] treat people with high cervical spinal cord injuries.[10] ECS needed to be integrated into daily therapy sessions. Demonstration ECS controllers were therefore taken out of the ECS room and used in the department. The once unfamiliar task of programming ECS controllers became easier with practice. Patients were given the opportunity to trial ECS on a regular basis as a therapeutic intervention to control some occupational therapy departmental devices such as the televisions. As a result of this renewed focus on ECS we were able to include ECS recommendations in discharge reports. Despite the ability to do so, such recommendations were often not included unless a funding source had been identified. The failure to do so decreased the likelihood of patients who would have benefited from ECS from receiving such technology.

Integrating ECS into regular therapy sessions required considerable set-up time and individual attention. The high patient to therapist ratio of 14:1, operating in the department necessitated group occupational therapy sessions making the provision

[8] Such a record combines those who may have sustained a bony injury with little or no neurological deficit with those who are paralysed in all four limbs and trunk.
[9] Treating people with high cervical spinal cord injuries was previously considered too challenging for new graduate occupational therapists.
[10] In 2005 each of the 4 occupational therapists working in spinal cord injury unit had at least one patient with a high SCI.

of individual attention challenging. The failure to use mounting systems appropriately occasionally resulted in a therapist having to spend an entire session positioning a switch. The ECS were upgraded and expanded for use on the spinal wards. A ceiling mounted television and a DVD, player were purchased for two wards and installed at a bed close to the nurses' station in each ward as these beds were identified by nursing staff as the most likely to be used by persons with high SCI. New ECS controllers were purchased and programmed to control a television, a DVD player,[11] an IR electrical socket set[12] and an adapted call bell on two wards. Universal mounting systems and microphone stands with boom arms were purchased for mounting both ECS controllers and switches for patients use when in bed. This meant that when patients were familiar with the technology in a therapy setting they were then able to have an ECS set-up on the ward for use at night and on weekends. The utilisation of this set-up was varied. Successful use depended on the compliance of ward staff in setting up the switch and ECS controller once the patient was in bed, and caring for the equipment when not in use. Ward use also required some assertiveness on the part of patients in order to communicate their needs to the ward staff and ensure that they could use the equipment as required in contrast to having to rely on ward staff to control the televisions. Suitable patients were afforded the opportunity to use ECS in the wards at night and at the weekend. This use of ECS allowed them to control a television, DVD player, a choice of on/off appliances (such as lamp or radio) as well as activate a call bell.

In addition I compiled a portable ECS stored in a small suitcase. It included a *Senior pilot* (multi button single function ECS) a portable DVD player, an IR electrical socket set, and a buddy button switch. This allowed some ECS use on other non-spinal wards or other therapy areas within the hospital. This portable ECS was easier to set-up during therapy sessions. The portable system was augmented with a comprehensive switch assessment kit and some universal mounts. The switch assessment kit had a variety of switches allowing for quick substitution of one switch for another during assessment or therapy. Thus patients could trial different switches with their occupational therapist. The universal mounts were flexible mounts that could be locked into any desired position to allow a clear view of the display and attached to a wheelchair to allow it to travel with the wheelchair and thus with the patient. Similarly the mounts could be positioned for suitable secure

[11] At the time there was only one communal small screen television positioned at the end of each ward.
[12] Electrical socket set is activated by an IR signal switching power on or off and is suitable for turning on a lamp, fan or similar on/off appliances.

and stable switch access. These tools facilitated more satisfactory use of an ECS in occupational therapy treatment allowing patients to familiarise themselves with ECS and to control electrical devices while learning how to use a switch and to scan as a means of control. Once set-up a patient could work alone, in contrast to the traditional setting, where a patient with a high SCI required one-to-one therapeutic intervention.

Both therapists and patients thus began using ECS in everyday occupational therapy sessions and it became a realistic consideration for inclusion in discharge planning. However, there was no formal policy, procedure or funding source for the provision of such technology which frustrated me as a clinician and provided the impetus for this current study.

2.3 The technological biosphere

This study with its African roots and Irish branches was also influenced by the technological environment in which people with high SCI live. The world we live in changed rapidly as we progressed from the industrial age to the age of information and technology. The most noticeable changes have occurred in the last 15 years with the development of miniaturisation, increased capacity for storage and power, and high levels of wireless connectivity (Bühler, Engelen, & Soede, 2011). With these advances have come powerful applications which have contributed to an almost seamless integration of technology into society. In Ireland and throughout the Western World daily life is mediated by technology collectively referred to as Information and Communications Technologies, ICT.[13] This integration of technology in everyday life is epitomised by the use of smartphones. Telephones have not only been replaced by mobile handsets, those handsets have now been replaced by computers (smartphones) that act as a telephone as well as a computer with capacity that is comparable to a desk top computer. Simple daily activities such as watching television or listening to a radio are now digital experiences aided by computers that allow the user to customise their preferences and select how, when and where they make use of entertainment.

ICT is supported by the wide availability of wireless local area networks (Wi-Fi) and personal area networks (Bluetooth® and ZigBee) (Emiliani, Stephanidis, & Vanderheiden, 2011). While it is somewhat artificial to subdivide the components of

[13] Information and communication technologies (ICT) refer to a unified group of technologies incorporating a wide range of individual technology systems that together provide information and communication. It includes computers, software, telephony, broadcast media, and any type of audio and visual transmission and processing.

ICT, which are function as an integrated system of interrelated parts, three components will be described separately in order to clarify the components of ICT: computer access, telephony, and audio and visual transmission.

Computer access

Although computer access as a specific topic falls beyond the scope of this study a short introduction to computer access for people with high cervical spinal is required because most information and several forms of communication are increasingly computer based. In addition, technological advances should include computer and ECS integration. Initially computers were restricted to personal computers and normally intended for a single user in their own home or office. A person with a high SCI could therefore modify a computer for their own use through adaptive hardware and software. There is now a proliferation of networked computers that allow multiple users to use the same computer terminals by each accessing their own profile, such as in a hospital containing computer terminals on the wards as well as in therapy departments. In this networked situation, a person with a high SCI requires adaptive hardware which needs to be mobile and particular software available on every computer. In addition computers are not restricted to desktop personal computers (PCs) and also include laptop computers (laptops), personal digital assistants (PDAs), tablet computers (tablets) and smartphones. The increased use of PCs has been associated with increased efforts to make the computer accessible to all and assistive technology (AT) products have emerged that enable access to computers. See Appendix 1 for a summary of computer access products suitable for people with high SCI.

Telephony

Telephone access for people with high SCI is possible as part of an ECS through IR dialling of a specialised IR telephone (Curtin, 1994). Mobile telephones are used as an alternative and as an addition to landline telephones. People with high SCI are likely to use a mobile telephone but to require physical assistance to dial and possibly hold the telephone (if a headset is not used). Mobile phones, and to a greater extent smartphones, are essential communication devices for people of all ages (Greig, Harper, Hirst, Howe, & Davidson, 2008). They are tools for communication through traditional telephone calls, and the use of text messaging (SMS), as well as enablers of business and leisure via social networking

(Facebook), email and professional sites. Mobile telephones may even be used as an emergency call system.

Advances in mobile telephony, such as reduced size, have resulted in increased access difficulties for people with disabilities (Nguyen, Garrett, Downing, Walker, & Hobbs, 2007). Possible access methods include the use of car kits, wireless headsets, and the use of voice recognition. None of these technologies allows full, reliable, hands-free access without the addition of an assistive device such as a mouthstick or adapted switch. Difficulties include turning on the phone, terminating a call, and dialling accurately (Hreha & Snowdon, 2011). Two switch accessed Bluetooth® products[14] suitable for people with high SCI are not commercially available in Ireland. These products require a headset to be put in place which can be irritating if worn for long periods. They also require the use of speech-driven dialling that is included as an option in most mobile telephones. These access methods are useful for making and receiving telephone calls but not for accessing the range of other enjoyable, popular and commonplace features such as messaging, internet access and the use of apps.[15] Since the completion of data collection for this study, technological advances have enabled switch accessible smartphone control as explained in Appendix 2.

An alternative method of telephony is the use of voice over internet protocol.[16] This is the use of computer programmes or apps to provide voice to voice communication using an internet connection. Computer based telephone has been found helpful for people with multiple physical disabilities (Lancioni et al. 2011). This study considers telephony as an integrated function of ECS.

Audio and visual transmission

Accessing audio and visual transmission can be facilitated using ECS. Broadcast services, that include radio and television, provide information and communication. Unlike computers and telephones, they tend primarily to provide unidirectional information transmissions. As technologies merge, some bi-directional information exchange is possible and users can interact with the transmission and make selections. Initially this consisted of simple channel selection. However, integration

[14] Easy Blue, Zoomate AbleData.
[15] Apps, or applications, the name for small programmes that execute specific functions on a phone or tablet such as a weather app – for weather forecasts, or a reading app for online book reading.
[16] VOIP is voice over internet protocol involved in the use of computer applications to transmit telephone calls using the internet (like Skype).

with computer and network technologies (internet and digital television) allows a variety of selection options and minimal user input as in digital voting. Users can choose to pause, record and play back television recordings. Broadcasters also offer online internet viewing of content. The nature of television viewing has become a complex process that commonly involves channel surfing and programming features. Accessing these features is challenging for a person with a high SCI as they have insufficient hand control to use remote controls to make television selections or they may require computer access for online television viewing. However, it is possible to use an ECS to access these television functions or use adaptive computer technologies such as voice activated or head mouse to watch television online.

Video streaming[17] capacity of devices such as smartphones and computers via broadband internet connections and 3G networks allows easy access to a variety of video. It is possible to access full length movies through online movie subscription services or watch short clips of video. The functionality of video streaming has wide reaching applications from educational to recreational to business uses. Instant video communication is possible worldwide through the internet. These technologies have an important role to play in enabling people with physical disabilities to participate in a wide range of daily occupations (Verdonck & Ryan, 2008).

Radio content is transmitted by radio frequency, digital radio and internet radio. Like television, radio offers several digital technological choices. Radio is available on-demand by accessing pre-recorded programmes on the internet and internet radio makes radio transmissions available worldwide. Selecting standard FM and AM radio stations is possible through remote control that can be integrated with an ECS. Surfing worldwide radio stations or internet requires computer access which is made possible with adaptive technologies.

Music consumption has also become digitised through the increased popularity of portable digital music players that allow listening to music on-the-go and also stores large digital music libraries. Music players are also now embedded in other devices such as mobile telephones, smartphones, tablets and handheld game consoles (Verdonck & Ryan, 2008, Appendix 3). Accessing music players is challenging for people with disabilities. The choices contained within them, a feature of their design

[17] 'A method of relaying data (especially video and audio material) over a computer network as a steady continuous stream'.(Oxford Dictionary, http://www.askoxford.com).

central to the pleasure that can be obtained from them, is therefore not available to many people with high SCI.

ICT and high SCI

Full active participation in a technological society requires access and control of ICT now so prevalent in our everyday environment. Current lifestyles dictate that independence includes satisfactory engagement with an information society as:

> *many different areas of life that are key to independence including information, interpersonal communication, and environmental control, … becoming more crucial every day given the emerging technological environment,* (Emiliani, Stephanidis, & Vanderheiden, 2011, p. 101).

The use of modern technologies poses many difficulties to people with no voluntary upper or lower limb movement with which to access the interface of specific devices (Bühler, Engelen, & Soede, 2011). Living with a high SCI or similar physical disability involves activity limitations and participation restrictions resulting in both challenging and rewarding use of technology as described in the following case study extract from my reflexive diary:

> *[Name], a 35 year old woman with high SCI, injured for 13 years began by using Dragon dictate[18] which she described as very slow and frustrating. She has since begun using Dragon Naturally Speaking v 7[19] and has written a thesis using this. She describes Dragon Naturally Speaking as useful, but as frustrating especially when using the internet because dictation can be interpreted as commands and result in sending emails instead of opening applications. She also received funding 8 years ago for an ECS that provide her with a voice control ECS that controlled her doors, television and phone calls. This was however not successful and she experienced some difficulty with house wiring which affected all the phones. She is now using a [ECS controller][20] with head switch, for DVD and television. She was able to control her front door with the ECS but the electronic door mechanism is broken. She also reported unsuccessful use of an intercom at night time.*

[18] Dragon Dictate – is an old voice activated software package that recognises discrete words and responds best to staccato speech.
[19] Dragon Naturally Speaking v7 – voice activated software recognises continuous speech and allows fluent dictation.
[20] A switch accessible static display ECS.

> *[Name] also hopes to have an accessible phone soon, although she has been using Skype*[21] *successfully and reports that it is easy to use and she is able to ring all her friends from her computer using Dragon Naturally Speaking in conjunction with Skype "I could even use it if the house was on fire". Although she is an avid reader she was unsatisfied with a page turner which she described as "very frustrating, huge metal, scary" and too slow to turn and inaccurate. She does occasionally read from a computer but finds that tiring and prefers reading a normal book held open with a clothes peg with pages turned by her care giver* (Extract from Reflexive diary I,[22] p. 6, dated 5-06-07).

Advances in technology also offer considerable potential uses to people with activity limitations (Emiliani, et al, 2011). However, these rapid technological advances have not extended to everyday assistive technologies such as wheelchairs, walking aids and aids for care and hygiene which have remained largely unchanged for the last two decades (Bühler, et al., 2011). It is even more surprising that advances in electronic assistive technologies are substantially slower than mainstream advances resulting in a society where the users of assistive technologies lag behind their able bodied counterparts in their potential to enjoy a wealth of modern electronic devices.

3. A word about spinal cord injury

The technical focus of this study is ECS and the human focus is people with high SCI. SCI as a condition and the disruption it causes is introduced in this section while Chapter 2 (section 5) discusses the complex consequences of living with a high SCI in more depth.

Damage to the spinal cord within the vertebral column (commonly referred to as the spine) results in SCI.[23] Damage can be either traumatic or pathological. Traumatic damage is due to mechanical insult caused by hyperextension or compression of the vertebral column (motor vehicle collision, fall, and sports injury), introduction of a foreign body (bullet, knife, and bony fragment[24]), or electromagnetic shock.[25] Pathological damage may be due to abnormal tissue growth, narrowing of the

[21] Skype – computer programme that provides voice over internet telephony.
[22] See chapter 5 section 6. A reflexive diary was kept from the initial stages of this study and was used to journal my personal reflections on the research process and my associated thoughts.
[23] Bony damage to the spine may however not always result in spinal cord injury.
[24] Bony fragments may occur secondary to vertebral fractures.
[25] Electromagnet shock secondary to a high velocity gunshot or lightning strike that may not traverse the spinal column but still causes damage.

vertebral space,[26] a disease process (such as tuberculosis or syphilis), or disrupted vertebral blood supply (Somers, 2010). The extent of a SCI depends on the location of the injury with higher lesions resulting in paralysis of all four limbs and the trunk – called tetraplegia or quadriplegia[27]. Classifications of SCI are detailed in Chapter 2.

Sustaining a SCI results in sudden physical, psychological and occupational changes (Glass, 1999; Kennedy 2007; Trieschmann, 1988). SCI causes muscle paralysis, anaesthesia, and autonomic dysfunction. In layman's terms, a SCI results in loss of movement, loss of feeling, and loss of bladder and bowel control (Kennedy & Rogers, 2000, Somers, 2010). Life with a high SCI means living with a paralysed body which requires the greatest level of physical assistance because muscle paralysis results in a loss of control of all extremities as well as the trunk. In terms of the WHO International Classification of Functioning (ICF) a SCI results in participation restrictions and activity limitations that are further confounded by environmental and personal factors (WHO, 2001; Somers, 2010).

SCI is experienced as a radical disruption (Kleiber, Brock, Lee, Dattilo, & Caldwell, 1995); as a catastrophic life event (Chen & Boore, 2008); as incomprehensible (Lohne, 2009); and as causing a 'schism' in people's lives (Ostrander, 2008). SCI and other sudden acquired disabilities are described as causing a biographical disruption affecting the body, time and the self (Bury, 1982, Hammell, 2004a). This disruption involves loss including loss of control and loss of independence (Dickson, Allan, & O'Carroll, 2008). Previous life roles are threatened as a result of physical inability or difficulty in performing tasks such as caring for children and generating an income (Seymour, 1998; Hammel, 1999; Somers, 2010; Ville, 2005). New roles that may have to be adopted include the sick role, personal assistant employer[28] role, resource manager role and assistive technology user role (Hammel, 1999). These roles need to be merged with pre-existing roles including parent, partner and employee where possible. Cole (2004) describes how a young man refused to allow his mother to care for him as he did not want to be a child again. In contrast others accept being put to bed as a mature adult by a parent as an unavoidable reality. Paid care becomes an essential means of preserving pre-existing roles and preventing regression to a childlike status within a family system.

[26] Possible due to arthritic conditions.
[27] Quadriplegia is the commonly used term in Ireland but tetraplegia is the preferred clinical term used internationally.
[28] Managing ones physical assistance may mean adopting the role of employer and require finding and managing personal assistants.

Psychological adjustment to life with a SCI depends on the effective utilisation of coping strategies as opposed to level of injury and completeness of injury (North, 1999; Nolan, 2010, Kennedy, Nolan, & Smithson, 2011). The quality of personal resources facilitates psychological coping (Kennedy & Rogers, 2000). Adjustment to life with a SCI has been estimated to occur anytime between 6 months and 9 years. (Dijkers, 1999; Oliver, Zarb, Silver, Moore, & Salisbury, 1988; Ville, 2005; Sand, Karlberg, & Kreuter, 2006) and in reality can be a lifetime process. The lived experience of such adjustments are described in a qualitative study in terms of three themes: *I'm the same but different: continuity and change of self'*, capturing the impact of SCI on identity, *It's definitely different: learning to manage an altered body*, reflecting the task of dealing with altered body function and appearance and *Seeing things differently: from catastrophe to challenge,* referring to appraisals, coping and resilience in the face of change (Nolan, 2010). Smith and Sparkes (2005) describe the process of embracing hope following injury as reflected in narratives of restitution, quest or chaos.

It is important to highlight that adjustment to the disruption of a SCI can be considered a positive experience resulting in posttraumatic growth (Chun & Lee, 2008), resilience (Bonanno, 2004) and hardiness (Kinder, 2005). These findings are consistent with counterintuitive findings that suggest a satisfactory quality of life following disability and high SCI in particular (Albrecht & Devlieger, 1999; Hammell, 2004b) and with my previously reported personal experience of rehabilitation in Africa. Similarly Abrantes-Pais, Friedman and Lovallo (2007) found higher quality of life for people with tetraplegia than those with paraplegia. Hammell (Hammell, 2004b) identified choice, control and use of time as important for ensuring quality of life for people with high SCI. She suggests that control is dependent on the environment and opportunities provided including access to ECS (Hammell, 2004a).

4. A word about occupational therapy

I conducted this study as both a qualitative researcher and an occupational therapist. My clinical experience as an occupational therapist is at the heart of my motivation for embarking on this research journey and it is important therefore to provide an occupational therapy context.

Occupational therapy is an allied health profession with a diverse scope of practice which includes paediatrics, physical and mental health interventions and SCI

rehabilitation amongst other specialities. As the title implies, the focus of occupational therapy is on enabling engagement and participation in occupations that are meaningful and purposeful to maintain health and wellbeing for the person (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996; Townsend & Polatajko, 2007). The World Federation of Occupational Therapists defines occupational therapy as:

> *a client-centred health profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement* (WFOT, 2010).

Explaining my profession to others is always challenging for me as my occupational therapy interventions reflect a wide range of everyday tasks and activities that are common sense to me. This can make occupational therapy interventions seem almost mundane as they centre around occupational activities that can be considered:

> *routine, mundane, ordinary … usual … taken for granted* (Hasselkus, 2006, p.629).

These ordinary everyday activities include things such as: dressing, grooming, feeding, going to work, playing, driving, making phone calls, and switching on the heating. However executing these can often be extremely challenging for individuals and achieving them following an injury or illness can be immensely personally meaningful. Previously valued occupations may no longer be possible following SCI and new occupations and new sources of meaning need to be found (King, 2010). For example some people with high SCI reported finding new meanings in activities such as appreciating music or spending time with special people in their lives (Hammell, 2004b).

Occupational therapy as a profession has changed and grown since its humanistic and pragmatic inception, aimed simply at improving the human condition through meaningful occupation (Kuczynski & Richard 2010). Similarly, SCI rehabilitation, established by Sir Ludwig Guttmann, originally sought to improve the physical condition of those with SCI (Cole, 2004). This parallel illustrates the close

philosophical relationship between occupational therapy and SCI rehabilitation. Occupational therapy underwent a paradigm shift to become medically aligned, influenced by the dominant positivist philosophy of the 1930's. This improved the scientific and medical status of the profession and enhanced professional recognition (Kielhofner, 1997). However occupation was reduced to its component parts based on biomechanical, neuromuscular and sensory integrative principles in physical settings or on psychodynamic principles applied in mental health settings, thus losing the unique focus on occupation.

The later development of community based initiatives coincided with the protest and social reform activities of the 1960's and challenged the medical model and the mechanistic orientation of occupational therapy. The rehabilitation movement adopted a societal view of disability fostering the belief that people with disabilities could live independently in the community with appropriate supports (Kuczynski & Richard 2010). Occupation could no longer be viewed simply as the sum of its component parts. A holistic, dynamic, transactional approach that takes contextual, personal and occupational factors into account was required in order to work with persons on their desired and necessary occupations (King, 2010).

Although occupational therapy may strive for a consolidated knowledge base and intellectual consensus, theoretical diversity is valued as an indication of maturity of the discipline (Hammell, 2011). Occupational therapy, as a relatively new discipline, has several influences and incorporates diverse theoretical models and assumptions. It is not necessary to explore these but some of the concepts and assumptions that underpin them are appropriate to this study. These include occupational therapy as an art and a science, autonomy and interdependence as goals of occupational therapy (Turpin, 2007), occupational therapy as a person-centred profession, and occupation as understood to include activities of doing, being, becoming and belonging (Wilcock, 1999).

The influences of both medical and social sciences are evident in the historical progression of occupational therapy. Occupational therapy thus straddles both a medical understanding of conditions like SCI as well as an understanding of the lived experience of SCI. Occupational therapy can therefore be described as both an art and a science (Turpin, 2007). In relation to high cervical injury, occupational therapy is better conceptualised as an art concerned with the phenomenological body while also acknowledging the physiological body and its impairments.

Occupational therapy can be understood to either alter the way the world is presented to a person by changing the environment or alter the way the person interprets the world by facilitating experiences in it that are meaningful (Turpin, 2007).

The dominant bias towards a biomedical approach adopted by many rehabilitation teams however values occupational therapy more as a science (Hammell, 2006). This biomedical bias is evident in commonplace practices such as referring to individuals as *patients* and to rehabilitation centres as *hospitals* despite people being medically well. Physical independence is the acknowledged goal in medical rehabilitation settings that privilege physical prowess. Wilcock (1999) describes the resulting *central belief* in the value of personal physical independence as being *stuck in a rut* and failing to acknowledge the wider scope of occupation. Physical independence is valued by Western egocentric ideology which privileges individualism and considers community living possible through independence (Hammell, 2009) In contrast interdependence values interpersonal reciprocity and acknowledges the inherent social nature of communities. The concepts of interdependence and autonomy are particularly suited to people with high SCI whose physical independence is significantly restricted.

Autonomy is preferred to the term independence in the current study in an attempt to avoid the *ideological preoccupation with physical independence* as suggested by Hammell (2006, p 129). Cardol, De Jong, and Ward, (2002) distinguish between two types of autonomy which they describe as executional and decisional. The latter refers to the ability to exercise choice while executional autonomy refers to the ability to act as one wishes. While executional autonomy is often unachievable for people with high SCI, decisional autonomy is both possible and necessary and linked to quality of life. Living with a high SCI requires learning a type of verbal direction so that, despite physical impairments, the person can still be in control of their lives through verbal communication (Bromley, 1998) and decisional autonomy (Cardol, et al., 2002). Autonomy, or the opportunity to make choices, can be restricted for people living with high SCI by the context in which they become physically dependent on others (who tend to make choices for them). A person-centred approach aims to facilitate autonomy through choice. While a person-centred approach strives for equal power and effective collaboration between occupational therapist and the person, a power differential is almost inevitable

(Hammell, 2006). This study sought to incorporate a person-centred approach focused on occupation.

Occupation can be considered in terms of dimensions of meaning described as doing being, becoming (Wilcock, 1998) and belonging (Rebeiro, Day, Semeniuk, O'Brien, & Wilson, 2001). Doing involves keeping busy, exploring opportunities and contributing to others. Being is not purposeful and includes time to reflect, to appreciate art, music and nature, to discover the self and spend time with special people. Becoming involves developing possible lives with new opportunities that facilitate a continuity of self as opposed to permanent biographical disruption. Belonging involves support, friendship, social interaction and reciprocity (Hammell, 2004a). These categories are better suited than traditional notions of occupation[29] for people living with high SCI.

4.1 High SCI, occupation, and occupational therapy

High SCI causes biographical disruption and a *cessation of doing* (Hammell, 2004a, p. 298) that may be described as occupational disruption. Occupational therapy aims to facilitate occupation for those with high SCI because

> *the importance of occupation in reconstructing a life worth living following biographical disruption, or filling life with meaning, cannot be overstated … engagement in personally meaningful occupations may not solely influence the quality and meaning of living, but survival itself* (Hammell, 2004a, p. 301).

While occupational therapy focuses on enabling engagement and participation in occupations that are meaningful, identifying such occupations for people with high SCI can be challenging (Law, et al., 1996; Townsend & Polatajko, 2007). Daily occupation becomes focused on personal care routines designed to manage incontinence and reduce risks (Somers, 2010). These everyday occupations require planning to ensure that physical needs are met and risks are kept to a minimum and therefore allow little scope for spontaneity (Dickson, et al., 2008). Working and physical hobbies, like sailing and fixing motorcycles, are no longer possible without assistance and adaptation. A person may no longer be able to do the simplest tasks and the ability to feed oneself, to scratch one's nose or to even maintain balance

[29] Occupation considered as self-care, work, and leisure activities.

while sitting in a chair become impossible. Occupations inevitably become more sedentary and require increased corporeal engagement:

> *I release my thoughts into speech or writing or anything else, rather than into any other movement. It is still doing, but less doing* (Cole, 2004, p. 35).

The occupational disruption caused by a high SCI requires a re-evaluation of roles and responsibilities facilitated by occupational choices and the redefining of meanings of occupation to include *being* as well as *doing* that together facilitate *becoming:*

> *Occupational therapists are in the business of helping people transform their lives by facilitating talents and abilities not yet in full use through enabling them to do and to be. We are part of their process of becoming* (Wilcock, 1999, p.5).

Occupational therapy interventions for people with high SCI require the therapeutic use of self and the need to be empathic, attentive and able to make time for individual one-to-one therapy sessions. The provision of individual therapy sessions is itself challenging for occupational therapists in SCI rehabilitation which adopts a model of parallel therapy sessions based on a low therapist to patient ratio. During each intervention session an occupational therapist moves between 2-6 patients. Patients with high SCI however are unable to participate in sessions without facilitation and thus may be left observing others while unable to participate in their own therapy. Reilly asks the question

> *Is occupational therapy a sufficiently vital and unique service for medicine to support and society to reward?* (Reilly, 1962*, p.87*).

Her question reflects the daily clinical and ethical dilemma of working with this patient group. This inevitably raises questions about the value of occupational therapy for patients with high SCI. Based on my clinical experience of SCI rehabilitation it appears that patients have a preference for physiotherapy above all other multidisciplinary interventions. Most seem to favour the physical intervention of a physiotherapist in place of the practical occupational focus in occupational therapy. For many, physiotherapy holds out the alluring promise of a return of physical function. Even a person with high SCI requires regular hands-on

physiotherapy to ensure his entire body range of movement is maintained with gains that are tangible and can be measured in degrees and millimetres. This preference for physiotherapy could be misinterpreted as a devaluing of occupational therapy. Swain and Bamford however (Swain & Bamford, 1996) identify an inverse relationship between level of injury and the role of occupational therapy. They claim that the higher the level of injury, the more important occupational therapy becomes, a belief that may be based on the fact when there are a lesser number of attainable physical goals, occupational therapy may be better suited than the more physical therapies to address psychosocial issues.

On a pragmatic level, occupational therapy facilitates environmental adjustment by advising on housing adaptations and alterations (AOTA, 2010). Of relevance to this thesis is the long standing history of incorporating assistive technologies[30] in occupational therapy interventions to improve occupational performance (Reilly, 1962; Polgar, 2006; AOTA, 2010). Mouthsticks are a fundamental type of AT for people with high SCI function as tools for physical activities such as drawing, painting, depressing buttons, turning pages, moving chess pieces and even signing signatures (Bromley, 1998; Hammell, 1991).[31] Successful use of a mouthstick requires strength and endurance of the facial and neck muscles as a mouthstick is held between the teeth and manoeuvred using neck movements (Hammell, 1991). Despite their functional use the acceptance of these devices in the early stages of rehabilitation is often poor and patients are not motivated to become proficient mouthstick users. Their successful adoption is more overt in community settings.

Occupational therapists, in collaboration with other multidisciplinary team members, also advise on larger assistive technologies such as wheelchairs, shower chairs, hoists and accessible motor vehicles (Curtin, 1993; Hammell, 1991). More recently electronic assistive technology offers huge scope for people with high SCI as computers have become more widely available and accessible. The promise of electronic assistive technology for those with high SCI and the increase in accessibility has created a need for occupational therapists engaged in SCI rehabilitation to include computer access as a basic therapeutic intervention. However successful intervention requires a person-centred approach that

[30] Described as ‘enabling devices’ by Mary Reilly.
[31] Use of a mouthstick also requires a docking station that facilitates independent access as well as suitable work surfaces such as a good bookstand or easel.

acknowledges the person's readiness to engage and to consider such technologies which, in some cases may only occur following discharge from rehabilitation.

Occupational therapy intervention for people with high SCI is a complex endeavour that requires a collaborative person-centred approach to provide the opportunities to experience new occupations and give old occupations new meaning. It should include the provision of facilitators of occupation such as ECS that may affect quality of life:

> *It is up to the occupational therapist entrusted with care of (people with high SCI) to maximise the opportunities that are now available to them and ensure that the high quadriplegic patient has a greater quality, and not just quantity, of life* (Hammell, 1991, p.340).

5. Words, phrases and nomenclature

This study is about technology and requires an understanding of both technical details and some unavoidable technical terminology. It is about the use of ECS, a type of electronic assistive technology, by people with high SCI. ECS represents just one form of assistive technology. Other assistive technologies such as wheelchairs and computer access are not included in this study. ECS and similar technologies are classified using several terms sometimes interchangeably and sometimes differently leading to some confusion. This section aims to describe how the different terms are used by defining a range of terms and abbreviations associated with the topic of ECS and clarifying key terms that are used throughout this thesis.

5.1 Assistive Technology, AT

Assistive Technology is:

> *used to compensate for functional limitations, to facilitate independent living, to enable older people and people with activity limitations to realise their full potential. Some technologies even if not purposely designed for people with activity limitations, can be configured in such a way as to provide assistance or assistive functions when needed* (Emiliani, et al., 2011, p.102).

Cook and Polgar (2008) describe a continuum of assistive technology ranging from commercially available to fully customised and modified technology as reflected in the US public law definition[32] which includes off-the-shelf as well as customised or modified AT (US Public Law 182 -364. The Assistive Technology Act of 1998, as amended 2004). The WHO definition[33] extends AT to include commonplace objects like reading glasses (WHO, 2004). All definitions describe AT as facilitators of functioning and of specific tasks. Assistive technology devices range from simple aids for activities of daily living such as shoehorns, bed levers, and adapted cutlery to complicated communication devices. Because there is such a wide range of assistive technologies, efforts have been made to classify different types of technology (Bauer, Elsaesser, & Arthanat, 2011). Cook and Polgar (2008) differentiate between assistive versus rehabilitative or educational technologies, high and low technology, hard and soft technologies, appliances versus tools, general versus specific technologies, and commercial versus custom technologies. They describe hard technologies as tangible, readily available and easily purchased including hardware, software and assistive devices. In contrast, soft technologies are described as less tangible and include services and skills required for assistive technology provision such as needs assessment, installation and modification of technologies (Cook & Polgar, 2008). Both hard and soft technologies are important for successful application of assistive technology. In practice however hard technologies are favoured over soft technologies:

> *Most clinicians work in a climate of cuts to service delivery, limiting the capacity to deliver these. In the author's (Waldron) experience, clinicians are able to justify time assessing for AT devices and applying for funding to their employers, however additional time for trial, set-up and follow-up is seen as a luxury* (Waldron, 2008, p. 61-62).

Tools require manipulation skills for effective use and thus may require some training and practice for successful utilisation. A skilled user can use a tool effortlessly but the acquisition of such skill is a precursor to its use. Appliances in contrast, require no skill from the user for effective use such as splints, eye glasses, and seating systems. In contrast, specific skill is required for successful manipulation of communication devices, powered wheelchairs and canes (Cook & Polgar, 2008). Cook and Polgar (2008) suggest that ECS can be classified as

[32] "Any item, piece of equipment or product system whether acquired commercially, off the shelf, modified, or customised that is used to increase, maintain or improve functional capabilities of individuals with disabilities".
[33] "AT is an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which the tasks can be performed " p.14.

appliances depending on their function. In my opinion this classification is inadequate however, because ECS involve skilful switch use and manipulation of the control interface.

AT may be classified according to the complexity of the device. Low technology devices describe inexpensive, simple to make or easy to obtain devices such as walking sticks, dressing sticks, modified eating utensils and splints. High-technology devices include expensive complex electronic devices such as powered wheelchairs and electronic communication devices. High technology is also known as electronic assistive technology (section 5.2). This complex nomenclature reflects the range of items that can be considered assistive technology. While acknowledging this diversity, the current study focuses on ECS, a narrow and specific type of assistive technology which are classified as a type of hard technology and also as an electronic assistive technology and something which can be used as a tool.

5.2 Electronic assistive technology

Electronic assistive technology also known as high technology is defined as:

> *A subset of assistive technology which comprises communication devices, environmental control systems, personal computers and the interface which permit their integration with information technology and with wheelchair control systems* (Grist, Hanspal, Inman, & McClemont, 2000, p.3).

The term electronic assistive technology is used in Europe, while in North America high technology is the preferred term (Weber, Dow & Pearson Rees, 2002). In Europe, electronic assistive technology includes communication devices as well as powered wheelchairs and computers, which are often integrated with ECS. This study has a specific focus on ECS and it therefore excludes powered wheelchairs, alternative augmented communication, computer access and robotics.

5.3 Environmental Control Systems, ECS

ECS are potentially beneficial for people with high SCI. ECS are defined by Ripat (2006) as:

> *assistive technologies (AT) that provide a person with a disability the opportunity to access and operate multiple electronic and electrically powered devices in their environment. An (ECS)… generally consists of an*

> *input switch interface that can be customised to the user needs, and a control unit that includes an integrated feedback system which sends an output signal to a target device* (Ripat, 2006, p.79).

This technology provides simple alternative access to everyday electrical appliances and devices. In both North American and European academic literature the term ECS is used interchangeably with the term Electronic Aids to Daily Living (EADL). The ISO 9999, classification of assistive devices, classifies these devices as *assistive products for controlling from a distance,* defined as:

> *devices for enabling remote control and operation of electronic and electrical equipment within the living environment to enable independent living* (ISO, 2007, p. 51).

There is however a geographical divide over the choice of term and some differing interpretations of terms. Electronic Aids to Daily Living is the accepted term for ECS in North America and is endorsed by many writers (Buxton, 2007; (Jutai, Rigby, Ryan, & Shone Stickel, 2000; Rigby, Ryan, Joos, Cooper, Jutai, & Steggles, 2005; Rigby, Ryan, & Campbell, 2011; Ripat & Strock, 2004; Ripat, 2006; Stickel, Ryan, Rigby, & Jutai, 2002; Tam, Rigby, Ryan, Campbell, Steggles, Cooper, & Goy, 2003). The term was incorporated by Cook and Hussey (2002) into their foundational assistive technology text which is the primary text for the training of Assistive Technology Practitioners (ATPs) who are certified by the Rehabilitation Engineering and Assistive Technology Society (RESNA) in North America (Weisman & Weber, 2011). Their incorporation of the term was an endorsement that has led to the ascendency of the term in North America and the wide adoption of EADL in several academic publications. The adoption of the term EADL is less common for North American users as reflected in the continued use of the ECS by commercial suppliers (Ablenet, 2011). The use of EADL pertains primarily to North America and in my experience EADL is an unfamiliar term in Ireland, the United Kingdom and much of Europe.

Lange and Smith (2002) propose the use of the term EADL as an umbrella category for all electronic enabling devices. They use the term loosely to include home automation (see below) and some smart house (see section 5.5) functions such as weather monitoring sensors. While they do not include items such as computers and powered wheelchairs in their description of EADL they acknowledge that there

is a blending between categories including computers, robotics and EADL. It is claimed that the name change improves funding as it better describes the function of this technology. However, no evidence is provided to substantiate this claim (Lange & Smith, 2002). Additionally, in Europe the abbreviation EADL first appeared in rehabilitation literature as an abbreviation for an outcome measure, the Nottingham Extended Activities of Daily Living score which has been used extensively in rehabilitation evaluation studies (Garrod, Bestall, Paul, Wedzicha, & Jones, 2000; Law, Fielding, Jackson, & Turner-Stokes, 2009; Nicholl, Lincoln, & Playford, 2002). The Nottingham Extended Activities of Daily Living Score measures mobility, kitchen tasks, domestic tasks, and leisure activities in a structure similar to other standardised screening tools such as the Functional Independence Measure. Similarly the term environmental control can be confusing and is used in commercial industry interchangeably with HVAC, heating ventilation and air-conditioning or as the control of allergens in the environment (Lange & Smith, 2002). The term EADL has been extended to include electronic memory aids in Swedish studies (Boman, Tham, Granqvist, Bartfai, & Hemmingsson, 2007; Erikson, Karlsson, Soderstrom, & Tham, 2004). Similarly Vincent, Drouin, & Routhier, (2002) included verbal reminders and automatic functions as components of what they called ECS. Erikson et al (2004) in a study with brain injured participants used the term electronic aids to daily living without defining the term. Their study loosely included traditional ECS such as door openers, television and stereo control, and window shades without ever using the term environmental controls. Electronic aids to daily living was used as a blanket term that included computer reminders, water alarms, and an overheating function on the cooker. These technologies are traditionally considered features of *smart housing* (section 5.5).

The term ECS appears to be the dominant term used in practice in Europe, Ireland and the United Kingdom (Hawley et al., 2007; Hoogerwerf, Lysley, & Clarke, 2002; Judge, Robertson, Hawley, & Enderby, 2009a; Orton, 2008; Palmer & Seale, 2007). In addition ECS is the favoured term in SCI literature (Anzai, Young, McCallum, Miller, & Jongbloed, 2006; Hammell, 2004b) and in the engineering field (Cincotti et al, 2008; Craig, Moses, Tran, McIsaac, & Kirkup, 2002; Craig, Tran, McIsaac, & Boord, 2005; Tran, Craig, Thuraisingham, Boord, & Wijesuriya, 2008). Most importantly ECS is a term recognised by users. As the study is a European one, located in Ireland, the choice of terminology has been aligned with the European adoption of electronic assistive technology and ECS as the preferred terminology.

5.4 Home automation

Home automation (also called domotics) refers to the mainstream integration of the electrical components of a house to provide central control, to enhance comfort and to be labour saving (Barlow & Venables, 2004).This seemingly futuristic field can include control of lighting, heating, ventilation, air conditioning, home entertainment systems, security systems, and other appliances such as pet feeders (Lange & Smith, 2002). Control is achieved using a centralised control point that can be a stand-alone device or computer based. The latter can be linked to the internet to allow for remote control of the house. This mainstream field has several commercial suppliers of product lines including Control4 (Control4, 2011) and Home Automation Systems (HAS, 2011).[34] Home automation systems include actuators, sensors and controllers. Actuators include motorised blinds, curtains, door openers, and locks. Sensors range from motion sensors to intruder sensors to light and temperature sensors. Controllers are the user interface. These range from small portable remote controls to large touch screen consoles including television screens and even iPads or iPhones. For a summary of technical details of home automation see Appendix 4.

Some ECS installations incorporate elements of mainstream home automation. The primary barrier to their application is the user interface. While home automation successfully integrates several electronic devices, physical control of them is only possible through a controller designed for the able bodied. Unlike ECS, mainstream controllers are not switch accessible. In addition, they do not include scanning of functions and thus require discrete control through direct access by pushing buttons on remote controls or control panels. Some home automation is computer controlled with a computer screen or even a tablet (like iPad) as the interface. If a person with a disability is to use computer controlled home automation additional assistive technology is required to facilitate computer access (like a head mouse or special switches).

Access via traditional remote controls is referred to as direct access and requires adequate finger dexterity to manipulate individual buttons as well as gross upper limb movement to manipulate the remote control. For example when watching television one needs to pick up the remote control and then select a button to adjust the volume. Direct access can be possible for some people with disabilities through adaptation and modification. Someone with poor individual finger dexterity may use

[34] Many of these belong to the trade organisation CEDIA – Custom Electronic Design and Installation Association.

a pencil in a palm strap to press individual buttons. Similarly, proficient mouthstick users may be capable of accessing individual buttons. These adapted methods of access may require the remote to be mounted in a stable position for successful use, possibly on a customised wheelchair table.

Home automation could adopt a *universal design* approach (or *design for all*) which involves designing products and environments so that they have the greatest possible use by the largest number of people without the need for adaptation. This could be done by taking into account the preferences of all potential users as opposed to designing them for the average user. In this way products designed using universal design concepts could be made accessible for people with severe physical disabilities (Emiliani, et al., 2011). Employing these principles in industry would of course require a balance between profitability and business viability. Although universal design offers hope for greater accessibility for persons with disability, the extent of accessibility may still fall short of the needs of those with high SCI because people with such injuries are a marginal group of users whose needs are often perceived to fall outside the feasible range of universal design.

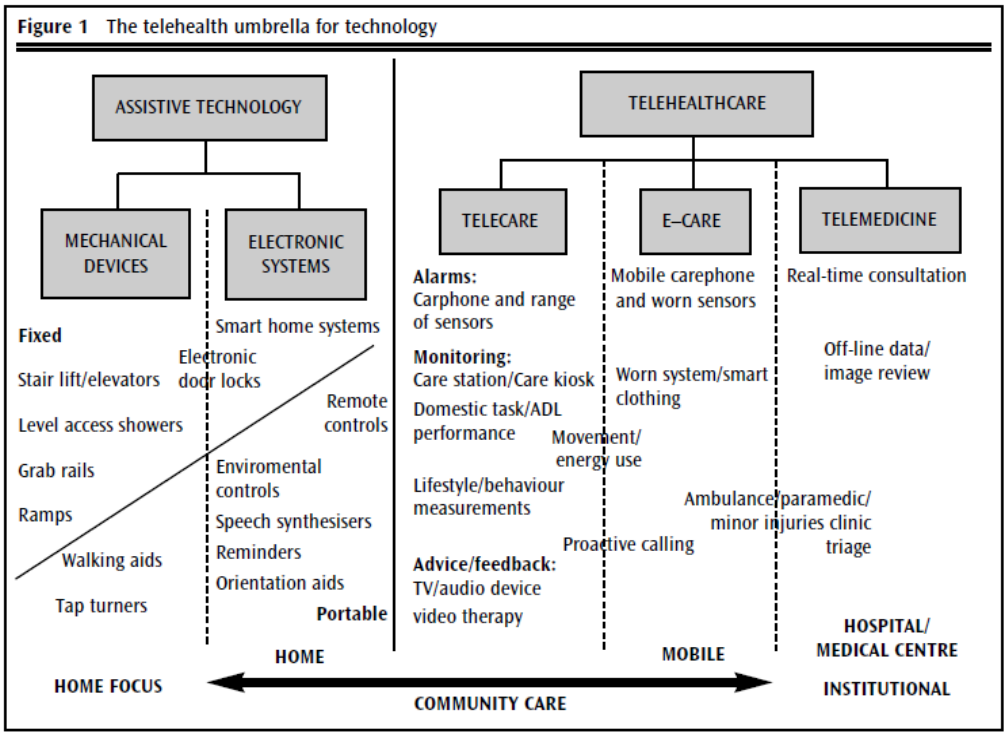
5.5 Smart housing

Smart house technology is an extension of home automation and offers many of the features of ECS together with monitoring and automation functions. These extended functions can be useful for people with cognitive impairments as they allow increased security and safety through the inclusion of memory aids, automatic door closing and automatic powering off. As a result, the application of smart house technology is particularly promising for older people (Stefanov, Bien, & Bang, 2004). Smart housing has six overlapping primary functions – comfort; energy management; multimedia and entertainment; healthcare; security and safety; and communication (Bierhoff et al., 2009). The application of smart homes to health care is also called telehealthcare. It includes telemedicine, passive and active alarms, monitoring, and risk minimisation (Barlow & Venables, 2004) and is described in Figure 1 overleaf, Doughty et al.s' (2007) model which separates assistive technology including environmental controls (ECS) from telehealthcare.

Smart house technology and ECS overlap and some studies merge the two terms as they overlap in functionality (Brandt, Samuelsson, Töytäri, & Salminen, 2011).

This study does not extend the definition of ECS to include smart home technology and focuses solely on ECS as an individual technology.

Figure 1: Diagrammatic representation of the components of telehealth (Doughty et al., 2007 p. 8)



Source: Doughty, K., Monk, A., Bayliss, C., Brown, S., Dewsbury, L., Dunk, B., . . . Ward, D. (2007). Telecare, telehealth and assistive technologies - do we know what we're talking about? *Journal of Assistive Technologies, 1*(2), 6-10. Accessed online at (08.09.09). http://www.telecareaware.com/otherpages/jat11-12debate_article.pdf

6. In Summary: The context of this study

The context of this study presented in this orientation chapter includes a broad overview of the technological society, SCI, assistive technology, and occupational therapy in Ireland. More specifically it focuses on people with high SCI living in a technological society and their relationship with technology from the perspective of an occupational therapist. The study originates from an increased demand for ECS in occupational therapy intervention at [hospital]. Envisaged expansion included the development of a starter-pack suitable for people living in the community who have no ECS. Adopting an occupational therapy person-centred focus required an exploration of the users' perspective of ECS through this qualitative study. Chapter 2 describes the specific scope of this study.

Chapter 2: The specific context of this study

The broad context for the present study was introduced in the previous chapter and the specific scope of the study will now be described. The description begins by clarifying related topics and possible lines of investigation that are excluded in this study. The specific context is then presented by introducing ECS in some depth with reference to the specific Irish context and the relationship between ECS and occupational therapy. The need for ECS is also described. The chapter concludes with a clarification of SCI rehabilitation in Ireland.

1. Scope of this study

This study is focused on the insider experience of ECS. Although ECS are a single type of AT and it would be informative to include other associated AT, such as computers and powered wheelchairs, this study specifically explored ECS use for people with high SCI as this is a specific identified need for this population. Therefore there is no discussion of computer-based technologies, alternative augmented communication (ACC) devices, powered mobility, or robotics. The exclusion of computer based AT may be questionable in the light of recent advances leading to the integration of ECS and computers. These technologies were however not common at the time that this study was initiated (2006) when a decision was taken to focus on realistic ECS experiences and to exclude computers. Similarly, it may be argued that some AAC devices include ECS functionalities and could be included in this study. These devices are primarily intended to be communication devices and were not considered appropriate for the target population of people with high SCI who are unlikely to require expensive AAC devices because most have normal speech and language.

The focus on the personal experiential aspect of ECS also led to the decision to exclude a formal evaluation of ECS and AT services in Ireland. Such an investigation would require quantitative evaluation that, although complementary to this study, was considered not to be suited to the intended qualitative investigation concerned with personal experience rather than procedural and service investigation.

ECS are suitable for people with many different physical and cognitive limitations, and while the findings may have some relevance to a wider population, the study focuses specifically on people with high SCI. The investigation does not extend to all levels of SCI and thus omits reference to people with paraplegia. The study was conducted from an occupational therapy perspective, although the assessment, recommendation, training and maintenance of ECS ideally requires a multi-disciplinary team (Cook & Polgar, 2008). Such a team does not exist in [hospital], where I work, and occupational therapists are the primary discipline concerned with ECS. Likewise while the topic is relevant to a larger European and worldwide context this study specifically sought useful insights from people with high SCI living in Ireland using Irish health and social care systems.

2. Environmental Control Systems (ECS)

Living in a technological society involves interacting with a variety of electrical appliances and devices. ECS are a type of assistive technology that allow some control over these appliances and devices.

ECS are designed specifically for people who are physically unable to manipulate and control electrical devices in their own environment because they are unable to turn on switches or press buttons such as those on a remote control. The range of devices that can be integrated into an ECS is vast. It includes: audio visual appliances such as televisions (including satellite systems); hi-fi stereos; DVD player/recorders; lights (stand alone and entire room or house); door openers and locks; telecommunications including telephone intercoms and video relays; telephones and mobile phones. Lange and Smith (2002) describe several functions of ECS, including: communication (telephone and intercoms); education (audio visual entertainment systems and page turners); leisure (audio-visual entertainment and toys); household management (lights, doors and blinds) and self-care (electric beds).

ECS have progressed from large static systems performing a few limited functions to smaller portable devices with hundreds of possible functions (Weber Dow & Pearson Rees, 2002). The first ECS, the POSSUM had peripherals connected directly to a very large single central processing unit (Dickey & Shealey, 1987). For several years, reliable access to ECS for persons with high SCI relied on indirect

access using switches. It is now possible to access controllers from powered wheelchairs, computers, and by voice (Hawley, 2002; Lange & Smith, 2002).

2.1 ECS User groups

Although ECS were originally designed in the 1960's for persons with polio and SCI (Dickey & Shealey, 1987; Lange, 1998; von Maltzahn, Daphtary, & Roa, 1995; Ripat & Strock, 2004), studies of ECS now include people with a range of physically disabling conditions including high SCI (McDonald, Boyle, & Schumann, 1989; Palmer & Seale, 2007; Rigby et al., 2005; Rigby, Ryan, & Campbell, 2011; Tam et al., 2003; Van Laere & Duyvejonck, 1986) cerebral palsy (Harmer & Bakheit, 1999; Croser, Garrett, Seeger, & Davies, 2001; Hawley et al., 2007), traumatic brain injury (Erikson, et al, 2004), stroke (Palmer & Seale, 2007), Parkinson's disease, spina bifida, severe arthritis, (Vincent, et al., 2002) Guillian Barre, (Rigby, et al., 2005), transverse myelitis (Tam, et al., 2003), Freidrich's ataxia (Harmer & Bakheit, 1999), multiple sclerosis (von Maltzahn, et al., 1995; Harmer & Bakheit, 1999; Ripat & Strock, 2004) muscular dystrophy and other progressive neuromuscular disorders (Harmer & Bakheit, 1999; Jutai, et al., 2000; Stickel, Ryan, Rigby, & Jutai, 2002; Ripat & Strock, 2004).

ECS studies that inlcude participants with high SCI include a single case study (Van Laere & Duyvejonck, 1986), a study of 26 people with injuries at the C6 level or above who had used ECS for at least a year (McDonald, et al., 1989), and three studies of ECS users and non-users who had high SCI (Rigby, et al., 2005;[35] Rigby et al, 2011;[36] Tam et al., 2003[37]). In addition most ECS research studies that include multiple pathologies include people with SCI (Harmer & Bakheit, 1999; Maguire, McCann, & Swallow, 2001; McDonald, et al., 1989; Novak, 1998; Ripat & Strock, 2004).

2.2 ECS Components description

An ECS consists of a central processing unit (controller) with visual display, control interface (control switch) and peripherals (appliances or electronic devices) (Dickey & Shealey, 1987; Ripat & Strock, 2004). In the course of this study a user-friendly introduction to ECS was written for an Irish audience in Spinal News,[38] Appendix 5 (Verdonck, 2007, Verdonck 2008a; Verdonck 2008b; Verdonck 2008c). While

[35] 32 people with high SCI.
[36] 36 people with high SCI or conditions at or above C5/6 level.
[37] Tam et al., (2003) investigated 36 persons functioning at C4/5 spinal level (all C5/6 tetraplegics and one Guillian Barre Syndrome, one Transverse Myelitis, one peripheral neuropathy).
[38] Spinal News is the magazine of Spinal Injuries Ireland a charity run by and for people with SCI.

photographs have not been included here Appendix 5 provides an inexperienced reader with examples of all these components.

ECS Controller

The central processing unit, the controller, is the primary ECS component which links all other elements. It is similar to a television remote control. The controller usually consists of a visual display that offers static or dynamic choices. The user selects from the available choices by using a switch or a control interface. The controller then transmits a signal to the appropriate target appliance.

There are a variety of commercially available controllers that vary in terms of size, access method, appearance, display, functional capacity and customisable features. Photographs of some of these are available in Appendix 6. They transmit a variety of signals including IR, and radiofrequency (RF). IR is the most common signal used in ECS. It requires line of sight and allows simple control of devices such as televisions. There are a variety of different RF transmissions including X10, Bluetooth® and Wi-Fi signals. RF transmission is less common in commercially available controllers but has the advantage of not requiring line of sight. X10 is a widely used home automation transmission that uses existing domestic AC wiring to transmit signals. A third, seldom used form of transmission is ultrasound which uses high frequency sound waves to control appliances (Cook & Polgar, 2008). This does not require line of sight but does require close proximity of a few metres to the target device.

The signals that are transmitted by the controllers are *learned* by the controller through programming while in training mode. Some devices are simple to program and can easily be adjusted by either the user or therapist. Other devices require specialised programming. The controller *learns* the necessary signals from all the desired peripherals thus becoming a universal remote control that can direct several devices.

Accessing the controller can be either direct, and involve pressing a button on the controller using a hand, knuckle or mouthstick (or other body part or pointer). Alternative access can be indirect via voice, joystick or switches depending on the features of the controller. Switch access requires scanning but direct selection is 5 to 10 times faster than scanning (Weber Dow & Pearson Rees, 2002). A variety of scanning options are currently available. Automatic scanning involves the

continuous presentation of items one at a time. The user selects a desired item by activating a switch when the item is presented, thereby stopping the scan. This can be a lengthy, slow process especially if several options are available. It requires accurate, reliable switch use and considerable patience. Step scanning is the stepwise advance of each item one at a time through repeated pressing of the switch.[39] One disadvantage of this method is that repeated switch activation may lead to muscle fatigue (Cook & Polgar, 2008). Inverse scanning involves activating a scan and then releasing the switch when the desired item is reached. Some controllers offer a grid of choices that best suits another type of scan, called line and row scanning. This is a type of partial automatic scan. The controller scans items in groups for example line-by-line. The appropriate group of items is selected using a switch and then the individual items in the selected group are scanned individually allowing the selection of the desired item. Scanning rates are adjustable according to user requirements.

Static displays use small lights located beside each static option which are sequentially illuminated. Dynamic displays use dynamic symbols, numbers and letters that show items more clearly than static displays but can also be considered confusing due to their dynamic fleeting appearance. Newer developments have given rise to the integration of controllers with both smartphones and tablets. The controller options are thus displayed on the mainstream device.[40] Computer tablets and smartphones are designed for direct access requiring digital dexterity limiting their application for people with high SCI.

Control interface

The control interface is also called the transducer. Controllers may be accessible using one, two or more switches, a joystick, voice activation or physical interaction with the controller display (direct access). Direct access involves using buttons that are features of the controller or by making contact with virtual buttons on the display. This method allows mouthstick access; however, some displays rely on electro conductivity requiring adaptation of the mouthstick.[41] Switches are the most common interface (E. Steggles, personal communication, 23 March, 2009). Selection of a suitable switch depends on the user's ability to physically use the

[39] If a second switch is used one switch can advance the scan and the second switch can select the item, if one switch is used the selection my require a small waiting time to confirm there will be no further advancing scan.
[40] Smartphone option requires a Bluetooth® switch for access. Tablets are not switch accessible, requiring direct access of the Tablet display screen and thus not suitable for people with high cervical spinal cord injury.
[41] Conductive materials can be used to cover mouthsticks to enable their use with such interfaces (like a stylus sock).

switch repeatedly. This requires appropriate mounting of switches as well as suitable switch selection. Voice offers another access method for controllers designed to be speech-driven but these often require supplementary switch access for improved efficiency (J. Leslie, personal communication, 21 March 2009). Joystick access can be direct, wired to the controller, or may be integrated with a wheelchair control. Joystick access permits simple, multi-directional selection of icons on a dynamic display.[42]

Peripherals

The final elements of an ECS are the target devices. These are the most important as they provide the motivation for using the ECS such as a television. Technological advancements have increased the list of appliances that can be controlled as described above.

3. Environmental Control Systems in Ireland

A European study, The HEART study examined AT provision in European countries including Ireland and concluded that:

> *The Republic of Ireland has no legislation which provides statutory provision of [ECS] equipment for people with disabilities* (Alastuey, Kerdraon, Ekberg, Kemppainen, Peters, Healy & Cooper, 1993, p.62).

Attitudes towards disability and inclusion in mainstream society are improving but there is a lack of supporting legislation across Europe including Ireland (Kemppainen, 2011). There is support for the provision of AT in Ireland as outlined in the government publication, *Towards 2016 Ten-Year Framework Social Partnership Agreement 2006-2015*. This agreement addresses key social challenges which people with disabilities face in order to achieve a participatory Irish society in which:

> *people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community* (Department of the Taoiseach, 2006, p.66).

[42] Integration of wheelchair joystick with controller is dependent on the features of the wheelchair and may require an additional interface between the controller and the wheelchair.

Living a full life to the greatest extent possible for people with high SCI can be facilitated through the use of AT and ECS in particular. In addition, *The United Nations Convention on the Rights of Persons with Disabilities* requires the promotion of AT for people with disabilities (United Nations, 2006). Article 3 supports: respect for everyone's inherent dignity, freedom to make their own choices and independence; full participation and equal opportunity. These principles would be well supported through the provision of AT including ECS. These principles are however not supported by legislation and Ireland has not ratified *The United Nations Convention on the Rights of Persons with Disabilities* (although it has been signed and ratified by most European countries). Another European initiative, *The European Disability Strategy 2010-2020,* strives for the independence and integration of people with disabilities and includes the promotion of assistive devices as an aim (European Commission, 2010).

ECS are not considered a common type of assistive technology and there are no transparent policies governing the provision of ECS in Ireland. There are no known statistics pertaining to ECS use in Ireland. In practice many people who may benefit from using ECS do not have access to them and in many cases have no or little knowledge of ECS. Limited information and funding sources appear to be the primary reasons for the low incidence of ECS use observed in community settings (E. Breen, personal communication, 6 March 2008). ECS funding difficulties are world-wide. In the USA, ECS are the least funded type of assistive technology by health insurers (Lange & Smith, 2002) and in Ontario, Canada there is no funding for EADL (Stickel, et al., 2002). Poor funding has motivated research initiatives in a bid to validate the need to secure funds for this purpose (Rigby, et al., 2005; Stickel, et al., 2002). Potential users have to use various funding sources such as insurance claims, private funds and fundraising activities (Stickel, et al., 2002) and in some cases may require more than one source of funding.

In Ireland, those with ECS often purchase them privately or through charitable sources.[43] Others are able to include the cost in housing adaptations, which can be government funded through the Housing Adaptations Grant for People with a Disability.[44] However, this funding pathway is rare due to the small value of the grant in comparison with the cost of both physical housing modifications and the

[43] Such as Irish Motor Neurone Disease Association (IMNDA) and Cheshire Ireland.
[44] Housing Adaptations Grant for People with a Disability formally called the Disabled Persons Grant is mean tested financial assistance for part of the costs of housing adaptations and is administered by local authorities.

cost of ECS. Occasionally ECS are funded by community occupational therapy services[45] with the support of local Disability Service Managers. This requires prioritising the ECS at a local community level. The Health Service Executive (HSE) is the only known source of possible public funding for ECS in Ireland. There are no other specifically allocated funds for this purpose. A value added tax (VAT) refund may be claimed for privately funded ECS (Citizens Information Board, 2011a). The purchase of an ECS does not routinely include on-going maintenance costs, so that in the event of equipment failure there is no arrangement for formal support for repairs or replacement. Complaints about poor follow-up after installation of ECS have been reported in other countries (Novak, 1998; Maguire, et al., 2001; Croser, et al., 2001; Stickel, et al., 2002; Vincent, et al., 2002) and can lead to abandonment and to systems becoming out-dated and insufficient (Novak, 1998). Lack of information on ECS has been reported by users in Canada and the majority (52%) of Northern Irish users surveyed reported having received no information about ECS prior to receiving their own ECS (Maguire, et al., 2001; Stickel, et al., 2002).

Knowledge of ECS in Ireland for both potential users and allied health professionals, including occupational therapists, is observed to be varied and poor in some areas. The Citizens Information Board has developed an online AT data base at www.assistireland.ie (Citizens Information Board, 2011b) which is comparable with European initiatives such as the European Assistive technology Information Network (EASTIN) (Andrich, 2011). However on investigation the website was found to not cover ECS comprehensively nor is it up to date as it relies on suppliers to provide the content (Citizens Information Board, 2011b). Try-it.ie an assistive technology loan library that facilitates the loan of electronic assistive technology is another potentially useful resource. It too, however, only includes a few basic ECS, but is a good source of information for people who need information about switches and mounts (Try-it.ie, 2011). Training courses and seminars which include some ECS content, are offered to people with disabilities, therapists, educators and employers by a non-governmental organisation that provides assistive technology education through a programme entitled *The National Assistive Technology Training Service.*

[45] There are no allocated budgets in for community occupational therapy services but funds are occasionally used for environmental control systems when the need is recognised and funds are available.

There is only one known AT service in Ireland provided by a non-governmental organisation[46] with one AT centre in Dublin with two satellite clinics in Limerick and Waterford. The [AT service][47] and continues to provide some AT assessment integrated with a specialist wheelchair seating service. Frustrated by the reliance on suppliers of electronic assistive technologies the [AT service] has recently expanded its services to include seeking quotations, making funding applications and installing electronic assistive technology including ECS (C. Fitzsimons, personal communication, 9 September, 2011).[48] The [AT service] has also facilitated an increase in provision of powered wheelchairs,[49] that have integrated ECS functionality through IR senders built into wheelchair control systems. The wheelchair based ECS is however limited by its failure to provide ECS bed access which requires a second privately funded ECS that can be used in bed.

The [AT service] is not integrated with the Health Service Executive (HSE) nationally. In comparison, other countries have specialised AT services integrated with and funded by their health service with formal referral and supply processes. For example Norway, comparable to Ireland in terms of population, has a uniform national assistive technology system with 18 assistive technology centres (T. Sund, personal communication, 31 September, 2011). While the [AT service] facilitates the inclusion of ECS There are no formal policies or procedures linking rehabilitation services with assistive technology services and the link is dependent on the level of interest and expertise of individual therapists leading to inequalities in the services offered to individuals (E. Little, personal communication, 6 April, 2007).

There are three known commercial suppliers and installers of ECS in Ireland.[50] Suppliers provide and install ECS based on occupational therapy recommendations. Occasionally suppliers have been known to provide privately funded ECS without professional assessments or referrals. Referrals made from the national spinal injury centre between 2001 and 2006 were not prescriptive nor based on a comprehensive ECS assessment as this was beyond the remit of the occupational therapy department at the time. Thus there was a reliance on suppliers to provide users with advice and recommendations. As ECS became integrated into

[46] Dublin-based charitable organisation that primarily provides assessment and treatment for children with physical disabilities.
[47] The [AT service] piloted a Technical Liaison Officers (TLO) programme ten years ago that had people with physical disabilities with AT training acting as liaison between [AT service] and potential AT Users., but is no longer operational (Craddock & McCormack, 2002).
[48] But was not doing so at the time of the inception of this project.
[49] Provided by the Health Service Executive.
[50] There were only 2 known suppliers at the start of this study.

occupational therapy, referrals to suppliers became more prescriptive and detailed. Suppliers run commercial businesses that require profitability to remain operational and their products and services are therefore expensive and usually limited to an initial installation. Extra maintenance incurs a cost that can be high as Irish suppliers may have to spend time and money traveling long distances to users' homes. In contrast in the UK, NHS mediated supply includes service contracts in the initial funding applications, thereby ensuring that equipment maintenance is provided by suppliers. Although such a system can ensure function, it does not ensure suitability nor does it prevent non-use of ECS and equipment can become out-dated (Novak, 1998). Ensuring ECS remain useful requires a regular professional review by a suitably qualified occupational therapist or other relevant professional such a rehabilitation engineer or assistive technology technician.

4. Occupational therapy and ECS

As society advances technologically, electronic assistive technology is becoming less specialised and not confined to experts such as rehabilitation engineers and occupational therapists working in assistive technology services. Increasingly occupational therapists need to be aware of mainstream developments, such as those in home automation that may be applicable to service-users (Verdonck & Ryan, 2008). The American Occupational Therapy Association (AOTA, 2010) recognises the role of all occupational therapists in selection and training in the use of ECS but in North America electronic assistive technology and ECS are considered to be the responsibility of accredited Assistive Technology Professionals (ATP) (Weisman & Weber, 2011). Similarly specialist expert ECS services operate in parallel to wheelchair services in the United Kingdom resulting in poor integration of basic equipment and electronic assistive technologies (including ECS) (Stead, 2002a). In Ireland, however, community occupational therapists agreed that they should be able to carry out assessments and prescribe electronic assistive technology thus challenging assumptions that electronic assistive technology is the remit of experts only (Stead, 2002a). However, only one third of those surveyed reported being able to do so and almost half (48%) reported having been asked by service-users to assess for and prescribe electronic assistive technology but had not been able to do so (Verdonck, McCormack, & Chard, 2011b, Appendix 7).

The inclusion of ECS provision, as part of routine occupational therapy intervention at th [hospital], has progressed over the last 8 years from simply providing a demonstration, to full involvement in the assessment, training and recommendation of appropriate ECS (Chapter 1 section 2.2). This change appears to be the result of professional development of occupational therapists[51] as well as changes in patient demographics,[52] demands of patients,[53] and improvements in technology. Patients are now introduced to ECS early in their rehabilitation and learn how to use ECS both in the occupational therapy department and on the wards. Discharge plans for people with high SCI include recommendations for ECS as well as referrals to the specialised assistive technology service. However, most people with high SCI in Ireland are discharged without ECS and are unlikely to receive them through public funds as these recommendations are often not fulfilled. This is a significant issue, impacting on their future quality of life, which needs to be addressed. This is not reflective of the recommendations of the Disability Act 2005 (Houses of the Oireachtas, 2005) which states the rights of persons with disabilities, and places new responsibilities and pressures on the health services and the wider population to respond appropriately and in a timely manner to ensure that these rights and entitlements are met.

5. Spinal cord injury

A basic introduction to SCI and to the biographical disruption caused by high SCI was provided in Chapter 1 (section 3). This section introduces the reader to SCI terms that will be referred to in this thesis. It begins with an overview of SCI classification, tetraplegic functional levels and SCI incidence. The remainder of the section seeks to describe what living with high SCI is like by describing living with: a changed body, risks, constant company, and equipment in a changed environment and with a *new me.*

5.1 SCI overview

SCI is classified according to level and severity of injury. Injuries are broadly divided into tetraplegia, involving upper limbs, lower limbs, and trunk and paraplegia, involving the lower limbs only. Tetraplegia refers to an injury at the neck or cervical level while paraplegia refers to a chest or lower back injury at the thoracic or lumbar

[51] Remit extended to inclusion f ECS in daily interventions.
[52] There increased incidence of people with high SCI is based on clinical observation that has not been ratified through any known formal investigation.
[53] Patients appear to expect access to technology.

vertebral level. Functional abilities for people with tetraplegia vary according to neurological level of injury summarised in Table 1. For the purpose of this study this introduction to SCI will focus on tetraplegia and on high SCI in particular. High SCI refers to injuries sustained at or above the C4 neurological level resulting in paralysis of both upper and lower limbs with no active elbow, hand or wrist movement (Bromley, 1998). This is of relevance to this study because such physical abilities are used to access technology.

Injuries are classified as either complete or incomplete. An incomplete lesion results in some preserved motor and/or sensory function below the level of the injury. Spinal cord injuries are classified according to the system published by the American Spinal Injury Association (ASIA) and endorsed by the International Spinal Cord Society (Maynard et al., 1997). The assessment form can be found in Appendix 8. The neurological level of injury is defined as the most caudal level with preserved bilateral motor and sensory functioning. Sensory level is assessed through pin prick and light touch scores of dermatomes associated with each spinal level. Motor function is assessed through manual muscle testing of key muscles for each level. In addition to level of injury, this classification also includes an ASIA impairment scale represented by a letter: A, injury is complete; B, incomplete with preserved sensory function; C, incomplete with little motor reservation;[54] D, with moderate motor preservation;[55] and E normal motor and sensory function. (Maynard, et al., 1997) (See Appendix 8). Thus injuries are referred to by vertebral level, by degree of impairment and by completeness e.g. C5 ASIA C complete or T12 ASIA A incomplete.

The incidence of SCI worldwide varies from 13.1 per million per year in Ireland (O'Connor & Murray, 2005) and 14.5 per million per year in Australia (O'Connor, 2002) to 42.4 per million in Canada (Pickett, Campos-Benitez, Keller, & Duggal, 2006). For a full review see Van den Berg, Castellote, Mahillo-Fernandez, and de Pedro-Cuesta (2010) and Cripps et al. (2010). This variation is partly accounted for by the fact that SCI is not a notifiable disease and statistics are recorded in different ways in different countries (Hammell, 1994).

[54] Motor function is preserved below the neurological level, and more than half the key muscles have a muscle grade of less than 3/5.
[55] Motor function is preserved below the neurological level, and more than half the key muscles have a muscle grade of grade 3/5.

Table 1: Possible functional ability and necessary equipment associated with neurological levels of SCI (Adapted from Adler & Pedretti, 1990)

Neurological level of injury[56]	**Motor function**	**Possible functional ability and necessary equipment**[57]
C1,C2 and C3	Limited head and neck movement, (paralysis of the diaphragm)	Ventilator dependent, mouth-stick use, head/ chin control powered wheelchair with tilt function for pressure relief, shower trolley, hoist for transfers, adapted van, ECS, computer access using assistive technology.
C4	Head and neck movement, shoulder shrug, and partial innervation of the diaphragm	May require minimal respiratory assistance, mouth-stick use, head/ chin control powered wheelchair with tilt function for pressure relief, shower trolley, adapted van, ECS, computer access using assistive technology.
C5	Head and neck movement, shoulder shrug and flexion, elbow flexion and supination	Feeding using wrist extension splints, specialised cutlery in a palmar strap, a plate guard and pre-cut food, drinking (bilateral heel of hands grasp), shaving using electric razor held in bilateral grip between the heels of both hands or strapped to the hand and using a wrist extension splint, hoist for transfers, propelling manual wheelchair short distances on smooth surface; powered wheelchair with joystick for outdoor mobility, driving an adapted van from a powered wheelchair, computer access using assistive technology, ECS.
C6	As above with wrist extension and pronation	Use of tenodesis grip, independent feeding, grooming, dressing using adaptive methods and assistive devices, some household tasks (such as cooking a simple meal), transferring with a sliding board, independent propulsion of manual wheelchair is possible but powered chair is more suited for outdoor use and other challenging environments, computer access using assistive technology, limited use of ECS.
C7	As above with elbow extension, limited finger extension (limited grasp)	Independent in personal activities of daily living using fewer assistive devices, performs some household duties such as laundry, transfers with/without transfer board independent manual wheelchair propulsion, driving adapted car, computer access using assistive technology.
C8	As above with finger flexion	Independent in personal activities of daily living without assistive devices.

[56] ASIA A, complete injury.
[57] Achieving functional ability is dependent on several factors including motivation, physical morphology, cognitive ability and available assistive devices.

Global demographic trends indicate that traumatic SCI is four times more common in males than in females (Swain & Bamford, 1996) and most common in those under 50 years of age. These world-wide demographic trends have been relatively consistent for the last 30 years with the exception of an increased occurrence of cervical injury which now accounts for a third of all injuries (Swain & Bamford, 1996; Wyndaele & Wyndaele, 2006; Roe, personal communication, 18 October, 2011). A bimodal age distribution is reported with peaks in young adults between 15 and 29 and in older adults over 65 (Van den Berg, et al., 2010). People over 50 years of age are more likely to suffer non-traumatic injury resulting in incomplete tetraplegia (Scivoletto, Morganti, Ditunno, Ditunno, & Molinari, 2003). One Irish study (n=46) reported a higher male to female ratio of 87% (vs. 80%) and a higher proportion of cervical spinal cord injury of 50% (O'Connor & Murray, 2005).[58] While a more recent study on a larger sample (n=382) found a 37% incidence of tetraplegia and a 74.9% prevalence in males showing Irish demographic trends that are more consistent with international data (SII, 2009).

Admission statistics for the national spinal injury centre in Ireland for 2008, 2009, 2010 are presented in Table 2 overleaf. It is however not possible to extract accurate incidence of high SCI from these statistics due to recording insufficiencies. The figures include people with non-spinal neurology that includes both tetraplegia and paraplegia due to disease of the spinal cord. This means that some classified as non-spinal neurology would also have high SCI. The category traumatic tetraplegia does not only include high SCI but those with incomplete injuries who may have preserved function as well as those with injuries at the C6 and C7 level who have some preserved hand function (see Table 1 for description of functional differences for SCI levels).

Table 2: Irish spinal injuries rehabilitation statistical summary for calendar years 2008 - 2010 (Roe, personal communication, 18 October, 2011)

	2008	**2009**	**2010**
Spinal cord injury service discharges per year	123	145	141
Non spinal neurology[59]	5	13	28
Males/female %	71/29	69/31	62/38
Average length of stay	125 days	87 days	77 days
Traumatic tetraplegia	29%	28%	27%

[58] C4/C5 is reported as the most common level of injury.
[59] The spinal cord injury programme also provides rehabilitation for some other pathologies such as Guillian Barre and Multiple Sclerosis.

Spinal Injuries Ireland (SII) has a registered membership of 1519 of whom 604 have cervical spinal cord injuries (J. Carthy, personal communiucation, 12 October 2011). While this data base is voluntary and not audited it does provide an indication of the incidence of SCI in Ireland. SII records indicate that, based on functional ability, 79 registered members with high SCI would require ECS to access technology themselves and a further 106 would be likely to benefit from ECS to access technology.

5.2 Living with a changed body

Living with a body changed by high SCI means: living with paralysis, living with sensory absence and living with double incontinence. It also frequently means living with pain and with spasm. Body changes involve alterations to sexual function, cardiovascular function and thermoregulation. The most visible consequence of a SCI is muscle paralysis necessitating the use of a wheelchair. For those with high SCI the severity of paralysis necessitates constant physical assistance in addition to the use of the hallmark wheelchair. Not all cervical SCI are the same and the impact of each injury is dependent on the neurological level of the injury as detailed in Table 1. Small increases in physical ability characteristic of each neurological SCI Level as outlined in Table 1.[60] Those with injuries between C1 and C3 neurological level require respiratory support and permanent ventilation. The use of a ventilator compromises verbal communication and can initially require compensatory forms of communication until the person learns the art of talking while being ventilated.[61] Those with injuries at the C5 level retain some shoulder and elbow flexion which may be used for feeding and basic grooming using wrist extension splints. For those with injuries at the C4 level the only possible voluntary movement is shoulder shrugging and use of the neck and head, as described by an individual with high SCI:

> *You can't move. You wake up, you go to get up and you can't. You can't move. And that's hard* [Bob] (Dickson, Allan, & O'Carroll, 2008, p.413).

Physical assistance is required for tasks ranging from bathing to feeding and scratching one's nose to turning the pages of a book:

[60] Small increases in physical can occur in the acute stages of the rehabilitation as the neurological level of spinal injury can become lower. This may mean someone's functional ability changes from a C5 level to a C6 level for example. See Table 1 for an understanding of such functional changes.
[61] Demonstrated by Christopher Reeve at the opening of the Atlanta Paralympic Games.

> *You could not get up to get a glass of water that sense of frustration has never gone there is a permanent annoyance that you have to depend on someone else for the rest of your life for everything* (Cole, 2004, p. 30).

These physical changes disrupt the sense of body-self unity and one's previous perception of a smoothly functioning body and require the assimilation of a new disabled self-identity (Smith & Sparkes, 2002; Van Manen, 1990; Yoshida, 1993). Sensory losses also contribute to an experience of the body as a foreign object separate from the self (Seymour, 1998). The absence of sensation in the trunk and limbs has been described as a sensation of floating

> *I felt like a balloon being wafted around. It's a sensation of nothing…To me to me it was a sensation … it wasn't numbness. It is nothingness … My head floating* (Cole, 2004, p.31).

> *It was, and is, odd, because I can't feel it, but it still feels or looks like your own body. But then, you see, when you are just sitting down, the only sensation you have is of where you are sitting. You may be looking at your knees, but you don't actually feel them. There is no sensation as such. It did not feel so much like your body because it was not going to do what you told it to. To some extent it's an appendage, and to some extent still the same* (Cole, 2004, p.32).

Some experience phantom pain in areas of the body that otherwise lack sensation (Cole, 2004). Kennedy, Frankel, Gardner, and Nuseibeh, (1997) reported a 41% incidence of pain one year post injury for people with all levels of SCI. Others experience neuropathic pain in areas of preserved sensation that arises from the nervous system itself (Somers, 2010). This pain for some is constant and for others it fluctuates it may be triggered by sensory stimulation or arises spontaneously and is located in the nervous system at or near the level of the injury. Pain can be so severe that it is more debilitating than the primary paralysis (Siddall & Middleton, 2005).

SCI causes altered muscle tone which may present as spasticity[62] and/or flaccidity in high SCI (and may also be associated with intermittent spasms)[63] (Maynard,

[62] "Spasticity is a velocity-dependent increase in muscle tone in response to passive movement" (Somers 2010, p. 28).

Karunas, & Waring, 1990). Spasms, a type of hyper-reflexive response can also occur in response to cutaneous and proprioceptive stimuli including pressure ulcers and urinary tract infections (Swain & Bamford, 1996). They can be painful, disrupting and cause dangerous position changes:

> *They used to throw me out of bed or out of the chair … The worst times were when the nurses put me to bed and my legs spasm up and hit them. I hit the nurses, but it was not me who did it … Watching your legs in spasm when you have no control, like someone else is doing it … watching your legs is peculiar* (Cole, 2004, p.83).

Changes in mobility and tone can result in a decreased passive range of movement or contractures that can make transferring between bed and wheelchair and other tasks such as dressing and showering challenging for carers (Swain & Bamford, 1996). Upper limb contractures can also be disfiguring and effect one's body image and self-esteem as well as the perceptions of others who misinterpret physical limitation as a sign of cognitive impairment (Somers, 2010).

Bowel and bladder problems are one of the most common and distressing consequences of SCI. A SII survey found an incidence of at least occasional bowel problems in 76% of 382 adults surveyed (SII, 2009). Bladder and bowel care following cervical injury typically requires considerable intimate physical assistance from a caregiver.[64] Urinary incontinence is managed using catheterisation[65] and bowel incontinence is managed by a bowel programme.[66] In addition bowel and bladder management require adhering to suitable diet and adequate fluid consumption.

Living with both bladder and bowel incontinence is associated with lower quality of life and depression (Hicken, Putzke, & Richards, 2001; Oh, Shin, Paik, Yoo, & Ku, 2006). Bladder and bowel incontinence has profound psychosocial effects including embarrassment and social isolation related to the fear of *having accidents* (Somers, 2010):

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[63] Spasticity is more common in cervical and thoracic injuries as well as in incomplete injuries.
[64] Independent catheterisation is uncommon in high SCI (Bloemen-Vrencken, et al., 2005; Oh, et al., 2006) and an indwelling catheter, which requires frequent manual emptying is more common.
[65] Intermittent catheterisation involves inserting a catheter into the bladder every 4 to 6 hours, Suprapubic catheterisation requires surgical construction of an abdominal orifice that leads directly to the bladder.
[66] A bowel programme induces bowel movements at regular scheduled times (Ash, 2005). This is a time consuming and invasive process that has been described as "one step too far" because it was considered too invasive (Dickson, et al., 2008).

> *… you feel like a kid again having accidents. And, obviously, you can't clean yourself up, someone has to do it for you. So you're like a kid. It's all just anger and embarrassment [Joe]* (Dickson, et al., 2008, p.414).

If not managed effectively bowel and or bladder issues can interfere with sexual function, employment and social activities (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2006; Bloemen-Vrencken, Post, Hendriks, De Reus, & De Witte, 2005; Pagliacci et al., 2003).

Sexual function is affected by loss of voluntary movement, sensory loss, altered muscle tone, risk of bowel or bladder incontinence and reduced spontaneity (Somers, 2010). Despite some changes to genital function associated with SCI most remain sexually active post injury (Kreuter, Sullivan, & Siösteen, 1996; Leibowitz & Stanton, 2007; Sakellariou & Sawada, 2006; Westgren, Hultling, Levi, Seiger, & Westgren, 1997). However sexual activity and sexual satisfaction are reported to decrease post injury (Levi, Hultling, Nash, & Seiger, 1995). Sexual dysfunction was reported in 83% of an Irish sample in a survey of quality of life (SII, 2009).

Other disrupted bodily functions caused by SCI are heterotopic ossification[67] and cardiovascular effects of reduced exercise tolerance, exercise induced hypotension, reduced venous return, reduced stroke volume, and reduced cardiac output (Somers, 2010). Similarly high SCI is associated with difficulties with thermoregulation due to disrupted neurological connection between the spinal cord and the hypothalamus that controls vasodilation and vasoconstriction either increasing or decreasing body temperature. There is a loss of control over shivering and sweating below the level of injury (Somers, 2010). This occurs irrespective of climatic conditions and can cause severe discomfort especially at night and necessitates caregiver assistance to adjust environmental temperatures.

5.3 Living with risks

Living with a high SCI not only causes disruption to previous lifestyle and activities, it also introduces a variety of risks. The two primary risks for people with high SCI are pressure ulcers and autonomic dysreflexia. Other risks include risks of urinary tract infection and respiratory and circulatory complications. People with SCI are

[67] Heterotrophic ossification is the pathological formation of new bone in soft tissue such as muscle of the hips, knees and elbows. It is most common in the first six months post-injury (Bromley, 1998; Swain & Bamford, 1996). It can trigger spasm, pain and autonomic dysreflexia as well as decreasing range of movement. It can be managed pharmaceutically with varied levels of success (Van Kuijk, Geurts, & Van Kuppevelt, 2002).

prone to skin damage that may develop into pressure ulcers as a consequence of decreased sensation, circulatory changes and immobility. Reducing the risk of pressure ulcers involves using pressure relieving wheelchair cushions and pressure relieving mattresses. Choosing to be seated anywhere other than on cushions poses a risk of skin breakdown. Pressure relieving mattresses are large noisy electronic devices that constantly adjust pressure by varying inflation levels. Alternatively a person may require regular manual turning to change position in bed (Swain & Bamford, 1996). Sustaining a pressure ulcer can have fatal consequences and requires strict management of pressure areas involving long periods of bed rest that means that they are not able to sit up in their wheelchairs thus enforcing further activity restriction.

High SCI[68] runs the risk of experiencing autonomic dysreflexia a medical emergency which can lead to brain injury[69] if not responded to promptly. It is triggered by noxious stimuli below the lesion causing an excessive sympathetic response that cannot be inhibited by the brain due to spinal cord disruption. Triggers include bowel and bladder problems such as urinary tract infection, bowel impaction, and catheter blockages.[70] It can occur in those with injury at or above T6 and is managed by removing or managing the noxious stimuli or by medication (Swain & Bamford, 1996):

> *It is characterised by a sudden increase in blood pressure, bradycardia, pounding headache, and flushing and profuse sweating above the level of the lesion ... It is often accompanied by anxiety. Additional signs and symptoms that can occur include flushing or sweating below the lesion, piloerection ("Goosebumps") above, or sometimes below the lesion, blurred vision, spots in the visual fields, nasal congestion, muscle spasm, paraesthesias in the neck and shoulders, and cardiac arrhythmias* (Somers, 2010, p.32).

Respiratory muscle paralysis may include the diaphragm and intercostal, and abdominals thus reducing respiratory function and increasing the risk of infection. Chest infections was reported in 38% of an Irish sample of people with all levels of SCI (SII, 2009). Immobility and changes to vascular tone increases the risk of

[68] Or above T6 level of injury.
[69] Autonomic dysreflexia can result in renal failure, cardiopulmonary failure, seizures, retinal haemorrhage, loss of consciousness, cerebrovascular accidents, hypertensive encephalopathy or coma (Somers, 2010).
[70] Other possible stimuli include labour, sexual intercourse, ejaculation, heterotrophic bone formation, ingrown toenails and abdominal conditions (Somers, 2010; Swain & Bamford, 1996).

developing a deep venous thrombosis (DVT) or a blood clot in the deep veins or the risk of pulmonary embolism, if a DVT embolizes and moves to the pulmonary artery it can cause a possibly fatal obstruction (Bromley, 1998; Somers, 2010). These circulatory risks are higher during the acute stage of injury but risk continues with long term immobility. Living with such risks contributes to a need for constant company in case of medical emergency that requires immediate intervention

5.4 Living with constant company

Living with the physical changes resulting from cervical injuries and their associated risks requires 24-hour assistance. Care is usually provided by family members and hired care givers (called personal assistants), home helpers and community nurses. With appropriate support, it is possible for a person with a high SCI to live in the community in their own residence interdependently (Hammell, 2004c). Family members and personal assistants provide all a person's basic care and comfort needs including bathing, dressing, hoisting, feeding, positioning limbs after spasms, turning pages of a book or newspaper and scratching their nose. Community nurses provide intimate care including manual bowel evacuation[71] and may also assist with bathing. They assist the person and their family to monitor skin integrity, provide dressings for pressure ulcers and facilitate the provision and maintenance of pressure relieving mattresses. Some community physiotherapy services provide therapeutic maintenance aimed at preserving passive range of movement of all four limbs and respiratory support to prevent complications. Community physiotherapists educate family members and carers to provide basic limb and respiratory maintenance including passive mobilisations.

Planning, co-ordinating and managing care is a complex process that can involve multiple players including family members social workers, and charities that provide carers.[72] In Ireland, the person with a SCI seldom co-ordinates their own care despite having the ability to do so. Finding suitable carers can be challenging as the demands of living with high SCI requires some flexibility from carers to provide care when needed and not only when scheduled (L. Bramich, personal communication, 13 November, 2011). Additional support may be available in the form of home help.[73] Funding for care is provided by various sources including HSE, charity and private funds. When family members are unable to provide assistance, or when care

[71] This is considered a specialist nursing skill requiring training at the rehabilitation hospital which itself can cause discharge delays in waiting for community nurses to be trained.
[72] Organisations such as Enable Ireland, Centre for independent living (CIL), Cheshire Ireland, Irish wheelchair association IWA.
[73] Home help provides assistance with household chores such as cleaning, cooking and laundry.

packages are not available, full time, institutional care, provided at considerable state expense, may be the only option. Paradoxically, budget restrictions to care packages have resulted in a recent pattern of prolonged hospital stays for people with high SCI followed by discharge to institutional care such as nursing homes, both of which are more costly than care provided in the community. While institutional care may be the only option for some, Canadian studies have linked quality of life for people with high SCI to interdependent community living resulting in increased choice and autonomy (Hammell, 2004b). In addition to living with constant care, living with a high SCI involves living with equipment and encountering physical environmental barriers.

5.5 Living with equipment in a changed environment

Equipment required by people with high SCI includes: shower-chairs/shower-trolleys, hoists,[74] beds and mattresses,[75] manual wheelchairs, powered wheelchairs,[76] standing frames and tilt-tables.[77] In Ireland the supply, maintenance and family education on their use is facilitated by a community care team including community occupational therapist, nurse, and physiotherapist. Equipment is funded as part of the Department of Health's general budget for all aids and appliances including walking aids such as crutches, wheelchairs and small devices such as adapted shoe horns but does not extend to ECS. Aids and appliance funding is only available to people with a medical card.[78] At a community level, funds are shared between all disciplines and client groups so that teams are required to prioritise spending on items like powered wheelchairs as well as catheters and dressings. The current system is likely to be revised as part of the HSE proposed procurement policy due in 2012.

Having a high SCI means that everyday life is lived surrounded by pieces of equipment for a person with high SCI. Getting up usually requires a hoist. The day is spent in a powered wheelchair with a chin control, supportive seating, tilt-in-space functionality,[79] as well as wheelchair trays and or arm gutters to position paralysed upper limbs. Even community travel requires the use of accessible public transport

[74] With community nurses.
[75] With community nurses.
[76] Current economic pressures are threatening powered mobility supply due to restricted community budgets.
[77] Regular therapeutic standing is recommended to facilitate perfusion, bladder drainage and reduce spasms and is facilitated by a tilt Table or standing frame.
[78] A medical card issued by the Health Service Executive (HSE) and allows the holder to receive certain health services free of charge. Receipt of a medical card is based on need and means assessment.
[79] Tilt in space function allows pressure relief and thus aids maintains skin integrity.

or an adapted vehicle with a lift and lowered floor. Travel involves being seated in the wheelchair as opposed to being transferred into a seat.

Returning home after rehabilitation requires overcoming physical barriers. Even weekend visits home during rehabilitation may require structural housing adaptations including the provision of ramped access[80] and the removal of some hinged doors to ensure that door widths allow wheelchair access. Long term housing adaptations and extensions are often required to facilitate wheelchair use and personal hygiene (Somers, 2010) and can be funded through a Housing Adaptations Grant for People with a Disability. However in an Irish survey, 54% of people with SCI stated that the grant was inadequate to meet their housing needs (SII 2009). Necessary modifications may require extra private funds. Occupational therapists advise families on suitable home modifications but the process is lengthy. The median time for finding suitable accommodation after discharge in Ireland was reported to be 12 months (mean time was 36.55 months) (SII, 2009). Most people with SCI are discharged home to unsuitable accommodation that typically involves living in a downstairs living room furnished with a hospital bed and a commode. It may not be possible to bathe or toilet in suitable facilities at home, until building modifications are completed. A typical suitable modification for a person with high SCI provides a downstairs living-cum-bedroom with a large level access bathroom. If ECS, that includes door-opening, window-opening, intercoms, curtain-controls and blind-control, are to be included housing modifications need to include suitable wiring for these controls.[81]

5.6 Living with a new me

Thomson et al 2003 cited by Hammell (2004b):

> *suggests that people who have sustained a life – disrupting injury such as spinal cord injury, need to find a new "I am" as well as a new "I can"* (Hammell, 2004b, p.615).

Despite all the challenges discussed above, a good quality of life is still possible (Albrecht & Devlieger, 1999; Hammell, 2004c) but requires assimilating disability into the context of peoples' lives and identities (Carpenter, 1994). This new identity is often closely linked to wheelchair dependency, as a person with a SCI is viewed as:

> *in a wheelchair, as a wheelchair ... that guy in the chair* (Cole, 2004, p.34).

[80] May be possible using a portable ramp if the gradient is suitable.
[81] It is possible to retrofit door openers and window controls but customised builds are of a higher standard.

Dealing with a new or changed identity has been linked to lowered self-esteem and self-worth (Fichtenbaum & Kirshblum, 2002) and a loss of identity and a sense of feeling invisible has been reported (Dickson, et al., 2008):

> *I don't have an identity any more. I can't stand up and be counted anymore - you don't get that when you're in a wheelchair* (Dickson, et al., 2008, p.416).

Depression, anxiety (Chevalier, Kennedy, & Sherlock, 2009; Migliorini, New, & Tonge, 2009) and feelings of helplessness (Craig, Tran, & Middleton, 2008) have been associated with SCI. An Irish study reported that at least 57% of participants reported at least occasional depression (SII, 2009). Furthermore suicide has been found to be the leading cause of death in people under 55 with SCI (Charlifue & Gerhart, 1991) and is five times more likely amongst those with SCI (Hartkopp, Brønnum-Hansen, Seidenschnur, & Biering-Sørensen, 1997).

In contrast Hammell (2004a) suggests that engaging in valuable occupations, setting new goals and changing ideas about what is meaningful, can lead to the development of a valued life and the experience of a new sense of self-worth. Individual adjustment varies considerably and has been conceptualised as either *moving forward* or *withdrawing from society* (Chen & Boore, 2008). *Moving forward* and developing a valued life is supported by participants in a study of people with high SCI who reported a sense of themselves as *able and valuable* (Hammell, 2004b) and as embracing a new identity involving altered roles and associated activities. Although some element of identity change is inevitable there is also evidence for a crucial continuity of self that serves to help negotiate such identity change (Carpenter, 1994; Cole, 2004; Nolan, 2010). Rehabilitation aims to equip people with the skills required to live with SCI.

6. Rehabilitation services in Ireland

Sustaining a high SCI in Ireland results in the admission to a specialised acute care facility in Dublin for surgical and medical management. This may be preceded by a short stay in a local hospital (throughout Ireland). Once medically stable, patients are then transferred for a period of rehabilitation to the only rehabilitation hospital in Ireland. This hospital is also in Dublin and is the site at which this research study originated and is where I work and is referred to from here on as [hospital].

The treatment of SCI has progressed since the first record of its occurrence in hieroglyphics as a condition *not to be treated*, to one resulting in low life expectancies during the First World War, to one where recent improved medical care has increased survival rates but also increased the incidence of people living with high SCI (Swain & Bamford, 1996). Spinal injury rehabilitation was pioneered by Sir Ludwig Guttmann who established Stoke Mandeville Hospital in Aylesbury (United Kingdom). Early rehabilitation focused on the prevention of pressure ulcers and urinary tract infections and the provision of nutrition to improve life expectancy of those with paraplegia initially and subsequently to those with tetraplegia (Reeve, 1999; Cole, 2004).

Specialised multi-disciplinary[82] rehabilitation programmes are now acknowledged to be the most appropriate and effective intervention for those who sustain a SCI in the western world (Trieschmann, 1988; Inman, 1999; Kennedy, 2007). Most programmes, including the [hospital], Ireland adopt a biomedical approach that not entirely suited to those with high SCI (Hammel, 2006). Despite some psychosocial interventions, therapeutic goals are largely based on improving physical independence and facilitating suitable discharge. Occupational therapy goals likewise typically adhere to this prioritisation of independence and functional rehabilitation:

> *an assumption that the purpose of rehabilitation is to achieve a high level of independence in self-care has often served to deny rehabilitation services to those with the highest cord lesion* (Hammell, 2004b, p. 607).

For most service-users, daily occupational therapy intervention includes personal care tasks such as dressing, wheelchair mobility and strengthening or compensation strategies such as tenodesis.[83] Occupational therapy has an important role to play in occupational goal setting in a multidisciplinary SCI rehabilitation. The role however is less clear for people with high SCI where functional *independence* is not feasible. Defining appropriate physical therapeutic goals for persons with high cervical spinal cord injuries is challenging, as only limited, realistic physical goals are possible due to the severity of injury involved. The application of a biomechanical approach typically applied to the majority of

[82] The team comprises service-user, family members, nurses, rehabilitation consultant, medical officers, physiotherapists occupational therapist, social workers, psychologists and sometimes speech and language therapist, each who play a specific role in rehabilitation.

[83] Tenodesis grip is produced with active wrist extension that results in passive shortening of de-enervated finger flexors resulting in closing of the fingers. This grip can be used to pick up light objects.

those with SCI is of little relevance to those with high level cervical injuries. However the exploration and application of occupational goals is highly relevant for those with high SCI together with the use of ECS which can enable these.

The ultimate goal of rehabilitation is discharge and community reintegration and independent living with a SCI (DeSanto-Madeya, 2006; Duff, Evans, & Kennedy, 2004; Dunn & Dougherty, 2005; Nelson, 1990). Rehabilitation aims to assist service-users to achieve their maximum potential and to achieve suitable life goals through education, therapy and the provision of assistive technology (Scherer, 2005). The end result is intended to be the highest level of autonomy and the adoption of suitable social roles (Cardol, De Jong, & Ward, 2002; van de Ven, Post, de Witte, & van den Heuvel, 2008).

Economic pressures have resulted in recent decreases to the average duration of rehabilitation (Hammell, 2006; Kennedy, 2007). In Ireland the national spinal cord centre reported a reduction in the average length of stay from 125 days to 87 days over one year in 2009 (Table 2).[84] This reduction compromises psychosocial adjustment required to come to terms with a SCI (Ville, 2005). On completion of rehabilitation, service-users are discharged home to their own communities across Ireland. They are invited to attend yearly outpatient reviews at the Dublin-based hospital but their general health care is managed by community care teams, including community occupational therapists. In addition, there is a limited discharge liaison nursing service based at the national spinal injuries centre that carries out home visits. SII provide two outreach workers who also conduct nationwide home visits.

7. Summary of the context of this study

Life with high SCI involves living with physical social and pragmatic changes. Living with a high SCI in Ireland as elsewhere involves extensive care from family, carers and health service providers. This extensive care does not however include useful technology such as ECS. ECS provision and use in Ireland is erratic and appears to be largely privately funded. Although there are some improvements in knowledge of ECS and the inclusion of ECS in rehabilitation programmes, these improvements have not resulted in improved community use of ECS. Using ECS can make accessing telephones and audio visual transmissions integral to living in the

[84] Figures based on average length of stay in 2008 and 2009 (Roe, personal communication, 18 October, 2011).

contemporary information age, possible for people with high SCI. Occupational therapists can play a role in facilitating the use of ECS. A comprehensive exploration of ECS for people with high SCI focused on the user perspective would provide a valuable backdrop to the development of this role and is the focus of this current study. Chapter 3 provides a literature review of ECS investigations in order to explore contemporary understandings of ECS.

Chapter 3: Environmental Control Systems

This chapter aims to answer the question: *What do we know about ECS?* and by reviewing the extant literature on the perspective of service users asking: *what do they think about ECS?* Answering these questions is a challenging task as this area is relatively under-researched. This may be associated with low user numbers and the relatively small population of people with high SCI. Observed low levels of ECS use indicate poor acquisition levels as opposed to low need. The nature of ECS literature is highly varied and includes comment, review, survey, case study, outcome measurement and qualitative investigation. However there are no randomised controlled trials or large longitudinal multi-centre studies (Brandt, et al., 2011). This chapter will discuss the evidence which suggests that ECS are useful, beneficial and satisfactory and the associated improvements in independence, quality of life and participation. The review begins with a broad overview of the available ECS evidence before evaluating that evidence in terms of dominant themes including: uses and functions, independence, participation, quality of life, user satisfaction and carer benefits.

1. Types of ECS studies

Chapter 2 reported on the definitions, elements of ECS (parts, users and systems) and services available in Ireland. The variation in terminology used in Europe and North America and the use of a wide array of terms has led to a diverse body of literature on ECS, which also varies in terms of the evidence presented. This review only explores ECS literature as ECS is the primary interest for people with high SCI. It does not extend to studies primarily focused on smart home technology which has a broader application, particularly for people with cognitive deficits. The first section introduces the nature of the evidence available and attempts to place it in context before discussing the main topics of investigation in later sections. A broad range of papers on ECS have been published and these are presented next and grouped under relevant headings.

1.1 Review of services

The first group of ECS publications can be classified as service evaluations or service reviews. These include a survey of Finnish ECU users (Kanto-Ronkanen, Leino, & Salminen, 2003) and three service evaluations carried out in the United Kingdom (Cowan & Turner-Smith, 1999; Maguire, McCann, & Swallow, 2001; Novak, 1998). Three of these focused exclusively on ECS while the fourth service evaluation focused on electronic assistive technology including ECS. The latter, considered by the authors to reflect the *users' perspective,* did not explore the experience of using ECS but evaluated the provision of electronic assistive technology. It raised a series of concerns regarding funding, referrals, training and maintenance based on a sample of 135 postal surveys. It also highlighted a specific concern in the United Kingdom about waiting time delays of up to 3 years (Cowan & Turner-Smith, 1999). A smaller study (n=29) used structured interviews and questionnaires and concluded that some ECS were oversupplied while others were outdated or poorly-planned (Novak, 1998). The third survey, based in Northern Ireland, was primarily a service evaluation which used questionnaires in ECS users' homes (Maguire, et al., 2001). This revealed some non-use (15%) as a result of physical deterioration or equipment failure as well as concerns over delays for repairs. Together these four reviews highlight some issues, such as delays and outdated equipment, for ECS service provision in countries where ECS are provided routinely to those who need them. In Ireland and other countries, however, the lack of provision of ECS is itself the primary concern.

1.2 Evaluation of technology and trials

A second group of studies focus on technical aspects of ECS. The largest, longest-lasting SCI ECS study involved 52 people with high SCI and took 44 months to evaluate 8 specific ECS devices (Sell, Stratford, Zimmerman, Youdin, & Milner, 1979). Their evaluation played a valuable role in introducing the role that ECS could play for people with high cervical spinal cord injuries. However, ECS technology has made considerable advances in the past 30 years, and their study was about specific ECS items available in the 1970's, which now serves only to underpin the historical context of ECS research (Sell, et al., 1979).

Craig, et al. (2005) conducted a database search for studies reporting on technical aspects of ECS which revealed possible technical variations[85] in studies of ECS for

[85] Technical variations include – eye gaze, eye blinking, movement switches, speech driven and brain computer interfaces (BCI).

people with disabilities. They concluded that the studies reviewed failed to provide sufficient evidence that users technologies were used effectively by service users. The focus of the reviewed studies was on technical and conceptual aspects, as opposed to practical utilisation, by those for whom technologies are intended.

A comprehensive qualitative investigation explored expert users' experiences of using speech-driven ECS (Judge, Robertson, Hawley, & Enderby, 2009a). These findings highlighted the value of using speech as an input method, but also the fact that speech alone was unreliable and required supplementary switch-access to be used when the speech-recognition is not effective. Expert users' willingness to *struggle on* and accept poor reliability and high error rates was attributed to the high value placed on ECS and the speed of speech as opposed to switch-access (Judge, et al., 2009a). An associated study of speech-driven ECS employing the same methodology[86] investigated the views of assistive technology professionals and found issues similar to those identified by users in the earlier publication including reasons for success and failure (Judge, Clarke, & Hawley, 2011a). Perhaps surprisingly, speech-driven ECS have also been considered a viable option for people with severe dysarthria, which renders a person's speech unintelligible to listeners. A trial of a computer based ECS highlighted the advantages of the speed of this direct access method despite poor accuracy with a high error rate (Hawley et al., 2007). This means that it may take several attempts to successfully activate a television. These studies indicate that while users value speech as an input method, it requires refinement as expressed earlier by Hawley who highlighted the need to combine switch access with speech (Hawley, 2002).

Brain computer interface approaches have been used in some research trials including one in which ten people with high SCI successfully used brain signals to control television functions (Craig, et al., 2002). Craig, et al., (2005) subsequently reviewed research trials using brain computer interface approaches. However, while these approaches may be incorporated into future ECS use, as they are not yet commercially available, they are not considered clinically relevant for the purposes of this review.

Clinical investigation of ECS has been restricted to trials of specific systems. These trials do not extend to many commercially available devices, and therefore are of limited usefulness regarding technical issues such as failure of some ECS features

[86] Qualitative framework approach.

(Vincent, et al., 2002). While short trials or very small trials (n=5-11) are usually considered of limited value, investigating specific ECS using these methods has some cumulative value. Trials ranging from one-off trials and short period trials of 1 to 16-weeks have been used to evaluate ECS equipment and services. Each trial was evaluated using a variety of qualitative and quantitative data collection methods, as outlined in Table 3 overleaf.

Some studies, although not setting out to evaluate specific ECS, include details of the devices used by participants (Harmer & Bakheit, 1999; Hawley, 2002; Novak, 1998; Palmer and Seale, 2007). Harmer and Bakheit (1999) described the number and types of ECS used by research participants. Eleven of the 16 used outdated large static hardwired devices.[87] It is interesting to note that, despite taking place 8 years prior to the study by Palmer and Seale (2007), the same type of ECS systems were being used in each study[88] and findings from both studies demonstrate that users found ECS to be useful. The use of outdated ECS systems were also found in two surveys (Novak, 1998; Maguire, et al., 2001). While all these studies were conducted in the last 13 years, some ECS systems in use were considerably older.[89] It is evident that the user experience of ECS in the United Kingdom is often based on old systems. Despite the inclusion of outdated ECS systems in some studies, the reported user experience of ECS is generally a positive one.

1.3 Users and non-users

ECS studies can also be grouped according to their focus on users and non-users of ECS and are presented in table 4. ECS are not available to all those who need or desire them, as a consequence of poor funding and scarcity of information and education about ECS (Cowan & Turner-Smith, 1999; Stickel, et al.,2002; Brochard, Pedelucq, Cormerais, Thiebaut, & Remyneris, 2007). Non-users can therefore be considered potential users and their incorporation in ECS studies is common.

[87] POSSUM PSU6 and PSU3 and STEEPERS SEC.
[88] 4 of 14 used PSU6.
[89] From the 1980s.

Table 3: Summary of Environmental Control Systems research trials detailing location, trial length, trial size, technology used, data collection method and findings

Study	Location	Length of trial	No. of participants	Technology used	Data collection methods	Findings
von Maltzahn, W. W., Daphtary, M., & Roa, R. L. (1995)	United States of America	16 weeks	5 new users	Modular - own design.	No of ECS functions used, interview, psychological questionnaire	Most important ECS functions were telephone and attendant call; most used functions, were the control of various entertainment devices; individuals with a positive outlook on life used ECS more frequently.
Croser, R., Garrett, R., Seeger, B., & Davies, P. (2001)	Australia	2 weeks	8 users	Variety of mainstream and ECS components.	Questionnaire to assess perceived frustration and independence	ECS use increased independence, decreased frustration and decreased time taken to complete the task.
Vincent, C., Drouin, G., & Routhier, F. (2002)	Canada	12 weeks	5 new users + 5 carers	Customised developer-designed ECS including some smart house technologies such as reminders.	Quebec Users Evaluation of Satisfaction with Assistive Technology, Life-H	Global satisfaction with ECS; Increased satisfaction with activity performance (measured by Life-H).
Erikson, A., Karlsson, G., Soderstrom, M., & Tham, K. (2004)	Sweden	1 week	11 new users	Computer based ECS and some smart house technologies such as reminders.	Interview-Empirical Phenomenological Psychological method	Identified qualitative themes: *Plunging into* an ECS equipped environment; *Landing* and feeling comfortable; Incorporating the *new* into daily activities and *Taking off* in the future
Hawley, M. S. et al (2007)	United Kingdom	6 week	5 experienced users [90]	Speech activated computer based ECS.	Performance measured - recognition accuracy and speed of access; questionnaire.	Accuracy of Speech-driven ECS 78.6%, and 2x faster than switch access.

[90] *New to speech as input*

The first comparison study of people with high SCI explored differences between users and non-users of ECS. Differences in activity patterns between 7 users and 13 non-users were identified, with the users being able to participate in more activities (Efthimiou, Gordon, Sell, & Stratford, 1981). Another study, based on three outcome measures: Psychosocial Impact of Assistive Devices Scale (PIADS); Lincoln Outcome Measures For Environmental Controls (LOMEC); and The Functional Autonomy Measuring Scale (SMAF);[91] illustrated a statistically greater functional ability amongst users than non-users (Rigby et al., 2005). The use of outcome measurement is detailed in section 1.4 below. Differences in quality of life between users and non-users has also been shown in a Canadian study (Rigby, et al., 2011). Users and non-users also participated in the development of an ECS outcome measure which subsequently showed functional differences between the groups (Tam et al., 2003).

Some studies included users and non-users in a bid to increase sample sizes but this inclusion can make findings less clear. For example Stickel, et al. (2002) included non-users in an exploration of ECS satisfaction to create a sample of 40. The body of the study focused on satisfaction ratings of 20 users at two time intervals. The inclusion of non-users served as a comparison to clarify the importance assigned to individual elements of the outcome measure. Non-user ratings mirrored the ratings of importance provided by the users but non-users were unable to rate actual satisfaction, the primary focus of the study (Stickel, et al., 2002). An associated study[92] included non-users to evaluate the imagined perception of the psychosocial impact of receiving ECS (Jutai, et al., 2000). Similarly Rigby et al. (2005) evaluated the anticipated psychosocial impact for non-users and found them to be no different statistically than the actual psychosocial impact reported by users (Rigby, et al., 2005). Although the inclusion of non-users and their anticipated positive effects of ECS highlight the inequality between users and non-users the inclusion of both appears to be primarily a method of increasing sample sizes when using outcome measures. Outcome measures by definition measure the outcome of ECS. It appears contradictory to measure outcome of something anticipated. It is also possible that the outcome measures are not sufficiently sensitive to differentiate between users and non-users.

[91] SMAF is a tool primarily used in a geriatric setting to measure autonomy.
[92] Three studies reported different aspects (Stickel, et al., 2002) (Jutai, et al., 2000) (Rigby, Renzoni, Ryan, Jutai, & Stickel, 2000) of a larger overall study (Stickel, et al., 2002) (Jutai, et al., 2000) (Rigby, et al., 2000).

The decision to include non-users in two studies (Jutai, et al., 2000; Stickel, et al., 2002) is better understood in the context of the larger study of which they form a part (Rigby, et al., 2000). The larger study also included a conference presentation of qualitative data based on 58 interviews of both users and non-users. Findings show differences between the two groups using the Health Promotion Model of Quality of Life (Rigby, et al., 2000). These findings are based on thematic analysis of semi-structured interviews conducted in combination with the outcome measurements reported by Stickel, et al. (2002) and Jutai, et al., (2000) thus one can assume that participants' responses were influenced by these tools and do not reflect pure participant led qualitative disclosure. The Health Promotion Model of Quality of Life was again applied in a user non-user comparative study in a later study (Rigby et al., 2011). A summary of the studies of users and non-users can be found in Table 4 overleaf.

1.4 Outcome measurement

The anecdotal nature of early ECS research, based primarily on non-standardised interviews, was complimented by a later trend in ECS research of employing standardised outcome measures. This trend reflects a parallel move towards the use of outcome measurement in the wider AT field (Fuhrer, 2001; Rust & Smith, 2005). The Quebec Users Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers, Weiss-Lambrous, & Ska, 1996) which rates users satisfaction with assistive technology and the Psychosocial Impact of Assistive Devices Scale (PIADS) (Jutai & Day, 2002) designed to measure quality of life for AT users are two prominent psychometrically validated outcome measures applied in the field of AT. Both these measures have been applied in ECS studies.

The QUEST is an outcome measure specifically designed for assistive technology use and comprises two scales that evaluate satisfaction with the AT device and the AT service. The device scale incudes items pertaining to dimension weight, adjustments, safety, durability, simplicity of use, comfort and effectiveness. The service scale measures service delivery, repair services, follow-up services and professional services (Demers, Monette, Lapierre, Arnold, & Wolfson, 2002a). It is a measure of satisfaction with AT and has been used in a five person ECS trial to evaluate a non-commercial ECS (Vincent, et al., 2002) and in a study of 20 ECS users to evaluate consumer satisfaction with ECS (Stickel, et al., 2002).

Table 4: Summary of studies involving users and non-users of ECS, detailing sample sizes, data collection methods and findings

Study	Sample sizes	Data collection/outcome measure	Findings
Efthimiou, J.,Gordon, W.,Sell, H.& Stratford, C.(1981)	7 ECS users and 13 non-users	Activity Pattern Indicator comparing users and non-users	Users functioned more independently and participated in more activities than the non-users.
Jutai, J., Rigby, P.,Ryan, S. & Shone Stickel, M. (2000)	16 users 21non-users	Comparison of users perceived impact compared with non-users anticipated impact measured using the Psychosocial Impact of Assistive Devices Scale (PIADS).	Non-users' and users' PAIDS scores did not differ statistically.
Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J., & Stickel, S. (2000)	19 ECS users and 19 non-users	Qualitative semi structured interview.	Differences in qualitative themes presented in three categories: being, belonging and becoming considered to indicate greater quality of life for users than non-users.
Stickel, S. M.,Ryan, S.,Rigby, P. J. & Jutai, J. W. (2002)	20 ECS users and 20 non-users	Comparison on users and non-users using Functional Independence Measure (FIM), and Quebec Users Evaluation of Satisfaction with Assistive Technology (QUEST).	Users satisfied with ECS, users' satisfaction was stable over time, non-user and users rate importance of ECS equally.
Tam, C., Rigby, P., Ryan, S., Campbell, K. A., Steggles, E., Cooper, B. A., & Goy, R. (2003)	15 ECS users and 21 non-users	Comparison on users and non-users using Measurement of Control Using Electronic Aids to Daily Living, (MCEADL) and Functional Independence Measure (FIM) administered twice to establish test-re-test reliability.	Users accessed more electronic devices than non-users; MCEADL was shown to have good internal consistency and good test-retest reliability.
Rigby, P., Ryan, S., Joos, S., Cooper, B., Jutai, J. W. & Steggles, E. (2005)	16 users 16 non-users	Comparison on users and non-users using Psychosocial Impact Of Assistive Devices Scale (PIADS) and the Lincoln Outcome Measures for Environmental Controls (LOMEC) and The Functional Autonomy Measuring Scale (SMAF)	Psychosocial impact of ECS was positive for users and statistically equal to anticipated impact for non-users; Users had better performance than non-users for instrumental activities of daily living and for 75% of 12 daily tasks.
Rigby, P., Ryan, S. E., & Campbell, K. A. (2011)	15 users 21 non-users	Comparison of users and non-users based on Quality of Life Profile-Physical Disabilities (QOLP-PD)	Users rated their satisfaction with QOL significantly higher for total QOLP-PD scores and for four of the nine domains

The PIADS, is also an assistive technology outcome measurement and has three sub-scales: the Adaptability scale measures eagerness to try new things; the Competence scale measures efficiency, usefulness and independence; the Self-esteem scale measures happiness and frustration (Jutai, et al., 2000). Users of ECS, including those with neuromuscular conditions and those with SCI were found to have positive PIADS scores interpreted to mean high quality of life (Jutai, et al.,2000; Rigby, et al., 2005). Ripat and Strock (2004) used the PIADS in a repeat measures trial to record changes occurring during the process of becoming used to using ECS. Findings supported other studies which found that the anticipated psychosocial impact was similar to the actual impact of receiving ECS. However there were no statistical differences in PIADS scores at four stages (before, during and after becoming accustomed to using ECS). Results suggest poor sensitivity of the PIADS to small but clinically relevant changes that may have been detected by qualitative investigation (Ripat & Strock, 2004). In an associated study, the PIADS was included in an investigation of experienced users' perceptions of the impact of ECS and when compared to new users they were found to have similar PIADS score, illustrating stability of psychosocial impact of ECS for both new and experienced users (Ripat, 2006). This finding is similar to an earlier study that reported stable PIADS scores for 16 ECS users over time (Jutai, et al., 2000). The value of the PIADS as a discriminative measure of impact of ECS on life is questionable as it shows that new users, experienced users and potential users of ECS all view ECS equally positively. The tool was designed as an indicator of quality of life associated with assistive device use but fails to distinguish between stages (Jutai & Day, 2002). The possibility that ECS use does impact quality of life is likely in light of clinical observations of impact for ECS users at different stages of using ECS but the measure does not indicate how ECS impact at different stages. The use of the PIADS appears to support the common-sense expectation that ECS will have a positive psychosocial impact on users. However, it offers little detailed insight into the nature of the psychosocial impact of ECS.

The use of ECS specific outcome measures was first reported by Harmer and Bakheit (Harmer & Bakheit, 1999) who used an adapted version of the unpublished Lincoln Outcome Measures for Environmental Controls (LOMEC) in a mixed methods study. The LOMEC was adjusted to develop the Measurement of Control Using Electronic Aids to Daily Living, (MCEADL) which aimed to measure the functional benefit of ECS usage (Tam et al., 2003). The MCEADL is divided into three parts: Control and use of ECS; Functional impact of ECS, and User's ratings

of ECS devices and services. It has demonstrated reliable and consistent psychometric properties[93] based on a sample of 15 ECS users and 21 non-users. A third adaptation of the LOMEC was used in an investigation of people with SCI and appears to be a precursor to the MCEADL, despite its publication after the publication of the MCEADL, The study reported in 2005 appears to be have been conducted before 2003 (Rigby, et al., 2005). The MCEADL offers some potential as an ECS specific outcome measure but there is no reported further application of its use. This may be an indication of the complexity of the tool as it aims to measure the specific devices accessed using ECS and the functional impact as well as assessing services and devices. These three parts possibly reflect different areas of concern that may not match specific research objectives. In addition although the tool measures functional impact it falls short of reflecting the specific value of ECS to individuals.

Other outcome measures applied to ECS research include the Canadian Occupational Performance Measure (COPM) (Ripat, 2006), the Functional Autonomy Measuring Scale (SMAF) (Rigby, et al., 2005), the Life-H (Vincent, et al., 2002) and the Quality of Life Profile – Physical Disabilities (QOLP-PD) (Rigby, et al., 2011). The variety of outcome measures, reflective of different aspects of ECS use, while useful in individual studies, prohibits the overall evaluation of ECS use and comprehensive comparison across studies which would require the application of the same outcome measures in all studies.

1.5 Qualitative investigation

A shift towards qualitative enquiry in ECS research has occurred in the last decade. Exploration of ECS use is well suited to qualitative investigation due to the expansive nature of ECS use in daily life that is difficult to restrict to single dimensions such as satisfaction or psychosocial impact. In addition, small sample sizes makes the statistical analysis required for quantitative investigation problematic. The value of qualitative data is reflected by the inclusion of some quotations in both descriptive and quantitative studies such as von Maltzahn, Daphtary, & Roa, (1995), Stickel, et al. (2002) and Bonner & Auterson (2003). In addition some mixed method publications have used qualitative findings to substantiate and expand on quantitative results such as a semi-structured interview to expand on the outcomes of the adapted LOMEC (Harmer & Bakheit, 1999) and

[93] Test-retest reliability, and internal consistency.

open-ended questioning to supplement the PIADS (Ripat, 2006). Studies focused on the users' perspective employing qualitative methodology are presented in Table 5, overleaf. Some of these studies are unpublished thesis findings and conference proceedings and not therefore readily accessible and were accessed through conference attendance[94] or personal communication with the authors (Buxton, 2007; Judge, Robertson, & Hawley, 2009b; Rigby, et al., 2000; Stead, 2002b).

A number of qualitative research methodologies have been adopted including narratives (Ripat & Strock, 2004), grounded theory (Palmer & Seale, 2007; Stead, 2002b), phenomenology (Erikson, et al., 2004), framework analysis (Judge, et al., 2009a; Judge, et al., 2009b; Judge, et al., 2011a; Judge, et al., 2011b) and naturalistic inquiry (Buxton, 2007). The data produced through qualitative inquiry are intended to be rich, deep and descriptive. However, it can be challenging for researchers to articulate findings and for readers to interpret them, as they are presented in a wide range of formats including codes, themes, sub themes and categories. Table 6. Judge et al (2009a) presented 5 main themes with 5 to 17 sub themes within each. Palmer and Seale (2007) found 8 categories, Buxton (2007) described 8 codes, and Erikson et al (2004) discussed 4 stages when first using ECS (Table 6). The themes that emerged ranged from practical and technical ones, to those describing the benefits and deeper meanings of living with ECS. These qualitative investigations are an important contribution to the knowledge base as they focus on users' opinions, attitudes and views of ECS and would warrant a meta-synthesis to identify shared elements (Hammell, 2007). These studies are individually useful but combining them may be more valuable (or possibly inconclusive). Such a meta-analysis falls beyond the scope of this study and a summary is presented below and in Table 6.

[94] The individual conference proceedings are also available to members of the Rehabilitation Engineering And Assistive Technology Society of North America RESNA and Association for the Advancement of Assistive Technology In Europe AAATE.

Table 5: Summary of qualitative ECS studies, indicating sample sizes, methodology and topic of focus

Authors	**Sample**	**Methodology**	**Topic**
Bell, P. & Hinojosa, J. (1995).	3 users	Open-ended interview	Impact of ECS on daily life
Harmer, J., & Bakheit, A. M. (1999).	16 ECS users	Mixed methods– questionnaire and semi-structured interview	Effect of ECS on functional abilities
Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J., & Stickel, S. (2000)	19 ECS users and 19 non-users	Semi-structured interviews (associated with a quantitative study)	Impact of ECS on daily life
Stead (2002b)	6 users	Grounded theory, semi-structured interviews	Users' perspective of use of ECS - impact of quality of life
Ripat, J., & Strock, A. (2004)	7 users	Mixed methods – PIADS outcome measure and open ended questioning	Acquisition of ECS
Erikson, A. ,Karlsson, G., Soderstrom, M., &Tham, K. (2004)	11 traumatic brain injured users	Empirical phenomenological psychological method, interview	Acquisition of ECS
Palmer, P. & Seale, J. (2007)	14 users	Grounded theory, semi-structured interview	Attitudes to ECS
Buxton , J.C.(2007)	2 users	Semi-structured interview	Acquisition of ECS
Judge, S., Robertson, Z., Hawley, M., & Enderby, P. (2009)	12 users	Framework analysis, semi-structured interview	Users' perceptions of Speech ECS
Judge, S., Robertson, Z. & Hawley, M.S. (2009)	Users & professionals (n=unknown)	Framework analysis, semi-structured interview	Use of ECS
Judge, S., Clarke, Z., & Hawley, M. S. (2011).	8 Professionals	Framework analysis, focus group and interview	AT professionals' perceptions of Speech ECS

Table 6: Qualitative ECS studies for all populations summarising findings described as categories and themes

Author	**Research focus**	**Category**	**Themes/ Codes**
Bell, P. & Hinojosa, J. (1995)	Impact of ECS on daily life		Getting out
			What do I do with all this time
			I found an easier way
Harmer, J., & Bakheit, A. M. (1999)	Effect of ECS on functional abilities	Increased independence	Provision of ECS made it possible to live alone
			Able to socialise more
		Increased feelings of self-worth and happiness	Strengthened family relationships
			Given meaning and purpose in life
			Reduced feelings of frustration caused by the disease
		Increased feeling of control over the environment	More confidence to be independent
			Prevented need for institutional care
Rigby, P., Renzoni, A.M., Ryan, S., Jutai, J. & Stickel, S. (2000)	Impact on daily life	Being	Reduced physical dependence
			Do things for personal health and safety
			Value of independence
		Belonging	Control over personal space and activity
			Change in interpersonal relationships
		Becoming	Reduced carer workload and worry
			Increased opportunities in daily life
			Greater access to computer
Stead, A. (2002b)	Value of ECS		Independence
			Quality of life
			Meaning
			Cost benefits
			Benefits for carers
			Risks and safety
			ECS Not for everyone

Author	**Research focus**	**Category**	**Themes/ Codes**
Erikson, A., Karlsson, G., Soderstrom, M., & Tham, K. (2004)	Lived experience in an ECS training apartment		*Plunging into* an ECS equipped environment
			Landing and feeling comfortable
			Incorporating the *new* into daily activities
			Taking off in the future
Ripat, J. & Strock, A (2004)	Users' perceptions of the impact of electronic aids to daily living	Narratives from users (Themes were not reported)	*Feel safer… more independent and make things simpler'*
			The (ECS) was not going to help me get up and walk; it's not a 'cure-all'
			Easy to use
			I don't want to be without it…don't like to ask nurses to do too much
			Do things on my own, can do what I want, when I want it.
Palmer, P. & Seale, J. (2007)	Users attitudes to ECS	Part of me	Utility transcended
		Indispensable	
		Changed my whole outlook	
		Very very helpful	Utility denied
		Useful	
		Good points and bad	
		Extremely limiting	
Buxton, J. (2007)	Users' perceptions of ECS		The excitement of anticipation
			The long wait was worth it
			A feeling of safety
			Spreading the word
			I am in my glory now
			The ECS is my friend
			Hearing yourself constantly asking for help
			Now I can do what I want, when I want!

Author	**Research focus**	**Category**	**Themes/ Codes**
Judge, S., Robertson, Z., Hawley, M. & Enderby, P. (2009a)	Users perception of speech-driven ECS	Failure	Human issues
			Reliability
			Technical issues
		Success	Determination
			Resilience
			Simplicity
			Speed of operation
			Use of voice
			Personalising the device
			Compensation tactics
		Background	Cognitively able
			Computer literature
			Tolerant
			Computer voice recognition experience
			History of long term ECS use
			Support from carers
		Interface	Aesthetics
			Microphone
			Feedback and interaction
		Usage	Risk
			Security
			Independence
Judge, S., Robertson, Z. & Hawley, M.S. (2009b)	Professionals and users perceptions of ECS	History of ECS use	
		Assessment	
		Risk assessment	
		ECS use	
		Provision of ECS	
		Perception of current ECS	

Author	**Research focus**	**Category**	**Themes/ Codes**
Judge, S., Robertson, Z., & Hawley, M. S. (2011).	Professionals' perceptions of speech-driven ECS	Background	Disability, condition or cognitive ability
		Speech-driven ECS usage	Last resort when switch input is not acceptable
			Back-up device
			Risk assessment
			Extensive training
		Interface	Understanding of how to talk to the device
			Aesthetics
			Microphones
		Success	Voice patterning
			Modifying control words to be phonetically distinct
			Use of voice when unable to access other system
		Failure	Reliability
			Sound interference
			Changes to voice
			Condition that affects memory or cognition
			Difficulties interfacing with some peripherals, training new functions and limited menus.

Qualitative studies have contributed the following to the body of knowledge about ECS:

- ***Practical and technical themes***: *access to information about ECS* (Stead, 2002b), *upgrading of ECS* (Stead, 2002b), *reasons for success or failure of ECS* (Judge, et al., 2009a; Judge, et al., 2011a; Judge, et al., 2011b;), *users' background and experience* (Judge, et al., 2009a; Judge, et al., 2011b) and *interface features* (Judge, et al., 2009a; Judge, et al., 2011).

- ***Benefits of ECS***: *cost savings* (Stead, 2002b), *care giver benefits* (Rigby, et al., 2000; Stead, 2002b), *independence* (Judge, et al., 2009a; Rigby, et al., 2000; Stead, 2002b), *improved quality of life* (Stead, 2002b), *risk management, security* (Judge, et al., 2009a; Rigby, et al., 2000), *very helpful* (Palmer & Seale, 2007) and *useful* (Palmer& Seale, 2007).

- ***Themes focusing on meaning:*** Stead (2002b) described *meaning* using sub-themes such as *time alone*, *freedom* and *decreased burden of care* (resulting in more balanced relationships) (Stead, 2002b). Buxton (2002) also described meaning using themes such as *I am in my glory now* and *the ECS is my friend* (Buxton, 2007). Palmer and Seale's findings also include elements of meaning ascribed to ECS such as *Part of me* and *Indispensable.*

- ***Themes focusing on users' attitudes:*** In an exploration of users' attitudes to ECS, Palmer and Seale (2007) used *codes* such as: *part of me*, *changed my whole outlook* and *indispensable*. Findings from these qualitative studies (themes or codes) indicate the deeper psychological meanings of ECS for users compared to traditional (quantitative) results that focus on physical and functional benefits.

Qualitative inquiry yields both expected and unexpected findings. While most ECS research focuses on the expected positive aspects of ECS, Palmer and Seale (2007) offer a balanced perspective with themes that included *good points and bad* and *extremely limiting.* These negative aspects could be attributed to the use of outdated ECS equipment (Steepers fox, Possum PSU6, Possum companion) (Palmer& Seale, 2007). Similarly Stead (2002b) found that ECS are *not for everyone* and identified *unhappy users* (Stead, 2002b).

2. What the evidence tells us

An exploration of existing literature demonstrated a range of different approaches to the study of ECS. This review was conducted in order to examine *what is known about ECS* and, by reviewing the known ECS literature, to explore *what users think about ECS.* In summary the initial review highlighted that what we know about ECS is based on scant evidence and limited application of a variety of outcome measures predominantly based on Canadian samples with little consistency of measurements between studies. The reviews of service provision, are predominantly based in the United Kingdom and while attempts to compare users and non-users indicate some functional differences they fall short of providing insights into *what users think of ECS.* Qualitative studies have begun to explore users' perceptions and convey a wide array of opinions and experiences including practical issues, benefits, meanings and attitudes towards ECS.

Reviewing such a broad literature base was seen as central to providing an understanding of previous studies that have underpinned ECS research, which is itself relatively under-researched. The next stage was to further examine issues raised by this initial review by returning to the literature. While a conventional data-base search was conducted, it was clear that studies focusing on ECS users' views, perceptions and experiences were sparse. The search was extended to include searches for any academic publication that featured ECS. A comprehensive search for abstracts was carried out on electronic databases: CINAHL, PubMed, Science Direct and Web of Science for the years 1980 to 2011, using environmental control systems/ units as well as the following search terms: electronic aids to daily living, domotics, electronic assistive technology, and home automation. This yielded some new studies supplemented further by hand searches,[95] conference proceedings[96] and thesis collections. From these sources six recurring primary areas of investigation were identified including: 1) uses and functions of ECS; 2) independence; 3) participation in activities; 4) quality of life; 5) satisfaction and 6) carer benefits. These six areas will now be discussed in turn.

[95] Hand searched journals: Assistive Technology; Disability and Rehabilitation; Disability and Rehabilitation: Assistive technology; Technology and Disability; Journal of Assistive Technologies.
[96] Hand searched cconference proceedings: – Rehabilitation Engineering and Assistive Technology Society of North America RESNA, Association for the Advancement of Assistive Technology in Europe AAATE.

2.1 Uses and functions of ECS

ECS are considered to be useful for people with severe physical disabilities including high SCI. As ECS are designed and intended to enable control of the environment it is assumed intuitively that they will be experienced as useful and beneficial by users (Dickey & Shealey, 1987; Lange, 1998; Wellings & Unsworth, 1997). There is some literature to support these assumptions that also reflect the *useful* code as used in the grounded theory study by Palmer & Seale, (2007).

The possible uses of ECS have been described in Chapter 2. Use of ECS has been considered in terms of functions of ECS – the frequency of use of functions and importance of functions. Approaches to recording the uses of ECS have included a data logger (von Maltzahn, et al., 1995) electromagnetic counters (Symington, Lywood, Lawson, & MacLean, 1986) and questionnaires (McDonald, et al., 1989; Mann, 1992). A descriptive study based on a postal survey of 29 ECS users, described the most important ECS functions in order of importance as telephone, television and lights (McDonald, et al., 1989). A trial of 5 people using a modular ECS supports these findings, rating telephone as the most important function with entertainment the most used (von Maltzahn, et al., 1995). A Finnish study reported door opening as the most frequently mentioned function in a postal survey (Kanto-Ronkanen, et al., 2003). It is possible that participants in other studies may not have door openers as part of ECS. A single study also explored the time saving function of ECS by asking how long it took users to do tasks (Croser, et al., 2001).

A study based on an interview and structured questionnaire identified improved home security as the greatest functional improvement identified by 16 users and 13 carers (Harmer & Bakheit, 1999). Ripat (2006) used an occupational therapy outcome measure, the Canadian Occupational Performance Measure COPM with 15 experienced ECS users. The COPM allowed users to identify the most important functions of ECS as opposed to being offered researcher chosen options. This yielded 67 unique items that were then analysed thematically into seven categories. These experienced ECS users identified functions of independence, productivity, entertainment, safety needs, communication of basic needs, and socialising. In contrast (McDonald, et al., 1989) provided pre-determined options, including ECS as an aid to independence, as a communication tool, and as an aid to interacting with other people thereby restricting the responses of participants (McDonald, et al., 1989).

Usage rates for ECS are higher than other AT reaching almost 100% in both a French and a United Kingdom study (Brochard, et al., 2007; Cowan & Turner-Smith, 1999). Non-use has been attributed to unsuitability of systems due to users' functional deterioration, unrepaired ECS and lack of set-up following a house move (Cowan & Turner-Smith, 1999; Maguire, et al., 2001). High usage rates have also been associated with high perceived psychosocial impact measured using the PIADS in comparison with lower PIADS scores for users of low technologies like reading glasses (Jutai, et al., 2000).

2.2 Independence

Although the term independence is considered contentious in Chapter 1 section 6, and the term interdependence is favoured, all ECS studies suggest that ECS improves independence, often without providing a definition of independence. McDonald, et al. (1989) found 93% agreement with the statement: the ECS provides independence (which was not defined). Similarly participants in a 2-week Australian trial provided high ratings when asked to specifically rate independence (the ability to do a task alone) for each device using a researcher-designed 10-point scale (Croser, et al., 2001). In a comparative study users were considered to be more independent than non-users based on the ability to do more activities without help (Efthimiou, et al., 1981). *Independence* has been described as being able to live alone and socialise more, based on semi structured interview (Harmer & Bakheit, 1999). Findings from ECS studies include themes of *Independence* (Judge, et al., 2009a; Stead, 2002b) *Reduced physical dependence, the value of independence* (Rigby, et al., 2000) and a more descriptive *Now I can do what I want when I want* (Buxton, 2007). Thematic analysis of postal replies from both users and carers presented independence to be an important factor in users' lives (Kanto-Ronkanen, et al., 2003). Likewise thematic analysis of COPM results of experienced users included the theme of *Increasing and maintaining independence* (Ripat, 2006). Studies that show positive PIADS scores suggest improved independence for users because independence is considered a component of the competence dimension in the PIADS (Ripat & Strock, 2004; Rigby, et al., 2005; Ripat, 2006). Similarly three studies that used adaptations of the LOMEC, indicated that users were more independent than non-users for several ECS specific tasks (Harmer & Bakheit, 1999; Tam, et al., 2003; Rigby, et al., 2005).

ECS are designed to allow users to control devices and thus the literature shows that they do as intended and as expected. Independence is used as a catch-all phrase to include functional ability, living alone, socialisation, competence, choice and autonomy. Independence is not a discriminative term and its non-specific use does not contribute to a further understanding of ECS. Findings tell us that ECS enable people to do some tasks with less assistance supporting the biomedical understanding of the term independence which implies physical independence. The literature however falls short of providing a wider interpretation of how ECS might affect interdependence. As social beings we are more inclined to be interdependent: supporting and relying on each other (Hammel, 2006). For people with high SCI the reliance on others is a given but their ability to support others interdependently has not been considered in ECS studies. Total physical independence is unlikely for a person with a high SCI and the biomedical preoccupation with achieving independence thus values something that is unrealistic. Interdependence that involves social reciprocal relationships is a more appropriate goal that physical independence.

2.3 Participation

In the literature independence is closely related to participation. While independence tends to imply physical autonomy, participation incorporates activity and engagement in meaningful occupation and social exchanges. The investigation of participation has gained importance since its inclusion in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) although this was preceded by the occupational therapy interest in the value of activity participation (Yerxa, 1993). Participation is an expected outcome of ECS that has been measured in several ways. Rigby et al. (2005) used the SMAF to show that users were more independent in instrumental activities of daily living. Adaptations of the LOMEC also illustrated participation for users[97] in categories of occupation, comfort, communication and security. There are some differences between studies that may be attributed to differences in type of ECS (Harmer & Bakheit, 1999; Rigby, et al., 2005).

A comparison of 7 ECS users with 13 non-users, all male participants, in 1981 analysed activity patterns based on both frequency and duration of activities (Efthimiou, et al., 1981). This study not only found differences between users and

[97] Compared to non-users in Rigby et al, (2005) and compared to tasks without the ECS by Harmer and Barkheit (1999).

non-users in terms of control of household appliances but differences in activity patterns. For example users engaged in more active activities such as travelling in the community and spending time in education. The study also administered some psychological assessments to see if activity differences were correlated to personality but found no relationship. Some of the activities investigated were not directly facilitated through ECS use. The authors suggest that ECS use has a wider impact on activity participation that includes increased engagement in other activities such as travel and education. It may be that ECS use stimulates users to become more engaged in travel and education through increased personal expectations and it may be that users of ECS are more likely to seek other forms of activity engagement. This line of thought is again speculative and suggests a potential impact of ECS use that has not been adequately explored.

The opportunity to socialise is not a traditionally expected outcome of ECS use and has not been a specific focus of research. However socialisation has been linked to ECS use (Kanto-Ronkanen, et al., 2003) and is reflected in qualitative findings including *getting out* (Bell & Hinojosa, 1995), *able to socialise more* (Harmer & Bakheit, 1999), and as a category of COPM responses, *socialisation with friends and family*. These findings suggest that ECS use can be related to enhanced socialisation. Improved access to telecommunication through ECS use may explain improved abilities to socialise but this link has not been explored. Socialisation may be viewed as an element of interdependence that may be facilitated through increased ability to participate equally in social exchanges using ECS as an aid. This notion is however speculative and has not been explored in any known study. A contrasting viewpoint may be that as technology and ECS improve the ability to control increasingly versatile and complex home entertainment systems, its use may negatively affect socialisation by providing increased user comfort and desire for home entertainment. The relationship between ECS and socialisation is an under researched area.

The literature shows that ECS use is associated with increased participation in activities (Harmer & Bakheit, 1999; Kanto-Ronkanen, at al., 2003; Rigby et al, 2005). The evidence does not provide a convincing causal link between ECS and increased participation nor does it explore the nature and extent of participation. The effect of ECS use on participation in socialisation, education and travel has not been investigated fully. The meaning of participation for people including those with high SCI may be better understood in light of the concept of occupation that

involves doing, being, becoming and belonging (Hammell, 2004a) as opposed to categories of instrumental activities of daily living, comfort, communication, security and socialisation. According to ICF terminology, participation refers to life situations (WHO, 2001) and one of the aims of occupational therapy is to facilitate participation in life situations. Participation could therefore be explored in terms of lived experience rather than being restricted to researcher defined categories.

2.4 Quality of life

Improving quality of life is often cited as a reason for recommending ECS but measurement or demonstration of impact on quality of life is a complex issue as quality of life is subjectively experienced (Ripat & Strock, 2004; Hammell, 2006). Quality of life is used loosely throughout the literature and most studies report improvements to quality of life as a consequence of ECS use (Jutai, et al., 2000; Maguire, et al., Novak, 1998; 2001; Ripat & Strock, 2004; von Maltzahn, et al., 1995). One must however question if the experiential meaning of quality of life has been dealt with in any of the current literature pertaining to ECS as quality of life improvements are illustrated using researcher-designed questionnaires and not by seeking user opinions. Several weak claims of improved quality of life are evident in the findings of some studies. A survey in Northern Ireland demonstrated improved quality of life for 93% of ECS users although it is unclear how quality of life was defined or measured (Maguire, et al., 2001). It is likely that yes/no questions were used giving little scope for opinions outside those asked in the questionnaires and thus poorly reflective of individual subjective quality of life. Similarly von Maltzahn, et al. (1995) reported improved quality of life based on interviews that explored how five people used ECS and the factors affecting ECS use. The study did not investigate quality of life and the finding of improved quality of life is based on reports of increased sense of independence and control. Likewise Novak (1998) conducted an audit of ECS use in 29 people's homes using a questionnaire, the details of which are not provided in the study. He found that two thirds of users reported:

> *ESC substantially improved their quality of life and made them less dependent on carers* (Novak, 1998, p. 90).

It is not clear if quality of life and less dependence on carers were separate items on the questionnaire and the evidence does not appear to be substantial as claimed. Again it appears that quality of life is presumed to be quantifiable and measurable

with yes/no options. One study reports that 7 out of 8 persons trialling ECS for two weeks reported decreased frustration, although one person found it increased frustration (Croser, et al., 2001). Decreased frustration was loosely linked to an improved quality of life, although the instrument used to measure frustration was a researcher-designed rating scale without demonstrated psychometric properties making the findings open to individual interpretation.

High PIADS scores have been found for both ECS users and potential users and it has been suggested that ECS has a role to play in improving quality of life and enhancing autonomy (Jutai, et al., 2000; Ripat, 2006). The assumption that high PIADS scores reflect high quality of life implies that quality of life is related to all categories of the PIADS including adaptability. Adaptability involves eagerness to try new things which may be a reflection of personality rather than quality of life. Similarly competence includes usefulness that relates to the device more than the person. The self-esteem category that includes happiness is more closely aligned to quality of life. The utilisation of PIADS as a quality of life measure is limited. On a similar theme, (Jutai, et al., 2000; Ripat, 2006;. Stickel, et al., 2002) suggests that:

> *ECS would also provide for mental stimulation, and both a vocational and vocational opportunities, which in turn would positively influence quality of life* (Stickel, et al., 2002, p 120 -121).

Quality of life is not a direct focus in these publications. However an assumption of a link to quality of life was made in a conference presentation (Rigby, et al., 2000) that analysed qualitative data from 19 users and 19 non-users according to the Quality of Life model (QOL model) that considers three categories – *Being*, *Belonging* and *Becoming*. The QOL model has also been used as the basis of an outcome measure the Quality of Life Profile – Physical Disabilities (QOLP-PD). This outcome tool demonstrated differences between users and non-users but was not able to establish a causal link between using ECS and quality of life as it investigates quality of life in general terms and not specifically defined in relation to ECS use (Rigby, et al., 2011). The QOL model bears some resemblance to an occupational therapy based interpretation of occupation as *Doing, Being*, *Belonging,* and *Becoming* (Hammel, 2004a) offering a useful lens for the consideration of ECS by occupational therapists. However on closer examination the definitions of *Being, Belonging,* and *Becoming* differ from those in occupational therapy literature. In the QOL model *being* incudes physical health, thoughts feelings and beliefs. In

occupational terms *being* is about spending time reflecting, time with others and appreciating nature, art, music. It involves activities that may not be considered productive or that are not inherently purposeful but which are meaningful. *Becoming* in the QOL model involves expressing individuality and choice and pursuing dreams. *Becoming* includes *Practical becoming* that involves doing which is a separate fundamental category in the occupational sense. It also includes *Leisure becoming* representing things you do for entertainment. Both these sub categories *Practical becoming* and *Leisure becoming* appear to include aspects that fit with the occupational category of *Doing*.

Ripat and Strock (2004) used mixed methods to explore quality of life using the Lifestyle Performance Model. Findings suggest that the use of ECS enhances autonomy, individuality, volition, predictability and self-efficacy which together contribute to an improved quality of life (Ripat & Strock, 2004). Other qualitative findings include themes that relate to improved quality of life such as *increased feelings of self-worth and happiness* that are based on strengthened relationships, meaning and purpose in life, and reduced feelings of frustration caused by the disease (Harmer & Bakheit, 1999). Buxton identified a theme of *I am in my glory now* that can be interpreted to reflect enhanced quality of life (Buxton, 2007). Stead (2002b) also identified *Quality of life* as a specific theme.

Although there is a general consensus that ECS improves quality of life, the quality of life evidence to support this is poor. Quality of life is a personal construct that has been reported in several publications, many of which appear to base their findings on responses to a yes/no question. The PIADS cannot be considered an adequate quality of life measure and only one study uses a standardised quality of life specific measure (Rigby, et al., 2011). Qualitative studies provide more convincing evidence of improved quality of life reflected in the identification of positive themes. An in-depth understanding of living with ECS that takes into account both positive and negative effects is required to explore the effect of ECS on quality of life.

2.5 Satisfaction

Satisfaction with ECS is a common theme throughout much of the literature. In a mixed methods study that employed both an adapted version of an outcome measure (LOMEC) and a semi structured interview, 16 ECS-users reported high satisfaction despite using large, bulky and outdated equipment as observed by the researchers who anticipated some level of dissatisfaction (Harmer & Bakheit, 1999).

The use of outdated ECS is not uncommon (Novak, 1998; Palmer & Seale, 2007) as systems are expensive and unlikely to be updated on a regular basis (Wellings & Unsworth, 1997). Living in the age of technology, it seems unlikely that users will remain satisfied with such outdated ECS if the technology around them continues to progress so rapidly.

Vincent et al (Vincent, et al., 2002) conducted a 5-person, 3 month trial using a customised non-commercial[98] ECS that included some smart home functionality such as verbal reminders and automatic functions.[99] Findings were based on five individual case studies that included the use of the QUEST and Life-H to measure satisfaction. The Life-H measured satisfaction with activity performance (meal preparation, sleep, hygiene, and telecommunications) facilitated by smart home functions that extend beyond the capabilities of ECS as defined in this thesis. Users reported high levels of global satisfaction[100] with ECS according to the QUEST. Vincent et al (2002) expressed surprise at users' satisfaction despite technical difficulties. Three of the planned ECS applications were not installed and others were considered to be not effective by users (according to a developer-designed questionnaire). Vincent, et al. (2002), reported that users were most satisfied with ECS while caregivers reported that intermittent functionality made them feel unsafe leaving participants alone and allied health workers expressed disappointment with the efficacy of the ECS system. High levels of satisfaction may have been related to the functions that did work in the system most of which related to smart home functionality, such as reminders. Although technical issues may have been apparent to allied health professionals, users may have only considered the successful functions when completing the QUEST. These positive findings may also indicate a bias in the QUEST towards positive satisfaction in contrast to interviews that may have elicited balanced critique. The functional abilities enabled by the ECS also need to be considered in contrast to living with no technical supports. Thus, for participants satisfaction may be considered relative to having no technology. The use of in-depth qualitative methods could have provided insights to users' full experience and explored reasons for users' satisfaction and care-givers' dissatisfaction.

[98] Designed by a research and design team.
[99] Such as automatic stove power off after use.
[100] Item-by-item analysis revealed moderate satisfaction with comfort, follow-up service, versatility, durability, effectiveness and adjustments.

The QUEST also demonstrated global satisfaction with ECS that was stable over time for 16 users with neuromuscular conditions (Stickel, et al., 2002). Users were most satisfied with simplicity of use, maintenance, weight safety and dimensions, and less satisfied with costs, follow-up services, delays and device compatibility. These two studies illustrate the possible application of the QUEST as an outcome measure in evaluating assistive technology services and ECS in particular. The QUEST however included some elements not suitable for ECS (Stickel, et al., 2002) and the stability of the measure may also reflect a lack of sensitivity to changes in satisfaction over time. However, this can only be investigated by comparative studies incorporating other ways to investigate satisfaction over time.

Two qualitative studies using grounded theory investigating users' perspectives and users' attitudes towards ECS found themes indicating some dissatisfaction with ECS as expressed in novel themes not reported elsewhere in the literature (Palmer & Seale, 2007; Stead, 2002b). Stead's data analysis included a theme entitled *not for everyone* reflecting the reality that, like most equipment and services, ECS do not suit everyone (Stead, 2002b). Research participants in the study were all experienced ECS users having embraced ECS in their daily lives and yet were able to articulate the fact that ECS are not likely to suit everyone. This highlights the need for caution when considering ECS in order to ensure that ECS is suited to each individual. Similarly, it is usual to expect a level of abandonment common in all AT use (Wessels, Dijcks, Soede, Gelderblom, & De Witte, 2003).

When Palmer and Seale (2007) explored users' attitudes to ECS they also found codes reflective of some dissatisfaction including a description of ECS as *extremely limiting.* Clearly, ECS do not remove the need for physical assistance with positioning, feeding and even scratching oneself. This theme also reflected limitations of individual systems suggesting a need for continual updating and extending of ECS. This is reflected in another category *it could be better* which identifies the need for improvements in ECS. This category was of interest because it matched my clinical experience of potential users' frequent criticism of existing ECS when first introduced to them. The category of *good points and bad* captured the sense of ECS as both a nuisance and a convenience. Users thus articulated a balanced view of ECS highlighting the value of in-depth qualitative investigation that might reveal both positive and negative perspectives largely absent in quantitative studies.

Reported high levels of satisfaction require further investigation. While users appear to be satisfied with ECS the measurement of level of satisfaction is based on one outcome measure with validated psychometric properties for other various types of AT and populations (Demers, et al., 2001a; Demers, Wessels, Weiss-Lambrou, Ska, & De Witte, 2001b, Demers, et al., 2002a; Wessels & De Witte, 2003; Wressle & Samuelsson, 2003). The extrapolation of these findings requires caution as the studies involved small sample sizes of 5-20 users (Vincent, et al., 2002; Stickel, et al., 2002). Other reports of satisfaction were based on researcher-guided investigations with predefined expectations and outcomes. In addition some indications of dissatisfaction are revealed in qualitative findings that are not reflected in quantitative findings which poses the question – *what do users really think about ECS?* When users are asked about satisfaction with ECS, the response may relate simply to satisfaction with having ECS in contrast to having no ECS. It is likely to be more satisfactory to have an ECS, despite possible criticisms thereof, than to live without ECS. If users were instead asked, what they were dissatisfied about or how they would like their ECS improved the findings might be different. Available qualitative findings are more aligned with clinical experience that identifies user dissatisfaction with some features including lack of integration with mobile telephone functions such as text messaging, the unattractive appearance of devices, and limited flexibility for use in different positions, for example, wheelchair-based systems that cannot be used in bed. Results relating to satisfaction with ECS cannot be considered conclusive and requires further investigation to clarify the relationship between satisfaction and possible negative evaluations of ECS, by allowing participants scope to explain how they live with ECS including difficulties, criticisms and challenges as well as benefits and values.

2.6 Carer benefits

Improvements for care givers are an assumed benefit of ECS but these have not been adequately substantiated with evidence (McDonald, et al., 1989; Stickel, et al., 2002). Symington et al., (1986) found ECS reduced the workload of carers in a nursing home by an estimated equivalent of one hour a day, due to less frequent demands from residents. This finding is however dated and based on institutional living that is no longer the norm for people with high SCI. There is some evidence that ECS can allow users to be comfortable alone without carers for longer periods (Harmer & Bakheit, 1999; McDonald, et al., 1989; Novak, 1998) which may give rise to the assumption of carer benefits.

> *Relieving families of being constantly within calling distance or on alert* (Von Maltzahn, et al., 1995, p 222).

Vincent et al. (2002) aimed to evaluate the possibility of ECS replacing some home services. While this small study of five participants indicated mild improvements for users, no improvement for carers was reported as they experienced stress when the system did not work properly. This finding cannot be generalised due to the small sample size, the technical difficulties of an unreliable system used in the study and the inclusion of several smart home functions making the specific effect of the ECS component unclear. A home based questionnaire audit of ECS found reduced care costs in two of 29 ECS users as a consequence of the ability to spend nights alone by using a reliable personal alarm system for summoning help (McDonald, et al., 1989). In contrast, findings from a semi-structured interview that formed part of a mixed method study reported reduced care needs in 13 of 16 participants. Two participants reported being able to be alone for 13 hours or more, six participants could be alone for between 4-9 hours, and seven reported being able to be alone for up to 3 hours after the installation of an ECS (Harmer & Bakheit, 1999). This is the only study to clearly illustrate that users can enjoy significant increases in time spent alone with the ECS.

Seventy percent of ECS users lived in apartments compared with 25% of non-users in Stickel et al.'s (2002) study. Rigby et al. (2005) report a similar statistic with twice as many ECS users compared with non-users able to live alone with personal assistance. In contrast, in Northern Ireland only 24% of ECS users lived alone (Maguire, et al., 2001). Interestingly there were no differences in hours of formal care given to either group in Rigby's study. This could indicate that those living with family may require assistance from family members to supplement formal care while those living alone may use ECS to supplement formal care. Such differences in unpaid assistance were explored in another study that showed non-users require 2.5 times more hours of unpaid assistance from family and friends than ECS users (Rigby, et al., 2011). Ripat and Strock (2004) suggest that the benefit of ECS may not be cost saving but relate to a subjectively improved quality of life, best explored using a qualitative study and reflected in the theme *reduced carer workload and worry* (Rigby, et al., 2000).

Similarly Stead's analysis included cost benefit as a theme for those living at home using an ECS in comparison with living in institutional care (Stead, 2002b). Although possible financial benefits may result from the use of ECS, this topic has not been systematically investigated. It appears that the use of ECS may not formally reduce care hours provided and may thus not result in actual financial benefits. If ECS reduces the load placed on carers this may have other financial benefits such as reducing the need for other household assistance such as home help which may now be done by carers during periods of reduced need. The financial implications of ECS warrant further investigation. A suggested focus for such an investigation is the potential reduction in initial care package possible through the inclusion of ECS in a discharge plan. Having ECS when discharged could mean fewer care hours are required in contrast to discharge without ECS. If those discharged without ECS acquire them at later stage their acquisition may or may not result in a reduction in care hours originally allocated to them. This may involve an initial expense to set-up ECS, limited on-going maintenance costs and overall long term savings in terms of care.

3. What ECS users think

This review has introduced a variety of concepts and supporting evidence which are challenging to summarise and on the whole inconclusive. Ripat reviewed 11 ECS publications and commented that:

> *the majority of evidence of the impact of the (ECS) on individuals is anecdotal or collected using non standardised instruments* (Ripat, 2006, p 81).

A systematic review of ten studies of ECS and smart home technology for all people with impairments demonstrated some support for activity participation, improved quality of life and user satisfaction with ECS but was inconclusive due to poor quality evidence (Brandt, et al., 2011).

This chapter has explored what is known about ECS and focused on the users' perspective. This focus has led to the conclusion that the users' perspective is poorly represented and inadequately explored in the current literature. Recent qualitative studies have however begun to provide some richer insights. Two studies in particular provide some insights into the experience of first using ECS (Buxton,

2007; Erikson, et al., 2004). Additionally, Judge et al (2009a) investigated the use of speech-driven ECS from the users' perspective providing some data on one type of ECS. Palmer and Seale (2007) developed what they refer to as an *embryonic theory* based on a grounded theory investigation of ECS users' perceptions that linked severity of disability and attitude towards ECS hypothesising that there is a link between perceived utility of ECS and upper limb impairment. This study however did not conclude with a testable theory and requires further investigation leaving the reader searching for more information about the users' perspective. On the whole the qualitative evidence provides valuable insights but is highly variable and difficult to summarise (see Table 6).

The inclusion of outcome measurement has strengthened the evidence supporting the need for ECS in a positivist sense. However the few studies that adopt valid and reliable measures are based in one geographic area[101] with small ECS user sample sizes[102] limiting the extrapolation of findings. These measures are also disappointing when investigating the users' perspective as they are based on pre-defined categories and do not appear sensitive to some difference between users and non-users, nor are they sensitive to changes in experiences over time.

In summary the evidence reviewed in this chapter shows:

- There are high usage rates for ECS for people with a variety of impairments.
- ECS have many functional uses
- ECS increases the ability to do some tasks independently (physical independence) such as control television and make phone calls
- ECS use increases participation in several researcher-defined categories
- There is an evident inequality between users and non-users illustrated by comparative studies that shows greater functional abilities for users
- Non-users anticipate the same benefits from ECS as those experienced by users suggesting that non-users would use ECS if they were available to them.

The evidence also suggests that:

- ECS facilitate activity participation including socialisation, education and travel
- ECS use improves quality of life as indicated by a single outcome measure

[101] Ontario, Manitoba and Quebec, Canada.
[102] PIADS -16 users (Jutai et al. 2000), 7 (Ripat and Strock 2004)16 users (Rigby et al 2005), 15 users (Ripat 2006); QUEST n=5 (Vincent et al 2002) and n= 20 (Stickel et al)

- ECS provide potential benefits for carers and family members.

In addition evidence from studies of user' satisfaction is ambiguous. The quantitative evidence appears to convincingly show that users are satisfied. However the collective body of evidence does not support this, casts doubts on such a claim and begs the question: *what do users really think about ECS?*

A greater understanding of the full impact of ECS on daily living requires in–depth, qualitative investigation of what it is really like to live with an ECS. Research needs to be designed so that ECS users can report their own views and experiences to the researcher rather than being led by researchers preconceptions. Findings based on the real experiences of users are needed instead of assessing ECS use based on broad undefined categories assumed by professionals and researchers to represent users' experiences. The existing literature is limited to particular geographic locations and there are no known Irish studies. The experiences in Ireland may be different to those in other countries due to the lack of availability of ECS in Ireland as discussed in Chapter 2 section 3. In addition most studies involve demographically variable participants with few studies that focus exclusively on people with high SCI.

On the basis of a comprehensive review of the literature there are significant gaps that leave the following questions unanswered:

- What are the experiences of ECS for Irish people with high SCI?
- What is it like to live with an ECS?
- What does using ECS mean to people who use them?
- What causes user dissatisfaction?
- What do users really want from ECS?

The identification of these gaps, led to the initial aims of this study, which were to:

1) Explore what Irish ECS users and potential users think about ECS.
2) Investigate what people with high SCI living in Ireland want from ECS.
3) Explore a possible way to make non-users become users in order to redress inequality of access.

4) Describe what it is like to live with and without ECS, in a bid to understand the implications for participation, interdependence and quality of life.

In the next chapter the suitability of a phenomenological methodology for exploring ECS for people with high SCI is examined by providing an overview of both philosophical and methodological phenomenology.

Chapter 4: Methodology

Preceding chapters have provided the backdrop for this study by describing both the context of the study and reviewing existing knowledge of environmental control systems. Chapter 3 indicated a need for further investigation of ECS. A comprehensive, multi-centre, quantitative investigation based on standardised outcome measures is required (Brandt, et al., 2011; Ripat, 2006) but was however not feasible for this single-researcher investigation. Such a study would also not provide the appropriate information for improving utilisation of ECS in Ireland for people with high SCI. Moreover, existing research in ECS has generally explored that which can be measured such as use of ECS; functional benefit; rating of ECS (Harmer & Bakheit, 1999; Rigby et al., 2005; Tam et al., 2003) satisfaction (Stickel, et al., 2002; Vincent, et al., 2002) and psychosocial impact (Jutai, et al., 2000; Ripat, 2006; Ripat & Strock, 2004). To understand clearly how ECS can enable people with high SCI engage in occupations that they want to do required a person-centred exploration.

It is clear that ECS are beneficial and are linked to improved quality of life through improved independence and participation. However, little is known about what users think of ECS and what it is like to live with ECS. While the literature review highlighted the positive impact of ECS, some qualitative findings and clinical experience suggests that these findings may not accurately reflect the full reality of what it is like for the users and what they think. A comprehensive exploration not based primarily on researcher-led quantitative investigation would help to clarify the users' perspective and address the knowledge gap identified by reviewing the literature. This focus on the users' perspective is supported by legislation in some countries which requires that healthcare clients have direct input into the planning, development and evaluation of health care services. In addition there is an increasing interest in how patients experience health care and share in decision making (Johannsson, Oleni, & Fridlund, 2002; Ford, Schofield, & Hope, 2003) This in-depth qualitative study therefore focuses on real experiences and perspectives of ECS use by people living with high SCI in Ireland. This chapter explains the chosen phenomenological methodology by explaining the research objectives as well as the suitability of a phenomenological lens for an occupational therapy study of high SCI.

1. Research objectives

This study intended to provide insights on which to base improvements in ECS use both in rehabilitation and community living for people with high SCI in Ireland. Therefore a person-centred focus that seeks an understanding of the perspective of people with high SCI living with and without ECS was adopted. This study was not only about what it is like to live with ECS and high SCI, it was also about an occupational therapist gaining an understanding the practical application of ECS to assist other occupational therapists to enable non-users of ECS to become users. This involved the development and trial of an ECS starter-pack. This study was motivated by my personal clinical experience of repeated expressions of dissatisfaction by patients and professionals with occupational therapy for people with high SCI. ECS offers a potentially meaningful therapeutic intervention during rehabilitation as well as potentially enabling increased activity participation in community settings. The scarcity of ECS in Ireland for this population and the lack of any known ECS research underlie the need for the current study.

The two guiding research questions for this study were:

- *What is it really like to live with ECS?*
- *What does it mean to live with ECS?*

To explore these questions required findings the best suited methodology

2. Methodological choice

The methodological choice was challenging as it needed to facilitate an in-depth exploration of the insider perspective as well as providing practical information on which to base an ECS starter-pack. A variety of methodologies are suitable for the investigation of the insider perspective such as grounded theory, ethnography, case studies, narratives, and phenomenology (Creswell, 1998). Grounded theory has been applied in ECS research previously (Stead 2002b; Palmer and Seale, 2007). The use of grounded theory could have been used in this study to develop a theory about the meaning of ECS as well as to develop a theory about what it is like to live with ECS as. Data could have been gathered in focus groups involving ECS users. These theories could have then been tested or developed further using individual interview data. While this may have been a useful approach, a wider investigation of

users' experiences not specifically focused on the development of theory was favoured. In addition a grounded theory approach focused on the meaning and on living with ECS may not have provided sufficient information about what people think about ECS to inform the development of a starter-pack. Alternatively, an ethnographic study would have been particularly suited to exploring how ECS affect families, carers and communities. Such a study could have described and interpreted a cultural or social group's experience of ECS. Participant observation, the hallmark of ethnography, focuses on observing behaviours as opposed to exploring peoples' interpretation of experiences. The application of ethnography to this study would have required several hours of participant observation of several ECS users and several ECS non-users. It may have also involved similar participant observation of people using an ECS-starter-pack possibly complimented with interviews. However, the nature of ECS use is itself sporadic and observing users would have involved several periods of non-use requiring extended participant observation to ensure useful data was gathered. Such intensive field work would not been possible with limited resources available. In addition it would be challenging to use ethnographic data to compile a starter-pack. Case studies were also considered as a possible method. This would have involved in-depth analysis of multiple cases prior to developing an ECS starter-pack. Followed by a single case study of a pilot trial of the starter-pack .The pack could have been given to several new users and analysed as parallel case studies. Data could have been gathered using in-depth interviews for all cases and narrative analysis could have provided valuable insights into the individual experiences. While case studies were suited to the research objectives, phenomenology was considered the best fit for exploring the two primary research questions: *What is it really like to live with ECS and what does it mean to live with ECS?* Phenomenology which seeks to understand the meaning of an experience such as living with ECS best represented the intention to investigate an insider perspective of life with and without ECS. In addition it was considered appropriate for providing insights into what people think of ECS on which to base the development of an ECS starter-pack.

Phenomenology is a philosophy based on the study of the human experience as it is perceived by an individual (Creswell, 1998). It is complex to both understand and articulate, making it a difficult approach for the novice researcher (Finlay, 1999). It encompasses several philosophical concepts that provide a framework for exploring lived experience. These concepts originated from different philosophers and evolved as phenomenology developed. Key concepts of relevance to this research

project are described in this section. This is not intended to be a comprehensive review of phenomenology but rather to provide an understanding of the philosophical underpinnings and insights into the application of phenomenological research methodologies.

3. Philosophy of phenomenology

The first contribution that phenomenology made to scientific enquiry was the inclusion of experience as a valid subject for study - the focus of much occupational therapy research. In 1900 Edmund Husserl (1859-1938), credited as the father of phenomenology, introduced the notion of experience based on the concept of *intentionality* in contrast to dominant positivist paradigm at that time (Langdridge, 2007). *Intentionality* refers to being aware of things as they appear by consciously attending to things (Barber, 2004). This involves a relationship between what is experienced and how it is experienced that is described as *directedness-at-objects* (Smith, Larkin, & Flowers, 2009). Experience as a conscious affair that could be explored and understood was in contrast to the dominant concept of the time that considered understanding to be an internalised inaccessible affair (Park Lala & Kinsella, 2011). *Intentionality* introduced a relationship between a person and objects which was further extended by the concept of the *lifeworld. The lifeworld* provides the stage for all experiences and includes the concrete world as well as the unobservable. Van Manen (1990) described four *lifeworld essentials* through which life is experienced and which provide meaning: lived time (*temporality*), lived space (*spatiality*), life with others (*relationality*) and lived body (*corporeality*). These concepts are easy to relate to occupational therapy which is concerned with: peoples' use of time for engaging in occupations, their use of space and physical environments, as well as peoples' social interactions and relationships. These are all important occupational therapy considerations in light of body impairments.

Husserl focused on *bringing things back to themselves* to see things as they are, by adopting what is termed a *phenomenological attitude* in contrast to the natural attitude prevalent at the time (Park Lala & Kinsella, 2011). A *phenomenological attitude* requires suspending all assumptions to *see as if for the first time* (Langdridge, 2007). The suspension of assumptions is called *epoché* or bracketing. I was attracted to the use of bracketing in this ECS exploration because I did not want the investigation to be guided by the existing knowledge base that I had identified as unsatisfactory nor did I want to assume my own preconceived ideas

were accurate reflections of the actual experiences. Hurserl introduced two processes. The first, *phenomenological reduction*[103] aimed at identifying the essence of the experience through bracketing (Smith, et al., 2009), and the second, *eidetic reduction* involves trying to consider alternative ways of seeing phenomena in order to transcend the particulars of the situation and their variations to find out *what something is like* and thus identify the essence or the core defining characteristics of a phenomenon (Smith & Osborn, 2008). Phenomenology for Husserl was purely descriptive and transcendental and based on the belief that the essence of an experience could be revealed (Langdridge, 2007).

Heidegger (1889-1976), a student of Husserl, in the 1920's opposed Husserl's purely descriptive transcendental concepts and focused on *understanding the nature of existence itself* (Langdridge, 2007, p.39) adopting an existential stance and thus introducing the interpretation of meanings and a hermeneutic[104] approach to phenomenology (Park Lala & Kinsella, 2011). Heidegger used the term *dasein* directly translated as *there of being,* to refer to human subjectivity. This refers to, *the uniquely situated quality of 'human being'* (Smith, et al., 2009, p.16). *Dasein,* or being, includes that which is not observable and Heidegger considered things to have both visible and hidden aspects thus providing scope for interpretation. The concept of *being* was introduced in Chapter 1 (section 4) as meaningful occupation that involves non-purposeful use of time like enjoying nature, art, music, the company of others or being alone.

Heidegger also characterised the way we interact with the world as *intersubjectivity:*

> *the shared overlapping and relational nature of our engagement in the world.* (Smith, et al., 2009, p. 17).

This means that phenomena are related to other things and to time (Smith, et al., 2009).This implies that understanding *being* requires the consideration of *intersubjectivity* or simply put a person's interactions with objects in space and time.

Heidegger further developed the concept of bracketing with the notion of *foreunderstanding* that makes bracketing cyclical and more reflexive (Smith, et al., 2009). The concept of *foreunderstanding* involves being aware of the influence of

[103] Reduction is a misleading term because it is not the same as reducing down. Phenomenological reduction refers to finding the essence or reducing to the very core of things.
[104] Hermeneutics involves interpretation and understanding of meaning.

presuppositions on interpretations as opposed to disregarding them. Heidegger argued that presuppositions can never be fully transcended (Wilding & Whiteford, 2005) This concept means that as an clinician my experiences influenced this study but that I was aware of this influence.

In 1943, Sartre, proposed that there are no essential qualities in human nature and thus we are *condemned to freedom* through choice (Langdridge, 2007). This freedom means that we are self-conscious and seek meaning constantly. For Sartre, being human is a developmental process of becoming ourselves which is constantly changing through choice and that each person is responsible for their actions. Again this relates to the occupational therapy concept of becoming that is a result of doing and being (Chapter 1). Sartre also acknowledged that individual choices are restricted by bodily limitations (such as SCI) and by social relationships (such as that between carers and people with SCI).

In the Phenomenology of Perception (1945) Merleau-Ponty a psychologist and a philosopher described man as being *condemned to meaning*. He considered consciousness to be embedded in the body (Langdridge, 2007). This embodied position means that one can never share another's experience as it is uniquely experienced through their own body (Smith, et al., 2009). Thus phenomenology aims to gain the insider perspective of embodied experience, that for people with high SCI, is particularly important as it is experienced through damaged bodies.

The hermeneutic slant in phenomenology begun by Heidegger was further developed by Gadamer who also focused on the interpretive aspect. His work focused on an analysis of literary and historical texts and in 1960 in his publication *Truth and Method* Gadamer extended the concept of intersubjectivity by emphasising both the historical and cultural aspect of knowledge (Langdridge, 2007). The interpretation of phenomena involves a conscious understanding of both culture and history and is thus based on existing knowledge (vs. bracketing).[105] Gadamer used the term *fusion of horizons* to refer to the merging of the interpretation of an experience with one's preconceptions (Langdridge, 2007). This implies a dynamic relationship between the interpretation and the experience which in turn influence and are related to each other. In addition Gadamer suggested that

[105] This is in contrast to Husserl concept of bracketing that insists cultural and historical knowledge needs to be suppressed in order to reveal the true phenomenon.

preconceptions may only become clear during interpretation and can be dynamically influenced by that interpretation:

> *the phenomenon, the thing itself, influences the interpretation which in turn can influence the fore-structure, which can then itself influence the interpretation* (Smith, et al., 2009 p. 26).

This means that interpretation of experience and indeed researching lived experience is likely to be a dynamic process that continually influences itself and is influenced by previous thinking which suggests that true bracketing of preconceptions is impossible. Even identifying preconceptions is difficult as they too are influenced by the phenomenon and may only become apparent through interpretation. Thus there is a dialogue between new and old concepts in any analysis. Identification of the researcher's own influence, on the analysis of a phenomena permits one to openly participate in this process (Smith, et al., 2009). This process of reflexivity provided a licence to both contribute to and be influenced by the interpretation during this study.

This brief overview of the background and development of phenomenology helps to set the scene and explicate my own thinking when exploring the design of this study. Such a philosophical exploration enabled me to understand the concepts of phenomenology that I considered congruent with both the research objectives and occupational therapy philosophy. This understanding was necessary so that I was able to conduct this study as a phenomenologist as well as an occupational therapist.

4. Occupational therapy, philosophy and phenomenology (and high SCI)

Phenomenology is a natural fit for occupational therapy. Several phenomenological concepts match the philosophical underpinnings of occupational therapy including: the *lifeworld*; the notion of conscious experience (intentionality); and Heidegger's concepts of *Dasein* or *Being* (experiencing the world that is not observable) and *intersubjectivity* (the relational and transactional nature of experiences). Both phenomenology and occupational therapy share a focus on meaning:

> *Attention to intentionality and the lifeworld bring to light unique vantage points in the study of human occupation. These phenomenological constructs have potential to contribute to understanding about what people want to do, are able to do and how they do it, within the everyday social cultural, political world in which daily occupations are embedded*. (Park Lala & Kinsella, 2011, p. 202).

Occupational therapists are concerned with what people do (phenomena) and in so doing how they occupy time, how they occupy space or environments, and how they engage in social occupations all of which are constituents of the *lifeworld.* Occupational therapists also focus on the impact of body impairments on the ability to do (occupation) which highlights the importance of *embodiment*.

Phenomenology seeks to understand what it is like to consciously experience something (Smith, et al., 2009). Similarly occupational therapy seeks to understand the clients' perspective which includes understanding what it is like to experience something. It follows that phenomenology is a potentially useful methodology for the study of human occupation (Park Lala & Kinsella, 2011):

> *Phenomenology is increasingly being used by occupational therapists as an approach congruent with occupational therapy values concerning the uniqueness of an individual's experience and meanings, and understanding the individual as a whole in the context of his or her environment.* (Clarke, 2009, p. 38).

Phenomenology and occupational therapy share a concern with *being.* Human occupation can be considered to comprise *Doing*, *Being*, *Belonging* and *Becoming* (Hammell, 2004a; Wilcock, 1999). In comparison with the other dimensions:

> *Being is a particularly difficult dimension to understand* (Park Lala & Kinsella, 2011, p. 202).

Wilcock (Wilcock, 1999) points out the tendency for occupational therapists to focus on doing while being is neglected. Heidegger suggested that *being is the core of what it is to be human* (Park Lala & Kinsella, 2011, p.202). Being encompasses unobserved everyday elements of occupation that may be considered mundane and yet are meaningful (Hasselkus, 2002). Phenomenology encourages the exploration

of being alongside the traditional focus on doing. This is of central importance to people who are less inclined to *do* due to physical limitations and who may therefore place greater value on *being.* People with high SCI particularly can be considered to express value in being (Hammell, 2004b).

Intersubjectivity that acknowledges the relational nature of engagement in the world is reflected in transactional occupational therapy models such as the Person-Environment-Occupation Model (Law et al 1996). In addition occupational therapy endeavours to be holistic by attending to all *lifeworld* elements that are both observable and hidden. Occupational therapy is described as an art and a science or a *2-body practice* that is biomedical based on a physiological body and phenomenological based on the experiences of living in a body (Mattingly, 1994). Phenomenology is a useful methodology for understanding the *art* of occupation as well as understanding occupational therapy philosophy (Turpin, 2007).

It follows that there is an increasing use of phenomenology in occupational therapy research (Barber, 2004; Finlay, 1999; Hasselkus, 2006; Kinn & Aas, 2009; Park Lala & Kinsella, 2011; Raber, Teitelman, Watts, & Kielhofner, 2010; Wilding & Whiteford, 2005) and the use of interpretative phenomenological analysis (IPA) as a method in particular (Clarke, 2009; Cronin-Davis, Butler, & Mayers, 2009). People with high SCI experience the world through damaged bodies making Merleau-Ponty's concept, embodiment particularly pertinent. Life disrupted by SCI includes disruptions to the body as well as to time, relationships and space each of which are acknowledged as elements of the *lifeworld*. Understanding the uniqueness of life with a high SCI requires a methodology that acknowledges embodiment, altered choice and *lifeworld* disruptions. Phenomenology offers such an approach.

5. Phenomenology applied in research methodology

The application of phenomenology in research methodology is challenging because it requires an understanding of the philosophical concepts of phenomenology as described briefly above (Creswell, 1998). There are many variations of phenomenology which is represented by several academic schools of thought,[106]

[106] Duquesne school of phenomenology (Giorgi & Giorgi, 2008); template analysis (King, 1998); and interpretative phenomenological analysis (IPA)(Smith, et al., 2009); the open life world approach of Dahlberg, K, Dalhberg, H., & Nyström (2008); VanManen's (1990), lived experience human science inquiry; Halling, Leifer, & Rowes' (2006) dialogical approach; the Dallas approach (Garza 2007); Todres' (2005) embodied lifeworld approach; and Ashworth's (2003), lifeworld approach (the Sheffield school) . A full exploration of all of these approaches was considered to be beyond the scope of this study.

and the definition of what constitutes sound phenomenological research is highly debated (Finlay, 2009). There are wide variations and levels of agreement over the use of *epoche* (bracketing)*, phenomenological reduction* and *imaginative variation* (Langdridge, 2007). However, regardless of the choice of method the key dimensions of phenomenology include: *phenomenological reduction, lifeworld and intentionality,* the notion of *being* and of the *lived body* which have all been discussed above*.* The potential to reveal critical insights regarding experience is possible in phenomenology by questioning taken for granted interpretations, cultural assumptions and dominant discourses (Park Lala & Kinsella, 2011).

Selecting a suitable research method is daunting as methods are steeped in philosophy and can be difficult to access as a novice researcher (Finlay, 2009). This study employs two phenomenological methods, the phenomenological psychological approach (Creswell, 1998) also called descriptive phenomenology (Langdridge, 2007) and interpretative phenomenological analysis, IPA (Smith, et al., 2009). Giorgi argues that two phenomenological methodologies cannot be compatible in one study as they have epistemological differences (Giorgi, 2010). In this study the two methods are considered compatible. There is a progression from the initial descriptive phase (phenomenological psychological approach) to the interpretative later phase (IPA) which is rooted in psychological phenomenology with an added hermeneutic dimension (Smith, et al., 2009).[107] The initial phase of investigation focused on creating a descriptive understanding of life with and without ECS and the final phase expanded on this description through hermeneutic analysis of living with ECS. Husserlian bracketing facilitated a phenomenological attitude in the initial phase while the final phase was influenced by a *foreunderstanding* of the phenomenon based on initial findings. IPA values the individual nuance as opposed to transcending the ideographic as prescribed in psychological phenomenology. While these approaches differ they reflect the progression of the study from descriptive to interpretative, from broader to specific, and from shared to ideographic findings.[108]

[107] Hermeneutics is the theory of interpretation originally based on text interpretation then adopted in phenomenology to interpret experiences.
[108] This may reflect the progression of my comfort with phenomenology and my growing confidence in my ability to analyse a small sample in as much depth as possible.

5.1 The phenomenological psychological approach

The phenomenological psychological approach is a descriptive one based on the work of Husserl and incorporating both bracketing and phenomenological reduction. The phenomenological psychological approach explores individual descriptions to create a comprehensive understanding of the general or universal meanings of a phenomenon or experience (Creswell, 1998). There are some variations in how individual scholars[109] and their followers employ the phenomenological psychological approach but all employ the same fundamental process. The researcher poses a research question that seeks the meaning of an experience. The question is presented to participants, who have experienced the phenomenon of interest, most often in the form of a long interview. Data is then analysed within the phenomenological tradition. Sequential analytic steps include: understanding overall meaning through reading; identifying relevant statements from the data; transforming statements into clusters of meanings; arranging the transformations together to provide a general description of the unifying meaning of an experience; and constructing a phenomenological report that provides a better understanding of the essence or invariant structure of an experience (Creswell, 1998; Langdridge, 2007).

5.2 Interpretative Phenomenological Analysis IPA

IPA is an iterative, ideographic, hermeneutic, phenomenological research methodology (Smith & Osborn, 2008). It is founded on the phenomenological concepts of several philosophers including Husserl, Heidegger, Merleau-Ponty, Sartre and Gadamer (Smith, et al., 2009). The primary concern of IPA is exploring how people make sense of their own experiences:

> *IPA offers an established, systematic, and phenomenologically focused approach, which is committed to understanding the first person perspective from the third person position, so far as is possible, through intersubjective enquiry and analysis … committed to situating personal meaning and context.* (Larkin, Eatough, & Osborn, 2011).

A semi-structured interview is the exemplar data collection method used in IPA but other sources include focus groups (Palmer, Larkin, de Visser, & Fadden, 2010; Tomkins & Eatough, 2010) and interviews via email (Murray & Rhodes, 2005). IPA has been credited with making qualitative research more approachable as it

[109] Psychological phenomenologists include Giorgi, Polkinghorne, Moustakas and Colaizzi.

incorporates a clear step-by-step hermeneutic phenomenological method (Todorova, 2011). IPA includes similar steps to those applied in the phenomenological psychological approach. Steps include: reading and rereading; initial noting; developing emergent themes; searching for connections across emergent themes; moving to the next case; and finally looking for patterns across cases (Smith, et al., 2009).

The three major theoretical underpinnings of IPA are phenomenology, hermeneutics and ideography. It requires adopting a phenomenological attitude that involves reflexivity throughout. Experiences are considered embodied (Merleau-Ponty) and intersubjective (Heidegger, Sartre). IPA is concerned with the interpretation of meaning and thus is hermeneutic. Smith, et al. (2009) describe a hallmark of IPA to be the double hermeneutic of the researcher making sense of the participants' sense making of lived experience. Hermeneutic interpretation aims to uncover both visible and hidden meanings, and also involves dynamic foreunderstanding, a cyclical interactive process of partial bracketing and reflexivity (Smith, et al., 2009). The incorporation of bracketing is more in line with Heidegger's pre-understanding that influences how things are interpreted. Interpretation is a complex process that is both influenced by and influences our preconceptions, a process described by Gadamer as *a fusion of horizons*. This means that the data and the interpretation dynamically influence each other. The hermeneutic circle is the dynamic iterative process of moving back and forth between understanding the parts and the whole. This involves analysis of single words and sentences, singe extracts and the complete text, one interview and its entire project, one episode and a complete life (Smith, et al., 2009). The third underpinning of IPA is ideography or the focus on the particular rather than on generalisations. This results in a particular embodied situated exploration. Ideography is a particularly appropriate characteristic of IPA applied to occupational therapy as it too is inherently person-centred. The application of ideography in IPA involves moving between one case and all cases in a hermeneutic circle.

The adoption of IPA is increasing and Chamberlain (2011) attributes this ascendency to the appeal of researching *experience.* However, he reports that this increased use has led to its uncritical application with little reflection, a view supported by several publications including a review of IPA publications (Brocki & Wearden, 2006). Tordorova, in contrast, reports a steady increase in both the number and quality of IPA studies and specifically notes increased intensity and

deeper analysis (Todorova, 2011). Chamberlain (2011) suggests that IPA produces findings similar to grounded theory and produces themes that can be considered similar to thematic analysis. It follows that the popularity of IPA has resulted in a proliferation of publications that claim to be IPA but closer examination reveals that some studies, including occupational therapy publications, use IPA as an incorrect label for thematic analysis. This is true of a focus group study by Hawtin and Sullivan (2011) who describe *coding*[110] with no indication of phenomenological attitude or attention to the ideographic. Smith evaluated 293 IPA publications in a recent review and considered only 27% of the papers to be good examples of IPA, 55% to be acceptable and 18% to be unacceptable based on Smith's guide to evaluate IPA publications (Smith 2011). Some criticism of IPA queries its use of epoché, reduction and imaginative variation (Chamberlain, 2011) and methodical errors attributed to its failure to follow the scientific method (Giorgi, 2010). These claims have been refuted by Smith (Smith, 2010; Smith, 2011) one of the originators of IPA who describes IPA as a scientific method that is intended to include reduction and imaginative variation (Smith, et al., 2009). Both of the aforementioned are sometimes missing in academic reports as reviewed by Brocki and Weardon (Brocki & Wearden, 2006). They reviewed 52 IPA health psychology papers and noted differences in the interpretative aspect of IPA and how it is reported, if at all, but concluded that IPA is both useful and applicable. Choosing to use IPA requires caution as:

> *IPA can be easy to do badly and difficult to do* well (Larkin, Watts, & Clifton, 2006, p. 103).

It is misunderstood by some to be a simple descriptive method but if done well it requires commitment that can lead to powerful findings reflective of real life experience (Larkin, et al., 2006). It was in search of such powerful real life findings that IPA was chosen as method.

A primary strength of IPA is the acknowledgment of social and contextual factors influencing the construction of meaning (Todorova, 2011). This is consistent with the sociocultural context of environment integral to occupational therapy philosophy (Clarke, 2009). IPA is suitable for occupational therapy research as it recognises the researcher's (occupational therapist) input and allows the incorporation of occupational therapy knowledge and theoretical models in higher order

[110] Coding is a grounded theory term not applicable to IPA.

interpretations (Cronin-Davis, et al., 2009). The application of such theoretical models must be done with caution as the iterative process of analysis must firmly base such decisions on the data itself rather than decisions made prior to the analysis (Smith & Osborn, 2008). The misconception of choosing a model or theoretical framework prior to analysis fails to situate IPA within the philosophy of phenomenology that favours openness and seeing things as they appear not as they are expected to appear. Cronin-Davis, et al. (2009) incorrectly highlight the adoption of *a priori* knowledge as *an absolute requirement* (p.334) and suggest that one decides which particular model or theory is to be used to interpret the data before the analysis begins. Merrill, an occupational therapist, shared how she was instructed to adopt a model of occupational therapy prior to analysis in her doctoral study using IPA. In the spirit if IPA she however abandoned the initial model for more pertinent theory and models from both occupational therapy and feminist philosophy based on her analysis of data (S. Merrill personal communication, 1 July, 2011). No theoretical models were selected or applied in this study prior to data analysis.

6. Summary

The phenomenological methodological choice has been explained in light of relevant underpinning philosophical concepts. Phenomenology as a research method has been selected as particularly appropriate for the investigation of life with and without ECS for people with high SCI from an occupational therapy perspective. The philosophical underpinnings of the study include attention to *intentionality*, the *lifeworld* and its constructs (*temporality*, *relationality* and *spatiality*), *intersubjectivity*, *being* and *embodiment*. The adoption of phenomenological research involves recognising the role that the researcher plays in construction and analysis of data and the incorporation of reflexivity throughout the process. Simply put phenomenology was selected as it facilitates the primary objectives for this study - *finding out what something (life with and without ECS) is like* and *what it means to people with high SCI?* The next chapter describes the research design and methods.

Chapter 5: Research design and methods

The phenomenological methodology underpinning this study has been introduced in the preceding chapter. This chapter provides an overview of the study design and methods. It introduces the three research phases and their corresponding research methods. In addition it describes: ethical considerations, data management and analysis, quality control and reflexivity.

1. Research design

This study involved the development and use of an ECS starter-pack guided by the two research questions identified in Chapter 4:

- *What is it really like to live with ECS?*
- *What does it mean to live with ECS?*

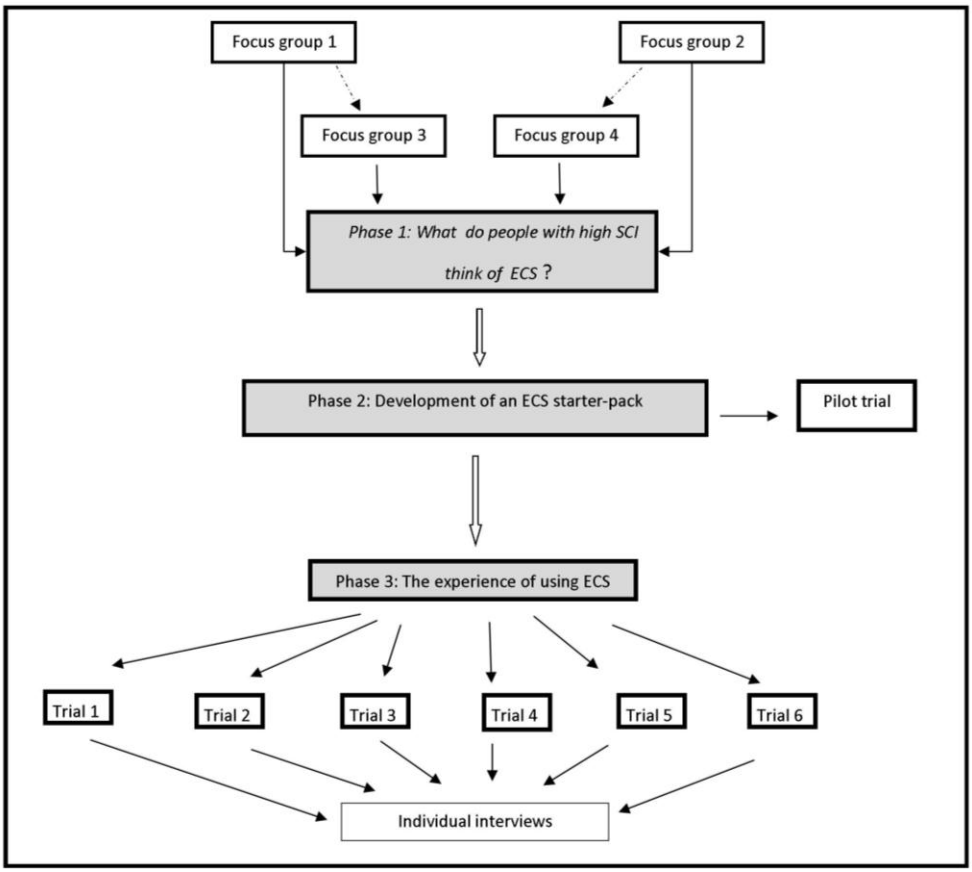
Exploration of these questions required three progressive research phases, Figure 2:

- Phase 1: What do people with high SCI think of ECS
- Phase 2: Development of an ECS starter-pack
- Phase 3: The Experience of using ECS

Phase 1 explored the broad insider perspective based on the experiences of both ECS users and non-users elicited through focus groups. Phase 2 involved the development of a starter-pack based on the insider perspective uncovered in Phase 1, and involved a pilot trial of the starter-pack. Phase 3 then explored the use of that starter-pack from the users' perspective evaluated using individual in-depth interviews. Although this study may not conform to a typical mixed-method design that combines qualitative and quantitative methods, the study is a multi-method one (O'Byrne, 2007). It combines different data production and gathering methods of focus groups, practical intervention and in-depth interviews. It also incorporates different data analysis methods at each phase. The rationale for each phase and its corresponding research method is discussed below while the detailed research

procedures for each are presented in Chapter 6 (Phase 1) Chapter 8 (Phase 2) and Chapter 9 (Phase 3).

Figure 2: Overview of the research design and phases



1.1 Phase 1: What do people with high SCI think about ECS?

Phase 1 was considered the appropriate starting point for developing a person-centred ECS starter-pack by asking:

- *What Irish ECS users and potential users think about ECS?*
- *What people with high SCI want from ECS?*

In addition Phase 1 explored the primary research questions of *what it is like* and *what it means* to live with ECS. As this study sought to understand the experiences of living with ECS the initial phase of the research required a general exploration of the perceptions of ECS held by people with high SCI. Focus groups were selected as the data collection method as they allow for the exploration of multiple opinions, thereby producing a multi-vocality of attitudes, experiences and beliefs (Madriz,

2003). As findings from Phase 1 were needed to inform Phase 2, the creation of an ECS starter-pack, focus groups were considered particularly appropriate as they reflect the opinions of more people than would be possible using individual interviews.

Questionnaires and structured interviews were considered as possible data collection methods. These were however not favoured as they were less likely to facilitate freedom of expression and opinion and more likely to be researcher-led (Krueger & Casey, 2000). A structured interview was considered likely to produce superficial information on the practical aspects of ECS but to lack the depth that might emerge from a group discussion. Morgan (1997) suggested that focus groups may yield more in-depth information on routine topics compared to superficial views uncovered through interview as participants challenge each other and contest differing opinions. Focus groups encourage participants to truly articulate their opinions and even make adjustments to their views through discussion and debate with others (Morgan, 1997).

The hallmark of focus groups is their explicit use of group interaction to produce data and insights (Kitzinger, 1994; Morgan, 1997). They are intended to be true to life and to reflect how opinions are produced and expressed (Flick, 2006). Morgan (1997) defines focus groups as:

> *a research technique that collects data through group interaction and on a topic determined by the researcher* (Morgan, 1997, p.6).

During World War One, Robert Merton used *the focused interview*, now commonly accepted as the first *focus group*. He examined the persuasive use of propaganda to create public support for the war effort using focus groups as the data collection method (Morgan, 1997). The dominant positivist epistemology of the time, however, meant that the focused interview was not accepted as a credible research method (Morgan, 1997). Focus groups were revived in the 1950s by market researchers who used them to survey consumer opinion. These groups proved inexpensive, easy to administer and accurate in their assessment of consumer preferences and continue to be used as a primary research tool in the multi-faceted market research industry (Krueger & Casey, 2000).

According to Morgan the increased use of qualitative research methods in the last two decades has resulted in an increase in the use of focus groups as a valid data collection tool in areas such as social research, communication studies, education, political science, public health and marketing (Morgan, 1997). Recent technological advances have extended the mechanism of focus groups to include virtual groups through the use of teleconferencing and video conferencing facilities (Smith, Sullivan, & Baxter, 2009) and on-line internet based groups (Finch & Lewis, 2003; Tates et al., 2009; Zwaanswijk et al., 2007). Such virtual technologies enable focus groups to be conducted anywhere, at any time and with participants based in different locations including their own homes.

Focus groups can be used as a primary data collection method, as a self-contained methodology or in combination with other methods (Morgan, 1996). Traditionally focus groups have been used either as a precursor to other research methods or as validation of other quantitative or qualitative findings. As a precursor to other research methods, focus groups are a useful tool for an initial participant-focused exploration of a topic. Such findings can then inform subsequent stages of research by providing a framework of relevant topics, lines of enquiry or possible anticipated findings. Focus groups are commonly used in the construction of questionnaires and surveys. When used to validate findings, focus group participants may be asked to discuss preliminary findings. Alternatively, focus groups can be used as a type of data triangulation allowing comparison of findings from different data collection methods (Flick, 2006).

Focus groups have been used for programme planning (Wyatt, Krauskopf, & Davidson, 2008), product and service development (Warholak, Murcko, McKee, & Urbine, 2010), evaluation research (Massey, 2011), understanding patients' thoughts and concerns (Lane, Huyck, & Troyk, 2011), developing educational tools (Rolnick et al., 2009; Stellefson, Chaney, & Chaney, 2010) developing clinical tools (Kastner et al., 2010), and validating language translations of existing tools (Bruijning, van Nispen, Verstraten, & van Rens, 2010). As a primary research tool focus groups have been used to investigate topics in assistive technology such as acceptance of new technologies (Dorsten, Sifford, Bharucha, Mecca, & Wactlar, 2009), assistive technology service developments (Ripat & Booth, 2005) and perceptions of electronic memory aids (Dry, Colantonio, Cameron, & Mihailidis, 2006). Focus Groups have also been mentioned in the development of outcome measures such as the PIADS and the QUEST. However, it is not possible to critique

the role of focus groups in the development of these measures as they have not been formally reported on but rather described as a single step in the development stage of these outcome measures (Demers, et al., 1996; Jutai & Day, 2002). Focus groups have also been used in occupational therapy research aimed at understanding clients' perspectives, and for exploring occupational therapists and students views of services (Hollis, Openshaw, & Goble, 2002).

Focus groups are a popular choice of data collection for researching lived experience and have been used to explore experiences of multiple sclerosis, the early postnatal period, communication with Huntington's disease, the use of physical restraints, functioning and disability in SCI and end of life experiences (Courts, Buchanan, & Werstlein, 2004; Forster, McLachlan, Rayner, Yelland, Gold, & Rayner., 2008; Hartelius, Jonsson, Rickeberg, & Laakso, 2009; Janelli, Dickerson, & Ventura, 1995; Kirchberger et al., 2010; Munn et al., 2008). Findings from such studies provide valuable insights into living with conditions. For example multiple sclerosis is richly described as devastation, and as a situation in which nobody listened as well as one requiring the maintenance of control and self-advocacy (Courts, et al., 2004). Comparative focus groups of people with Huntington's disease, family members and carers also highlighted the need to include the person with Huntington's in assessments and intervention planning (Hartelius, et al., 2009). A large scale, world-wide, multi-centre focus group study claiming to investigate the lived experience of people with SCI revealed thousands of relevant concepts[111] that were subsequently organised according to ICF components. This quantitative approach to data analysis revealed that while the majority of concepts were represented in the ICF, several concepts were not[112] thus inadvertently highlighting the value of focus groups in producing unexpected, variable data that may better reflect reality than carefully constructed frameworks such as the ICF (Kirchberger, et al., 2010).

Despite the popularity of focus groups research in phenomenological studies, Webb & Kevern, (2001) contest their suitability for researching the lived experience and suggest that focus groups and phenomenology are methodologically incompatible as focus groups are intended to examine the group versus the individual experience. This argument is particularly pertinent in phenomenological schools of thought that focus on the idiosyncratic individual experiences, such as IPA.

[111] 3,122 early post acute concepts and 4,423 long term concepts.
[112] 36 early post acute concepts and 113 long term concepts.

Application of IPA to data collected using focus groups requires examining each individual participant's experience in isolation from the collective group experience. Two such methods for applying IPA to focus groups have been described and published after this study was conducted (Palmer, et al., 2010; Tomkins & Eatough, 2010). While acknowledging this criticism of focus groups as a data collection method for interpretative phenomenological methods, focus groups were considered suitable for the initial exploratory stage (Phase 1) of this study that adopted a descriptive phenomenological approach rather than an ideographic focus.

Using focus groups produces data through the dynamic interaction of participants in groups that Morgan (1997) refers to as *magical synergy* which increases participant insights through active engagement with other group members. Once engaged with the topic, participants reflect and refine their individual views by asking questions of each other and stimulating discussion (Finch & Lewis, 2003). Focus groups are well suited for:

> *topics that people could talk about to each other in everyday life – but don't* (Macnaghten & Meyers, 2004, p. 65).

ECS is such a topic suitable for discussion but people with high SCI may not get the opportunity to discuss this with others. Focus groups are suited to the exploration of views, opinions, attitudes and experiences (Morgan, 1997). The manner in which focus group research is conducted and data analysed is highly variable and dependent on the research question and underlying methodology (Morgan & Bottorff, 2010). Focus groups can be suited to grounded theory, content analysis, thematic analysis and phenomenological analysis as applied in this thesis.

A review of the literature revealed several positive benefits of ECS and studies reported few and often no negative findings (See Chapter 3). These findings suggest a possible bias towards positive outcomes solicited through data collection tools such as surveys and other outcome measures where participants may not have been encouraged or given the opportunity to report on negative aspects. Focus groups were intended instead to give participants freedom to discuss all aspects, positive or negative, of life with or without ECS and to explore unique features of the Irish experience. This broad perspective was seen as essential to capture multiple opinions and is consistent with the over-arching phenomenological

epistemological methodology of the study. Phase 1 research procedures are described in detail in Chapter 6.

1.2 Phase 2: Development of an ECS starter-pack

The second phase involved the development of the ECS starter-pack which was evaluated and adjusted in a one-person three-week pilot aimed at eliciting a user's perspective. It was not a traditional research phase and failed to follow a predictable structure of data collection and data analysis or method. It was the practical intervention phase that linked Phases 1 and 3. The rationale underlying Phase 2 is fundamental to the primary intention of this study: to produce an ECS starter-pack that would ultimately increase the use and availability of ECS for people with high SCI in Ireland. At the time of writing there was no such pack in existence and no precedent for its use, nor was there a service for the design and provision of such a pack in Ireland. This situation, while not ideal, is reflective of clinical practice in Ireland. The belief that it is possible for an occupational therapist to design and install a simple ECS pack without technical support provides the underlying rationale for this phase. The provision of such a pack would provide a possible way to facilitate ECS use in a resource limited setting that functions without an assistive technology service or other specialised staff such as rehabilitation engineers or technicians. Such a setting would be common in Ireland, and indeed for many occupational therapists even those employed in specialist spinal injuries units.

The design of the pack was based on several sources. Support for this stage was sought in Canada as ECS literature is dominated by Canadian studies (Jutai, et al., 2000; Vincent, et al., 2002; Stickel, et al., 2002; Rigby et al., 2005; Ripat, 2006; Ripat & Strock, 2004). A prominent, occupational therapist who had published work on ECS responded to my inquiries and referred me to a co-author, a clinically based occupational therapist. Elizabeth Steggles who had established an ECS service based in a SCI rehabilitation facility in Ontario, Canada. She agreed to provide expert consultation for the development of the pack. The Canadian situation offered a useful comparison for this study as there are similar funding limitations within an established occupational therapist-led service based within a spinal injuries centre. In contrast however, the service was well developed and a source of useful information about ECS for people with high SCI. The Canadian service also had access to a different range of technologies sourced in North America in comparison to those available from Irish European suppliers.

Once the ECS starter-pack was designed and compiled it was trialled in a single-person pilot study supported by video and photographic evidence. This pilot provided feedback on which the final pack was based. The pack was modified, used and evaluated in Phase 3. Phase 2 is discussed in detail in Chapter 8.

1.3 Phase 3: The experience of using an ECS

In the third and final phase the ECS starter-pack was customised by an occupational therapist for use in peoples own homes. The study culminated in six in-depth interviews of people with high SCI who used the starter-pack. This allowed the broad perspective uncovered in the first phase to be explored in further depth using IPA. The starter-pack developed in Phase 2 was given to six persons with high SCI to use in their own home for eight weeks. This phase initially involved a practical element similar to the pilot trial in Phase 2 involving customisation of the pack for six participants. On completion of each trial, data was collected using in-depth semi-structured interviews, the most common data collection method for IPA studies (Smith, et al., 2009). In-depth interview provided rich and thick description of the experience of living with an ECS. Semi-structured interviews were preferred to unstructured interviews as they allowed for the use of an interview guide with accompanying prompts. The flexible nature of this data collection method allowed for some structure with a participant-led discussion of topics, free flowing conversation and iterative questioning developed around the overarching topic: the experiences of using the ECS starter-pack. Phase 3 research procedures are discussed in detail in Chapter 9.

2. Alternative considerations for the research design

Like most doctoral research this study evolved over time and alternative methods and designs were considered. Initially the study was envisaged to include outcome measurement alongside qualitative investigation in a mixed methods study. This initial decision was based on the dominance of these measures in the ECS literature then available (Jutai, et al., 2000; Rigby, et al., 2005; Ripat, 2006; Ripat & Strock, 2004; Stickel, et al., 2002; Tam et al., 2003; Vincent, et al., 2002) and in general assistive technology research (Chan & Chan, 2006; Demers, et al., 2002; Demers, et al., 1996; 2001, 2002; Demers, et al., 2001a; Derosier & Farber, 2005; Stickel, et al., 2002; Wressle & Samuelsson, 2003) and the use of the PIADS outcome measure for AT (Andrich, Pedroni, & Vanni, 2003; Demers, et al., 2002; Derosier & Farber, 2005; Pettersson, Ahlström, Törnquist, 2008; Rigby, et al., 2005; Ripat,

2006). On closer examination outcome measures indicated satisfaction and positive psychosocial benefits associated with assistive technology. All but one failed to reveal anything about the experiences of using ECS from the users' perspective. A single study based on both the PIADS and the Canadian Occupational Performance Measure (COPM) provided limited insights into the users' perspective and highlighted the value of qualitative investigation (Ripat, 2006). A deeper understanding of life with and without ECS would not emerge from a quantitative study alone.

Initially in-patients in a spinal injuries unit and those living in the community were considered as two potential comparative groups. The preference for the inclusion of in-patients was based on my clinical bias from working in an in-patient setting and my intention of improving rehabilitation practice. However, this was logistically not feasible on account of the small numbers of in-patients with high SCI. It became apparent that understanding the use of ECS required an insight into community living not yet experienced by in-patients. The inclusion of users and non-users was thus favoured as consistent with a focus on community based rehabilitation (Hammell, 2000).

A mid-trial interview initially considered for inclusion in Phase 3 was abandoned as ECS experts advised that participants were unlikely to have become sufficiently accustomed to using ECS to enable them to provide valuable insights after only 4 weeks of use (J. Leslie, personal communication, 19 March 2008; Steggles, personal communication, 11 March, 2009). An interview on completion of the trial was considered to be a better option and a better reflection of the entire trial.

A fourth phase, consisting of a focus group of trial participants was also considered. This phase was also abandoned as the interview data collected in Phase 3 was considered sufficiently rich and the methodology sufficiently rigorous. It was also considered too demanding to ask research participants, who had already facilitated trials in their own homes across the country, to then travel to one location to partake in such a group. Furthermore, from a methodological perspective a final focus group was not considered a logical progression from the in-depth IPA investigation carried out in Phase 3.

3. Ethical considerations

Ethical approval for this study was sought and granted by the Medical Council and the Ethics Committee at the [hospital] and the Research Ethics Committee of [University]. Approval was granted before any research work commenced. Approval from the Ethics committee at the [hospital] followed a four-step process and [University] approval was expedited based on the hospital approval. Letters of ethical approval can be found in Appendix 9.

This study was conducted following ethical guidelines: informed consent, right to privacy and anonymity; protection from harm; sensitivity and duty of care. Participants were provided with full written information about the research in a patient information leaflet (Appendix 10). All participants provided informed consent including consent to video and audio recording and the use of such recordings for academic publication. Consent also included a revocation of consent to facilitate their right to withdraw at any time without giving a reason (Appendix 10). Participants were reminded throughout the study that they were able to withdraw from the study if they so choose. All identifying information was removed and participants selected their own pseudonyms which have been used throughout the thesis. Anonymity not confidentiality is all that can be promised in any qualitative study (Smith et al., 2009). If sensitive issues had arisen during the research participants would have been referred to the appropriate community or hospital based professional.

The [hospital] ethics committee recommended, in line with good research practice, that recruitment be conducted via an intermediary to prevent researcher coercion of participants. Thus Spinal Injuries Ireland (SII), agreed to seek participants on the researchers behalf. The study was announced in the 2007 Summer issue of *Spinal News*, the quarterly magazine of SII, (Appendix 11).

4. Data management and analysis

The quantity of data produced through in-depth qualitative investigation makes data management and analysis challenging. Computer software can assist both data management and data analysis by centralising and organising the data and analysis (Creswell, 1998). While there is some debate about computer-aided data management (Smith, et al., 2009) the choice to use computer technology in this

study reflected the overall context of this study - life in a technological age. The use of computer software was particularly suited to my style of working. Computer software enabled quick location of excerpts and speedy comparisons for analysis (Creswell, 1998). ATLAS.ti (Muhr, 2004; Muhr, 2011) was used in both Phase 1 and Phase 3 and details and examples of how the software was incorporated into data analysis are provided in Chapters 6 and 9.

Mind mapping software was also used in a less traditional application of computer software to aid data analysis (ThinkBuzzan, 2011). The organisation of emergent themes and their interrelationships were captured in a dynamic process of mind mapping. Several versions of inter related maps were created to provide visual tools for the organisation of themes and patterns between themes. An example of a mindmap can be found in Appendix 12.

Phase 1 focus group data was analysed using a thematic analysis based on the psychological phenomenological approach well suited to this phase due to its descriptive in nature (Creswell, 1998) as described in detail in Chapter 6. Themes were identified by the adoption of a phenomenological attitude of *seeing things as if for the first time*.

Phase 3 interview data were analysed using IPA. Interviews provided added depth to the understanding of the subjective descriptions from focus groups of living with and without ECS. IPA provided a rigorous method for analysis that involved hermeneutic interpretation influenced by the foreunderstanding provided by Phase 1 findings. IPA was suited to the specific situation of being the researcher as well as being the developer and installer of the intervention pack. This linked me inextricably with the data production as I was responsible for creating the experience that I was exploring. This means that my perspective may have had some bearing on the experiences. IPA acknowledges the researcher's perspective and what is more relies on this for in-depth data analysis (Smith, et al., 2009). Moreover IPA was considered suitable because it provided a methodology that preserved the individual nuance of each participant while still analysing the shared experience across participants. This is consistent with a person-centred approach and with the orientation of occupational therapy. Data analysis of Phase 1 and Phase 3 data are described in detail in Chapters 6 and 9.

5. Quality control

Quality control applicable to quantitative research investigations are unsuited to qualitative investigation due to epistemological differences (Carpenter & Hammell, 2000). The application of primary quality indicators: validity, reliability and generalizability are inherently inappropriate when applied to qualitative studies as qualitative findings are inherently not statistically measurable (Krefting, 1991). Several different types of quality control criteria and guides have been developed and applied to qualitative investigation as reviewed by (Meyrick, 2006).[113] Ensuring quality in qualitative research involves both the evaluation of the findings as well as evaluation of the methods and methodology (Carpenter & Hammell, 2000). This study employed Yardley's (2000) guidelines for ensuring that qualitative analysis is both rigorous and sound. This required attending to four key dimensions *sensitivity to context; commitment and rigor; transparency and coherence; and impact* and *importance*. These dimensions were applied throughout the study and will be referred to again in Chapter 11.

Sensitivity to context is assured in this study by the combination of my clinical experience of SCI rehabilitation and an in-depth understanding of the literature that focuses on ECS and people with high SCI. Sensitivity to context included an awareness of my positive bias towards using ECS based on over 14 years of clinical experience of working with people with high SCI as well as an awareness of my privileged position in ECS through conducting this study.

Commitment and *rigor* were achieved through immersion in the available literature on ECS including access to unpublished theses and conference presentations; and engagement in prolonged debate throughout the research process with two supervisors and an expert peer to refine the analysis and findings. One supervisor had experience of IPA methodology and psychoanalysis, the second supervisor had experience of qualitative occupational therapy research and the peer was a clinical specialist in the area of ECS. Analysis was long, arduous, and at times tedious. Commitment to rigor delayed the identification of the final findings. Rigour was ensured by a prolonged period of data analysis and a determination to seek interpretations beyond the obvious initial themes.

[113] Including credibility, transferability, dependability, and confirmability (Licoln & Guba, 1985); Authenticity requires that research be reliable, representative, trustworthy and credible that is assessed through close evaluation of the researcher. Plausibility assesses if the findings are credible based on both the data from which the findings originate and based on existing theory (Carpenter & Hammel, 2000).

The use of extensive verbatim quotations provides the reader with links to the source of findings to provide both *transparency and coherence. Transparency* was also ensured through record keeping including fieldwork diaries, journaling which incorporated reflexive bracketing and documentation of the individual steps in the research. These records were intended to make research efforts transparent and excerpts are presented throughout the thesis to allow readers to evaluate the rigor and quality of the research conducted. Coherence was assessed by considering the findings in light of existing knowledge and personal clinical experience as well as that of the clinical expert.

Findings were constantly reviewed to ensure both *importance* and *impact* for participants and for others who might benefit from the use of ECS. The findings include important considerations for service providers such as occupational therapists, rehabilitation professionals and policy makers. Verification includes dissemination in the form of publication in academic journal publications, professional conference presentations and invited keynote presentations. In addition, findings have been shared with rehabilitation staff at [hospital] through lectures, seminars, and in-house conference presentations and the quarterly newsletter of SII, *Spinal News,* have requested a summary of the findings for their non-academic dissemination.

Specific trustworthiness strategies recommended for phenomenological investigation include member checking and triangulation (Cronin-Davis, Butler, & Mayers, 2009). Member checking is however a contested concept for some phenomenologists (Smith, et al., 2009) (Giorgi & Giorgi, 2008). While Colaizzi's method for example includes member checking as a validation step, Giorgi and Giorgi (2008) argue that such validation is inappropriate and unnecessary, as the analyst is a professional whose professional experience facilitates an interpretation of the raw data to provide an understanding of the experience that is relevant to that profession. This professional interpretation or disciplinary meaning he believes is unlikely to be understood by the participant who describes the raw experience. Giorgi & Giorgi considers that the participant is not able to validate the findings as they are not privy to this level of analysis (Giorgi & Giorgi, 2008). Member checking is thus not incorporated in this study as it was considered unnecessary and inappropriate. Although individual participants may have been able to assess findings for coherence, the findings were considered to have progressed further than the individual level of experience or recollection of the data production stage.

Assessment of findings was more appropriately conducted by the three-person supervisory team who were privy to all the data, intermediary analysis, and researcher-reflective commentary.

Triangulation is the process of confirming findings by comparing and contrasting two or more sources (Denzin & Lincoln, 2003). Data triangulation was broadly applied in this study as Phase 3 data was considered in light of Phase 1 data. This application of triangulation does not conform to the traditional process of verification where Phase 1 findings would be verified by Phase 3 findings. The combination of focus groups and interview data collection methods could be considered to provide a form of methodological triangulation. The study is a dynamic evolving study with focus groups producing broad findings and later interviews providing in-depth personal perspectives. Combining the two methodologies to provide triangulation would be questionable as they investigate different experiences – life with and without ECS and life with an ECS starter-pack.

6. Reflexivity throughout the study

The inclusion of reflexivity and positioning of the self are common recommendations for qualitative investigations (Finlay & Gough, 2003; Hammell & Carpenter, 2000; Smith, et al., 2009). As the researcher is an integral part of a qualitative investigation, I was both influenced by the data and had an influence on the data through data collection and evaluation (Hammell & Carpenter, 2000). Reflexivity involves an open sharing of oneself and one's position, as I have detailed in Chapter 1 (the origins of the study). While reflexivity is appropriate in all qualitative investigation, it is integral to phenomenological methods (Smith, et al., 2009). Reflexivity is integrated throughout this thesis and is defined as:

> *the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes* (Finlay & Gough, 2003, p.108).

Reflexive commentaries are included as concluding sections in this and subsequent chapters and are presented in a smaller italicised font with verbatim excerpts indented as in section 7 below. Reflexive commentaries disclose the interaction of the researcher and the unfolding research process by including excerpts from

reflexive diaries and reflections at the time of writing. These reflexive sections are intended to create a common thread between the different chapters and provide an insight into the dynamic reflective process underlying the study.

7. Reflexive commentary

Initially the literature search that revealed a predominance of quantitative and outcome measure ECS publications lead me to assume my work would have to follow the same lines, however I felt relieved when I realised that qualitative research is both valuable and legitimate.

> *My supervision meeting was a relief because having had little qualitative research experience myself it now became a realistic option. The suggestions of using a qualitative focus group made sense, namely using a smaller group of subjects with more to say. My research plan was beginning to feel more realistic and useful not just something that I would be well advised to do. My passion for the topic was starting to spread to a passion about the methodology too*. (Reflexive diary I, p.25, 18-11-06,).

My appreciation of my chosen qualitative method continued throughout the study:

> *Qualitative research is so very interesting, wow; I can't wait to share it. The AT research that I have read about seems so bland now*. (Reflexive diary II, p.49, 21-9-07)

I did not initially feel the same affiliation for phenomenology. My occupational therapy education left me devoid of the philosophical tools to inform my search for a methodology. While being well versed in models of human occupation I was naive to the wider philosophical stance underpinning the profession and of general philosophy. I believed that I already adopted a person-centred approach congruent with occupational therapy philosophy but on closer examination my efforts were far from person-centred and rather more in line with a biomedical model not uncommon in spinal cord rehabilitation The biomedical approach is recognised as the source of some of my frustration in carrying out rehabilitation with people with high SCI as their needs are poorly served by an approach that focuses on elements such as strengthening, endurance, balance and compensation. Such issues are far removed from the realities of living with paralysis of all four limbs which excludes possibilities of strengthening. Attempts to understand their experiences of rehabilitation were not likely to be fruitful from a biomedical stance thus I sought to embrace a philosophy that was truly person-centred.

My first exposure to phenomenology was the work of Van Manen (1990). As an introduction, his work was challenging for me as I did not fully comprehend its philosophical content. Despite these difficulties I became more engaged in his hermeneutic phenomenological human science and phenomenological lifeworld structures namely corporeality (lived body) spatiality (lived space), temporality (lived time) and relationality (lived human relation). It was clear that these were useful concepts when exploring the lives of people with SCI as they experience life through damaged bodies, changed lived spaces, disrupted time and new human relations as a result of their injuries.

The search to understand the methodology required much reading, searching, debating with supervisors and peers, and then more reading and examining the underlying philosophy of phenomenology in more depth until I began to understand. On reflection my initial response to phenomenology is a drastic contrast to the spirit of this Chapter 4:

> *Hermeneutic Phenomenology – I am petrified of this! I understand the basic concept but it still scares me. I have read some of a thesis about the lived experience of adolescent burn victims and the thesis was horrible to read for me – I like the idea of reflexivity, and the use of narratives and can anticipate their inclusion in my work but the thought of trying to weave my findings into the frame work of corporeality, spatiality, temporality and relationality makes me nauseous. It's really not me and I fear it will ruin writing my thesis for me. I may be totally off the mark but I'd rather be using an OT frame of reference or similar*. (Email to supervisor dated 13-7-07).

My understanding of phenomenology was also a journey throughout the study. In Phase 1 I adopted a descriptive phenomenological approach that loosely incorporated thematic analysis with a phenomenological lens. At the time my fuller understanding of hermeneutic phenomenology and methods such as IPA were underdeveloped. When I began analysis of Phase 3 data my phenomenological knowledge was substantially greater than it was in Phase 1 and I felt able to use IPA which required much more patience and rigor than the analysis applied in Phase 1. Once I completed Phase 3 I was tempted to return to Phase 1 data and improve the depth of the analysis possibly by using IPA. This was not feasible and would have obscured my primary findings and I disciplined myself to leave the findings as they were initially.

Designing the study was a challenging task. I needed to choose a way of gathering information progressively to create an ECS starter-pack that would be reflective of the users' perspective while still gathering data about what ECS mean to those who use them. I also needed to ensure the project was realistic so that I was able to complete in the allocated time frame and that the data and findings produced would be manageable. I began with rather grandiose ideas of a multi-phase study with several interviews, video diaries, outcome

measurement and qualitative data – all of which together would have been unmanageable and likely to lack a specific focus. And although it is presented here as a relatively smooth journey I needed to adjust the study as it progressed. For example: focusing on people in the community rather than in hospital. My initial focus was on in-patients based on my clinical background. The original study design involved in-patients and outpatients however review of the methodological literature soon made me reflect on my error of focus. ECS are primarily community living issue and I needed to understand their role and meaning from an outpatient perspective if I wanted to improve my in-patient therapy.

My final design although complex - I found both manageable and suited to the studies objectives.

Chapter 6: Phase 1 procedures

The previous chapter provides an overview of each phase of the entire study together with a rationale for the selected research methods applied in each phase. This chapter describes in detail the initial phase of the study that consisted of focus groups of users and non-users of ECS. Focus groups were selected as a starting point for the research as a means of seeking a broad understanding of the experiences and expectations of ECS use by people with high SCI living in Ireland. In addition, Phase 1 provided practical information required for the development of the starter-pack in Phase 2.

1. Focus groups as a research method in Phase 1

Focus groups were selected for Phase 1 of this study as a suitable approach for both exploring the experiences of people living with and without ECS as well as providing valuable suggestions to assist in the compilation of an ECS starter-pack for use in a later phase of the study. Although the use of focus groups for novice researchers may not be recommended (Hunt Joseph & Griffin, 2000), I considered my experience of group work as an occupational therapist to provide me with the appropriate experience to make focus groups manageable. This phase of the study explored the experiences and opinions of ECS users and non-users and was concerned with the meaning-making that becomes observable through focus group interactions that were video and audio recorded.[114]

2. Phase 1 research procedures

This section includes information on Phase 1 procedures including: participants; the research team; use of video recording, focus group processes; data collection and data analysis.

2.1 Participants

Participants include both ECS users and non-users. The inclusion of non-users was strategic as the proposed starter-pack in Phase 2 was intended for use by non-users in Phase 3 and therefore their opinions were relevant in terms of its development and contents. In addition, clinical experience suggested that the non-

[114] Recordings were consensual.

users may have very little knowledge of ECS but may still have views and opinions and be able to reflect on what life might be like with ECS as their non-use was understood to be based, not on choice but on lack of ECS provision. The focus of this study on people with high SCI who could benefit from ECS required suitable research participants who met the following criteria:

- Traumatic or non-traumatic SCI at a neurological level of C3, C4, C5
- No known traumatic brain injury
- Aged 18 years and above
- Bilateral upper and lower limb paralysis
- Inability to feed independently
- Inability to use a standard television remote control without assistance
- Use of powered wheelchair with chin control or joystick, or manual wheelchair propelled by carer
- Post discharge from rehabilitation[115]
- Resident in the Republic of Ireland
- Sufficient cognitive ability to provide informed consent and to follow and recall instructions
- Ability to communicate verbally in English.

While high SCI is technically defined as injury at the level of C4 (Bromley, 1998) the selection criteria included injuries at level C5 due to the clinically identified functional similarities. Some people with injuries at the C5 neurological level have functional abilities and limitations that are comparable with persons injured at the C4 level. The inclusion of functional criteria of inability to feed oneself was intended to exclude persons with recorded C5 level injuries who had greater functional abilities. The inability to use a standard television remote control device determined the functional need for ECS. Failure to consent to the use of photographic recording equipment was not considered to be an exclusion criterion.

Suitable persons were identified with the assistance of two SII outreach workers[116] using the SII electronic national data base with injury level used as the primary search criteria. Once all members with injuries at C5 and above were identified the outreach workers applied the inclusion criteria – *inability to feed oneself and*

[115] The need to try out ECS in a current living environment was deemed more important than post discharge living arrangements.
[116] Outreach workers are familiar with the spinal injured population in Ireland and conduct annual visits to members throughout the country.

wheelchair dependent to each individual record based on information or their recollection of each person. They excluded anyone known to have significant lower limb voluntary movement. This initial review of the data base by SII outreach workers yielded a list of forty nine potential participants. Each of these were sent postal invitations[117] to participate in the study (Appendix 13). One outreach worker identified another potential participant during a routine outreach visit who was also invited to participate and who brought the total number of potential recruits to 50.

As SII outreach workers were unable to contribute any further to the recruitment and identification of participants due to other work commitments I followed up each response and non-response to the invitation. Twenty six people responded via prepaid post, email or telephone. Ten people suitable to participate in the study were non contactable and further fourteen responded to telephone inquiry. Of 40 responses, 37 were positive while three people declined to be involved, Table 7. Another potential recruit responded to the magazine request for volunteers in the study announcement (Appendix 11) but failed to meet the selection criteria.[118]

Table 7: Details of participant recruitment

	Total	Yes	No
Postal replies	26	24	2
Telephone follow-up	14	13	1
Not contactable	10	-	-
Potential participants	50	37	3

A response rate of 37 persons was surprising as the daily challenges and risks involved in living with high SCI might be considered potential deterrents to participation in research. Focus groups were planned based on further telephone calls to all 37 persons. The telephone calls ascertained if potential participants:

- met the inclusion criteria,
- were availability to participate in focus groups on planned dates,
- were prepared to travel to a venue in Dublin and/or Cork,
- were ECS users or non-users?

[117] Postal invitations included prepaid reply slips.
[118] Excluded as he had also sustained a significant brain injury.

Of 37 potential participants one had significant hand function and was able to use a standard television remote control with no difficulty. Three had functional use of a teneodesis grip,[119] which meant that they had more hand function than the others and some ability to use a standard television remote control. Two others were still in acute care facilities. Thus 6 did not meet the inclusion criteria and a further four were not contactable by phone, leaving 27 possible participants (N=37-(6+4)=27).

Due to the wide geographic location of recruits, two venues were initially considered for the focus groups, one in Dublin and one in Cork.[120] Five of the 27 suitable recruits were unable to travel to a focus group in Dublin or Cork and another four were only able to travel to Cork. As four was considered too few for a single focus group, Dublin was selected as the best location for the groups. This resulted in a sample of 18 people who were prepared to attend focus groups in Dublin.

Three of the 18 were however unable to attend on the planned dates due to other commitments.[121] They were excluded in order to create suitably sized groups. The final fifteen recruited participants were homogenous in terms of physical dependence and the need for ECS but demographically heterogeneous in terms of gender, marital status, age and time since injury (Table 8). As discharge to residential care is sometimes the only option for persons with such severe disability and as ECS are potentially useful in residential care settings, living in a residential facility was not considered a reason for exclusion in this study.[122]

The final sample is presented in Table 8 overleaf. The small source population from a small country made it likely that the individual participants would be identifiable through demographic information and therefore only limited demographic information is included. In addition in an attempt to increase anonymity, pseudonyms[123] are used throughout this thesis.

[119] Tenodesis grip is produced with active wrist extension that results in passive shortening of de-enervated finger flexors resulting in closing of the fingers. This grip can be used to pick up light objects such as a remote control not reflecting the inclusion criteria.
[120] Dublin, in the east, and Cork, in the south, were selected as both are populous areas that are easily accessible.
[121] Including clashes with personal care schedules.
[122] Four people lived in residential facilities.
[123]Participants selected their own pseudonyms.

Table 8: Participant details and focus group attendance (n=15)

Pseudonym	Gender	Age yrs.	Injury Level	Years since discharge	Living	ECS	Focus group/s attended			
							FG 1	FG 2	FG 3	FG 4
Joe	male	48	C4	31	home	no	*		*	
Emily	female	27	C3/4	1	home	no	*		*	
Peter	male	20	C3/4	1	nursing home	no	*			
James	male	26	C4/5	6	home	no	*			
Jerry	male	55	C3/4	22	home	no	*		*	
Mathew	male	34	C4/5	7	home	no			*	
Frank	male	43	C4/5	6	nursing home	no			*	
Jane	female	37	C4/5	12	home	GEWA*prog*	*			*
Susan	female	32	C4/5	6	home	GEWA*prog*			*	
Jim	male	24	C4/5	1	university residence	GEWA*prog*		*		*
Michael	male	22	C4/5	2	home	PROTEOR*Keo*		*		*
Ciara	female	57	C4	29	nursing home	GEWAprog		*		*
Dave	male	38	C3/4	3	home	PROTEOR*Keo*		*		*
Richard	male	44	C4/5	1	home	PROTEOR*Keo*		*		*
Paul	male	43	C3/4	23	home	X-10		*		*

ECS = environmental control systems, FG= focus group

It was intended that Phase 1 would consist of two groups of people with each group meeting twice, at the same venue two weeks apart, resulting in a total of four focus groups referred to as focus group 1 (FG 1), focus group 2 (FG 2), focus group (FG 3) and focus group (FG 4). Participants were allocated to focus groups in an attempt to create one ECS user group and another ECS non-user group each with six to eight members. Attending two focus groups aimed to provide the participants with two weeks between groups to reflect on their personal experiences which they could then report on in the second group. In addition, for those with no previous understanding or experience of ECS, the first focus group (FG1 and FG 2) would provide an introduction and it was anticipated that they would have formed stronger opinions before the second group (FG3 and FG4).

A participant information leaflet and the consent form were posted to the fifteen participants prior to the focus groups (Appendix 10). All Participants provided consent on the day of the focus groups and were reminded that they could withdraw this consent at any time without providing a reason.[124] Each person also provided some basic demographic details prior to the focus groups (Appendix 14).

Carers and family members were not invited to attend groups to avoid creating unmanageable sized groups and to ensure the focus groups only explored the users' perspective rather than the perspective of significant others (Hunt Joseph & Griffin, 2000). The likelihood of personal acquaintances within the groups was strong due to the small population of people with high SCI in Ireland. However, only a few participants knew each other having attended rehabilitation or community groups and organisations together. People with high SCI in this study were considered to be a marginalised group with a similar physical disability that would provide common ground and facilitate open disclosure amongst peers in a permissive environment (Madriz, 2003). Similarity in terms of SCI between participants may also, however, result in the assumption that others would understand their personal opinions and lead to participants failing to articulate their views fully if not facilitated to do so (Finch & Lewis, 2003; Macnaghten & Meyers, 2004). This was not observed in these focus groups.

[124] Each participant was given copies of their consent form, in addition copies were placed in their medical records at [hospital].

2.2 The research team

Although this study was conducted by a single researcher the selection of focus groups as a data collection method required the creation of a research team of six people. I acted as moderator and one of two colleagues acted as co-moderators in each group. Similarly one of two therapy aides acted as a general assistant in each group. The final group member was a videographer. The research team was briefed about their roles prior to data collection and provided an opportunity to trial their group roles in a pilot group. The pilot focus group was also conducted to test the technical and practical issues related to running research focus groups, with volunteer [hospital] staff-members role-playing people with high SCI.

Moderation involved facilitating the group discussion through probing for fuller responses and focusing on deeper thinking and personal views (Finch & Lewis, 2003). I also identified irrelevant divergences and redirected the discussion to the research topic. This was done with caution as some divergences produced valuable related insights such as the relationship between mouthstick and ECS (Finch & Lewis, 2003; Flick, 2006). Anticipated divergences included discussions on computer access, rehabilitation issues, current community services, and personal medical issues such as pressure care and infections. Brief discussions on such topics were not stopped but longer discussions were postponed until after the formal group ended. Moderation involved managing simultaneous dialogue and facilitating individual contributions from all participants by encouraging the reticent and managing the dominant (Finch & Lewis, 2003; Morgan, 1997). A flexible moderation style allowed the group to self-direct the discussion and participants to question each other directly. This facilitated interaction between participants (horizontal interaction) in addition to the anticipated interaction between myself and participants (vertical interaction). The focus groups sought to facilitate active discussion by all members in order to allow the extended exploration of views, opinions and experiences of ECS. The development of an equalitarian and trusting atmosphere to enable this to occur was dependent on careful and thoughtful handling of the groups.

Two selected co-moderators were colleagues with qualitative research experience, some group experience, as well as relevant SCI clinical experience.[125] Both offered to assist in the focus groups based on their own interests in the research project

[125] One co-moderator was an occupational therapist and the second was a psychologist.

which meant that I did not have to actively recruit co-moderators. Neither suitable co-moderator was available for all four scheduled dates and thus one co-moderator attended the first focus groups (FG 1 and FG 2) and the second attended the second two focus groups (FG 3 and FG 4). While it may have been possible to have chosen a different co-moderator who could have attended all groups the two colleagues who offered to assist had the relevant experience required unlike other colleagues without group or research experience. In each focus group the co-moderator, seated opposite the moderator, used an analogue tape recorder to audio record the groups, but did not actively participate in the discussions. The co-moderator had roles that were not overt. They made comprehensive notes during each group that detailed the content of the discussion. They were asked to note topics that appeared to be important to participants as they arose. They also observed the non-verbal interaction during groups to note interactions not evident in the transcriptions. They were also asked to observe the moderators influence on the group and provide feedback on the moderation to improve future groups. In the concluding stages of each group, the co-moderator was then asked to provide a summary of the group. This content summary was presented based on an immediate reading of their notes about content and important topics. The purpose of these summaries was to conclude each group by focusing on what had occurred during the group. These summaries provided an opportunity for participants to expand on the discussion by commenting on the summaries, making corrections and adding content. The summary was also intended to provide participants with things to think about between groups which may have improved their ability to participate in subsequent groups.

One of two therapy aides was included in the research team as a general assistant. As neither were available for all four focus groups, one person assisted in FG 1 and FG 2, and the other person assisted in FG 3 and FG 4. The therapy aides were occupational therapy staff members working on the days of the groups who were relieved of their other duties and made available for the focus group by the occupational therapy head of department. The possible unpredictable nature of focus groups (Hunt Joseph & Griffin, 2000) and possible anticipated discomforts for people with high SCI required the help of a general assistant. Possible difficulties anticipated for the groups in this study included one or more participants experiencing distracting spasms, or becoming unwell due to a blocked catheter or other medical event. The general assistant acted as an observer, seated outside of the group unobtrusively but able to attend to individual participants' needs such as

drinks of water or repositioning of limbs when spasms were experienced, allowing the group to proceed uninterrupted. In addition participants could, if necessary, be escorted from the group to seek medical assistance on site, at [hospital] by the therapy aide.

The research team was completed by a videographer. The videography was a volunteer who worked at [hospital] as a psychology assistant. This person had no formal videography training and I trained her how use the video camera and how to record the focus groups prior to the actual data collection phase. During focus groups the videographer was positioned outside of the group behind the moderator's right shoulder. She operated the video camera panning across participants to attempt to record visual data to complement the audio recording. The videographer wore headphones in order to check sound quality. In addition this person changed video tapes during the break.

2.3 Video recording

Video recordings were selected despite Morgan's (1997) advice against their use based on a concern that video cameras are intrusive and that quality recordings depends on specialised lighting and recording equipment. In preparation for the focus groups support was sought from the university audio visual media services department who advised on the purchase of a high quality microphone and also provided some technical tips to facilitate high quality recordings. A high quality microphones connected directly to the domestic digital video camera,[126] was suspended from the ceiling of the room at the centre of the group ensuring full audio coverage of all participants. Digital audio tracks were produced from the video recordings in addition to full video recordings to ensure data integrity in case of data capture failure (Krueger & Casey, 2000).[127] All digital recordings (video and audio) were copied to an external hard drive as back-up. A step-by-step data gathering protocol, Appendix 15, was developed to ensure that the focus groups proceeded without technical delay.

The data recording process was trialled during a pilot focus group and no technical issues were noted. The recording equipment was also tested a week prior to the first focus group and an unexpected technical issue of poor audio quality was

[126] A back-up video camera was available in case of technical failure.
[127] In one group the audio was retrieved from the video recording as the co-moderator failed to record part of the group.

encountered. The source of the poor-quality was unclear as the pilot group had not presented the same problem. The issue was resolved by removing the electricity supply to the camera because the high quality microphone picked up noise interference from the electricity supply.

2.4 Focus groups process

As mentioned it was not possible to have the same co-moderator and therapy aid for all four groups in this study due to conflicting clinical and personal commitments. In addition, some participants were only able to attend one of the focus groups. Success relied on participants turning up for the groups, active participation and guidance from the moderator (Krueger & Casey, 2000). Participants were reminded about the groups by telephone, and as long distances were involved for some, participants had their travel costs reimbursed. Other incentives were not considered appropriate as participation was intended to be voluntary.

The venue for the focus groups needed to be appropriate for participants in terms of access, ambiance, likely associations, size, privacy, and distractions (Finch & Lewis, 2003). The [hospital] was selected as the venue for all groups as it had a room of the appropriate size,[128] ambience, familiar and accessible for all participants. A purpose-designed group room, booked through the occupational therapy department, provided appropriate ambience and privacy. However it was not possible to avoid potential associations of being *back in rehab* or *in an occupational therapy group*. These possible associations were discussed in team debriefing sessions but did not appear to influence the content of the focus groups.

It is recommended that focus groups should run for about one and half to two hours (Krueger & Casey, 2000). Focus groups in this study were planned to last one and a half hours with a short break to allow for position changes, essential to counteract participants' immobility. One of the four groups required an extended break due to external noise interference from a helicopter landing at [hospital].

Group exercises have been recommended as a way to encourage participation (Kitzinger, 1994). However, they were not included in this study as they would have been inappropriate if paper based[129] and potentially reminiscent of school exercises and therefore liable to make participants feel uncomfortable. The first 2 focus

[128] A large accessible room was required to facilitate 9 large power wheelchairs and the research team.
[129] People with high cervical spinal cord injury are physically unable to participate fully in paper based exercises.

groups (FG 1 and FG 2) were instead preceded by the provision of an ECS introductory pamphlet, Appendix 16, to provide visual cues for group discussion. In addition an introductory video was played in the group room while waiting for all members to arrive. This was chosen because it showed how a simple ECS works. I designed and compiled the pamphlet specifically for use in this study. In addition I designed, captured, edited and uploaded the video to the internet[130] for this study.

Two questioning routes, Appendix 17, were compiled based on Krueger and Casey's (2000) extensive guidelines to facilitate the flow of conversation within the groups. This involved selecting opening questions, introductory questions, transition questions, key questions and ending questions. Questions were short, clear, easy to say, open ended, one dimensional and progressed from the general to the specific. Timings for each set of questions were also planned. Questions explored participants' anticipated and actual use of ECS as well as the impact of ECS on lifestyles. The questioning route went through several revisions. An academic supervisor made suggested changes to wording of questions and allocated timings. In addition Elizabeth Steggles (the clinical expert) suggested further prompting for questions to which people might not respond at length. Changes included reducing the number of questions and increasing the amount of time allocated for each question to encourage participation by all.

The questioning routes (Appendix 17) and the data gathering protocol (Appendix 15), for the focus groups were piloted in a focus group with colleagues. Five occupational therapists role-played participants in the pilot focus group and responded to all the proposed questions for both questioning routes. This familiarised me with the questions and while I attempted to take notes during the pilot focus group I was unable to manage the group moderation and note taking. I found both myself and group members distracted by note taking, and therefore decided that the co-moderator would be responsible for note taking in the research focus groups. Minor word changes were made to the questions following the pilot focus group but most questions were found to be suitable. Other minor adjustments were made to questioning routes between the first and second groups to include extra prompts for questions that did not elicit answers easily but no major topic changes were made. The final questioning route can be found in Appendix 17.

[130] Can be viewed at http://www.youtube.com/watch?feature=player_detailpage&list=UUIXl9nb85g5ao3-d-6aKp5A&v=egd-_TLhtjY

Questioning routes were reviewed after each focus group. Follow-up focus groups groups (FG 3 and FG 4) included a summary of the previous group's (FG 1 and FG 2) content as a memory prompt for the repeat focus groups. The second questioning route was designed to continue the discussion begun in the first focus group with a more specific focus on their expectations for ECS for a person with a high SCI. The requirements of a starter-pack in particular as well as its anticipated impact were also explored. The questioning routes were not used prescriptively but as a guide allowing for relevant diversions, extra questioning, probing and group-led topic progression. In FG 3 and FG 4, the second meeting of each group, the questioning focused on ECS in particular and minor divergences to other types of technology which had occurred in the first two groups were discouraged.

Consideration was also given to group dynamics and interactions within a group between members (including the moderator) (Manor, 2000). In some instances, participants identified with each other and addressed their comments to each other rather than to the entire group. On the other hand, at some stages, participants choose not to engage with other participants if they were offended or annoyed by their contribution. The group process and dynamics were observed and recorded by both the moderator and the co-moderator and used to interpret some of the interactions for example an animated exchange between participants talking about the use of mouthsticks. Dynamics were also recorded using video footage. These observations provided insights to some of the emotional responses that may not have been reflected in verbatim transcriptions.

The research team met before the pilot focus group to describe the aims of the research and individual team member roles. Each research team also met briefly prior to each focus group to remind all members of their roles and the aims of the focus groups. Once each group concluded and participants left, the research team met to debrief. Despite the concrete nature of the topic under discussion, many interactions were considered emotive and found to be moving by the team. Team members were eager to share their reflections on the groups such as comments on how previously known participants had changed as well as reflections on the personal impact of the group on themselves as members of the research team. As moderator I facilitated four debriefing sessions and then led four brain storming session to identify team members' perception of initial themes from each group. In addition I compiled brief group summaries based on a combination of the co-

moderators notes and my own recollections of each group and recorded personal reflections in a reflexive diary.

2.5 Data collection

The four focus groups were conducted in September 2007. Not all participants attended both focus groups, Table 8. focus groups attendance was as follows:

- Focus group 1 (FG 1): seven people, six of whom were ECS non-users.
- Focus group 2 (FG 2): six people all ECS users.
- Focus group 3 (FG 3): three people from FG 1, and three new participants (five non-users).
- Focus group 4 (FG 4): all six members of FG 2 and one from FG 1 (all ECS users).

Table 9 provides a summary of focus group demographics and Table 8 provides some individual demographic information.

Table 9: Composition of focus groups in terms of ECS use, gender, wheelchair use

	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Total sample
ECS user	1	6	1	7	8
ECS non-user	5	0	5	0	7
Male	4	5	4	5	11
Female	2	1	2	2	4
Powered wheelchair	4	6	5	6	12
Manual wheelchair	2	0	1	1	3
Total Group size	6	6	6	7	15

Both Jane and Susan who participated in FG 1 and FG 3 respectively revealed during the group discussion that they did use ECS despite reporting otherwise during telephone recruitment. Jane was unable to attend FG 3 but she attended FG 4 as an ECS user. FG 1 and FG 3 intended to be ECS non-user groups were mixed groups and FG 2 and FG 4 consisted only of ECS users. While there were some inconsistencies in attendance, it was not considered to have adversely affected the focus group purpose, namely to explore *What Irish ECS users and potential users think about ECS?* and *What people with high SCI want from ECS?*

Consensual audio and video recordings were made of all four focus groups as described in section 2.3. Video recording was selected to provide visual data to aid with accuracy of transcription and to record elements of group dynamics. One member's dissatisfaction with another's comment for example was recorded by his moving his wheelchair to face slightly away from the other participant. Facial expressions also provided clues to the importance of some comments not adequately recorded by audio only. Recordings were transcribed verbatim from digital audio recordings. Video was useful on two occasions to identify the speaker in inaudible passages due to simultaneous talking or mumbled speech (Hunt Joseph & Griffin, 2000; Macnaghten & Meyers, 2004).[131] Transcriptions took several days to complete and to edit.

2.6 Data analysis

Data analysis of focus groups was conducted using a phenomenological attitude including a bracketing of researcher preconceptions based on existing literature and personal experience. This meant that the data were not considered in light of existing theories or concepts. I avoided anticipating the findings prior to analysis. For example I did not actively seek themes such as ECS satisfaction or quality of life as suggested in the literature. I also viewed the data as it occurred as opposed to having a preconceived framework such as the Matching Person and Technology Model (Scherer, 2005) or the ICF (WHO, 2001). Similarly I kept aside anticipated themes based on clinical experience such as a desire for computer based ECS. Therefore, no theoretical framework was applied to the data and themes were not preconceived. In addition data analysis also focused on practical issue as I sought to gather opinions and suggestions to assist in the development of an ECS-starter-pack (Phase 2).

Thematic analysis is commonly used as a method of analysing focus group data, but identification of it as a discrete method is difficult as a variety of terms are used when referring to it such as a *descriptive, exploratory approach* (Ripat & Booth, 2005) or simply *analysis leading to themes* (Courts, et al., 2004). Thematic analysis was selected instead of adopting a method *for methods sake* (Holloway & Todres, 2003) and Braun and Clarke (2006) argue that:

[131] In total only one short passage was not possible to decipher despite video recordings.

> *thematic analysis should be seen as a foundational method for qualitative analysis... (and) should be considered a method in its own right.* (Braun & Clarke, 2006, p. 78).

As thematic analysis is not confined to one epistemological school, and its flexible approach allows theoretical freedom, it was considered appropriate for this first phase of research (Braun & Clarke, 2006). The data analysis process involved thematic analysis based on an adaptation of focus group analysis principles outlined by Krueger and Casey (2000), and influenced by the psychological phenomenological approach (Creswell, 1998) which is also referred to by Langdrige as descriptive phenomenology largely based on the work of Giorgi (Langdridge, 2007) and illustrated in Figure 3 overleaf.

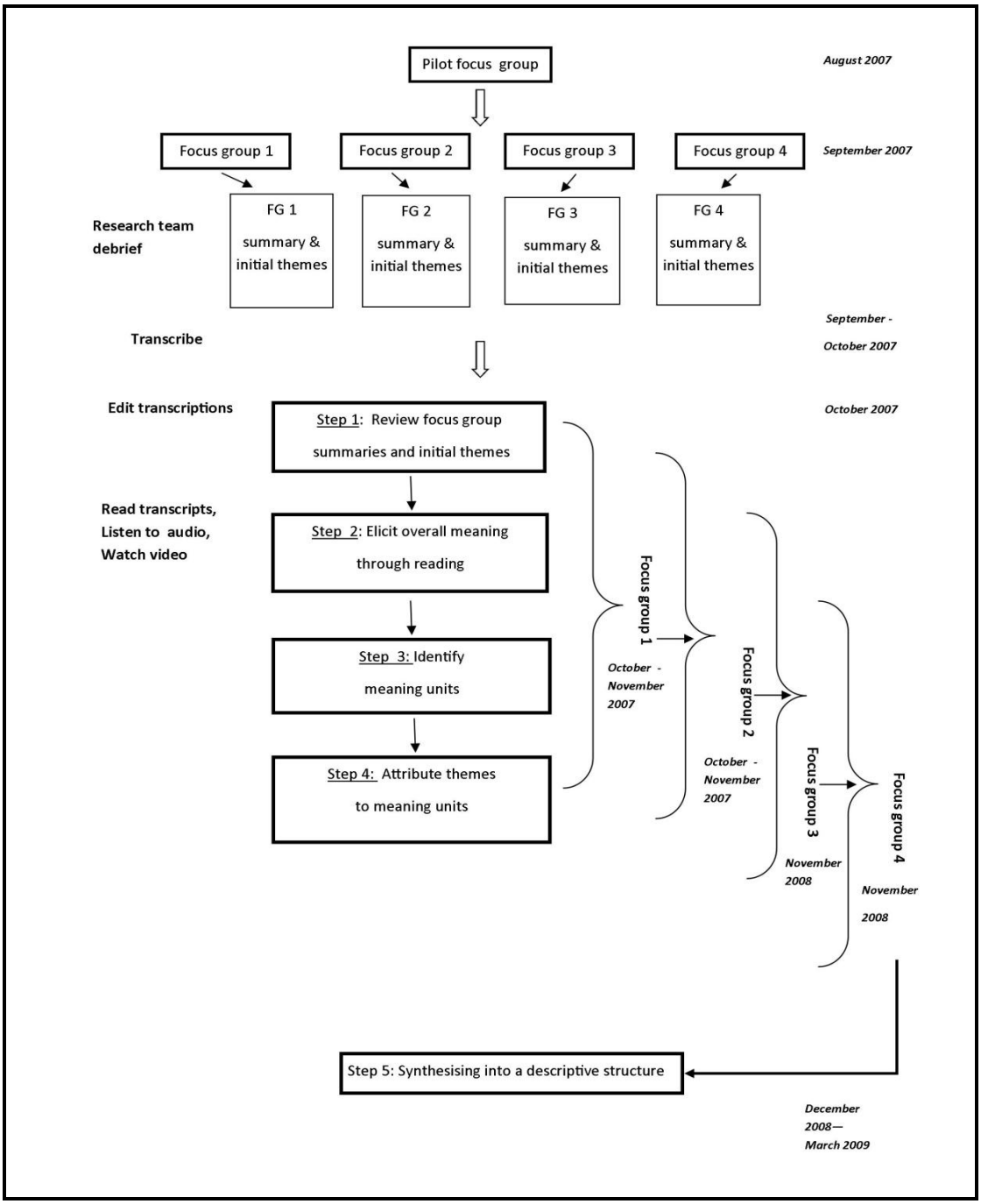
Analysis involved sequential steps: 1) reviewing the focus group summary and initial themes (Krueger & Casey, 2000); 2) eliciting overall meaning through reading; 3) identifying meaning units; 4) attributing themes to meaning units; and then 5) synthesising these into a descriptive structure (Langdridge, 2007). While analysis is presented as a step-by-step process it is an iterative, interactive process. It involves moving forward and backward between steps in a data analysis spiral of cyclical procedures of data management, reading and making notes, describing, classifying and interpreting, and representing and visualising (Creswell, 1998).

The first step involved reviewing focus group summaries[132] and initial themes.[133] Reviewing these was considered a useful step prior to reading entire transcripts. This step was included possibly out of phenomenological naivety as it is an unusual step for inclusion in a phenomenological study which traditionally leaves identification of themes to a later stage.

The second step required reading and rereading transcripts to gain a global sense of the data, a step complimented by listening to and watching recordings. This step began with editing the transcripts and watching the videos to ensure transcriptions were accurate. The video footage also provided a richer experience of reviewing the focus groups as interactions not included in verbatim transcripts could be incorporated into the analysis. Each entire transcript was re-read prior to identifying meaning units.

[132] Summaries compiled based on co-moderator notes and my own reflections.
[133] Initial themes were compiled by research team during each debriefing.

Figure 3: Phase 1 data analysis process



The third step involved identifying meaningful quotations or *meaning units* through careful re-reading of transcripts (Giorgi & Giorgi, 2008). This step was facilitated through use of computer software, ATLAS.ti (Muhr, 2004). Transcripts, focus group summaries and initial themes were all imported into ATLAS.ti as primary documents for analysis. The transcripts were read in ATLAS.ti and quotations considered to be important were highlighted to represent meaning units (Appendix 18). Identification of meaning units depends on the type of study being carried out. While a psychological study for example may focus primarily on the identification of

emotions or beliefs, this study adopted an occupational lens and focused on occupation, participation and environmental aspects (Langdridge, 2007). This step required me to identify the boundaries of the topic being explored to avoid attending to irrelevant topics. Topics identified for exclusion in analysis included computer access and medical issues.

The fourth step involved assigning themes (named *codes* in ATLAS.ti) to each meaning unit (Appendix 18). The themes assigned were based on the initial list of emergent themes as well as novel themes as they occurred resulting in the propagation of a long list of themes. Langdridge (2007) refers to this as evaluating the significance of meaning units. Giorgi and Giorgi (2008) call this making transformations from the implicit to the explicit.

Finally constituents were synthesised into a structural description of the essence of the shared lifeworld experience. This involved merging, re-arranging and conceptualising themes. As an iterative process this frequently involved returning to the data and the earlier analysis. The final categories and themes are detailed in Chapter 7. This step did not employ any statistical analysis of themes based on prevalence. The importance of themes was instead based on the impact of the themes as reflected in facial expression, tone and signs of consensus from other participants. This means that a theme may have only appeared once but presented as pivotal to the experience and was therefore included in the final findings. In contrast, a theme such as computer access was prolific but not directly relevant to the research questions and is therefore omitted in the final findings. This step did not involve ATLAS.ti and themes were instead organised by hand in mindmaps.[134]

It has been suggested that focus group analysis requires attention to each individual group member (Morgan, 1997; 107). My analysis however focused on the entire data set. This approach is consistent with the theoretical underpinnings of descriptive phenomenology which seeks to identify the essence of an experience for all participants and thus an individualistic focus would not have been beneficial for this phase of the research. Early comparisons of individual focus groups led to the decision to merge all data as the themes and experiences expressed were shared between groups, and both users and non-users articulated insights into the experience. Merging of data meant that the final step of creating a description of the

[134] Mindmapping software had not been acquired at this stage.

shared experience and opinions on ECS involved data from all groups. Tasks for each step were diarised to provide an audit record.

3. Summary of Phase 1

Phase 1, *What do people with high SCI think about ECS?,* involved four focus groups with a total of 15 participants. Each group was video and audio recorded and data was gathered with the help of a research team that was briefed before and debriefed after each group. Each focus group involved a moderator, a co-moderator, a general assistant and a videographer. Focus groups were conducted using focus group questioning routes and a technical data gathering protocol, and were preceded by one preparatory pilot focus group. Focus group summaries were compiled after each focus group and initial themes identified by the research team. Each focus group was transcribed and the merged data was analysed thematically in five steps using the psychological phenomenological approach. Data management was aided through the use of ATLAS.ti computer software. The analysis culminated in a structural description of the experience of living with ECS comprised of several themes arranged in categories as detailed in the next chapter.

4. Reflexive commentary

The focus groups made me feel immediately obliged to provide some basic ECS information to people with high SCI in Ireland:

> *My main reflecting after this group is my obligation to provide users and potential users with ECS information (Reflexive diary II, p. 47, 21-09-07).*

I was able to do this through four magazine articles in Spinal news (Appendix 5).

I was pleased that the focus groups appeared to be beneficial for the participants. As a researcher I was aware that I was asking them to help me out but was not sure of the definite personal benefit for each participant. Watching the video taken at the concluding of FG 3 made me aware that some participants were slow to depart and actively sought to exchange contact details (I had not noticed on the day). In addition after the fourth focus group:

> *The co-moderator said at the end of the group "they got so much out of it!" (Reflexive diary II, p.47, 21-09-07).*

As a single researcher I was pleased to have the support of a research team:

> *I was surprised by my own anxiety about the group and really relieved to have a research team acting as co-investigators (Reflexive diary II, p.36, 05-09-07)*

I found focus groups as a data production and collection method less challenging than I anticipated. Despite my anxieties on which I based my choice to use a questioning route, on reflection I would have favoured a topic guide because it is more suited to flowing conversation. The use of a questioning route can also be criticised as moderator led discussion and on refection my questions particularly in the follow-up focus groups were influenced by my personal anticipation of a starter-pack rather than embracing of a truly phenomenological attitude. despite this my reflections were positive and affirming such as diary entry after the first focus group.

> *I feel privileged to have such a personal insight into people's lives… I really liked the silences and what came out of them spontaneously, I also liked the fact that they (participants) talked to each other without including me at times. (Reflexive diary II, p. 36, 05-09-07)*

Several research design decisions were supported as the groups progressed including the need for debriefing:

> *The focus groups place the research team in a room full of "quads" who shared some of their own life with us; this was an emotive experience that I was not fully prepared for. I did not anticipate how emotive groups would be and how they affected all of us in the room. It was an unusual situation –people with similar situations sharing what it is like to live as a high tetraplegic. (Reflexive diary II, p. 48, 22-09-07).*

In addition the use of video recording was more valuable than initially intended because people with limited body movement have highly expressive faces and for example may even point to another using their facial expression.

I battled when describing the data analysis in Phase 1 as it was primarily thematic and I perceived a pressure to align myself with a phenomenological school of thought. My data analysis may be criticised for not adhering specifically to an analysis process credited to an acknowledged scholar such as Giorgi but applying such a prescriptive and rigid method did not suit my overall objective of gathering information on which to develop a starter-pack not only a phenomenological description.

4.1 Reflective summary of focus groups

Focus Group 1

FG 1 progressed well with no noticeable issues with conversation and with adequate flow requiring little moderation. I adjusted my questioning accordingly using the questioning route as a guide instead of a prescriptive text as was originally anticipated. FG 1 was intended to be a non-users group however Jane revealed that, despite a recruitment record of having no ECS, she was in fact an ECS user. I considered asking her to leave the group and attend the users group but as comparison of users and non-users was not a primary focus of the study this was not considered necessary. In addition she had participated in the introductory phase of the group and established herself as part of the group and her departure would have been disruptive to the group process. Jane's involvement in the group was useful and contributed to the flow of the overall discussion as she provided the non-users with a perspective of how she lived with ECS thus facilitating discussion that was not primarily researcher-led.

Focus Group 2

FG 2 in contrast to FG 1 required more prompting and more reliance on the questioning route to facilitate progression. The group also became distracted by divergent themes such as computer access requiring active moderation to delaying these discussions until after the group:

> *At times I felt like I was just going through the motions of the group and found it challenging to be a moderator, having to keep the topic on track and to pull in the quiet people and then manage everyone talking at once. (Reflexive diary II, p. 38, 09-09-07).*

Participants seemed to relish being with people with similar experiences and were eager to compare experiences beyond the scope of the group such as night time bladder management. The group was interrupted by a noisy helicopter landing at the hospital. This required a forced break allowing participants to chat about other issues casually. When the helicopter noise abated and the group resumed it was possible to refocus on ECS and suggest that non research topics be discussed after the group was concluded .The group was fractious at times with one participant digressing and frustrating some other participants but it was possible to moderate past this and continue the discussion.

Focus Group 3

Two participants who had attended FG 1 did not arrive for FG 3 despite both expressing an interest in the group. Telephone calls revealed that both had forgotten about the focus group. In addition two participants who were unable to attend group1 attended group 3. In summary group 3 had six participants, four of the participants from group 1, and two new members, one of whom then was also found to be an ECS user but had been incorrectly recorded as a non-user. Susan had travelled a substantial distance and taken time off work to attend and could not be asked to leave the group based on her ECS use. Again the inclusion of a user in a non-user group facilitated discussion and in hindsight was a useful error.

The group did not flow as well as group 1. This may be partially attributed to the change in group composition but was more likely a result of the specific questions included in the questioning route. Many of the questions focused on a starter-pack and the lack of experience of the group as a whole made it hard for them to contribute when asked what a starter-pack should be like. Other more open questions may have facilitated better flow however those questions were considered necessary to inform Phase 2 of the study.

Group 3 started and ended late, and included an extended break as requested by the participants. One participant fell asleep during the group with audible snoring but then woke sporadically to make valuable contributions on aspects that were emotive to him and which were clearly visible in his facial expressions on the video recording. His participation was encouraged through direct questioning to prevent him sleeping and to engage him in the discussion which appeared to be of interest to him. It seems likely that his sleepiness was caused by an external factor, like what possibly medication or the fatigue associated with SCI. One group member said he was challenged by the topic as he admitted having reflected on the topic between FG 1 and FG 3 and was finding his ideas were changing.

Focus Group 4

FG 4 unlike FG 2 (the first users' group) and FG 3 required very little prompting and I adhered less closely to the questioning route.

> *I was happy with the group but found being a moderator exhausting and difficult at times to keep up with the momentum of the group as the discussion progressed without me so to speak. What a noticeable contrast to the first time this group met. Why was it so different? Was it me as a moderator or was it the content of the group* (Reflexive diary II, p. 47, 21-09-07).

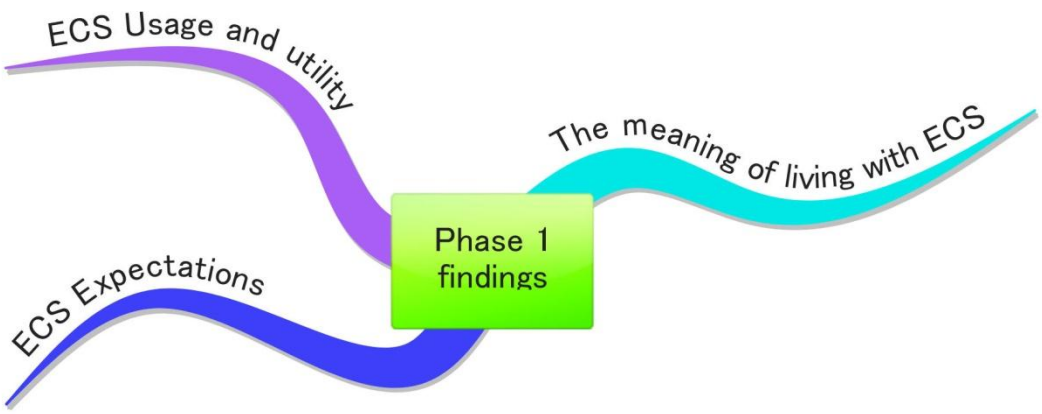
This contrast may be attributed to greater experience in group participants and therefore a better ability to provide insights into living with ECS as well as more ideas about what an ideal pack should include based on that lived experience.

Again one participant tended to divert from the topic and was eager to discuss other personal care issues but the group itself was aware that the topic was inappropriate and ignored his comments and reverted to discussing ECS.

Chapter 7: Phase 1 findings

This chapter presents the findings from Phase 1: What do people with high SCI think about ECS. Data from all four focus groups were merged and analysed using thematic analysis with a phenomenological attitude, following data collection and transcription, as described in Chapter 6. This multi-step analysis revealed several themes related to the research objectives. In addition thematic analysis provided insights to inform the development of an ECS starter-pack in the next phase. The themes are presented in three descriptive categories, Figure 4. Themes and categories are presented in italics. The first category, *ECS Usage and utility*, incorporated the practical aspects of ECS. The second category, *ECS Expectations*, described what the participants would like to have and what they expected from an ECS. The final category, *The meaning of living with ECS* and is closer to the phenomenological aspect that this study sought.

Figure 4: Descriptive categories of Phase 1 findings

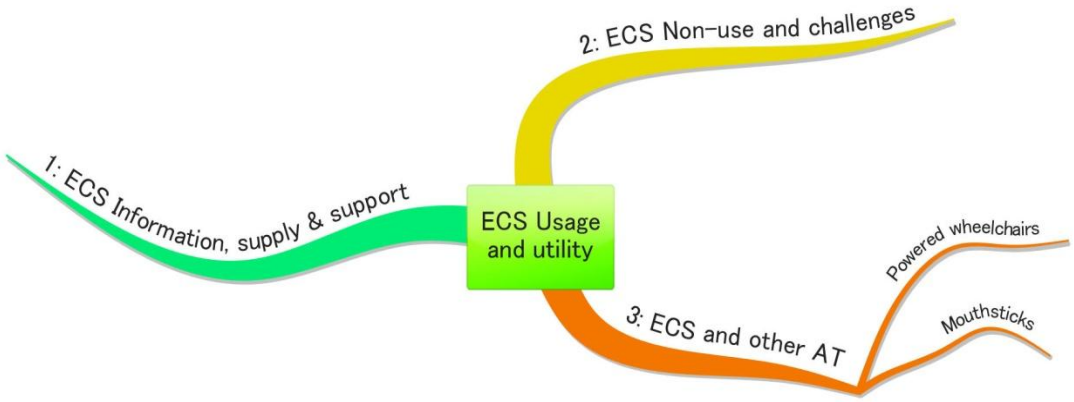


Findings are presented below supported by verbatim quotations from the four focus groups. Omitted text is indicated by … and edits intended to clarify quotations appear in brackets ( ). Individual quotations appear alone but passages of conversation are merged with no line breaks between speakers to indicate continuous discussion reflective of group interaction. Each extract is referenced to the group in which it occurred by the abbreviation FG (focus group) followed by the number of the group FG 1, …, FG 4.

1. Category 1: ECS Usage and utility

The category entitled *ECS Usage and utility* incorporated the descriptions of practical ECS issues. People described a variety of ECS that included different controllers; a variety of appliances such as televisions, DVD players, intercoms, IR telephones, alarms, air-conditioning, external doors, windows, IR lights and computer access,[135] and desired functions of ECS including television control, page turning for reading, and curtain-control for light and temperature regulation. How ECS were used depended on both individual physical ability and physical positioning. Some accessed ECS or devices directly using a mouthstick or a knuckle while others used indirect access via switches.[136] Those who were able to use direct access when sitting required indirect switch access when in bed. Specific requirements of individual ECS also varied as described by Michael who did not perceive a need for IR lights based on his upper limb function while Paul, who had no upper limb movement, stated that control of lights was essential for him. The descriptions of how ECS are and can be used revealed three themes, Figure 5. The first theme within this category is entitled *ECS Information supply and support,* the second is *ECS Non-use and challenges* and the third is *ECS and other AT.*

Figure 5: Themes within Category 1: ECS Usage and utility



1.1 Theme 1: ECS Information, supply and support

The first theme in the category *ECS Usage and utility* is *ECS Information, supply and support*. This large category reflected comments about the experiences of obtaining and maintaining ECS for users and about the ECS services available to them. While it was not the intention of the study to focus on or evaluate existing

[135] One person's ECS was linked to his computer mouse allowing computer navigation.
[136] Including a sip and puff switch.

ECS provision, it was necessary to gain insights into peoples' ECS experiences and perceptions of available ECS services in order to provide users' insights on which to base the starter-pack in Phase 2.

All felt that information on how to use technology was scarce and that successful use relied on the ingenuity and perseverance of the individual to get the item to work:

> ***Frank****: You just have to adjust it to suit yourself basically. No-one does it for you* (FG 3).

ECS users also complained that suppliers did not explain installations to them. Jane and Dave both gave descriptions of systems becoming unusable and failing once the technicians had left, even though they had worked perfectly during installation or repair:

> ***Jane****: Especially if something is working intermittingly … so when the guy was demonstrating it, it had worked perfectly, and of course the minute he was gone – disaster* (FG 4).
> ***Dave****: … the technician must have been out 20 or 30 times, trying to fine tune it. It would work grand and they'd go away and ten minutes later it wouldn't be working* (FG 2).

People agreed with the notion that being able to programme an ECS controller themselves would be useful:

> ***Jane****: It would be important to know yourself.* ***Dave****: They should be easily programmable so if you can't programme you should be able to talk someone else through being able to programme instead of having to get a technician to come out.* ***Paul****: Maybe a technician for an initial set-up but I think we've far more power given to somebody and flexibility if they can learn how to programme it themselves.* ***Michael****: It is more reliable as well.* ***Dave****: If you need to rely on a technician it could be months before someone comes out to re-programme it.* ***Jim****: Or if you change a device it might not work, you have to re-programme to a different TV or different DVD you know* (FG 4).

This would avoid dependence on suppliers and could empower the user to choose how he/she uses their ECS. This requires controllers that can be easily programmed and users need to be educated to be able to do so. Jim assumed that the internet would be a valued resource for proving information on how to programme devices. Being able to programme one's own controller in turn may negate the long waiting periods for minor adjustments, a sentiment that even Ciara, who had relied on experts for her ECS maintenance for several years, agreed with.

ECS were supplied by a variety of agencies, funded both privately and publicly,[137] with no apparent guidelines or policy for supply or maintenance. Everyone agreed that there was a more limited range of ECS and fewer suppliers in Ireland in comparison to some European and North American countries:

> ***Paul****: very limited range of companies who actually do it, and those who do it don't do it very well* (FG 2).

Some ECS users felt that they had been oversupplied:

> ***Paul****: Dave's case and my case of you know doing an initial over supply of sophisticated complicated systems and that you now find that 70% of it is wasted money* (FG 2).
> ***Michael****: (A) company come out and say we can do this and that, and it all sounds good. It's in now, and it costs money and I don't use it all* (FG 4).

It was suggested that oversupply may have resulted from reliance on the supplier because the user did not have sufficient experience or knowledge of what was available. Some were cynical about the motivation of the suppliers and three group members Dave, Richard and Michael expressed the opinion that suppliers were primarily sales persons with a focus on profit:

> ***Dave****: (He) is a salesman, he's not an OT or a physio, he doesn't really know what you need, but he does know how much he wants to sell you, so he's going to push for the biggest most expensive thing rather than what you actually need* (FG 4).
> ***Richard:*** *The people that sell the environmental controls, are a bit like people who come in and replace your windows, they try and give you the*

[137] One participant had his mobile phone and PlayStation™ controller adjusted to be switch operable, a very generous service not traditionally expected from such an agency.

> *most expensive package … They're not really thinking about the person in the chair, they are just thinking of the money they are going to make on it* (FG 4).
>
> ***Michael**: … these people come out, and not like they are malicious, but they can take advantage of you not knowing what you need and what's out there* (FG 3).

Despite Richard's cynicism, he appeared the most satisfied with his ECS:

> ***Richard:** I have had no problems, I just went for a basic - I went for the front door (opener), didn't go for back door (opener) (FG 2).*

Richard was one of the participants who been introduced to ECS during his rehabilitation and this had possibly equipped him to be able to make informed ECS decisions and facilitate his satisfaction reflected above. Similarly Emily, having been discharge only 20 months prior to participating in the focus groups, also had some knowledge and experience of ECS and reflected that this was useful when she was assessed for ECS in the community as it enabled her to actively participate in the assessment. In response, Joe highlighted the value of having appropriate ECS language:

> ***Emily**: (The occupational therapist) showed me a lot of the stuff and that's how I knew about the GEWA when I was speaking to the man in the [AT service]. I knew about some of the equipment he was telling me about which I found very useful because otherwise, it's just that people don't explain it as well. You are kind of, well, if I didn't know about it, I don't think he would have explained things as well as [occupational therapist] did so yeah, I did find it good. **Moderator**: part of rehab? **Susan**: Yeah. **Joe**: Just to be able to have the language to be able to talk about it to someone. It's all right saying to look something up but you can't look something up unless you know what you are looking up* (FG 3).

In contrast others had relied on commercial suppliers for information and training. Dave revealed that he had no knowledge of ECS until he had to contemplate independent living:

> ***Dave****: When I left the hospital I went home to my parents and was completely unaware that there were such things as environmental controls until I was actually leaving to live independently and then it was just basically someone came from a company and said we can do this and it was done, but there was no looking into different ways of doing the same thing, like with door openers, it was just this is the door opener and this is the button to open it and that was it. There was no thought put into whether you can manage.* ***Moderator****: so is it choice you are looking for then?* ***Dave:*** *It's letting people know what's available instead of just thinking it's one thing. As far as I was concerned when I was asked about environmental controls it was the big box called the KEO which was unwieldy and it worked everything, and to me that's all it was. I didn't know there was other options. So you think this is great, I can open my doors, and when you start using it, it is not half as good as you thought it was, and you end up then, start looking into it and getting on the internet and you realise that you don't need half the functions it has on it in the first place and just a simple remote control would have done what this big box would do. It's making you aware of what's out there in the first place* (FG 4.)

Dave was dissatisfied with having to rely on the supplier who failed to provide full information about all the options. Participants expressed frustration at the limited knowledge of agencies and suppliers:

> ***Dave****: very often you see something that will work for you, and you go to the so called experts and they've not got a clue about what's available in the first place* (FG 2).

A loan system was viewed as a favourable alternative to reliance on suppliers for prescribing equipment as it would provide real experience of systems prior to purchase or supply:

> ***Paul****: I think the idea of the technology loan thing would be a really good idea, if you were coming out of rehab you would have a number of systems on trial for a month or two, not just a week or two, a decent trial length, would be useful* (FG 2).

Emily, who had been assessed a few months prior to the focus groups and had yet to receive her ECS, expressed her frustration at having to wait for the initial assessment and then for funding and supply.[138] This waiting problem was echoed in discussions about equipment repairs. All felt that there was poor technical support if equipment should fail (an opinion based primarily on power wheelchair repairs for the non-users). However, there was some discrepancy between people in relation to this issue and Ciara reported that she would have her ECS fixed within a day:

> ***Ciara****: if something was broken like, the controls, for the telly and the phone I just nearly couldn't live without it, I would just keep on and on about it till I got it fixed up. I think you have to be, once you know they are available* (FG 4).

Similarly Jane also reported quick repairs but suggested that she would be persuasive enough to ensure this, as she hated to be without it (her ECS):

> ***Jane****: well I actually have been so lucky because it has been dropped so many times but only once was there a problem with it and the guy from [clinic] came and fixed it. I pestered him. I think once you get used to it, it's hard to be without it* (FG 1).

Others were not as fortunate. Jim would have to wait a week at least and others even longer:

> ***Dave****: Just say my door doesn't open properly, that could take 2-3 months before somebody comes out to fix that door, so that is 2-3 months where you are relying on somebody to do things for you* (FG 2).

This was echoed by Susan who had a broken doorbell for over 9 months with no sign of repair or replacement. The inability to make one's own repairs was based on preserving the manufacturers' warranty and was another source of frustration. Paul suggested that spare parts for an ECS could be purchased directly from the supplier and be kept at home to ensure speedy repairs for improved reliability instead of waiting over a week for a technician. Alternatively it was suggested that back-up equipment should be available from the suppliers or repair company. Joe also

[138] She had still not received the ECS that she was assessed for 2 years after she attended the focus groups.

suggested peer support and sharing of information to facilitate independent use, problem solving and repairs:

> ***Joe****: if there was anyway of this of setting up a way of people being able to share all this information and being able to contact each other because very often, people have figured out this stuff* (FG 3).

1.2 Theme 2: ECS Non-use and challenges

The second theme in the category *ECS Usage and utility* was *ECS Non-use and challenges*. It became apparent that ECS use was considered challenging by some participants based on both experience and perception of what ECS use could involve. Emily who had no ECS described ECS as difficult and anticipated that her family would require time and possibly some training to understand how ECS might work. Jane agreed that becoming accustomed to ECS was challenging:

> ***Jane****: getting used to them can be draining* (FG 1).

Susan described the initial stage of learning to use her static display ECS which involved poster *cheat-sheets* to help her learn the individual functions of each button. This learning process eventually led to proficiency and she described using her ECS all day everyday:

> ***Susan****: I couldn't be without it (ECS) now, you know. I can't sleep until I know I have it there with me* (FG 3).

ECS users discussed some difficulties with the speed at which tasks are possible using ECS such as answering a phone while scrolling through a television tuning menu which caused a delay in accessing the telephone menu on the ECS resulting in missing a telephone call:

> ***Richard****: I find that with the phone as well, cos if I'm watching television and the phone rings, by the time I get it back to answer the phone, the phone usually hangs up* (FG 4).

These descriptions of difficulties were balanced by descriptions of successful, seamless use:

> ***Ciara**: The one that I do use is the (GEWA) 'prog', it's for my phone, and when I am in bed I can control the TV, radio, DVD and answer the phone as well. And make some calls through it, it's just a suck and puff thing* (FG 2).

Paul suggested that successful ECS use requires personal commitment and effort:

> ***Paul**: proper mentality to buy into the struggle, even if it breaks* (FG 2).

For some, the challenges led to non-use or abandonment. Reasons for non-use included: complexity; lack of need; over supply; poor reliability or unsuitability. People described several items of technology that they chose not use including voice activated software (Dragon dictate), a Headmouse (SmartNav), a voice activated telephone (an internet purchase), a voice activated ECS, two ECS controllers, page turners, an IR phone, and an electronic door opener:

> ***Ciara**: I did have a control for the door. It's just too much of a nuisance really, because people are coming in and getting you up anyway like, you know. There was no point; I got it taken out altogether. The door closed one day and I couldn't open it and carpenters had to come up and break the door down* (FG 2).

She chose not to use the door opener as it was unreliable and she felt she did not need it living in a residential care facility. Three other users also cited difficulties with door controllers. Michael said that the door did not close properly and could be blown open. Paul had issues with door failure due to cold conditions during winter, and Dave described reversing the power wheelchair into the door to ensure that it was closed. Participants expressed a general intolerance and resulting non-use for things that didn't work satisfactorily.

Dave chose not to use his first ECS controller as he found it unreliable because it opened the wrong window or door, a technical issue that should have been easily solved with simple reprogramming of the doors and windows.[139] He also considered it to be too complex and too expensive for his needs and to have too many functions:

[139] The problem appeared to have been peripheral with both the front and back door controlled by the same IR code. Usually IR will not reach the wrong door as it relies on line of sight. In Dave's small living unit this was not the case and signals were reaching the wrong door. This should be solved with simple reprogramming of the doors, windows and the ECS controller.

> ***Dave****: And the Keo is sat there on my book shelf with thousands of pounds of equipment* (FG 2).

Similarly Jerry, having considered himself a non-user, recalls having tried to use a GEWA *prog* several years before but finding it too complicated. Interestingly, Jerry said that he was considering trying the GEWA *prog* again after hearing the successful experiences of others.

Non-use was also related to over supply mentioned in the previous theme ECS *Information supply, support*. Interestingly all acknowledged the need for ECS supply to be realistic and modest rather than as extensive as may be possible to avoid oversupply and possible non-use. Non-use was also discussed as a timing issue:

> ***Joe****: … awful lot of it is about timing too. When you hear about something at the right time* (FG 3)

This idea suggests that people become receptive to ECS at different stages which highlights the complexity of successful adoption of ECS and the importance of readiness to accept and use ECS. Living with high SCI was described as becoming *conservative/ resistant to change* that in turn may provoke a resistance to technology as it would require personal adjustment. Interestingly, this resistance to change sentiment was expressed by both users and non-users. Users favoured keeping their existing ECS and non-users admitted being resistant to trialling ECS:

> ***Emily****: it works so why would you try and change it. If you know it's going to work and then if you change it, it might not work* (FG 3).

This idea was introduced by a non-user who offered an alternative to the optimism expressed by other non-users in the group. His tone at the time was apologetic as he implied that he was not that useful to the discussion, but in fact his candid honesty was thought provoking for other participants.

> ***Joe****: (My) resistance to technology is the fact that it tends to make you very dependent on it and limits you to it* (FG 1).

He went further in the following group:

> ***Joe****: I have become very conservative about what I use, and what I don't use, but that's the thing about me and maybe about spinal injuries in general. You become very, very conservative about change because what you can do, you can do and usually, if you change one thing you have to change something else and that changes something else* (FG 3).

Other group members did not respond to this statement at the time but the theme re-emerged later. Two new members of the group who had been unable to attend the first meeting commented:

> ***Susan****: I just don't like change once I get used to it* (FG 3).
> ***Frank****: if you get used to it; stick with what you know* (FG 3).

This resistance to change is a barrier to the successful use of technology. Joe suggested that:

> ***Joe****: you could … make people aware of how conservative they become because it took me a long, long time to realise that I wasn't right all the time* (FG 3).

This conservative nature attributed by Joe to people with high SCI also manifested as an initial resistance to technology expressed by exploration of non-technological solutions first:

> ***Paul****: the maximum effort should be made to do things without assistive technology, and learning to become just self-managing, whether it is turning the pages with your finger, or work using the phone with your own hand, and then those that aren't satisfactory I think that then after that, then assistive technology* (FG 2).

In addition to trying to do things without technology there was also a belief in the value of doing things with other simpler AT before requiring ECS.

1.3 Theme 3: ECS and other AT

The third theme in the *ECS Usage and utility* category is *ECS and Other AT*. Although focus group questioning initially focused on ECS in isolation, participants

were unable to discuss ECS without reference to other AT, specifically mouthsticks and wheelchairs. It was made clear by participants that one has to consider ECS in conjunction with mouthsticks and powered wheelchairs. For people with high SCI there appeared to be an AT triad consisting of ECS, mouthstick and powered wheelchair. Both mouthstick and powered wheelchairs were useful for executing some tasks in the absence of ECS and in conjunction with ECS.

Mouthsticks

Use of mouthsticks, while not anticipated, was a strong theme in all four focus groups,[140] Non-users of ECS were able to do some tasks with a mouthstick including accessing television remote and light switches:

> ***Jerry****: Mouthsticks all over the place. Mostly for turning pages, pressing buttons and pushing things around. You can do loads of things with mouthsticks* (FG 1).

The successful use of mouthsticks meant that Joe strongly recommended that mouthstick education should precede technological training and use of ECS. Interestingly, it was not only non-users who were proficient mouthstick users:

> ***Paul****: My mouthstick is my hands for the last 25 years, and it doesn't require batteries* (FG 1).

Ciara, also an ECS user was an exemplary mouthstick user who painted, wrote, operated a computer, dialled the phone, read a book (turned pages) and accessed her ECS all with her mouthstick. Mouthstick use was interestingly described as a natural effortless activity that required very little conscious effort and which becomes so integral to daily life that sometimes people forget that they are using a mouthstick and even speak and drink without removing it:

> ***Ciara****: I drink as well, with a stick in my mouth you just get so used to it, you know.* ***Paul****: I am the same, sometimes I have to become conscious of actually putting it down or else I end up talking to people with a stick in my mouth and it's just that you're using it so much* ***(MR agreeing)*** (FG 2).

[140] Three of the participants who were ECS users had some upper limb movement which means that they were less likely to require a mouthstick, as they could use typing sticks or similar devices strapped to splinted hands.

Peter also hinted that for him the mouthstick functioned as a type of thinking aid similar to the use of a pen:

> ***Peter****: Stuff that you can do with a mouthstick to keep your mind ticking* (FG 1).

Not all participants were mouthstick users but those who used them reported they facilitated independence. Those who did not use a mouthstick regularly found the prospect a daunting one. Although hesitant to use a mouthstick themselves they were able to acknowledge the skill involved:

> ***Peter****: it sounds like a disaster, reading books with the mouthstick and that. I just couldn't hold the page down and trying to hold the mouthstick in my mouth and read at the same time* (FG 1).
>
> ***Matthew****: I've never really tried using a stick in my mouth really, but the thoughts of trying to set it up … if you were in bed, and having it positioned in such a way that I could get it … read a page with a stick in my mouth or something like that; putting it down and picking it up and that* (FG 3).

Richard was not a mouthstick user but informed the group that he had only been home from rehabilitation for 11 months suggesting that he may consider using a mouthstick in the future. This confirms a clinical observation which is that people tend to only adopt mouthsticks after living away from rehabilitation for some time.

Effective mouthstick use requires practice and set-up with appropriate structuring such as having a large work surface to house remotes and books, or securely mounted remote controls. Paul, Joe and Jerry described having cups for their mouthsticks in several places at home and work. Paul for example has a cup glued to the side of his computer that he used with a small keyboard.[141] A power wheelchair can also be useful when using a mouthstick.

Powered wheelchairs

Similarly powered wheelchairs were experienced as integral to ECS or substitutes for ECS. As an alternative to ECS, powered wheelchairs allowed positioning to reach a light switch (with or without a mouthstick) or to push swing-through doors open:

[141] He called it a cherry keyboard that has fewer buttons than standard keyboards requiring less neck range of movement.

> ***Dave****: I find the power chair isn't just there to get me from A to B. It helps me eat, helps me work the TV, closing doors, it's so much more than just a means of transport* (FG 2).

Richard accessed his ECS using his powered wheelchair chin control as a joystick. Powered wheelchairs were also used to adjust seating positions such as when spasms disrupted sitting balance. Powered wheelchairs facilitated reaching for mouthsticks, using switches and accessing ECS. Most[142] participants found that, although it was possible to access ECS directly using a knuckle, finger or mouthstick whilst seated in a power chair, they required a switch when in bed:

> ***Michael****: I use a buddy switch when I am in bed* (FG 2).

Humorously, Dave added a wry comment:

> ***Dave****: once I am in bed I am pretty useless, the story of my life* (FG 2).

Powered wheelchairs were seen as essential for satisfactory ECS use as they together negated the need for physical assistance:

> ***Richard****: She said she doesn't need a power chair (to Jane), but even if I wanted to go to the television or the computer I'd need someone to push me, by having the environmental controls I don't need help … to do anything* (FG 4).

In response to Richards comment, Jane, who used a manual wheelchair, admitted that she was unable to use her ECS while in her manual chair, and needed to be seated in a lounge chair or bed so that she could use a switch mounted behind her head.

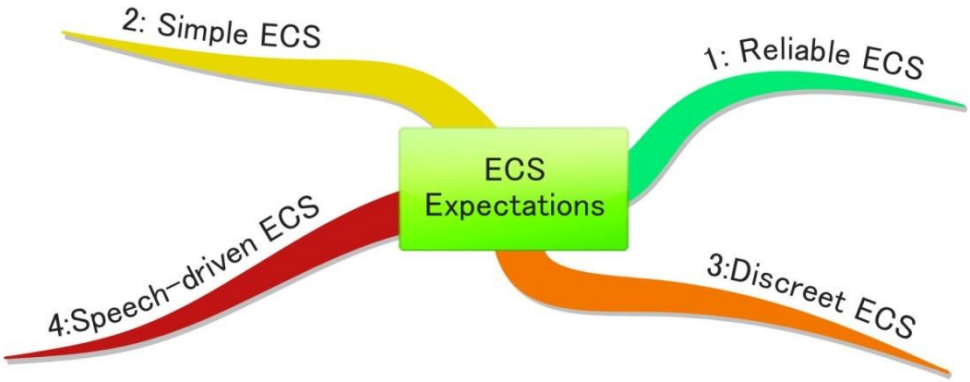
2. Category 2: ECS Expectations

The second category of *ECS Expectations* incorporates the features of ECS identified as required and desired (Figure 6). Content for this category largely emerged from probing during the focus groups for information that would be useful for Phase 2. I thus co-constructed this data with the participants. The data contained

[142] Michael, Jerry, Susan, Ciara, Dave, Peter all required switch access in bed. Jane did not use a mouthstick or knuckle and thus used a switch at all times.

however in this category was found throughout each focus group. Some of the themes in this category were found to be absolute ECS requirements for people with high SCI while others were ideal features. Ideally ECS were required to be: 1) reliable; 2) simple; 3) discreet; and 4) speech-driven (Figure 6).

Figure 6: Themes within Category 2: ECS Expectations



2.1 Theme 1: Reliable ECS[143]

The need for reliability was reflected throughout the group discussions. This is not surprising as reliability is an essential and basic requirement of all technology:

> ***Paul****: … the unreliability has to be worked out of it, that wouldn't be acceptable in a car for example, it wouldn't be acceptable for brakes not to work sometimes* (FG 4).

Reliability is essential if ECS are to be used autonomously by people with high SCI:

> ***Dave****: Suppose just to allow you to be more independent, cause that's the whole idea of an environmental control system, you aren't relying on people. And security, as long as you know it's going to work and they know it's going to work well* (FG 2).
> ***Jane****: I think as Paul said, a good communication system, so that you can contact them if needs be. Otherwise you can be (left) on your own* (FG 4).

Reliability ensures that users are secure and feel confident with ECS. Many participants commented on how poor reliability made them feel vulnerable:

[143] This theme was initially named Robust and foolproof but Reliable is a closer match to the wording used by the participants.

> ***Frank****: It's all about reliability. The last thing you want to do is to be reliant on something and it doesn't work (laugh) that's not nice. That's the worst thing* (FG 3).
> ***Paul****: If something breaks or is unreliable, you end up … losing confidence then, giving up on it* (FG 2).
> ***Susan****: … if there was a power cut, I'd be afraid because I would have no-one. You know, you have to manually twist the door when you are on the inside so you know, if you are left on your own, you are kind of, god forbid if there was a fire or anything like that, you are finished* (FG 3).

Reliability of ECS is also important as it facilitates safety:

> ***Paul****: I think the security thing is a huge part of it, is that people are leaving hospital to come home, you have to provide them with a level of security and one of those is communications, the other one is being able to get in and out of house, rooms and that, unassisted. You can't be 100% reliant on somebody else* (FG 2).

There were many references to poor reliability of items used by participants:

> ***Jerry****: a voice controlled phone … but it is not very reliable* (FG 1).
> ***Ciara****: I did have one of them speak ones, I did not last at all, I found it unreliable* (FG 1).
> ***Jane****: reliability, something that doesn't break down, something that can work consistently, ... voice activated … controls, the ones I have tried don't work all the time, is really infuriating* (FG 3).

The descriptions of unreliable alarm and call systems and inaccessible switches is troubling to hear. The physical set-up of an ECS has to be reliable. If a switch is not accessible the system can no longer be used. Michael and Dave, spoke about how, when they lost contact with a switch while in bed, they were left stranded with no form of communication:

> ***Michael****: I've got a … phone … but then if I move during the night and I … lost the button, I wouldn't be able to control the phone and it's my communication* (FG 2).

> ***Dave****: the call system is there and I can call anyone if I need it, with a big button, I just put it next to my pillow and I can whack it with my hand , but when I went to hit the button it slid off the bed and it meant I had nobody for hours because I had no way of contacting anyone because the only way which was through a button which was now dangling off the bed.* ***Michael****: Yeah it's a huge risk with all that stuff.* ***Dave****: And it worries you then because you think if anything did go wrong. Say if you catheter blocked or something you have no way of contacting anybody* (FG 2).

Call systems, personal alarms and communication required to enable people to be alone must be reliable. Michael found his IR phone to be unreliable and Paul complained that hands-free telephones are of poor quality making it hard to hear the other person or to be heard:

> ***Paul****: I find the sound of all the hands free … phones … are all as far as I am concerned they are all simplex systems … if there's background noise, where I am the other people can't hear you, but the other type of one if there is background noise where they are I can't hear them.* ***Jim****: just crackling.* ***Paul****: Yes exactly, it cuts off.* ***Jim****: Yes very frustrating (FG 2).*

Paul also had to abandon an X10 alarm as it activated incorrectly several times:

> ***Paul****: I actually have disconnected most of it now because the units used to activate on their own … I have one linked into the alarm for example and it activates itself, even the panic alarm which is seriously not good* (FG 2).
>
> And then again:
>
> ***Paul****: I could actually activate the panic alarm, and that actually activated a couple of times on its own, which the Gardai (police) were really upset about, so I had to disconnect it so* (FG 4).

Paul's decision to disconnect his alarm system illustrated how the theme of *reliability* is closely related to the theme *Non-use* discussed as part of *ECS Usage and utility*. ECS were unlikely to be used:

> *unless they work really well, all the time, early on.* (Paul, FG 1).

Reliability also related to support and the lack thereof in the experience of participants as described in *ECS Information, supply and support.* It was felt that a back-up system that included the possibility of borrowing replacement controllers and devices was required for ECS to be foolproof:

> ***Susan****: There is just no back-up service there, no. That's what I find really poor* (FG 3).

As this was not a reality they considered and discussed other ways to ensure that ECS was reliable including the possibility of independent management of technology. This appeared impossible as devices were specialised items not available from mainstream suppliers. People expressed a preference to rely on themselves rather than on others and were frustrated by reliance on suppliers and in some cases on technology. This discussion merged with that of simpler methods including mouthsticks which were described as reliable in comparison with electronic technologies, for example reading with a mouthstick rather than a page turner (Ciara), and using swing doors instead of using door openers.

Having more than one way to access devices and or controllers also improves reliability, for example having a door opening button that can be activated with a switch as well as ECS IR control of a door. Practical suggestions to make ECS more reliable included making controllers heavy duty and waterproof, with a longer battery life and therefore more robust. Participants were frustrated with currently available devices, as there was a perception that mainstream technology had improved by becoming *so small so reliable (*Frank, FG 3). The groups agreed that such improvements did not feature in ECS and in general simpler things were considered to be more reliable by everyone.

2.2 Theme 2: Simple ECS

The second expectation is that ECS should be simple (Fig 6). All people favoured things that were simple - simple to use, simple to understand, simple to set-up and simple to fix. Both Joe (a non-user) and Paul (an ECS user) suggested that simple solutions should precede technological ones:

> ***Joe****: (There is a) need to be taught how to get around the problem to have a practical approach to doing something. A rubber band and a paperclip kind of approach rather than default to high tech approach* (FG 1).

> ***Paul****: … maximum effort should be made to do things without assistive technology, and learning to become just self-managing, whether it is turning the pages with your finger … using the phone with your own hand, and when those that aren't satisfactory I think that then after that, then assistive technology* (FG 2).

There were several suggestions and examples of simple substitutes for ECS functions based on mainstream products listed in Table 10 (on page 161). Many used swing doors that can be pushed open using a power wheelchair, negating the need for door openers:

> ***Michael****: The doors, I didn't go for internal doors, as it wasn't worth it, I just got double swinging doors, that you can push through, because they are expensive, and the less things that can break down as well* (FG 4).

Similarly some used mouthsticks or a knuckle to access a variety of mainstream remote controls. Joe described how he managed several remotes using his mouthstick:

> ***Joe****: I find it really handy to cluster remotes though. Just a sheet of cardboard or something with Velcro® and 3 or 4 remotes on them and they are all together. You are using them for stereo, TV or whatever. Same if I'm in the sack (bed) and looking at TV and then I just have a couple of remotes and the phone in front of me* (FG 1).

Jerry, despite having no active limb movement, used his feet (together with a chin control powered wheelchair) to open doors and cupboards:

> ***Jerry****: opening doors or cupboards or anything. I find I can kick them open with my feet* (FG 1).

Cordless and mobile telephones with headsets or speaker functions were useful for some. Matthew used a plug-in mobile phone earpiece which he attached to his shirt lapel and then he would *bite* the switch as if it were a specialized switch and use voice tags to dial pre-stored numbers.

Other simple solutions included touch lamps and contact switches[144] and generic remote control appliances like heaters and fans. The latter were controlled either by universal remote and a mouthstick/knuckle or integrated into ECS. Baby monitors were also used as an always-on intercom system. However, these failed to provide privacy:

> ***Michael****: I just used a baby monitor that's linked up, but that's no good because I want to watch TV like I don't want to keep my parents awake* (FG 2).

Dave used wall socket timers with some success:

> ***Dave****: I have the TV on a timer, and then when I am in bed I don't have to worry about remote controls at all because it's all automatic* (FG 2).

While this meant that he was able to watch television alone at night he also described falling asleep and being woken by the television or the television powering off while he was watching something as the timer had been pre-set.

Mainstream solutions are favoured because they are normal (Michael, FG 2) and easily repaired or replaced:

> ***Joe****: I like things I can fix myself and (I) make them out of fairly simple stuff* (FG 1).

> ***Joe****: they're all good reasons to use generic stuff, those things that are bought in any shop … so if it breaks … you just go, get another one. For my money what this research ought to show up that whatever you do, you should get away from the specialist stuff because that is channelling people down the very narrow view again* (FG 3).

Frank felt strongly that modern ECS should and could be mobile phone based and therefore capable of incorporating Bluetooth® technology:

> ***Frank****: well you see, everyone has a mobile phone with them now* (FG 3).

[144] These lights are operated by touch not traditional flick switches and are freely available for purchase.

Table 10: Suggested simple ECS solutions from research participants

Mainstream product	Application	Replaces
double hinged door	powered wheelchair pushes through	electronic door controller
cordless phone	with headset or speaker function	IR ECS phone
cellular mobile phone	voice tags for dialling	IR ECS phone
mobile phone earpiece	switch can be bitten	IR ECS phone
cordless phone	taped to trousers using double sided tape	specialised phone and mount
string	mobile phone	wheelchair mount
mp3 players	audio books	page turner
laptop with internet	online and audio books	page turner
baby monitor	as a personal alarm	call system
touch lamp	powered wheelchair to aid contact	specialised lights
multiple mainstream remote controls	controls mounted on table/ stand accessed using a mouthstick	ECS controller
universal remote controls	knuckle	ECS controller

Adopting mainstream technology was not however without difficulties as for example touch screens and laptop mouse pads do not respond to inanimate objects like mouthsticks:

> ***Paul****: I think the touch screen, I don't think it works with a mouthstick* (FG 4).

Despite favouring mainstream technologies people still considered ECS important but thought that they too should be simplified:

> ***Paul****: simple pieces of technology, or environmental controls, that work well rather than extensive systems* (FG 2).

People felt that ECS controllers needed to be simple to avoid abandonment as described by Dave earlier. It was also felt that the entire ECS should not be complicated to set-up or adjust:

> ***Michael****: Not too complicated to set-up hassle free as possible, so that anything I'm using can be set-up by someone or if I have to ask them it's not a big deal* (FG 4).

It should also not be too complicated and oversupplied as described earlier. Most felt that they did not require control of every door, window and blind:

> ***Richard****: one window (opener) should be enough - there are blinds, you don't really need it and with and someone coming in to put you to bed at night they close the blinds* (FG 2).

As Richard mentions human care will still be necessary and thus some technology may not be economical if the task concerned can be done once or twice a day by a carer. When using AT there was also a preference for simplistic options such as push button window openers that can be operated with an elbow, head or mouthstick:

> ***Dave****: I've just got on the walls near the windows I've got push buttons so I can open and close the window … I hit it with my arm or my head or whatever is just closest and that opens the window* (FG 2).

The physical set-up can be made simpler through thoughtful external structuring such as a customised surface for all electronic devices including an ECS controller:

> ***Paul****: … it was made up with timber … I drew out a design of it somebody could make it so about maybe 3 feet 4 feet long, probably 5 feet long, at 45 degrees its mounted on the wall, and as I say there's a phone on it, I have one of those cherry keyboards, rather than a big full size keyboard, and the intercoms on that, so it just makes a huge difference* (FG 2).

Similarly, Joe brought photographs of the simple reading stand he had described in a previous group as an example of a simple solution.

The theme of *Simple ECS* is closely related to the other themes of reliability and non-use. Simplicity was considered to improve reliability and facilitate on-going use. Simple things were also considered easier to fix oneself thereby facilitating autonomy (discussed later in section 3.3). The need to do one's own repairs is

related to the dissatisfaction with service providers discussed in the theme of *ECS Information supply and support*. Finding simple ways to use mainstream objects empowers the user. This means that repair and maintenance could be as simple as a trip to the local electrical supplier. Mainstream items were also considered to look more attractive.

2.3 Theme 3: Discreet ECS

The third theme of *Discreet ECS* (Fig 6) illustrates the consensus from most participants[145] that ECS should be hidden or look pleasing, and be as small and discreet as functionally possible. Even one of the smallest ECS controllers was considered by Dave and Michael to be too large to be mounted on a wheelchair. Michael did not want his to be an *eyesore* and both he and Dave considered the *Keo*, which at the time was one of the smallest controllers, to be too large:

> ***Dave****: … it was the big box called the Keo which was unwieldy* (FG 4).
> ***Michael****: … I only like using the Keo in bed as it's a big thing, and I'm not going to mount it to the chair* (FG 4).

This concern about appearance extended to the home as well. There was description of their homes having unnecessary *large boxes*, *holes* and *wires* and as being *too medical*:

> ***Michael****: I built an extension, and I have these boxes in front of the door, and anyone who comes in asks 'what is that there?' It's not a big deal, but still* (FG 4).
> ***Joe****: the bits and pieces that I do have, I always try to keep them discreet, or as discreet as possible, or I try to use standardised stuff that it isn't obviously sort of that medicalised vibe off of it* (FG 1).
> ***Dave****: Designs can be tidy and small, there is no need to put big boxes everywhere* (FG 4).

It is of course important that items are mounted for best functional use as well as appearing discreet:

[145] Jerry said he did not care about appearance.

> ***Paul****: So mountings, like even the chin control with this chair, the mounting that came with the chair, was terrible. So I actually sourced my own and just got it mounted in a far more reliable and neater sort of way* (FG 4).

While the discussion focused on discreet ECS, participants also favoured normal appearance as highlighted in associated discussions about powered wheelchairs. Some favoured manual wheelchairs as they were considered less obtrusive and more normal looking. The primary aesthetic concern was the size of controllers that made them obtrusive rather than discreet:

> ***Paul****: Ease of use and neatness. You (Michael) were saying you don't want that big control thing, some of them have a big display like* (FG 4).
> ***Dave****: discreet* (FG 4).
> ***Paul****: it needs to be discreet, relatively … discreet* (FG 4).
> ***Dave****: Once you be discreet, I know the only thing with the Keo was, that it was huge, once you went outside … everyone would be looking at it* (FG 4).

Jerry was the only person to offer a contrasting opinion.[146]

> ***Jerry****: It doesn't bother me but having switches around my head now. I don't care what it looks like* (FG 3).

2.4 Theme 4: Speech-driven ECS

The final theme of *ECS expectations* is Speech-driven ECS (Figure 6), summarised by Paul:

> ***Paul****: Computer, voice recognition, is increasingly hopefully for high quads … becoming a viable option* (FG 4).

A speech-driven ECS was considered conceptually ideal for people with high SCI and was suggested for inclusion in a starter-pack. All had trialled voice-activated software and over half were proficient users.[147] In addition several used voice tags to dial telephone numbers on mobile phones. It follows that speech-driven ECS were considered a natural preference. Even Jerry, who was not a voice activated software user, acknowledged the potential value of speech-driven ECS.

[146] Talking about his wheelchair.
[147] Four out of the six participants in FG 1, and three out of six in FG 2 were regular Dragon Naturally speaking users.

> ***Jerry****: It would be great if someone did come along to sort these things out. Put them all on voice control, that's what I reckon anyway is the way to go* (FG 3).

While participants were optimistic about its possible application they were sceptical about reliability based on poor personal experiences of voice activated and speech-driven ECS:

> ***Jane****: … everything that was said to it had to be said in about ten different ways so I completely lost faith in voice activated controls* (FG 1).
> ***Jane****: I had a voice activated control system put in at one stage and it was very, very inconsistent and very frustrating. It was called DEXTER ... at the stage it was to work the television, and the phone and the lights, supposedly, and you had to say something like 'Dexter, wake up', or something like that, but it was so frustrating, I'd have to call Dexter about 20 times in different tones of voice, and it was a disaster so it all had to be taken out* (FG 4).

Despite her experience she still expressed the hope that speech-driven ECS had improved since she had tried it:

> ***Jane****: I think voice activated is brilliant, but I don't know if it's at the right level yet. So something consistent* (FG 4).

There was a concern that speech controlled ECS would be *limited* (Joe, FG 3), dependent *on the strength of your voice* (Emily FG1), and not be reliable as a result of ambient noise or different accents:

> ***Dave****: A lot of it is the noise around and I think different accents it struggles with as well.*
> ***Jim****: Yeah if you've got the flu* (FG 2).

Jane and Paul in FG 4 agreed that speech-driven ECS were more important for those with no upper limb movement:

> ***Jane:*** *Yeah, the higher the injury voice activated comes into it more* (FG 4).

Frank was passionate about the potential application of Dragon to ECS as both a cheap and reliable option. He vocalised his frustration that no such product exists in his experience:

> ***Frank****: … there should be a lot more out there … voice activation systems. The software is there so …. I reckon anything with a remote, you can control. I can't understand why they can't marry them up ... You could buy a phone … with the Bluetooth® ... I can't see why it's not married up with a remote and the job is done. No one is out there doing it, all the technology is out there* (FG 3).

And again later in the same session:

> ***Frank****: it's all out there. Someone just has to marry it up, especially with the voice activated stuff because it is so cheap and it's so good now. So if you can get that to switch something, like on a remote and marry those two up. Everything is voice activated. I can't see what the big deal and is it such a big problem I don't know if there is anyone out there that's given much thought to it* (FG 3).

Paul described a sound switch[148] which is of interest as a possible option for a call bell in bed when switches can be lost*:*

> ***Paul****: … there was a call system and it was quiet good … I had one that was called voice control but it wasn't voice recognition but you could set it that it the TV or doors opening or whatever would not set it off but yet with voice you could activate it, so you did not rely on having a switch near you or anything* (FG 2).

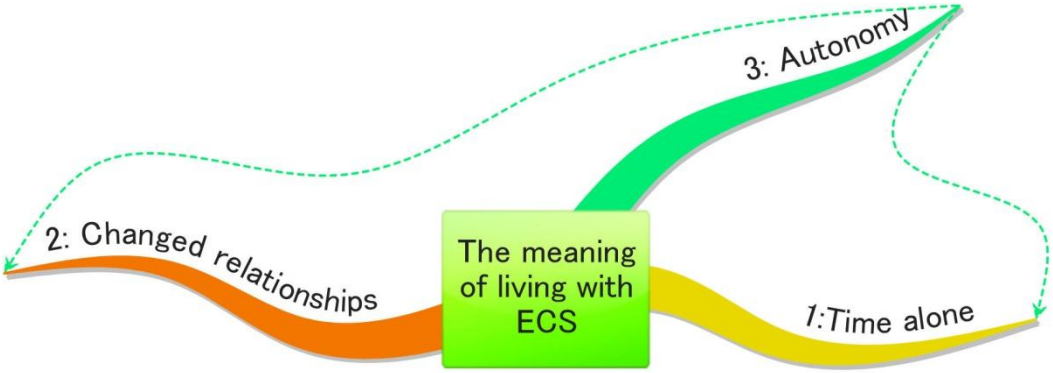
3. Category 3: The meaning of living with ECS

The third category, *The Meaning of living with ECS* represents participants' interpretation of actual and anticipated[149] experiences of ECS and the meaning that they ascribe to the phenomenon (Figure 7). Despite the dissatisfaction with *ECS Information, supply, and support,* as well as the many challenges described, people

[148] This is the most basic form of voice activation. It is the use of a sound to trigger a switch which can then signal an alarm. They can be calibrated for both duration and volume of noise required for activation.
[149] Despite not having ECS non- users were able to discuss what life with ECS would be like and what it could mean, partially facilitated by the inclusion of one ECS user in each group.

placed great value on ECS. This third category was reflected in three themes: *Time alone* and *Changed relationships*, both of which were linked by a third theme of *Autonomy* which reflected the overall meaning of the lived experience of ECS.

Figure 7: Themes within Category 3: The meaning of living with ECS



3.1 Theme 1: Time alone – *not a shadow with you*

Having ECS meant being able to choose to spend some time alone. Time spent alone allowed increased psychological space, privacy and, for some, the ability to be away from home. *Time alone* was discussed as a valuable experience by those with access to ECS, and expected to be such by non-users:

> ***James****: (It) would be nice to be on your own too* (FG 1).
> ***Jerry****: I think that's very important. You could spend much more time on your own* (FG 1).

Users reflected on their ability to enjoy solitary time when they first acquired ECS:

> ***Jane****: I can now be on my own and it just makes such a huge difference* (FG 1).
> ***Ciara****: It's just great to get away you know like, without all people around you* (FG 2).
> ***Jim****: It's nice to have some time on your own, even if it's only an hour, or half an hour, just somebody not, not asking someone to do anything* (FG 4).

This time alone appears to be more than a physical experience:

> ***Michael****: It's not being alone it is (interrupted)* ***Richard****: Just having space.* ***Michael****: It's just not people you know. Wherever I go there is usually someone I can ask to pick up the water bottle if I drop something, but it is*

> *people, it is not a shadow with you, a PA or something.* ***Dave****: You're not being babysat* (FG 2).

While accustomed to having high levels of care, some found the necessary dependency and the lack of privacy difficult:

> ***Paul****: I know other friends of mine like having their (personal assistants) there always beside them all the time. That can freak me out* (FG 2).

Despite having high SCI that traditionally requires long care hours, some users were able to spend long periods away from care givers and possibly even away from home. This ability to spend time alone was attributed to the combination of having ECS and the independent mobility offered by a powered wheelchair:

> ***Paul****: I'd often work at home for 6 or 7 hours without anybody being around* (FG 2).
> ***Michael****: There's nothing better, I have my own shadow behind me, I have all these hours of PAs, they are grand people like. It's just that I hate them being around. I hate having people around. Go off on my own, open the door. Go out anywhere* (FG 2).
> ***Jim****: That's what I do as well you know, I do the same thing. I might just go out the door and could be gone for 2 hours and just head off the middle of nowhere, the sea, down the lake* (FG 2).

Other examples of time spent alone included other technologies such as time at a computer doing leisure or work activities and listening to audio books. Some also talked about time spent enjoying nature alone:

> ***Ciara****: even just getting out around the grounds on a sunny day on your own is a big thing, as opposed to having to have someone wheel you all the time* (FG 4).

Time alone was attributed to both having a power wheelchair and ECS. The power wheelchair meant they were able to move around as they liked, and the ECS meant that they could open and close doors or summons help when needed. Time alone is also related to changed relationships.

3.2 Theme 2: Changed relationships – *not being babysat*

ECS changed the relationship dynamic between people with SCI and their family and care givers. Changes included less apologising, reduced annoyance and a decreased burden of care. People with high SCI can be constantly physically dependent on others. For several participants the reality of having a high SCI meant needing 24-hour care:

> ***Dave****: Before your accident you didn't rely on people to do so much for you. You might say to your friend give us a lift here or give you a lift there on occasion, not every single day on every aspect of your life having to ask someone to help you* (FG 2).

Dependency on friends, family and caregivers can then define the relationship in a fixed dynamic consisting of the one always requiring help and the other who always has to provide it:

> ***Joe****: It definitely changes relationships. As it is, if you are completely dependent then obviously that is your relationship with them; that becomes the relationship and it becomes a major dynamic in the relationship, whereas if you can be a lot less reliant or calling on people then it takes some of that out of the way* (FG 1).
>
> ***Michael****: It (ECS) definitely helps in a relationship of any sort, it just means you contribute more. Give, give or take, take, take* (FG 2).
>
> ***Dave****: That's what it felt like before I had any kind of technology, it felt like you're constantly taking off people, would you do this for me, can you do that? You don't seem to be able to put anything back in everybody's life* (FG 2).

Caregivers often have to do whatever the person is doing for example:

> ***Jane:*** *If I spend two hours reading, my carer spends two hours reading as well* (FG 1).

Participants spoke movingly of always having to ask for help and thus always apologising. Despite the familiarity and regularity of the constant need for assistance, it violates expected interpersonal dynamics and frequently results in the adoption of a persistently apologetic manner:

> ***Jane****: It's so nice not having to call someone all the time.* ***Jerry****: Absolutely, they are going to get fed up. You know? They are absolutely going to get fed up. They'll say, not again ... they've only just sat down and I realise I've forgotten this.* ***Jane****: It's always, "I'm really sorry but would you mind"….* ***Joe****: I think that's think that's important though, that relationship thing is really important in that situation because it changes the dynamic of every relationship you have. I'd absolutely agree with Jane that's its important* (FG 1).

In addition, the nature of this care was described as being annoying for both parties because the caregiver had to be constantly present:

> ***Jerry****: I just live with my mother, she's a bit old. There's nothing good about getting her up* (FG 1).
> ***Jim****: You don't need to be annoying people then you know. That's what you feel like, you keep asking someone to do something, that's what I feel, like I'm annoying them or interrupting them or when they are doing their own thing you know watching TV or something and you have to say to them that "you wouldn't mind lifting my bag", when they are well in watching something, you feel a xxxxxx like* (FG 2).
> ***Dave*** *(It) must be fairly annoying for somebody to be called just to open a door.* ***Michael****: It's even annoying having them there.* ***Jim****: Half the time there is nothing to do* (FG 2).

The alternative, made possible by the use of ECS, is to have help on request:

> ***Dave****: It makes a big change 'cause then again the people that are used to doing everything for you have time on their own, and they are not thinking I have to go and make sure that Dave can get in or out, or he can do this or that, it is not being babysat 24 hours a day anymore you know and people are only there when you actually ask them to be there they don't feel they have to be there for you* (FG 2).
> ***Michael****: It's great to be able to do something without asking someone, all along you ask enough people to do things* (FG 2).

Those without the technology had an understanding of how their needs could become a burden on their family and carers and perceived that ECS could offer the

potential benefit of '*lightening the load' (Jane).* For ECS users the burden of care for the caregiver was reduced, even leading on some occasions to a reduction in the number of care hours needed:

> ***Jane****: It really eases the load for families and carers, really* (FG 1).
> ***Michael****: What you would say is that I will need less PA hours 'cause of these controls* (FG 2).
> ***Paul****: I mean 6 hours now is not an issue. I used to have ten and a half hours PA (a day) down to 70 hours (a month)* (FG 2).

People also discussed the concept of burden of care when talking about the commonly experienced cycle of worry. Caregivers and family members worried about the person with a spinal injury, who in turn often worried about the care giver worrying about them:

> ***Emily****: They can go on and do their own thing and not have to worry. You know, worry about you. Don't have to change the channel, I know I keep going back to the TV but just to change the channel or turn on the light if it gets dark outside or anything. They don't have to worry about getting right in before you need them straight away* (FG 1).
> ***Jane****: I can make phone calls which is great because it means I can be on my own in the house, and I mean, that is a complete change of life experience, instead of having people worrying, "Oh Jane is on her own if the house goes on fire." I can now be on my own and it just makes such a huge difference* (FG 1).
> ***Dave:*** *Before like they can't go to the shop cause they are worried to leave you for 5 minutes cause you can't do anything on your own, and now it's not a problem to go away for an afternoon or a morning or whatever you know* (FG 2).

They also referred to increased individual and family confidence and independence. This was facilitated by the enhanced sense of safety and security afforded to those who had a reliable ECS to raise an alarm or call for help:

> ***Dave:*** *And security, as long as you know it's going to work and they know it is going to work, well* (FG 4).

Need for carers

Despite the freedom technology offered these users, it did not replace the need for human care and Paul asked the group:

> ***Paul****: Do you think your assistive technology makes a difference between being able to be say spend a night without anybody being around and like being able to spend your night on your own?* (FG 2).

It seemed that while they were all comfortable being alone and able to call for help, they all still needed help to be close, often in the same house:

> ***Dave****: I tried that a few weeks ago. I always have somebody in the house with me and I said I want to try be on my own at night and the call system is there and I can call anyone if I need it, with a big button. I just put it next to my pillow and I can whack it with my hand but when I went to hit the button it slid off the bed and it meant I had nobody for hours because I had no way of contacting anyone because the only way which was through a button which was now dangling off the bed.* (FG 2).

Being physically trapped when alone and in bed was, however, not the primary concern. The major reason given for needing support was the fear of medical complications that accompany high SCI, such as autonomic dysreflexia.

3.3 Theme 3: Autonomy – being able to do what you want

The two themes in the category of *meaning* discussed above can be considered as separate aspects of the over-arching theme *Autonomy*. Each theme relates directly to this central concept of being able to, *do something yourself* (James) or *do what you want* (Peter). This autonomy results in an ability to spend quality time alone and in the transformation in relationships that occurs as a consequence of proficient and regular use of ECS. In addition, autonomy encompassed issues relating to active participation, independence and choice.

Users described the change in active participation since acquiring ECS:

> ***Jane****: It has changed so many things for me … it's like giving a quadriplegic arms and hands that work* (FG 1).

Accordingly those with ECS said that they would now find it hard to be without ECS technology:

> ***Susan****: I couldn't be without it now, you know. I can't sleep until I know I have it there with me* (FG 3).

Without ECS, simple tasks like changing television channels or turning pages of a book could only be carried out with caregiver assistance:

> ***James****: if you had these things in your house, you wouldn't have to bother your family all that much* (FG 1).

Non-users were also able to anticipate the autonomy that might result from having ECS:

> ***Emily****: If I had it (ECS), I'd feel more independent. I wouldn't have to rely on my PA for everything. Independence, even if it's only a tiny bit of independence because I don't have any independence at home* (FG 1).

This independence meant less reliance on others:

> ***Paul****: For me, just even the confidence to do a lot of things yourself without anyone needing to be around, just self-reliance* (FG 2).
> ***Richard:*** *By having the environmental controls I don't need help, someone to do anything* (FG 4).

There was increased freedom for the ECS user and caregiver. Being able to use ECS meant that users were less reliant on care givers and that, reciprocally, caregivers also had more freedom from the demands of users. In contrast to the traditional concept of giving independence to the client, Dave referred to this freedom as giving caregivers more independence which in turn positively impacts the dynamics of the caregiving relationship.

ECS users described the increased choices and options made available through ECS:

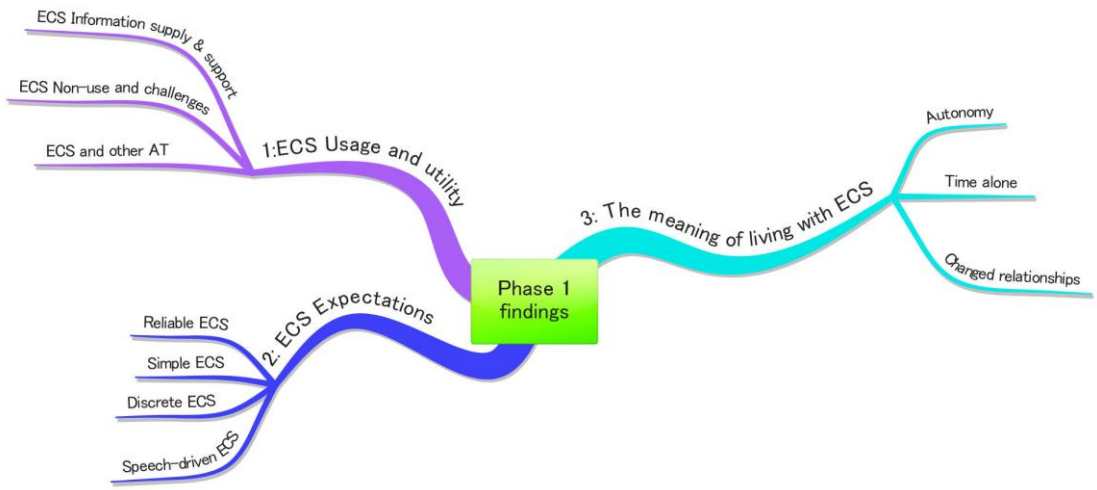
> ***Jim****: Gives you the choice to choose what you want to do* (FG 1).

> ***Dave****: When I got the controls there was far more that you could do for yourself, so it feels like you're living your life instead of hanging around waiting for other people to help you live your life* (FG 4).

4. What do people with high SCI think of ECS in summary

Four focus groups yielded a rich but diverse data set spanning many topics that have been described here in several themes arranged into three categories, *ECS Usage and utility*, *ECS Expectations* and *The meaning of living with ECS*, Figure 8. These categories are interrelated, for example *ECS Expectations* are based on experiences and perceptions of *ECS Usage and utility*, and meaning requires successful usage which is enhanced if ECS meet expectations. The individual emergent themes assigned within and between categories are also interrelated. For example *ECS Non-use and challenges* is inextricably related to reliability. The assigning of themes to categories is not absolute but intended for improved coherence.

Figure 8: Overview of Phase 1 Findings: What do people with high SCI think of ECS?



The *ECS Usage and utility* category describes some of the practicalities of ECS use in Ireland highlighting the dissatisfaction with reliance on suppliers, the risks of non-use and the relationship of ECS with other AT. These findings point to the need for improving ECS provision in Ireland, as well as the complexity of ECS use that involves inevitable challenges and requires integration with other AT. This study was unable to address ECS provision in Ireland directly but did consider the possibility of a starter-pack aimed at providing increased exposure for people with high SCI. The theme *ECS non-use and challenges* suggests however that a starter-pack may be challenging and that some people may simply choose not to use it. The final theme in this category provides a reminder of the need to consider both mouthsticks and powered mobility in the provision of ECS and in the starter-pack in particular.

The *ECS Expectations* category provided a useful guide to the things to be considered when designing a starter-pack based on users' perceptions. The starter-pack to be developed in the next phase of this study would ideally need to be reliable, simple, discreet, and speech-driven.

The final category validates the need for ECS and its potential contribution to peoples' lives by facilitating autonomy, providing time alone and changing relationships. The meaning of life with ECS is further explored in Phase 3 which explores people's experiences of using the ECS starter-pack.

Phase 1 findings are not discussed in depth here, but are instead integrated with findings from the entire study in Chapter 11. Focus group findings relevant to the designing and provision of a starter-pack will be referred to again in the next chapter.

5. Reflexivity

This chapter was challenging to write as I needed to reflect the initial analysis conducted in 2007 and 2009, but having embarked on rigorous IPA for the third phase of the research I wanted to begin my focus group analysis again and seek more depth. I could not do this for several reasons – I did not have the luxury of time to do so and my initial findings were what informed the rest of my study so I needed to reflect those findings even if somewhat immature on reflection.

Although I fully intended to make use of the participants own language I often found myself defaulting to acknowledged or technical terms for example I continually refer to scanning but the more intuitive term used was scrolling.

I did make some noticeable changes especially to theme names such as robust and foolproof –which reverted to reliability because that was the word the participants used and I think this as a descriptive piece requires authentic users' language. Unobtrusive and aesthetically pleasing were also replaced with the participants' favoured phrase 'discreet' which is synonymous with unobtrusive and also encompassed elements of aesthetics.

Chapter 8: Phase 2 procedures and findings

The previous chapter described the findings of Phase 1: what do people with high SCI think about ECS? Focus group findings revealed positive perceptions of living with an ECS for both users and non-users' thus supporting the intention of this study to develop and trial an ECS starter-pack. In addition people expressed expectations for ECS and described living with and without ECS which provided some insights about important elements for a possible starter-pack. Phase 2: Development of an ECS starter-pack was a precursor of the third aim of this study:

- *Explore a possible way to make non-users become users in order to redress inequality of access.*

The decision to develop a generic pack may be considered to conflict with the Matching Person with Technology MPT Model which calls for an effort to match a person with the most appropriate technology by considering all options (Scherer, 2005). However choosing to develop a generic pack was not intended to disregard the concepts of this model but rather to consider its application in a resource limited environment where access to a variety of technologies is not possible. In place of selecting from a variety of devices to match a person, selection can be based on variable set-up options and choices of functionality. In developing the pack efforts were made to identify components that allowed flexibility of set-up as well as to cater for the needs of people living with a high SCI. The spirit of the Matching Person to Technology model was incorporated by offering choice within the pack and in how to set-up the pack as detailed in Chapter 9.

This chapter begins by describing the ECS starter-pack named the Generic Electronic Assistive Technology pack (the GrEAT), and then describes the development of the GrEAT which involved the following sequential steps: 1) gathering information; 2) selecting constituents for the pack; 3) the pilot trial using the pack; and 4) compiling the final pack.

1. The ECS starter-pack, The GrEAT

The GrEAT pack consisted of two ECS controllers,[150] switches, mounts, telephones, a stand-alone sound-activated alarm system, and instructional audio visual materials (see Table 11). Appendix 19[151] includes photographs of the contents of the GrEAT.

Table 11: Contents included in GrEAT Pack

Environmental controllers	Switches	Mounts	Communication	Other
• PROTEOR *Keo* • SICARE *Senior pilot*	• neck • micro lever • mini cup • micro light • sound-switch	• medium clamp based Flexzi • short Velcro® based Flexzi • magic arm	• SICARE *QuickPhone* • mobile phone • Bluetooth® headset • wireless personal alarm	• double IR electrical socket • information booklet • demonstration • DVD • spare batteries • video camera

2. Information gathering

The development of the pack required identifying the requirements for the starter-pack and identifying suitable components that would meet these requirements. Information gathering incorporated several strategies including literature review, review of Phase 1 findings, visits to ECS users' homes, and consultation with an expert occupational therapist which are described here.

2.1 Literature review

A review of the literature provided little useful information that could be applied in developing the GrEAT. Important ECS functions identified in the literature as discussed in Chapter 3 (section 2.1), include telephone, television, lights and door opening. Most publications did not detail the ECS used and those that did reflected a combination of non-commercial ECS not available for inclusion in the GrEAT and outdated ECS controllers. Von Maltzahn et al. (1995) conducted a 16 week, 5 person trial of a modular generic ECS-pack, with a speaker phone (adapted from

[150] Environmental controller also known as environmental control unit: the central specialised device that receives a signal from an input device and sends signals to target devices. It may be considered the processing unit.
[151] An electronic version of the booklet will be made available at : www.cora.ucc.ie

RadioShack), X10 sockets and IR for television and a bed controller. While it was not possible to use the same components, the successful use of a simple combination of elements was applied to the GrEAT. Similarly in Manitoba users all received the same ECS controller which was customised for each user (Ripat & Strock, 2004; Ripat, 2006). These three studies supported the intention to use the same ECS controller in a generic pack. Previous research trials varied in length as detailed in Chapter 3 Table 3. Croser et al. (2001) who conducted an eight-person trial using an assortment of ECS components selected for each participant concluded that a 2-week trial, while promising was too short. A trial needs to be longer than 2 weeks but not necessarily as long as 16 weeks. The most comprehensive information available in the literature covered speech-driven ECS as detailed in Chapter 3 (section 1.2). This review indicated that speech-driven ECS are desirable but challenging to use, suggesting that they may not be suited for a short term trial. Following this review of the literature, Phase 1 findings were reviewed.

2.2 Phase 1 findings

Review of the focus group findings highlighted the following as important features for a starter-pack:

- Abandonment of assistive technology can be reduced by ensuring reliability, functionality, and simplicity of all components.
- Devices should be reliable.
- Consideration should be given to the interaction of all assistive technologies used by an individual, including powered wheelchairs. An ECS needs to work alongside or be integrated with a powered wheelchair and mouthstick.
- An ECS should be accessible by switch as well as accessed directly using a mouthstick.
- Technology should be discreet with a mainstream appearance and be as small and neat as functionally possible.
- Simplicity is a key desirable feature both for individual components and for entire ECS.
- High-tech and low-tech assistive technologies are equally valuable.
- Reliable speech-driven ECS is highly desirable.
- A back-up system is desirable in case of system failure.

- Users and potential users require information and support throughout the introduction, set-up and utilisation of ECS.
- Supporting documentation is required to support installation customisation and on-going use of ECS.
- ECS should be modular so that they allow for expansion by adding individual components.

2.3 Home visits

ECS with a variety of devices and different set-ups were observed in action in five homes, offering insight into their practical utilisation in real-life and revealing possibilities for the research trial of the GrEAT in Phase 3. Users' perceptions were observed informally during these visits as described below. Suppliers identified potentially suitable people to visit in Ireland and Canada.[152] While they were not formally considered research participants they were considered informants and were thus asked to provide informed consent before sharing their experiences and opinions (Appendix 20). Those who agreed to a video recording of their use of ECS also provided photographic and video consent (Appendix 20).

Ireland

Two home visits were conducted in Ireland, one to a man living in a rural area with high SCI and one to a man in Dublin with a neurodegenerative condition. Both men had extensive ECS.

The middle-aged farmer with a C4 SCI living in rural Ireland was using a GEWA *progress*[153] supplied through a personal trust fund. He expressed dissatisfaction with the initial installation and some disagreement over payment and the quality of the work. He reported that his system had been struck by lightning twice which had destroyed his IR telephone and adjusted the functionality of the GEWA *progress.* He replaced the telephone once but on the second occasion resorted to using the loudspeaker function on a standard phone with personal assistance. He only used the ECS at night when alone, favouring personal physical assistance when it was available. ECS use required positioning a switch using a mount when in bed – a process described as awkward by both the user and his family. He reported that he not been shown by the supplier how to add new devices to the GEWA *progress*

[152] One person who had been previously identified as unable to participate in Phase 1.
[153] GEWA *progress* is a large environmental control device with a dynamic colour screen, it is manufactured by adapting a PDA with specialised software and additional hardware that includes IR transmitters.

although his brother-in-law had added a new device on one previous occasion. The system had included an electronic door opener which was no longer linked to the ECS. He expressed some dissatisfaction with not having anyone with whom to discuss technology. At his request I added a new menu and IR codes for his new DVD player during the visit.

The second ECS user was living in an independent living unit. He was an experienced ECS user and had been using a buddy switch[154] with an environment control system (POSSUM *companion*)[155] for several years to control his television, DVD player, digital television, lights and telephone. His first ECS was fixed to his bed in his parents' house but at the time of the visit he had a new ECS (*Keo*), mounted to and integrated with his powered wheelchair. It was controlled through the wheelchair controller (a mini joystick) which used menus rather than switch scanning to navigate through the ECS. The joystick was used to move up, down, left or right between menu icons on the *Keo*. Once an icon was selected he would wait for the system to time out and thus activate the selected button. Some joysticks offer a fifth action, downward press, which intuitively might have allowed the selection of an icon. However the *Keo* was not designed to receive such a signal. The selection of an icon was registered by highlighting a button and then waiting for *Keo* to respond to that selection. The user was using *Keo* with a 4 x 5 configured menu (Figure 9). His system included control of lights, curtains, blinds and doors. He could use the landline telephone and control his digital television. He reported some difficulty integrating his mobile phone with the *Keo.*[156] The visit illustrated how the *Keo* can be used in a complex set-up integrated with wheelchair control. This level of control was beyond the scope of the trial but illustrated the flexibility of the device if needs became more complex or funding became available for additional features such as door-opening.

[154] Buddy switch - a large disc shaped single press switch.
[155] POSSUM *companion* – an older ECS controller.
[156] The Bluetooth® function of the *Keo* was paired with an automatic door opener preventing it from pairing with his phone.

Figure 9: Photograph of complex 5x4 *Keo* menu including door opening, lights, blinds, and some television control, captured in an Irish home

Canada

A Canadian supplier facilitated home visits to three people using ECS in Ontario, Canada. One person was using a comprehensive computer-integrated speech-driven ECS called the SAJE *powerhouse*. The other was using a commercially available universal remote control called the PHILIPS *Pronto* and the third was using a SICARE *Pilot,* a stand-alone speech-driven ECS that includes integrated switch scanning.

The SAJE *powerhouse* included a headpiece with a speaker and a microphone mounted onto a ribbon switch which itself was mounted to a powered wheelchair. The user activated the listening function of the system by accessing the ribbon switch with her head. She used the ECS through soft spoken verbal commands. The control centre/ computer was stored in a cupboard in the house. She had been using the *powerhouse* successfully for over six years and stated:

> *I'd rather you cut off my arm than take (the ECS) away.*

She was observed surfing television channels, controlling a sound system, moving her bed up and down, opening doors and making telephone calls. She reported that she had opened doors and telephoned friends at night while sleep talking as she had becoming so accustomed to using her ECS. While the system appeared to be highly appropriate for the client group in Ireland, and reflected the desires expressed in the focus groups, it was not available in Ireland and therefore not a viable option for a research trial. In addition, the user described the process of

learning the appropriate voice commands for the *Powerhouse* ECS as challenging, thereby making a speech-driven controller unsatisfactory for a short trial.

The second user had a higher level of physical function[157] and used a pencil in a universal cuff to access the touchscreen universal remote control. The PHILIPS *Pronto* had both X 10 and IR functionality. This simple, attractive looking piece of equipment was viewed as satisfactory because of its size and normal look. The user of this system also expressed her dependence on the ECS:

> *If I didn't have it I would be bored … I wouldn't know what to do without it.*

The PHILIPS *Pronto* possessed qualities noted as desirable in the focus groups such as simplicity, attractiveness and mainstream appearance. However, it was not easily accessible to people with high SCI except through the use of a mouthstick. In addition, it did not integrate with a telephone system. Consequently, it was not suitable for the trial, though it illustrated how mainstream technologies have potential benefits as assistive technologies.

The third user had used a SICARE *Pilot* for 10 years enabling him to live alone in his own house with limited personal assistance despite having a high SCI:

> *It's nice to have a bit of freedom.*
> *It gives me something I can actually do myself and that's handy.*

He used simple voice commands to activate his ECS which provided auditory feedback. He was also able to use two switches if the voice commands were not accurate. When in bed, he used a sip and puff switch to access the ECS mounted at his bed side. His comments echoed the high value placed on time alone that was expressed in focus groups:

> *The most important thing is that I can be alone for a bit. I can have some space.*

[157] C5 injury resulting in some preserved upper limb function.

The SICARE *Pilot* appeared to be a possible device for inclusion in the GrEAT pack, but its functionality was not as refined as the *powerhouse*. As it required a combination of voice and switch use for satisfactory control, it was considered overly complicated for use in a trial.

Conclusions from home visits

- A satisfactory ECS includes both safety and entertainment features through access to communication (telephone) and to audio-visual systems (television and radio).
- It is possible to adjust some commercially available ECS in situ in people's homes.
- Successful positioning of a switch can be time-consuming.
- The complexity of the set-up of an ECS can be highly variable depending on the desires of the user.
- Satisfaction with systems is variable and appears to be related to the users' perception of ownership of the ECS and perceived support from suppliers.
- Too much technology can be overwhelming and lead to abandonment.
- Joystick or speech-driven control is preferred to access through scanning.
- Wheelchair control and an ECS can be integrated.
- Speech-driven ECS require integration with a switch to either access the listening function or as an auxiliary access method.
- Satisfactory speech-driven ECS, while readily available in Canada, are not viable for use in a short-term Irish trial due to poor availability, cost, complex specialised installations and the time required for clients to become accustomed to using speech-driven ECS.
- Mainstream technologies have ECS potential, but lack switch-accessible functionality.

2.4 Consultation with an expert occupational therapist

I consulted with Elizabeth Steggles (ES) a Canadian-based occupational therapist with expert clinical ECS experience. ES had previously facilitated academic research into the use of ECS and had presented several workshops on ECS for assistive technology professionals including occupational therapists. ES was willing to act as a *therapy practice sponsor*[158] as required by the sponsorship funding body.

[158] Therapy practice sponsor supports the researcher in applying the research project to a clinical setting. The nature of this supervision is primarily clinical as opposed to academic aimed at ensuring best clinical practice.

Telephone and email support were provided by ES throughout the planning and implementation of all three phases of the study. Face to face consultation was possible in 2009 during a visit to Canada. Liaison with ES identified the required and desirable features of the GrEAT, as well as selecting the final components. ES also facilitated and accompanied me on Canadian home visits.

2.5 Required and desirable features for an ECS starter-pack

The information gathering led to the identification of functions required in the GrEAT:

- Independent access to a telephone
- Security provided by a call system to summon attention
- An IR socket set to allow control of plug-in electrical devices such as heater, fans and lamps
- Access to entertainment and information through control of IR appliances such as television and radio
- A back-up control system
- A selection of switches suitable for head and chin access
- Flexible mounting options for both switches and controller.

In addition the GrEAT required the following features:

- Switch accessibility
- Direct accessibility – suitable for mouthstick or knuckle access
- IR transmission[159]
- ECS controller with a dynamic graphic display
- Simple installation and capacity to be modified by an occupational therapist
- Reliability of components
- Adaptability – allowing both simple and complex set-up and configuration
- Upgradeability to allow the system to have extra peripherals and functions added
- An attractive, modern appearance
- Small size and weight
- Mountable and portable
- Low-battery warning

[159] Radio transmission and X-10 were excluded for ease of installation.

- Economical
- Comprehensive instructions for training and support.

Other features for the GrEAT that were considered desirable rather than essential included:

- Reliable speech-driven controller
- Mainstream appearance
- Integration with mainstream technology such as mobile telephone
- Integration with powered wheelchair
- Integration with computer
- Wireless switch access
- Waterproof
- Long-life battery.

Limited funds were available as the project was funded through a research grant which was intended to cover all research expenses, as well as the purchase of equipment. The budget of €2,800 for a GrEAT pack automatically excluded more expensive items and limited the amount and range of equipment that could be included. Installations had to be retro-fitted, so door access was both too expensive and logistically impossible for repeated short trials. Time constraints also meant that two trials needed to occur concurrently, thereby necessitating two full packages. The exact components of the pack that would meet these requirements were selected on the basis of an internet search and liaison with suppliers.

3. Selection of constituents for the GrEAT

Selection of the specific components for the GrEAT involved identifying several possibilities, followed by a process of elimination based on the requirements and desirable features outlined above. Final decisions were pragmatic and based on estimations of cost together with a clinical judgement of what might constitute a successful trial based on both internet search, and liaison with suppliers.

3.1 Internet search

Academic texts about assistive technology could not provide specific and up-to-date information on specific devices (Cook & Polgar, 2008). Armed with some understanding of ECS available in Ireland in 2009, an internet based search was conducted over a three month period to gather information about possible devices. This endeavour included conducting a Google search using *Environmental Control Systems, electronic aids to daily living,* and *electronic assistive technology* as search terms. The search also encompassed well-known assistive technology sites such as *www.assistireland.ie., www.ablenetinc.com*, *www.abledata.com* and *www.abilitynet.* The search was extended to known suppliers and manufactures including: *www.proteor.com*, *www.possum.co.uk*, *www.gewa.se* (no longer operational – now *www.abilia.se*), *www.rslsteeper.com*, *www.angelecu.com*. The information gathered was current in 2009, but is already out-dated at the time of writing given the rapid pace of technological advancement. The use of commercial internet sites led to an expansive list of possible devices, some of which appeared more than once with differing names and suppliers. The primary aim of the initial search was to ascertain potential devices, their features, cost and possible suppliers. The search sought to identify

- Stand-alone portable ECS controllers[160]
- Suitable IR telephones
- Switches that would be suitable for people with high SCI
- Mounting options for both the stand-alone ECS controllers and switches.

A list of possible components is provided in Table 12 and photographs of some controllers are found in Appendix 6. The controllers offered similar features including switch access,[161] scanning and an IR learning function. Table 13 provides a summary of the comparative features considered in selecting a controller. The two suitable controllers for the pack were the PROTEOR *Keo* and the POSSUM *Primo*. Both were programmable by an occupational therapist, had dynamic graphic displays with battery indicators, were modern looking, mountable, portable, upgradable, and suitably priced.

[160] ECS features integrated into powered wheelchairs and augmentative and alternative communication (AAC) devices were excluded.
[161] With the exception of the PHILIPS *pronto.*

Table 12: List of ECS controllers, IR telephones, switches and mounting options identified through internet search

ECS Controllers	Infra-Red Telephones	Switches	Mounting Options
• GEWA *Control prog* • GEWA P*rogress* James II • PHILIPS P*ronto* • POSSUM *Compact* • POSSUM *Freeway* • POSSUM *Companion* • POSSUM *Primo** • POSSUM *Vivo* • PROTEOR *Keo** • PROTEOR *Keo with blue tooth** • SICARE *Light* • SICARE *Senior pilot* • SRS L*ite* • SRS *Intellec* • STEEPERS *Active500* • TASH Mini relax • TASH Relax II • TASH Relax III	• GEWA *Jupiter** • POSSUM *sero** • SICARE *QuickPhone** • SRS *Intelliphone** • *STEEPERS Puma**	• Chinswitch* • Sip and puff switch • INTEGRAswitch (sip and puff type) • Radio switch* • Lever switches* (various sizes) • Micro light switch* • Mini cup switch* • Buddy buttons* (various sizes) • Trigger switch*[162] • Ribbon switch* • Sound switch*	• Flexzi mounts* • Gooseneck mount • Magic arm mount (Manfrotto)* • Microphone stand* • MOBILIA Modular mounting system • STEALTH G*atlin* swing away mount

** Components considered suitable for inclusion in the GrEAT.*

[162] Small square switch that requires considerable force to activate.

Table 13: ECS controllers comparison table, (items shaded grey were considered to be suitable for inclusion in the GrEAT)

Controller	Size	Cost	Display	Programmable	Aesthetically suitable	Available in Ireland
PROTEOR *Keo*	suitable	<€1500	dynamic graphic	yes	yes	yes
POSSUM *Primo*	suitable	<€1500	dynamic graphic	yes	yes	yes
GEWA *Progress*	suitable	>€1500	dynamic graphic	yes	yes	yes
GEWA *Control Prog*	suitable	<€1500	static	yes	no	yes
Mini Relax	suitable	<€1500	static	yes	no	no
The James II	suitable	<€1500	combination	yes	no	no
SICARE *light*	suitable	>€1500	dynamic text	yes	no	no
SRS Intelec	suitable	>€1500	dynamic graphic	expert	yes	yes
SRS lite	suitable	<€1500	combination	unknown	yes	yes
POSSUM Vivo	suitable	>€1500	dynamic graphic	expert	yes	yes
PHILIPS *Pronto*	suitable	>€1500	dynamic graphic	expert	yes	no
STEEPERS *Active500*	slightly too big	unknown	dynamic graphic	unknown	yes	no
Relax II	slightly too big	<€1500	static	yes	no	no
Relax III	slightly too big	<€1500	static	yes	no	no
POSSUM *Compact*	slightly too big	>€1500	dynamic text	expert	no	yes
POSSUM freeway	too big	<€1500	static	expert	no	yes

The internet search revealed suitable hands-free IR telephones with similar functionality, all of which were suitable for inclusion in the GrEAT. All the suppliers offered a similar assortment of switches and mounts. Suck and puff switches were not considered suitable for the trial due to hygiene concerns as switches were to be reused by different participants. In addition, their cost was prohibitive as part of a low-cost research trial. The radio switch was also excluded on the basis of cost. The search identified a variety of switch types suitable for inclusion in the trial including the chin switch, a lever switch, micro light switch, mini cup switch, buddy buttons, trigger switch, ribbon switch and the sound-switch. Mounting options included: the low cost option of using a microphone stand; universal camera-mounting systems adjusted for assistive technology use, two flexible mounting systems that are bent into place – the Flexzi mount[163] and the gooseneck,[164] customised swing-away mounts and modular systems that can be customised. The search also revealed a wide range of peripheral devices, ranging from door-openers, intercoms, to curtain-controllers. These were excluded from the search results as they were expensive, and required specialised installation that was beyond the scope of a short term trial.

3.2 Liaison with suppliers

The researcher liaised with suppliers in Ireland and Canada. Liaison with a Canadian supplier was aimed at acquiring information on how to supply and support an ECS, as well as information about a wide variety of controllers. Information sought from the Canadian supplier was conceptual, focused on implementing the trial as opposed to identifying specific components that may not then be suitable or available in Ireland. Networking with Irish suppliers was intended to assess the feasibility of conducting the trial in Ireland and identifying specific components best suited to the planned Irish trial.

Canada

A not-for-profit, environmental control supply organisation based in a physical rehabilitation hospital in Ontario, Canada was visited. This service had no allegiance to any particular manufacturers. It was established by expert occupational therapist Elizabeth Steggles but at the time of writing was operated by a single engineer. The service supplied a wide variety of ECS components from various suppliers. The installations integrated products from different suppliers into single systems. The engineer demonstrated a variety of controllers including the SICARE Lite, Mini

[163] modular flexible tubing mount.
[164] Flexible metal rod mount.

Relax and Relax II. Practical advice on how to conduct installations for the GrEAT trials was gained through an understanding of how the Canadian service operated. The engineer recommended using manuals to provide users with as much information as possible and advised that the manuals should be arranged from front to back, moving from the simplest instructions at the front to complicated information at the back. He also suggested colour coding of cables[165] and matching devices. The researcher implemented both of these suggestions in the pack. The engineer also advised integrating X10 in the GrEAT. However this option was not pursued on account of researcher inexperience and the X10's reported lack of stability in Ireland.

Ireland

The two potential controllers: the PROTEOR *Keo* or the POSSUM Primo were identified through the internet search as described earlier. The choice was based on availability, cost, features and ease of installation. Ascertaining the ease of installation necessitated support from suppliers and the researcher contacted both known suppliers of ECS in Ireland.[166] One supplier facilitated a visit to his workshop and was able to offer some support in terms of teaching how to program and adjust the *Keo*. He made suggestions for mounting options, including the use of a microphone stand and the suggestion of a telephone (the SICARE *QuickPhone*) that he recommended on the basis that it worked well with the *Keo.* The supplier also suggested integrating the *Keo* with wheelchair controls through purchase of an accessory called the *ECU module*. This would allow users to access the *Keo* through their wheelchair controller. A further suggestion involved the inclusion of *Keo* IR receiver for a computer mouse that, when used with the *ECU module*, allowed a user to control a computer mouse.

A meeting with the UK-based representative for POSSUM provided information about the POSSUM *Primo*. The representative also offered support, including suggesting a visit to their factory in the UK to learn how to program the POSSUM Primo. He was, however, not the primary supplier of this product in Ireland, making it necessary to purchase equipment from the Irish supplier. A number of unsuccessful attempts were made to meet with the Irish supplier within the time constraints of this project, and this inaccessibility of the supplier made the POSSUM *Primo* and the POSSUM *Sero* phone less viable as pragmatic choices.

[165] Colour coding was possible using thin multi coloured cable marking tape.
[166] In 2009 there were two ECS specific suppliers in Ireland. A third company has recently joined the market.

3.3 Component selection

Clinical judgement was used to select components considered to be most suitable for the trial. Potential suppliers estimated costs, and anticipated delivery dates were obtained for each possible component. Final decisions were pragmatic, and aimed at ensuring that both the pilot trial and the first two trials could proceed as planned and within budget (€2,800 per pack).

Controller

The controller selected for the pack was a PROTEOR *Keo.* The POSSUM P*rimo* and the PROTEOR *Keo* were both suitable for the trial as they were similarly priced. They had equivalent features including: dynamic graphic display, touch screen (allowing direct access), switch accessibility, extensive memory, easily programmability, IR learning and simple adjustment of input and scanning settings. The PROTEOR *Keo* was available with Bluetooth®, enabling integration with participants' mobile telephones. This desirable Bluetooth® feature made the *Keo* the preferred choice for inclusion in the pack. The POSSUM *primo* was not favoured for the trial as it was considered that the lack of support from the supplier would threaten the success of the trial. The SICARE *Senior pilot* was selected as an inexpensive back-up controller. This was included in the pack so that research participants would have an ECS during the trial if the primary controller, the *Keo,* failed.[167] While it was not possible to discern any differences between the IR telephones, the SICARE *QuickPhone* was selected on the basis of local availability and support from the supplier of the *Keo.*

Switches

Severe physical limitations as imposed by a high SCI mean that switches are often the most suitable access device as they can be activated with minimal physical activity. A single switch can be activated using head, neck and chin movements. Six suitable switches capable of being used by a person with a high SCI using chin or head control were selected. The variety of mechanical properties of the switches catered for personal preferences in switch activation for participants. A chin switch has its own transparent tube mount that is worn around the neck and provides simple chin access to a switch. Lever switches are hinged switches suitable for lateral contact. The mini lever switch was selected as a suitable size for chin contact

[167] The *Senior pilot*, while it offered back-up was simpler and functionally different to the primary controller. The features of the *Senior pilot* would have excluded it as a primary controller as it is unattractive, dated and not as reliable as other controllers. Its inclusion was however based on its perceived suitability as an emergency system.

and because it is less conspicuous than the larger lever switches. A micro light switch is a delicate small lever switch that requires light pressure to activate. It was considered a suitable alternative to the mini lever switch that requires more pressure to activate. Buddy buttons were initially considered suitable, but their size made them less suitable for chin or head access. A small specialised buddy button called the Mini cup was selected as suitable. A mini cup switch is a small disc switch that is activated in the centre of the disc making it suitable for downward central pressure, regarded as an alternative choice for chin access. The selection included a trigger switch, a device that is similar to a mini cup switch, but requires more precise access and offers more resistance than the mini cup. A ribbon switch was excluded on the basis that it was considered aesthetically undesirable based on its size. The pack also included a sound-switch as part of a stand-alone alarm system. Using voice to activate a switch was considered a suitable alternative to switch access in the event of technical failure of the controller or when traditional switch access was not possible. A joystick was considered a desirable option in place of a switch, but was excluded based on cost and lack of suitability for use in bed.[168] In addition the absence of an active select option for navigation limited the function of the joystick offered by the *Keo.* In contrast switch access is more reliable for use while in bed. A radio switch that would enable wireless connection of switches to the *Keo* was excluded based on cost.

Mounts

The selection of mounts was based on the need to identify universal mounts suitable for multiple users as the pack was developed to be used by multiple participants. The wheelchair-mounted, swing-away mount was unsuitable as it was client specific rather than a universal mount. It would have been possible to use a modular mounting system, but this would have required extra time and financial resources. A modular system demands a skilful set-up which required time beyond the scope of the planned trial. The cost of the modular systems was also prohibitive in comparison with the purchase of two single universal mounts.

Two dynamic mounts - the magic arm mount and the Flexi mount - were selected. Mounts were selected to offer flexibility of set-up and stability once set-up. Manufactured by a photographic mounting company, the magic arm mount provided

[168] It would have been challenging to mount a joystick for satisfactory use in bed. This mounting would require repeated setting up each time the participant moves from bed to wheelchair and if their position in bed changes from long sitting to side lying for example.

the greatest flexibility, with a clamp base that could be attached to a bed, wheelchair or table. It comprises a hinged arm on a ball socket base, allowing easy adjustment of the mount for better positioning of the switch or controller. The mount is locked into place using either a knob or a lever lock. Mounting a switch or controller required a suitable mounting plate to be attached to the end of the magic arm mount. The Flexzi mount was identified in Canada as an aesthetically pleasing simple device, with either a Velcro® or a clamp base. The mount is a modular tubing unit that can be bent into place. It is suited for light objects such as the *Keo* as it does not maintain its position if the weight of the mounted object is too great.

Alarm system

The GrEAT required an alarm system to ensure it could provide comfort and security for independent use. Specialised assistive technology intercom systems designed for use with an ECS require wired installation and are costly. It was desirable to include an intercom in the pack but this was beyond the scope of a starter-pack. Commercially available wireless security cameras that could be linked to a participant's television were considered for inclusion, but ultimately excluded owing to the occupational therapist's unfamiliarity with the device and the fact that - they did not offer functional benefit without the inclusion of a door-opening system. A portable personal alarm activated by a sound-switch was selected as a stand-alone inexpensive call system. The switch accessible wireless personal alarm consisted of an adapted wireless doorbell. The alarm unit is portable and can be carried by a caregiver. The wireless button has a switch socket. Any switch can be used to activate the alarm. The sound-switch was selected as a hands-free access method. It was intended for use in bed if switch access was unreliable or in case of equipment failure.

The close monitoring of the anticipated cost of the GrEAT pack influenced some of the selections described above. Desirable items that were excluded due to budget constraints included: *Keo* ECU module, *Keo* IR receiver, Sip and puff switches, mini joystick, small lever switch and a radio switch.

4. Pilot trial

The final development of the GrEAT involved a one person, 3-week pilot trial with the following objectives:

- Assessing the suitability of individual components
- Collaborating with the pilot participant to prioritise and select final constituents of the GrEAT
- Assessing the integration of the components
- Evaluating feasibility of occupational therapist installation of the GrEAT
- Familiarising the occupational therapist researcher with the procedures involved in setting-up the GrEAT such as designing menus for *Keo* and recording IR signals
- Creating audio-visual information sources[169] for participants
- Assessing data recording methods planned for Phase 3
- Observing a person with high SCI using the GrEAT and gaining insight into that *lifeworld* and the impact of the GrEAT.

The pilot trial was a flexible learning process that involved continuous adjustments, aimed at identifying an effective strategy to facilitate one-day installations required for the Phase 3 trials. The pilot participant did not participate in an in-depth interview and thus did not contribute directly to Phase 3. The data collection method was trialled during the pilot to assess the recording quality of the audio and video recordings planned for use in Phase 3.

4.1 Planning the pilot trial

A pilot participant, Owen (pseudonym), was selected from the recruits identified in Phase 1 of the study. He was known to the researcher and had been consulted during the funding application for this project. Owen was selected based primarily on geographic location. He was also not suitable as a trial participant as he anticipated purchasing his own ECS through charity and personal funds and this purchase would coincide with the timing of Phase 3 trials. Owen's geographic location allowed several visits to be made during the pilot trial which allowed for multiple alterations within the trial period. His busy study schedule dictated suitable times for visits and the pilot trial allowed him to trial some equipment prior to the

[169] Booklet and DVD.

purchase of his own ECS. He had not participated in Phase 1 and therefore required an updated participant information leaflet (Appendix 10).[170] He consented to participating in the study and also provided photographic and video consent (see Appendix 20). The three-week pilot trial was scheduled to be completed two months prior to the scheduled Phase 3 trials to allow sufficient time for preparation.

4.2 Preparation for pilot

The components included in the ECS starter-pack for the pilot study are listed in Table 14. A week prior to the scheduled pilot, switches, mounts, the *Keo* and the *Quickphone* were not available,[171] providing a real world experience of encountering delays with acquiring technology. This delay was however averted as the contents for the starter-pack were acquired on loan. [Hospital] supplied switches, mounts and an IR electrical socket set on temporary loan and the ECS distributor supplied a demonstration *Keo*.

The supplier met with the researcher for 3.5 hours to provide *Keo* programming training. This included assisting the researcher to copy the IR codes for the IR phone from an IR remote control into a GEWA *prog.*[172] This would ensure that I could add the relevant IR codes to phone menus in the GrEAT *Keo* at a later stage. I therefore did not need to purchase the remote for the phone. Customised menus were created in the *Keo*, including a start-up page that linked to a television page, a DVD page, a phone page and two buttons for the IR socket (see Appendix 21 *Keo* menus used in the pilot trial). The IR codes for the electrical sockets were recorded on the *Keo.* The other menus were not functional as they excluded IR codes. As it was not possible to locate mounting plates suitable for both the *Keo* and the switches, it was necessary to fabricate temporary mounting plates. This necessitated sourcing suitable bore[173] bolt that was only commercially available in a meter long rod. The bore had to fit the magic arm mounting receiving end. This required cutting the rod manually and hand filing the bolts to remove rough edges. The mounting plates were manufactured from remnant splinting material.

[170] The participants' information leaflet was the same as that used in Phase 1 with the focus group information omitted and dates adjusted from 2007 to 2009.
[171] The switch and mount provider supplier was on sick leave, the *Keo* and *QuickPhone* had been purchased for the pilot but were out of stock.
[172] GEWA *prog* a stand-alone controller but was used in this instance as a recording and storage device for IR codes for the phone. The GEWA *prog* was loaned from the rehabilitation hospital.
[173] Bore – size of the bolt, usually a measure of diameter.

An information booklet was compiled by the researcher. It contained details of the components of the package together with instructions for use and a list of suppliers. This booklet was the first draft of the GrEAT information booklet that was adapted and improved during the pilot trial (see information booklet section 6.2). The final information booklet is available in Appendix 19.

Table 14: Contents of the ECS starter-pack used in the pilot trial

Environmental controller	Switches	Mounts	Communication	Other
• PROTEOR *Keo*	• neck • trigger* • micro lever • mini cup • micro light • sound-switch	• short Velcro® based Flexzi • medium Flexzi clamp based • magic arm	• SICARE *QuickPhone* • wireless personal alarm	• double IR electrical socket • draft information booklet

** not included in the final GrEAT pack.*

4.3 Pilot trial description

Owen, a 37 year old male with a C4 SCI was living in an independent living unit in a charity-owned housing estate for people with physical disabilities. Owen was awaiting an assessment from a [AT service] who would advise on appropriate equipment. His living unit was new, modern and simply furnished. Modern commodities included a large screen computer mounted on a high counter suitable for powered wheelchair access, a flat screen television and a beer tap. It was surprising to discover that he had some access to a television by using the chin control for his powered wheelchair which was possible as his *Quickchair* included an IR ECS feature. This cast some doubt as to his suitability for the pilot as he, unlike those anticipated to participate in the trials, had an ECS pack albeit with only one constituent – a powered wheelchair. This however did not provide access to technology when in bed, nor did it provide telephone access or an alarm feature. Due to Owen's level of physical disability, he required 24-hour care provided by a caregiver who slept in an adjoining room and monitored Owen using a baby monitor. Owen was eager to experience an ECS and share his opinion on the suitability of the pack and its components for both himself and others.

Initial installation

The generic package was discussed in detail using the first draft of the GrEAT information booklet. The rapport was jovial and both the researcher and Owen made light of the technical challenges involved in installing the pack. The package was customised for Owen, who provided informed consent having read through the research information package. The process was observed by a caregiver as Owen was never alone, highlighting his severe physical dependence and reduced personal space. The initial installation focused on selecting a suitable switch and a physical setup for the *Keo* and a switch. Owen trialled four mechanical switches: the mini cup, the micro light, the mini lever and the trigger switch. He was able to access the *Keo* using all the switches except the trigger switch, which required considerable force, rendering reliable access impossible. He favoured the micro light switch as it required the least effort and was highly reliable and comfortable to use. The micro light switch was mounted on the magic arm mount to allow suitable, reliable positioning. Owen and his caregiver expressed some concern about possible switch use in bed as he had a rotating mattress and severe spasms which might prevent predictable bed positioning to facilitate switch access. They both however displayed willingness to attempt to use a switch in bed and to find their own solution that night. A chin switch was discussed as an option but was not available at the start of the trial. Owen had previously considered a speech-driven ECS,[174] but had found it unsatisfactory. The *Keo* was mounted using a second magic arm mount.

The *Keo* and its menus were demonstrated, including activating the IR power sockets, activating a Bluetooth® connection to the researcher's mobile phone and then dialling stored numbers. The *Keo* was paired with Owen's mobile phone via Bluetooth®. This involved adjusting his mobile phone to make itself visible and to allow default pairing with the *Keo* at all times.[175] Owen then selected telephone numbers to assign to the memory numbers M1-M10 on the *Keo* (see phone page and phone book page in Appendix 21). These were stored on the *Keo*. The DVD and television menu[176] were then adjusted by recording IR signals from Owen's own remote controls (television, satellite, and DVD remote controls). This involved aligning the remote control (such as a television remote) and the *Keo*, selecting the programming mode on the *Keo*, selecting the learning function, selecting a button

[174] ECS available in Ireland called Butler, but no high S users were known to the researcher.
[175] This was achieved by adjusting the settings on Owen's mobile phone.
[176] Owen chose to use digital television (SKY) channel up and down instead of television channel up and down on the television menu as he always watched digital television.

on a *Keo* menu, sending an IR signal from the source remote (television remote or similar), and recording that signal into the *Keo*'s memory. Activating the newly trained button on the *Keo* transmitted the learned IR signal, thereby causing the target device to change channel or similar function. This process was repeated for each relevant button on the *Keo* Menu. This laborious process was observed by Owen as an educational and participatory experience. The *Keo* was programmed to control Owen's two televisions and a DVD player in his bedroom. The IR codes for the double electrical socket had been recorded prior to the pilot. Owen used the socket set to control both a lamp and a fan. Owen was able to access the *Keo* using a micro light switch proficiently, thereby allowing for an upgrading of the scanning speed from 1 second, to 0.7 second and then to 0.5 seconds within a 2 hour period. On completion of programming the *Keo*, Owen was able to use the *Keo* via a switch to make phone calls, switch on a lamp and a fan, navigate the television channels, and use his DVD player. He was able to dial numbers on his mobile and use a Bluetooth® ear piece. The sound-switch intended to activate the wireless alarm was trialled as the primary switch for the *Keo* for in-bed use. The standard microphone had been replaced with a noise cancelling computer microphone purchased from a computer store. Owen was able to control the *Keo* with loud vocalisations to activate the sound-switch with the television on and the volume loud. He planned to use the sound-switch that evening from his bed to control the *Keo* and make mobile telephone calls. The use of vocalisations for complex switching was strange and robotic requiring Owen to make a noise each time he wanted the switch activated. It was unlikely that the sound-switch would be a satisfactory switch for all ECS access for a young man. The pilot trial was documented using both photographs and amateur video footage.[177] This documentation was used in the information booklet and a demonstration DVD (discussed below). Owen was not issued with an IR land-line phone or a personal alarm as they were unavailable on the first day. Once the basic installation was completed he was eager to use the pack:

> *I'd better get this thing charged so I can fiddle around with it tonight in bed.*

This enthusiasm after a protracted afternoon of watching the pack being set-up provided encouragement for the continuation of the pilot and the remaining study.

[177] Video footage was recorded using a tripod mounted digital tape video camera

Continued installation

The installation of the pilot pack continued four days later at a time selected by Owen. This delay was unexpected as his study schedule had not been considered when initially planning the pilot. It however highlighted the realities of research participants other commitments that need to be considered in such a study. Owen was pleased with his successful use of the GrEAT for the first four days of the trial. He complained that the battery life was poor, a problem attributed to the use of Bluetooth® pairing with his mobile telephone. He was, however, able to ensure that the *Keo* was always charged as he was able to monitor the battery indicator on the display. He returned one magic arm mount as he had attached the micro light switch to a mount on his powered wheelchair intended for mounting a wheelchair control switch (now integrated into his headrest). Owen reported that he had not needed the sound-switch as he had been able to use a switch mounted on a magic arm while in bed, despite his expectation that this would not be possible. This confirmed expectations that using a sound-switch for all ECS access is not ideal and unlikely to be a preferred method of access. In addition the ability of Owen and his caregivers to successfully use a mount with no expert assistance supported the desire to encourage ownership of the GrEAT through collaborative set-up.

Owen reported that his mobile telephone became disconnected from the *Keo* after 30 minutes, requiring reconnection to access the phone. This was made possible by adding a blue tooth connect icon to the start-up menu (see Figure 10) menu. This icon is unique as it accesses the pairing function in the *Keo* without the need for a user to program this function.

Figure 10: Schematic diagram of the altered *Keo* start-up page with connect to Bluetooth® phone on bottom left button

Television	**DVD**	**Phone**
Socket 1	Socket 2	To Bluetooth menu (obsolete)
Connect BT phone	IR phone page	

The focus of this second visit was the installation of the IR SICARE *QuickPhone* telephone. Unfamiliarity with this item meant that I was unsuccessful in my first attempt to link the telephone to the *Keo*. This cast doubts on the feasibility of its inclusion in the GrEAT. I questioned my technical ability to include a telephone in the pack. In addition I was concerned that the phone had been an exorbitant purchase if it was not possible to include it in the pilot study. The price posed questions of its suitability. The IR codes for the telephone had been obtained from the Irish supplier and had been recorded in a portable IR unit (GEWA *prog*). This portable IR unit was the source of the IR codes that were to be copied into the *Keo* to allow access to the *QuickPhone*. Initially, it was not possible to copy these IR codes into the *Keo,* again questioning the suitability of the phone for inclusion in the pack. The IR codes stored on the GEWA *prog* were recognised by the phone but when copied to the *Keo* the IR signals transmitted from the *Keo* were not registered by the phone. I could not comprehend the reason for this and telephoned the supplier resulting in the successful use of a second method of learning for the *Keo.*[178] This valuable lesson was applied in several instances later during the trials when difficulties were encountered trying to copy IR signals into the *Keo*. Once the *Keo* was programmed, Owen was able to use it to access the hands-free IR telephone. However, poor phone call quality was encountered and the interference was identified as resulting from the internet connection. It was resolved through internet disconnection. One of Owen's primary concerns was his need to reduce his need for constant care which would only be possible through a call system and monitoring system. A monitoring system had not been envisaged in developing the pack. However the *QuickPhone* has the capacity to be activated by an incoming call to provide a listening-in feature. If someone rang the phone and the user was unable to answer the phone, the caller could activate the call remotely using an access code if the *QuickPhone* had been programmed to allow this. Following activation and testing of this feature, Owen regarded it as useful as it allowed him to be alone in his own apartment, while still contactable by a caregiver.[179] His need facilitated the exploration of unknown functions of the phone expanding the scope for its inclusion in the pack. This was an unexpected development. It was possible for Owen to dial the *QuickPhone* from the *Keo* enabling him to make a simple emergency call. The telephone numbers stored in the *Keo* (M1-M2) could be dialled using either the mobile phone or the *QuickPhone*. Dialling using these stored

[178] The *Keo* comes with two learning methods. Method one involves sending an IR signal once while the second method involves sending the signal twice.
[179] Residents of the independent living housing units shared carers thus Owen was required to be alone for periods of time.

numbers was a slow process, however, as the *Keo* sends a single IR signal for each digit of the telephone number, increasing the possibility of incorrect dialling. The supplier had previously advised using the *QuickPhone* memory capacity to record pre-dialled numbers assigned to 5 quick dial buttons. Consequently, the researcher used the phone's own 5 quick-dial buttons to record Owen's priority telephone numbers. Each of these quick dial buttons could be activated with a single IR code. This required constructing a new phone memory page for IR phone pre-dial numbers that was linked to a new key on the main menu. An IR phone page was constructed (see Figure 11) and IR codes for the quick dial numbers were recorded on the *Keo*. Photographs and video of the IR phone were taken to provide material for the information booklet and DVD. Although this required some posing by Owen, the use of small personal cameras made the experience seem less invasive. Owen and his caregiver engaged in humorous interactions during these recordings alleviating an air of stress and facilitating natural expressions. While Owen was identifiable in these recordings and photos effort was made to avoid inclusion of personal items and expansive coverage of his home. Owen was encouraged to view the footage and photos but he declined saying he trusted the researcher and would view the final products when they were completed.

Figure 11: Schematic diagram of IR phone page on pilot trial *Keo*

1	2	3
4	5	
Pick up/ put down phone		**Back**

Follow-up visit

Prior to the third research visit the [AT service] had conducted a home visit, providing Owen with three items to trial – a chin switch, a ROLLTALK[180] and GEWA IR telephone. Owen used the chin switch with the GrEAT, but opted not to use either the telephone or the communication aid. He had no need for the phone as he was able to use the *QuickPhone* supplied in the GrEAT. Owen judged that the

[180] Rolltalk is a communication device with an integrated ECS.

ROLLTALK was bulky and had limited functionality as it had only been set-up to make phone calls and to control the living-room television. The ROLLTALK appeared to offer potential benefits for Owen as it included computer and telephone functionality. However, the failure to set-up all its features and to provide Owen with training on its use contributed to his choice to not use device.

Two Flexzi mounts, a sound-switch and portable personal alarm were obtained from the switch supplier and were issued to Owen. The Magic arm mount with fabricated mounting plate was replaced with a medium size Flexzi mount that was attached to Owen's wheelchair tray and the *Keo* was attached to the Flexzi mount with Velcro®. Owen was satisfied with the clamp, but suggested that a shorter length may have been more suitable. However, he declined the offer of a short Flexzi mount with a Velcro® base as he favoured the clamp because it was more secure, demonstrating his awareness of the need to protect the equipment. Despite successful use of the micro light mounted on a magic arm mount Owen returned both as he favoured using a chinswitch and the Flexzi mount that required less effort to set-up. He used the chin switch while in bed and creatively had the mounting tube taped to his t-shirt each night to prevent the switch from rotating around his neck.

Owen was eager to trial the personal alarm system so he could re-evaluate the necessity of having 24-hour in-house care. He appeared eager to explore an option that may allow him to be in his home alone, an experience that had not been possible since his accident. The sound-switch was replaced (the first one was on loan from the [Hospital] occupational therapy department. This was then attached to the portable cordless alarm). Owen selected the sound of a dog barking from the choice of chimes possible on the alarm. This was considered a humorous choice for all except the caregiver who would be carrying the alarm. Selection of this annoying sound was a way for Owen to exert some authority. The sound-switch was adjusted so that Owen could activate it, but it would not be activated by other loud noises, such as the television. Owen was satisfied with the operating range of the alarm as it could be activated in the carers' office from his housing unit.

Owen reported that the land line was essential for him as he did not use his Bluetooth® headset when in bed, thus preventing independent use of his mobile phone. Owen enjoyed being able to make telephone calls while in bed as he was required to be in bed for several hours more than that required for sleep purposes in

order to preserve his skin.[181] He also considered the listening-in function to be useful, as it allowed him to be alone for short time periods when a caregiver could ring in to listen to him on the phone. A commercial telephone filter was attached to the phone line to allow dual use of the phone line for internet and telephone access without resulting in disturbance on the telephone line.

The *Keo* required a small adjustment as the television channel down function scrolled down 4 channels instead of one. This error was to be repeated several times during the trials. The remote controls that are used with complex digital television navigation screens have sensitive directional controls requiring a light press to navigate in single increments. The supplier had warned of the difficulty of controlling digital television with an ECS and this difficulty became apparent in the pilot study. This erroneous IR was re-recorded to scroll down once only. Although Owen had access to his DVD player and could navigate television channels while in bed, he was unable to select the relevant television channel for the DVD player. The channel up and down buttons on the *Keo* transmitted signals that changed the satellite channel up and down. As Owen could not adjust the television channels, buttons for these were added to the television menu and IR codes were recorded on the *Keo*.

Video footage recorded throughout the pilot trial was edited to compile short videos of Owen using the chin switch to access the *Keo* and control the television, satellite, DVD player, fan and land-line phone. In addition, several photographs of the component parts of the GrEAT pack were taken. The recording equipment intended for data collection during Phase 3 interviews was tested during a mock interview with Owen. While it may have been ideal to conduct an interview using the interview guide planned for the trial this was decided against. He had already provided access to his personal world by facilitating three research visits and had provided valuable feedback during the trial. The content of the mock interview was unrelated to the research, and intended for rehearsal rather than data capture. This allowed rehearsal of the data capture procedures and quality testing of both sound and video recordings.

[181] Owen's busy study schedule required him to spend several hours in his wheelchair posing a potential threat to his skin this was balanced by spending extra hours in bed on a pressure relieving mattress.

Final visit

The final pilot trial visit took place four days later. Owen reported difficulties with the Bluetooth® pairing of his mobile phone and the *Keo*. The issue was resolved by modifying his mobile phone settings.[182] Owen used the *Keo* primarily while in bed to make mobile telephone calls. He expressed an interest in purchasing a new mobile phone and was concerned that any new telephone would need to be compatible with a *Keo.*

Owen and his personal assistant (PA) reported satisfaction with the simplicity and function of the sound-switch and the personal alarm. During this visit Owen was alone for the first time in contrast to all previous encounters when a PA had accompanied Owen. He was able to be alone without a PA as he was using the sound-switch and the personal alarm. He was able to activate the sound-switch which would in turn activate the alarm carried by a PA in another housing unit. The PA then called Owen's land line and activated the listening-in function which operated as a monitor, thus negating the need for a PA to be in the house at all times and allowing a quick telephone call access the alarm activated by Owen. While his quiet demeanour understated his enjoyment of his ability to be alone it was a new and unusual experience for a person with a high SCI already highlighted in the preceding focus groups.

Owen was able to view the edited instructional videos intended to be used as demonstration tools for the GrEAT pack. He received personal copies of the videos. He then provided informed consent to allow public internet access for all five of the videos. He also approved the updated second draft booklet containing the new photographs. The final photographs of the GrEAT set-up in use when Owen was in bed required for the booklet were captured during this visit. Taking these photos were postponed until the end of the trial as they were considered the most invasive and better suited to the end of the trial once a trusting rapport was well established and both parties felt comfortable with photographs being taken with Owen in bed.

The trial ended after three weeks. Owen asked to keep the GrEAT for a further 4 weeks for personal use, while he planned to order his own ECS. This request was testament to his need for an ECS reaffirming the value of the trial for Owen and its

[182] The issue was resolved by changing Owen's phone settings from 'show phone' to 'hide phone' and then back to show phone'.

success as a research intervention. The supplier was informed that Owen would like to keep the *Keo*. In addition, Owen asked to be taught how to add pages and functions to the *Keo,* requiring a further visit beyond the scope of the pilot study. This extra visit highlighted the flexibility of the pack to be upgraded and confidence in adjusting the *Keo*. During this visit, the researcher demonstrated how to create an extra page that Owen used to control extra satellite television functions and confirmed the expectation that collaboration would facilitate a sense of personal ownership of the technology for the participant. While this may not be true of future participants it was a hoped for possibility.

4.4 Researcher clinician role

Owen reported frustration with [AT service] due to long waiting times for assessment, re assessment and recommendations.[183] The [AT service] had facilitated the ECS functionality of the powered wheelchair, which was programmed by the wheelchair supplier, providing him with a satisfactory level of control of television channels. He did not agree, however, with their preliminary recommendation to use a ROLLTALK as an ECS as it was both large and complex and better suited to its primary function as an AAC[184] device. Owen preferred a smaller, simpler, stand-alone ECS controller. He consequently expressed a preference for my assistance as an alternative to the [AT service]. I clarified my role and explained to Owen that I was unable to provide an assessment, advice, or recommendation for ECS, though I could provide information on his participation in the trial and his reported preferences based on the trial. I furnished Owen with reports which were also sent to [AT service].

4.5 Findings from the pilot trial

With Owen's collaboration, the pilot trial fulfilled its objectives of integrating appropriate individual components. It also demonstrated that the GrEAT pack could be successfully installed by an occupational therapist. The GrEAT was observed to have impacted on Owen's *lifeworld.* He was able to spend less time with a caregiver and reported an appreciation of this change. Using the GrEAT offered him access to activities like making phone calls, watching DVD and capacity to choose. The pilot trial provided an opportunity for the researcher to become familiar with the individual components and their set-up. Both an instruction booklet and a demonstration DVD

[183] His initial assessment occurred in September 2008 and in March 2009 he was waiting for final recommendations (6 months later).
[184] AAC – augmentative and alternative communication.

were compiled during the pilot trial and approved by Owen. The data-recording methods planned for later trials were tested and found to be satisfactory.

The installation process was time consuming and technically challenging at times. Maintaining a collaborative approach was demanding when technical issues were encountered and Owen became a little disinterested. The collaborative approach was however maintained, aimed at empowering Owen to have a comprehension of the technical aspects and options within the GrEAT. He exhibited some ownership by requesting further instruction on completion of the trial. Frustration during installation was heightened by time constraints imposed by the busy schedules of both parties. Time management presented itself as a concern for Phase 3. Technical issues may lead to incomplete installations based on time constraints. The trial occurred in the participant's home, that I found to be an unfamiliar environment for a hospital-based researcher. This environment appeared ideal for a phenomenological investigation.

In addition to fulfilling stated objectives the pilot trial provided valuable information for the development of the final GrEAT pack and phase 3 of the study. A number of specific decisions were made relating to the contents of the pack as a consequence of the pilot process. These findings and decisions are detailed in Table 15 overleaf.

4.6 Pilot study limitations

The primary limitation of the pilot trial was a single-person, non-specialist installation by an occupational therapist. A team approach may have been more satisfactory and efficient. This was, however, essential in order to determine the feasibility of a similar single-person multi-participant trial planned for Phase 3. If the research design had included expert installation of the pack, the researcher could have assumed a more objective role which was not possible within the limited available resources.

The GrEAT pack was installed by an occupational therapist and not by an ECS expert or engineer and therefore it is not known if installation by a professional would have been more satisfactory for users.

Table 15: Pilot trial findings and corresponding decisions for the GrEAT

Findings from the pilot trial	Decisions based on the findings of the pilot trial
1) A chin switch is suitable and does not require a mount	1) Chin switch to remain in the GrEAT
2) The trigger switch was not suitable for chin access	2) Trigger switch removed from the GrEAT
3) A clamp base mount is likely to be more stable than a Velcro® base	3) Medium size clamp-base Flexzi mount to be included in the GrEAT
4) Switch access in bed is possible using magic arm mounts	4) Magic arm mounts included in the GrEAT to provide flexible mounting options including in bed switch access
5) Magic arm mounts with a lever locking action are more obtrusive than knob locking action	5) Knob-locking action magic mounts to be included in the GrEAT
6) Proficiency of scanning can develop rapidly	6) Scanning speed may be adjusted as proficiency improves during initial set up or after a few days
7) An IR land-line phone is required for in bed phone access	7) IR land line phone to be included
8) A listening function is a valuable feature of the *QuickPhone*	8) The *QuickPhone* to be included in the GrEAT
9) Telephone line interference is likely if the phone lines provide internet access	9) A telephone line filter was included in the occupational therapist's toolbox to combat telephone line noise
10) Mobile phone access is required to provide a satisfactory communication function	10) Bluetooth® function of the *Keo* is a required feature for mobile phone integration in the GrEAT (confirming choice of *Keo* vs. POSSUM *Primo*). Mobile phone to be added to the GrEAT to ensure compatibility
11) A Personal alarm and sound-switch worked as a stand-alone call system	11) Personal alarm and sound-switch to be included
12) IR codes require on-site testing during set-up to ensure accurate function	12) Set-up the GrEAT must include testing of every recorded IR
13) There are two suitable IR recording methods in the *Keo,* the second longer method is required for recording phone IRs	13) Second method of IR recording to be used when necessary
14) A novice *Keo* user may require information to make adjustments to the *Keo* once they have gained some proficiency	14) Demonstrate how to add features to the *Keo* during the set-up of the GrEAT
15) The Flexzi mount and the magic arm mount were unobtrusive and easy to attach, negating the possible need for a stand-alone mount for the *Keo* such as a microphone stand[185]	15) Microphone stand removed from GrEAT
16) Researcher role confusion for research participants is possible	16) Researcher role needs to be made clear during trials

[185] The supplier failed to provide a microphone stand intended to be used in the pilot trial.

As a research trial, the pack was supplied and customised to function in Owen's home. A clinical assessment was not included in the study. This does not reflect normal clinical practice and the trial cannot therefore be considered as an evaluation of a standard occupational therapy intervention. The findings relate instead to a research scenario that involved providing a generic pack and asking the pilot participant to use all the constituents instead of offering him a choice of only using his preferred components. The assessment process involved assessing if the GrEAT pack could be used successfully by Owen. This process may however be similar to resource poor clinical situations that can offer limited interventions. In such situations the assessment process may involve making the most of the limited resources through customisations similar to those used in this trial.

The pilot trial differed in format from the process planned for Phase 3. Owen was not offered free choice of which components of the GrEAT he wished to use as the trial was functionally focused and Owen was therefore expected to trial all components, provide feedback on each of these and facilitate photographic and video recordings. If Owen had participated in Phase 3 trials he may have chosen not to use some elements of the pack. He did however find all the components useful suggesting he may have benefited from the lack of choice. Alternatively all components were useful for him with clinical guidance and the prescriptive approach was beneficial as it fostered experience of the entire pack.

The pack itself was also limited by availability and cost. It would have been preferable to have trialled a second controller such as the POSSUM *primo* alongside the *Keo* to allow a more impartial decision on which controller to include in the pack. The decision to use a *Keo* was biased by clinical experience and supplier support. In an ideal situation, support from both suppliers would have been preferable. The choice to include a *Keo* rather than a *Primo* was, however, supported by the integration with a mobile phone, considered by the pilot participant to be an important feature. If funds had been available, the pack may have included more components and, provided a broader range of options. For example, the inclusion of an ECU module and an IR mouse receiver would have allowed integration with powered wheelchair and computer. A mini joystick would have also been a useful addition, enabling easier access other than by scanning.

The pilot study failed to trial the inclusion of the *Senior pilot* as a back-up controller. In addition the video camera intended for use as a diary camera was not included in the pilot study. The usefulness of including both the *Senior pilot* and the video camera in the final pack were not assessed during the pilot trial and their inclusion may be questioned.

Owen had previous experience of ECS and scanning. He had been introduced to, and had trialled an ECS during his rehabilitation and using his powered wheelchair to access his television had provided further experience. His experience cannot therefore be compared to the experience of someone with no previous exposure to ECS. Definitive conclusions about the feasibility of successfully installing the GrEAT for someone with little or no experience cannot be made based on this single pilot trial.

5. Compiling the GrEAT

The contents were selected based on the information search and the pilot trial as described above. Contents included in the final pack are listed in Table 11. A few minor changes were made to the GrEAT pack used in the pilot study in compiling the final GrEAT (Table 14). The trigger switch was excluded as it was not suitable for chin access. A second controller, the SICARE *Senior pilot,* was added as it was not possible to provide back-up support for all participants to the same level as that provided during the pilot trial.[186] The researcher planned to programme a *Senior pilot* with priority functions for each participant so that if the *Keo* failed the participant would be able to use the SICARE *Senior pilot* as a downgraded substitute. A mobile phone and Bluetooth® head set were included in the pack to ensure compatibility with the *Keo*. A video camera with IR control was added to the pack to provide the option of a diary camera for participants to record their thoughts. The final pack included a demonstration DVD and the final information booklet written edited and compiled by the researcher (see below).

5.1 Purchase of contents

Following the pilot trial, the remaining components were purchased to comprise two full GrEAT packs. The *Senior pilot*s were purchased directly from the manufacturer and the switches, Flexzi mounts and mounting plates were purchased from a

[186] Support offered through video conferencing such as Skype was considered but not included as it required computer and internet access for participants that could not be supplied within the scope of the study.

company in the United Kingdom who were the primary suppliers to all specialist ECS suppliers. The IR sockets, magic arm mounts and a sound-switch[187] were borrowed from [hospital] for the trials. A second *Keo* and IR telephone were purchased from an Irish supplier to ensure technical support was provided. The use of a variety of suppliers was a cost saving effort. Sourcing suitable compatible mobile phones was challenging and involved several visits to mobile phone providers to test compatibility and source the cheapest phones available from the two primary mobile phone networks in Ireland.[188] This posed an unexpected challenge as compatible phones were more expensive than anticipated.[189]

5.2 Information booklet

The starter-pack was intended to be easy to use and to require little or no support following initial installation. A comprehensive information booklet was provided to facilitate self-directed use by participants. The booklet was designed and assembled by the researcher prior to and during the pilot trial with Owen's assistance (Appendix 19). The booklet included an extensive step-by-step description of how the components could be set-up and how the ECS, including scanning and making telephone calls, worked. Photographs of the component parts and Owen using the GrEAT were taken on a digital camera throughout the pilot trial. The book was compiled in stages and with Owen's collaboration. He was given a draft copy of the booklet on day 1 of the trial and approved further drafts and the final copy of the booklet which included photographs of himself.

The booklet was divided into five sections:

1) Contents : a list of all pack components with photographs
2) Basic information – how to use it: provided step by step instruction for all the components.
3) Adjustments, what next: described possible further uses of the pack and detailed possible ways to adapt the pack contents.
4) Resources: provided technical details of the components, suppliers and useful websites.
5) Technical manual: included copies of the technical manufacturer manuals for the environmental control unit, IR phone, portable alarm, the magic arm mount and the mobile telephone.

[187] The sound-switch was loaned as the supplier was unable to supply a second sound-switch.
[188] O2 and Vodafone.
[189] I sought a mobile telephone for €50 and had to purchase one for €130 to ensure compatibility.

The booklet was colour printed in A5 size and presented in an A5 ring binder. Booklets were not re-used and each participant was issued with their own copy.

5.3 DVD

A demonstration DVD was recorded, edited and compiled for inclusion in the GrEAT pack. Each participant was issued with a personal copy. The video was captured and edited by the researcher using a MiniDV video camera mounted on a tripod. The raw video was downloaded from the digital video tape to a computer hard drive. The footage was edited into five simple clips using a commercially available video editing package. Recording and editing videos was a time consuming process. The short clips illustrated the pilot participant using the GrEAT pack. The first video (ninety seconds) was entitled *Basic ECS* and highlighted the mounting system, the ECS controller, the use of a mounted switch, a mobile phone and an IR socket to switch on a fan and light. The second, (two minutes) was entitled *ECS, television, satellite and DVD* and focused on the use of the ECS to control a television in two different rooms. In this video, the pilot participant used a chin switch to demonstrate surfing[190] of television channels on both terrestrial and satellite television. He also demonstrated the ability to control an external DVD player. The third (one-minute) video was entitled *Infrared Telephone* and demonstrated the ECS being used to dial and receive telephone calls on an IR telephone. A fourth video (I min, 40 seconds) entitled *Environment Control System Control of a Bluetooth® Mobile Phone* demonstrated the dialling of a mobile phone using the environmental control. The final video clip (40 seconds), *Sound operated switch and portable alarm,* demonstrated the use of a pilot participant's voice to activate a stand-alone portable alarm. The pilot participant provided consent to have these videos available on the internet (Appendix 20).[191] These videos were uploaded to YouTube and were available at the time of writing.

6. Summary of Phase 2

Phase 2 involved developing an ECS starter-pack, the GrEAT. This involved identifying the requirements and possibilities for the pack, selecting suitable components and testing these in a pilot trial. The pilot trial facilitated the finalising of

[190] Surfing – navigating through television channels.
[191] Videos are available at http://www.youtube.com/user/MicheleOT#p/u/3/b-57rMjAaE8 and http://www.youtube.com/user/MicheleOT#p/u/4/QmS31-02vkY and http://www.youtube.com/watch?v=Cjx7PwNqqk8 and http://www.youtube.com/user/MicheleOT#p/u/6/RWYUq2ikOlY and http://www.youtube.com/user/MicheleOT#p/u/7/hhAKfKPO4MA

the GrEAT pack to be used in Phase 3. During the 3-week trial period the contents of the final GrEAT pack was determined collaboratively in line with Owen's experiences and preferences. The final pack included an information and instruction folder, 2 ECS controllers, 4 switches, 2 mounts, 2 phones and spare batteries. The installation procedure was also improved during the pilot period through increased checks on function and the provision of different mounting options which allowed Owen time to learn and to increase his scanning speed. Owen trialled a variety of switches and favoured a chin switch, rather than mounted switches for in-bed use. This switch also became the preferred switch for in-wheelchair use. Owen valued having both a landline and a mobile phone. A stand-alone back-up system consisting of a sound-switch and a voice-activated wireless personal alarm was provided for use in the case of technical failure. A telephone listening-in function was activated which allowed a family member or carer to ring the phone and therefore functioned as a sound monitor to assess the situation from a distance. During the 3-week pilot period, Owen was videoed and photographed in order to provide a record of potential uses which were included in an information folder and DVD for trial users. The pilot study assessed the feasibility of the trial GrEAT pack for further evaluation in a larger subsequent trial.

7. The phenomenological perspective in Phase 2

A phenomenological attitude was maintained throughout Phase 2. Although this chapter is largely descriptive and procedural, the research experience also involved a brief glimpse into the pilot participant's lifeworld and to a lesser degree the lives of the home visit informants. This phase reaffirmed the suitability of the phenomenological choice of methodology. In home visits my enquiries about ECS facilitated a sharing of daily lived experiences and provided a bridge into the *lifeworld* of ECS users.

The three-week pilot study involved several visits of a few hours each which allowed an introduction to the double hermeneutic considered integral in IPA (Smith, et al., 2009) as the researcher I observed him making sense of the experience and I in turn sought to make sense of his sense making. While an in-depth phenomenological investigation was beyond the scope of the pilot trial, Phase 2 was however conducted through a phenomenological lens. Owen's *lifeworld* included elements of physical dependence, vulnerability, and reliance on television as an activity and insights into life with a high SCI were unavoidable. His reliance on

others was unavoidable despite his apparent comfort in asking for his needs to be met. It was apparent that Owen's temporality was affected by his injury. Research visits had to be scheduled to occur in the afternoon to allow for his complex morning care routines. In addition days that Owen attended college were not suitable as he was forced to return to bed early in an effort to prevent pressure ulcers. His body dictated actions demonstrating an embodiment of lived experience that cannot be truly accessed.

8. Reflexive comments

On writing this Chapter 8

Writing this chapter was challenging as it required creating an accurate and replicable description of a tedious and complex process. The process was instinctive and similar to standard therapy intervention making it hard to record all my actions. The phenomenological lens that I adopted for the entire study also implies a level of interpretation of this methodical stage beyond the mere procedures that can be described in a step wise fashion. I found myself asking "why is this so hard to write, it should be simple" leading me to realise that Phase 2 was in fact not simple.

The GrEAT

The pack was given the name GrEAT (generic electronic assistive technology) in the early stages of this study. At the time I was confused by the array of terminology and had decided that I was going to use EAT throughout the study. Following extensive reading and debating with supervisors I then identified that ECS was in fact the most accurate term to be used in the study. I however retained the pack name despite some concerns that it should reflect the ECS focus:

> *Is the name GrEAT misleading? Should it be more about ECS rather than electronic assistive technology? The term was selected initially when I was not sure where the research would lead within the EAT field with options to include computers and phones. I have stuck with this because it is catchy but am I misleading people? (Reflexive diary IV, p. 6, 10-10-08).*

Initially I hoped to develop a new and exciting ECS starter-pack that challenged the status quo and that better reflected peoples' desires:

> *I am being constantly challenged in my thoughts about technology. My options are to follow the path that's easy, reliable and not progressive, or take a risk and step into the future but possibly jeopardise my research. I feel that technology is*

> *improving all the time and becoming more common place in everyday society and this should be reflected in the study. I am not an engineer or a computer scientist, so I am not sure if my expectations of technology are accurate, but I think it should be possible to use mainstream technology in a ECS pack without relying on the tried and tested AT ones that have dominated the markets for 15 years. I would hope to provide something progressive but fear it will not be possible or reliable (Reflexive diary IV, p.17, 24-10-08).*

Unfortunately I had to revert to a pack reflective of the practice at the time and I was also constrained by finances. If I had had more funding:

> *I may have explored other elements for the pack such as using a computer based ECS that integrated commercially available voice activated software with a USB IR transmitter, X-10 integrated with IR, speech-driven SICARE Pilot , and door controllers (Reflexive diary IV, p.33-34, 12-12-08).*

The individual components were expensive and I was concerned that the quality of the pack was going to be reflective of funding constraints:

> *Is money going to stop me? One controller may cost €1800 leaving no budget for anything else. Compared to commercial installation I am not charging for my time – and that appears to be a considerable expense for most ECS installations (Reflective diary IV, p.25, 21-11-08).*

This made me realise the reality of the cost of ECS which at least partly explains why they are not easily provided. In addition it made me realise that the time I was planning to invest in installing the GrEAT was also of financial value making me consider the possible future restrictions for the installation of such packs which would require time provided by occupational therapists in the HSE. Employers will need to agree to allow occupational therapists the time required for such installations.

The choice of which controller to include was a long process that began clinically. I noted how a client in the hospital immediately selected the Keo over the GEWA prog on 21-10-08 in my reflective diary. Then on the 14-11-08 I met a UK based POSSUM salesman at a conference that led me to consider the primo unsuitable:

> *meeting the possum rep was good but scary. Their systems are expensive and seem to require an engineer for installation and a service contract for maintenance. Do I pursue this as an option or do I favour a simple manageable product. At this point POSSUM is not the best product for my pack. (Reflective diary IV, p.20, 14-11-08).*

I considered trialling both the Keo and the POSSUM primo during the pilot. This was not possible because I could not source a primo to loan and I was unable to travel to UK to learn how to programme it. If I had managed to include both controllers I would have been confused and the trial may have been unsuccessful due to my own technical inefficiencies.

Installing and Customising the GrEAT

I purposely conducted the entire Phase 2 myself to assess the feasibility of an occupational therapist developing and installing a ECS pack by collaborating with the user whom I feel is the one who best understands how to set-up a ECS. I wanted to challenge the association of ECS with experts:

> *I am challenging the perceptions of expertise in ECS. The client is the expert and clinicians need to facilitate the clients' decisions (Reflexive diary IV, p.43, 8-01-09).*

I am however concerned about how realistic my assumptions are:

> *I need to be cautious with my recommendations. My assumption for the GrEAT is that a technically unskilled occupational therapist can install the pack based on my success, but am I truly unskilled? I have dabbled with ECS and other technologies both assistive and mainstream for years. On the other hand is this perhaps a realistic expectation for occupational therapists that they be able to install a simple pack as part of rehabilitation especially in high SCI rehabilitation. (Reflexive diary IV, p.36, 17-12-08).*

Despite my intentions to be able to do Phase 2 alone I needed help. On reflection I am not comfortable *with my reliance on one single supplier. I felt that I had no other option at the time and without the supplier I would have not been able to complete the pilot trial as I did not identify other support to facilitate my project. I encountered negative feedback from both home visit clients and the pilot participant in connection with the supplier who appears to have a sizable stake in the market. This negative feedback echoed sentiments revealed in focus groups of dissatisfaction with suppliers. This concern about suppliers complaints re-affirms my decision to develop a generic pack that I install thus providing a similar experience for all participants that is not dependent on an external supplier. Clinically I remain concerned about the dissatisfaction with the supply of ECS in Ireland.*

I intended to seek support from the [AT service] for this project but I failed to pursue this actively. I had encountered their service as an occupational therapist which left me frustrated with long waiting times for client assessments that seldom offered new insights to hospital based assessments other than alternative product recommendations. I perceived their recommendations to not consider everyday financial constraints, unlike my planned project

which has a tight budget. The [AT service] was re-organised during this study and had been merged with another department. This limited their availability to offer specific ECS assistance. On reflection I thought that they were experts in the complex assistive technology recommendations and that I was seeking to develop a simple starter-pack that was too simple for the scope of their practice. In hindsight I may have benefited if I had actively sought their input and support for the pilot project and the research trials.

The pilot trial

Initially I was anxious that Owen may not have embraced the GrEAT because it required switch use with scanning in contrast to access integrated with his wheelchair chin control (which he was accustomed to). However he clearly expressed a need for its use in bed and he also required phone access and actively engaged in the use of the GrEAT.

> *Every time I visit Owen he requests some small change to the Keo such as adding a function. This demonstrates that it is a versatile object. In addition my skill is improving through his demand. This has been a very intense two weeks (Reflective diary V, p. 8, 12-3-09).*

His overall reaction to the GrEAT was slightly subdued as he had realistic expectations for the GrEAT having been exposed to ECS both in rehabilitation and in community living. On completion of the pilot I commented:

> *I am very glad. The pilot has been very useful, very time consuming but contributes well to the next stage (Reflective diary V, p. 7, 3-3-09).*

Chapter 9: Phase 3 procedures

1. Overview

This study aimed to explore the experiences of living with an ECS. Phase 1 explored general perceptions of ECS users and non-users. Findings from this phase indicated a need for an in-depth exploration of the experience. Individual interviews were selected as the most appropriate approach. As the provision of ECS for people with spinal cord injuries in Ireland is poor, this study included the provision of a starter-pack to participants who were suitable informants. A generic ECS starter-pack of an ECS was developed in Phase 2. Following a pilot trial with one participant, the starter-pack was used with 6 participants. After completion of each trial, one in-depth semi-structured interview was conducted with each participant. This chapter describes all the elements involved in Phase 3: participant selection, the trial schedule, the research procedures, and data analysis using IPA. The research procedures are detailed including preparation, execution and termination of the trials as well as data collection.

2. Participants

Sample sizes for IPA studies are unconventionally small due to the in-depth focus on the experience of a homogenous group. Sample sizes of four to ten are usual (Smith, et al., 2009). This study aimed to recruit six participants. The possibility of technical error or non-use was also considered, and it was important to ensure that a minimum of four people would participate in final interviews following the 8-week intervention period.

Participants were recruited as described in Chapter 6. Participants identified in Phase 1 were also eligible for inclusion in Phase 3 (n=27). Fourteen of those we were deemed unsuitable for Phase 3 as they were ECS users, had unintelligible speech,[192] had died or had participated in the pilot trial in Phase 2 (Table 16). The remaining 13 persons were telephoned, reminded of the research project and invited to participate in Phase 3. Seven of those were also excluded leaving a sample of 6 participants (Table 16). Two people were excluded due to geographical isolation and the associated difficulty involved in traveling to their homes. Three

[192] The persons speech was difficult to understand on the phone and thus not suitable for transcription.

participants lived within 57 km and the remaining three lived between 205 and 283 km of the research base.

Table 16: Selection of participants for Phase 3 showing considered sample and selected sample

Initial criteria for exclusion from Phase 1			**Final criteria for exclusion from Phase 1**	
ECS user	9		Not contactable	1
Previous ECS user	2		Not available for trials	3
Pilot participant	1		Awaiting own ECS	1
Deceased	1		Geographic isolation[193]	2
Speech considered unintelligible	1		**Total**	**7**
Total	**14**		**Invited to participate in Phase 3**	**13**
Original sample identified in Phase 1	**27**		**Selected for Phase 3l**	**6**
Considered for Phase 3	**13**			

The final sample of six included two who had not been physically able to participate in Phase 1 focus groups. The remaining four had participated in Phase 1 as ECS non-users. All but one had sustained traumatic spinal cord injuries.[194] Each participant selected a pseudonym which was used throughout the study. Details of the six participants can be found in Table 17 overleaf.

All participants provided informed consent and were posted the Patient Information leaflet and Consent Form Appendix 10.

[193] As the trial required researcher installation, geographical location was considered important in determining the feasibility of travelling and setting up concurrent trials in relatively close proximity to each other.
[194] The non-traumatic injury was due to a spinal arteriovenous malformation, a congenital defect of the circulatory system that results in structural abnormalities causing decreased perfusion of the spinal cord and resulting paralysis.

Table 17: Phase 3 participant demographic details and participation in focus groups and trials

Pseudonym	Gender	Age (yrs) [195]	Injury Level	Years since discharge*	ECS	Living	Participation in focus groups and ECS trial				
							FG 1	FG 2	FG 3	FG 4	Trial
Emily	f	29	C3/4	3	no	with parents	*		*		*
Peter	m	22	C3/4	3	no	nursing home	*				*
James	m	28	C4/5	8	no	with parents	*				*
Mathew	m	36	C4/5	9	no	with parents			*		*
Patrick	m	65	C4	19	no	with wife					*
Bridget	f	55	C5/C6[196]	35	no[197]	with partner					*

[195] Phase 1 focus groups took place in September 2007 and Phase 3 trials occurred between May 2009 and January 2010 thus accounting for the discrepancy between Table 17 and Table 8 in Chapter 6.
[196] Despite C5/6 neurological level of injury that would indicate possible tenodesis, Bridget was unable to feed herself and her tenodesis grasp was non-functional.
[197] No environmental control systems at the start of the trial, did receive her own POSSUM Primo during the trial.

3. Trial schedule

Six trials were conducted between May 2009 and January 2010. Components were purchased, prepared and assembled to make up two complete GrEAT packs. Two trials ran consecutively but staggered slightly to facilitate installations and travel to participants' homes, Table 18. Each trial commenced with a 1 to 2 day installation period in the home of each participant. The GrEAT pack was installed and left with participants for an eight to ten week trial period. On completion of each trial the pack was removed and the participant interviewed. Packs were then reused for subsequent trials

Table 18: Schedule of Phase 1 trials

Month	Pack 1	Pack 2
May	Trial 1 – started 20-5-09	Trial 2 began 22-05-09
July	Trial 1 end 16-7-09 (8 weeks)	Trial 2 end 28-07-09 (9 weeks)
	Trial 3 start 30-07-09	
August		Trial 4 Began 6-8-09
September	Trial 3 end 21-09-09	
	Trial 5 begin 30-9-09	
October		Trial 4 end 8-10-09 (10 weeks)
November		Trial 6 Began 19-11-09
December	Trial 5 end 8-12-09 (9 weeks)	
January		Trial 6 end 21-1-10 (9 weeks

4. Phase 3 procedures

This section describes the preparation of each participant for the trials, installation and customisations of the GrEAT. An expanded description of the intervention for one participant, James, is included in Appendix 22. James installation is judged to be a good representation of the process experienced by each participant.

4.1 Preparation for trials

The logistics of each trial was initially discussed by telephone with each participant. Each trial began on a day and at a time that suited the participant and was logistically feasible taking travel arrangements into account. Prior to each visit the contents of the GrEAT pack was prepared, checked, cleaned, replaced if necessary

and the ECS controller was charged. Disposable batteries were replaced prior to each installation. The instructional information booklets were assembled as per description in Chapter 8 (Appendix 19). A demonstration video was burned to DVD as per description in Chapter 8. The IR codes of the land line telephone and the IR electrical socket were recorded and stored in both *Keo*'s memories.

4.2 Installation and customisation for each participant

A visit to each participant's home took place mid-morning to accommodate personal care routines. I installed and customised each GrEAT pack unaided. Installations took between three and seven hours to complete over one or two visits. The second visit was required for a variety of reasons. I encountered technical difficulties with a landline telephone in the first trial and returned to the participant's house when the issue was resolved while another participant's setup was too complex to complete in a single day. One participant's circumstances changed and he required a second visit midway through his trial to include newly installed digital television programming and a landline telephone.[198] Throughout the installations I adopted a collaborative approach which involved participants as much as possible, in order to increase the participants' sense of ownership. I also hoped that participants would understand the pack and feel empowered to make their own adjustments as desired during the trial.

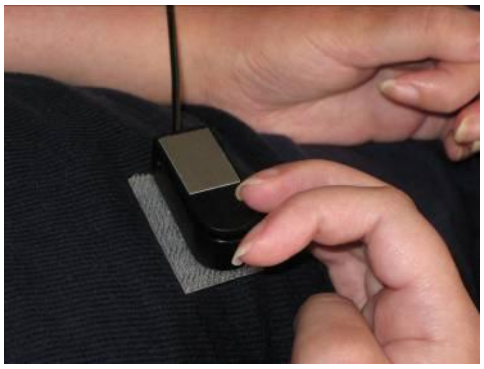
Each installation, with one exception,[199] began with watching a demonstration DVD developed during the pilot project. The DVD consisted of five short video clips. The video was intended to prompt discussion on how each individual participant envisaged using the GrEAT pack. Participants were also supplied with the GrEAT information booklet to further aid the discussion (Appendix 19). The booklet was presented in a small ring binder and was introduced as an aid to support the use of the pack throughout the eight-week trial period (and possibly thereafter).

Participants were offered four switches and two mounts (see Chapter 8 Table 11). Switch and mounting selections were facilitated through participants trialling their choice of switches to access the *Keo*. Participants chose one or two[200] of the four switches and one or two of the mounts but were able to keep all four switches and

[198] His apartment did not have a landline installed at the time of the initial installation.
[199] Bridget chose not to watch the DVD and was more interested in seeing the actual pieces of equipment set up and demonstrated in her own home.
[200] Two different switches were required by some for use in bed and use in the wheelchair.

both mounts for the trial if desired. Some participants[201] chose to keep more than one switch and or mount to use at leisure during the 8-week trial. Participants were encouraged to mount the *Keo* on either a magic arm mount or on a Flexzi mount. While all participants kept at least one of these mounts it became apparent that Matthew, Emily and Bridget preferred not to use a mount for the *Keo* as they favoured placing it loosely on their laps or on a wheelchair tray.[202] Although some participants kept a magic mount initially, these were not used by any participant during the trial as the Flexzi mount was the preferred, easier to use option. Similarly, although mounts were intended to be used to position switches and thus ensure participants were able to access them reliably no one used a mount in this way. Bridget chose to use a micro lever switch that she placed loosely on her lap and tapped with her fist. Emily chose to use a micro light switch which she secured to her clothes using Velcro®. She was able to press the micro light switch using a small preserved idiosyncratic movement in her index and middle fingers (see Figure 12).[203] In addition, a mount was not required with a chin switch which was itself mounted on a tube placed around the neck. The chin switch, the most popular switch was used by four of the six participants (James, Peter, Patrick, and Matthew) and was also the preferred switch choice for Owen, the pilot participant. James used two switches: a mini cup switch that was mounted on the chin control of his powered wheelchair as well as a chin switch which he used while in bed.

Figure 12: Emily using her index and middle finger with a micro light switch



[201] James kept a magic arm mount and a mini lever switch to trial for bed use. Matthew kept an extra mount and switch for use when in bed.
[202] The use of a mount for the *Keo* was advised as it ensured the *Keo* would not be damaged and it also placed the screen in a visible position making it easier to use. However, the collaborative approach led me as a researcher to abandon my traditionally prescriptive stance of insisting on the use of a mount for the *Keo* and allow them to choose to use it un-mounted. I did insist on their retaining a mount so that during the trial so that they could use it if needed
[203] Emily had no gross upper limb movement but was able to flex the distal interphalangeal joints of her first two fingers.

Each participant identified the particular tasks they wanted to be able to do using the GrEAT. These tasks included making telephone calls, turning on a lamp and/or fan, watching television, watching DVDs, navigating digital television, listening to music and calling for help. Table 19 overleaf summarises individual participants' choice of devices, switches, and mounts. The sub-components for each desired task were then analysed in order to identify the exact functions required on the ECS. Sub component tasks included turning television volumes up and down, changing channels and recording, pausing and using playback television features.

4.3 Setting up the *Keo*

The *Keo* was programmed and customised for each participant. This involved planning a person specific menu for each participant. The *Keo* can be programmed to have a 3x3 or a 5x4 configuration. This means the dynamic screen offers either nine or twenty options at one time. The 3x3 configuration was selected for the trials in order to make the *Keo* simpler to use. Possible menu structures for the *Keo* were planned in collaboration with each participant on paper. Several possible 3x3 menus were designed to include all the desired features and buttons arranged to suit the individual. These plans included links between menus. Once the content of the menus were agreed they were created on the *Keo*. The participants selected suitable icons[204] for each button from a library stored on the device. This dynamic planning and constructing process involved some re-organisation and expansion of the initial plans. This process is described in detail for James in Appendix 22. Each pack was used by three participants and thus the menus were redesigned for each participant and each *Keo* was programmed three times.

Individual choices are detailed in Table 19. All participants chose to control at least one television. Some wanted to access either one or both telephones. The desired control of the television varied from simple volume up/volume down channel up/ channel down to complicated management of satellite digital programming including recording programs and watching pre-recorded programmes and even pausing television while watching. This meant that some participants were able to pre-program their television. The complexity of set-up of the *Keo* menus ranged from one single menu for Patrick to twelve menus for James.

[204] Icon – a digital symbol.

Table 19: Details of individual GrEAT customisations detailing switch, mounting, and device choices

Participant	***Keo* Mount**	**Switch Choice**	**Switch Position/Clamp**	**Devices Controlled**								
				Television	**Digital television**	**DVD player**	**Telephone**	**Mobile phone**	**Radio**	**Fan**	**Lamp**	**Wireless alarm**
Matthew	lap/ beanbag tray	chin	under collar of golf shirt	*	*		*	*	*	*		
Emily	lap	micro light	Velcro® to clothes, thumb activation	*	*	*		*			*	
James	flexzi mount	mini cup & chin (bed)	on wheelchair chin control cup	* x2	*	* x2	*	*	*		*	*
Patrick	flexzi mount	chin		*								
Bridget	lap	micro lever	stabilised with carpet tape	*					*			*
Peter	flexzi mount	chin switch		*	*		*	*				

All menus needed to be programmed once they had been designed. Each button was either linked to another menu or enabled to send an IR code. Each IR code was inputted through manual learning from original remote controls. This involved aligning the original remote and the *Keo*, sending an IR signal from the original remote and recording this with the *Keo*. During the process of programming the *Keo* some menus were altered as participants identified extra functions that were desired which required either assigning extra buttons on existing menus or constructing entirely new menus. This process took several hours depending on the complexity of desired use and the technical difficulties which arose while programming the *Keo* (these are discussed in more detail in section 4.5 below).

Participants tested all the buttons themselves to ensure the IR was effective and to familiarise themselves with the use of scanning to access the buttons and menus. I offered to increase the scanning speed once participants were familiar with the operation of the *Keo*. Increasing the speed of the scanning increased the error rate but decreased the overall frustration of having to wait for the scan to complete when errors were made. I also set the *Keo* to only complete 2 scan cycles at a time. This meant that if the incorrect line was selected it would only be scanned twice before moving back to general scanning. This 2 cycle and fast scan made switch use generally more efficient if participants were able to adjust to the fast scan. (For details on how scanning works see Appendix 19).

The *Keo* had Bluetooth® capability and thus could be paired with a mobile telephone. Only Patrick and Bridget chose not to use the *Keo* with a mobile telephone. The other four participants had their mobile telephone paired with the *Keo* and were able to use a selected switch to access the *Keo* which in turn dialled the mobile telephone. Each individual selection of up to ten telephone numbers could be stored in the *Keo*'s memory which could then be accessed via the standard telephone memory menus in the *Keo* (Figure 13 and Figure 14). When the *Keo* was paired to a mobile phone the telephone menu connected to a hidden extra menu that allowed the user to choose between the landline and mobile phone when making a call.

Figure 13: *Keo* standard telephone menu with buttons linked to memorised telephone numbers labelled M1, M2, M links to second telephone menu in Figure 14

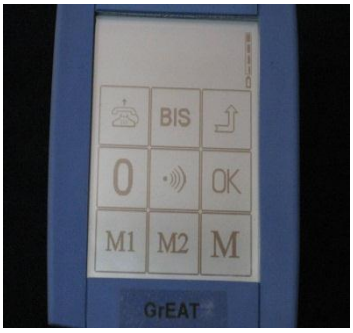
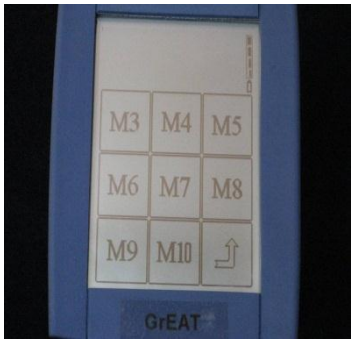


Figure 14: *Keo* telephone menu 2 with M3, M4, M5 ... M10 transmit memorised telephone numbers



A video camera that could be controlled using the Keo was included in the GrEAT pack. This was offered to participants as a means of recording their thoughts in privacy by using the video as a diary camera. Emily appeared receptive to the idea of controlling a video camera but decided not to use it as a diary camera during the trial. Matthew also considered using the video camera but did not do so during the trial. The remaining participants declined to have a video camera in their GrEAT pack.

The sound-switch and portable alarm was only selected by two participants Bridget and James. Both considered the portable alarm to be a useful item that would enable them to call for help at all times. Emily and Patrick did not require an alarm as their partner slept in the same room as them and they chose to call for help without a call system. Peter was also able to call for help with ease as he was living in a nursing home with a bedroom close to the nurses' station. Matthew was unable

to activate the alarm as he slept with a facemask restricting use of his voice to activate the switch.

4.4 Two trials that differed

Two participants, Patrick and Bridget's whose trials differed from the other trials are described.

Patrick's choice not to use the GrEAT

Patrick's installation of the GrEAT was the most straightforward of all installations involving the programming of a single menu that allowed him to control his television channels, television volume and an electrical fan. Despite the simplicity of the set-up Patrick abandoned the GrEAT as he could not operate a switch consistently and did not understand the scanning function. Patrick himself suggested that he may have *banged his head* when he became paralysed but review of his extensive medical chart showed no record of any cognitive loss that would have excluded him from this trial. I offered a second visit a week after the installation and after three weeks to aid his use of the GrEAT but this offer was turned down by his wife. I suggested making some adjustments over the telephone and was able to do so with his daughter's assistance. She was able to slow down the speed of the scanning and make the screen brighter and easier to see. Despite these adjustments Patrick discontinued his use of the GrEAT.

Reflections about Patrick

I found Patrick's trial stressful and questioned myself throughout his trial:

> *Prior to his interview: How do I feel? Anxious. Did he use it? What quality of information will he provide? How switched on is he, will he give me anything? Will I need to probe? How will I control myself and not be too leading? What do I want to know? – What it is like for a man with nothing for 19 years to have something? Is it too hard? Does he have no support? Does he actually have a need? What does he really think? Does he have a brain injury? For me he is interesting because he is older, rural and had had his injury for a long time (Reflective diary IV, p.58-59, 21-09-09).*

I assumed that he had not been able to use the GrEAT based on several telephone calls to his family. At the interview: The first words from his wife were:

> *I don't think we will do any more with this. (Fieldwork diary p.38 dated 21-9-09).*

This was clear indication that as a family they had not been able to incorporate the GrEAT into their lives. After the interview I queried the reasons for this:

> *He did not use the ECS at all. Why? His wife? Senility? Technology failure? Set-up failure? I did expect this. Patrick found it very difficult to use, but I thought he could have used it with step-by-step help from his wife which did not happen. Bottom line – it requires some set-up and support from his wife and Patrick has poor comprehension (Reflective diary IV p.60 dated 22-09-09).*

This posed some interesting questions about non-use and the role that family members play in technology use that I consider to be worth exploring but beyond the scope of this study. At the time my initial response when I arrived to conduct the interview was to exclude him from the sample as he had not shared the experience of living with an ECS. His insights did however provide me with a more realistic and fuller perspective of the trial and the reality of non-use. As the researcher I worked very hard to make the most of the interview so that Patrick would become a useful informant. I was obviously nervous and unsure of how to proceed with the interview as the interview guide was clearly not relevant for this interview. Despite this I was able to thread some of the concepts from the interview guide throughout the interview. I was concerned that I coerced him to talk of the ECS however his interview reflects themes far broader than living with ECS (see Patrick's mindmap in appendix 29.).

Bridget's own ECS

Bridget unexpectedly received an ECS of her own midway through the trial. I was unaware of this until I telephoned to schedule the end of the trial and her interview. Her ECS consisted of a POSSUM *Primo* and an IR telephone. She continued to use the call system consisting of a sound-switch linked to a personal alarm which was part of the GrEAT pack. The sound-switch was activated by making a loud sound which in turn activated a wireless portable doorbell carried by her care giver. This call system allowed her to contact her care giver independently. She asked to keep the sound-switch and alarm on completion of the trial and as she was one of the final participants this was possible.

Reflections about Bridget

I considered excluding Bridget from the study:

> *I was afraid that I would have to exclude Bridget from the research as she had not shared the experience of using the GrEAT. I am relieved that she has still used an ECS, the POSSUM Primo instead of the Keo. Her interview was very rich and highly informative … I wonder 'Did the GrEAT trial facilitate her acceptance and successful use of the POSSUM?' Was some exposure the precursor to acceptance? Did Bridget need slow exposure so that the Keo was an introduction prior to the full installation? … Was it my fault that she could not use the Keo through poor switch assessment? I did not have the option of a large jelly bean switch like the one she is now using so successfully but I could have posted one to her … Bridget turned down the offer of an accessible telephone as part of the GrEAT pack. It is thus surprising that she now uses a similar telephone and talks positively about being able to use it (Reflexive diary IV, p.76, 8-12-09).*

Her experience introduces interesting concepts about the timing of exposing people to ECS. It would be interesting to explore the influence of successful use of one item of technology on subsequent success – such as her use of the sound-switch that preceded her successful use of the POSSUM.

> *Bridget's successful use of the POSSUM surprised her. But was she more prepared for it after the introduction to ECS by me? She had no expectation of her successful use of an ECS thus the GrEAT was not a success. It did however provide some expectation of what is possible. Therefore when the POSSUM was installed she had some small expectation which facilitated her acceptance and then the realisation of the value of it through successful use. (ATLAS.ti Memo, 4-2-11).*

In addition her experience highlights a fundamental limitation of the study. The GrEAT was only a temporary trial while her own pack was hers to keep and this is likely to have made her experience different.

4.5 Technical difficulties

Technical difficulties were encountered during the installation and trial period including difficulties with the IR telephones, a Bluetooth® headset, recording IR signals, battery failure, and with the sound-switch. Most of these were overcome without extensive external support.

Recording IR signals

I experienced some difficulties recording signals from some source remote controls. The *Keo* allows two different methods of recording IR signals. The first is a single send and receive method while the second method involves sending the signal twice. After several failed attempts to accurately record television IR signals I resorted to the second method when recording most television signals. I had similar difficulties recording the IR codes for the landline telephone when preparing for the trials and again used the second recording method.

Digital television

Recording the IR signals used for navigating the complex television programming menus posed challenges. Once recorded, the directional buttons up, down, left and right often transmitted IR signals that were too long. Thus when using the *Keo* to access a digital television menu, the IR signal resulted in navigation in increments larger than one for example if the down button was selected it would move two or three positions instead of moving down just once. It took several attempts to record clear short IR signals that navigated in the desired single increments.

Telephones

The IR telephone and the mobile telephone also caused some difficulties. I was unable to install the landline IR telephone in the first trial despite following the same procedure that I had employed successfully during the pilot study. I abandoned trying to install the telephone in the participant's house and conducted some testing off-site and sought technical support from the supplier. The supplier reported inconsistent performance of the same model of telephone citing differences in the quality of the telephone lines as a potential cause.[205] After several attempts to use the phone at different locations I returned the phone to the manufacturer who replaced the unit. I was then able to install the telephone successfully in the participant's house and the participant was able to make telephone calls using the *Keo*. He was however unable to receive calls. It became apparent that the handset of the phone was not disengaging the phone and thus the phone remained engaged. I resolved the issue by attaching felt pieces to the handset to improve the contact with the disengage button. This solution was highly unsatisfactory considering the cost of the telephone. I contacted the manufacturers who claimed to

[205] The same supplier had recommended the same model of telephone as being the best available quality phone at the time of planning the pilot study.

be unaware of the issue and unsympathetic to my complaint which they attributed to operator error. I reiterated that the phone was being used as a hands-free phone not involving the handset and that operator error that was unlikely. It became clear that this design fault did not concern the supplier and I did not have the personal resources to pursue the matter further. The issue did not occur again during the trial as three of the participants chose not to use the landline telephone, two participants reported using it only a few times and only one participant used the phone extensively with no reported difficulty. Interference from internet connections that shared landline cabling was avoided by using a filter on the telephone line.

Some mobile telephone models did not permit the *Keo* and the mobile phone to be paired for long periods of time without the phone disconnecting from the *Keo*. When this occurred I included a Bluetooth® pairing icon from the *Keo*s library of icons on the start-up menu. which enabled the participant to pair the mobile phone with the *Keo* prior to making any telephone calls.

James' mobile phone Bluetooth® headset did not work with the *Keo*:

> *Yeah my mobile phone did not work really well with it either. I am not sure why I had my headphones in but it just wouldn't. I couldn't hear anybody in the headphones, sorry I could hear them in the head phones but they couldn't hear me talk back. I don't know why like. I could dial out with it but I just couldn't hear anybody talking or they couldn't hear me talking* (James Line 80).

James' mobile phone only allowed pairing with one Bluetooth® device at a time meaning that if it was paired with a *Keo* it could not be paired with a headset.

Battery failure

The battery in one *Keo* failed and required replacing which resulted in one participant experiencing a ten day break in his trial while awaiting a replacement to arrive by post. His trial was therefore extended by two weeks.

Back-up ECS

The SICARE *Senior pilot*[206] ECS controller included in each GrEAT pack was intended to be used as a back-up device. My intention was to identify the most important tasks for each participant and then record the IR signals for these on a *Senior pilot* remote. Due to the wide geographic location of participants and my limited availability to provide technical support to participants I hoped that if the *Keo* failed participants could use a *Senior pilot* as a back-up. This was however not feasible. It became apparent that the *Senior pilot* was not considered a suitable substitute once participants had experienced extensive access to the *Keo*. In addition the technology was noticeably inferior. I attempted to set-up a *Senior pilot* for the first participant but had to abandon the effort when I failed to successfully input the digital television IR codes. It was not possible to replicate part of the set-up on a second ECS controller within the time allocated for installations. I offered the *Senior pilot* to the second participant who had some previous knowledge of the product and she expressed dissatisfaction with it based on its large size, unattractive appearance and lack of compatibility with digital television programming. I decided not to include the *Senior pilot* in the remaining four trials.

Personal alarm

The personal alarm system consisting of a sound activated switch and a portable wireless alarm was only used successfully by one participant. James reported limited use of the alarm system as he was unable to adjust the sensitivity of the sound-switch so that it would not be activated by his use of voice activated software while still being easily activated by his low and quiet voice. He chose not to use the switch at night as he feared he may wake his parents unnecessarily due to false alarms if the switch was too sensitive. Bridget in contrast felt she could not be without the alarm and asked to keep it at the end of the trial.

4.6 Follow-up

I did not offer any formal follow-up support during the trial. I asked participants to notify me if they experienced any difficulties. Only one participant informed me of battery failure (described above). This issue was resolved without a follow-up visit. I chose to contact one participant twice during his trial as I suspected that he may have been experiencing some difficulties – a concern confirmed by telephone. His

[206] *Senior pilot* is a large ECS controller with 14 large illuminated buttons with a choice of transparent symbols that can be placed under the keycaps. Each button can be assigned to a function and can record an IR code. It is single switch accessible through scanning.

family however turned down two offers of a follow-up visit. I was able to provide one of his family members with telephone support that enabled her to adjust the settings of the *Keo*.

4.7 Data collection using interviews

Data were collected using semi-structured interviews that elicited rich detailed first person accounts of the experience of using ECS. On completion of each trial one individual semi structured interview was conducted with each participant in their own home in a location of their choice - a bedroom or living area. They were interviewed alone with no caregivers or family in the room and I provided frequent physical assistance during the interviews e.g. holding a glass of water or moving a spasming limb. Interviews lasted from 41 to 56 minutes (average 49 minutes).[207] Interviews were preceded by social exchange and the setting up of recording equipment. A technical interview procedure guide was followed to limit technical difficulties during the data collection (Appendix 23). Anticipated technical difficulties included interference from electrical appliances that may affect the quality of recordings, poor lighting, reaching the end of the digital tape and equipment failure.

Each interview was both audio and video recorded digitally Participants were reminded of their informed consent and their right to revoke this consent. They were again asked to provide verbal and video-recorded consent to be interviewed and recorded. All consented.

The video recordings were transferred to a hard disk drive after each interview as a means of back-up but were not analysed. The mp3 audio recording was used as a source for transcription. I transcribed all the interviews verbatim. On completion the transcriptions were checked for errors and amended by re-listening to the audio recordings. Each transcription was then analysed using IPA.

Interviews were conducted using an interview guide based on my understanding of IPA, clinical experience of SCI and of ECS as well as on the Phase 1 findings (Appendix 24). The interview was intended to elicit autobiographical descriptions of individual participant experiences of using the GrEAT. The guide was used flexibly allowing divergences in questions depending on the progress of the interview. New interesting concepts not anticipated in the interview guide were explored further

[207] Matthew 41 minutes, Emily 55 minutes, Patrick 45 minutes, James 56 minutes, Bridget 54 minutes, Peter 45 minutes.

through open questioning. The interview guide was used to varying degrees depending on individual participants. One interview was so rich and self-directed that very few of the planned prompts were used and on reflection, the prompts that were employed halted the flow of the interview rather than facilitated it. Another participant provided simple replies with little elaboration and I relied heavily on the interview guide to facilitate a difficult, unreflective interview.

After the interview I wrote brief research summaries for participants. These reports provided the technical details of the research trial. I noted that the participants had been involved in a research trial and that I had not offered any formal assessment or recommendations following the trial. I provided some information on the participants' abilities to use the ECS and their personal desire to acquire a similar system if appropriate. These reports were forwarded to their occupational therapists and the [AT service] if requested and copied to their [hospital] charts.

4.8 Termination of trials

All participants returned the GrEAT packs. Returned items were recorded on an inventory sheet (Appendix 25). Bridget kept the sound-switch and the portable alarm. While I did not formally evaluate the use of the GrEAT and its contents I was able to make some observations when taking the pack back from participants and during their interviews. It was apparent that Emily and Matthew did not use the mounts at all during their trial period. The decision taken by technology users not to use prescribed mounts could be a possible topic for further clinical research. Emily and James used the IR sockets and still had devices plugged into them at the time of their interviews.

5. Data analysis: Interpretative Phenomenological Analysis (IPA)

IPA was selected as the research method for Phase 3. Data management involved a computer package ATLAS.ti (Muhr, 2007, Muhr, 2011) and analysis was aided by a combination of repeated listening to audio recordings on an MP3 player computer based mind-mapping using iMindmap (ThinkBuzzan).

The use of computer assisted qualitative data-analysis (CAQDAS) programmes is uncommon in IPA (Smith, et al., 2009). ATLAS.ti in particular is tailored for use for grounded theory and needed to be adapted for use with IPA. Details of how ATLAS.ti was used for thus study are found in Appendix 26. The rationale for using CAQDAS was to facilitate the cyclical iterative nature of the analysis by continually returning to the original data with ease thus validating the emerging findings (Langdridge, 2007). The software package was used as a data management tool and played no active role in the generation of the findings as is common in statistical software applications.

Mind mapping was a unique addition to IPA encouraged by Smith et al. (2009) who call for creativity in IPA. The use of mindmaps to aid IPA and thematic organisation is not known to have been documented in the academic literature. However their use has been discussed on an internet based IPA forum (Verdonck, 2011a).[208] Mindmaps were used to summarise the initial analysis of individual interviews, create a thematic preliminary summary for each participant, cluster similar themes between participants and analyse and arrange the final shared thematic structure. Examples of these mindmaps illustrating the progression between maps is found in Appendix 27.

While there is no one single method for conducting IPA data analysis Smith et al.(2009) have provided a heuristic framework for analysis which was used to guide analysis of Phase 3 data. An overview of their recommended method is depicted in a mindmap in Figure 15. Table 20 overleaf, describes how analysis was conducted in this study including how ATLAS.ti and mindmaps were used at each step.

Each interview was analysed individually in order to honour the IPA commitment to an ideographic focus using the initial four steps as described by Smith et al (2009) as in Table 20. Comparative analysis of all six participants subsequently followed the individual analysis in the final step. Analysis began 21-8-09 and lasted 9 months and an audit trail is provided in Appendix 28.

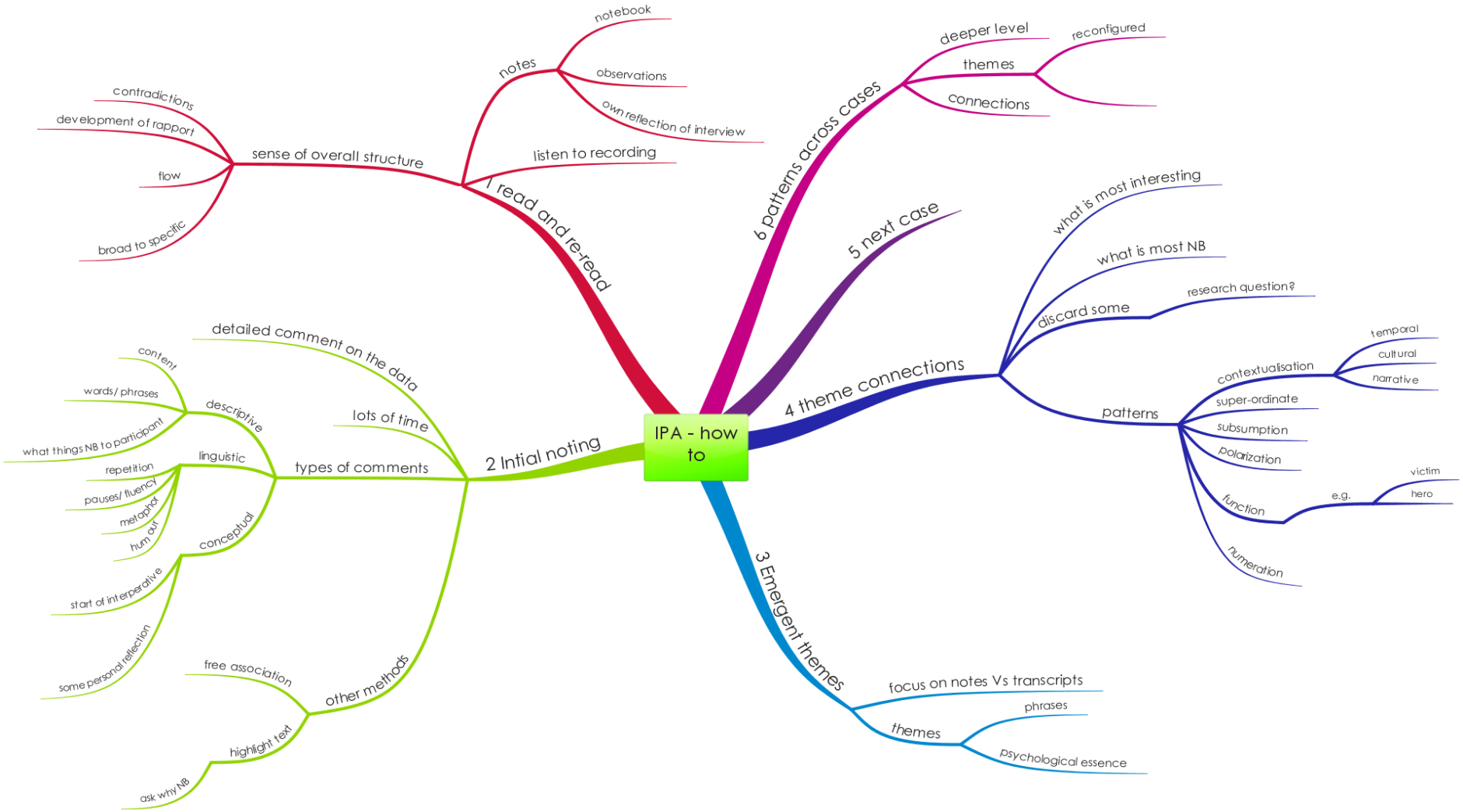
[208] http://groups.yahoo.com/group/ipanalysis/messages/4016?threaded=1&m=e&var=1&tidx=1

Table 20: How IPA was applied in this study including the use of ATLAS.ti and mindmapping

Step 1: Overall sense of interview:	Transcribe, listen and re-listen to interviews, read and re-read transcripts	Observations and reflections noted in reflexive diary Transcripts were loaded into ATLAS.ti as primary documents[209]
Step 2: Initial noting	Highlighting of free quotations and recording of detailed comment[210]	Free quotations in ATLAS.ti
Step 3: Interpretation	Identify individual emergent themes	Assigning of themes (called codes in ATLAS.ti) to free quotations
Step 4: Connections between themes	Organise relationships of emerging themes	Reviewing themes using ATLAS.ti Dynamic mindmapping Narrative summary report
Step 5: move to next interview Repeat step 1-4 for each interview		
Final step: seek patterns across all cases	Combination and navigation between all themes	Dynamic mindmapping merging mindmaps to produce and final mindmap of shared themes. Joint narrative compiled using ATLAS.ti.

[209] In a new group called a hermeneutic unit, a term used in ATLAS.ti software to reflect a discrete data set. While the term implies finding meaning (hermeneutic) it is used only as a label without a function.
[210] The nature of these comments were largely descriptive with some linguistic and conceptual notes. Similarities, differences, contradictions and amplifications were noted (Smith & Osborn, 2008).

Figure 15: Overview of the IPA process (adapted from Smith, J., Larkin, M. H., & Flowers, P. (2009). Interpretative phenomenological analysis: theory, method and research. Los Angeles; London: SAGE.)



The second step considered to be the descriptive phenomenological step, focused on the participants own description of the experience and the beginnings of interpretation. This initial noting step is traditionally conducted on hard copies of transcripts in a large right-hand margin (Smith, et al., 2009). I however chose instead to record comments for each quote electronically using ATLAS.ti (see Appendix 26).

The analysis then progressed to the interpretative phenomenological level in identifying individual emergent themes in Step 3. The identification of these themes focused on the commentary (initial noting)[211] rather than the raw interviews in an analytical shift to include both the participants and myself as co-constructors of the data. This process involved the transition of initial notes into themes (Smith, et al., 2009). Themes were identified to represent the psychological and occupational essence of the described experience. I attempted to identify unique themes for each interview by bracketing ideas that had emerged in previous analysis and intentionally not merging themes across interviews.

Step 4, searching for connections across emergent themes was aided by the use of dynamic mind-mapping to identify relationships between themes in a schematic map of the interview contents and themes for each participant (for an example see Appendix 27). This process included abstraction and subsumption that produced superordinate and subordinate themes respectively (Smith, et al., 2009). Themes were clustered and rearranged several times. Some themes were dropped because of their lack of fit in the emerging structure and dearth of rich supporting evidence (Smith & Osborn, 2008). The use of ATLAS.ti facilitated the on-going review of these themes as they emerged ensuring the analysis remained firmly linked to the data (Langdridge, 2007). Analysis culminated in the production of a single case study narrative report for each participant. These narrative accounts were shared with a supervisor and the clinical expert to validate their content.

The analysis shifted to the next case in step 5 which required the repetition of steps 1-4 to produce other ideographic mind-maps of themes for the other participants and accompanying narrative reports (Smith, et al., 2009). This process was replicated for all six participants. Emergent themes were sometimes observed in subsequent interviews but the researcher aimed to differentiate between re-

[211] Initial noting was in the form of comments attached to identified free quotations.

occurring themes and new emerging ones and thus populated several new themes that were particular to each participant (Smith & Osborn, 2008). Some of these themes were later merged but their initial identification was aimed at retaining the individual nuance of how that theme occurred for individual participants. For example – *being alone (Matthew)* and *feeling safe alone (Bridget)* were similar related themes but with dramatically different meanings.

The sixth and final step sought patterns across all cases. This step involved a combination of navigating between themes (*codes* in ATLAS.ti) and merging mind-maps of themes. Appendix 29 illustrates the progression from individual mindmaps to an overall summary mindmap. This included active dialogue with the data to find connections between cases and to consider shared themes and individual nuances of such themes. This step involved renaming, merging and restructuring themes to reflect the entire sample in a move from the particular to the shared (Smith, et al., 2009). Themes became more theoretical in this step through the identification of higher order themes representing shared themes. This step was crucial as it required the identification of the most important group themes. Such a selection was not based on the occurrence of the theme but rather on its significance to the research question and the described experiences (Smith & Osborn, 2008). Themes then needed to be assessed in an iterative process of reviewing all the transcripts. The final representation can be graphical or tabular and both were selected as methods to display these research findings in the next chapter.

6. Reflexive commentary

I assumed the role of researcher throughout this trial. As an occupational therapist I was also drawn to assume the role of therapist and to view the participants as clients. I consciously resisted this and was overt about my role as researcher to the participants. This was particularly notable when providing participants with research reports. I clearly stated in these reports that the participants had not been assessed nor had any recommendations been made and instead provided a record of their involvement in the research and details of the technology used be each person.

If I had supplied the GrEAT pack as an occupational therapist not a researcher I would have included a comprehensive assessment and considered more person specific options not included in the generic pack such as using a larger buddy button switch for Bridget. Such deviations would have made timely completion of all six trials very challenging or even impossible. It was thus essential to issue the pack as a generic set that I customised to

individual needs. For the specific purpose of this research study a more homogenous group was created through their use of a standard pack. It is not possible to intuit how the participants experience may have differed if the approach taken was more in line with a therapeutic intervention and answering this question would involve a different research methodology.

I found Phase 3 challenging. I had to balance my instincts and habits as a clinician with my role as researcher. Adopting a collaborative approach I tried to let the participants make as many of their own choices as possible. This meant that at times I did not use my own clinical judgement. In my efforts to ensure they were directing the installation and customisation I failed to acknowledge my own relevant and useful clinical experience. This was apparent in terms of mounting. Several mounts were included in the GrEAT and I anticipated that they would be used to mount the Keo but this did not happened:

> *I did not insist on using a mount for the Keo with Bridget as other participants had chosen to not use the mount. In hindsight the POSSUM was mounted and this was likely to make it easier to use as the screen was always visible. In addition the small micro lever switch was too small for Bridget and the jelly bean switch used for the possum was easier to use. My installation was less suitable than the engineers. I was so focused on ensuring I had Bridget's co-operation and staying client focused I omitted some clinical reasoning of my own (ATLAS.ti Memo dated 25-5-11).*

I was also restricted by my inclusion of small switches in the GrEAT. I instinctively knew that Bridget required a big buddy button but as it was not included in the GrEAT I helped her use a micro lever switch. I did so as I was restricted to the research tool – the GrEAT. In hindsight I should have sourced and posted her a big buddy button. Ironically she did in fact not use the GrEAT pack as intended and her experiences are based on other ECS not the GrEAT.

Maintaining the researcher role while conducting the interviews was particularly challenging when I was confronted by participants' misunderstandings and their obvious need for education about ECS. I resisted the temptation to offer information and my clinical opinion as an occupational therapist on several occasions. For example Matthew mentioned how voice activated ECS are unreliable while I had experience of a highly successful voice activated system available in North America. Offering this information at the time it is felt would have adversely affected the flow of the interview and Matthew's own disclosure.

I was disappointed with the customisation of Peter's GrEAT. I forgot one of Phase 1 findings – to consider other AT. While I had ensured the Keo could be accessed using a mouthstick I had not made this overt in the booklet or during installation. I did not show Peter how he

could use his mouthstick to access the Keo. I think he may have found the GrEAT more satisfactory if he had incorporated his mouthstick. Peter's uncle had made him a wooden frame that secured both his phone and remote allowing direct access using a mouthstick. The frame also included a slot for the mouthstick while not in use. Peter used the mouthstick for sending texts on his phone which was not possible using the ECS provided. Peter did not realise that the ECS remote control included in the pack could be controlled directly using a mouthstick too (an error on my part). Peter favoured using the mouthstick as it is a direct access method in contrast to the scanning function needed to use a single switch.

If I were to question my efficiency and skill in both designing and installing the GrEAT I would rate myself as adequately competent. This study however did not seek to investigate my competence but instead sought to explore if I as an occupational therapist was able to both design and install a useful generic electronic assistive technology pack.

My application of ATLAS.ti and mindmapping to IPA deviates from the norm but both were essential tools for me in this study. The traditional three column IPA method described in most IPA doctoral theses did not suit my way of working and the sheer volume of data made computer data management favourable. It may be argued that quickly moving through transcripts using computer software removes one from the original transcripts. However I felt my analysis was firmly grounded in the data as I lived with the voices of each participant in my head for several days and listened to interview recordings as often as possible. I am pleased to have discovered both these useful tools and would like to share their possible application with others.

Using IPA required that I acknowledge my preconceptions. As a spinal injury occupational therapist I had expectations that the use of the ECS would be primarily positive and the experience likely to be described as improving quality of life. My perceptions of ECS had also been influenced by Phase 1 findings and thus I was primed to recognise concepts that were found in Phase 1. In order to monitor my own perceptions and their evolution throughout the data analysis process I engaged in reflexive practices and include relevant excerpts throughout.

IPA was suitable to ensure my analysis was rigorous. I was tempted to assign themes immediately and proceed to seeking patterns across all cases prior to completing initial analysis of all the interviews. Adopting the IPA step by step approach guided me to delay these steps and on reflection improved the quality of my analysis and aided its originality based on the data as a whole not my immediate assumptions. My audit trail (Appendix 28) reflects how initially I assigned themes too soon not completing step 2 first. In analysing Matthew's interview I assigned themes as I made comments. During analysis of Emily's interview I realised my error and adjusted my method and adhered from then onwards to

identifying quotations and making comments, and only considering themes once all the quotations had been identified.

Between cases I tried not to apply previous themes unless they occurred naturally. I named themes as they occurred for each person and this allowed individual nuances to appear in the initial stages of analysis. This ideographic focus provided a richness to the final themes that, although shared, also had slight nuanced differences for the individual participants so that themes were shared but still individual.

Chapter 10: Phase 3 findings

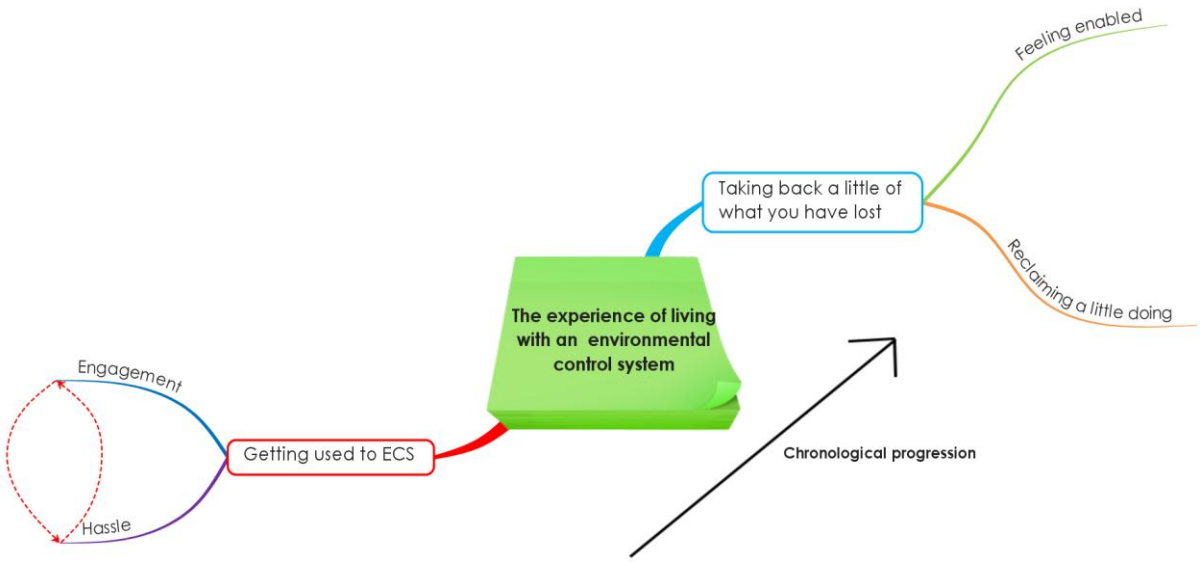
This chapter presents the findings from Phase 3, the experience of living with an ECS, as described by the participants. IPA analysis revealed two superordinate themes, each further divided into two subordinate themes, which are described in detail.

Verbatim quotations from interviews are provided in support of each theme. Omitted text is indicated by … and interjections by the researcher appear in square brackets **[interjection]**. Edits intended to clarify quotations appear in brackets ( ).

The experience of living with an ECS for the research participants is encapsulated in two chronologically and dynamically related themes. The first, a precursor of the second, is *Getting used to ECS.* The second theme *Taking back a little of what you have lost* emerged only when participants were able to get used to ECS.

The chronological relationship between themes is illustrated in Figure 16. The first theme *Getting used to ECS* has two subordinate themes; *Hassle* and *Engagement.* The second theme *Taking back a little of what you have lost* consists of two overlapping subordinate themes; *Reclaiming a little doing* and *Feeling enabled.*

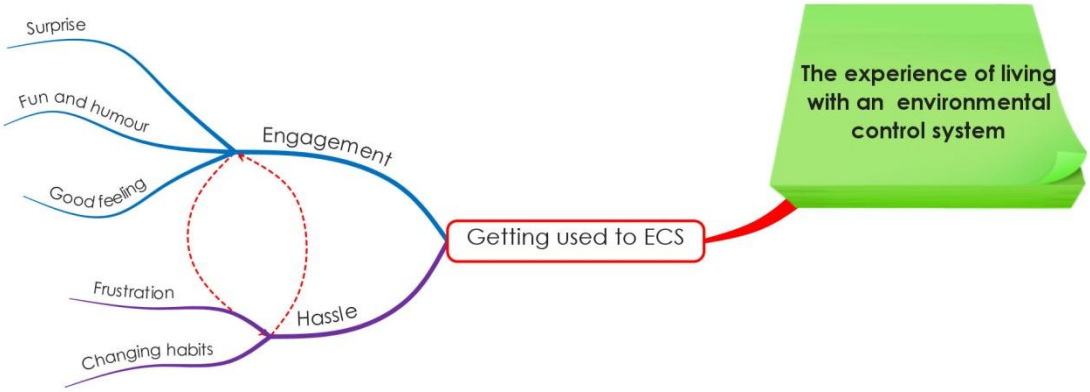
Figure 16: Overview of Phase 1 superordinate and subordinate themes



1. Superordinate theme 1: Getting used to ECS

The first theme *Getting used to ESC* represents both the challenge for participants in becoming accustomed to using an ECS and the subsequent engagement with it. These components are separated into two subordinate themes entitled *Hassle* and *Engagement* (see Figure 17 below). The dynamic relationship between *Hassle* and *Engagement* was evident in the lively interaction described by participants between experiencing the *hassle* and enjoying the *engagement.* Overcoming the *hassle* requires engaging with the system and paradoxically then that *engagement* can lead to the experience of *hassle*. Participants seemed to ask themselves, *is the hassle worth it?* To answer that question they needed to engage in the use of the ECS. Some participants described a chronological progression during which the hassle became less as a consequence of engagement which in turn made using the ECS simpler.

Figure 17: Phase 3 superordinate theme 1: Getting used to ECS

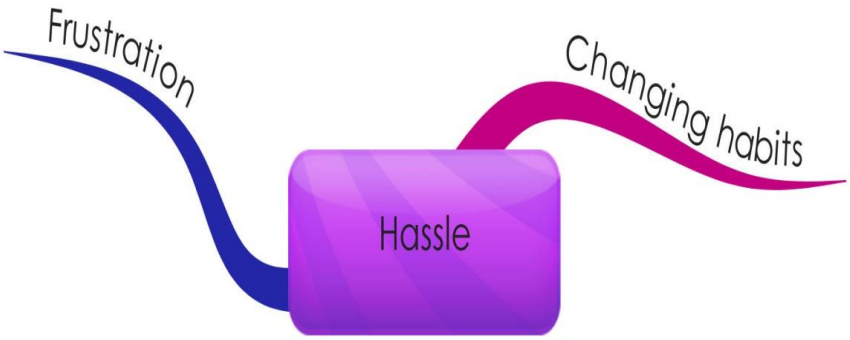


1.1 Subordinate theme 1: Hassle[212]

The hassle involved in using an ECS was apparent in each interview and has therefore been identified as the first subordinate theme of *Getting used to ECS*. For participants, hassle appeared to derive from frustration and from the necessity to alter familiar behaviours, - see Figure 18 overleaf.

[212] A problem brought about by pressures of time, money, inconvenience, etc.: Finding a decent place to have lunch in this neighbourhood is always a hassle (http://dictionary.reference.com/browse/hassle, accessed on 10-6-11).

Figure 18: Elements of subordinate theme 1: Hassle



For each participant, using an ECS involved effort and adjustment as all were living in the community and dependent on family and carers unaccustomed to such technology. All the participants described having to *get used to* the ECS as a *hassle* requiring effort. Emily offered the realistic insight that using ECS requires effort which needs to be weighed against potential benefits. The effort required is described as considerable. Peter and James reported that they were hesitant at the start of the trial and Emily's interview began with her description of how challenging she found the trial initially:

> *I just found it really hard to start to get into the routine of using it or like using it by myself … it just was really weird at the start. (Emily, line 6).*
> *I was kind of like, "g-d these are more like a bother than a helpful" (Emily, line 8).*

James said that he was unsure that he would be able to manage the technology at the start of the trial but found the learning process easy and quick. He engaged easily in this process which facilitated his successful use of the pack:

> *And I think in the beginning when you showed me I think I said to myself, "blimey I am never going to get through this". But after, as I told you, maybe after maybe an hour or an hour and a half I did get the hang of it (James, line 203).*

The effort required appeared to decrease as the participants became accustomed to the technology. For Matthew the satisfactory use of the ECS and any assistive technology involved perseverance. He felt effective use required persistent personal effort:

> *The more that you use it the more little shortcuts or things that you think, "Oh no there is no need to do that I can do it that way" (Matthew, line 19).*

James was surprised that he found the ECS easy and that he speedily mastered it. He described how he learned how to use the ECS by teaching himself to get used ECS:

> *I think I spent a full night not watching anything just flicking through the channels with the thing making sure that I got used to it like. I never settled on any programme. I'd go into a programme and I just say, "ah well, I'll have a go at this," and come out of it again back into the planner and go into another programme. Programmes that I had no interest in, just a matter of getting used to it (James, line 39).*

Emily also reported that the effort involved in becoming accustomed to the ECS was worthwhile in the longer term as her speed improved with practice. She described using the ECS as rewarding despite experiences of frustration at times. The frustration of learning how to use the ECS was in sharp contrast to the ease of reliance on others:

> *I suppose it does feel good like, but it feels kind of frustrating as well because you would. I would feel to myself you know if someone else came in they'd have it done in two minutes where as I have to go this, this, this you know? But it's just a matter of getting used to things I think you're using them constantly then it's not going to take as long you know like whatever four months down the line it could be as fast as just somebody else coming in and doing it, you know (Emily, line 46).*

The learning process was more challenging for Bridget who found the GrEAT difficult to use. When she was introduced during the trial period to a second brand of environmental control (POSSUM) she found it easier to use. In the interview she tried to make sense of the difference between ECS. She suggested that the *Keo* was introduced at the wrong time as she could not identify any functional differences between the two devices and even suggested that the second one (POSSUM) *looks more difficult*:

> *I found it (Keo) a bit difficult to use. I just couldn't grasp it. I got, I got, even though it looked very simple and [partner] showed me a good few times to use it. I just couldn't. I couldn't kind of, I couldn't get to grips with it. How to use it. What um, he used it for me and showed me again and I still found it very difficult, you know, to use it … Maybe another time I would have picked it up. Very simple you know, and then when I got this equipment (POSSUM Primo) and it was shown to me I don't know why my brain just kicked in and switched on. It, um, I picked it up like straight away and it even looked, this looks more difficult … than what you gave me, but obviously it's the same thing. But I just found it a lot easier to manage even not being able to use my hands. I could use it better. (Bridget, line 5).*

Because Bridget was accustomed to, *not being able to use my hand,* she had no expectation of being able to use anything including the *Keo* and the POSSUM. She tried to understand how she was then able to use the POSSUM although the *Keo* did not suit her:

> ***Bridget****: … the one you gave me it just didn't work for my brain … I am sorry I but … it just did, it just didn't work for me.* ***[It just did not suit you?]*** *Yeah it just did not suit me … I just could not, I couldn't work it right … I couldn't work it. But I took, like this one, I only had to be shown it twice, and it clicked with me.*
> ***Interviewer****: And what do you think the difference was?*
> ***Bridget****: I can't explain it because I don't know why I was able to pick on this one straight away. I got no teaching. I was just shown it twice. I wouldn't be brilliant on the pickup of modern technology like that. I always would have to be shown a good few times, you know. And I just, I just took to it like a duck to water (Bridget, line 7-9).*

Bridget described two different experiences with two similar ECS. Her initial exposure to ECS, although not successful, may have contributed to a positive experience with the second ECS. Exposure to technology changed her expectations of and ability to engage with the ECS. In addition she had been deprived of the experience of doing anything independently for 36 years. Engaging in the use of technology like this was a contrast to her familiar life for over 3 decades. It is likely then that Bridget was overwhelmed by the effort of becoming accustomed to using the ECS and by its functionality:

> *I am absolutely overwhelmed with what I have at the minute … thrilled … delighted to have it, but, I you know. I think I have enough now so at the minute to try, and let it soak in (Bridget, line 134).*

She felt that she had a limited capacity to grapple with the challenges of technology as she had physical health issues to deal with:

> *there is kind of only so much that I can take on board at the minute, and I think I am doing very good, I am doing very well for even being interested in it, do you know, at all in the first place (Bridget, line 164).*

Patrick was injured 19 years previously and he too had been unable to actively do anything for almost twenty years. However, in contrast to the other five participants, Patrick chose not to use the ECS. For him, it seemed to simply require too much effort and *hassle.* He also reported that he had very simple needs such as access to a few select television channels and volume control, which in his opinion did not justify an ECS and its' associated *hassle.* He considered that he had adequate control of his television as his wife was always close enough to be called to change a channel, even when asleep at night:

> *That (ECS) wouldn't be a terrible advantage to me really. (Patrick Line 15).*
> *Hassle, I suppose it would not be worth the hassle of it afterwards (Patrick Line 40).*
> *only a couple of channels that I need and it wouldn't be worth the hassle of having something to do that (Patrick Line 118).*

Changing habits

The theme of hassle involves the element of changing habits. The introduction of an ECS required some change in habits. All the participants lived with a high SCI and had become accustomed to a particular lifestyle and associated routines. A change of habit would therefore pose its own challenge. It is likely that reliance on others had resulting in a learned dependency. Not having an ECS necessitated a high level of assistance from others and the use of other adaptations for example using a mouthstick. Incorporating an ECS into a life of routines is difficult or even impossible. Patrick was unable to change his 19-year old reliance on his wife even

to participate in a short 8-week trial. In contrast the other participants made use of an ECS in spite of also having developed routine habits over time.

Being dependent on others for all physical activities inevitably results in becoming accustomed to dependency and this learned dependence is apparent in all 6 interviews. Dependency is likely to facilitate passivity irrespective of personality and motivation and all participants demonstrated some passive learned dependence. Patrick was unable to even consider an alternative to his dependence. When asked how he felt about having to rely on his family to do things for him he gives an unexpected reply:

> *Sure it's great of course, anything at all. One day you might not be able to do anything for yourself wouldn't you be delighted if you found anyone to do anything for you? (Patrick Line 129).*

This is in contrast to other participants who were more likely to talk about dislike of being a burden on family members. Rather than focussing on being a burden, Patrick appeared to focus on the fact that his family were enablers for him, that they do the things he can't do for himself and that this is a positive thing. The possibility that his reply was a defensive, flippant one cannot of course be ruled out.

Acceptance of the way things are as the status quo is a common thread running through these interviews. While this may seem passive, perhaps it is an adaptive coping response when dealing with less than ideal circumstances including living with a high SCI without the assistance of an ECS. An inevitable learned dependence is therefore adopted with apparent acceptance. For example when Emily was asked what it would be like to no longer have the ECS she considered that:

> *I'll probably just go back into the old habit, the old habits (Emily, line 139).*

Likewise James reflected on what it would be like without an ECS initially said that it *will be hard*. He immediately corrected himself as he realised that *they* (his carers) will still have to come. It did not sound right to him to say he will find it difficult because he will still be able to have his needs met by his carers in what has probably become a cycle of accepted dependency:

> *when you do take it away it will be really hard to go back into the whole, (pause) it won't be hard like they will still have to come (James, line 5).*

Emily was accustomed to and clearly dependent on established routines. She managed her personal assistants creatively to do tasks such as preprograming her television schedule. This routine negated the absolute need for an ECS to change television channels:

> *I had the girls (personal assistants) here during the day and they'd set my TV for the evening (Emily, line 6).*

Both Emily and Matthew talked about having *people there all the time.* They had become accustomed to needing to have someone with them all the time as they were constantly reliant on others:

> *I am so used to having somebody there (Matthew, line 14).*

While they necessarily were resigned to this habitual dependence Matthew, Peter and Bridget all reported that they disliked it. Emily expressed a need for privacy and Matthew, despite being accustomed to having *people there all the time*, also reported that *it drives me mad* having to call all the time. Peter reports being accustomed to dependency and eager to do more for himself:

> ***Interviewer:*** *And what is it like having to call someone? What do you think about it?*
> ***Peter:*** *It's alright (chuckles) No choice. Well it's, I am used to it at this moment so. I'd like to do it myself, just did not get around to it (Peter, line 180 -181).*

This excerpt captures the paradox involved for Peter of accepting dependency while wishing to be more independent. The fact that he has not got *around to it* suggests that it would require effort to do so and the need to make this effort may in itself have been a barrier.

Prior to the current trial Peter was using a mouthstick to control both his mobile phone and his television remote control. Using the ECS was challenging for him as he was in the habit of relying on a mouthstick. Initially he favoured the mouthstick

but as he used the ECS he began to understand it's potential benefits. Peter acknowledged that the mouthstick was problematic as it was not durable, was prone to falling out of reach and was demanding on his jaw. In contrast, a neck switch is always accessible and cannot fall out of range. In addition, when the neck switch moved Peter was able to manipulate it back into a favourable position using his head and neck:

> *It's around your neck, it's there, it's not going anywhere (Peter, line 98).*
> *No it moved forward a bit and went around … (my) neck and stuff, but you could still use it, you could always get back to it. You could always position your neck and chin to pull it around (Peter, line 100).*

Peter was encouraged to be an active participant during the installation phase. However, he paradoxically adopted the passive role of *receiver of* care during interview. When given the opportunity to suggest improvements to the ECS he stated:

> *I don't know if it could be set-up to work better, I don't understand the technology (Peter, line 69).*

I had expected Peter to provide a more insightful response including possible improvements to the system. Instead he claimed to have had no understanding of the technology.

James admitted to having been aware of ECS but of never having looked into them as he had become accustomed to living his life as it was. In trying to make sense of why he did not pursue ECS he suggested that he expected them to be more complex and that he was *stuck in a rut* of having things done for him without considering the alternatives:

> *I always knew there was some sort of environmental control system out there, but, I don't know I never went down the road of actually researching to try and get something … if you had never given me the trial like I probably would never have gone down the road of doing it … Whether that's out of pure laziness or … I am stuck in a rut the way I am … I'm in my own little bubble here doing. I'm getting people to call; I am calling people in to do it.*

> *And not that I'd be happy with doing that, but I never thought that it (ECS) would be so simple (James, line 163).*

Emily had applied for an ECS but had been unable to access funding. She admitted to having become a little complacent as a result and had not actively pursued acquiring ECS:

> *even though I was very optimistic and positive … and I always knew that I was going to need these things. I was always kind of putting them off and I was saying, "sure I'll use them when I get into my house" or "if I get them … I will use them" (Emily, line 203).*

Frustration

Frustration is the second intrinsic element of the subordinate theme *Hassle.* Many participants experienced some frustration with both the technology itself and the system for acquiring ECS.

Frustration with the technology included frustration with scanning as an access method, dissatisfaction with the speed of use and some technical difficulties with using an ECS. Matthew expressed frustration with the speed of the environmental control and its lack of responsiveness:

> *The only negative thing that I'd say is the frustration if it doesn't work the first time … That would be the only thing like the frustration of not being able to do something like quickly (Matthew, line 19).*

Peter described using the ECS as irritating due to his own impatience and the frustration involved in scanning:

> *Irritating, (the ECS) takes too long and you get frustrated with it (Peter, line 26).*
> *And waiting for the remote to scan through all the different things, you can get straight to the point (with a mouthstick) (Peter, line 43).*

Similarly using a switch was tiring and tedious for Matthew who described the lengthy process of using the ECS while simultaneously highlighting its effectiveness:

> *So it is I mean it's a long way to do it but I mean it works like (Matthew, line 68).*

Matthew appreciated that the scanning speed could be increased resulting in increased efficiency and less frustration but recalled that he had initially declined to have the scanning speed increased. On reflection he realised he would have preferred this option. Matthew also identified a few ways to improve the functional use of the ECS through changing the menu structure and using different switching sites and different switches. He highlights that such adjustments only become apparent with repeated use:

> *from using it you kind of find short cuts you could say and just have the buttons set-up a bit better. Like certain buttons beside each other as opposed to on a different menu all together … the only way that you see that is from using it and then you can see how something can be made easier … and then speeding it up as well once you get used to it and then perhaps having the button (switch) in a different place (Matthew, line 73-75).*

Despite extensive use of the ECS, James did not use the sound-switch or his mobile phone. His mobile phone Bluetooth® headset could not be paired[213] with the ECS. In addition he was unable to use the sound-switch reliably despite seeing a call system as preferable to a baby monitor:

> *(I) found it very hard to get a setting on my voice. I have a low voice so trying to get it just to (respond to my voice), and I use Dragon Naturally[214] on the computer so I am talking to the computer the whole time and I really had to have the setting a bit higher so that it wouldn't pick up my voice activated software and it was just. I just found it impossible … if I got the right setting for it (James, line 62).*

There is a physical demand involved in using an ECS. Peter suggested that there is a potential for eyestrain when having to switch from utilising the screen of the ECS and the television. The use of a chin switch can also be tiring:

[213] Paired is a technological term for two items of technology that are linked together so that they can exchange information.
[214] Dragon Naturally – refers to Dragon Naturally Speaking a computer software package that allows James to control and input data into his computer through voice activation.

> *Your chin gets pretty sore as well depending on how much you use it, if you are flicking through the stations you can hold the button down so you don't have to keep going back to the scanning through it. If you want to flick through the stations you can just hold it on down and then just click up once and down again and it will scroll down like that because I thought previous that you had to scan, once you press the button it has to re scan again (Peter, line 79).*

Frustration expressed by participants extends beyond the utilisation of the actual ECS to wider issues also. James, Emily, Peter and Bridget expressed frustration with the health system. James had considered applying to the Health Service Executive for an ECS via a community occupational therapist but had not found her to be supportive. His experience highlights the common reality that people with high SCI are unlikely to acquire an ECS through the official channels:

> ***James****: No. I think I mentioned it once the OT I had up here and it was the whole fobbing off thing. That it's a very expensive material ... In other words (pause) jump and get it yourself.*
> ***Interviewer****: Do you think she knew what you were talking about?*
> ***James****: Oh yeah. Well I think she did. She definitely knew what I was talking about. There was um I think, I am not sure what she was thinking, you can't blame her for thinking about it as, there are other people who need more essential things than you need a TV control. But in my eyes (sniggers) I didn't think that at all. I think that was every bit as essential as an airbed for somebody else. Maybe that's being selfish but, you know. It probably is, being selfish like for to get a TV control and take a poor airbed off somebody or. It's all a money thing, so. Hopefully now I will be able to get one myself this time (James, line 195-197).*

Emily too had been seeking her own ECS:

> *getting environment controls in Ireland is a, it's just a joke. I am still waiting for the ones that they assessed me for at the [AT service, satellite clinic] and I am waiting for them through the health board. I was told that they are a priority 4 or something. So um, that's a bit of a pain really. And it's kind of; it's just a kick in the teeth really (Emily, line 192).*

> *The fact then that you don't get them when you are hoping to get them. You know when I got assessed in the [AT service, satellite clinic] I was so happy. I was like I was getting this and I was getting like the socket thing and you know I was thinking oh this is great now I will be able to use these things in my new house. Which obviously did not happen, I did not get that either but then it's just like delayed six months and then its delayed a year and I am just like, "whatever" (Emily, line 203).*

Emily was clearly disillusioned with her experience of seeking an ECS. Her ability to describe a positive experience of the research trial indicates that although she may have had negative feelings about ECS as a result of her failure to acquire her own, they did not prohibit her from having a positive experience during the research trial.

James clearly articulated the difference between what he thinks is essential and what is likely to be considered essential by others:

> *I don't think people look on it as an essential part of a person like me's life* ***[and you?]*** *Oh I think it is (essential) because if you can do all those things for yourself you are taking back a bit of your dependency like (James, line 158).*

James thinks that the cost is prohibitive and that funders are likely to prioritise spending on other priorities like beds:

> *I suppose it's trying to pay for these things, they are not cheap trying to get somebody to fork money out for every person with a high dependence injury … they think the money can go towards something. Something better but, better in my eyes is one of those (an ECS). But better in their eyes is more beds (James, line 158).*
> *It is. A bit of a sticky grey area, you don't, nobody wants to part with money for things that they don't think is an essential part in someone's life (James, line 199).*

These extracts highlights how not being able to do something as basic as turning on or changing channels on a television can become a form of occupational deprivation. These taken for granted abilities are for James as essential as having an airbed to prevent pressure ulcers. He did not blame the occupational therapist for

having a different point of view and in a similar way he excuses the Health Service Executive for not knowing what it is like to not be able to control their television:

> ***James:*** *I wonder what they would feel like if that (the ability to change a television channel) was taken away*
> ***Interviewer****: And they don't really know do they?*
> ***James:*** *They don't, Ah they don't. I suppose you can't fault them for not knowing really (James, line 158-161).*

James accepted the reality that he is unlikely to receive an ECS as a matter of course and was considering self-funding his own ECS. However, he appreciated too that they are expensive and one cannot expect to receive one as a Christmas gift:

> *(I)t's not exactly a book voucher or anything (James, line 60).*

Peter was clearly frustrated by the on-going negotiations around his care package which might or might not include an ECS. *They* want several levels of safety for Peter where *he* would be happy with a simple solution. *They* (the care providers and the Health Service Executive), are overly cautious in Peter's eyes. *He* is frustrated by the level of safeguard required and the relationship between the parties seems to lack a person centred focus. Peter's mother was content with the security offered by the use of an ECS that includes a telephone:

> *My mother said before she would not feel comfortable with me being by myself with nothing set-up for emergencies. But when I explained and showed her the Keo she said that she would be happy and comfortable to have me by myself in the flat so. (Peter, line 188).*

Bridget did not express overt frustration with the system. She instead is disappointed that she had not received an ECS sooner. Her experience of acquiring an ECS demonstrates the arbitrariness of the process which is frustrating to both clinician and client. Bridget reported that she had forgotten she was going to get an ECS and that she had not seen or trialled it prior to its installation. She said that she had been lost in the system:

> ***Interviewer****: And did you know it was coming?*
> ***Bridget****: I had forgotten totally about it because it had been a long time, since she had spoken about it would be a year or so … but then because I*

> *was in [name] hospital for an operation, serious, and then I was seriously sick and ill after it. It just got forgotten and, you know like I had no interest …*
> ***Interviewer**: Did you know what it would look like when it arrived?*
> ***Bridget**: It was a total surprise. I had no idea what it was going to look like or how I could use it or anything about it (Bridget, line 69-72).*

During her interview Bridget suggests that she has missed out on the benefits of having such technology earlier. She is unsure if it had been available ten years earlier but expresses regret that it was not available for her:

> *You wonder why wasn't that there years and years ago (Bridget, line 42).*
> *It's a pity I didn't get it years and years ago … That it wasn't available to me years ago (Bridget, line 101).*

James suggested that providers of health care do not comprehend the benefit that ECS also provide for family and carers. Instead of providing ECS they leave the care burden to others such as personal assistants and family members:

> *I don't know, they, because, I think they think that there is other people that can do that for them. Maybe they just leave the burden on other people to do it (James, line 156).*

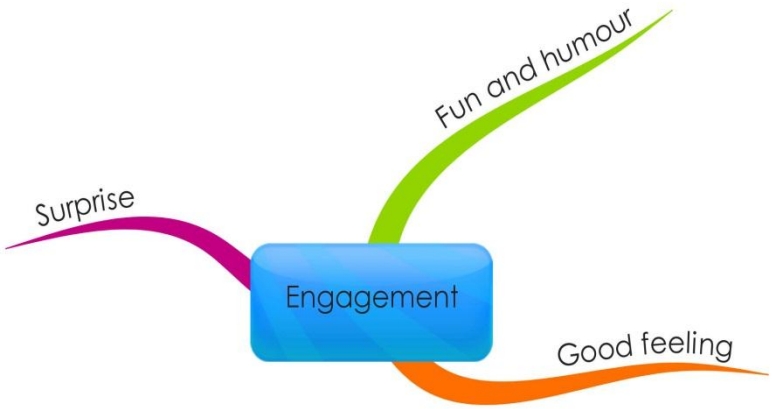
James says that ECS should be an essential part of life for someone with a high SCI in the same way as a powered wheelchair is:

> *(E)everybody should have one of these leaving on discharge. I know it's not.* ***[Do you think?]*** *Well yeah because it would be an essential part of their lives even though it's not. I don't think it will ever happen …. If you need something like that, it's no different from having a wheelchair. It's giving you something. Like a power wheelchair can get you around the house and a control can set you up doing what you want. People would be obsolete soon (laughs) … But um, I did think that if at all possible maybe down the road, I don't know but, I don't think it will happen anytime soon, that people will be given a piece of machinery like that just to turn on the television or to put their lights on (James, line 154).*

1.2 Subordinate theme 2: Engagement

The second subordinate theme of G*etting used to ECS* is *Engagement*. *Engagement* comprises good feeling, fun and humour and surprise (Figure 19).

Figure 19: Elements of subordinate theme 2: Engagement



Getting used to using an ECS was experienced as challenging and is represented by the subordinate theme of *Hassle.* Nevertheless most participants were able to experience *engagement* and the *hassle* was ultimately balanced with positive experiences of feeling good and having some fun. This e*ngagement* required overcoming some of the *hassle* in order to experience the effort as worthwhile. Levels of perceived engagement varied substantially between participants.

While reflecting on the trial during interview Emily, James and Matthew each identified things that they might have done differently. This is an interesting progression from the initial hesitation discussed as *hassle:*

> *(I) probably should have had it like at the start and I know you had said it as well 'do you want it to go a bit quicker?' and I just said 'no' at the start but once you start using it you get used to it so I could have gone a bit quicker (Matthew, Line 71).*
> *I know I did not use the extension lead as much as I should have because I kind of forgot about it. I just used it for that light. I know I could have plugged in plenty of things into it like, which again is brilliant like. So that would be handy too that you can plug fans, heaters, lights (James, line 96).*
> *I think I should have connected more things up (Matthew, Line 201).*

Emily criticised herself for not engaging more in the trial and making more use of the ECS indicating that by completion of the trial she had come to perceive the effort involved as worthwhile. Peter overcame the hassle by becoming used to the ECS thereby making more use of it:

> *Once you get the hang of it, you tend to use it a lot more (Peter, Line 49).*

Bridget was proud of herself for engaging with the technology as she cited her recent medical condition as a possible reason for being disinterested in learning a new skill:

> *So like, you know some people probably, I don't know maybe everybody is different but maybe somebody wouldn't even be interested in it … after just last year being near, you know, near death experience like … you know to a couple of months ago I got this and now I am on cloud 9, you know. So like that's how much it means to me (Bridget, line 168).*

Good feeling

The theme *Engagement* included an element of good feeling. Overcoming the sense of hassle and engaging with the ECS resulted in positive feelings for Bridget, Emily, Matthew, James and Peter.

Bridget's interview is scattered with positive phrases such as *fabulous, that good*, *served me brilliant*, *fantastic purpose*, *absolutely brilliant*, *it was brilliant absolutely brilliant*, *absolutely fantastic, terrific, mad like, and unbelievable.*

While Emily began her interview by describing the initial hassle she also described how she used the ECS and offered praise for them:

> *It's just lovely like. Yeah its nice. (Emily, line 158).*
> *I think they (ECS) are brilliant (Emily, line 201).*

James suggested that he would not like to live without the ECS and likened it to a drug. Like a drug it gives pleasure and fosters dependency. Continuing the drug analogy he suggests that his desires are selfish like the motivations of a drug user:

> *And when I was, like when you give me the piece now to use I don't think I'd be able to, well I will have to go without it for a while but I think eventually I will try and get it because it's like a drug you've given me now. I'll be in detox for a couple of weeks (laughter) Yeah! (James, line 163).*

Similarly Peter described using the ECS as addictive particularly with repeated use:

> *At first with the Keo, I did not use it too much, but then when I was here (the apartment) by meself, and so on, I got used to it, and it grows on you after a while, because you can use it more and more. You get sort of addicted to it as well. (Peter, line 10).*

Being able to control the radio and television gave Bridget a *great feeling:*

> *I'd turn it off and turn on the radio and that gives you a great feeling (Bridget, line 84).*

Matthew in contrast to Bridget and simply referred to his use of an ECS as positive:

> *It's been very positive for me. (Matthew, line 99).*

Fun and humour

The second element of *Engagement* was fun and humour. Engaging with the ECS was enjoyable as it enabled a change of roles and led to enjoyable *messing.*[215]

Emily described *messing about* with the ECS to turn on her lamp or navigate through the television options. This expression implies that Emily had fun using the ECS in an aimless fashion. This messing involved having choices and being able to flippantly change choices without having a reason or needing a productive outcome:

> *They'd (personal assistants) still set the TV for me but I'd use it and I'd kind of just mess around a bit like as in the programme might come on but I might be like, "yeah but I'm not that interested in that" so I might mess around with … Just to mess around with it and usually you'd have an hour anyway to find*

[215] *Messing* is phrase that stems from the English expression *to mess around/about* defined by the Oxford English dictionary as: *behave in a silly or playful way* or *spend time doing something in a pleasantly desultory way: messing about in boats (Oxford University Press, 2011).*

> *something … just like mess about turn up the volume, turn down the volume. To just try get used to it (Emily, line 27).*

James, like Emily, messes with it to get used to it as part of the learning experience. He describes this learning to use the ECS as fun. He describes how making errors while learning was inherently fun as in learning any new pleasurable task. This involved making some mistakes in order to learn but that became part of the process and James reflects that making such mistakes was a bit of fun too. He was playing as he tried to get it right. He used the phrase for a change as he is unaccustomed to having this sort of fun:

> *It was a good bit of fun for a change because you ended up getting a bit frustrated with yourself because you just missed that button by a split second but after a while it was fine (James, line 19).*

For James the fun was not restricted to the functionality - i.e. changing the channels. It was also fun to use the remote. It was fun to have a device to use and play with:

> *I think I like the fact actually of using it as opposed to just changing the channels. You know when you are not used to using a control yourself, to have something for yourself. It um, it's great to have something that you can just go into and just mess around with it (James, line 41).*

He continued to describe the ECS as a new toy in a similar manner to someone describing their mobile phone or game console:

> *It was like, messing around like, it was just playing around. It was like a new toy. And it is like a new toy to someone. It's a good toy (James, line 43).*

Matthew did not talk overtly about having fun using the ECS but acknowledged that the experience of watching sport alone can be more enjoyable:

> *I would watch a bit of sport like. It was a big part of my life before my accident and it probably is equally so now obviously now without physically playing the sport, but um yeah I do, I mean I do like to watch the tablet (television) and things like that the last thing you want when you're watching a soccer match or a rugby match is someone else in the room talking away or answering questions or asking the questions so it is. It's kind of nice just*

> *to have your own time yourself and be able to do all of that by yourself (Matthew, line 12).*

James echoed this sentiment of being able to enjoyably watch television alone:

> *I had it I just had the free rein to do anything on sky. I could, it didn't bother me like, and I did not have to have someone looking over my shoulder while I was watching, not that I was watching anything that I shouldn't of been watching (James, line 33).*

Surprise

Surprise was the third element of *Engagement*. The new ability to do things was sometimes considered amusing as it facilitated a change in roles for the participants who had become able to change the television station or answer the phone for a carer or family member. This change is surprising and comparable to the experience of a young child eliciting laughter while doing something for the first time because the action is both unexpected and joyful.

James described the humorous side of being able and taking people by surprise when he answered the phone. This indicates how James, his family and friends have become so accustomed to his inability to initiate activity that it comes as a surprise. He enjoyed surprising them by doing a task considered simple and routine by the able bodied:

> *But to hear the house phone ringing and for me to answer it - it's funny to hear people's reactions when I do answer the phone. To have somebody who probably hasn't heard James answer a phone in about 11 years answer the house phone … 'James! Are you alright?' I'm fine are you ok like? To hear even the first time like. My mum went to town to do some shopping and she rang the house phone for something and it was me that answered (James, line 176).*
>
> *I would have given them (friends) that number just for them to ring it just to test it out like and when you do pick up yourself and you just answer the call and, you go "hello" and they go "it's weird to hear your voice". Instead of, "hold hold on hold on I'll get him for you now", but um yeah it was fun - a fun experience (James, line 186).*

Bridget too, found humour in her new-found ability which surprised and altered things for both her carer and herself:

> *Because he realises the enjoyment I get out of being able to, you know and, I think we can actually have a laugh about it. At the idea of me being able to, (chuckles) being able to turn the telly on or turn it off or turn it up or turn it down and then pause it and you know, change the channels and then switch it off and on to the radio and change stations and he thinks this is great that I actually can do these (Bridget, line 103).*

James described how he was able to catch his parents out by turning on and off a light:

> *I gave a couple of frights as you do. People would be in and they did not at first my mom and dad did not know that I could use the light socket they just thought I could use the TV and the phone. (Laughter) but um yeah if they come in to give me tablets or something, I knew myself that* ***[They did not know?]*** *No, that … would be a bit of a laugh like so. I just flick the light on (laughs) and then flick the light off again. Ah it took them about ten minutes to cop (James, line 92).* [216]

Peter also engaged in banter with his father by changing the television channels unnecessarily:

> *I just used to irritate him a lot with it as well, on purpose and stuff … yeah keep changing it just to annoy him, it's good (Peter, line 196).*

Both Peter and James joked about their family being lazy and not wanting to constantly provide help:

> *I think my family is pushing me to, "that would be worth the money you know". I think it's through their laziness somehow (laughs). They don't like turning the control. They are pushing me, they are pressuring me into buying one (while laughing) (James, line 58).*

[216] James used the phrase *to cop* meaning to realise, and understand what is going on. In this case they are not aware that James is controlling the light and it takes them a while to realise this -*to cop.*

> *And everyone else, I think they got relief that I don't ask them to do it anymore, especially my dad. He doesn't like doing much anyway (chuckle) (Peter, line 188).*

Both the person with high SCI and their families have become accustomed to a dependent relationship but the ECS changes that dynamic. The acceptance of this situation requires effort on both sides. Now that there is an alternative the carer can be *lazy* and prefer the user to *do it themselves.* This allowed for an exchange of banter about not wanting to ask for or provide help.

For Peter, humour was used to reflect the playful nature of the relationship with his father. He diffused the annoyance of having to ask and having to do by making light of the situation by complaining about how lazy his father is and how his father valued the ECS just because it lightened his workload. It is also possible of course that his father was happy to see Peter doing something himself and rather than directly expressing his pleasure he focuses on the relief that he gets by indirectly praising Peter's ability to do something for himself by using the ECS:

> *Yeah he (father) thought it was the best thing ever. (Chuckle)(Peter, line 194).*

The experience of engaging with the technology did not match participants' expectations. Expectations included not being able to get used to the technology, not expecting technology to be necessary, and the technology not being personally relevant. Participants were surprised by the enjoyment experienced by use of the ECS. They discovered that they could do more with the ECS than they expected, and that doing so was easier than expected.

There appeared to be a low expectation for AT prior to the trials. James expected the ECS to be an eyesore and is surprised that it looks like part of his wheelchair. Matthew thought his options were limited and that voice activated ECS were not efficient enough:

> *I've always been looking out for probably more so voice activated but I don't think that is just there yet … because I am limited movement wise you will always be limited to the amount of things that you can control (Matthew, line 5).*

James was surprised both by his ability to do more (the functional change) and by the technology itself. He had not expected the ECS to be so simple. He recalled seeing and using an earlier ECS during his rehabilitation but considered the trial ECS to be far more suitable for him. He thought:

> *There is no way I am going to get the hang of that thing (the older ECS controller) that used to, I know that had a lot of menus on it and you had to get used to everything. But, um this (the Keo) it's so much simpler so much (more), compact like it's not an eyesore it's just. It's good (James, line 140).*

James had considered ECS to be unsuitable for him based on his initial exposure:

> *Yeah it was in the rehabilitation. She showed it to me briefly it's like a rectangular little box and it had ABCDE but think it was. When she was asking me to use it I just found it, difficult. A lot more difficult than this one anyway. There were no pictures on the screen to guide you onto the next menu and I am sure if you took the time that you probably would get used to it. Maybe I just did not have the time … maybe I was, I was only shown it briefly … so obviously I wasn't going to pick it up that fast but I did answer a phone with it .... And dialled out (James line 191).*

Emily had recently received a recommendation for that same ECS controller with a complex static display that requires the user to memorise several functions. Both Emily and James considered it too difficult to use and not aesthetically pleasing:

> *I'm sure you get used to the red one (older ECS) if you were like using it for, year or something but, you know what I mean with all the numbers and there's no, and you have to remember what's under each number. But this (the Keo) is just, just easier, it's just nice (Emily, line 158).*
> *Yeah because under the 9 boxes you have you know your TV your DVD and you can see what each one is where as with the red box it's a number and you have to remember what's under the number you know so, I just think that the design is better. That's what it is, yeah the design is much better and the fact then that you can just turn it on and it goes off as well, goes off by itself and you know it's just a better. It's a nice size (Emily, line 160).*

> *I think the last piece of environmental controls I did see was the piece 10 years ago and that just looked ugly. That (the Keo) doesn't (James, line 163).*
> *It's too bulky (James, line 193).*

In contrast James liked the small switch that he had used mounted on his wheelchair chin control:

> *I think this (mini cup switch) was just more, tidier actually. You can't see it at all actually. Yeah that was great (James, line 120).*

Patrick expressed an interest in using the technology but ultimately it did not meet his expectations:

> *Anything that I'd be able to use is a big advantage, you know all them things, they are a big advantage (Patrick Line 140).*

Unlike Patrick, the other five participants were surprised by both the workings of the technology and the impact it had on their lives. All expressed an initial element of hassle as described above leading to some hesitation in their individual expectations for successful use of the ECS. Thus when they actively engaged in using the system they were surprised.

Bridget explained how she appreciated the ECS because she had lived without it and had now mastered it. She had become accustomed to using an ECS although she may have had no idea of its potential before acquiring it:

> *that in itself is great and its only when you haven't got it and then you get it being able to use it and master it like I have that means a hell of a lot to me. It's fabulous (Bridget, line 145).*

Bridget had been living with high SCI and without an ECS for 36 years. The experience of having an ECS was unexpected and unbelievable:

> *And that's, that's great, that's unbelievable like. To have that feeling after years and years that's mad like. That's a great feeling you know for*

> *somebody like me, you know. It's great … so simple and yet so brilliant (Bridget, line 88).*

Bridget identifies her successful use of the sound-switch as the reason for her changed expectation of technology. She had not anticipated her own ability to master the new technology as she is not technically minded. This in turn changed her personal expectations for her use of a laptop:

> *It's (her attitude to technology) changed since I got this … Actually since you brought your equipment to me … its changed because I saw what the technology was there … and the, the speech … (sound-switch) switch and I thought well if that's there, there's other things, you know that I could handle or master … and even though I couldn't really get to grips with It … And um, then when I got this, and I mastered it. I thought well, you know which somebody like me wouldn't be very (pause) technically minded. I did get the hang of it, so like, I can eventually when I get going at the laptop I will (Bridget, line 131).*

Mathew wanted an extensive voice activated ECS that is not purely computer based. In his opinion while no such system exists, it should be a reality because of the advancement of computer base voice activated software:

> *It would be fantastic like to be able to control TV or lights or radio or whatever, skylights anything like. If the voice software works on a computer it just, it just doesn't, it seems ridiculous that it can't do more stuff than that (Matthew, line 37).*

Matthew thought that ECS should have functionality similar to mainstream products such as voice activated software. He suggested that the advancement of mainstream products should advance assistive technology as the markets merge and able bodied persons make use of products that are suitable for people with disabilities:

> *But its still, it's like as if it's, I mean, with all of the things that you can get now you would imagine that you could just literally get something that's ideal and perfect but it's just I suppose there isn't as much demand for it, its obviously, well for people with disabilities as a start, it's obviously a limited*

> *amount of a limited market there. Even I suppose what's slowly happening with Dragon.*[217] *I find is that some of my friends are using it that obviously don't need to use it. Say just purely for dictation in word or writing up reports and its great so I think the more people start using it that don't need it the quicker it might develop and I mean that would be great (Matthew, line 91).*

Bridget's involvement in this trial has increased her expectations of the potential of technology for people with spinal cord injuries. She had incorrectly assumed that technology is now readily available for people being discharged from rehabilitation. For her it makes sense that discharge would include technology. She is unaware however of the reality of current discharge policies:

> ***Interviewer:*** *And people going home now, say newly injured, what do you think of this technology. What's your opinion about this technology in connection with people who are going home?*
> ***Bridget:*** *Oh, they won't know themselves, absolutely; they will not know themselves it will be brilliant for them, for people, quadriplegia paraplegia that would be coming home now with all the technology that's out there now. You know it will be a whole new world, do you know, it's going to mean so much to them that they won't know themselves. It will be. They will not be like me because I did not have anything … and now I have it. (Bridget, line 142-143).*

James had great expectations for assistive technology when he was discharged from rehabilitation. He mistakenly had expected his wheelchair to have some ECS functionality:

> *I always thought that when I came out of hospital that, that (my power wheelchair) would be turning the TV on and doing things. But um I don't think that it does it just puts the lights on, on the chair (James, line 167).*

James' expectations of assistive technology have changed since then and he contradicted this expectation when he talked about how one would not expect him to be capable of controlling his environment from his wheelchair:

[217] Dragon – Dragon Naturally Speaking, voice activated software for computer control and input.

> *(Y)ou wouldn't think to look at my wheelchair now that I myself can use Sky,[218] TV, radiators heat anything like that. You wouldn't think to look at, that I could use things around the house with that (Keo) (James, line 140).*

James was surprised that he could control digital television using the ECS. He had imagined that something could do so but thought it was not a possibility:

> *I remember maybe I don't know two or three years ago I used to say to someone, 'wouldn't it be great if somebody had invented something that would go through the menus in Sky (digital TV provider)' which looks so simple when you do it by the control (James, line 136).*

Emily had not expected to use the ECS to navigate her television as she was accustomed to watching preprogramed television. She was surprised when she remembered that she could change channels despite the preprograming and enjoyed doing so:

> *They'd (personal assistants) still set the TV for me but I'd use it and I'd kind of just mess around a bit like as in the programme might come on but I might be like 'yeah but I'm not that interested in that so I might mess around with the, you know like go up and down and select things go out of it (Emily, line 27).*

James' parents were also surprised by his ability to be alone using the ECS and they tended to check on him out of habit:

> *The only time when my dad would come in would be to check and see if I was alright because they would be so used to me calling and when they did not hear me calling I suppose it took a while to get used to that to. So they would have to pop their head in every now and then just to see, "are you alright?" (James, line 35).*

[218] Sky, British Sky Broadcasting Group, a pay-television satellite broadcasting company operating in the United Kingdom and Ireland.

2. Superordinate Theme 2: Taking back a little of what you have lost

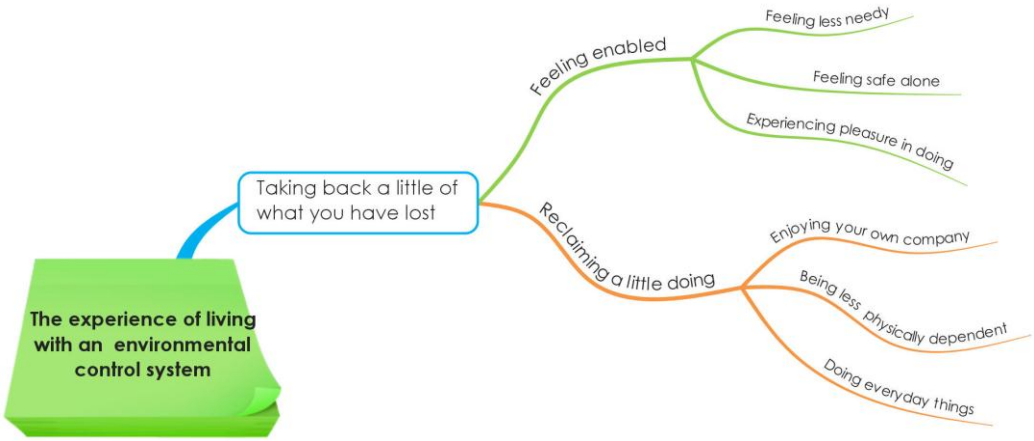
The second superordinate theme is *Taking back a little of what you have lost*: This theme originated from a quotation by James:

> *Oh I think it is because if you can do all those things for yourself you are taking back a bit of your dependency like. Taking back what you lost. You are getting something back. I know it's only to turn on a television or put on a light but it is something a person does every day. An able body person do(es) every day (James, line 158).*

This theme represents the benefits arising from having engaged in use of the ECS. *Taking back a little of what you have lost,* has two subordinate themes namely: R*eclaiming a little doing* and *Feeling enabled*. These two themes represent the practical and the psychological benefits experienced by participants in the study. The five participants who were able to *engage* and overcome the *hassle* of *getting used to* using an ECS experienced this second superordinate theme and were able to *reclaim a little doing* and experience *feeling enabled*. The components of *Taking back a little of what you have lost* are represented in Figure 20.

It is only *a little* that they can take back and only a *little* that they can do. The participants used several words to describe the extent of the change involved: *it's only a small task like turning on a TV programme or turning on a light (Emily, line 54); small bit of independence (James, line 126); that bit of freedom (Peter, line 183); it might be only something tiny that you can do it yourself (Emily, line 133); given me a little bit of independence (Matthew, line 21); makes you that little bit more self-sufficient (Matthew, line 43) that little bit of independence (Matthew, line 37); you need a little bit more independence for yourself (Emily, line 46); a great bit of freedom … that bit of independence (Matthew, line 7); small bit of freedom (James, line 132);* and *feel a bit more comfortable (Matthew, line 63).*

Figure 20: Phase 3 superordinate theme 2: Taking back a little of what you have lost



While the magnitude of change was described as small, this was only in contrast to having no or almost no ability. They are therefore *big* things for the participants as explained by Emily:

> *They are only small things. They are like tiny things to people who are able to do them but they are big things to people who aren't, you know?(Emily, line 131).*

It follows that they also paradoxically use antonyms referring to the experience as huge or big: it makes a big difference (Bridget, line 103 + line113), it's a big help (Bridget, line 154); it would be a big thing, for someone like myself to have (Peter, line 123); it would make a huge difference (Matthew, line 37) it obviously would make a huge difference (Matthew, line 57). For participants the change is considered small in quantity but with a paradoxical substantial impact.

2.1 Subordinate theme 1: Reclaiming a little doing

The first subordinate theme of *Taking back a little of what you have lost* is *Reclaiming a little doing* (Figure 21). It encompasses doing everyday things, enjoying your own company and being less physically dependent.

Figure 21: Elements of subordinate theme 1: Reclaiming a little doing

A person with a high SCI can physically do very little and *doing* often becomes a cognitive task. For example Matthew described how he was restricted at times to thinking about how to use the pack prior to actually using the ECS. (This was because he was reliant on someone else to set it up for him). When Matthew woke early he lay in bed thinking about how he could *do* things:

> *I could be lying in bed at night like if I am awake which I might wake I might wake an hour before I have to get up, and my head, I'd just be thinking of stuff and then you go, "Yeah I wonder?" (Matthew, line 19).*

As a consequence of her physical deficits, Bridget's daily interactions for the past 36 years relied primarily on verbal description and request. In contrast using an ECS was a physical task that Bridget unexpectedly can do. The physical nature is proven by Bridget's inability to describe how it works without a physical demonstration:

> *It is difficult it's difficult to explain how it works without kind of showing you. You know showing you would be (easier than explaining) (Bridget, line 45).*

Doing everyday things

Doing everyday things was one of the elements of *Reclaiming a little doing*. Bridget talked about being able to do things that she hasn't been able to do for 36 years. Using the ECS was a physical activity that involved doing and, despite her physical limitations, she was able to do by using it and no longer needed constant assistance:

> *That's a lot, because when I can do that now meself. I don't need somebody standing beside me all the time having to actually physically do everything for me, you know (Bridget, line 88).*

Bridget could 'do' television, radio and telephone:

> *I don't want to look at you (television), I'll turn you over to something else. Or I will turn it off and I will listen to the radio. Or I'll, do like Chris Tarrant and I'll phone a friend. (laughter) I can be. I can pick up the phone and* ***[and do you?]*** *oh yeah! And have a chat (Bridget, line 86).*

James and Emily identified a range of simple things that could be done with an ECS:

> *Something to help you turn on the light, turn on the television, turn on the stereo (Emily, line 129).*
> *Like switching on a light. I never thought it would be that simple really. You know I never thought it would be that simple and I know you can, there's a way of pulling curtains and things as well. I am not sure now but that would be great too (James, line 98).*

Emily, James, Peter, Matthew and Bridget all identified browsing through television channels as a common past time enhanced by use of the ECS. Watching television is inherently solitary and enjoyable. It is an activity that involves surfing channels and selecting programming options if using digital television systems. Watching television in this normal way was facilitated by using the ECS to programme and surf channels like:

> *an able bodied person could, like you know, without even thinking just flick the switch go up and down on the channels to see what's on. Whereas I used to have to call [partner] for to do that for me (Bridget, line 113).*

Doing this is in stark contrast to having to call someone and *have someone looking over my shoulder* or becoming *stuck* watching something one is not interested in:

> *When I was using Sky (digital television) it was frustrating having to call someone every hour to change the channel as opposed to when I had it I just had the free rein to do anything on Sky. I could, it didn't bother me like,*

> *and I did not have to have someone looking over my shoulder while I was watching (James, line 33).*
> *You are not stuck with looking at something that you don't really want to see (Bridget, line 84).*

Emily also identifies the choices made available by ECS. As a result of using it she can make spontaneous choices to phone whomever she wants or watch whatever she likes:

> *And it gives you an option as well, if (you) want the light turned on, if you want the TV turned on or off. You might have a headache. You might want to turn the television off (Emily, line 129).*

Matthew also identified the notion of *doing television:*

> *Just be able to do what you want on the television (Matthew, line 14).*

Television and radio was important to Patrick as it was for the other participants. However, not having an ECS did not limit his television watching as he was able to ask his wife to change the channel. He watched television during the night using ear phones as he had difficulty sleeping. His wife slept in the same room:

> *Well I watch the TV as well its only occupation that I have. You know it keeps, you know, how shall I say, it I suppose it keeps my mind busy to a point (Patrick Line 23).*

Television and radio provided entertainment, cognitive stimulation and a link with the real world and current affairs:

> *I watch the television alright but otherwise you know your mind will go a bit (Patrick Line 19).*

Patrick was reliant on his wife to change channels so that he did not become stuck watching something he would rather not. He acknowledged that his wife disliked being woken at night to change the television channel as she could not go back to sleep. Although in the same sentence he explained that this was necessary:

> *You know I only call [wife] in for a second to change. It might be different in bed because maybe [wife] might have to get up to change a channel or I'd have to wake her, she have the remote outside of the bed - she can change the channel. But you know you get tired of one programme and you'd rather go to another channel (Patrick Line 32).*

Bridget watched television in a way that she considered to be like a normal person. Television was important for Bridget as it facilitated her social inclusion. She felt able to converse as a normal person as she had the same information as others and therefore shared their leisure experience of watching television. In social settings her oral proficiency overshadowed her inabilities:

> *I meet people the next day. I am not a social outcast. I can chat and talk and I don't feel, um, I don't feel as if, for want of better word, as being an invalid that you can't co-operate with anybody you can just sit and chat with anybody with able bodied people. You know, what you saw last night (on television). You can have a chat about the soaps, and you know and the bit of craic that's going on in them … world affairs comes on at least you're not sitting in the corner, you know, when everybody else around you is talking about stuff they would know about. Well at least I would know about them as well, you know? And that makes me feel, a fair good bit part of being able to live like a normal human being as well. And even if I go out, when I go out to the shops and meet people and you know and they chat to me. At least I can co-operate and chat with world events. I can be the same as they are (Bridget, line 91).*

Television and radio provided an important link with the real world. Television is a source of information and relaxation and is an occupation that can be shared with everybody else thus providing an escape from disability and isolation as described by Bridget:

> *Because I can interact with the world on TV. Because I can, I can enjoy looking at soaps for a bit of relaxation, I can go and look at the serious stuff by looking at sky news or CNN, looking at world affairs or RTE 9 o'clock news and see what's going on. You are not actually confined to a bedroom, in [village]. You can forget who you are and the way you are because you are looking at the outside world the same as everybody else is … when they*

> *are in at night home from work and look at, there are a couple of million people looking at the same thing and I am actually one of them that can look at these current affairs and world affairs and join in then what I would see that night on (television) … soaps … world news (Bridget, lines 90-91).*

Bridget likes music and enjoyed the ability to control the radio which she always had on in the background. The first thing she did in the morning was to switch on the radio using the ECS:

> *Yeah oh yeah the first thing in the morning the radio goes on* ***[Aha! and you're the one who puts that on?]*** *I put that on yeah.* ***[Whereas before?]*** *Before I'd have to wait on [partner] to come and put it on. So it's fabulous (Bridget, line 93).*

James initially did not choose to control his DVD player as he said he was unlikely to use it while alone. However after using the ECS for one night he asked to have it added to his system. He explained how having control of the DVD player enabled him to enjoy watching box sets as he was able to navigate through the entire disc without help. This use of DVD technology is taken for granted by most people:

> *Actually yeah I started watching box sets. So I think I started watching Smallville (television series). My friend gave me the seven seasons (laughs). That's what I have been doing! For the last, I'd go to bed every night and I'd have this and I don't think that dad would have appreciated coming in every 40 minutes or every hour or something for a new episode. And it was great that if I missed something. You know when you're watching a box set I can just flick back and I got them. So I never really missed anything so. It was great for that (James, line 205).*

The five participants who engaged with the system used either an IR land-line telephone or their own mobile phone linked to the ECS. Using a telephone is typically a solitary private task. However making a call without an ECS for participant's necessitated assistance. Thus being able to use a telephone independently was novel:

> *to be able to ring somebody without having to get somebody out, gave me my own independence again like so, I never had that I had to get someone*

> *to dial my phone for me but I didn't when I was making a call from the phone (IR phone) over there (James, line 31).*

Bridget highlighted the fact that she can now use the telephone independently:

> ***Bridget**: Oh yeah the phone is, the phone is great now. I wouldn't be that big a talker on the phone. But as I said it's there if I, when I need it and if I need it and it's there and I can use it when I need it, you know.*
> ***Interviewer**: Is there a difference in how much you used it before and now?*
> ***Bridget**: Oh, well, no, but the point is I can use it on my own now of course, you know. Where before I would have to get [partner] to*
> ***Interviewer**: So it's a different experience using it?*
> ***Bridget**: Yeah it's totally different experience, to me because I can be independent of getting somebody to make phone calls for me (Bridget, line 95-105)*

Emily also referred to her newfound ability to use the ECS with her mobile phone to chat to her sister or friend when desired.

Being less physically dependent

Being less physically dependent was also an element of *Reclaiming a little doing* (Figure 21) ECS enabled participants to do things for themselves without having to call anyone. They had become accustomed to being unable to *do*. The reclaimed pleasure of being able to do something independently was a common theme for participants: *Just to be able to do something (Emily, line 29); Again it's to be able to, the independence to do it yourself like, to be, to be able to do all these things (James, line 98); I can actually do it myself (Bridget, line 91);*and *It's just good to be able to do things yourself (Emily, line 56).*

James reflected on his experience of having to return the *Keo* to have the battery replaced. Being without it meant that he was *not able to do what I wanted.* He lacked the ability to make immediate choices and exercise executional autonomy. He acknowledged that he could *do what I want* without the technology but this involves using decisional autonomy and having *someone else to do it for me*. He himself made this important distinction between requesting someone to do something for him (decisional autonomy) and actually doing something for himself and by himself (executional autonomy):

> *When I sent it back there that week it was frustrating because not to be able to do what I wanted to. Like I still do what I want to but I'd have to get somebody else to do it for me, which was frustrating (James, line 37).*

James appreciated the ability to *do it yourself* and enjoyed doing so:

> *Having it (ECS) is you just have that, you can do it yourself and I like doing things for myself and when you can't do that it's frustrating (James, line 54).*

Enjoying your own company

Enjoying your own company was another element of *Reclaiming a little doing* (Figure 21). Being able to spend some time alone was a type of solitary doing referred to by participants. The ability to simply enjoy their own company was novel and became possible because they were able to call for help and therefore manage without having someone in the same room. Being alone encompassed therefore the experience of some privacy. The ECS reintroduced the forgotten novel experience of being able to be alone:

> *I suppose I didn't realize what it's like anymore to be on your own because I am so used to having somebody there and not that I want to be on my own all the time, but it is, its, I actually had forgotten what it's like just to kind of have nobody here or nobody in the room (Matthew, line 14).*

James had not been able to be alone for over five hours for a decade:

> *It was great that I could use that and I didn't need to call anybody and I could spend, I actually did spend up on five six hours without anybody coming near me and it was handy because I had never had that, in about 10 or 11 years I'd say (James, line 5).*

For Matthew it was not even about being alone in the house but just being alone in a room. He was accustomed to always having someone else in the same room as himself:

> *Nobody in the room and just be able to do what you want on the television (Matthew, Line 14).*

This precious time alone is in stark contrast to the rest of his day which is highly organised and procedural involving many carers, nurses, family members and work colleagues. The ECS gave Matthew the ability to be alone for *an hour* or more. This was especially important for him when he was watching sport on television:

> *It's the only time during the day that I don't have somebody with me. I have somebody with me from 9 to 5 basically every day and then at home. So it is it's kind of nice to give you that bit of independence as well (Matthew, line 7).*

Matthew made the connection between being alone and independence and almost uses them interchangeably above. Emily also reflected on her newfound ability of being able to choose to be alone:

> *So you don't have to depend on people to be there around all the time. You can say to somebody, "Oh yeah, go out, don't worry about me. I'll be fine" (Emily, line 135).*

Time alone was an opportunity for participants to enjoy their own company a rare occurrence for persons with high SCI. Peter spoke passionately about being alone:

> *Peter: Ah I'd love it!! I like being by myself* ***[Why?]*** *don't know. It's just peace and quiet. People don't irritate you and everyone likes being alone* ***[Do you think?]*** *Yeah definitely. Everyone likes their own space and to do what they want as well. I get, I don't like people around me the whole time. I like my few hours by myself (Peter, line 135).*

James battled to articulate what the ECS gives him. He resorted to describing it as allowing him some time alone:

> *Probably a g-d send to me anyways, and also to my family because it actually gave me the small bit of the (pause), I mean I could be in the room on my own which I couldn't be beforehand and I could use the Keo (James, line 3).*

For Matthew there is however a limit to his ability to be alone:

> *Well just purely that I can be on my own. I can be self-sufficient for a period of time (Matthew, line 10).*

> *It just gives me that time on my own (Matthew, line 84).*

He has people around all the time which makes even a short time alone valuable:

> *Well just to even, just even being here like spending a bit of time on your own. Like as I said I always have somebody around me. Nurse comes in, in the morning gets me up. Go up to the breakfast mom and dad are there. My PA comes over at about nine she's with me until five, I am in work until five. Come home. Have dinner and stuff so there is always people around. And to be honest I don't, I wouldn't feel comfortable anyway being on my own for longer than three quarters of an hour or an hour just purely if something, my catheter blocked or I mean I can spasm, my arm fall off the chair, or I don't know just little things like that that I just wouldn't be comfortable spending too long on my own. But it is nice to have half an hour or an hour on your own. It just you are with people all day everyday so it is just nice to have that quiet time to yourself (Matthew, line 41).*

Matthew was quick to add that he doesn't seek this solitude all the time and he appears to be both accustomed to and comfortable with not being alone Likewise Peter has people around him all the time and thus enjoyed the contrast when he was alone:

> *Some people are different; maybe they want someone around them all the time. I look forward to my time by myself as well yes (Peter, line, 145).*

Peter described how an ECS is necessary if he needs to be alone as it enables him to call for help:

> *So it (ECS) could be a necessary tool to have, if you are by yourself for long periods and stuff (Peter, line 123).*

In contrast to the help provided by others which involves a constant presence technology can be less obtrusive and one can *just leave it there*, close by available to be used when the need arises:

> *Yeah. I just leave it there and if I feel like turning on the telly or if I wanted to turn the station to anything or if I got fed up looking at it (Bridget, line 84).*

Being physically dependent on people limits privacy while using an ECS provided a little privacy. Emily highlighted the importance of privacy throughout her interview. She wanted her use of the ECS to be a private matter:

> *Privacy is a big thing with me and my own, like, private area. I'd have the privacy to do with the environmental controls things that I wanted to (Emily, line 115).*

James was frustrated by his lack of privacy as he used a baby monitor that was always turned on and would have liked to have had an alternative such as a call system (which he was unable to use successfully in the trial):

> *Privacy! It would be great like if you had something that would work. If it worked right like. Privacy of me being able to be on my computer or on the phone even. To make phone calls with friends and NOT have somebody listening. I have got a monitor but everybody can hear it. They are outside listening to it, they know what you are talking about and its nice (to) call up friends and, not that I have any big secrets, but you know to have the privacy or even get a phone call from somebody. To receive a phone call from somewhere, be able to answer it yourself. Which I could with the phone but they can still hear you outside (James, line 66).*

While Peter was accustomed to being dependent on others he was particular about who he was dependent on. He preferred to maintain an element of privacy and control. For example he would have preferred an alarm system that did not involve an outside company but rather relied on his own support network of family and friends:

> *You don't want to be hassling, other people through a, through this call system, whatever, they were talking about that, it rings the company and then they ring the number. You don't want to be hassling people too much. You want to, to be able to control it yourself. Be more independent and automatically ring the number on your phone and if not to change to the next number (Peter, line 133).*

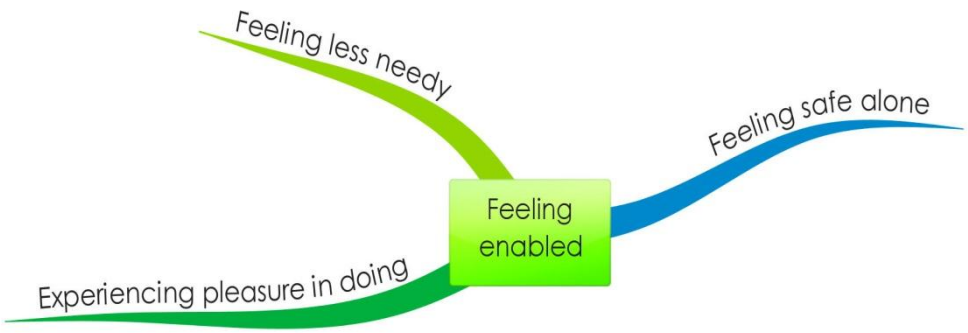
Matthew's tone was a little surprised when he described the experience of being alone which he referred to as having his own space and quiet. Space provided privacy which was novel for him as he usually had people around all the time:

> *Just to have my own space because I **never** have my own space, but just to have your own space and quiet (Matthew, line 7).*

2.2 Subordinate Theme 2: Feeling enabled

The second subordinate theme of *Take back a little of what you have lost* is *Feeling enabled.* It encompasses the emotional aspect of what it feels like to be able to take back a little of what you have lost. There are three components to *Feeling enabled*: experiencing pleasure in doing, feeling safe alone, and feeling less needy, as depicted in Figure 22.

Figure 22: Elements of subordinate theme 2: Feeling enabled



Experiencing pleasure in doing

Feeling enabled included experiencing pleasure in doing (Figure 22). In describing her experience of living with an ECS Emily included feelings. The ECS evoked an emotional response of feeling good and feeling better about yourself:

> *You feel better about yourself because you are doing it yourself (Emily, line 52).*

Using the ECS facilitated the regaining of some ability and this was pleasurable. Being able to do something herself without calling for help is a great feeling that reminded Bridget of what it felt like not to be dependent which means so much to her:

> *Looked at the clock and I needed, or knew a programme was coming on at 3 or 4 o'clock. I don't have to be calling him I can actually do it myself and that in itself is a great feeling, you know, as I said it's like a feeling that I had. It's actually like as if I had before I was, I became dependent on everybody for everything and this is the one piece of technology that I've got that has made me independent … has made my life an awful lot easier and better and mentally and physically better. Its, its, it means so much to me. You know it's fabulous (Bridget, line 78).*

Bridget's ability to do something was a source of pleasure for her. It was a joy for her as she could do things she thought that she would never do again thus removing an element of occupational deprivation:

> *Its great independence. Mentally it's, it's you get a great joy it's like you get a great kick out of it. You get a great feeling that "I can do this on my own" you know. Look at this it's fabulous I can change the stations. I can do something that I wasn't able to do, um, that I could only do 36 years ago … when I was walking around you know. I could physically do, turn on any telly when I was walking around and now in the last … 7 weeks, I can do it again on my own without the help of somebody else. After 36 years its amazing how independent you could feel. It's absolutely amazing, do you know? To think that you can, you know, do something for yourself … mentally it means an awful lot (Bridget, Line 76).*

Using the ECS provided James with a simple pleasure. Both his caregiver and his family appreciated the value of the ECS for him as it gave him the ability to do something:

> *(The personal assistant) he was impressed with it like. I am sure he is like mom and dad that it's good for you to have something yourself that you can do like (James, line 142).*

Emily echoed this sentiment explaining how *it makes you feel good:*

> *(ECS) make you feel more independent because you can, it's just the fact that you can do something, it might be only something tiny that you can do it yourself. And like whatever, four months ago you would not have been able*

> *to do it yourself without it … It's just nice to be able to do something especially when you, when you physically can't do it. So it's nice to just be able to have something to help you do it … It makes you feel good (Emily, line 133).*

This experience of pleasure is related to the theme of engagement which includes having fun by messing. There was an element of getting your own back as participants used the ECS to change television channels, answer phones and switch on lights when their family, friends and caregivers did not expect them too (see engagement).

Feeling safe alone

Feeling enabled included feeling safe alone (Figure 22). Participants were enabled to have their own space while feeling safe. This element of *Feeling enabled* overlaps strongly with the element of enjoying your own company that appears as part of *Reclaiming a little doing*. It differs in that it represents the emotional feeling of safety when able to be alone as a consequence of having an ECS. In contrast enjoying your own *company* encompasses the act of choosing to be alone and the enjoyment thereof. This too has an emotive element and could be presented as part of *Feeling enabled* but it fits more closely with the sentiment of *doing* and thus appears as part of *Reclaiming some doing.*

Privacy was facilitated by feeling safe alone. For Bridget and Peter the ECS facilitated a sense of personal safety and security for times when they would be alone. Bridget felt less vulnerable when she was alone and she praised the call system as being *a third person*. Being able to use her voice to activate the sound-switch that activated the personal alarm made her feel less afraid:

> *I'd love to have it like, you know (the soundswitch). As I said it's like a person, another person in the house being able to walk around, if I got in distress or if somebody was coming to the door that I would see that [partner] was down the yard … It made me in a way, that I was not afraid because I could call for help so quick (Bridget, line 15).*
>
> *As I am a person who is not able bodied. So that's how good the time switch (call system) was for me. As I said it's like a third person in the house so both day and night it has a fantastic purpose and it served me brilliant (Bridget, line 17)*

Peter valued the ECS for the security it offered. When asked how he would feel when the GrEAT was removed Peter answered he would lose *some extra peace (Peter, line 200).* His family needed to find a way that Peter could be left alone while being able to summon help if he required assistance or suddenly experienced one of the adverse consequences of high SCI such as autonomic dysreflexia. Peter's mother was content with the security offered by the use of an ECS that included a telephone:

> *My mother said before she would not feel comfortable with me being by myself with nothing set-up for emergencies. But when I explained and showed her the Keo she said that she would be happy and comfortable to have me by myself in the flat (Peter, line 188).*

Following the trial Peter concluded that an ECS would be able to provide the necessary security that would enable him to be alone:

> *If I needed I could cut back on hours some places, if I felt more secure with the Keo or different device (Peter, line 147).*

His use of the words: *If I need to cut back* indicated that he was ambivalent about substituting human assistance with assistive technology. This may reflect his involvement at the time of interview in negotiating his care package. A care package would not typically include a comprehensive ECS. Although Peter liked the idea of cutting back hours he was not sure if this was a real possibility and if it would be sufficiently safe and reliable to satisfy care providers. While Peter talked about spending time alone he still had someone close by when he was *alone.* He anticipated that, despite the plan for him to spend some time without care, it was likely that *somebody* may need to be available during this time:

> *Yeah been by (myself) once or a few times but only for half an hour, or an hour, but there is always someone around or the next door or something. When I move in I think there is an hour and a half gap in between, but I think somebody might step in for the meantime. I can have, I can call an alarm system if something happens (Peter, line 125).*

Peter was even considering spending nights without care if he had an ECS, *if I was here by myself at night time* (Peter, line 167). This appeared unlikely despite it being

physically possible as there was no precedent nor understanding of the possibility of him being safe alone with technology. It is more likely that he will receive more care hours and no technology. Emily, like Peter considered being left alone with no one else in the house in the future. However, neither of them had expressed much conviction about this possibility nor was it voiced as a priority, despite it being physically possible. The participants were all accustomed to physical dependence on others and did not view technology as a safe substitute as they had no experience or evidence of this as a possibility. They are unaccustomed to feeling safe alone:

> *I am so used to having somebody there (Matthew, line 14).*
> *There is always somebody around as you know yourself, there is always someone in this house (Emily, line 6).*
> *I would never perceive being ever left on my own in the house, you know (Bridget 156).*

While participants valued being alone they did not feel safe on their own with no back-up. They all needed to have someone close by that they could call on either by using an ECS or just by calling out. Peter was accustomed to having nursing home staff close by:

> *In [name] where I am … I am in my room by (myself) so. If I need someone there is someone there, but it's nice and peaceful and quiet (Peter, line 137).*

Using an ECS provided some peace of mind and helped participants and their families to feel relaxed. Peter said it offered extra peace. For Bridget the ECS was like another person, that made her feel more relaxed and safe and thus helped her to sleep better:

> *I am more relaxed, more relaxed at night. I sleep better. I am more relaxed during the day because I know that I am only within a whisker of calling somebody and they will (come). Even if I don't need anything, but to know that there is somebody hanging around and it works brilliant. Absolutely brilliant (Bridget, line 27).*

Bridget described the interplay of mental stability and physical feeling:

> *So that's where something like the switch comes into play believe me it has a lot of uses mentally … to me means an awful lot because once I am mentally stable I am OK. By having it I physically feel better (Bridget, line 21).*

Feeling less needy

The third component of *Feeling enabled* was feeling less needy (Figure 22). This is more extensive than feeling more independent as it includes feeling less frustrated, less annoyed, and feeling less of a burden and thus less indebted to others and obliged to show constant gratitude. Bridget talked about being able to do things that she was able to do 36 years ago. She no longer needed assistance all the time for everything as she is able to *do:*

> *That's a lot, because when I can do that now (myself). I don't need somebody standing beside me all the time having to actually physically do everything for me, you know (Bridget, line 88).*

The ECS lessened the need for dependence on someone for help with simple tasks and for constant calling. This was frustrating for Bridget who felt that her requests were annoying. She described her internal strife between not wanting to call for help which can be *annoying* and the frustration of doing *without it* or *putting up with it:*

> *you always had to be calling, calling and then you'd feel you're annoying people You're, do you know like, you know you'd feel, ah look it, leave it there, you know, you'll do without it or put up with it and then, a little bit of frustration would set in and then you would say, "Ah look I'll call, I'll get it turned on" and then when it would be turned on, its left on (Bridget, line 150).*

Similarly Bridget described the frustration of wanting to change a television channel and having to wait until someone has finished their own conversation before they can be asked to change the channel for her:

> *if something was on (the television) and … that I was never really into … someone came in and turned on the telly and they had to go outside for something … and it was turned up like. Oh my … it would drive me nuts, you*

> *know … I'd be stuck like and I would have to wait, and wait and wait for somebody and you get frustrated after waiting for maybe a quarter of an hour or if somebody was speaking to somebody else that they couldn't come back in to me (Bridget, line 86).*

Asking for help is annoying but having to call for help is frustrating. Calling out is not the same as asking someone in the same room. As a consequence of using ECS James does not need to *get somebody out*. He does not need to be totally reliant for everything:

> *without having to get somebody out, gave me my own independence again like (James line 31).*

In contrast to the acceptance of dependency on others, using an ECS provides some relief from a sense of being a burden on others. While one of the expected benefits of using an ECS is a decreased burden of care this usually refers to relief for carers rather than for users of ECS. Being less of a burden reflects the users experience more accurately. By being a little more able one does not have to constantly experience being a burden. James is aware of the freedom of not being a burden on others when he uses an ECS:

> *I just myself sometimes I feel that every time I call someone, every time I call someone I am putting a burden on someone now getting them back here to stick on something even if I am half way through a programme and I don't like it I got to bring them back in again so … I can watch five minutes of a programme turn it off, go watch another programme turn that off if I don't like it and a, that's the thing, that's what I like about it. That's what; I think it's the freedom and the independence of it (James, line 144).*

He is free from having to ask for and be grateful for assistance. Bridget described having to ask for help to change channels as a hassle and a bit of a pain. Again this reflects the user rather than the caregivers' perspective:

> *That was bit of a hassle like, like he never minded doing it like, for me but that was it's a bit. A bit of a pain really (Bridget, line 115).*

Matthew expresses this as feeling *more comfortable* because he is not constantly asking for help:

> *It makes me feel a bit more comfortable. Like it kind of makes it easier then asking them to do other things because if you like have given that bit of time or whatever. I don't like just constantly asking and asking. I am sure they appreciate the time as well (Matthew, line 63).*

James described being able to do the things that he wants to do as *freedom* as he does not need to call anyone:

> *the freedom to do things that I want to do? Things that I have an interest in that, where I don't have to get someone to do it for me … I can use anything in my room like, anything here. I don't need to call someone to do it … I think it's the freedom and the independence of it (James line144).*

The ECS gives James' family and carers some freedom:

> *I did not have to call them every time. It gave them that small bit of freedom that they wouldn't have to be in and out to me the whole time. So um, I am sure that small bit of respite (James, line 132).*

Having to call someone to simply change a channel can be annoying for the person being called. Having to call for help can be frustrating for Bridget and she admits that sometimes she chooses not to call in order to prevent putting a carer under pressure:

> *calling them again to turn it over or you just say, "Ah bloody hell, leave it" … so you just leave it and you don't want to keep putting the carer, you know, under pressure to keep coming in and out and in and out and in and out … and doing things for you when they are doing other things as well, you know (Bridget, line 145).*

Bridget does not articulate the burden on her caregiver as a specific topic but the quotation above suggest that she is aware of this *pressure* on [partner]. Without an ECS James feels himself to be a burden on others. Like Bridget he is aware of the demand he is making on others and at times has resisted the desire to call for help

and rather *give them a break.* Thus having the ability to do tasks alone he no longer has to *feel bad calling them.*

Having an ECS could be of considerable benefit to family and carers who would be required to do a little less as a result. Matthew however suggested that such a benefit may not be important (not a big deal) indicating that in his opinion his carers may not benefit from the ECS as they are accustomed to providing his care needs. Alternatively he may be minimising the impact of his dependence on them:

> *It is ... annoying for me and I am sure it's annoying for who I call because sometimes when you are watching something. If I watch a program sometimes and I have called someone to come in and turn it I kind of feel bad calling them again. Sometimes I would watch the programme just until its finished and then, call somebody. Give them a half an hour sitting down maybe, give them a 10 minute break (small giggle) but um this is great like, like I can, I can do everything that probably they want me to do (Bridget, line 146).*

For Peter without it:

> *it is a big disadvantage that you don't have it because you need to ask someone to change the station (Peter, line 123).*

But Matthew does not seem to have the same opinion:

> *I mean it would obviously would make life easier for them as well. It's not a big deal really (Matthew, line 53).*

However, he contradicts this statement a few minutes later:

> *If there was carers around like it obviously would make a huge difference because you wouldn't have to be asking them to do everything all the time (Matthew, line 57).*

Having to call people is frustrating. Without an ECS James had to always *bring somebody in:*

> *Having to actually bring somebody in to do it for you … when this (ECS) goes back like I do know that it will be back to frustrating times for me just having to call people. I think that's the part that I, I don't like, calling people to do things for me. I'd much rather do those things for myself (James, line 54).*

James values executional autonomy over decisional autonomy as he is able to do things himself instead of always having to involve someone else. Matthew agrees with this sentiment:

> *It drives me mad having to ask or call somebody all the time to change channels and stuff (Matthew, line 5).*
> *(You can) watch whatever you want on the television without any hassle without having to call anybody (Matthew, line 7).*

3. Summary

This short 8 week trial for six people provided them with an opportunity to experience living with an ECS summarised as *A little autonomy in a dependent world* – see Figure 23 and Table 21.

While each person's experience was unique the participants shared the essence of living with ECS which *involved getting used to using the ECS* and in so doing being able to *take back a little of what they have lost. Getting used to ECS* was both a *hassle* and was *engaging*. The hassle involved challenging learned dependency and coping with frustrations both technical and service related. In contrast, engagement yielded unexpected experiences, good feelings and fun. Participants who were engaged in the use of an ECS then were able to *take back a little of what they had lost* both in *doing* and *feeling* enabled. Doing encompassed doing everyday things like surfing television channels and making telephone calls. By doing people were less physically dependent and they were able to be alone enjoying their own company. The feelings of enablement associated with ECS use included: experiencing pleasure in doing, feeling safe when alone and feeling less needy.

Figure 23: Phase 3 shared themes and their relationships

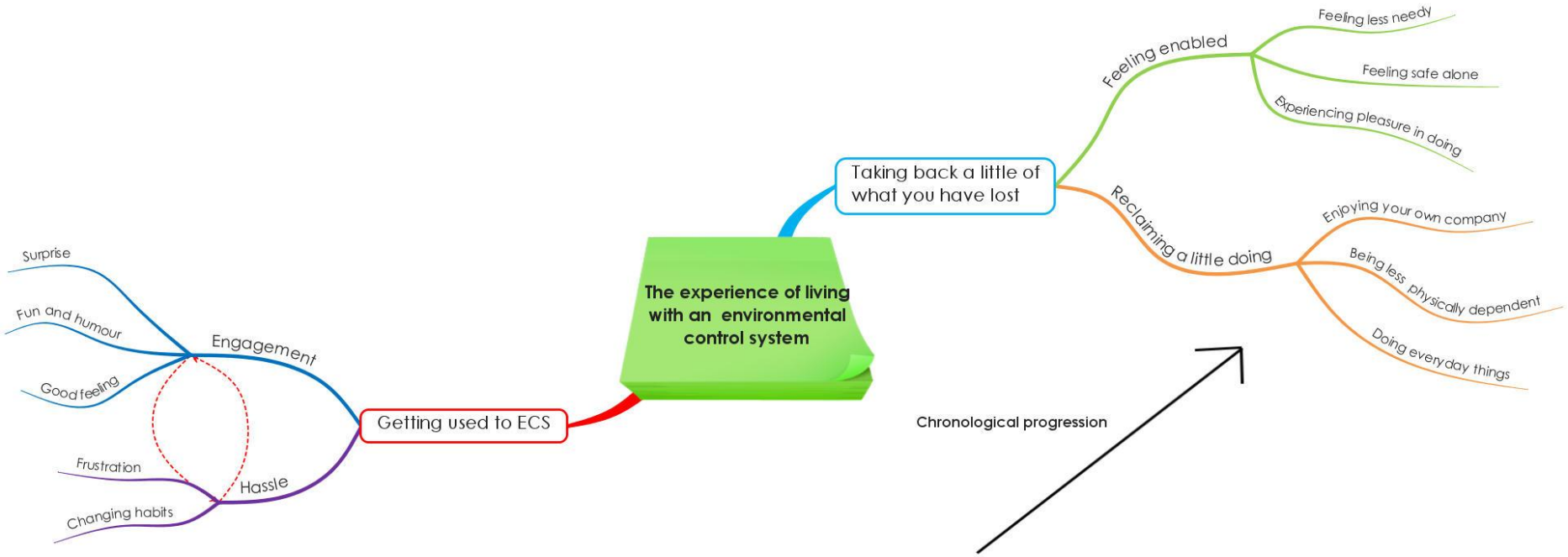


Table 21: Phase 3 list of themes, *A little autonomy in a dependent world*

Superordinate theme	Subordinate theme	Elements
1: Getting used to ECS	Hassle	Changing habits
		Frustration
	Engagement	Good feeling
		Fun and humour
		Surprise
2:Taking back a little of what you have lost	Reclaiming a little doing	Doing everyday things
		Being less physically dependent
		Enjoying your own company
	Feeling enabled	Experiencing pleasure in doing
		Feeling safe alone
		Feeling less needy

4. Reflexive commentary

Naming themes challenged me to balance the participants' own words with recognised terms. Initially I used terms like abandonment but that is a term that has its own connotations based on other research and theory, the nuance in this study was the hassle that was not worth it which is more expressive than the concept of abandonment suggestive of people giving up on an opportunity or being noncompliant. Getting used to ECS in contrast is transactional decision if ECS are considered not worth the effort.

Debating and reviewing themes with my supervisor was invaluable; she helped me refine my themes by helping me "hear my own ideas and words", reflected back to me. For example – "taking something back", was concept that I rushed over until we realised together that it accurately reflected a theme that encompasses so many of the concepts and is not specific to James but enlightened the other interviews.

I began to realise the magnitude of these findings – that ECS have a role to play in providing freedom and I as an occupational therapist have an obligation to lessen the occupational deprivation of many people with high SCI. A deprivation that Bridget had experienced for 36 years, Patrick for 19 years, Matthew for 9 and James for 8.

I was also struck by how normal so many of the described activities were but to a person with a high SCI who had been unable to do them for many years they were amazing feats – like just turning on the radio in the morning when you wake, and having the choice to switch it off if you don't like that song!

Chapter 11: Discussion and conclusion

This concluding chapter provides a discussion of the combined findings of the three phases of this study and the related conclusions. It includes real world implications and recommendations for the practical application of these findings as well as suggested areas for further study. It also details the strengths and limitations of the study.

The original motivation for this study was a desire to improve occupational therapy for people with high SCI. My exposure to environmental control systems (ECS), as a clinician, led me to believe that ECS could, and should be useful and important for people with high SCI. It was however apparent that, in Ireland, most people with high SCI were unlikely ever to receive their own ECS. This was a source of real frustration for me and led to my desire to change the status quo. This made me consider a simple way of increasing ECS availability for this admittedly small population. I thought that as an integral part of spinal injury rehabilitation it should be possible to provide everyone with high level injuries with an ECS starter-pack in a similar manner to providing a wheelchair.

As a person-centred occupational therapist attempting to improve ECS provision for people with high SCI in Ireland I needed to focus on the users' perspective of ECS and maintain a person-centred approach. A literature search (Chapter 3) did not provide substantial insights into the users' perspective and instead re-affirmed general assumptions – that ESC are useful and beneficial. There was also some evidence to indicate that users appeared to be satisfied with ECS. I questioned this latter finding based on my clinical experience which indicated that potential users were not entirely satisfied with existing technologies.[219] There was no satisfactory exploration of the insider perspective which I considered essential for understanding use and non-use of ECS. Having identified a substantial gap in the literature, this multiphase study sought to explore the users' perspective of ECS and the meaning they ascribed to living with ECS. It focused on two intertwined and guiding research questions:

[219] Possible negative aspects or perceptions or experiences of ECS are also suggested in two qualitative studies (Palmer and Seale 2007; Stead 2002).

- *What is it really like to live with ECS?*
- *What does it mean to live with an ECS?*

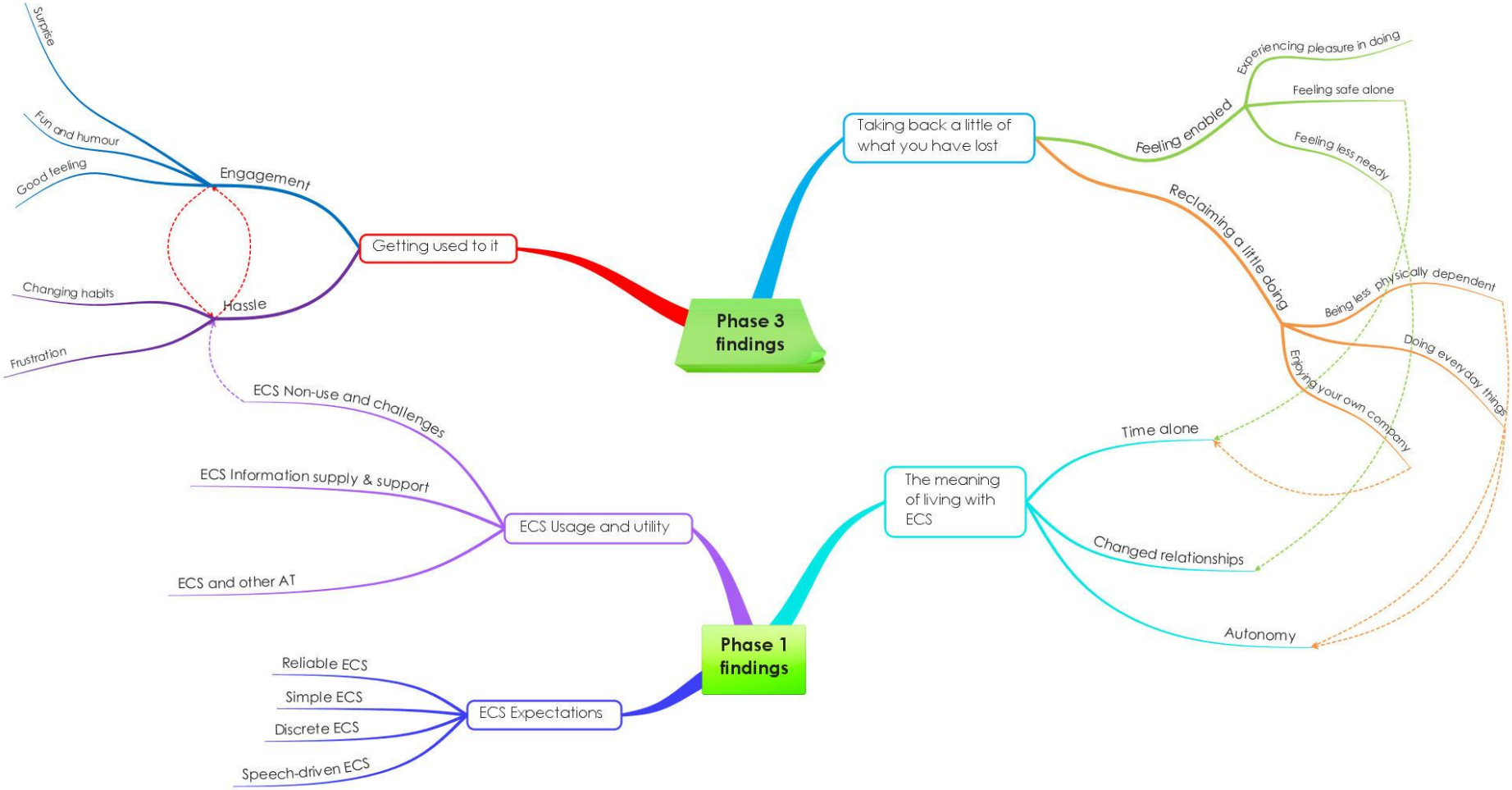
Although this study involved a practical aspect of developing an ECS starter-pack, that intention was focused on: *what it is like,* and *what it means,* for the insider, in order to ensure that the pack was relevant and useful for them. The study was inherently phenomenological - aimed at understanding the meaning of the lived experience of a phenomenon (using ECS) by exploring what it is like. The methodological choice in retrospect was not a choice but rather a natural fit for the primary research questions.

This study involved:

- Exploring what people think about ECS in focus groups while attending to both ECS users' and non-users' expectations of a starter-pack as well as their experiences of living with or without ECS.
- Developing and subsequently trialling, and adapting a generic ECS starter-pack with one person based on the findings from both users and non-users.
- Exploring the experiences of six people who lived with the pack for 8 weeks.

Taken together, these individual sources of data provided rich insights into both practical and experiential aspects of using ECS for people with high SCI. This chapter will discuss the overall research findings in light of the primary research questions - *What is it like to live with ECS* and *what does it mean?* These two questions are interrelated and possibly even inseparable, making it challenging to present them separately. Descriptions of what it is like to live with ECS provide insights into what it means, and likewise meanings are derived from the experience of living with ECS. However to provide clarity *the experience of what it is like* will be discussed first, followed by a discussion of *the meaning of the experience.* This discussion can be read together with Figure 24.

Figure 24: Merged mindmaps of Phase 1 and Phase 3 findings showing all themes and links between themes



1. What it is like to use ECS – The interplay of hassle and engagement

Using ECS was found to involve a dynamic relationship between *Hassle* and *Engagement* as described in Chapter 10. Engaging with ECS involved encountering some hassle. The focus on the positive aspects of using ECS, which dominate the existing literature, is challenged by this real world exploration which was considered by the clinical expert (ES), to accurately represent her experience: that ECS, while useful, are not easy to use and can be challenging. Overcoming that hassle requires effort (active engagement) which can then lead to engaging occupations facilitated by ECS and enjoyment of ECS use. Active ECS use was likely to involve encountering more hassle which in turn could be overcome if the meaning of living with ECS was considered worth the hassle.

1.1 Hassle

Using ECS was described as a hassle which at times required a change of habits and inevitable frustration with the ECS. In Phase 1, focus group participants described this hassle as part of *ECS Challenges and non-use*, by introducing the notion of having to change habits as well giving a generic description of challenges similar to those described as frustrations in Phase 3. These frustrations were elaborated in Phase 3 to include frustration with scanning and switch use as well as frustration with the healthcare system that made the provision of personal ECS unlikely.

There has been little discussion of such difficulties previously with the exception of Judge et al. (2009a) and Judge et al. (2011) who briefly present poor reliability, sound interference, voice changes, personal cognitive limitations and technical difficulties interfacing with other devices as reasons for failures of speech-driven ECS for both users and professionals. Palmer and Seale (2007) also suggest challenges in the categories *Extremely limiting, Could be better,* and *Good points and bad points* included in ECS users' phrases that indicate that users would like their ECS to be improved and may suggest some frustration that is not overtly articulated in the findings.

The most obvious consequence of hassle is non-use, noted in Phase 1 in the theme of *ECS non-use and challenges,* and also reflected in Paddy's non-use of ECS in Phase 3. While non-use of AT is well documented in the literature (Copley & Ziviani, 2004; Johnston & Evans, 2005; Phillips & Zhao, 1993; Scherer, 2005; Wessels, et al., 2003). Non-use specifically of ECS is not extensively documented.[220] In fact, ECS use exceeds other types of AT use (Cowan & Turner-Smith, 1999). The findings of this study show that it is crucial to acknowledge that non-use may be one outcome of providing ECS, that may be considered positive and to accept that ECS are *not for everyone* (Stead, 2002b).

1.2 Engagement

A unique contribution of this study lies in the uncovering of the associated theme – *Engagement.* No known ECS study has described the use of ECS as *engaging,*[221] suggesting the comparative richness of the experiential focus in the design of this study in revealing new aspects of ECS use. For those who were able to overcome the hassle, the very use of ECS was *engaging* and resulted in good feelings, fun and humour and surprise (Chapter 10 section 1). ECS use was found to be engaging as illustrated by James staying up all night just flicking through television channels, and then watching an entire box set of a television series. Such descriptions suggest the achievement of a state of flow,[222] an indicator of meaningful occupational engagement. The occurrence of the theme may have been elicited by the stated adoption of an occupational therapy lens that inherently focuses on occupation and occupational engagement. The ECS were described as fun, enjoyable, and pleasurable to use and suggesting a link to improved quality of life. This association between pleasure and ECS use has not, to my knowledge, been made previously. However an association has been found between pleasure and posttraumatic growth following SCI (Chun & Lee, 2008). Chun and Lee (2008) present the experience of meaningful engagement as a theme which included participating in activities that were described as fun and enjoyable. This relates to another theme in Phase 3: *Experiencing pleasure in doing.* Pleasure is most vividly described in terms of *messing* by several participants (as described in Chapter 10). *Messing* is something I understand to be a normal everyday experience – and not necessarily an indicator of quality of life. Rather it is a taken for granted aspect of

[220] Some noted non-use in surveys (Maguire, McCann, & Swallow, 2001; Novak, 1998).
[221] Buxton (REF) included a theme of *I am in my glory now* that may have included similar evidence to support the theme of *Engagement.*
[222]Flow occurs when an activity is all-encompassing and one becomes fully engaged in doing that activity (Csikszentmihalyi 1990; King, 2010).

normal everyday life for able bodied persons, and such supports another theme: *Doing everyday things*.

2. The meaning of living with ECS

The meaning of living with ECS is subjective and therefore cannot be definitively measured. It therefore warrants a study that uses a qualitative design such as this one. It may be tempting to try to summate the meaning to a single statement such as captured by the theme *Taking back a little of what you have lost* or *Autonomy* but doing so would overshadow the rich depth of the complexity of what ECS use meant to people in this study. ECS use meant: *Experiencing pleasure in doing; Time alone; Being less physically dependent; Doing everyday things; Enjoying your own company; Changed relationships, Feeing enabled; Feeling safe alone; and Feeling less needy.* It would be inadequate to describe these components simply as *Taking back a little of you have lost.*

A link between autonomy and ECS has previously been identified in a mixed methods study and studies relating autonomy to high PIADS scores' (Jutai, et al., 2000, Ripat, 2006; Ripat & Strock, 2004). Choice and control of one's life as elements of autonomy are also articulated in the existing literature in themes such as, *Control over personal space and activity* (Rigby, et al., 2000) and *Now I can do what I want, when I want*! (Buxton, 2007) and quotations such as *being able to do what you want* (Peter) and, *can do what I want, when I want it* (Ripat & Strock, 2004). In addition there are extensive references to improved independence with ECS. This independence I considered to incorporate an element of autonomy - doing things without help, but it fails to explore the meaning of choice implied by autonomy but not necessarily by independence. Autonomy in relation to high SCI is considered to include organizing one's own social roles, affairs and relationships (participation) as well as feeling comfortable with the way of living (self-determination) (van de Ven, et al., 2008). *Changed relationships* identified as a subordinate theme of *Autonomy* in Phase 1, relates to *Being less physically dependent* and *Feeling less needy* as a result of having ECS in Phase 3. These themes fit well with the extended concept of autonomy that involves relationships as described by van de Ven, et al. (2008). In addition their inclusion of *feeling comfortable* supports the inclusion of *Feeling enabled* and *Feeling safe alone* in particular and as a constituent of autonomy. In a qualitative investigation of people with high SCI, Hammell (Hammell, 2004b) identified autonomy, choice and control

as important contributors to quality of life. It follows that it is possible to make a connection between ECS providing autonomy and thus enhancing quality of life. *Autonomy* as described in Chapter 7 is less expansive than *Taking back a little of what you have lost* discussed in Phase 1. If a different methodology, such as thematic analysis, had been applied in Phase 3 the theme of autonomy would have been applied as opposed to developing a new theme that better represents the nuances of living with ECS for people with high SCI.

The magnitude of what ECS can offer is paradoxically described as *little* but also as highly important, and it contrasts starkly with what people with high SCI are not typically able to do. Clearly if their inabilities are compared with the abilities provided by ECS, the inabilities would far outweigh the abilities. However, it is this very magnitude of inability that makes *anything that I'd be able to use* (Patrick) so valuable. This *little* relates to the physical things that one can *do* using an ECS but does not extend to the fuller meaning of living with ECS as described if all the themes are considered cumulatively. ECS do not negate the effects of living with a high SCI but instead offered a *little lost* ability back. This view is briefly mentioned previously as a quotation, *it's not a cure all* (Ripat & Strock, 2004). ECS can only offer a little, perhaps reflected in a previous reported category: *Extremely limiting* (Palmer & Seale, 2007).

This study provides a possible conceptual framework for the meaning of using ECS that describes the resulting autonomy as *Taking back a little of what you have lost.* This theme represents the interplay of changes to participants' ability *to do (Reclaiming a little doing)* and the way that ability makes them *feel (feeling enabled).* While elements of both these themes occur in some of the literature, no existing study has explored that experience (life with ECS) with the depth uncovered in this study nor has any study been located that presented a comprehensive description of the experience. These two themes are highly interrelated as demonstrated by one component that occurs in both themes *Being alone,* discussed in conjunction with *Doing* and *Feeling enabled*. These will be discussed next.

2.1 Doing

Doing is a central concept within occupational therapy and a crucial dimension of the meaning of occupation (as discussed in Chapter 1). ECS enable users to *do* despite significant physical impairment. The occupational disruption (Chapter 1, section 5) that accompanies SCI may be lessened somewhat as reflected in the

theme *Reclaiming a little doing.* Life lived without ECS presents many barriers to everyday occupations. Such occupations which may seem mundane are inherently meaningful to those who do them (Hasselkus, 2006), and include things as simple as choosing to telephone someone or choosing what to watch on television or using volume control on a device. Being able to use ECS facilitates *Doing everyday things* and in contrast having no ECS results in occupational deprivation, particularly considered in the light of current societal norms.

We live in a technological society where daily activities are mediated by technology, we effectively *do technology* or *do through technology* (Chapters 1 and 2). Watching television, a non-essential passive leisure activity twenty years ago, is now considered a normal interactive everyday activity integral to most peoples' lives. People in prison are entitled to watch television, and even babies and small children have content specific television programmes but people with severe physical disabilities are denied the opportunity to choose what they watch on television unless they ask someone else to execute that choice. Watching television is no longer a passive activity. We can choose what we want to watch and when we want to watch it. Similarly mobile telephones are an everyday item used by almost everyone including older adults and many young children. Even poverty stricken African countries enjoy extensive mobile phone networks and people are becoming more likely to have a mobile phone than a permanent abode. Having a mobile phone means that we are able to communicate with anyone, at any time, and in almost any place. People with high SCI however require physical assistance to use a telephone, and may even have to *share* their conversation with whoever assists them. And yet it is entirely possible to execute simple activities such as controlling television and making telephone calls without assistance by using ECS. It follows that without that occupational deprivation is likely if ECS are not available.

Doing meaningful things has been linked to quality of life for people with high SCI (Hammell, 2004b), but in this study d*oing everyday things* is about simple normal living. *Doing everyday things* is not considered an indicator of quality of life in this study but rather an indicator of living life itself. It is necessary to first live life and then to enjoy quality in that life, both of which can be facilitated for people with high SCI by ECS use.

Doing by using ECS has been partially represented in previous studies as independence, referring to the ability to do things without assistance. This aspect of ECS use is represented in this study as *Being physically less dependent,* a component of *Reclaiming a little doing*. Independence as described elsewhere (Chapter 3) falls short of providing an understanding of what *doing* things meant to those who use ECS. This theme is however presented not in isolation (as in other studies) but as part of the larger theme *Reclaiming a little doing* that is related to *Feeling enabled*. The ability to *do* also involved a change in how the user felt and thus included *Experiencing pleasure in doing.* Feeling is totally subjective and thus cannot be measured or reflected in quantitative measures of independence such as studies that measure independence in functional abilities using a standardised outcome measure (Harmer & Bakheit, 1999; Tam et al., 2003; Rigby et al., 2005). [223]

2.2 Feeling

The meaning of living with ECS was also expressed in terms of how it made people feel. This study has shown positive feelings that users expressed, feeling enabled, feeling less needy, feeling less reliant on others and feeling safe. Significant physical disability is accompanied by an unavoidable physical dependence on others for assistance with normal tasks like dressing, eating and even toileting. In contrast, it is possible to be independent of others with ECS and to control one's physical environment such as using a television, stereo and telephone. This is possible and even surprisingly simple as described by James and Bridget in Phase 3. These are normal, taken for granted things, but for those who have been denied these activities through disability, being given the opportunity to *do* such simple things is *brilliant* (Bridget), and *essential* (James). All users in this study represented by: users in Canada and Ireland (home visits Chapter 8 section 3.3); users in Phase 1; the pilot participant in Phase 2 and participants in Phase 3, expressed not wanting to be without ECS. Similarly ECS has been described by experienced users as *Indispensable* (Palmer & Seale, 2007). This can be understood as an emotional issue as not having ECS will impact on how people feel.

Feeling enabled is particularly relevant for people with high SCI who are living with a *new me* (Chapter 2). The biographical disruption that results from SCI necessitates establishment of a new identity as a person with a SCI (Carpenter 1994; O'Connor 2004). Adjusting to such an identity change is likely to be easier if the person feels

[223] Such a s the LOMEC, Lincoln Outcome Measures For Environmental Controls, measures functional impact of ECS.

enabled. ECS thus have a role to play in facilitating positive self-perception or reaffirming the value of self (Hammell, 2004). The very nature of the new me can be described as a *becoming* involving transformation and self-actualisation (Wilcock, 1999) and is considered to be the combined product of *being* and *doing*. Drawing on Wilcock's (1999) occupational theory, it is likely that because ECS can enable *doing* and *being* they also contribute to *becoming* represented in this study by the theme *Feeling enabled*. *Feeling enabled* included feeling safe alone, feeling less needy and experiencing pleasure in doing.

Feeling safe alone is something able-bodied people take for granted. I am not afraid of the possibility of falling out of my chair as a result of a spasm, nor am I afraid of becoming unwell with autonomic dysreflexia. Bridget described how uneasy she felt when a stranger came to her front door and as she watched from her bedroom, she was aware that she was unable to respond in any way. This vulnerability associated with physical dependence could be alleviated by knowing that she was able to call for help. The anxiety of living with SCI and the resultant risks are not removed by having ECS but they can make one feel safer. ECS recommendations are likely to stress the safety aspect of ECS as safety is easily perceived as a responsibility of health providers and if ECS can be linked to safety they are more likely to be included in a care package. ECS is thus perceived as contributing to users' safety by enabling them to be discharged to live with less support and with less risk. This pragmatic argument while valid, does not fully take into account the psychological importance of feeling safe which is a human right. It was only through exploring descriptions of feeling unsafe when living without ECS that the value of feeling safe for people with high SCI became apparent. Safety concerns have been identified in the existing literature. Buxton's thematic analysis of two interviews also identified a theme entitled *A feeling of safety* that reflects the users perspective of feeling safe as opposed to the medical concept of safety (Buxton, 2007). Ripat and Strock (2004) include a similar narrative *Feel safer*.

Without ECS, people with high SCI and their families may feel unsafe resulting in a cycle of worry clearly identified by participants in Phase 1 of this study. This finding is consistent with a previously identified theme *Reduced carer workload and worry* (Rigby, et al., 2000). This worry cycle in turn affects relationships. Findings from Phase 1 of this study indicate that the use of ECS can avert worry and result in *Changed relationships* by making people *feel less physically dependent* and *less needy* supported by phase 3 findings. Interestingly, the theme *Changed*

relationships identified in Phase 1 did not re-appear as a strong theme in Phase 3. While Phase 1 participants discussed how ECS affected others, individual interview data instead focused on the individual users' perspective. Although interviews did include questions about their perceptions of how others viewed ECS, their responses were primarily reflective of their own experience which is the focus of a phenomenological exploration. Phase 3 instead offers insights into how relationships may change as a result of how ECS makes people feel and how it alters what they can do. ECS use resulted in people *feeling less needy* as a result of *being less physically dependent*. Being less dependent allowed them to spend some time alone thus affecting the nature of relationships.

Feeling enabled also included feeling less needy. Life with SCI or with any physical disability has been described as involving a state of being continually indebted. Galvin (2004) describes reliance on others as living with *perpetual obligation* that requires *irrevocable gratitude* which involves constant apologising and thanking of others. This was clearly reflected in Phase 1 quotations such as *I'm really sorry but would you mind* (Jane) and *you wouldn't mind* (Jim), *and constantly apologising* (Emily). Even for people with less severe SCI[224] there is a need to establish a balance between enforced reliance on others and making an equal contribution in relationships (O'Connor, Young, & Saul, 2004). Such contribution is facilitated through ECS use and illustrated by Paul in Phase 1 who described his pleasure in doing some tasks for his wife.[225] ECS have the potential to alter the dynamics of a relationship as users are less likely to feel permanently apologetic, both parties may be less annoyed, and there is a decreased burden of care for both parties. One of the previously recognised benefits of ECS is the facilitation of communication, socialisation and relationships (Harmer & Bakheit, 1999; Kanto-Ronkanen, et al., 2003; McDonald, et al., 1989; Ripat, 2006). Participants in this study and in another by Rigby et al. (2000) discussed the effect that an ECS has on actual relationships as opposed to just the physical facilitation of communication. Having an ECS can change relationships by increasing the repertoire of abilities and thus reducing the extent of physical demand placed on others. This is important as meaningful relationships have been found to contribute to improved quality of life for people with high spinal cord injuries (Hammell, 2004b).

[224] Paraplegia.
[225] Making reservations, booking flights.

2.3 Being alone

The ability to be alone is a dominant theme throughout this study. It occurs as one of three themes in the category of *Meaning* in Phase 1 and as a component of both *Feeling enabled* – feeling safe alone and *Reclaiming a little doing* – enjoying your own company in Phase 3. It appears to be an aspect of living with ECS that is both a physical state and a psychological experience.

The concept of time alone, so central to this study has surprisingly not been a feature of other ECS studies and has only occurred once as a subtheme of meaning (Stead, 2002b).[226] This may be because research to date has been predominately conducted by those with a medical background and a biomedical frame of reference that focuses on the ability to be alone as a physical construct implying being without formal carers. Being alone is therefore considered and reported in terms of being able to have fewer care hours resulting in less expense. Time alone has only been considered in terms of safety as opposed to being psychologically beneficial. Safety concerns often result in a person with a high level injury having to have constant company, which means that they are always being looked after as a precaution. This feature of living with significant impairment is therefore described as *annoying.* Being constantly supervised is unnatural for adults who are reduced to child-like status of always needing someone around,[227] and described as *annoying*. Adults with high SCI are often restricted to either feeling unsafe alone or having to endure constant company. It is not surprising then that users,[228] non-users and those who were given the opportunity to use the starter-pack all highlighted the value of being enabled to spend time alone.

The value of being able to be alone is supported by research into quality of life for people with high SCI. Being alone is included alongside spending time in nature, listening to music, appreciating art or spending time with special people as *meaningful use of time beyond doing* (Hammell, 2004b, p. 614).

This thesis shows that ECS enable being – being alone, and being safe alone. *Being* is both a phenomenological concept – *Daesin* or *being* (Heidegger) and a category of occupation –alongside *doing, belonging and becoming.* In an occupational sense it is harder to conceptualise *being* in contrast with the more

[226] Stead's (2002) sub theme of time alone was distinct from the theme of benefits for carers supporting the importance and meaning of this theme to ECS users.
[227] Even a four year old can spend some time alone in a familiar environment.
[228] Including ECS users in Canadian Home visits.

intuitive *doing*. *Doing* is visible while *being* may not be. In the phenomenological sense *Being* is central to who we are and it involves being true to ourselves, solitude and being able:

> *To think, to reflect and to simply exist (Wilcock, 1999, p. 5).*

Being alone was a reoccurring theme throughout this study suggesting that the importance of being able to spend time alone extends far beyond immediate safety concerns. Time alone emerges in this study as something which provides an opportunity for being, being with yourself as well as being by yourself which yields obvious mental health benefits.

3. What does this study add to our knowledge of ECS use?

ECS are acknowledged to be useful and beneficial by users and professionals but to date the real experience for those who use ECS, who need ECS and who rely on ECS has not been explored or articulated in depth. This study offers such an exploration of the lived experience of ECS for a small sample of Irish people with SCI. Just as occupational therapy is a two-bodied practice, encapsulating both art and science (Mattingly, 1994) the findings of this study reflect two bodies of information – practical outcomes and philosophical (phenomenological) findings. The practical aspects relate to the pragmatic everyday application of ECS through the use of a starter-pack. The phenomenological aspect of the study explored living with ECS and began with a broad exploration of life for those with and without ECS. Then through the provision of a short trial of ECS, previous non-users were able to experience what it was like to live with ECS. The combined results provide rich insights into what it is like and what it means to use ECS and bear some resemblance to themes distributed in previously identified in qualitative studies.

While there is some qualitative exploration of the use of ECS none is as extensive and as comprehensive as this study. The grounded theory approach of Palmer and Seale (2007) and Stead (2002b) indicate the potential complexity of what it means to live with ECS. Neither however focused on the lived experience nor did they provide satisfactory depth in their findings. Stead (2002b) included meaning as a theme but failed to expand on this in any depth, although she did include a brief mention of time alone, a key finding of the current study. Palmers and Seales' (2007) categories entitled *utility transcended* and *utility denied* are interesting and

suggest a deeper meaning of ECS. Despite grounded theory design, both studies failed to culminate in a tested ECS theory and thus only provide lists of categories, themes and codes related to ECS use without meaningful explanation or a conceptual framework of relationships. This study in contrast explored the meaning of living with ECS and found it to be complex and to have at its core the recovery of a little autonomy in a dependent world. This complexity refers to the progressive elements (superordinate themes) of *Getting used to ECS* that preceded the *Taking back a little of what you have lost*. This chronological relationship is important and is supported in the only other known phenomenological exploration of ECS. Erikson et al (2004) described progressive themes of *plunging into an ECS equipped environment* followed by *Landing and feeling comfortable* and *Incorporating the new into daily activities*, and *Taking off in the future*. Their study also described the challenge of getting used to using ECS that eventually allows *taking off.*

In a relatively under-researched area it is not surprising that my study makes some unique contributions to the knowledge base. The first contribution is the identification of the challenges and hassle involved in becoming used to using ECS. Although this finding corresponds with both my clinical experience and that of the clinical expert (ES) it has not been reported in the academic ECS literature. This underlines the fact that ECS cannot be considered suitable for all. As Stead (2002b) explains ECS are not for everyone. One participant in Phase 1 admitted that he was hesitant to embrace ECS as he felt he would then be reliant on it and favoured instead his own simple solutions. He offered a balanced insight as to why ECS may not suit him. One participant in Phase 3 was unable to use the ECS starter-pack demonstrating the reality that although ECS may be meaningful for some users they are not suited to all.

The second contribution is the identification of ECS use as engaging. This theme, illustrated with colourful descriptions of fun, humour, surprise and good feeling, offers a contrast with the hassle. The dynamic relationship between these themes is useful clinically alerting clinicians to both positive and negative aspects of ECS use as well as emphasising the need to overcome the hassle by the facilitation of engagement.

The study also advocates caution when considering the magnitude of its benefits. While it is easy and tempting to say ECS offers huge changes to quality of life, the theme *Taking back a little of what you have lost* indicates that ECS provides limited

benefits and the impact of SCI is not negated by ECS as users still will require physical assistance for the majority of physical personal tasks (dressing, feeding, toileting).

This study also provides a convincing link to autonomy and in so doing expands on other existing research that indicates enhanced independence through use of ECS. This study highlights the multi-faceted nature of autonomy provided by ECS that includes both being able to do physical tasks as well as the impact on feelings. The inclusion of how ECS make people feel highlights the value of information revealed through in-depth qualitative investigation. There is some evidence for these feelings interspersed within some qualitative studies but is clearly missing in the dominant quantitative body of ECS research.

Although the positive psychosocial impact of ECS has been found in outcome studies reviewed earlier (Chapter 3), this study explored the nature of such impact by revealing that ECS make people feel enabled, less needy and safe alone. In addition they enable people to do everyday things. While this study did not set out to investigate the effect of ECS on others such as relatives or carers, the effects were suggestive of positive changes in relationships as a result of using ECS.

This study confirms that ECS facilitates participation for people with high SCI through facilitation of occupation through doing, being and becoming. This illustrates that ECS are essential contributors to occupation and occupational engagement and that the failure to provide them leads to occupational deprivation. Occupational therapists have a role to play in ensuring that those who can limit occupational deprivation through ECS are afforded the opportunity to experience ECS and acquire them if they so desire.

This study provides evidence of how ECS enable *Doing, Being*, and *Becoming.*[229] However it is important to point out conceptual differences from previous studies linking ECS use to being and becoming. Rigby (an occupational therapist) applied a non-occupational therapy model of quality of life categories entitled *Being, Belonging* and *Becoming* that are defined differently[230] to the occupational categories and which are described in more depth in Chapter 3 section 2.4.

[229] The change in relationships resulting from ECS use could also be linked to belonging but belonging was not a dominant finding in this study.
[230] Being – physical being, psychological being and spiritual being; Belonging – physical, social and community; Becoming – practical becoming, leisure becoming, growth becoming.

Surprisingly this model does not include doing which is central to occupational therapy and the function of ECS, instead she includes a subcategory of *practical becoming* that includes *the things you do*. The quality of life model merges doing with becoming as opposed to the conceptually different *Becoming* in the occupational sense that is about self-actualisation and future potential resulting from doing and being.

The successful development of an ECS starter-pack shows that it is possible for an occupational therapist to install and customise such a pack. Doing so involved adopting a collaborative, occupation-focused and person-centred approach that was time consuming but important in terms of service user empowerment. By doing so, this study confirms that even in resource-limited settings it is possible for people to be given ECS by occupational therapists without technical or expert support. It thereby also de-mystifies assistive technology and assists in making it more of an everyday item than a specialised enterprise in a rehabilitation setting.

4. Quality control

Quality of the research, as introduced in Chapter 5, was maintained throughout the study according to Yardley's (2000) guidelines for ensuring qualitative analysis is both rigorous and sound. This required ensuring *sensitivity to context; commitment and rigor; transparency and coherence;* and *impact and importance* and is detailed in Table 22 overleaf.

Table 22: Summary of compliance with criteria for quality (Yardley 2000) in all phases of the study

	Sensitivity to Context	Commitment and Rigor	Transparency and Coherence	Impact and Importance
Across study	• In-depth understanding of high SCI and it's challenges (Chapter 1 & 2) • Wide literature search – with identification of gaps (Chapter 3) • Focus on people living in Ireland • Awareness of potential power differential between therapist and participants • Awareness of potential difficulties with use of video capture	• A thorough understanding of the existing ECS literature • In depth exploration of phenomenology • Prolonged debate with two supervisors and one clinical expert to refine analysis and final findings • Prolonged engagement with users and potential users	• Extensive use of verbatim quotations allowing the reader access to the source of the interpretation • Extensive supervision was used to constantly evaluate findings and challenge thinking • Constant reflexive activities - reflexive journal keeping, compiling field notes and memos (using ATLAS.ti)	• Findings were prepared across phases for dissemination amongst peers,[231] academics,[232] and users[233] (Appendix 30 & 31)
Phase 1	• Awareness that non-users may not have the opportunity to acquire ECS • Awareness that users had a variety of different ECS and different experiences • Awareness that data production and gathering in a group situation is influenced by group interactions	• Familiarity with group work and facilitation • Lengthy discussion and debate of focus group analysis and findings with two supervisors and a clinical expert [234]	• Phase 1 data analysis process detailed in Figure 3 • Findings are presented in Chapter 7as verbatim single excerpts as well as passages to provide context reflecting group interaction to demonstrate *transparency*	• Phase 1 findings were published in a peer reviewed publication and in two peer reviewed conference proceedings (Appendix 30 &32)

[231] In house lunch-time seminars at the rehabilitation hospital.
[232] Peer reviewed conference papers and publications.
[233] Findings prepared for magazine publication in *Spinal News.*
[234] Thematic progression is evident in the difference of findings in two publications Verdonck, M., Steggles, E., & Chard, G. (2009) and Verdonck, M. C., Chard, G., & Nolan, M. (2011a).

	Sensitivity to Context	**Commitment and Rigor**	**Transparency and Coherence**	**Impact and Importance**
Phase 2	• Pilot participant was expected to provide feedback on the technical aspects of the pack and its suitability and was therefore not asked to participate in a lengthy interview in addition to several visits to his home • While the pilot participant was waiting to order his own ECS, the trial controller was loaned to him on completion of the pilot study	• Several visits to the pilot participant's home, to make several adjustments and additions to the pack • Extensive engagement with a user (pilot participant)	• Visits documented in field work diary, and reflexive diary • Constant reflexive activities - reflexive journal keeping, compiling field notes and discussions with user	• Pilot phase published in conference proceedings book and presented at peer reviewed conference (Appendix 30). • Two poster presentations of the GrEAT have been accepted for 2012 conferences– (Appendix 31)
Phase 3	• Understanding that participants were only provided with a temporary trial of ECS not considered to be equal to being provided with their own ECS to keep • Bridget was allowed to keep the sound-switch and alarm as she requested • Awareness that I had provided and installed the pack and may thus may have been considered a *pseudo-expert* • Sensitivity to role of researcher vs. occupational therapist	• Attended IPA educational course • Listened to each interview several times to stay close to the data • Compared and contrasted individual participants themes in mindmap form • Supervisors commented on and debated the preliminary analysis for individual participants and the shared analysis • Clinical expert, having read the individual participant narratives, was able to critique the final thematic structure that culminated in some restructuring of superordinate themes to improve coherence	• Phase 3 Audit trail (Appendix 29). • Findings are presented as verbatim single excerpts and passages in Chapter 10 • The clinical expert ES evaluated the themes for *fit* with clinical experience thus supporting the credibility of the findings • The clinical expert assessed the *coherence* of the findings based on her clinical experience	• Phase 3 findings have been accepted for presentation at peer reviewed conference (Appendix 31)

5. Limitations

This expansive three phase study has several limitations which are discussed under headings below.

5.1 An ECS starter-pack

While this study details the specifics of an ECS starter-pack it does not provide a focus on the specific components of the pack. A formal evaluation of the pack was not included in the study design because this study was not about the pack itself but about the concept of providing access to ECS. It was about giving non-users an opportunity to experience ECS by using the GrEAT as a starter-pack.

This ECS experience explored in Phase 3 was reliant on the GrEAT pack. That pack was limited by funding and pragmatic restrictions. It was not possible to include a speech-driven ECS as desired which meant that I could not gain an understanding of the experience of this type of technology. I was interested in doing so as a consequence of the findings of Phase 1 that included the expectation for speech-driven ECS. Technological restrictions mean that ECS based on mainstream products like smartphones was not available at the time of the study despite being a desired item for inclusion in the starter-pack.

A trial of a starter-pack was selected as a way to introduce people to ECS. If funding had been available, each participant would have been provided with a starter-pack that they could keep if they so desired. Doing so would however have presented an ethical dilemma in terms of participant selection. Selection was ultimately based on pragmatics but if participants were to be given an ECS for longer term use the exclusion of some based only on geographic location would have been unethical. The decision to provide and remove each starter-pack was an ethically challenging one. If participants were to keep the GrEAT the study would have been limited to two single persons.[235] Although smaller sample sizes in qualitative research is permissible, and Eatough and Smith, (2006a; 2006b) has demonstrated how IPA can be applied to single person studies, I sought a larger sample size as I did not have the confidence to base my study on two persons as I anticipated variations between participants that may not have been apparent in a two-person study. In addition the award of my scholarship included recommendations for larger sample

[235] Funding only allowed the purchase of 2 GrEAT packs.

sizes. Using commercially available products in the GrEAT was an ethical consideration as it included the possibility of creating business opportunities and may have been considered a commercial allegiance to a single ECS supplier in Ireland however it must be noted that the installation did not involve the supplier (as is the status quo commercially). This did however not present itself as a notable concern as those involved in phase 3, who expressed a clear need for these ECS, were unable to acquire them due to financial restrictions. Only the pilot participant in Phase 2 purchased ECS from a commercial supplier but had expressed an intention to do so prior to his involvement in the study and considered the study to be an opportunity to trial before purchasing. While the specific components of the GrEAT pack are detailed here the exact devices are not considered integral to such a starter-pack and are thus not specific to a supplier or isolated products as detailed in section 6.4 below. In addition participants were briefed that their involvement did not equate to a clinical assessment nor to a clinical recommendation of specific ECS devices. They were provided letters detailing their involvement in the research trial for future reference and instructed to seek independent ECS assessment and recommendation if desired.

If funding had permitted it may also have been desirable to supply an ECS that was more extensive than a simple starter-pack. However such provision was not the intention of this study because such extensive provision would have been unrealistic in the resource-limited healthcare setting in which the research was conducted limiting the practical application of findings.

I ensured that all participants were aware from the start that the GrEAT pack was only provided on a trial basis. The idea of a loan rather than outright ownership was acceptable to all participants. Participants were in fact eager to have the opportunity to use ECS in order to have a realistic learning experience on which to base their potential future efforts to acquiring ECS if desired. On reflection I felt that the trials provided participants with education and information about ECS that had not been previously available to them in Ireland. Given that information can be empowering the provision of a starter-pack even for a brief specified period was considered justifiable.

The starter-pack may have been developed for use as an integral part of rehabilitation for people with high SCI but this option would have been logistically challenging and would have required support from already overburdened ward staff.

In addition it was not possible to anticipate having suitable in-patients who would offer consent to act as research participants for the desired length of time. Findings from Phase 1 of the study also led me to believe that ECS use is inherently home-based and that extensive use in a hospital setting, although a useful precursor to home use, would not reflect living with ECS.

Each installation and customisation took several hours due to the collaborative approach adopted. The generally positive experiences of using the GrEAT may be partially attributed to my installation and my interaction with people as an occupational therapist. As Turpin (2007) points out, occupational therapists work to change the environment that a person lives in such as through the provision of AT including ECS. In addition occupational therapists may facilitate the way the world is experienced by the individual by facilitating environments and/or occupations that give meaning (Turpin, 2007). While I did not formally evaluate my own interactions with participants I did keep a reflexive diary at every phase. Reviewing this diary and considering my personal recollections indicate clearly that I offered much of myself during these installations in terms of presenting the pack with some passion and as simple and easy to use while also working hard to ensure that the set-up made sense and was meaningful for each person.

This study shows that it is possible to involve the user in every step of the installation process. Providing supporting information was a requirement emphasised as important by participants in Phase 1. The specifically designed booklet and video were useful tools to meet this requirement. These simple tools will be freely available for others to use and adapt.[236] I felt confident leaving the participants to use the GrEAT because I knew that they had a booklet that provided step-by-step instructions detailing how to set-up and use the pack. Installations may have been quicker if I had asked the participants what they wanted to do and then designed the menus and had programmed the ECS myself. However including them at every step provided them with both the opportunity to make choices about how they wanted it set-up as well as proving education on how to set-up the equipment.

Managing all the technical aspects with no technical support may be considered a weakness of the study. It was my intention in this study to be self-reliant in managing the technical aspects of the installation to test my assumption that

[236] To be archived at Cork Open Research Archive www.cora.ucc.ie

technology is becoming accessible to health professionals and service users without requiring the intervention of technology experts. The process was not without difficulties as already discussed in Chapter 9 (section 3.4) but I was able to resolve all of these thus demonstrating that an occupational therapist can set-up an ECS and adjust it without technical assistance.

5.2 Scope of investigation and findings

This study did not explore existing ECS services and provision in Ireland and focused instead on one possible type of provision – an introductory ECS starter-pack. This study did not evaluate the GrEAT pack itself, but instead focused on the experience offered to users by the pack. This study did not detail the tasks executed by participants nor did it attempt to measure individual use of the GrEAT. This study did not explore the lived experience for carers and family members who live and work with those who have ECS. Findings thus do not support or refute the benefits for carers as a result of having ECS. This study did not investigate the levels of ECS knowledge of occupational therapists or people who can use ECS nor did it evaluate current AT training in Ireland.

This study did not focus on how ECS may have improved independence but rather showed how ECS improved autonomy that encompasses aspects of both doing and feeling. This study did not explore satisfaction, although Phase 1 findings indicate that Irish ECS users expressed some dissatisfaction with their ECS and the provision thereof. The category of *ECS Expectations* in Phase 1 captures some aspects that causes dissatisfaction including reliability, simplicity and appearance.

Quality of life is a subjective and therefore unquantifiable interpretation of how one perceives a life, and was not formally explored in this study. The meaning of living with ECS has been shown in both Phase 1 and Phase 3 to encapsulate more than the single subjective concept of improved quality of life. It is however possible to link current findings to existing quality of life investigations with people with high SCI. Hammell's (2004a) qualitative investigation found that people with high SCI considered quality of life to be dependent on autonomy and a meaningful use of time beyond doing (including time alone and with nature). These findings closely resemble the study findings suggesting that ECS improve quality of life by facilitating autonomy and being alone. Hammell's findings also indicate that technical resources such as ECS are facilitators of quality of life. Findings from this study do not include improved quality of life, but instead focus on ECS use that

enables a doing of normal things as a precursor to enhance quality of life. It is apparent that being able to use ECS having previously been deprived of their use, should improve a person's quality of life.

5.3 Doctoral study

One potential limitation is the nature of doctoral research itself as inherently resource and time limited. This study was conducted by a single researcher with little practical support apart from that provided by the academic team. This required creative use of resources. Phase 1 required that I create a research team that was comprised of volunteer work colleges. Further support was sought from SII at various stages during the study to assist with recruitment and design of patient information documents. Ideally I would have favoured conducting this study in a larger research team may would have included colleagues who could have conducted parallel research into the technical aspects of ECS. This may have facilitated the inclusion of new innovative products in the GrEAT. While I initially investigated such collaborations my scholarship required that I complete my study within a limited time frame which was only manageable as a single researcher.

5.4 Qualitative study

This study was qualitative in nature and was conducted on a small Irish[237] sample and its generalizability to other cultures or geographic locations warrants further exploration. Findings however were found to ring true with my own clinical experience and interestingly also to be consistent with the clinical expert's experiences. Her experience was based in another country, in another continent, and with people with different debilitating conditions who were of a different nationality and culture. This suggests that the findings may represent a wider experience of ECS rather than the experience of this small sample of Irish people with high SCI.

5.5 Phenomenology

The application of phenomenology by a clinician new to both research and philosophy may be considered a limitation. This limitation has been articulated through disclosure in reflexive research diaries and reflective comments throughout the thesis. I have sought to minimise this limitation through extensive reading, and further self-education in the field of phenomenology and by immersing myself in the

[237] Republic of Ireland, not including Northern Ireland which is part of the United Kingdom despite geographic proximity.

practice of phenomenological research. In addition, phenomenological analysis has been conducted through an occupational therapy lens and thus may exclude constructs of greater interest to purist phenomenologists or other disciplines such as psychology. On reflection this study has been conducted as an occupational therapist phenomenologist.

A specific phenomenological data analysis approach, such as Giorgi's method, could have been employed in analysis of Phase 1 findings possibly increasing the credibility of the analysis in the eyes of ardent phenomenologists. As an introductory phase of a larger study this was not considered necessary and a general overview was thought to be better served by a thematic analysis within a phenomenological frame work. My attempts to bracket my preconceptions can be challenged because as the moderator I played a role in the production of the data. On reflection I also found my own perceptions were shaped by the participants (Morgan, 1996). This interaction is a hallmark and an attraction of qualitative research (Hammell & Carpenter, 2000). Reflections of this interaction were recorded in a reflexive diary on a daily basis during data gathering and analysis. Alternatively although IPA may have been the chosen method for Phase 1, it was not selected as the study sought the shared perspective rather than the ideographic focus of IPA. While two methods of how to apply IPA in focus group research have been published since the data were analysed (Palmer, et al., 2010; Tomkins & Eatough, 2010) the depth inherent in IPA was not required in Phase 1.

5.6 Research sample

This study is limited to a exploring the experiences of a small Irish sample of people with the same single pathology – SCI. The findings represent the essence of living with ECS for them. While I do not make any claims about the generalisation of the findings to the larger other populations, corresponding findings have been found in part in other qualitative studies suggesting that the essence described may be in part reflective of the experiences of other people in different settings and with different pathologies.

Although the study is presented as a whole, participants in each phase had different experiences of ECS use. The first phase included experienced ECS users and non-users. The inclusion of non-users added a positive dimension as they provoked discussion and evoked greater clarity and richness of expression from users. Participants in the final phase were all new to using ECS and their experience may

differ from those who use ECS every day. Further investigation would clarify the experiences of users, non-users' and new users. The combinations of different data collection and data analysis methods may appear to be disjointed and possibly even incompatible. Efforts have been made to present the rationale for these selections and to integrate the various methods throughout the study with a reflexive thread.

5.7 Focus groups

Focus groups may be considered artificial, contrived and limited in comparison to participant observation that studies naturally occurring experiences (Kitzinger, 1994). This was however not a concern as this phenomenological study sought subjective self–report perceptions as opposed to objective realities. As a naïve researcher, choosing to use focus groups when I had no previous research experience of them, may have limited the quality of the data production. However this may have been true of other methods such as participant observation or research interviews. My experience of group work did provide some useful experience and the quantity of data produced was considered sufficiently rich and deep for this phase.

High cervical SCI imposes logistical challenges including, scheduling carers, accessible transport as well as managing physiological needs such as monitoring of bowel and bladder function, body temperature, fatigue and positioning. Despite all these potential complications, attendance rates for the groups were high. Individual interviews in participants' homes would have reduced the challenges for people to attend groups but logistically would have resulted in fewer peoples' opinions contributing to the findings. In addition it was feared that individual interviews may have failed to produce sufficient data from those who have little knowledge of ECS who are the target population. It is believed that the discussions that took place in the focus groups, particularly between users and non-users, provided insights and shared views of living with ECS that would not have been possible with individual interviews.

Only including four focus groups may be considered a limitation as more groups could provide further insights. Recruitment however only identified 15 suitable participants from across Ireland, thus limiting the data collection to two groups that could meet twice. The focus group design could have been extended to include focus groups with family members and carers and focus groups with occupational therapists. These would have provided other potentially useful insights for designing

the pack in Phase 2. However these groups would not adequately reflect the primary focus of the study – the experience of a person with a high SCI living with and without ECS.

5.8 Data collection and analysis

Video recording was used throughout the study and it is not known if its use limited or supported discussion or contributions of participants, although limitations did not seem evident when reviewing the video recordings and transcriptions in any of the three phases.

Considerable time and effort was required to become competent in the application of the computer software used in this study. No known software programmes have been designed for use from a phenomenological perspective and most phenomenologists advocate pen and paper based analysis (Finlay, 2009, Smith & Osborn, 2008). An inherent limitation of the computer software package is the fact that it was designed for use with grounded theory. The use of the software from a phenomenological perspective required devising a strategy and application of the tools of the software package as described in Chapter 9 section 5. The time and effort invested were however considered worthwhile as it reduced the work load and confusion in later stages of the data analysis and research particularly when summating the findings.

6. Practical real world implications

This study has implications beyond that of the completion of an academic thesis. The study was born out of an identified clinical need and was intended to have clinical implications for occupational therapists, for spinal injury rehabilitation and for people with high SCI. Seven clear implications of this study are identified as follows:

6.1 ECS need to be available to those with high SCI

The primary implication is that the positive effects on meaning of life with ECS obliges professionals to ensure that ECS are integral to life with high SCI, and to ensure that those who need ECS are able to acquire them. Having ECS will help provide an opportunity for people with high SCI not to simply exist but, through participating in everyday occupations, to live. Stead's thesis (2002) on ECS entitled - *Life support technology – redefined* suggests that ECS are life-saving. This and

other studies that focus on the users' perspective show that ECS are *essential* (James) for this group of people. The notion of their importance to users is also echoed in this and other studies:

> *I couldn't do without it (Palmer & Seale, 2007, p.22).*
> *I don't want to be without it (Ripat & Strock, 2004, p.70).*
> *I … nearly couldn't live without it. (Ciara FG 4).*

And, for those who need them ECS are: *Indispensable* (Palmer & Seale, 2007). All phases of my study indicated that most participants valued ECS and either did use an ECS extensively or could envisage using an ECS extensively.

6.2 Barriers to ECS provision and unrealistic expectations need to be addressed

While this study did not investigate the provision of ECS in Ireland, evidence suggests current barriers include poor funding, a lack of information, and limited opportunities and resources. Without funding being made available, people with high SCI will continue to suffer occupational deprivation. The necessity for ECS needs to be highlighted and funding actively sought and inadequacies of provision highlighted.

Poor levels of knowledge about ECS were revealed during the focus groups in Phase 1 and participants in Phase 3 were pleasantly surprised by their own experiences. This surprise was based on a combination of the new abilities offered through ECS use and their own surprisingly successful use of ECS. Both these indicate that the actual experience did not match the anticipated belief that it would be difficult for them to get used to using ECS and that ECS would not suit them. This suggests that people did not have access to accurate information about ECS use indicating a need to provide realistic information to both rehabilitation staff and to those who may use ECS. This requires the provision of accurate information and experience of ECS during initial rehabilitation, at out-patient services and within the community. Potential ECS users need to experience that ECS use is simple, is fun and can be individually adapted. They need to be provided with information best shared through an increase in active real experience with ECS.

While an associated study showed that Irish community occupational therapists acknowledged the benefits of EAT (including ECS) and felt that they had a role to

play in EAT assessment and provision, they perceived an inability to fulfil this role (Verdonck, et al. 2011b). This may indicate a need for improved ECS education for undergraduates as well as for experienced therapists as indicated elsewhere (Cowan & Turner-Smith, 1999; Gitlow & Sanford, 2003; Green, 1996; Hammel & Smith, 1993; Kanny, Anson, & Smith, 1991; Maguire, et al., 2001; Orton, 2008; Smith, 2000; Somerville, Wilson, Shanfield, & Mack, 1990). Up-to-date ECS knowledge, including the users' perspective such as described in this study, is required for occupational therapists at all levels so that ECS is acknowledged as an occupational therapy responsibility. In addition basic ECS education needs to be shared.

6.3 ECS are an occupational therapy responsibility

Doing is a concept central to occupational therapy, and occupational therapy interventions should be occupation-focused and therefore centred on enabling meaningful doing. Occupational therapy aims to facilitate people in doing what they want to do. People want to control their audio visual and other electronic devices and they want the opportunity to be alone and to feel safe alone. Without ECS, people with high SCI are deprived of being in control of these things. Using ECS allows the doing of occupations (both being and doing that contribute to becoming) and thus ECS is inherently an occupational therapy responsibility.

Having an ECS facilitates people with high SCI to feel enabled and by feeling enabled they also feel worthy to have such a system. Without the hands on experience James, Matthew, Peter, and Bridget did not consider availability of ECS a realistic or necessary option. However, interviews with them and with Emily after a trial period indicate that they all felt worthy of having an ECS. James described ECS as essential but also considered that his need to have them could be viewed as *selfish*. To Emily they are just as important as a wheelchair:

> *if someone just wants a new wheelchair I don't think that is more important than me being able to make a phone call, or turn on a light, you know (Emily, line 189)*

This quote also emphasised the importance of seeking the insider perspective.
Similarly, Peter described it as more than an entertainment system:

> *(It is) good to know … you have more security with it as an emergency system not just as eh (pause) entertainment purpose based product. It wouldn't be just that, it would be necessary for me (Peter, line 121).*

Findings indicate that life without ECS for some was a form of restriction and deprivation that they appeared to have become accustomed to. For Matthew using an ECS gave him a bit of freedom:

> *just a great bit of freedom for once (Matthew, line 7).*

His use of the expression 'for once' indicates how unusual it is for him to experience *a bit of freedom.* Freedom is an accepted universal human right and for Matthew the ECS allowed him to experience some of that freedom:

> *I mean it's just given me a little bit of independence. It's given me the ability to do something that I haven't been able to do for ten years (Matthew, line 21).*

Neither those with high SCI, who lack ECS experience, nor services providers can understand what it is like to live without ECS or to live with ECS. Occupational therapists therefore have to be advocates for those who have become accustomed to *managing* and *getting on with it*. We need to advocate for ECS use and provision based on the experiences of using an ECS and their meaning as uncovered in this study.

It would be naive to suggest that all occupational therapists can begin installing ECS immediately. ECS must be familiar and relevant to their practice, in the same way that some mental health interventions would require training for occupational therapists working in other specialised areas. Clinical experience of using ECS is important as advocated by Verdonck and Ryan (2008), not least in overcoming a lack of confidence or even a phobia regarding technology that results in it being perceived as sophisticated or specialised. In addition, ECS needs to be viewed not as a specialist area, but an area in which occupational therapists may need some technical ECS training. This training I believe can be minimal, as devices have become more readily available on the open market or through the internet, are simple to set-up and, if motivated, therapists are likely to learn *on the job* and from others. In addition if a collaborative approach is used the person who is going to use

the ECS may be able to assist in the setting up of the device through verbal instruction. This was clearly evident in Phase 1 where participants agreed that they should be able to adjust their own ECS (Chapter 7).

Successful installation and customisation is dependent on the interaction of the occupational therapist and the ECS user. I believe the tasks involved in setting up an ECS are the same as those required for setting up any AT. Set-up requires a person-centred, problem solving approach, grading of complexity, and therapeutic use of self by the occupational therapist. Instructing and supporting the user in learning how to use ECS requires the same skills as teaching dressing techniques – dividing the task into manageable component parts, assisting for success only when necessary by providing verbal cues and making environmental changes. This study has also provided insights into the challenges and hassles for the occupational therapist involved in learning to use ECS and the relationship with engagement that can be nurtured by facilitating ECS use for a user.

It is my fear however that pragmatic and organisational pressures threaten this collaborative approach that I believe is fundamental to the success of ECS use. Occupational therapist need to be allowed the time to adopt a collaborative approach which is challenging when resources are limited. Once occupational therapists become familiar with simple ECS starter kits, practice and experience with users will improve confidence reminding them of the importance of this collaboration for successful ECS adoption. It would appear occupational therapist must also beware that becoming an expert ECS therapist and basing interventions on their own experience rather than on those of the person who will use the ECS is counter-productive and not what users want and occupational therapist therefore need to embrace a collaborative approach.

6.4 An ECS starter-pack is viable

On reflection developing an appropriate user friendly pack was challenging. The primary reason for this was the difficulty of accessing information about ECS. The existing academic literature provided no useful information on either the contents or on the development of an ECS pack. The commercial literature was focused on individual products rather than on integrating systems for individual use. While the final pack, the GrEAT, is detailed in this study, it is the functionality of the pack, how it was customised for participants that was fundamental to its use (and success). The pack needed to control audio visual equipment, telephones and some simple

on-off appliances. This could have been achieved with the use of an assortment of different devices. The specific choices of equipment made in this study are less important than the necessity for all the components to be compatible and to be important to the individual user. The pack was flexible in that it could be used for one single function or multiple functions and was considered to provide a framework or building blocks which could possibly allow for further expansion. Future starter-packs are likely to have components similar to but not the same as those in the GrEAT.

Although some Irish occupational therapists have considered themselves to be unable to assess for and prescribe electronic assistive technologies (Verdonck, et al., 2011b), this study has shown that it is possible for an Irish occupational therapist to install and customise an ECS starter-pack. This can be facilitated by a step-by-step information booklet and demonstration DVD. Installation is enhanced by a collaborative approach with the user who is empowered by this process and together both parties can customise a suitable ECS pack using a collaborative, problem solving approach.

An ECS starter-pack is a viable way to provide people with a practical introduction to ECS. The pack may be provided on a temporary loan basis as a precursor to supply or purchase allowing the user to make an informed choice for their future ECS use. Alternatively a starter-pack may be used as a stepping stone to more complex installations that may later include components such as door openers and intercom systems. These more complex applications will require specialist installations that the user and the occupational therapist should collaborate, together with suppliers.

6.5 ECS may be *too much hassle* for some

The findings of this study caution against an *one-size-fits-all* approach by describing the hassles and problems experienced with ECS use. This highlights the possibility of choosing not to use an ECS if the hassle experienced is greater than the pleasure and benefits. Service providers need to acknowledge the inevitable hassle involved in ECS use and support users through the hassle if they are to enjoy the benefits of *feeling enabled* and *reclaiming some doing*. It is important that service providers can give people the opportunity to choose to be users or non-users based on practical experience rather than the current situation in Ireland where circumstance determines individual opportunity for ECS. ECS assessment and

provision can be likened to wheelchair provision and seen as an essential part of the rehabilitation process for people with high SCI. At the same time ECS should not be issued as standard and each ECS must be individual and customised collaboratively with the user. Most importantly ECS should not be viewed as suitable for all. Non-use should be based on realistic information and experience. Providing the choice to use or not use ECS must be the priority as opposed to ensuring all who might use ECS do use ECS. The choice not to use ECS must be considered a successful outcome if based on personal choice rather than as a failure or attributed to a person's *non-compliance.*

6.6 ECS use should be established as an early habit

People with high SCI need to be offered the experience of ECS use early in their rehabilitation so that they become an integral part of their decision making and total rehabilitation. This means that people with high SCI should be offered a starter-pack as early as possible. Living with high SCI was described in Phase 1 as acquiring habits that are not easily given up and are in fact essential to enable those living with high SCI to do some things for themselves. If ECS are introduced after these habits have been established the hassle involved in both undoing some of these habits and becoming used to using ECS, are more likely to be not worth the hassle. However if ECS are introduced early enough this could make the ECS a habit, as echoed by expressions of *couldn't be without it now (Susan, Jane, Ciara).* Similarly it appears that successful use for new users would require establishing ECS as an early habit.

However allowances must be made for individual differences described as a *timing issue* (Joe). A starter-pack needs to be available at different times for people so that they can experience ECS when they are ready. This means offering a starter-pack at the start of rehabilitation, as well as: during rehabilitation, on discharge from hospital and when living in the community. This may be difficult to achieve as bureaucratic processes and systems that govern rehabilitation service will challenge this concept favouring the identification of one uniform ideal time for introduction to ECS. Healthcare systems tend to favour bureaucratic simplistic systems rather than person-centred services as recommended by his study.

6.7 ECS must not be considered in isolation

Although this study focused on ECS their provision should not be done without considering other AT. The inclusion of powered mobility and mouthstick use in an

ECS study is unique within the known ECS literature and was an unexpected finding resulting from providing people with the freedom to discuss ECS on their own terms. The powered wheelchair, mouthstick and ECS triad uncovered in Phase 1 highlights the need for the integration of assistive technologies as advocated by Ding (2003). Both high and low technology assistive technologies are equally valuable (Scherer, 2005). The identification of the value of mouthsticks for people in his study highlights the need for their inclusion in rehabilitation in conjunction with electronic technologies. This is clinically challenging as mouthstick use is often not considered acceptable during the initial stages of rehabilitation.

7. What next?

As a pragmatic clinician I feel compelled to provide clear instruction on how to apply the findings of this study and move forward in ECS provision. People in Ireland with high SCI can be provided with the opportunity to use and gain individualised ECS through the provision and customisation of an ECS starter-pack. This will require a multi-faceted approach that must include the rehabilitation setting, outpatient clinics and more importantly must extend to the wider SCI community. It also requires the involvement of hospital and community occupational therapists, people with high SCI and their families and carers. In addition it requires a progression of using a small number of known reliable technologies as well as the more challenging modern devices such as modern smartphone and tablets not least as these are now part of everyday use for most people.

It is my belief that as society and technology become ever more intertwined all members of society (including those with disabilities) will become (and in fact are becoming) more adept using the technology. Customisation is becoming common place for many devices. Smartphones and tablet computers have customisable interfaces that each user makes their own by selecting what they want in the device and where they want to put it. The customisation of an ECS that may have appeared to be the realm of the expert five years ago should also be customisable and is now a far less daunting prospect for users. Occupational therapists and ECS users should expect to be able to customise devices (including ECS). Although the actual technology may have become more advanced and harder to understand the interfaces and the customisations have become simpler. This is a double edged sword because while people expect to be able to customise ECS most available ECS technology is outdated in comparison with smartphones and tablets and even

television services. This means that although the devices are customisable, doing so is less intuitive and does require some training and reliance on instruction manuals. Owen (pilot participant), Peter and James all made some adjustments to their ECS during this study proving that they could do so independently. It is hoped that they were empowered to do so by sharing in the installation process and by having a reference booklet and clear instructions.

Interestingly the future of ECS appears to be smartphone based (Verdonck, 2011b, Appendix 33). A product is now available that provides integrated switch access and IR sending for smartphones. This means that a person with high SCI or any switch user can use a smartphone or a tablet computer as an ECS which matches Frank's aspiration as expressed in Phase 1 of this study:

> *I reckon anything with a remote, you can control. I can't understand why they can't marry them up .... You could buy a phone … with the Bluetooth® .... I can't see why it's not married up with a remote and the job is done. No one is out there doing it, all the technology is out there (FG 3).*

Future ECS starter-packs are unlikely to include the same components used in this study but will be smart phone based. This means that ECS are more likely to be mainstream to fit better with the wishes of the service users as expressed in the *ECS Expectations* themes which emerged from Phase 1 of this study. Participants expressed a desire for- *discreet ECS* and *simple ECS*. The hope and expectation for *Speech-driven ECS* is another likely future development that should be possible by integrating phone based speech activated applications with ECS applications. The last theme in the same category, *Reliable ECS* highlights concerns about reliance on mainstream products. Mainstream products may be less reliable than specifically designed ones. Smartphones and tablets are fragile which makes them susceptible to damage due to moisture or bumps when mounted on a wheelchair. The battery life of a smartphone is poor and the demand on such a battery made by an ECS application may drain the battery. On the other hand using smartphones means that the devices are more easily replaced when broken.

The inclusion of mainstream devices in ECS starter-packs should lower the cost of a starter-pack significantly especially if a person is able to use their own smartphone which will in turn facilitate a perception of individual customisability. Further updating and development of the starter-pack will require more on-going work including updating of videos and of the information booklet. Most importantly it will require a

small number of highly motivated multidisciplinary team professionals who are committed to facilitating ECS use to further develop this work

7.1 During rehabilitation

Several ECS starter-packs need to be acquired for use during rehabilitation. These ECS starter-pack can be introduced early in rehabilitation and customised in collaboration with the person for whom it is intended, possibly even using their own smartphone or other device.[238] ECS use and customisation can be facilitated using the video and booklet. This will provide a person with high SCI with some control of their in-ward entertainment, as well as telephone access and control of devices in the occupational therapy department, as they decide, on a loan basis. Hospital-based SCI occupational therapists will become more familiar with setting up ECS through the use of starter-packs in the hospital setting. It is also important to acknowledge that some people may choose not to avail of an ECS starter-pack while in hospital or they may find the ECS to be too much hassle.

7.2 In the community

As patients and their families become familiar with ECS use and customisation in the hospital setting, they may be able to take a starter-pack home for short loan periods on discharge and to customise the pack for home use with minimal occupational therapy assistance. This can be accompanied by supporting video and information booklets like those developed in the GrEAT pack. Community occupational therapists need to collaborate with the user, their family and the rehabilitation team to facilitate on-going use of ECS. Community occupational therapists have already acknowledged their ECS role (Verdonck, et al., 2011b) and now need to be provided with the opportunity and confidence to fulfil this role and use ECS starter-packs. If the loan of an ECS starter-pack is successful and the user chooses to keep the pack on a long term basis this must be made possible. A system and funding model needs to be developed to allow this to happen and would have to include the entire community health care team. Alternatively a person may decide that ECS are not for them or they may choose to trial other devices and components before seeking their own ECS. Trials of other devices will require support from suppliers to provide ECS controllers on a loan or hire basis.

[238] Patients would be encouraged to provide these devices as part of their rehabilitation in the welcome booklet which would also suggest that an occupational therapist could assist them to customise the device and include ECS functions.

ECS starter-packs also need to be available for first time use in the community for people newly discharged and those who have been living without ECS for some time. Successful ECS use was described as being *about timing* (Joe). Those who may not consider ECS personally suitable while in rehabilitation need to be given the opportunity to use ECS in their own homes at a time that may be more suitable for them. Again it is imperative that the hassle is acknowledged and discussed to facilitate engaging with ECS use.

An ECS starter-pack is also required for hospital based outpatient clinics for demonstration and to be offered for trial to people who return to the hospital for review. Again this can be facilitated using the introductory video and booklet. Findings from this study should also be shared at all levels. Dissemination is planned to include: in-house lunch time information sharing sessions; national ECS and smartphone workshops for occupational therapists, people with high SCI and their family and carers;[239] as well as international academic publication and conference presentation (appendix 30).

The wider community incorporation of ECS starter-packs requires supporting community occupational therapists who do not feel able to fulfil their ECS role. This can be facilitated on an individual basis as well as through regional hands on workshops aimed at providing both occupational therapists and potential users and carers with an understanding of how to use and customise an ECS starter-pack.

This study has not identified how such a pack can be funded and this requires further investigation. However lack of funding should not be an acceptable excuse for denying ECS and thus perpetuating occupational deprivation.

7.3 Recommendations for the provision of ECS starter-packs for people with high SCI in Ireland

In summary the provision of ECS starter-packs must include:

- Securing funding possibly through commercial partnerships[240]
- Collaborative customisation with the user
- The option to choose not to use ECS
- Inclusion of modern mainstream devices – smartphones and tablet

[239] Workshops may provide a source of funding for some ECS provision
[240] Phone and ICT companies.

- Updating of supporting video and information booklets
- ECS starter-packs to be offered at start of rehabilitation, during rehabilitation, in preparation for discharge, on discharge, and in the community
- Raising the profile of ECS through dissemination
- Liaison with other local and international advocates for AT provision including wheelchairs and AAC, to create a forum to instigate change for people with physical impairments

8. Future research

In writing this final chapter I can say I have several unanswered questions and several ideas for further research. This study has to end but it has the potential to lead to further investigations. My immediate research interest is to investigate the users' perceptions of the newest smartphone ECS systems. This could involve a research trial similar to that included in Phase 3. The desire to explore this is based on my clinical interest in perusing a starter-pack more reflective of the technological society that we live in.[241]

If this study is to have the desired practical implications and provide evidence for changing current ECS practices for people with high SCI in Ireland further background information is required. There is a need to investigate the provision of ECS in Ireland, levels of ECS knowledge, and ECS education. Cost analysis of ECS provision and cost comparisons between ECS provision and extensive care provision in Ireland would be useful. This could clarify potential cost savings or extra unexpected costs not considered in this study. It would be important that cost analysis also consider the value of the psychological benefits of proving ECS and the associated costs living without ECS such as mental health issues such as depression and anxiety.

This study could be been extended in a fourth phase that would involve in-depth interviews with long term ECS users to compare and contrast their experiences with people using a temporary ECS in Phase 3.

It would be useful to see if the experience of living with ECS as uncovered in these findings is similar to the experience with other ECS users old and new, with other

[241] I would have favoured such a pack had it been available when this study commenced.

pathologies, living in different countries and settings. An extensive qualitative phenomenological, multi-centre study could provide insights into a shared essence of ECS use.

Other aspects that this study might have explored but I chose not to include all merit investigation in their own right or in combination. Things that I would have liked to have explored include: the experience of ECS for carers and family members; the experience of using speech-driven ECS, reasons for not using ECS mounts, and the experience of using computers for people with high SCI.

9. Concluding reflexive commentary

My clinical background based on several years of work as an occupational therapist did not prepare me for the academic rigor required for this task. Discipline and productivity were useful attributes that helped keep me to the task many times. I was eager to get the job done. Taking the time to do qualitative work properly was my greatest challenge. Accustomed to assessing patients comprehensively within one or two functional sessions I was not prepared for the time required to analyse my data. I now understand this requirement and can see how the quality of work was dependent on taking it slowly (an alien concept for me). The challenge of Phase 1 analysis then paled in comparison with the rigor demanded by IPA. When I attended an instructional IPA course I was resistant to the slow step by step, don't rush the analysis approach. I felt that I could see the findings the same way that I can see a new patient's functional ability and their potential relatively easily. Having forced myself to analyse each interview individually and holding back the assigning of themes, I now understand how important this was and I can see more clearly now in contrast to my initial blinkered view.

Using IPA as a research method in Phase 3 suited the research aims of this study and I think it aided me to increase the rigor of my analysis and the depth of my findings. As stated earlier, I could have analysed the interviews thematically using Phase 1 findings as a template of themes. While this would still have produced meaningful information the findings would have lacked the maturity and nuance afforded by IPA. As an occupational therapist and a researcher I am however concerned by the popularity of IPA that is leading to a method-focused research movement of people loyal to IPA. I cannot claim membership to this group myself. While I employed IPA as a useful method I would not consider myself an IPA researcher. My study in its entirety does not warrant full acknowledgement as an IPA study as it employed other methods. I would query IPA's suitability for future research as it is so intensive and time demanding. It is this very nature of IPA that makes me critical of some

emerging research that claims to be IPA but to me looks like it is just thematic analysis or poses the alternative question: is IPA in fact glorified thematic analysis itself?

I began this journey with a vision of making ECS provision a part of everyday occupational therapy for people with high SCI in Ireland. My pragmatic brain envisaged this to be a simple task of gathering evidence of how brilliant ECS can be and then using that evidence to force a change. The journey has however not been that simple. I have grown myself and blossomed into a phenomenologist and I now have real insights into people's lives. I have been privileged to gain an understanding of what life is like for those with high SCI. I am surprised by the nuances of my findings. I appreciate how the clinically relevant things often lie in the details, in the subtleties, the very things that large quantitative studies fail to capture and often overlook. While quantitative study is essential and valuable I have been re-born as a qualitative junkie.

I find the positive findings of this study to be truly encouraging and compelling. While I thought that this was something that needed doing now I see it as a calling, as something essential. I think now of all the occupational therapists I have met in all the SCI units in the United Kingdom and I want to share the deep and meaningful perspectives that I have gathered in the long and arduous journey. I then realise I have a much wider audience to address. This study and ECS for me is integral to spinal occupational therapy and I need to make sure all the relevant occupational therapists know this. I think it is hard to not become evangelical when completing a thesis but I think when the topic is so potentially life changing some element of evangelism is essential. This enthusiasm and evangelism continues now through accepted (Appendix 31) and anticipated further publications to occupational therapists and others.

I knew that I wanted to explore the unadulterated perceptions of people who could use ECS. Frustrated by the volume of studies that told me so little about the real person and the real experience of ECS I now really appreciate the value of adopting a phenomenological attitude that allowed me to see as if seeing for the first time. I now have a real passion for good qualitative research because I know first-hand how enlightening and real the findings can be.

Having completed this academic endeavour I fear that the real world is not going to be sympathetic to my new found knowledge. I fear organisational pressure; financial restrictions and arrogant and resigned acceptance that things do not require change is going to be a barrier to change. I think my greatest challenges are yet to come. The challenge now is taking this work off these pages and into the real world of practitioners and users from where they first originated.

The personal growth is not possible to fully articulate but I have come a long way from the person who included no verbs in the motivation section of my draft funding application. The implications of doing this study were wider than is documented in this thesis. There are several practical things that are not fully reflected in these pages. I made videos and information sheets. I wrote articles. I lectured to occupational therapy students. I advocated for the adoption of mainstream technology by all occupational therapists. I have broken computers and hard drives. I have experimented with phone based ECS and other associated technologies suitable for people with high SCI – such as computers access. I have chatted to various people with high SCI throughout the entire study to continually keep my focus on their experiences. Many of these chats have inadvertently led to discussions about computer access, wheelchairs, and prognosis. I have been pulled away from my desk to show someone how something works or to chat to a family member. I have written articles for SII and I have presented my work to other professionals. I have enjoyed it all.

10. Final words

This study process was initially conceptualised as akin to a growing tree in Chapter 1. I feel that the tree is still a sapling, far removed from its African roots, and its Irish branches have much more growing to do, but the intention behind this study will continue to grow and hopefully bear the fruits of increased ECS use for those with high SCI in Ireland. This is essential as the metaphorical tree is being fed by increasing technological offerings.

This thesis began with a word about occupational therapy and a word about SCI and ends with a word about the ECS lived experience. While the study was conducted by an occupational therapist and it involved people with SCI, its richness lies in the depth of the description of what it is like to live with ECS and what that means. This study is really about ECS experiences, experiences that clearly show that using ECS involves both hassle and engagement but if the hassle is considered worth it the user can take back a little autonomy and in so doing feel enabled and reclaim the ability to do. The meaning of this experience for these Irish people with high SCI is occupational involving doing, being and becoming with several additional nuances illustrated in the themes - *Experiencing pleasure in doing; Time alone; Being less physically dependent; Doing everyday things; Enjoying your own company; Changed relationships, Feeing enabled; Feeling safe alone; and Feeling less needy.*

Finally, imagine again as you did in Chapter 1 that you are sitting on a bus on your way home from town listening to your latest playlist on your headphones. Earlier you managed to get your personal assistant (and driver) to avoid major traffic congestion using a local traffic app on your smartphone. You check tomorrow's weather forecast and then the rugby scores on the mobile internet browser. Midway through reading a rugby report you receive a new email, which you open and post a short reply. When you arrive home before your PA has closed the door of the mini-bus you have unlocked and opened the front door, and switched on the lights. He follows you in to find you stationed in front of the television having turned on the power, the surround-sound and selected the pre-recorded crime investigation series. Imagine that all these tasks were executed using a single neck mounted switch linked to your smartphone via Bluetooth® and an IR sender.

This imagined scenario could be an accurate portrayal of any person with a high SCI living in Ireland in the near future if the practical and financial implications of this study can be met.

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