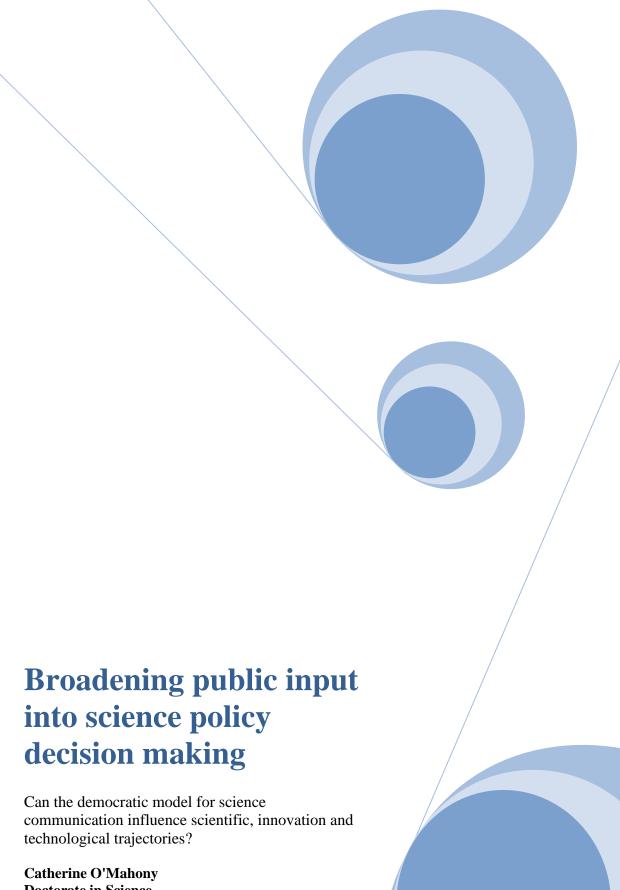


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Doctorate in Science National University of Ireland, Cork

Biochemistry Department March 2011

Head of Department: Professor Tom Cotter Supervisor: Professor Charles Spillane

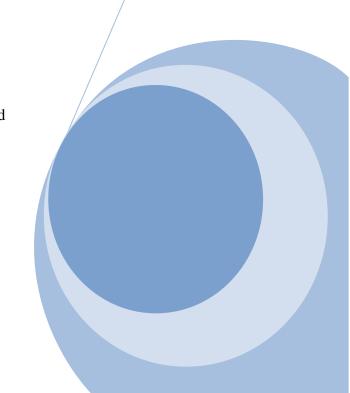


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I hereby declare that this thesis is my own work and that it has not been submitted by me for any other degree or professional qualification.

Signed:

Catherine O'Mahony

Date: 28th February 2011

Abstract

This PhD thesis investigates the potential use of science communication models to engage a broader swathe of actors in decision making in relation to scientific and technological innovation in order to address possible democratic deficits in science and technology policy-making. A four-pronged research approach has been employed to examine different representations of the public(s) and different modes of engagement. The first case study investigates whether patient-groups could represent an alternative needs-driven approach to biomedical and health sciences R & D. This is followed by enquiry into the potential for Science Shops to represent a bottom-up approach to promote research and development of local relevance. The barriers and opportunities for the involvement of scientific researchers in science communication are next investigated via a national survey which is comparable to a similar survey conducted in the UK. The final case study investigates to what extent opposition or support regarding nanotechnology (as an emerging technology) is reflected amongst the YouTube user community and the findings are considered in the context of how support or opposition to new or emerging technologies can be addressed using conflict resolution based approaches to manage potential conflict trajectories. The research indicates that the majority of communication exercises of relevance to science policy and planning take the form of a one-way flow of information with little or no facility for public feedback. This thesis proposes that a more bottom-up approach to research and technology would help broaden acceptability and accountability for decisions made relating to new or existing technological trajectories. This approach could be better integrated with and complementary to government, institutional, e.g. university, and research funding agencies activities and help ensure that public needs and issues are better addressed directly by the research community. Such approaches could also facilitate empowerment of societal stakeholders regarding scientific literacy and agenda-setting. One-way information relays could be adapted to facilitate feedback from representative groups e.g. Non-governmental organisations or Civil Society Organisations (such as patient groups) in order to enhance the functioning and socio-economic relevance of knowledge-based societies to the betterment of human livelihoods.

Acknowledgements

Our destiny is to run to the edge of the world and beyond, off into the darkness;

sure, for all our blindness;

secure, for all our helplessness;

strong, for all our weakness;

cheerfully in love, for all the pressures on our hearts.

In that darkness beyond the world, we can begin to know the world and ourselves.

St Thomas Aquinas

Beginning a PhD project involves stumbling in the dark, searching for robust research questions to steady your step and steer you forward. Yet it is in those moments of uncertainty, hesitation and misstep that the greatest knowledge comes. Not just knowledge of the subject area and your research's place in it, but self-knowledge; knowing what drives you to ask these questions; knowing what sustains you when searching for these answers; and ultimately knowing when the question has been answered and when it is time to search for new adventures.

I am grateful for the guidance and support of all those around me who helped steer me towards firmer footholds and provided me with respite when I needed it. I particularly wish to thank Dominic Glover, Michael John Gorman, Eileen Martin and Shane Morris who read sections of the thesis and gave considered feedback and encouragement. I also want to thank Sheila O'Mahony for her insight into social research and survey design, and Michael Cronin and Mindy Schouest for their guidance regarding sample sizes and research methodologies.

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Partners undoubtedly bear the brunt of a PhD obsession and obsession fittingly explains forgotten dinners, typing into the early hours, avoidance of sunshine and an intensely distracted nature. I dedicate this thesis to John. You have been a source of good-humour and great patience and an honest sounding board throughout these years; even if you only recently learned what I was researching...

Glossary of terms

Astro-turnfing

Astro-turfing occurs when companies or NGOs influence deliberations through the provision of supposedly 'grassroots' patient representatives who instead represent the perspective or advocate for the position of the company or NGO.

Civil Society Organisations (CSOs)

These are the multitude of associations around which society voluntarily organizes itself and which represent a wide range of interests and ties. These can include community-based organisations, indigenous peoples' organisations and non-government organisations (OECD, 2006).

Community Based Research

This is research which is conducted in collaboration with communities on issues of relevance to the communities.

Deliberative democracy

Deliberative democracy places an emphasis on mechanisms that encourage public debate on issues as well as encouraging collective reasoning and reflection. It is seen as an accompaniment to representative democracy rather than a replacement for.

Knowledge Valorisation

This is the process of disseminating and exploiting the results of projects with a view to optimising their value, strengthening their impact, transferring them, integrating them in a sustainable way and using them actively in systems and practices at local, regional, national and European levels (European Commission, 2009, p.1).

Public

The term public is used to designate the non-expert as distinct from an expert through knowledge or expert through experience, also known as lay-expert.

Patient group

This term includes patient groups and health groups. The first group i.e. patient group, is run by people who have a personal connection to someone with a rare disease and the second employ and are directed by paid professionals who do not usually have a family tie to someone with a rare disease.

Public Engagement with Science (PUS)

Public engagement: an umbrella term that encompasses many kinds of activity including science festivals, centres, museums, and cafes, media, consultations, feedback techniques, and public dialogue. Any good engagement activity should involve aspects of listening and interaction.

Researcher

This term denote someone whose job involves carrying out some degree of research and includes researchers from the natural sciences, engineering, technology, humanities, medicine, health, business, law and social sciences.

Science

Science is referred to in its broadest sense to include social, economic and human sciences in addition to the natural sciences, technological development and engineering.

Scientific literacy

The ability to locate relevant information and to judge its reliability and validity.

Self-efficacy

Self-efficacy is the belief that one is capable of performing in a certain manner to attain certain goals.

Social capital

Social capital has multiple definitions revolving around the concept that social networks have value. One definition suggests that social capital is a measure of the degree to which members of a community believe social institutions and the

major professions are responsive to public concerns as well as conversely the degree of perceived public trust and goodwill toward social institutions (Logan, 2001).

Subjective norms

Subjective norms relate to the influence of people within a social environment have on a person's behavioural intentions.

Introduction

Contemporary government and institutional policies are increasingly being reformulated to align with the concept of the knowledge society and to facilitate the creation and development of knowledge-based economies (Forfás, 2004; Department of Enterprise Trade and Employment, 2006). It is proposed that the effective development, management, distribution and use of knowledge will be key components in these new economies (OECD, 1996, p. 28). Entwined in this is the belief that the continuing advancement of scientific knowledge will be a key driver of social and economic progress in the knowledge economies of the future. Governments worldwide have committed vast budgets towards investment in fundamental research, applied research, technological development and innovation in response to this. Several questions remain however such as (a) what are the mechanisms or processes by which science, technology and innovation policies can or should be altered, and particularly science policy, to address the requirements² of a knowledge society, (b) what does this means for the governance of science, and (c) what stakeholders will influence and participate in discussions and decision-making regarding science, technology and innovation policies?

In many countries, science policy setting can be a top down effort with governments identifying scientific research trajectories through consultation with internal experts and external expert groups and other stakeholders, which align with social and economic aspirations. In the Irish context, selected members of the scientific and research³ communities are typically invited to participate in these discussions at an early stage through their involvement in consultative exercises such as foresight planning where they identify strategic areas for investment to improve the

.

¹ The term 'knowledge society' is believed to have arisen from earlier discussions on the topic of knowledge management. The term is particularly linked to management theorist Peter Drucker who first coined the term knowledge workers (Drucker, 1969).

² These include enabling the diffusion of knowledge to a broader tranche of stakeholders, enhancing the skills, competences and knowledge of the wider public and labour force, and promoting more flexible work arrangements and organisational change to support the new challenges of a knowledge based society (OECD, 1996).

³ Scientific and research communities include all of those involved in the natural sciences, engineering, ICT, and other related disciplines.

competitiveness of a country (Martin, 1996; Irish Council for Science Technology and Innovation, 2000). Alternatively scientists and researchers may be invited to sit on government (or institutionally) established committees to consider issues such as the risks and benefits arising from a particular application or the ethical considerations of a particular research endeavour. Many such government appointed committees have very little formal policy-making power and are limited to making technical recommendations or identification of options that can be then considered or amended by policymakers in consultation with politicians. There is potential for broader public stakeholder inputs into such decision making processes through membership of a lobby groups, or individual contacts with elected representatives. The inputs of public stakeholders can often happen at a later stage in the knowledge development process, e.g. at the technology dissemination stage, thus the public can often be limited to responding to the end products of innovation.

As some problems become more complex and exert their effects on a global scale, there is a need for a robust form of knowledge generation to address these issues e.g. climate change, energy crisis, and sustainable food production. Science is often charged with providing technological options and knowledge for addressing this task, with policy makers relying on scientific input to make final decisions and some scientists entering the policy arena as experts and guides. However, as some problems grow in complexity, it becomes clear that science can only provide some initial answers as the available scientific information relating to these issues may be uncertain⁵ or ambiguous⁶. In such instances, there have been proposals for a broader range of disciplines and expertise to be harnessed including lay-expertise and experiential knowledge (Funtowicz and Ravetz, 1993). Indeed, the proposed move towards a knowledge society means that more actors are involved in knowledge production such as the private sector, patient groups, government agencies, non-

⁴ In this dissertation, the term public is used to designate the non-expert as distinct from an expert through knowledge or expert through experience, also known as lay-expert (Genome Prairie, 2005). The public can take on different roles at different times which can be dependent on their activities i.e. consumers, patients, and their levels of interest in an area (interest groups).

⁵ Uncertain problems are those where the outcomes are identifiable, but it is impossible to calculate accurately the probability of them occurring (Stirling, 2005).

⁶ Ambiguous problems are those where the potential outcomes are unknown (Op. cit.).

governmental and civil society organisations. It is argued that if research is conducted in multiple areas both the authority of science and its monopoly as the main knowledge producer have thus lessened (MASIS Expert Group, 2009).

The identification of a broad range of actors as co-producers of knowledge helps reconfigure descriptions of the 'public' in terms of their perceived expertise, e.g. as 'lay' or experience-based experts and non-experts. This duality follows through into studies of how the public(s) enact themselves as 'being a member of the public', i.e. how they 'perform' in this role (Michael, 2010). Michael (2010) proposes two categories of public; the first is 'Publics in General' (PiGs), i.e. the public as a single entity, and the second is 'Public in Particular' (PiPs), i.e. publics as stakeholders in particular issues. The conception of a monolithic public has been identified as problematic (Dewey, 1927), and it is argued that viewing the public as a single entity can lead to the omission of potential participants in discussions and deliberations as undoubtedly some groups are excluded from these activities. The failure to recognise their exclusion means that alternative forms for their engagement are not proposed. Similarly, the concept of a monolithic public "reduces discursive diversity and elevates the norms and practices of more powerful groups over others" (Asen, 2003, p. 177) such that these groups may position themselves as representing the public will. Such considerations can provide vital inputs into the format and organisation of deliberative exercises to enhance both the process and, hopefully, the ultimate outcomes.

1.1 Deliberative inputs into the governance of science

The governance of science has reached greater importance in the last few decades which reflects broader developments such as potential changes in the modes of knowledge production, e.g. industry and government take an increased role in producing knowledge (although it is disputed whether these changes have happened in practice, see Weingart for discussion (Weingart, 1997), the increased interaction by non-governmental and civil society groups in policy processes, and some moves

towards deliberative democracy⁷ and increased public participation in policy debates. The increased interest in and scrutiny of science may result from living in a risk society⁸, which, it is argued, has led to increased reflexivity⁹ in science. It may also reflect the widespread social and policy misinterpretation of the Precautionary Principle and Precautionary Approach concepts which are overly focussed on risk and typically do not consider benefits or risks of scientific inaction (Morris and Spillane, 2008; Brand, 2009). Technological developments have made information more accessible and citizens are less inclined to believe in protestations about the autonomy of science. Instead, some citizens raise questions about the legitimacy of scientifictechnological policy making and demand greater evidence of the accountability of this process to the general public. Democratic participation in science can play out in two different arenas. The first is the political sphere and here the public engage with policy makers to deliberate and establish boundary conditions for science and technology. The second is concerned with utilitarian needs where the public is engaged in discussions and deliberations to help shape and adapt technologies to societal needs.

Deliberative processes are being promoted in policy setting both due to ideals of the deliberative democracy movement, and also because they help identify issues and concerns of the broader public which should be taken into account (MASIS Expert Group, 2009). This is particularly evident in areas such as urban planning, waste management or environmental policy (Chopyak and Levesque, 2002). Many scientific fields that aim to address societal problems or needs such as agricultural research, climate adaptation, environmental and sustainability research, have also begun to

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⁷ Deliberative democracy places an emphasis on mechanisms that encourage public debate on issues as well as encouraging collective reasoning and reflection. It is seen as an accompaniment to representative democracy rather than a replacement for (MASIS Expert Group, 2009).

⁸ The risk society is a concept first proposed and developed by Ulrich Beck and Anthony Giddens (Giddens, 1991; Beck, 1992). They felt that the modernisation of society had led to the creation of new types of risks, i.e. risks arising as products of human activity. These risks differ from natural disasters such as adverse weather as they are attributable to human actions. For this reason it is possible for societies to assess the level of risk being produced by these or to identify their potential future impact.

⁹ Reflexivity refers to the re-examination and changing of (social) practices in light of new information gained. In the case of science, this may explain in part the public rejection of GM following the BSE crisis and the continued public mistrust of science.

include a broader swathe of stakeholders in deliberations in order to enhance their decision making.

What is typically lacking however, are systemic initiatives to broaden public input into scientific-technological research. There are many possible justifications for increased citizen participation in decisions relating to the direction of scientific-technological research and these include *inter alia* the democratic requirement for the public to have adequate and understandable knowledge about science and its applications prior to forming decisions, to increase the scientific literacy of society, the need to increase public acceptance of science and resultant technologies, and to justify the levels of public investment in both fundamental and applied scientific research by taxpayers (House of Lords, 2000; Bhidé, 2008).

There have been some attempts to address the possible democratic deficits in the governance of science through a number of assessment and deliberative procedures such as participatory technology assessment exercises (Joss, 2002; Abels and Bora, 2005; Abels, 2006), consensus conferences (Andersen, 1999; Einsiedel, 2000; Rowe and Frewer, 2004; Kleinman, 2007), and citizen juries (Gooberman-Hill et al., 2008; Menon and Stafinski, 2008). Typically, these approaches show an increased desire to enhance decision making process and also recognise the need to engage in greater social assessment of the risks and benefits of the products and outcomes of scientifictechnological innovations. While these approaches have become more standard in countries such as Denmark (e.g. the Danish Board of Technology Assessment (Andersen, 1999)) and the Netherlands (e.g. participatory technology assessment activities by the Dutch Rathenau Institute (van Est, 2000)), they are practiced on a more ad hoc and a la carte basis in other countries where any significant impacts on policy-level decision making is questionable. In many such exercises, it is also not clear (a) how representative 10 the participants are, (b) whether they are accountable to the social group that they claim to represent, and often the topic for discussion has been pre-framed by the organisers, i.e. the focus on the topic is already decided,

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¹⁰ Self-selecting groups tend towards the inclusion of well informed and interested public members but this can also lead to a phenomenon known as astro-turfing where companies or NGOs place supposed 'grassroots' representatives in discussion groups to represent their perspective.

which does not allow the inclusion of all perspectives. The question then arises as to who can participate in discussions and deliberations about science and technology decision-making, and what mechanisms may be appropriate to facilitate this?

1.2 Different publics and different forms of engagement

This PhD thesis investigates a number of ways of broadening public input into science policy decision making (a) so that scientific-technological governance could become more representative of the relevant stakeholders, (b) so that it offers greater opportunities for citizens to discuss issues relating to particular research trajectories, and (c) so that it enables them to participate in decision making on matters relating to such research. The research in this PhD thesis is less focussed on the use of deliberative exercises relating to science and technology (such as consensus conferences and citizen juries) as these are well researched elsewhere 11. A four pronged research approach was taken in order to investigate the different types of public(s) and the different forms of engagement that could be employed to broaden public participation in decision making relating to science policy, and how to marry these formulations with different models of science 12 communication. Due to the case study approach undertaken in this thesis, an extensive literature review will precede each of the individual chapters and help locate the specific research questions within the individual contexts, but the main arguments for such an approach follow here.

The term 'public' is regularly used in relation to research into and the development and enactment of public engagement activities. However, this is without due attention to or investigation of who these publics are, what their interests might be in relation to an issue or topic arising from scientific or technological research, or what their expertise or knowledge is in relation to the same. The first two case studies explore mechanisms to facilitate the co-production of knowledge (Nowotny *et al*, 2003, Jasanoff, 2004) and do so by investigating two different configurations of the public. Similarly, while 'Public engagement in science', PES, and 'public participation in science', PPS, have been identified at international and European level as key

 11 For discussion of these initiatives see (Franklin $\it et \, al, \, 2007$).

¹² Science is referred to in its broadest sense to include social, economic and human sciences in addition to the natural sciences, technological development and engineering.

activities in addressing science and society issues, the usage of these terms is also not without problems. These activities are only one stage along a science communication continuum which ranges from one-way communication and disinterested/ignorant audiences through to participatory mechanisms and activists/co-producers of knowledge (Arnstein, 1969, van der Auweraert, 2005). The final two case studies examine how best to support public engagement in deliberations relating to science and technology, in what context, and for what purpose.

Irish patient and health organisations are the focus of the first case study which investigates their level of involvement in 'upstream engagement' activities (Wilsdon and Willis, 2004) relating to biomedical health research. Patient and health organisations have a dual role in this regard; they are the end-users of the outputs of the research and often are active lobbyists in relation to the regulation and licensing of drugs or in refocusing research agendas towards their own disease or syndrome. Their second role is as non-technical experts (Collins and Evans, 2002) who have a deep understanding of their own experience of their disease or syndrome and often a similarly deep understanding of scientific knowledge relating to the same. At an international level, patient and health organisations have been instrumental in shaping new organisational practices and new ways to facilitate deliberations concerning biomedical health research and related areas (Epstein, 1995, Rabeharisoa and Callon, 2004, Callon and Rabeharisoa, 2008, Akrich, 2008).

The second case study examines the potential for bottom-up approaches to interface with R & D systems and to influence research trajectories, and does so by exploring the possibility for a community based research model (CBR), i.e. a Science Shop, within a potentially resistant disciplinary area i.e. natural sciences (Fischer *et al*, 2004). In this initiative, interested publics in the form of local civil society organisations identify a research need/question which may be answered by researchers in a local research institution. The research is carried out in full collaboration with the CSO client (Biggs, 1989) with a large emphasis placed on translating knowledge into usable information for the CSO to act on in order to enhance social justice (Stoecker, 2002). The potential for co-production of knowledge rather than a client-expert relationship can be enhanced through encouraging action research projects involving CSO members or staff. This exploratory case study also

aims to identify what conditions might enable or constrain involvement in Science Shop research for staff in a local Higher Education Institution.

Researchers' perspectives on public engagement and public participation are interrogated in the third case study. This survey mirrors one carried out in the UK in 2006¹³ thus allowing for international comparisons in a topic area where there currently is a scarcity of research. The rationale for engagement in such activities is unpicked by examining normative, substantive and instrumental arguments (Höppner, 2009) and researchers' views on the purpose of such activities are examined in order to identify which model of science communication is to the fore in the minds of the research community in Ireland (van der Auweraert, 2005). An expanded version of Azjen's theory of planned behaviour provides insight into researchers' intentions to participate in future public engagement of science activities (Poliakoff and Webb, 2007) and to suggest potential supports and incentives to encourage participation.

The final case study investigates how nanotechnology is represented on YouTube by the user audience. This is undertaken to gain a greater understanding of public(s) perceptions and opinions relating to and their representations of nanotechnology, and to explore the influence of informal personal channels in the amplification of public perceptions of risk (Kasperson *et al*, 1988). These findings will be considered in relation to conflict resolution techniques which propose ways to offset or manage conflict over new technologies. The frames used by contesting groups in relation to new and emerging technologies will be explored as will the frames employed in 'upstream engagement' initiatives, e.g. the Nanodialogues (Gavelin, 2007), with the ultimate aim of suggesting ways to encourage engagement in deliberations relating to new technologies such as nanotechnology, whether this takes the form of shaping frames, shaping public perception and/or other activities. The normative assumptions inherent in this last question warrant further explication and particularly in light of recent research which argues that public involvement may not always be ideal (Rowe, 2010) and, as argued earlier, that the distinctions between publics need to be

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¹³ See: People Science and Policy (2006). Science Communication: Survey of factors affecting science communication: a survey of scientists and engineers. http://royalsociety.org/Factors-Affecting-Science-Communication/

understood so that those who wish to participate have a greater likelihood of their issues or queries being addressed.

1.3 Deficiency and ignorance – changes in the communication of science

Interest in the discipline of science communication has grown steadily since the 1970's and follows a growing concern voiced by the some segments of the public (particularly in Europe) in relation to science and technology as evidenced in Eurobarometer reports relating to science and technology¹⁴. The anti-nuclear sentiment amongst some groups that pervaded the seventies as well as the emergence of the Green movement led to science and technology being identified as likely scapegoats¹⁵. A number of health scares such as the Chernobyl and Bhophal disasters also shook the public's trust in technology despite the fact that these disasters related more to poor regulatory practice. The subsequent rise of lobby and advocacy groups critical of science and technology provided a rationale for broader inclusion of perspectives in debates relating to the public good, including decisions on the most appropriate use (or not) of scientific discoveries and novel applications. Despite efforts by politicians and governments in Western countries to shift the burden of science funding to the private sector (e.g. the Lisbon Agenda requires that two thirds of all science and technology funding be from private sources) science is significantly funded by public sources and this has also amplified public interest (Landriault and Matlin, 2009).

¹⁴ The Eurobarometer is a series of surveys which are regularly performed on behalf of the European Commission to measure public opinion regarding a number of topics. The most recent Eurobarometer report published in 2010 indicated that 58% of respondents across the EU agreed that: "We can no longer trust scientists to tell the truth about controversial scientific and technological issues because they depend more and more on money from industry" (European Commission, 2010).

¹⁵ Negative views of science and technology are presented as a problem rather than an opportunity for society, but this may be changing in the face of growing global challenges in areas such as climate change, energy, biodiversity, agriculture and food production. For instance, there are recently calls for a greater focus on science rather than advocacy by bodies such as the IPCC. In addition, prominent members of the Green movement (e.g. Stewart Brand) have reversed their views regarding opposition to nuclear power and now apologise for their prior efforts to slow down and halt technological developments in nuclear power. Similar views are espoused by high profile technophilic Greens such as Jim Lovelock (founder of Gaia hypothesis) who contends that the Green movement has lost its way due to its aversion to science and technology.

A range of efforts have been made to try to describe how science is communicated, and the first overarching model of science communication was proposed in the early nineties (Ziman, 1991). Communication scholars and those working in the social science arena suggested the deficit model as the *modus operandi* for science communication at the time and were quick to point out the problems associated with it. The deficit model describes a linear communication between the scientific establishment and the general public with the public seen as being deficient or lacking in knowledge about science and technology (i.e. empty vessels). The widely considered model supports the notion that animosity or distrust towards science or scientific knowledge is due to this knowledge deficit and that the scientific community need to communicate more clearly and fill this knowledge gap to engender public support for science.

Scientific literacy tests highlighted the general ignorance of the public in the UK and the US and much money and creative energy was poured into improving public knowledge about science. However, the assumption that increased knowledge would lead to increased acceptance of science was untested and surveys such as the Eurobarometer soon showed that the contrary was true; increased knowledge leads to increased suspicion or distrust (European Commission, 2001). In 2000, the House of Lords in the UK commissioned a report to examine the cause of public disconnection with science and propose ways in which to reconnect the public and science. The report recommended: "That direct dialogue with the public should move from being an optional add-on to science-based policy making and to the activities of research organisations and learned institutions, and should become a normal and integral part of the process" (House of Lords, 2000, paragraph 5.48).

1.4 Public engagement in science

In line with a move towards increased participation in policy setting, and in recognition of the expressed need for a more discursive approach towards science communication, so was there an increased focus on public participation in science communication. Institutions were encouraged to contribute to and help create a climate that allows for broader discussion of scientific issues in a similar way to discussions about other matters of public interest. These initiatives were considered

part of a broader programme of Public Engagement in Science or PES. PES is essentially an umbrella term that refers to initiatives that seek to consult with and involve the public in discussions and deliberations relating to science (Durant, 1999). The main difference between public engagement initiatives and those using the deficit model approach is how the public is viewed. Instead of their previous role of consumers of scientific knowledge and facts, the public is instead seen as important participants and contributors to the governance of science, with lay expertise and indigenous (informal) knowledge given greater credence as being an additional knowledge source. One particular example of this is the impact of the patient movement on AIDS research. The AIDS patient group movement were influential in changing the way biomedical research is conducted by helping to broaden discussions to include other stakeholders and recognise experiential knowledge (Epstein, 1995). This movement encouraged new modes of co-operation between stakeholders including researchers, politicians and medical doctors; it facilitated broader dissemination of knowledge and research methods relating to AIDS research, and sparked increased debate and discussion on the prioritisation of research (Löhnberg et al., 1999).

There have been several large scale events organised to facilitate the inclusion of layexpertise in deliberative exercises e.g. consensus conferences, citizen juries. These exercises, while laudable in relation to the participatory values they extol, have had limited success in their ability to influence government policy setting. Oftentimes these participatory events are seen as exercises in democracy and thus an end in themselves. Discussions regarding the focus of these events often occur without the input of the public and it is not always clear what methods will be used to link the outputs of these deliberations to policy. Or should this even be the purpose of these exercises? Perhaps a more constructive use of these exercises rather than supplementing expert opinion is in allowing citizens to challenge the frames created by experts in relation to scientific-technical issues (Strassnig, 2008). 'Framing' refers to the information provided about an issue that enables a person to decide whether the issue matters to them and how best to address it (Nisbet and Mooney, 2007). Reframing of issues to incorporate public concerns may help identify areas of conflict or help create more targeted communications. An additional concern is the lack of public participation into tangential policy areas such as innovation policy as

oftentimes the decisions made in this arena supersede other policy decisions i.e. decisions that might reflect the concerns or suggestions of the public, particularly if they are focussed on enhancing national competiveness and creating jobs. As Trench (2007) in his investigation into how Irish research organisations represent themselves online has shown, many institutions and groups have merely employed the rhetoric of dialogue and participation, and the deficit model of linear transmission of information prevails in practice (Trench, 2007).

1.5 Challenges for broadening public input into STI

The challenge of how to communicate science in a way that is meaningful for the broader public still remains. To some extent this hinges around what is considered meaningful for members of the public and this may differ between individuals and groups. Rather than providing more information, it may be necessary to provide information in a way that resonates better with disparate audiences and that will encourage greater dialogue and debate. A key competence in the knowledge society is information literacy, i.e. the ability to locate relevant information and to judge its reliability and validity (Eisenberg, 2008). This competence needs to be developed in the broader populace to enable the public to quickly locate useful or meaningful information, to be able to determine which is the more trustworthy of two conflicting pieces of information, to judge the validity of information and to evaluate the reliability of the source. One way of conceiving of this relates to the notion of technological citizenship i.e. the changing rights and duties of citizens living in the technological age (Frankenfeld, 2000). Frankenfeld (2000) identified the associated rights and obligations of technological citizens and these include the right 16 of access to knowledge and to participate in public decisions, the duty to achieve technological literacy and to engage with current problems. With such a concept in mind, it might

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¹⁶ The use of the term 'rights' suggests that there is a legal or natural right to access to knowledge and to participation in discussions relating to science and technology. The three primary international human rights instruments i.e. the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights do not state these rights explicitly. This which would suggest that Frankenfeld (2000) is encouraging the identification of the rights of access to knowledge and to participate in discussions and decision making relating to science and technology rather than identifying a legal requirement (Frankenfeld, 2000).

be possible to mobilise the public to engage in technological change not only as consumers but as citizens at a political level (Ibid).

However, rights have to be balanced with responsibilities and sceptical members of the scientific community have expressed disquiet over public engagement in deliberations regarding science particularly those that impact on research agenda setting (Taylor, 2007). While in this PhD thesis I agree with the normative belief that all citizens should be able to participate in discussions and have input into decisions that will affect their future, I am not suggesting in practice that this should be the case. There is an ongoing need to experiment with different methods that enable citizens to participate in scientific decision making and this PhD research investigates, explores, and evaluates these.

Patient and health groups' participation in R & D priority-setting

For most of the twentieth century science was carried out relatively unhindered by public demands and with the support of the general public. Quality control of science was assured by the peer review process and the epistemology of science grew with the description of replicable results and consensus amongst an expert peer group. Science's success in creating new, reliable knowledge meant that it is increasingly called upon to provide input into or suggest solutions to a growing number of problems, many of which lie outside its traditional knowledge boundaries (Gibbons, 1999). Such activities have led to an increased dissolution of the boundaries between different disciplines, the very boundaries that conferred expertise on the researchers and academics working within that discipline. The lines between institutions such as government, university and industry have also become more porous with new relationships emerging between the three (Etzkowitz, 2004). Globalization, intellectual property policies, and an increase in public-private partnerships are among the political economic factors that have led to the redrawing of lines.

As the lines between institutions grow fuzzier and expertise is appointed to an extended group of experts (including experience-based or lay experts), will we begin to see a more open system of knowledge production? Such a scenario is suggested (Nowotny *et al.*, 2003) at time when societal challenges are growing increasingly complex and solutions required when absolute scientific consensus on proposed solutions is not possible. This suggested increase in complexity may require new methods of knowledge production, while involving different actors and combining a broader range of expertise (Chopyak and Levesque, 2002; Nowotny *et al.*, 2003). Greater public participation in decision making relating to science may potentially answer a number of needs. Firstly it may help garner increased public support for science and share responsibility for science budgets in a time of global recession. Secondly, there are increased calls for accountability in decision making institutions worldwide, and science with its considerable influence on culture, health, local and international economies may yet have to increasingly answer the public taxpayers that fund it (House of Lords, 2000). This growing trend towards participation leads us then to ask the

question as to who should be involved in decision making in relation to science and technology.

Scholars of Science and Technology Studies (STS) have described the relationship between scientific knowledge and political power and highlight the paucity of public input into decision making on key decisions regarding knowledge creation (Jasanoff, 2003a, b; Rip, 2003; Jasanoff, 2005; Wynne, 2007). Collins and Evans (Collins and Evans, 2002) show that while these STS studies have shown the need to improve the legitimacy of science; they failed to identify who is a suitable expert for inclusion in decision making process regarding science. Collins and Evans prescribe a political and technical dimension within these scientific-techno decision making processes. As the beneficiaries of the technologies, services, and information that arise from scientific research in theory all should be involved in affirming the political legitimacy of decisions relating to science and technology. Technical legitimacy would require the input of relevant experts including both certified experts and non-certified experience based experts¹⁷. Who then are these potential non-certified experts? They could include the end-users of a technology or the beneficiary of a piece of research, and also people who have related experiential knowledge. These experts could identify the needs and concerns of a particular target audience or consumer, identify how a technology or idea will be received, and what risks or benefits might be associated with it based on their interpretation of its utility (Kahan et al., 2006). Indeed the decision making process itself may uncover further experts who have a potentially relevant contribution to make, thus the identification of experts could evolve during this process.

The focus of this chapter is on a specific case of stakeholder involvement in science-related decision making i.e. the participation of patient groups¹⁸ in decision making in biomedical research. Biomedical research is conventionally comprised of basic

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¹⁷ Use experience based expert here rather than the more commonly used "lay expert" as, in Collins and Evans paper, they argue for the inclusion of experts with relevant knowledge or expertise rather than general knowledge which may not be applicable (Collins and Evans, 2002).

¹⁸ We will refer to patient groups for brevity throughout this chapter but this term includes both patient groups and health groups. The first is run by people who have a personal connection to someone with a rare disease and the second employ and are directed by paid professionals who do not usually have a family tie to someone with a rare disease (Salama and Fitzgerald, 2004).

(fundamental) research, applied research and clinical research. In the case of this study, we consider biomedical research to be the early stage of the biomedicine innovation process. We exclude later stage clinical trials from consideration as this research relates to the testing of new (or adapted) technologies rather than the invention and development of wholly new technologies. Patient groups have a dual role in biomedical research. They are both stakeholders in research through their purchasing of medical products and their lobbying of government for research and development into particular therapies or therapeutics. They also are experiential experts in the field of biomedical research through their specific knowledge of their own disease or syndrome.

There has been a recent growth in patient group participation in health research related areas (Boote *et al.*, 2002) such as health services research and research on public health and prevention (Harrison, 2002). Despite these initiatives, the lack of systemic patient group participation in biomedical research is quite evident. Many research fields that aim to address societal problems increasingly call upon societal actors to enrich the decision making process for greater impact and/or equity. These include, *inter alia*; agricultural research (Levidow and Marris, 2001), sustainability research (Young *et al.*, 2005), and environmental research for development (Leach, 2005).

The vast majority of biomedical research aims to contribute to the health and quality of people's lives. For biomedical research to generate societal impacts on human health and wellbeing requires enormous international financial investment in both fundamental and applied (translational) research. Equity arguments aside, if participation of a broader range of societal actors in decision-making relating to such research could generate increased efficiencies then one would expect that decision making relating to this research would involve societal actors as well.

This PhD dissertation chapter investigates the extent to which patient groups as key stakeholders are engaged in decision-making regarding biomedical research in Ireland. The research aims to determine the current role of patients in biomedical research decision making, examine obstacles to the enhancement of their role and search for strategies to overcome these.

2.1 Decision making in biomedical research

Fundamental biomedical research provides knowledge for the initial stages of the biomedical innovation process which ranges from basic/fundamental research through to applied research, translational research (Woolf, 2008) and on to clinical testing and the deployment of therapeutics in medical practice. Priority setting for research is the province of a number of different actors.

2.1.1 Members of the biomedical research decision making network

Once a decision has been made by a funding source (or agency) to fund a particular project or programme, the funded biomedical research is typically conducted in laboratories and day to day decision making regarding research questions, project planning, timeframes etc are decided by the research group and the individual researcher.

Public sector funding for biomedical research is a deployment of taxpayers' revenue for specific areas of research or specific research groups (e.g. most successful, best track records etc). Different government departments allocate research funding across many areas of interest such as energy, agriculture, and health. There is also significant funding of biomedical research from the pharmaceutical and biotechnological industries that are major funders of research and increasingly outsource their research to universities and research institutes (Etzkowitz, 2004) as a means of harnessing new innovations. Private sector biomedical research companies also engage in complex mergers and acquisitions to develop their capacity for biomedical research and innovation. The private sector can also include charitable foundations with historical links to the pharmaceutical industry (e.g. the Wellcome Trust). Depending on the political economy of each nation state, a greater emphasis on socio-economic impact of biomedical research can bias biomedical research away from fundamental research to applied, translational, clinical and health systems research. Such a shift of funding emphasis has happened in Ireland recently for the Health Research Board funding agency.

The biomedical research community is not homogenous and consists of many different types of actors. Latour (2004) claims that the biomedical research community makes

decisions on what research to fund based on internal factors such as feasibility and on external factors such as personal curiosity, financial and political support, prestige, societal needs amongst others (Latour, 2004).

Patient groups represent one of the most unique cases of client-participation in research that can be envisaged. Client-participation in other areas of research such as agriculture, food, energy etc can mean that self-appointed groups can claim to represent the needs of farmers or consumers without any form of membership structure or accountability to the stakeholder group they purport to represent (Spillane, 2000). In the case of patient groups however, the patient is a member of the group because they are typically afflicted by the disease or malady, or they are engaged in the process of health care provision (whether development of new therapeutics or health services) for the patients. Hence, in the case of patient groups' participation criteria such as representation, accountability and more accurate representation of research needs can be much more closely met.

Patient groups also provide a third pillar of biomedical research funding that in theory can be more democratic than funding driven by state or shareholder needs. Many patient groups are private funders of research and fund disease or syndrome specific research. The general public has a more passive role in influencing research priorities and can do so through their support of particular charities who decide on their own research agendas or through their involvement with lobby groups who may canvass the government to adjust the focus of national spending on biomedical research.

There has been increased effort internationally to involve the public in decision making regarding biomedical research decisions. In the arena of risk management, a number of public institutions have run consensus conferences and citizen juries to gather insight into public concerns regarding stem cell research, xeno-transplantation and artificial reproduction techniques (Joss and Durant, 1995; Andersen, 1999). Other countries gather public input into decision making via national consultation exercises such as 'GM Nation', the public consultation in the UK on food biotechnology (Horlick-Jones, 2004). However, it is unclear as to the extent that public inputs (from individuals, groups or otherwise) actually influences the final decision regarding research agendas,

indeed it would seem that a reversion to peer-review¹⁹ is more common (Cozzens and Woodhouse, 1995).

2.1.2 The role of patient groups in decision making regarding biomedical research

Patient groups are important stakeholders (clients) in targeted biomedical research as their members are the beneficiaries/clients of the final products or knowledge derived from research focussed on their disease or syndrome. Patients (and their carers) are also experience based experts in relation to the disease or syndrome and increasingly are called upon in this role (Rangnekar, 2005). A third aspect of patient groups is that they are an example of a needs-driven private funding agency. Patient groups are unique in this endeavour however as they aim to represent the research needs of a very specific community (namely the patient sufferers and their families/carers) rather than having explicitly commercial interests.

2.2 Conceptualising client participation in science and technology

A socially robust science as envisaged by Notowny (Nowotny *et al.*, 2003), involves the inclusion of a broader swathe of societal actors. This PhD dissertation chapter focuses on the participation of patient groups in decision making relating to biomedical research. There is significant potential for patient groups to become involved in decision making at many stages in biomedical research processes. For instance, patient groups could interact with funding agencies and government departments to help decision making on research themes, programmes, priorities, assessment criteria for project proposals etc. Patient groups could also potentially influence individual research groups in relation to the research questions chosen or prioritised. Patient group influence within the biomedical research process would be more difficult to achieve such as analysing results or interpreting data (i.e. the obstacles to patients becoming

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¹⁹ Biomedical funding calls may take a number of different forms, but the two most common types are an open call which invites proposals on any biomedical topic (a bottom-up approach), and a targeted call related to a specific biomedical topic (a top down approach). The received research proposals in most cases are subject to evaluation and this is where an additional filter of 'the strategic relevance of the research' is employed. The group or individual appointed or self-nominated to evaluate the proposals often uses the comments from the peer review process in combination with other established criteria to make their/his/her final decision.

biomedical researchers *per se* will be significant). The participation of patient groups in decision making relating to the biomedical research process can be described in relation to the degree to which participation occurs and in relation to the objectives this participation aims to meet.

2.2.1 Degrees of client participation in research and development

There are multiple typologies of public, client or stakeholder participation in science, technology, innovation and research. An example is the typology developed by Stephen Biggs (1989) who examined the levels of farmer participation in an on-farm research project (Biggs, 1989). He draws a distinction between types of participation based on the extent to which participation occurs and the ultimate purpose of the exercise. Biggs describes how participation can be contractual, consultative, collaborative and collegial reflecting increasing levels of participant autonomy and influence. The level of patient group involvement in biomedical research processes has been investigated using a similar typology in this PhD dissertation chapter. Another useful typology is Arnstein's ladder of citizen participation which provides insight into a person's power to act in decision making processes. This eight rung ladder spans types of participation from tokenistic activities, e.g. a patient representative on a board of management, to enhanced power sharing, e.g. patient platforms that lobby for funding. Arnstein's ladder identifies full citizen control of decision making as its highest rung (and by implication the ultimate goal of participation) (Arnstein, 1969). Tritter and McCallum (2006) claim however, that the focus on decision making power as a measure of participation disregards the aims of a participation exercise, the methods used to involve parties, and the various publics involved (Tritter and McCallum, 2006). Patient representatives may have a greater role to play instead in helping frame the problems to be addressed (Thro and Spillane, 1999) rather than in actually identifying the specific biomedical research solution or route. Indeed full citizen control, i.e. where citizens hold the majority of the decision making power (Arnstein, 1969; PatientView, 2005) may be detrimental to decision making as it would be democratically impractical (i.e. research decision making by public referendum) and also suffer from the tyranny of the majority problem whereby the majority would direct what decisions are made and thereby there is the possibility that the needs of those without representation or without a strong voice e.g. those suffering from rare diseases or syndromes, would be neglected (Cooke and Kothari, 2001).

2.2.2 Arguments contra patient (client) participation in biomedical research

Gross et al (1999) have highlighted that there is often a mismatch between resource allocation for biomedical research and the actual burden of a particular disease in a country (Gross et al., 1999). Patient groups as funders and directors of research are essentially selfish (or transparent) in their identification of a research need, particularly in the case of rare diseases where only a few people in the population stand to benefit from such a research investment. However, Callon and Rabeharisoa suggests that the focus of modern biomedical research on the genetic level means that knowledge of an orphan disease gene may be of benefit to another sufferer group, and to all potential patients and hence have important research spill over effects (Callon and Rabeharisoa, 2003). For example, by demonstrating that a disease phenotype such as Muscular Dystrophy is associated with small genetic changes, it shows that we and our families are all only a few small genetic steps away from being sufferers ourselves. A mismatch can also occur between the research questions of interest to scientists and medical doctors, and the research priorities (needs) of patients as identified by Tallon (2000) in his investigation of preferred interventions in the treatments of osteoarthritis of the knee (Tallon et al., 2000). In this PhD chapter, the focus is on patient groups and the research is based on the assumption that patient groups may be better able to reflect the research priorities for sufferers as the patient group's board of directors or decision making mechanisms are typically comprised of patients or patient representatives.

2.3 Research Design

The level of biomedical research funding by patient groups is very large in countries such as the USA and the UK. While not as high in Ireland, funding by patient groups is still a significant proportion of Ireland's overall biomedical research budget²⁰. Patient groups in Ireland currently contribute 5% to the health research budget (Medical Research Charities Fund, 2009) and are examples of dynamic actors in national research agenda setting, displaying traits such as representiveness and accountability to clients (sufferers), which are more elusive traits in conventional biomedical research funding bodies.

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 $^{^{20}}$ See 2007 BioPolis report for overview of national funding of biotech research (Rafols, 2007).

2.3.1 Objectives and relevance of study

The objective of the patient group investigation is to gain a better understanding of the mechanisms and extent to which health and patient groups could be better involved in decision making and priority setting for biomedical research and development (R & D) in Ireland. An online e-survey was carried out in late May/early June 2006 to investigate the activities of a number of patient groups in Ireland in relation to biomedical research. In total, 120 patient group organisations were contacted during this time period and full responses were gathered from forty-one organisations (a response rate of 34%).

2.3.2 Methodology

The e-survey conducted using Survey Monkey was designed to identify *inter alia*; which patient groups were involved in funding biomedical research in Ireland and what type of biomedical research. The e-survey questionnaire is provided in full in Appendix A. Groups that were not involved in funding biomedical research were asked to indicate their interest in becoming involved in biomedical research or the reasons as to their reluctance to become involved in biomedical research.

The patient group survey tests two hypotheses. The research hypothesis (Ho) is that well funded groups have an interest in carrying out biomedical research. The alternative hypothesis (Ha) is that poorly funded groups are either (a) unable to or (b) have no interest in carrying out biomedical research.

A number of variables were considered such as (a) the total amount of money spent on research, and (b) percentage of total budget spent on research, and this information is used to identify how focused an organisation was on funding research. Open-ended questions were then posed to identify particular impediments or opportunities to funding research.

The survey was initially piloted on a market research lecturer with specialist knowledge on survey methods, an epidemiologist working on health research, a social science researcher who previously had surveyed Irish patient groups, and a biomedical scientist who had previously received funding from a patient group to carry out biomedical

research. The survey was revised following feedback from this group and then the questionnaire uploaded on the Survey Monkey website. An email invite was sent to the sample group of 120 patient groups and relevant umbrella groups in Ireland (see Appendix B).

The patient groups were identified through extensive web (e.g. www.activelink.ie), database and literature searches. Comhairle's²¹ directory of voluntary organisations (Comhairle, 2004) was particularly useful for identifying these groups. The sample group was comprised of all of the groups who had some link to health or a patient/sufferer group. The survey was administered through personalised emails and monitoring of individual responses to the survey invitation. The survey also requested that the respondent identify their organisation when completing the survey, so this ensured that the respondents were linked to a particular organisation. In a number of instances patient groups were contacted again to encourage their participation or, in the case of an incomplete form, to request further additions to their response. The results of the survey were collated and presented to the heads of the main funding agencies in Ireland i.e. the Health Research Board, Science Foundation Ireland, Enterprise Ireland, the Irish Research Council for Humanities and Social Sciences, and the Irish Research Council for Science, Engineering and Technology, with the aim of encouraging greater collaboration between funding agencies and patient groups.

2.4 Results

Forty-one patient groups completed the online survey out of the 120 organisations contacted which gives a response rate of 34%. As the sample size is quite small, it is difficult to extract statistically robust quantitative data from the figures. Equally, it is difficult to extrapolate from the findings to broader patient group practices. Nonetheless, these results give detailed qualitative information about specific patient groups in Ireland which provides a more detailed look into the barriers and opportunities faced by Irish patient groups in funding biomedical R & D.

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²¹ Comhairle is the Irish word for advice and this organisation has been renamed the Citizens Information Board.

2.4.1 Profile of Irish patient groups

In Question 3 respondents were asked to choose between four main categories as regards their primary activity i.e. health promotion, research, patient care/support or advocacy/lobbying. These categories were chosen following a review of the descriptions of the contacted organisations on Activelink.ie²² and the Comhairle directory. While the organisations contacted might engage in all four of these activities, the survey asked them to identify which activity they are primarily involved in. The organisations contacted predominantly work in the area of patient²³ care/support. Depending on how formal²⁴ these organisations are this support might take the form of sharing personal experiences and establishing a social network, to giving relevant information to patients and carers, or providing therapeutic treatments to patients. Health promotion was the next most common activity. Health promotion as defined by the World Health Organisation is "the process of enabling people to increase control over their health and its determinants, and thereby improve their health" (World Health Organisation, 2005, p. 1). In the case of the organisations surveyed here, health promotion took the form of information provision and organising events to raise patient/public awareness of preventative measures or ways to alleviate the symptoms of an illness/syndrome. Advocacy/lobbying in relation to support or funding for their disease/syndrome of interest is the next most common activities followed by health research. Health research (including biomedical research) is not that common an activity amongst the 41 respondent organisations and is usually combined with other actions rather than being a primary area of focus (Figure 2.1).

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²² Activelink is an online network for Irish Non-profit organisations

²³ The term patient is used here to denote the sufferer of a particular illness or syndrome but can also refer to a grieving parent or a patient's carer depending on the focus of the organisation.

²⁴ Some organisations are in effect support groups who communicate on an *ad hoc* basis members, while other organisations have more formal organisational structures in place such as being run by an organising committee, holding AGMs (Annual General Meetings), publishing regular newsletters etc. The number of sufferers or cases of a particular disease or syndrome usually corresponds to how formal the organisational structure is for the group.

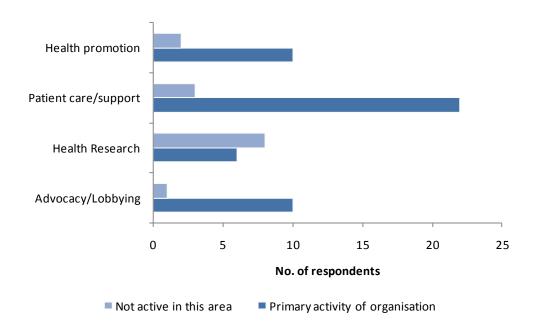


Figure 2.1: Main activity of patient groups (n=41)

A major objective of the survey was to determine how many of the Irish-based patient groups were involved in funding research into their disease or syndrome of interest (i.e. the extent of client-driven research). Question two asks whether the group/organisations funds research and development into their disease/syndrome of interest. Of the forty-one patient and health groups contacted, twenty-two of them fund research and development on their disease of interest and eighteen do not. One organisation (Irish Stillbirth and Neonatal Death society) plans to move into this type of work in the future (Figure 2.2).

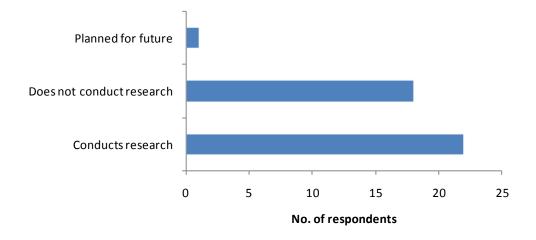


Figure 2.2: Responses from patient groups on their funding activities in relation to research into their disease of interest (n=41).

Biomedical research can include a myriad of sub-disciplines. Question 8 asks how much in terms of percentage of budget or actual amount is spent annually by the organisation on specified research areas i.e. basic/fundamental research, applied research, disease management, patient and palliative care, and epidemiology studies. Out of the eighteen respondents who detailed their spending activities on biomedical research and development, basic/fundamental research is the most commonly funded research followed by epidemiology studies and applied research (Figure 2.3). Respondents were asked to indicate what percentage of their budget is spent on the identified research areas and four groups i.e. Muscular Dystrophy Ireland (80%), Cork Cancer Research Centre (65%), Cancer Research Ireland (90%), and the Cystic Fibrosis Association of Ireland (60%), spend 60-90% of their budget annually on basic or fundamental research, with the remaining groups spending less than 15% of their budget on this form of research. The proportion spent on epidemiology studies ranged from 5-60%. Between 15-35% of budgets was spent on applied research. The majority of the groups were involved in several of the identified research areas e.g. Cork Cancer Research Centre spends 65% of their budget on basic or fundamental research, 15% on applied research, 10% on clinical trials and 5% on patient and palliative care and disease management respectively (Figure 2.3).

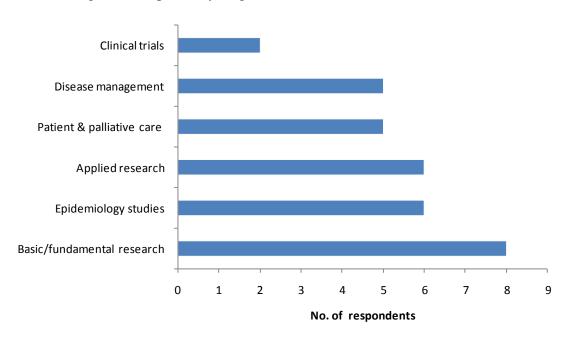


Figure 2.3: Type of biomedical research carried out by patient groups (n=24)

Question 5 queried whether the organisations considered it important to fund biomedical research in Ireland. In response to this question, a majority of twenty-seven groups (out of 41 respondents) considered it important to fund biomedical research in Ireland. It is not clear however from how this question was structured whether these responses refer to national funding priorities or the funding priorities of the organisation itself. A minority of seven groups were not in favour of this funding, and a further seven were unsure. The Fragile X Association of Ireland is one group who indicated that it was not in favour of funding biomedical research in Ireland stating in their response that "FX is an unlikely candidate for biomedical research. Our needs are more practical; support for families (respite, residential care, educational support)". This is in contrast to many international Fragile X patient groups (e.g. the FRAXA Research Foundation in the US and the Fragile X Research Foundation of Canada) who have a focus on biomedical research to better understand the biology of Fragile X and to develop new therapeutic options for FX sufferers. Amongst the other six groups not in favour of the funding of biomedical research in Ireland, these cited lack of staff and financial resources as reasons for them not funding biomedical research themselves (Figure 2.4).

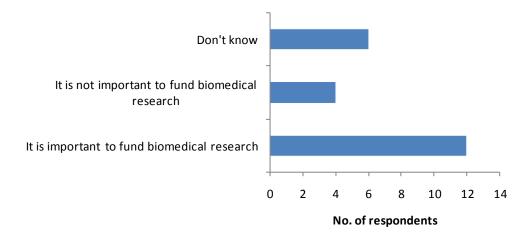


Figure 2.4: Respondents answers as to whether or not it is important to fund biomedical research in Ireland (n=41).

2.4.2 Spending on biomedical research

Question 6 queried how much the organisations spend on biomedical R & D funding per annum. Using responses to this question, the patient groups were profiled according to their specific spending on biomedical R & D. In this survey it was found that twenty-five out of forty-one patient groups do not spend money on biomedical research, while

fourteen of the remaining groups fund biomedical research to varying degrees. Cancer related patient health groups are the top three largest funders of biomedical research in Ireland (Figure 2.5). As identified in Figure 2.3, a number of patient groups do not fund biomedical research but fund other health research activities such as social research, epidemiology studies, and health educational research and thus these would not feature in the response to Question 6.

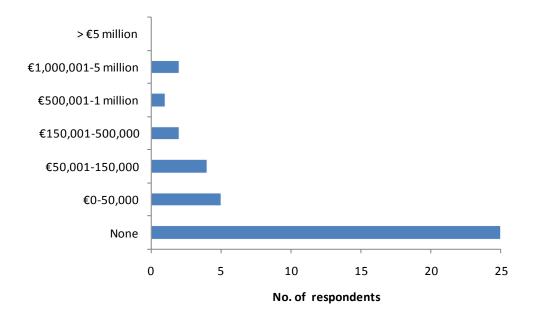


Figure 2.5: Overview of the responding organisations' expenditure on biomedical research per annum (n=40)

The relative size and budget of an organisation could play a large part in decisions about what activities may be undertaken. Question 57 asked the respondents to identify the numbers of full-time, part-time and voluntary staff in the organisation and question 58 asked for an estimate of the percentage of time spent by full-time staff on specific functions i.e. administration, fund-raising, management, communications and awareness raising, research-related, support services, accounting, information technology or other. Patient groups that fund biomedical research and those that do not fund biomedical research were compared according to the numbers of full-time, part-time and voluntary staff they have. The survey results for Question 57 indicate that organisations involved in funding biomedical research have a larger number of full-time staff (Figure 2.6) and the results of Question 58 indicate that the majority of full-time staff that work in these organisations are involved primarily in management and administration, followed by communication and awareness raising. The full-time staff

that work in organisations which do not fund biomedical research organisations are primarily involved in communication and awareness raising.

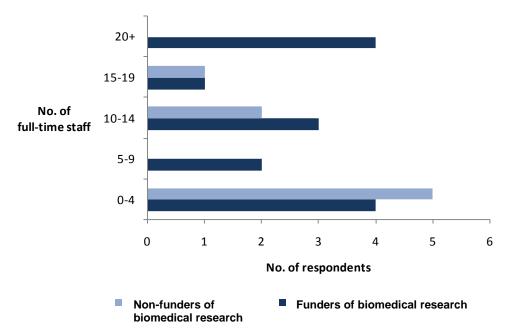


Figure 2.6: Comparisons of numbers of full-time staff in organisations that fund biomedical research (n=17) and in organisations that do not fund biomedical research (n=16)

There is also an indication of higher number of part-time staff in organisations that fund biomedical research than in those that do not (Figure 2.7). Question 59 asks for an estimate in the percentage of part-time staff involved in specified functions (as detailed above for question 58). Part-time staff who work in patient group organisations that fund biomedical research are primarily involved in fund raising. Part-time staff who work in organisations that do not fund biomedical research are mostly involved in administration.

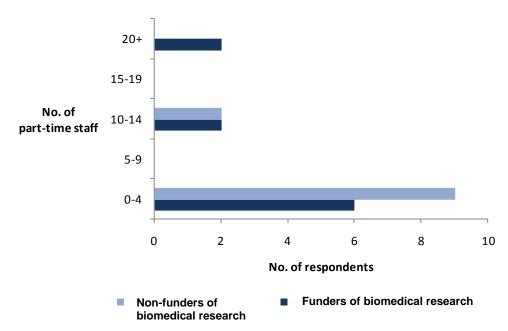


Figure 2.7: Comparisons of numbers of part-time staff in organisations that fund biomedical research (n=17) and organisations that do not fund biomedical research (n=16)

The amount of voluntary staff per organisation i.e. organisation that fund biomedical research vs. those that do not fund biomedical research, is similar (Figure 2.8). It is difficult however to discover the final value for these figures as respondents were given the upper limit of 20+ as a category for staff number and the final number of volunteers per organisation may be significantly higher.

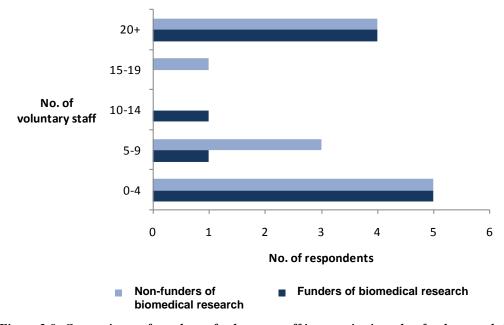


Figure 2.8: Comparisons of numbers of voluntary staff in organisations that fund research (n=17) and organisations that do not fund biomedical research (n=16)

Question 16 queried what the organisations' or groups' overall annual budget is. In comparing the annual budgets of the patient groups, disaggregated according to whether they fund biomedical research or not, we can see that budget size is strongly associated with whether the group funds research or not (Figure 2.7). From these results, it is possible that budget size may be more influential on decisions about whether an organisation funds research or not, rather than staff size. However, these two variables are linked, as larger budgets will allow for larger staff sizes. The budget of the majority of organisations that do not fund biomedical research is less than €100,000. When one considers the cost of biomedical research for a one person PhD is €36,000 plus per annum (including the cost of consumables, fees, travel funding, but excluding the cost of equipment), it is clear that such activity is beyond the means of patient groups with relatively limited annual budgets. Scientific researchers with a medical qualification, such as nurses or medical doctors, are paid substantially more than biomedical researchers with non-medical qualifications, and hence the costs of researchers with medical backgrounds will be substantially higher (e.g. €30,000 stipend per annum for PhD researcher in nursing). When compared, the patient groups that do not fund biomedical research identified advocacy and lobbying as being their main activity.

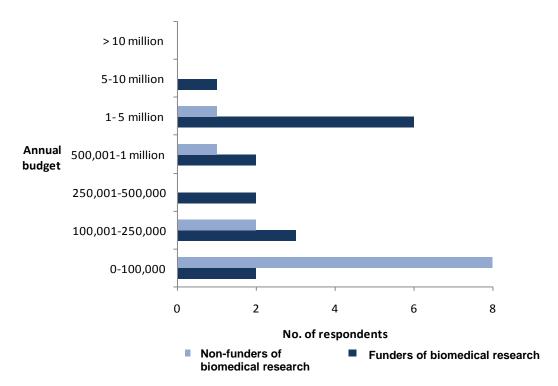


Figure 2.7: Comparison of annual budgets for organisations that fund biomedical research (n=17) and organisations that do not fund biomedical research (n=17)

2.4.3 Needs assessment by patient groups of biomedical research priorities

Many of the organisations surveyed identified patient needs as being of paramount concern. Question 26 asks whether the group or organisation has a mechanism for assessing the needs of patients in terms of research and development and Question 29 similarly asks whether the group/organisation has a mechanism for prioritising the needs of patients in terms of R & D. These questions were designed to determine if and how these organisations assess and prioritise patients needs (particularly biomedical R & D needs) in practise.

The majority of the respondents, twenty-four, have no mechanism for assessing patients R & D needs, six groups plan to have one in the future (combined with 'no mechanism' grouping), and seven groups have such a mechanism in place already (Figure 2.8). Previous needs assessments by the seven groups have included surveys and volunteer forums. When asked if such an assessment mechanism would be desirable, groups cited the cost and lack of knowledge as being the main disincentive to such a mechanism.

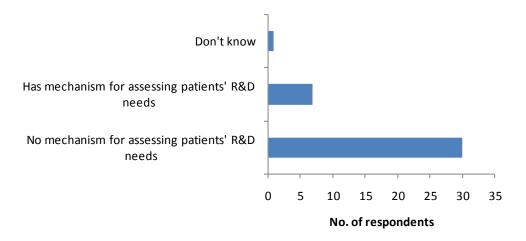


Figure 2.8: Overview of respondents in relation to whether they have a mechanism in place to assess patients' needs in relation to R & D (n=38)

Similarly, most organisations (twenty-one) have no prioritisation mechanism in place and seven plan to put one in place in the future. Those that do (six) organise public talks, gather inputs from general practitioners and paramedics and also survey patients and carers for feedback. Lack of money and expertise, i.e. in carrying out a needs assessment exercise are identified as two factors that prevent the surveyed patients groups from developing biomedical R & D needs assessments (Figure 2.9). Questions 28 and 31 ask whether mechanisms for assessing and prioritising patients needs in

relation to R & D would be desirable and the majority of groups answered yes with eleven out of seventeen respondents agreeing in relation to mechanisms to assess R & D needs and eight out of fourteen respondents agreeing in relation to mechanisms to prioritise R & D needs.

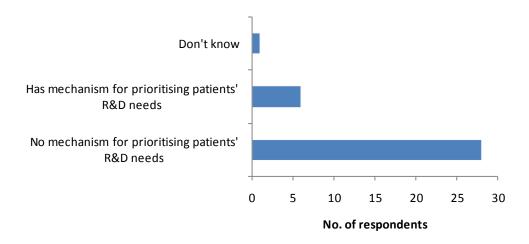


Figure 2.9: Overview of respondents as to whether they have a mechanism in place to prioritise patients' needs (n=35)

2.4.4 How representative of sufferers are patient groups?

A secondary question is whether or not decisions made relating to the patient group are representative of the needs or desires of the members and beneficiaries of the patient groups. Question 88 asks whether the organisation or group is membership based and majority of the groups surveyed (Figure 2.10) are membership based organisations. There is no indication of a predisposition of membership based organisation towards being involved in funding biomedical research or not, nor is there any link between membership size and such a preference when the two groups were compared i.e. those that fund biomedical research and those that do not. Membership size is correlated with the societal incidence of a disease/syndrome, i.e. the proportion of individuals in a population with a disease or syndrome, which is to be expected.

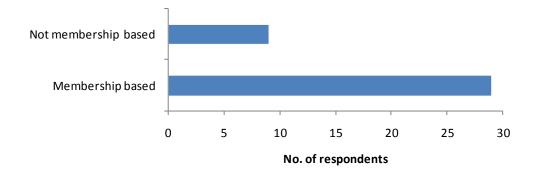


Figure 2.10: Proportion of respondents who are in a membership based organisations (n=37)

Membership based organisations potentially could have better representation of their members needs in decision making processes, as the organising committee or board of management is meant to represent its members. In practise, the level of engagement of the majority of members in the organisation's activities is the key issue regarding who is representing who. Organisational structures of membership based organisations can ensure that the representation of members needs is either weak or strong (i.e. even membership based organisations can be co-opted by a small number of individuals whose views may misrepresent the needs of the members). Hence, for the Irish patient groups we set out to determine who makes decisions regarding assessing and prioritising patients' needs in terms of biomedical R & D. Question 32 asks which members of the group or organisation are responsible for assessing the needs of patients in terms of R & D and Question 33 asks which members are responsible for prioritising the needs of patients in terms of R & D. The respondents were given a list of potential members to choose from and indicate which were responsible for assessing R & D needs, and for prioritising R & D needs of patients. Medical doctors were the group most commonly involved in assessing and prioritising R & D needs in the majority of patient group organisations, followed by CEOs, and patient representatives (Figures 2.11). Similar trends were evident when a comparison was made between organisations that fund research and those that do not fund biomedical research with medical doctors having a greater role in assessing and prioritising R & D needs of the patients. Needs assessment mechanisms as listed by the survey respondents include: surveys (although it was not made clear who was surveyed or what the focus of the survey was), research committees comprised of patient representatives, needs analysis carried out by patient and health organisation on sufferers, and online forums to allow feedback. Similar

mechanisms are used for prioritising biomedical R & D and also include peer reviews of proposals.

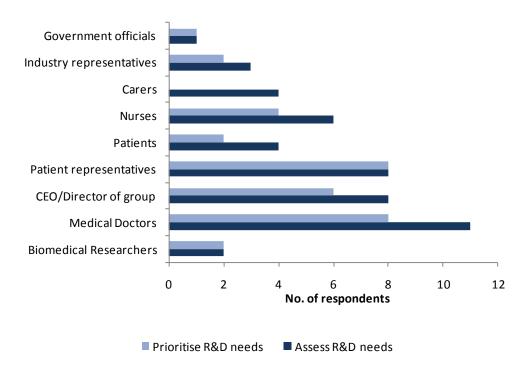


Figure 2.11: Indication of which members of the patient group are responsible for assessing needs (n=29) and prioritising needs (n=28) in terms of biomedical R & D.

2.4.5 Are patient groups accountable to their members?

One argued benefit of patient groups conducting research is that their representatives are the direct beneficiaries of this research should it prove fruitful. As mentioned earlier, the patient groups identified patient needs as being of paramount concern. Thus it would seem necessary to have an inbuilt method for ensuring the effectiveness of the research carried out as well as some method for ensuring the accountability of decision makers within the organisation. Question 61 asks if the organisation or group has a board of management and twenty-seven organisations indicated that they have one (n=34). In Question 62, the respondents were asked to choose from a list of potential board members and they indicated that patient representatives (eleven respondents) are to be the most plentiful on these boards, followed by lay persons (ten respondents) and medical doctors (nine respondents). These figures were analysed further and funding organisations were compared to organisations that do not fund biomedical research with regard to the make-up of their board of management. Patient representatives are present in greater quantity on boards of organisations that are involved in funding research

while lay persons are most common on the board of organisations that do not fund biomedical research (Figure 2.12). These findings suggest that the patient groups surveyed are representative in their management structure although there is a tendency towards the scientisation of decision making processes as seen in Figure 2.11.

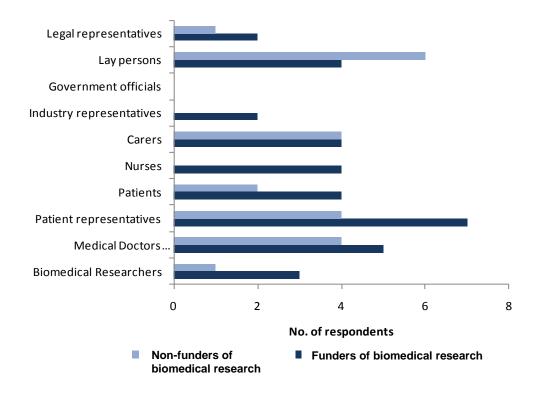


Figure 2.12 Representation on the board of management of organisations that fund biomedical research (n=11) and organisations that do not fund biomedical research (n=13)

Question 63 asks what the main mechanisms are by which the management decisions of the organisation are accountable to the needs of the members/sufferers. Seventeen groups (n=19) indicated that they already had mechanism in place and these mechanisms are detailed in Table 2.1. The Annual General Meeting is by far the most popular mechanism and usually allow members to cast their vote and review the annual activities of the organisation/group.

Table 2.1: Most popular mechanism employed by patient groups to ensure accountability of decision makers (n=19).

Mechanisms	# Respondents	Mechanisms	# Respondents
Annual General meeting	6	Newsletters	1
Board meetings	3	Research seminars	1
Information Days	1	Website feedback	1

Another concern for a patient and health organisation is how effective their funded research is. Question 37 asks whether the organisation has mechanisms in place to monitor or evaluate the effectiveness of the research they fund. The majority of organisations had no mechanism in place, twenty-three, but a few organisations, five, plan to put such a mechanism in place in the future (Figure 2.13). The reason given for their inability to provide this was cost, lack of manpower, and the perception that such a review was unnecessary. Similarly, Question 40 asks whether they have a mechanism in place to monitor or evaluate the effectiveness of research funded by other organisation on the disease of interest. The vast majority of organisations did not have such a mechanism in place, twenty seven, but agreed that there was a need for such a mechanism. Question 68 asks whether the organisation monitors recent advances in science and technology of relevance to their disease and twenty-five of the thirty-four respondents indicated that they engage in this practice. The main purpose for this monitoring as identified in an open-ended question (Q69) was to make the organisation aware of new developments, to develop best practice, to avoid replication and to use this information as a lobbying tool.

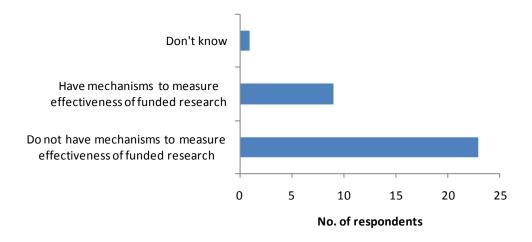


Figure 2.13: Mechanism for measuring effectiveness of research conducted by patient groups (n=35)

2.4.6 Communication efforts and influence of the patient groups

Not all groups are able to or indeed interested in conducting research themselves and have the potential role as conduits for relaying patients' needs to the funders of research or to research groups. Question 43 asks whether the organisation or group has any formal mechanism for communicating R & D needs to identified R & D funding sources i.e. the Health Research Board, the Wellcome Trust, Science Foundation Ireland, the Department of Health and Children, Pharmaceutical companies and the Food Industry. The majority of the organisations had no formal mechanism for communicating this information to the research funders suggested in the survey (Figure 2.14), nor did they identify other groups for such communication. Organisations that fund research communicated primarily with the Health Research Board and did so via their membership of the Medical Research Charities Group. Organisations that do not fund biomedical research communicated with the Department of Health and Children more often. Question 64 asks what the policy of the organisation is in relation to private sector funding. Only eight of organisations surveyed had a best practice guide or policy in place in relation to private sector funding (n=31), nine had a similar guide in relation to public sector funding (n=31) and twenty-nine were lacking policies relating to intellectual property rights in biomedical research of relevance to their disease/syndrome focus (n=31).

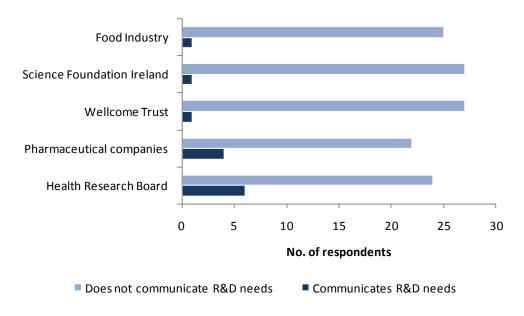


Figure 2.14: Mechanism for communicating R & D needs to R & D funding sources (n=34)

We wished to discover the most popular mechanisms for communicating their research findings to members and patients and Question 74 asks how research findings are communicated with suggestions of possible communication methods. Newsletters are the most popular method for relaying information to members and patients with thirteen of the twenty-nine respondents publishing a newsletter (Figure 2.15). The identified purposes for these communications are to (1) provide up to date information, (2) emphasise the need for research, (3) ensure better patient care, (4) raise awareness of the disease/syndrome, (5) ensure accurate responses to media enquiries, and (6) to lobby for better services

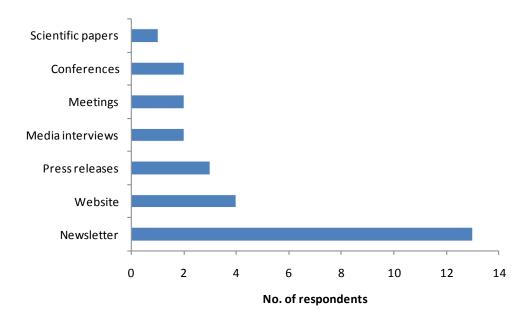


Figure 2.15: Medium used by patient group to communicate their research findings (n=29)

Question 72 asks to which groups their organisation communicates new research findings from a provided list and the respondents were invited to select as many targets of the communication as appropriate. The main target of these communications is the organisation's members, followed by patients and health officials (Figure 2.16).

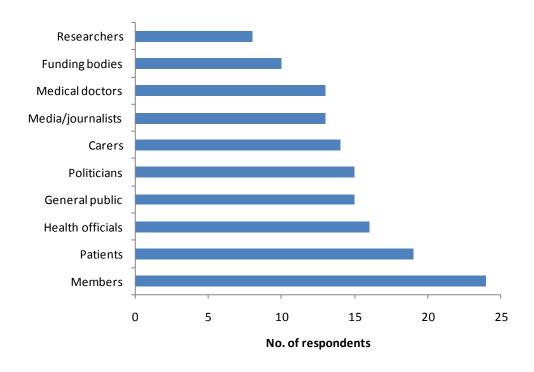


Figure 2.16 Overview of main communication targets of patient groups (n=32)

Question 21 asks whether the respondent is aware of the level of government (i.e. Irish government) funding on their disease of interest. Despite increased public funding for biomedical R & D in Ireland, twenty-one of patient and health groups surveyed are unaware of public research underway in Ireland into their disease as shown in Figure 2.17. Question 22 asks the respondents to rate the level of Irish government funding on biomedical research on their disease of interest. More than half of the respondents considered government funded research to be insufficient (n=40).

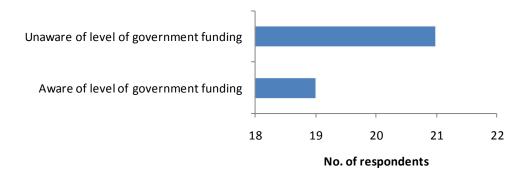


Figure 2.17: Awareness among the respondents of government funding into their disease/syndrome of interest (n=40)

While Ireland is an island state, many of the patient groups have chosen to look beyond this geographical restriction and have formed links at an EU and international level. The influence of a patient group can be identified through its involvement on national policy making committees and through its links with EU and international groups. Question 75 asks whether the organisation is a member of any national committees on policy in biomedical R & D funding in Ireland. Twenty-four out of the patient groups (n=32) had no representative on such committees (Figure 2.18).

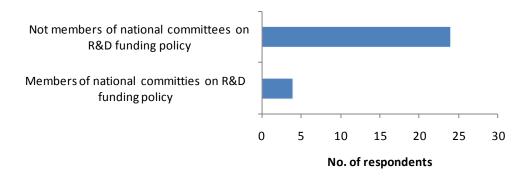


Figure 2.18: Presence of patient groups on national policy making committees (n=32)

Those with national representation on funding policy committees were involved with the Medical Research Charities Group (MRCG) or the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI). The organisations surveyed displayed a lack of awareness and knowledge of the policy groups that are influential in Ireland when asked which committees they would like to participate in. Question 78 asks what barriers are present towards gaining access to such committees in an open-ended question and the main barriers identified were lack of time, lack of personnel and lack of expertise. The cost of such initiatives was also a deterrent with a small membership cost being prohibitive for the smaller charities. Question 82 asks whether the organisation is a member of any committees on policy in biomedical R & D funding in Europe. Out of twenty-nice respondents, only one group is a member of such a committee. The Parkinson's Association of Ireland has an active membership in their European counterpart, the European Parkinson's Disease Association (EPDA). Similarly, Question 82 asks what barriers are present towards gaining access to such committees in Europe and the identified barriers are lack of time, lack of personnel, lack of expertise and also lack of funding for travelling expenses.

The survey participants were asked in Question 83 whether the organisations have active representation in groups who are influential in health research in Ireland, Europe and internationally (using a defined list). The majority of the respondents had

representatives in IPPOSI and MRCG (Figure 2.19). Several of the remaining patient groups planned on joining these organisations in the future, see below legend.

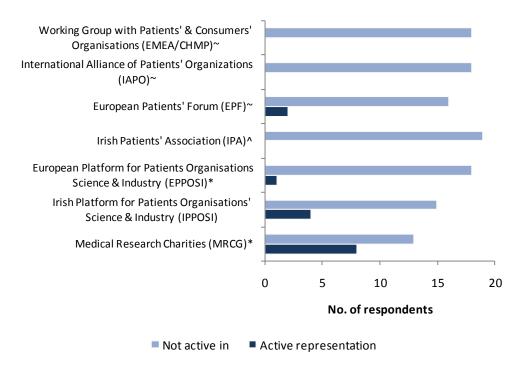


Figure 2.19: Active representation in national and international groups (n=25)

^ 3 groups plan to join in future, * 2 groups plan to join, ~ one group plans to join

An additional means for understanding the influence of an organisation is by examining its membership base. The majority of the respondents indicated that the organisation is membership based (Figure 2.10). Question 89 asks how many members the organisation has, and this number ranges from twenty to 4,500 members.

We can investigate the relative standing of patient groups in the research community by examining how they interact with researchers when conducting research. Biggs (Biggs and Smith, 1998) identified four levels of participation and these can be used here to examine a patient group's influence in research environments. Participation can be contractual where researcher uses the facilities or resources of the patient group to carry out research; consultative where the researcher consults with the patient group to identify problems and then find solutions; collaborative where the researcher and the patient group work together in the design and carrying out of the research and discuss the implementation continuously; or collegial where the patient group plays a major role in designing the research, defining the methods, analysing and interpreting the data, and implementing the outcomes. Question 11 asks for a classification of the level of

involvement of the organisation with identified groups i.e. research institutes, hospitals, companies, and universities and institutes of technology. Most of the patient groups have a contractual or consultative relationship with research groups. None have developed a collegial relationship with research institutes or industry despite having shared interests (Figure 2.20).

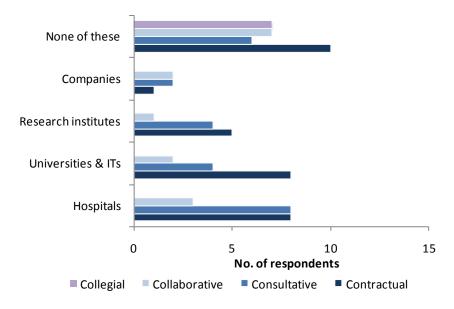


Figure 2.20: Analysis of the involvement of patient groups with researchers (n=28)

2.5 Discussion

2.5.1 Profile of Irish patient groups

The primary activity of most patient groups in Ireland is patient care and support, closely followed by health promotion. Health research is seen to be a secondary focus for these groups (Figure 2.1). This activity profile is typical of patient groups in Ireland as opposed to the US, France, the UK and Germany where patient groups exert a greater influence in the research funding area.

More than half of respondents indicated that they fund research and development into their own disease/syndrome of interest (Figure 2.2); however R & D is a broad term and can include a variety of research endeavours which differ according to the focus of the organisation and the desired outcome of the research. We examined how much was spent on the specific areas of research e.g. basic research, applied research etc. This information may provide insights into the funding strategy of a patient group e.g. do they claim to 'search for a cure', or pursue 'better patient care'. Of the eighteen groups who detailed their spending on biomedical R & D, the majority were involved in basic/fundamental research. While four of these groups allocated 60-90% of their budget on basic/fundamental research, the remaining four spent less than 15% on it (Figure 2.3). This would suggest that despite a professed interest in funding research (Figure 2.4), these groups are under other resource pressures.

2.5.2 Spending on health research

Healthcare is a €3.4 trillion industry worldwide and likely to grow with increasing life-expectancy and personal wealth. The pharmaceutical and medical devices industries' presence in Ireland has grown at a fast rate with a higher level of foreign direct investment than in other countries. These healthcare industries are increasingly dependent on high quality clinical research provided by specialists in well-equipped centres. Ireland has the potential to capture more industrial R & D activity if it can provide state-of-the-art resources in a range of domains, including basic biomedical sciences, information technology, bioengineering and drug development. ICT (Information and Communications Technology) companies are looking for engagement with the health services because the complexity of biological information and health care provides special challenges for the development of appropriate

information systems. The UK and the Scandinavian counties have realised the importance of linking their health services to their science and industrial development priorities and are investing in initiatives to bring them closer together. Ireland should do likewise by building the R & D potential within the health service and linking this with its investments in basic science (DETE, 2006).

While patient group budgets are relatively small in Ireland, figures show that they provide the equivalent of 5% of the total state spending on medical research (Medical Research Charities Fund, 2009). The patient groups were profiled according to their specific spending on biomedical R & D. Only a small number of patient groups have significant levels of funding for biomedical R & D. One third of the groups surveyed fund biomedical research. Cancer research is a primary research interest with the three largest funders of research focused on this area. Heart disease follows with the Irish Heart Foundation spending €150,000 - €500,000 on research per year (Table 2.3).

Table 2.3: Relative spending of patient groups on biomedical $R \& D^{25}$

Patient & health groups	Amount spent per year on biomedical	Proportion of budget spent on	
	R & D (€)	biomedical R & D	
1	0-50,000	>10%	
2	0-50,000	>10%	
3	0-50,000	>10%	
4	0-50,000	0-2 %	
5	0-50,000	>10%	
6	50-150,000	5-10%	
7	50-150,000	2-5%	
8	50-150,000	2-5%	
9	150-500,000	5-10%	
10	150-500,000	>10%	
11	500,000 -1 million	>10%	
12	1-5 million	>10%	
13	1-5 million	>10%	

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²⁵ Group 14 spends 50-150,000 p.a. on biomedical R & D, but did not indicate what proportion of their budget is spent on this; consequently they were not included in Table 2.3.

A third of the groups surveyed have a total budget of less than €100,000 per year. Undoubtedly this would prove a deterrent if they wish to become involved in research. Despite the cost of research, some of the less well-funded patient and health display a strong commitment to biomedical R & D funding. The annual budget was plotted against the percentage of the budget spent on biomedical research (Figure 2.21). What becomes clear from this analysis is that despite proportionally smaller budgets, many organisations were able to become involved in research and focussed much of their budget on this (>10%).

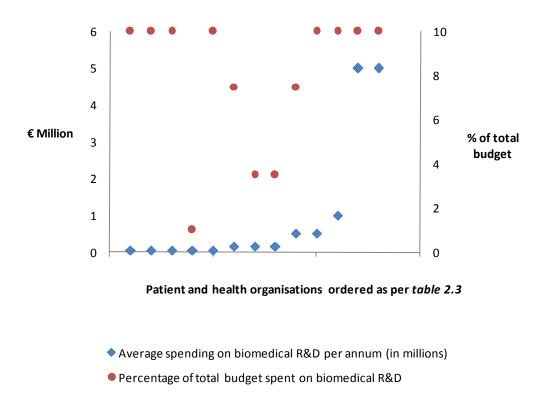


Figure 2.21: The average spending of the patient groups on biomedical R & D per year is plotted against the percentage spent on biomedical R & D of the total annual budget (n=13)

Other barriers to involvement in research are lack of resources such as staff (Figure 2.6), equipment, and expertise. There are huge time issues relating to funding research from establishing links with research communities, developing expertise in-house in order to identify strategic research areas to engage in, while also remaining abreast of latest developments and reviews of ongoing national and international research in related in tangential areas. One solution is to establish links with active research groups thus enabling the sharing of resources and expertise and the possibility of shortening the procedural steps required for engaging in research e.g. forming an ethics committee. Regardless these consultations can be lengthy particularly if the

patient group aspires to a more collaborative relationship on a research project (see Figure 2.20). Despite such obstacles there are particular benefits to patient groups becoming more involved in research, whether that is through funding their own research or in ensuring that the research needs of the patients that they represent are disseminated to the wider research community.

2.5.3 Meeting needs, representativeness and accountability

One of the issues explored in the survey was the extent by which patient groups may serve as a model for research funding organisations that articulate the biomedical R & D needs of their members in a representative and accountable manner.

Membership based patient groups can be representative of particular groups of health sufferers. In this survey, it was found that twenty-nine of the organisations surveyed (n=37) are membership based (Figure 2.10) and the majority of these groups have patient representation on their decision making boards (Figure 2.12). The level of patient representation was seen to decrease as groups become more involved in biomedical R & D, as groups shifted towards having a greater number of medical doctors and CEOs involved in decision making (Figure 2.11). Funding decisions made by the group on behalf of the sufferers can be subject to the scrutiny of the sufferers and their families. Table 2.1 shows that six of the organisations (n=19) indicated that they have mechanism (e.g. Annual General Meeting) in place to ensure that the organisers/ decision makers in the group are held accountable to their members. It is not clear how effective these methods are at ensuring the accountability of decision makers. AGM's occur too infrequently to enable members and the beneficiaries of a patient and health organisation to provide input and feedback. Surprisingly, patient groups do not utilise communication methods such as their website or a mailed or emailed newsletter for the same purpose. There is the potential here for patient groups to innovate in terms of using interactive web-based voting systems to gather feedback from members or patients.

An organisation that is truly sensitive to the needs of the people it aims to represent requires regular and comprehensive inputs to focus and steer the direction of the organisation. Many of the organisations surveyed identified communicating patient needs as being of paramount concern. When surveyed it was shown that patient groups do not have mechanisms in place to assess or prioritise their members' needs

regarding biomedical R & D (Figure 2.8 and 2.9). Lack of money and expertise were two main reasons given for this lapse and while these are valid reasons, there are multiple avenues for organising feedback from patients and sufferers such as online forums and research days which do not require many resources.

2.5.4 Communication efforts and influence of the patient groups

Participation requires two-way communication to ensure that the needs of the patient groups are being taken on board by national research funding agencies, and also to ensure that patient groups through their own funding of research are not duplicating efforts already being carried out. Our survey has shown that half of the patient groups are unaware of public research underway in Ireland and more than half of the respondents considered government funded research to be insufficient. This would suggest that despite the increased funding for biomedical research nationally, patient groups consider there to be an imbalance in resource allocation on publicly funded biomedical R & D.

Patient groups serve a vital role as communicators whether through disseminating research findings and developments to their members, as advocacies for a disease/syndrome engaged in lobbying the government, or by raising public awareness about a disease/syndrome and its sufferers. The survey results show that the communication efforts by respondents in relation to expressing R & D needs are below par despite expressed interest in communicating these needs (Table 2.4).

Table 2.4: Communication by patient groups in Ireland

	Yes	No
	# respondents	# respondents
Communicate R & D needs to researchers (n= 37)	3	32
Communicate R & D needs to funding sources (n=31)	4	25
On national committee on policy for R & D funding (n= 32)	4	24
Communicate new research findings (n=30)	4	15
Monitor recent advances in relevant research (n= 34)	25	8
Consider it necessary to communicate R & D needs (n= 36)	28	1

Not only are the patient groups unaware of possible research into their disease of interest in Ireland, but they are also unsuccessful in attempts to reach the ear of policy makers and budget spenders when the national research agenda is being drawn up.

The majority of patient groups have no representatives on national policy making committees for biomedical research funding. This issue was highlighted in the recent National Research Strategy for Health (Forfás, 2004) when only two groups representing the needs of patient groups (Irish Platform for Patients Groups, Science and Industry and the Mental Health Commission) made submissions to the development of the final policy document.

Some Irish patient groups are influential lobbyists at a European level and have powerful positions on large groups e.g. European Parkinson's Disease Association, despite lacking the same influence at national level. The groups surveyed displayed a lack of awareness and knowledge of the policy groups that are influential in Ireland (Figure 2.19). The barriers identified towards being involved in these committees or policy groups were lack of time, lack of personnel and lack of expertise.

2.6 Conclusions and recommendations

2.6.1 Barriers for patient groups

The main barrier identified by patient groups preventing them from becoming involved in research is lack of time and money. While some of these groups have substantial budgets, the majority of those surveyed have budgets of less than €100,000 to spend per year.

The majority of patient groups have between one and four staff members working full-time or part-time and their main activities are administration followed by awareness-raising and fund-raising. The time-pressures combined with limited staff number act as a deterrent to becoming involved in research. Some groups do not consider research to be a priority for their organisation. Other groups felt that they lacked the expertise to become involved in research, which may explain why patient groups have lower levels of patient representation on decision making boards as they become more involved in research.

The primary source of money for patient groups is private donations from fundraising activities. Government funding is considerable and the Department of Health and Children and the National Lottery are the main grant bodies for this sector. Certain diseases, namely cancer, receive greater support than others. Cancer is the second

largest cause of death in Ireland, which helps explain the continuing public support for research into cancer (Armstrong, 2001).

2.6.2 Opportunities for patient groups

Patient groups have strong potential to becoming dynamic players in the biomedical R & D arena. These groups are interested in biomedical R & D, especially in relation to their disease or ailment of interest. They are goal-oriented and the focus on end results resonates with biomedical scientists' desire to make discoveries that can lead to therapies. Some of the patient groups have had an influence on health policies through their membership base or their EU links. The most notable traits of these organisations are their management structures which are broadly representative of their membership base and sufferer group. This makes their involvement in terms of broadening the range of stakeholder groups involved in biomedical R & D decision making very desirable.

2.6.3 Policy recommendations

Inputs from an increased range of stakeholder groups into publicly-funded science policy have the possibility of creating a more user-directed, politically and economically stable R & D strategy. There are a number of measures that are necessary for patient groups to undertake to enable them to become effective facilitators and/or funders of biomedical R & D into their diseases of interest. These include:

- i) Patient groups could become more aware of the mandates and research interests of the different funding agencies. Patient groups need to be more aware of co-funding opportunities for biomedical R & D. This could involve contacting the different public funding agencies and identifying areas of overlap and potential collaborations in the future.
- ii) Organisations in existence to support patient groups e.g. the Medical Research Charities group, IPPOSI etc, need to advertise their potential services to the patient groups. While some of the patient groups were already involved with organisations such as the MRCG and IPPOSI, there is the potential for organisations to utilise the training and expertise offered by the MRCG to help them reorganise so that they can become involved in biomedical R & D.

(iii) Patient groups should collectivise to become stronger lobbyists. Patient groups need to give constant inputs into national policy consultations to ensure that the interests of their members are best served. Lack of time and money prevent most individual patient groups for increasing their efforts in lobbying government ministers. There is a need for a system which would allow better representation of the needs of the entire group of patient groups in Ireland in relation to biomedical R & D. This could be achieved by groups co-funding a specialist lobbying group analogous to the consumer group, IBEC (Irish Business and Employers Confederation).

2.6.4 Opportunities for biomedical R & D funding agencies

Stakeholder group consultations on biomedical R & D priorities could help biomedical funding agencies to ensure there is both a need and support for the spending of public money on biomedical R & D. This process could be improved by the following:

- (iv) Identify the potential health benefits of particular biomedical R & D strands. Certain funding agencies in Ireland are involved in funding research and the benefits or links between research and patient groups should be identified and potential collaborations investigated.
- (v) Work with other patient groups, funding agencies, and government departments to develop a cohesive policy on health research and biomedical R & D, which takes the identified needs of the patients into consideration. The recent Health Research Policy document (Forfás, 2004) showed a dearth of input from patient groups. The patient group survey showed a lack of awareness of government funding into the patient groups' disease or syndrome of interest. While some coordination of effort exists, there is the potential to develop this further and improve communication between the different actors in the biomedical R & D field as well as to coordinate spending on research.

2.6.5 Opportunities for biomedical R & D and health policy makers

Broad policies relating to biomedical R & D are charted by the Irish government based on policy submissions from a range of stakeholder groups. Such consultations are organised by government agencies such as Forfás. However, such consultations

are clearly not reaching patient groups as evidenced by this survey and there may be room for improvement of such consultation processes. The following recommendation may help to remedy this:

(vi) Increase efforts to raise stakeholder awareness of consultation processes prior to these occurring and also highlight the impact of these consultation exercises in terms of policy development. Consultation does occur with stakeholders on numerous policy papers, however some of these groups are not receiving this information or else they are not aware of the impact their submissions could possibly have.

Model for a bottom-up approach to research - the Science Shop

There is an unequal 'demand-pull' on scientific research and development across different groups and sectors of society. In the case of publicly funded scientific R & D, this can lead to a democratic deficit whereby only powerful and well organised groups, (e.g. industry sectors, farmers' organisations, medical bodies, community and voluntary sector) have the resources to interface with R & D systems and commission research in directions that favour their members' interests. In such scenarios, there is potential for disenfranchisement of weaker or more marginalised groups that may have knock-on effects in terms of social understanding of scientific research, political support for public spending on research, and on whether scientific research underway in universities is considered relevant to the needs of weaker or more marginalised groups.

Community Based Research (CBR) is research conducted in collaboration with communities on issues of relevance to the communities (Chopyak, 2003, p. 3) and is one possible solution to the inequity described above. Three basic principles have been outlined for community based research. Firstly CBR is a collaborative enterprise that aspires to full and equal participation of researchers and community groups in the research process. Secondly CBR aims to give authority to multiple sources of knowledge as well as encouraging greater variation in processes of discovery and dissemination. Thirdly CBR typically has a strong commitment to social action and social change in the interest of enhancing social justice (Stoecker, 2002). CBR can incorporate a range of research approaches which include action research, participatory action research, service learning, and Science Shops amongst others (Ibid). CBR approaches can differ in terms of how the research is conducted, the relationship between the participants, and how the research is used ultimately. Table 3.1 summarises the differences between some of these approaches. Action research and participatory action research aspire to the co-creation of knowledge and are focussed on using the knowledge generated as a tool for action. Service learning is a form of experiential learning in which students apply their academic learning to answer expressed needs in their local community. Science Shops "provide independent participatory research support in response to concerns experienced by civil society" (European Commission, 2003, p. 18).

Table 3.1: Approaches to community-based research, adapted from Savan et al (Savan and Sider, 2003)

Parameters	Action research	Participatory action research	Service learning: research oriented	Science Shops
Goal or orientation	Context-centred research	Problem-solving (Northern school) Liberation (Southern school)	'Engaged' campuses	Socially responsive research
Key elements	Participation Knowledge creation Action component	Participation Knowledge creation Action component Community control/ empowerment	Integration of academic study with service in community	Science Shops provide research service to community-based 'clients'
Participants	Communities External researchers (usually)	Communities External researchers (usually)	Communities University/college researchers	Communities University-based Science Shops NGOs functioning as Science Shops
Relationship between community and external actors	Co-ordination Co-operation Collaboration	Collaboration Degree of community control	Co-ordination Co-operation Collaboration	Client-expert relationship
Knowledge generation process	Co-generated	Co-generated, with high level of community input	Co-generated, with heavy student involvement	University-generated with heavy student involvement (Dutch model)
Time investment	Short to long-term	Typically long-term (where empowerment aspect is significant)	Variable	Usually short-term (one-time service)
Historical roots	Kurt Lewin and others in the US in the 1940s	Paulo Friere in S. America in 1970s; International Development practitioners	US in the late 1980s	The Netherlands in the mid 1970s

This chapter explores the potential use of a more bottom-up, demand-driven approach to scientific R & D, with a focus on the Science Shop approach as opposed to the other CBR approaches. There are two reasons for this choice. The first is that there is a Science Shop under development in University College Cork which enabled the investigation of this research approach. As the UCC Science Shop was only in pilot phase at the time with no research projects being undertaken, this allowed an investigation and assessment of the potential barriers to and opportunities for this initiative. It was anticipated that UCC could then use the findings to offset any issues that may have led to poor participation in Science Shop projects in the future. The second reason was to assess the potential of this approach to revitalise the civic mission of higher education and broaden public input into scientific R & D underway in UCC. This PhD chapter examines the potential for establishing a Science Shop within the College of Science, Engineering and Food Science at University College Cork, and ultimately to determine lessons learnt for implementation of Science Shops within other Irish universities, academic and research institutions.

3.1 Overview of the Science Shop approach

Science Shops facilitate scientific research being carried out on behalf of local civil society²⁶ groups usually within a University or Higher Education setting (Leydesdorff and Ward, 2005). In this approach a CSO, civil society organisation, contacts the Science Shop staff with an issue or problem. This request must meet a number of criteria before it is accepted: research is possible on the topic, the results will be made public, the findings are relevant to a wide range of people, the research question is not commercial, and the client is able to use the research findings. Once a problem or articulated issue or request is accepted the next step is to translate the request into a research problem in conjunction with the CSO and experts within the Higher Education Institution (Jørgensen *et al.*, 2004). The research problem may be situated in one discipline or require a multi-disciplinary approach. It may be beneficial to enlarge the problem to make it more suitable for a student or researchers or

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²⁶ Civil society groups/organisations are defined by the OECD as "the multitude of associations around which society voluntarily organizes itself and which represent a wide range of interests and ties. These can include community-based organisations, indigenous peoples' organisations and non-government organisations" (OECD, 2006, p 145).

alternatively the problem may require considerable refocusing to make the research manageable within a student's/researcher's/ CSO's time frame. The research findings and additional support are given to the CSO to enable them to make use of the results.

3.1.1 Undertaking a Science Shop project

Science Shop projects are typically undertaken by later-stage students such as final year undergraduate students and Masters students as part of the students' academic requirement. They are intended to be cost-effective research projects as they are usually funded by research monies already made available to the department for student research from the central funding system (usually there is an allocation of a small amount of funding for each final year undergraduate research project). In some examples, such as the Case Study below, the project may be undertaken as part of a PhD project which would require additional funding with monies sourced from national funding agencies, charities, European funding streams etc. Science Shop staff may also undertake some research on behalf of a CSO or may identify an interested researcher within the academic institution who would be willing to work for free with the CSO (although in some institutions they may require leave of absence from their paid duties for such free gratis work or be expected to conduct such activities outside of work hours).

Box 3.1 Case Study: Noise at Night project (van den Berg, 2004)

An example of a successful Science Shop is the 'Noise at Night' project which was undertaken by a PhD student in Groningen University in the Netherlands. A CSO approached the Science Shop for Physics with a problem. Local residents were complaining about the noise from a wind farm built on the Dutch-German border which was louder and more annoying than predicted even at distances of more than a mile. The wind developers and acoustic consultants disputed these complaints as their calculations showed that residents should not hear the turbines at all.

The Science Shop for Physics enlisted a student who undertook the research as part of his PhD. He applied knowledge about atmospheric physics in a new context and showed that strong winds at greater heights coupled with very light winds at ground level made the turbines noisier at night than during the day. This is due to atmospheric stability and was not noticed previously as the wind turbines had not been tall enough

for the effects to be noticeable. Wind turbines were also being built closer to domestic residences which is why the problem only became apparent recently.

The results of this research were presented to the local CSO who were able to vindicate their complaints to the wind developers. The student's research findings were published in academic journals and presented at international scientific conferences which triggered a flurry of emails from consultants and residents associations. In July 2004, the Ministry of Housing, Environment and Spatial Planning in the Netherlands advised that this effect should be investigated.

The above case study is certainly not typical of Science Shop projects, but highlights the potential for research into locally relevant problems to have a national and international impact. This is aligned with the stated aim of some Science Shops to "promote public influence on science and technology and enhance understanding among policymakers and education and research institutions of the research and education needs of civil society" (Mulder *et al.*, 2006).

3.1.2 History of the Science Shop initiative

The Science Shop initiative began in the Netherlands in the 1970s and arose from the environmental movement in Europe at that time. The original idea of the Science Shop was as a moderator between Universities and local civil society groups who could not afford to fund their own research. There have been four distinct waves or phases to the Science Shop initiative which differ according to time frame, geographical and institutional location, and focus of activity (Fischer *et al.*, 2004; Leydesdorff and Ward, 2005). The first wave occurred in the 1970s and was located in Dutch Universities with its genesis based on a debate regarding access to higher education and the 'democratization' of scientific knowledge. The second wave took place a decade later with the initiative spreading further into Europe and grew out of an expressed need of civil society groups to develop their own knowledge base with the assistance of the university. The third wave in the 1990s was focused on building social capital²⁷ and increasing inclusiveness. The Science Shop became a model for

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²⁷ Social capital has multiple definitions revolving around the concept that social networks have value. One definition suggests that social capital is a measure of the degree to which members of a community believe social institutions and the major professions are responsive to public concerns as

engaging the University in non-commercial objectives with groups previously excluded from such knowledge based exchanges. The final and fourth wave of the Science Shop initiative took place in the late 1990s with the EU accession countries developing their own Science Shops in collaboration with the Netherland network (Mulder *et al.*, 2001). The Science Shop concept therefore originated in Europe and is a largely European construct.

3.1.3 Diversity of Science Shop models within the European Union

At present, there are twenty-six Science Shops in the EU, located across fourteen countries (Leydesdorff and Ward, 2003). These Science Shops exhibit a wide range of organisational structures indicating that local-level research for tailoring to specific contexts is necessary to devise the optimal institutional structure for each Science Shop. Most existing Science Shops are located within a University; some within particular research departments, e.g. Chemistry Shop at Groningen University, while others are centralised within the University, e.g. Science Shop at Queen's University, Belfast. Some Science Shops exist as independent research institutes outside the University or Higher Education Institute and have their own dedicated research staff, e.g. Berlin Science Shop (Jørgensen *et al.*, 2004). Funding models for the Science Shops differ greatly and some receive support centrally from the Higher Education Institute while others are supported by local or national government, and others still rely on membership fees, grants, or charitable donations (Mulder *et al.*, 2006).

European public funding has contributed greatly to the development of a Science Shop network and this funding provides support, mentoring and sometimes sponsorship to developing Science Shops. The SCIPAS project, "Study and Conference on Improving Public Access to Science through science shops", was funded under the European Framework Programme 5 (FP5) from 1999-2001 and helped identify best practice in running a Science Shop as well as the pros and cons of different organisational options (Gnaiger and Martin, 2001). The INTERACTS project, Improving Interaction between NGOs, Universities and Science Shops, was funded under FP6 from 2001-2003 and sought to analyse the practices of Science

well as conversely the degree of perceived public trust and goodwill toward social institutions (Logan, 2001).

Shops using in-depth case studies (Jørgensen et al., 2004) to enable the understanding of knowledge transfer mechanisms between Science Shops and CSOs (Leydesdorff and Ward, 2003). These examples suggest that a mediation role of Science Shops is common to all variations of the model. Science Shops aim to engage in projects as determined by locally expressed needs and the desire of students to undertake particular projects. There is a notable difference in the ability to link particular disciplines and specialities to local research requests which is experienced in many Science Shops. Social welfare is a key area for Science Shop research while environmental issues seem to be most popular for research projects in the natural sciences (ibid). However, there may be a sampling bias in any such trends which could result from the influence of the Science Shop personnel and/or the groups that participate in Science Shops on what topics are worthy of study within the Science Shop model. Certain disciplines may at first glance appear esoteric to outsiders of the discipline with less scope for investigation of issues arising from everyday local context. This perception may be false however as is seen in the case study provided (Box 3.1), i.e. an esoteric area of science was linked with a Science Shop project to great effect.

The INTERACTS project has shown the difficulties experienced by Science Shops in engaging scientific staff in their projects, more so in countries outside the Netherlands. One explanation proposed for this is the lack of publication possibilities arising from Science Shop research, but this is unlikely as there are many publication outlets for participatory research. Science Shop projects may generate 'grey literature' which is not published or disseminated in formal channels and hence receive little attention or prestige among the wider scientific community (Mulder *et al.*, 2006).

3.1.4 What are the benefits of the involvement of students in Science Shop projects?

It is argued that students through their involvement in Science Shop projects learn how to apply knowledge in context as well as becoming aware of the local social impact of research. The students are typically responsible for undertaking research, liaising with the CSO and translating the research findings into useable information and recommendations. This ensures the broad development of student competences in areas such as communication, knowledge application, problem solving and cooperation (Teodosiu and Teleman, 2003). There is anecdotal evidence to suggest

that involvement in Science Shop projects has the additional benefit of student retention in less popular courses (Steve Harris, Science Shop Wales, personal communication). In some cases a Science Shop can be used to aid recruitment of students for the particular Higher Education Institute. The Rose report (Matthews, 2007) investigates secondary school students' perceptions of science and it shows that their preference for careers in science that benefit the broader population i.e. those with a medical/health theme, which could indicate a need of students for impact from their training and research. Science Shops show the potential impact of research across a broad range of disciplines and examples may resonate with students wishing to take up studies that can be linked beneficially to the local community or broader society.

Science Shop projects are intended to be problem-driven, not discipline-driven, thus curricula and research are expected to take up socially relevant themes in a multidisciplinary way. Science Shop staff have been involved in the development of methodological courses and have helped restructure curricula (Fokkink and Mulder, 2004). Science Shop projects can facilitate enquiry-based learning which enables the integration of research, teaching and learning in Higher Education with Science Shop case studies included in lectures and the opportunity for students to become involved in research. Sciences shops which focus on interfacing with civil society organisations (CSOs) allow problems articulated by CSOs to be brought to the attention of the Higher Education research community thus enabling Science Shops to influence local research agendas by changing focus within an existing research area, by acting as an incubator for new research themes, or by creating collaborative dialogues across disciplines that may not have existed previously (Hende and Jørgensen, 2001). Science Shop projects can facilitate knowledge valorisation²⁸ where academic knowledge and skills are tailored for use by society at large. The public understanding of science and research can be advanced with CSOs by highlighting the possibilities and limitations of current scientific thinking and approaches.

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²⁸ Knowledge valorisation is "the process of disseminating and exploiting the results of projects with a view to optimising their value, strengthening their impact, transferring them, integrating them in a sustainable way and using them actively in systems and practices at local, regional, national and European levels" (European Commission, 2009, p.1).

A criticism of research on Science Shops to date such as the SCIPAS project and the INTERACTS project is that it has focussed in identifying best practice for Science Shop organisation and development and does not critically evaluate the Science Shop concept itself as to what its benefits are and how these can be measured. The legitimacy of this approach within academic communities could be enhanced through empirical research into the actual impact of CSO focussed Science Shop involvement on their stakeholders needs i.e. participating HEIs, students and CSOs.

The current model of knowledge production creates two types of knowledge, usevalue knowledge and exchange-value knowledge (Stoecker, 2009). The first is created for immediate use while the latter is produced for exchange and relates more to the knowledge products and services that are exchanged in a knowledge-based economy. However, such a commodified view of knowledge production places little value in knowledge for knowledge sake, such as is generated by so called blue-sky research or fundamental research to understand the natural or physical world. It can be argued that the Science Shop approach enables both students and CSOs to become involved in the knowledge production process rather than remaining passive recipients of knowledge. A community that engages with the issues that concern them and knows what research can be carried out to address or help inform these issues is a knowledge-based community. Such community-level engagement helps foster not only a knowledge economy but a knowledge society. The expertise integral to CSOs is acknowledged but this potentially would be enhanced through harnessing the research resources of local HEIs as would students' and researchers' expertise. The principal impacts on CSOs from their collaborations with Science Shops are improved capacity and increased access to research resources across a wide range of disciplines (Gnaiger and Martin, 2001). Community based research approaches such as the Science Shop approach can help transform "who produces knowledge, who influences public knowledge, and who controls the knowledge production process" (Stoecker, 2007, p. 3). A criticism of community-based research is that despite emphasising the involvement of CSOs in research this does not always happen in practice. CSO involvement is often limited to data collection and they have less of a role to play in defining the research question or in identifying suitable research methodology (Stoecker, 2009). This may be due to general lack of training of the general population in methods of scientific enquiry or critical thinking, and is a deficit that

could be addressed through Science Shops facilitating training with CSOs on research methodologies and approaches. Capacity building approaches which improve the ability of CSOs to frame research questions and actively engage in research design and execution could be more empowerment oriented, than approaches where Science Shop staff perform such functions for the CSO as an external service. At present, most Science Shop staff work in partnership with CSOs and the student/researcher to translate an identified need into a time-bound research project. The aim of this approach is for the CSO to direct the focus of the research and to be involved in designing the research question. The most effective Science Shops will be those whereby research-literate empowered CSOs can independently interact with the student/researcher without the aid of Science Shop staff, i.e. Science Shop staff should aim to make themselves redundant over time and to yield the control of the research framing, design and execution to the CSO.

Involvement in Science Shop projects also enables CSOs to innovate as oftentimes CSOs rely on tried and trusted practices rather than conducting research into what is the optimum activity or good practice. For example, the Science Shop at Queen's University, Belfast, in conjunction with the Ulster Cancer Foundation tested the effectiveness of an online tutorial on the diagnosis of skin cancer for the professional development of General Practitioners. The tutorial proved so popular that it was taken on by the local health service as a training aid for health workers. The Science Shop approach can also be criticised for the client-expert relationship that is created between the CSO and the student/researcher undertaking the research, as this does not truly empower the CSO to engage in their own research. This criticism can be countered to some extent by changing the goalposts so that it is considered that a key aim of the Science Shop is to share information for action by the CSO. However, there are significant asymmetric power relations in any information sharing process which can be abused by those yielding the control and power, in this case the Science Shop staff. By engaging with a Science Shop, the CSO can utilise the studentgenerated findings to strengthen their practical or advocacy efforts without a large time commitment from the staff (op. cit.).

3.2 Can Science Shops be part of a new social contract with science?

A new social contract for science has been promoted which requires that scientific knowledge be socially robust and that its production be both transparent and participative (Gibbons, 1999). This request for a new social contract follows perceptions of the dissolution of boundaries between science and society. In this context, the triple helix describes the changes in the innovation system with an increased emphasis on knowledge production and the rise of the entrepreneurial university (Leyedesdorff and Etzkowitz, 1998). This new form of university not only creates knowledge but is responsible also for applying this knowledge to spin-out new products, applications and industry. Industry is involved in commissioning research and moves closer towards the academic model through the provision of training and the sharing of knowledge by industry. In the post world-war II era, governments have historically funded research into areas related to national need such as agriculture, health, energy, and defence research but the applied/commercial components of this research is increasingly privatised and the government role reduced to that of funder of public good research and regulator of individuals and private enterprise (Gibbons, 1999, Etzkowitz, 2004). The political economy of most countries (e.g. all of OECD countries) considers that the private sector is the most appropriate mechanism for the translation of applications of science and technology, with publicly funded translation of applications of science and technology limited to public goods and non-functioning markets.

While this model of knowledge transfer has the potential to accelerate efforts in creating a knowledge based economy (Inter Departmental Committee on Science Technology and Innovation, 2004) due in part to greater connectivity and ease of transfer between University and Industry, it is not without potential problems. This model of knowledge transfer may not be politically sustainable particularly in an economic downturn unless a broader range of societal groups are more actively engaged in the decision making process. Nowotny and colleagues argue that the old contract between science and society charged the scientific community with the task of producing reliable knowledge and communicating it *to* society (Nowotny *et al.*, 2001). As the boundaries between university science and industrial science become increasingly blurred, applied science and technology is conducted in "more open

systems of knowledge production" (Gibbons, 1999, p. 12). Depending on operational details, the Science Shop approach could contribute to greater transparency of scientific practices and broader public input into research agendas thus ensuring a more socially robust science and to strengthen a new social contract with science (Gibbons, 1999).

3.2.1 Public engagement in science

Recent social surveys in the UK and across EU member states indicate that while scientists and researchers are viewed in a positive light by the public, perceptions of uncertainty concerning the safety of certain outputs of science and the influence of business on science is having a negative effect on the public's trust relating to science (European Commission, 2005). It has been proposed (but not tested) that this lack of trust is due to the public feeling of exclusion from the scientific process, and resultant issues of loss of control and power regarding who decides what applied science or technologies are developed using public funds. The Science Shop model has the potential to facilitate greater dialogue and understanding between CSOs and the research community so that science-society conflicts are minimised (or amplified) at the local level (Wilsdon and Willis, 2004). In such a model, Science Shops could develop into informal and local participatory technology assessment agencies (Hagendijk and Irwin, 2006) thus providing a dual role and helping promote applied science and technological research that reflects the broader concerns of the members of the CSO. However, local needs may sometimes clash with strategic national or international needs (e.g. regarding energy security or climate change mitigation) and Science Shop/CSO alliances may be used to facilitate not in my backyard local priorities (nimbyism).

The rapid development in communications technology and the growth of the Internet has had a dramatic impact on Science Shops. Previously Science Shops were located at particular institutions and made their presence felt at the local level, but it is possible for local initiatives to have a global impact (see the case study Box 3.1 for an example of this). Science Shops can have an increased role in trans-European initiatives to increase public engagement and participation in science (European Commission, 2002). Previously, European funding was used to create and support the Living Knowledge International Science Shop network. This network shares

information on community-based research organisations and their activities as well as facilitating networking between organisations both virtually via their website and database and in person at the annual Living Knowledge conferences. The Public Engagement with Research and Research Engagement with Society (PERARES)²⁹ is the most recent trans-institutional activity of the Science Shop network. This project aims to strengthen the interactions between CSOs, the researcher community and the broader public through organising national and transnational debates on topics such as nanotechnology, domestic violence and Roma/Traveller's issues. The research questions arising from these debates, posed by CSOs, will then be fed back to partnering Institutions and research bodies. The development of trans-European and international projects such as PERARES means that Science Shop type initiatives are reaching a broader audience and have the potential to investigate community issues that are not limited by national boundaries rather they are global in nature.

3.2.2 Public participation in research and co-production of knowledge

Broader stakeholder inputs into scientific R & D processes are proposed to result in R & D that is more equitable, more sustainable, and with broader accountability (Irwin, 1995). The Science Shop approach is proposed as a form of participatory/demand-driven research mechanism that aims to broaden the active engagement of society in scientific R & D processes. Proponents argue that the Science Shop is a bottom-up, consumer driver approach to research which may prevent mismatches between the research questions of interest to researchers and the research priorities or needs of the broader public (Tallon *et al.*, 2000). From the perspective of the Science Shop staff, it will not be possible to research every question nor is it advisable. Instead by linking with CSOs Science Shops can filter the research priorities of groups representing communities and help influence the research agenda of a Higher Education Institution in this fashion. However, such filtering processes are in themselves political and have the potential to be used in a non-democratic manner where the power to choose what is researched or not lies with the Science Shop staff/committee.

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²⁹ For more details on the PERARES project please see a press release on the topic by the European Commission research office. This press release is available online at http://ec.europa.eu/research/index.cfm?pg=newsalert&lg=en&year=2009&na=na-181109. Last accessed April 29th 2010.

Studies investigating community-based research show that cross-institutional CBR models have the potential to improve the relevance of disciplinary research by bringing in a broader range of actors and facilitating rapid action on the results of a piece of research (O' Fallon and Dearry, 2002; Leung *et al.*, 2004). However, distinguishing between rhetoric and reality regarding participatory research models (Cooke and Kothari, 2001; Hall *et al.*, 2001) requires empirical research into the mechanisms by which Science Shops operate and their impacts on participants including CSO, student/researcher and HEI. Such empirical research should also be extended to an investigation of which questions were excluded and which CSOs are excluded by the Science Shop staff and its process of operation.

As argued by Stoecker (Stoecker, 2009), if knowledge is consumed without an understanding or awareness of how it is produced, then it is very difficult for these consumers to discern its quality and reliability. The Science Shop approach can enable this production process to become more explicit to those engaged. It also can facilitate the creation and sharing of knowledge for action by ensuring that the research findings are presented in a usable form (participatory technology development) and by making recommendations to the CSO on how to utilise the research. In making recommendations it is advisable that Science Shop staff and the student/ researcher/ student supervisor identify any potential biases which may skew their recommendations. There may be a role for external objective peer review in such evaluations as small groups equally may have distorted perceptions of their objectivity. As such self-awareness is not always possible, and there is a danger that CSOs could be influenced by the political agendas or ideological leanings of the CSO, the Science Shop staff or the student/researcher/student supervisor. Hence, as opposed to other forms of community-based research, Science Shops can be less participatory. The relationship between the CSO and the Science Shop remains that of client and expert so the potential for co-production of knowledge is limited to the early stages of the articulation of the research question. Yet, there is the potential for a more participatory approach to research and some Science Shops are engaged in such practices but these are very much in a minority due to the increased time pressures, complexity and loss of agenda control that such participation involves. Perhaps this is merely a misconception and participatory research can fit into similar time lines. The potential for such projects should be explored to ensure not only a bottom-up

approach to research agenda setting but also to engage a greater number of actors in the knowledge production process.

3.2.3 Civic engagement and Higher Education

The advent of mass participation in higher education has led to increased commentary on its changing role (Skilbeck, 2001; Englund, 2002). Higher Education Institutions are under pressure to meet the needs of a globalised knowledge society while maintaining their quality standards, and an additional purpose of higher education, as identified in by the Bologna process³⁰, is to prepare students to be active citizens. Active citizenship is defined as by Hoskins as "participation in civil society, community and/or political life, characterised by mutual respect and non-violence and in accordance with human rights and democracy" (Hoskins, 2006, p. 4). While many HEIs refer to their civic mission in mission statements and strategic plans, it is not clear how these stated intentions are translated into practice or how they support the development of the student as an active citizen or encourage greater civic engagement. One way to achieve this goal is to teach students how to critically interpret and apply knowledge in particular social contexts through their involvement in community-based research initiatives (such as Science Shop projects). Research has shown that participation in Higher Education is positively associated with civic engagement activities (Dee, 2004) and it is also clear that many HEIs are actively engaged whether through individual involvement with groups in the community or via institutional programmes such as service learning initiatives (Taskforce on Active Citizenship, 2007, Boland, 2008, McIlrath, 2009). What is missing however is the embedding of such initiatives within the higher education system and the provision of incentives for such activities. The provision of support for civic engagement activities as well as their recognition in promotional qualifications may encourage further staff to get involved in such initiatives. Similarly students would benefit from gaining accreditation for their involvement not to encourage disingenuous involvement rather to underscore national and international support for these activities and the development of social competences.

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³⁰ The Bologna process aims to create the European Higher Education Area where academic degree standards and quality assurance standards are comparable and compatible across the forty-seven participating countries. Details of the Bologna Action lines and the list of participating countries are available on the official Bologna website www.ond.vlaanderen.be/hogeronderwijs/bologna/.

3.3 Design of the Science Shop Study

Science Shops have been in existence since the 1970s and recently these initiatives have been greeted with renewed interest having returned as part of the agenda of science policy-making (Fischer *et al.*, 2004). Whilst Science Shops provide a wealth of expertise across many disciplines and utilise a definition of science which incorporates social science, humanities and the natural sciences, Science Shop projects typically relate to development, environmental, education, health, housing, labour or law issues (ibid). The amount of activity by the natural sciences in research is considerable and apart from individual one-off projects with local groups, this research ranges from meeting local (e.g. rare species conservation), national (e.g. energy security) and international needs (e.g. climate change modelling) needs. In addition, scientific research is conducted at different quality (scientific impact) levels where the international criteria of excellence in research have no or little relationship with local needs or priorities.

The identification of science and technology as the main drivers of the knowledge economy means that research institutes are often more interested in large scale high impact projects and in building relationships with industry rather than becoming involved in small projects linked to local needs articulated by CSOs (Jørgensen, 2003; Jørgensen *et al.*, 2004). A key issue for publicly funded research is the economic (not commercial) cost benefit in terms of benefits derived from costs spent on research and development. It could be argued that Science Shops should be publicly funded from local (government) sources rather than national if their main focus is on meeting local CSO needs.

3.3.1 Objective, methodology and relevance of Science Shop study

The Science Shop study focuses on the potential for academic staff within the natural and technical sciences within University College Cork to engage in Science Shop projects. The research is exploratory rather than evaluative in nature given the nascent form of the Science Shop under investigation and instead is focussed on identifying the potential impact of enabling and constraining factors on academic staff in participating in a Science Shop project.

An online e-survey (using Survey Monkey) was carried out in April of 2007 with academic staff in seven departments within the Science, Engineering and Food Science faculty in University College Cork. The questionnaire used is presented in Appendix C in the form that it was presented to the recipients. The findings from the survey are intended to help inform the design of the Science Shop, identify potential funding sources and help offset any issues that may have led to poor uptake of Science Shop projects. An additional investigative goal of the Science Shop survey is to raise the awareness of academic staff within UCC of the Science Shop initiative so that future research collaborations would be achieved more easily. It was decided to focus this chapter's research on academic staff as they act as gatekeepers within the University for such an initiative, are full time employees, and ultimately would help determine the success of a Science Shop through their involvement or lack thereof in Science Shop projects.

The objectives of the research were:

- 1) To identify opportunities and barriers for the implementation of a Science Shop initiative within the College of Science, Engineering and Food Science (SEFS) at University College Cork;
- 2) To identify optimal organisational structures and models for a SEFS 'embedded' Science Shop that would lever SEFS research expertise to meet local civic-groups' needs;
- 3) To investigate policy and institutional opportunities for the development and institutional sustainability of a SEFS Science Shop;
- 4) To identify the roles that CSO driven research through Science Shops can play in broadening public representation in science R & D policy and agenda setting.

92 academic staff members within SEFS were contacted during April 2007 and were given a link to a short e-survey (Appendix C). The survey was comprised of openended and closed questions in order to gather a range of opinions and suggestions on how a Science Shop could function best from staff within SEFS. Two departments were contacted from the Faculty of Food Science (Department of Food and Nutritional Science, Department of Microbiology), two from the Faculty of Engineering (Department of Civil and Environmental Engineering, Department of Process and Chemical Engineering), and three from the Faculty of Science

(Biochemistry Department, Chemistry Department, Department of Microbiology, and Zoology, Ecology and Plant Science Department). These departments were chosen to represent a range of department sizes from small to large, and to show a range of involvement in research with potential or lack of potential for local application so that the responses could be considered broadly representative of the SEFS academic community.

3.4 Results

Full responses were received from fifty staff members which gives a response rate of 54%.

3.4.1 Awareness of Science Shops

Question 1 asked whether SEFS staff were previously aware of Science Shops or similar initiatives. Most respondents were unaware of Science Shop initiative with forty-two respondents indicating their lack of awareness (Figure 3.1).

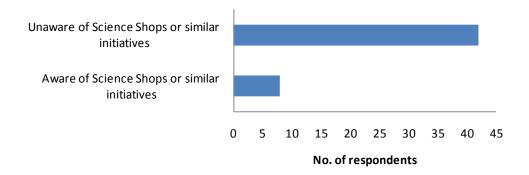


Figure 3.1: No. of respondents who were aware of Science Shops or similar initiatives (n=50)

When queried in Question 2 on whether they would consider community-driven research questions, the vast majority of respondents indicated community driven questions could be considered (Figure 3.2).

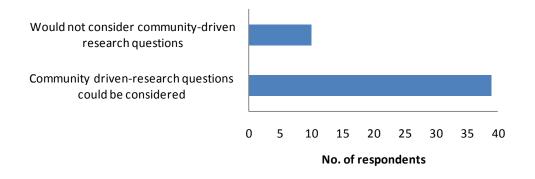


Figure 3.2: No. of respondents who would consider carrying out community driven-research questions in their group (n=50)

In response to Question 3, "Are there groups in the local community that you would consider it beneficial to establish SEFS research links with?", the majority of respondents were unaware of local groups with whom it would be beneficial to

develop research links, while a third of respondents were aware of suitable local groups (Figure 3.3).

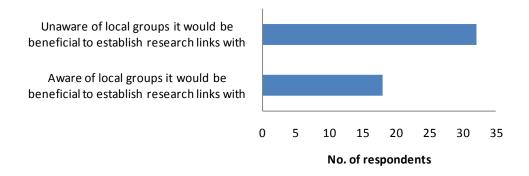


Figure 3.3: Respondents awareness of groups in the local community with whom it would be beneficial to establish SEFS research links (n=50)

The respondents identified schools and teachers as being the most suitable local groups to link up when asked in an open-ended question to identify groups in the local community. The next highest ranked answers were local government and environmental groups (Table 3.1)

Table 3.1: Identification of suitable groups in the locality to collaborate with on a Science Shop project (n=14)

Identified groups	Ranking
Schools/Teachers	1
Local Government/County council	2
Environmental groups	
Farmers groups	3
Local Industry	
Waste Producers	
Health Professionals	
Consumers	
Hospitals	4
Patient Groups	

3.4.2 Proposed organisation of the Science Shop

Respondents were asked to consider one of three research levels at which the Science Shop could link with University research in Question 2(b). Respondents considered undergraduate students to be the appropriate researchers to work on a Science Shop project; postgraduate students were the second choice (Figure 3.4).

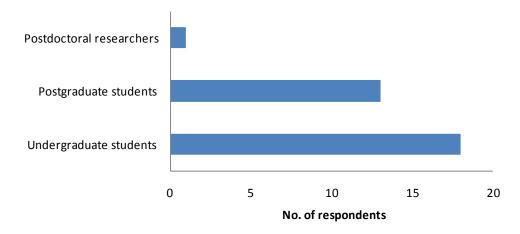


Figure 3.4: Respondents identification of the appropriate level to carry out such research (n=39)

Question 4 asks what the best approach for resourcing a Science Shop facilitated research project would be. In response to this open-ended question, respondents suggested that Science Shop projects could resourced by students carrying out the work as part of their academic work i.e. final year project. The second most popular suggestion was to utilise central university funds to cover the costs of running a Science Shop project (Table 3.2).

Table 3.2: Identification of best approach for resourcing a Science Shop facilitated research project (n=32)

Potential approach for financing Science Shop projects	Ranking
Free- as part of Final Year project	1
Central University Funds	2
SFI	3
SEFS	
Heritage Council	
Government	
EMBARK/UREKA	4
Funding Body	
Stakeholders	
Local Council	
Donations	5

3.4.3 Support structures and incentives to encourage involvement

In Question 6, the survey participants were asked to what extent they personally would be discouraged from getting involved in a Science Shop initiative using a predetermined list. Respondents indicated a lack of time and resources as the main factors discouraging their participation in a Science Shop project (Figure 3.5).

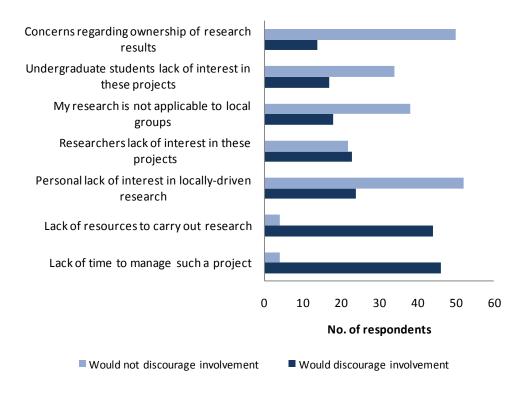


Figure 3.5: Respondents ranking of the factors that would discourage their involvement in a Science Shop project (n=50)

When asked for additional factors that might discourage their involvement in Science Shop projects, respondents reiterated that lack of time would be a major discouragement (Table 3.3).

Table 3.3: Respondents suggestions of other factors that would discourage their involvement in a Science Shop project (n=19)

Others factors that would discourage involvement in Science Shop	Ranking
Time	1
Relevance	2
Costs	
Unrealistic Expectations	3

In Question 5, respondents were asked to what extent they personally would be encouraged to get involved in a Science Shop initiative using a predetermined list of supports and incentives in place in other Science Shops. Respondents ranked the provision of full funding and the granting of awards to students involved in Science Shop projects as the factors that would most encourage their participation in a Science Shop project (Figure 3.6).

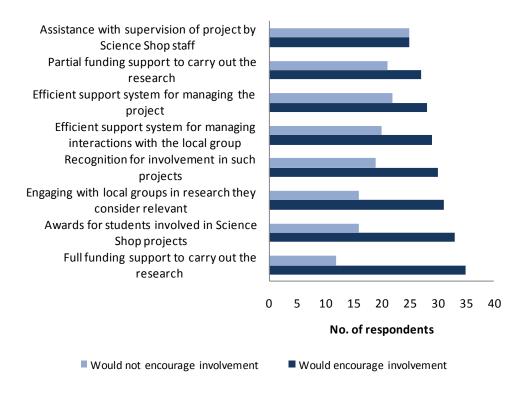


Figure 3.6: Respondents ranking of what factors would encourage their involvement in a Science Shop project (n=50)

When asked for additional factors that would encourage their participation, respondents indicated that matching of research interests would encourage them to get involved in Science Shop projects (Table 3.4).

Table 3.4: Respondents suggestions of other factors that would encourage their involvement in a Science Shop project (n=14)

Others factors that would encourage involvement in Science Shop	Ranking
Matched interests	1
Clear arrangement- time/work load	2
Interesting questions	
Low time cost	

Low cost	3
Short specific project	
Credit for students	

Respondents were asked to indicate their level of agreement with comments relating to the Science Shop approach. There was strong agreement from respondents that the Science Shop approach would improve the image of science with future students in the local community and make members of the local community more appreciative of the research ongoing in SEFS. There was strong disagreement with the comment that involvement in Science Shop projects would be a waste of research time for undergraduate students or researchers (Figure 3.7). There was also disagreement that Science Shop projects would have minimal benefit to local groups as not long-term.

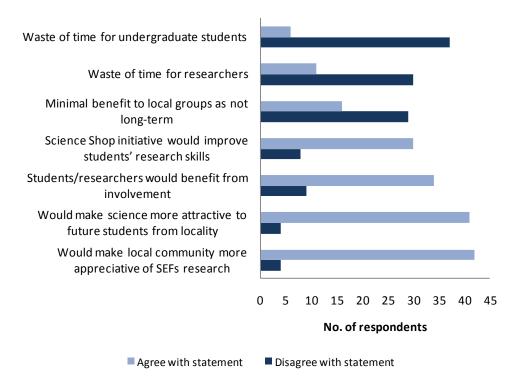


Figure 3.7: Respondents response to suggested comments regarding a Science Shop (n=49)

Respondents were then asked to provide final comment or advice relating to the development of a Science Shop in SEFS and Table 3.5 summarises their responses.

Table 3.5: Respondents' comments and advice in relation to the Science Shop (n=7)

Suggestions in relation to a Science Shop operating in SEFS

Run professionally rather than ad-hoc

Requires 5 year time commitment

Science Shop title should be modified to include Engineering

Need to regulate so that Science Shop work seen as part of overall work activities (not add on)

Source long term funds

Split projects between disciplines so that some areas aren't overtaxed

Structure projects so that research is of a high standard

3.5 Discussion

3.5.1 Awareness and openness towards Science Shop idea

The vast majority of respondents were unaware of the Science Shop initiative but expressed a great interest in carrying out community driven research within their group (Figures 3.1 and 3.2). It should be noted however that the respondents may not have been aware of the political implications of community driven versus community sourced research. A third of respondents were able to identify groups that they thought they would form beneficial research links with (Figure 3.4) and the top three suggestions of groups were schools and teachers, local government/council and environmental groups (Table 3.1).

Throughout Europe there has been a decline in the number of students taking science subjects in secondary education and this has had a knock on effect on the demand for science and engineering courses. The Lisbon Agreement saw the European member states decide to direct their energies towards the creation of a European Research Area which could compete internationally and lead towards increased innovation and knowledge creation. Key to this plan is the attraction and retention of talented and dedicated scientists and engineers. The expressed interest in academic staff in interacting with teachers and schools could be linked with the drop in the number of students in science and engineering; thus the Science Shop may be seen as a promotional aid for science and engineering departments and courses. Indeed, one of the main arguments for the Science Shop initiative is that it does attract students into research. Additionally, it has been shown that providing a Science Shop module attracts students into subject areas (O' Fallon and Dearry, 2002; Fokkink and Mulder, 2004) particularly those students who wish to participate in activities to help improve human health and to resolve environmental issues (Jenkins and Pell, 2006).

3.5.2 Proposed organisation of a Science Shop

Ireland's recent Strategy for Science, Technology and Innovation 2006-2013 has identified the need for an increased number of PhD students in order to achieve the national ambition of a knowledge society (Department of Enterprise Trade and Employment, 2006). The main funder of PhD research currently is the taxpayer and, despite efforts to increase industry spend on fostering research excellence, it seems

that government funds will be required to sponsor a growing swell of PhD students. There is pressure on Universities not only to try and harness alternative funding sources but also to accommodate the new PhD students, organise their supervision and identify novel research questions for them to investigate. Science Shops are one way of addressing these pressures for a number of reasons. Namely, they can forge new partnerships with local communities and highlight the benefits of continued public funding of research. Science Shop projects can be a rich source of new project ideas (Holzner and Munro, 2006) and also of course materials and potential publications. In some cases, Science Shop projects have provided an additional source of funding for the University (Gnaiger and Martin, 2001; European Commission, 2002).

Academic staff were asked for their suggestions on how a Science Shop could be organised and funded within SEFS. The majority of respondents were in favour of having undergraduate students work on a Science Shop project (Figure 3.4) and suggested that this arrangement would answer funding issues also as final year projects must be carried out by students in order to fulfil their academic requirements (Figure 3.5). It is interesting to note that, as seen in Table 3.2, local sources of government funding were seen as least relevant to locally-driven questions. Instead national funding agencies are considered to be a better source of funding. This may be due to a lack of awareness of SEFS staff of local sources of funding and an indication of their familiarity and ease with national funding structures. It would be worth investigating where local CSOs source their funding from and exploring options for harnessing other funding streams for the Science Shop initiative.

3.5.3 Support structures and incentives to encourage involvement

Research is a costly and time-consuming activity with no guarantee of a substantial breakthrough in understanding or the creation of a useful output whether a process, service or technology. Research in the natural sciences is even more expensive than social or humanities research due to the high cost of building/maintaining a lab, purchasing lab equipment for measuring, visualising and analysing material, as well as the continuous cost of lab reagents, equipment maintenance, and general consumables. There is also a huge time cost across both natural and social sciences for writing project proposals, supervising research students, preparing project updates and

reviews for funding agencies, amongst a myriad of other tasks. It is no surprise then that academic staff identified the lack of time and lack of resources/funding as being the major deterrents to becoming involved in a Science Shop project (Figure 3.5 and Table 3.3). The respondents indicated that concerns regarding the ownership of the research would not discourage their involvement and this may warrant further investigation as undoubtedly questions regarding Intellectual Property or dissemination of research findings could become problematic. Respondents also indicated that their own lack of interest in locally-driven research would not act as a discouragement nor would the lack of applicability of their research to local groups. These responses are somewhat contradictory and would warrant great elaboration.

Respondents indicated that in addition to the provision of funding for projects and of awards for students participating in Science Shop projects, they would be encouraged to participate in a project if they received support in managing the project and interacting with community groups. A large proportion of respondents also identified the need to match research interests so that participation would be beneficial across a number of criteria (civic engagement, personal interest etc) (Figure 3.6 and Table 3.4). Figure 3.6 also indicates that the assistance of Science Shop staff is a disincentive for half of respondents. The reasons for this are unclear and could be the subject of further investigation. Possibilities for this response could be that researchers may consider the involvement of Science Shop staff as time consuming and bureaucratic or as interfering/unqualified. In general, without the respondents having knowledge of the specific Science Shop and the personnel therein, it is difficult for respondents to accurately answer this question in the abstract. Additional factors that would encourage their involvement would be the matching of interests of the CSOs and the researchers, which one would expect, and this is a task typically carried out by Science Shop personnel. These findings suggest the need for greater clarification of the roles being undertaken by the various participants in a Science Shop project. Indeed many Science Shop use a 'contract' to delineate these roles and clarify what the expectations are for each participant in a project.

In the main, academic staff expressed very positive opinions in relation to the Science Shop approach and indicated that they thought a SEFS based Science Shop would have a dual impact of improving the image of science with future students in the local community and also help make members of the local community more appreciative of the research ongoing in SEFS (Figure 3.7). Academic staff did mention the need for long-term funding of projects to ensure continuity of projects and to maximise the benefits of the research (Figure 3.7 and Table 3.5). This word of caution ties in with an awareness of the dangers of short-term extractive research which can lead to disappointment amongst community groups when the forecasted benefits of their involvement in a research project are not realised.

3.6 Conclusions and recommendations

3.6.1 Barriers to becoming involved in a Science Shop project

The main barriers to becoming involved in a Science Shop project as described above are the lack of time and resources for academic staff considering becoming involved in such a project. The decision to double the number of PhD students in Universities is an indication of a national and European commitment towards the development of a knowledge based economy, but such a bold step will need considerable resources to be put in place and support provided for academic and administrative staff who already feel the weight of their professional commitments. The provision of a dedicated Science Shop may help ease some of these additional pressures through the regular provision of novel research questions, through the development of links to alternative funding sources, and through the development of support structures to ensure the smooth running of a Science Shop.

3.6.2 Opportunities for becoming involved in a Science Shop project

The Science Shop initiative has been shown to answer a number of requirements of the HEI. Firstly, through building links with community groups, the Science Shop helps the HEI address its fourth mission to engage with the community and "harness university education and research to specific economic and social objectives" (OECD, 1999, p. 9) as well as to "enhance intellectual, cultural, social and economic life locally, nationally and internationally"(UCC President's Office, 2007, p. 3). Secondly, the Science Shop can through its interaction with local groups help improve the public image of research and go some way towards helping appease the public paymasters. The Science Shop is an effective pedagogical model as performing research within a local social context can prove very motivational to the student as they see the direct

benefits of their research (Eyler and Giles, 1999). Thirdly, the Science Shop initiative provides the opportunity for a mutual learning experience and the co-development of knowledge where local communities have their research queries answered by academic experts to a high, robust standard. Researchers become aware of the needs of broader society which may help inform their future research interests and grant them access to experience based experts who may provide answers or suggestions that may lead to new knowledge (Nowotny *et al.*, 2003; Flicker *et al.*, 2008; Kysar, 2008).

The findings of this study indicate that there does not appear to be a particular disciplinary bias against working with the Science Shop, although some areas of research are more compatible with this research model and civil society groups may be more inclined to ask questions in relation environmental and health issues (although this is untested in the context of Ireland). The Science Shop needs to moderate the questions asked so that particular disciplines are not overstretched, and also to look for creative synergies which would utilise a greater variety of disciplines in answering the Science Shop questions.

3.6.3 Recommendations

Next steps for UCC Science Shop

- (i) Develop a database of ongoing research in the faculty of Science, Engineering and Food Science to identify possible linkages for future research collaborations, and an indication of which research groups or PIs (Principal Investigators) would be willing to engage in Science Shop activities.
- (ii) Work with Head of Departments and academic staff to redesign final year project so the time frame and academic requirements more easily match those of a Science Shop project.
- (iii) Develop a directory of CSOs and begin the process of articulating/extracting research questions.
- (iv) Source funding for a Science Shop liaison officer who can act as a link between the University and CSOs and also provide necessary support for the student and supervisor involved in the Science Shop project.
- (v) Meet with the University governing body in an effort to have the Science Shop be included in the strategic plan for the University thus ensuring the sustainability of the Science Shop initiative.

- (vi) Identify ways to incentivise staff and student involvement in Science Shop projects.
- (vii) Source long term funding for the Science Shop staff member to ensure continuity of the initiative.
- (viii) Provide a directory of projects to students at the beginning of the academic year and begin work on incorporating Science Shop projects into a wider range of disciplines.
- (ix) Broaden the support base for the Science Shop through identifying projects and initiatives ongoing in the University which have a similar focus as the Science Shop approach and develop links with these individuals and groups.

General recommendations

- (x) Link with Science Shop network to develop empirical research into the impact of involvement in Science Shop projects on the main stakeholders i.e. CSOs, HEIs, supervisors and students.
- (xi) Examine the potential for participatory research projects to be developed in tandem with 'typical' Science Shop projects.
- (xii) Create transnational projects that incorporate a variety of research disciplines in creative and innovative ways.

Involving researchers in public engagement in science

Scientific and technological innovation is considered central to the development of a knowledge economy, and scientific R & D has benefited from increased national and European funding in the last decade with this aim in mind. In tandem with an increased spend on R & D is a recognition of the need to enhance the public communication of science to increase public understanding of science and its relevance to socio-economic well-being, to ensure public support for science as well as ensuring accountability for the spending of (often) public monies (Carrada, 2006). Previous efforts towards the public communication of science exercises were based on the notion of a deficit 'empty vessel' public where any mistrust of science was likely due to a lack of understanding or knowledge about science, its benefits and how the scientific process operates. The 'deficit' model was criticised for its assumptions, firstly that the public was ignorant of science as determined by scientific literacy surveys, and secondly that this supposed deficit of knowledge was the cause of opposition to or questioning of science (Wynne, 1995). Wynne (1992) argues that the public regularly utilise scientific knowledge in their lives but in ways that are appropriate to them (Wynne, 1992). A report by the House of Lords (2000) suggests that public mistrust of science instead may be due to the reaction of the public to the way an issue may be framed as being solely a scientific issue which "distorts or excludes other legitimate concerns" (House of Lords, 2000, section 2.49).

Later research has shown that increased public knowledge can lead to greater public unease by some sectors of society, particularly in relation to research which is considered to be contentious by some (or all) sectors of society³¹ (Evans and Durant, 1995; Sturgis and Allum, 2004). In recent years, science communication has taken a more 'participatory turn' following indications from public opinion polls and attitude surveys (Office of Science and Technology and the Wellcome Trust, 2001) of the

More recently research by Allum and Sturgis has shown there is a small positive correlation between positive attitudes towards science and the knowledge of science of those surveyed. This seems to be due to focussed and 'local' knowledge about science rather than due to more general knowledge. A key outstanding issue in many such studies is how to differentiate between the depth or level of knowledge of science (across different scientific disciplines) of different members of the public and their level of support for scientific activities in different disciplines (Allum *et al*, 2008).

desire for greater transparency and greater public engagement in decision making processes regarding science and technology.

The arguments proposed for increased public engagement in science can be broadly categorised as normative, substantive or instrumental (Fiorino, 1990). The normative argument is that the public should be involved in decisions that affect them. Public engagement initiatives based on this premise may help inform the wider population of the latest developments and/or issues relating to science and technology and also may enable public input into and participation in decision making relating to science and technology. The substantive argument is that the public judgements in relation to risk are "as sound, or more so than those of experts" (Fiorino, 1990, p. 227). This argument recognises the contribution of lay expertise and public perspectives and values to the decision making process. The instrumental argument is that broader public participation in decision making makes the process more legitimate and can help contribute to other goals/ends such as better decision making, more socially relevant outcomes and/or increased public trust in researchers. The below table (Table 4.1) describes in greater detail the role of the participants and the extent of their participation based on differing rationales for public engagement.

Table 4.1 Rationale for public engagement (Höppner, 2009)

Normative		Substantive	Instrumental
Reasons	To empower citizens in agenda-setting and decision making as a democratic right	To improve agendas and decisions through the inclusion of diverse views, knowledge, value and belief systems	To endorse favoured decisions and favoured outcomes such as citizens' trust, consent and behaviour change
Role of engaged individuals	Active subjects with formative and reactive roles	Active subjects with formative and reactive roles	Passive objects with reactive roles
Room for input	Input into the extent and influence on agendas and decisions varies	Input into the extent and influence on agendas and decisions varies	No input that challenges predefined favoured decisions and outcomes
Relationship to the exercise of power in and over engagement	 attentive to power and framing issues quality criteria and measures to guarantee inclusive, fair and equal empowerment are central to contain the exercise of power 	- typically blind to power and framing issues since the focus lies on the actual input and the quality of outcomes	- blind to the exercise of power or even supporting and justifying the exercise of power by participants if their interests match with favoured decisions and outcomes

There has been a proliferation of activities over the past decades to answer this need for public engagement with many novel initiatives put in place and piloted³². Amongst many models and activities, these include deliberative exercises such as consensus conferences, scenario workshops, foresight and horizon scanning exercises which are focussed on broadening public (or defined stakeholder) inputs into discussions and decisions about science (Abels, 2006), experiential initiatives such as the OpenLab concept, and initiatives based on improved two-way communication between the public and scientific communities (e.g. Science Cafés, Science Gallery). A key actor in most types of science communication and scientific engagement activities is the researcher³³ but there are few studies on what motivates these key actors to participate in science communication initiatives. This chapter investigates the barriers and opportunities faced by researchers in relation to their involvement in science communication activities.

4.1 Researcher's involvement in science communication

The Wellcome Trust and MORI (Market and Opinion Research International) carried out a survey in 2000 of scientists' perception of the public understanding of science (PUS) and their contribution to this activity (Wellcome Trust/ MORI, 2000). The main conclusions of the 2000 survey were that while scientists felt it was their duty to communicate their research, only half of the respondents had participated in one or more science communication activities and their participation levels related to their feelings of confidence and competence to engage in these activities. It was suggested that funding agencies and scientific institutions should provide incentives to encourage participation in science communication activities and that media training should also be provided. These findings were echoed in a later survey by the Royal Society on the factors that inhibit or facilitate science communication by researchers (People Science and Policy, 2006). Increased investment by the British government and funding agencies in public engagement activities such as the Beacons for Public

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³² For further details of different public engagement initiatives see: (Research International, 2000).

³³ The term 'researcher' is used here to denote someone who's job involves carrying out some degree of research and includes researchers from the natural sciences, engineering, technology, humanities, medicine, health, business, law and social sciences.

Engagement³⁴ has led to a large increase in the number of such initiatives with close to 1,500 programmes being run in 2007 (Holliman *et al.*, 2009). However, from the perspective of the UK Research Councils, encouraging researchers to engage with the public remains a bottleneck in organising public engagement activities despite efforts to persuade them of the perceived benefits of this engagement (Research Councils UK, 2010).

4.1.1 Public engagement activities in Ireland

At present, science communication and public engagement efforts in Ireland primarily are focussed on attracting students into science, engineering and ICT careers to address the decline in students studying science at post-primary level and the decline in students taking up related courses at third level. The lack of interest in science as a career choice for Irish students contrasts sharply with the government commitment to double the number of PhD students by 2013 as a component of efforts make Ireland a world-class centre for research and development (Department of Enterprise Trade and Employment, 2006). Declining student numbers in science and technology are a threat to the sustainability of existing science and technology departments within universities where academic, technical and admin staff numbers (and departmental budgets) are inherently linked to the number of students electing to study in the department or discipline. The Department of Education and the Higher Education Authority in Ireland provide funding to universities and HEIs on the basis of student numbers and this is divided across departments/disciplines according to the quantities of students in each department/discipline. As a result of such pressures outreach efforts (many competing for the same students) have multiplied in an effort to address this issue and these include science weeks and festivals, institutional open-days, public lectures, workshops, teacher training, press releases, radio and newspaper interviews and exhibitions. Table 4.2 details some of these initiatives.

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³⁴ The Beacons for Public Engagement are collaborative centres based in Universities across the UK that aim to develop the capacity of University staff to engage with the public. The Beacons project has a budget of €9.2 million over four years. For more information visit www.publicengagement.ac.uk/.

Table 4.2 Public engagement activities in Ireland

	Total Budget	Activities	Spend on outreach	Target
Discover Science and	€5.2 million	- Discover Primary Science	€800,000	Primary level
Engineering (DSE)	(2007) – publicly	- Young Scientist Competition (partial funders)	€150,000	Post-primary level
	funded	- Sponsorship and Partnership	€1.12m	Primary, post-primary and third level
		[50% goes to STEPS to Engineering]		
		- Science Week	€400,000	Primary, post-primary and third level,
		- Science.ie		general public
		- Discover Sensors		Primary and post-primary level
		- Greenwave		Post-primary level
				Primary and post-primary level
FÁS	€1 billion (2008)-	Science Challenge Programme	€1.5 m pa	Internship programme for third and fourth
	publicly funded			level
Science Foundation	€179 million	- Outreach via Centres for Science, Engineering	Small % of total budget	Primary and post-primary level
Ireland (SFI)	(2009) – publicly	and Technology (CSETs)		
	funded	- Speaker for Schools programme		Primary and post-primary level
		- Summer Research placements (UREKA)		Third level
Engineers Ireland	Primarily private	STEPS to Engineering	€600,000 (from DSE)	Primary and post-primary level
	sponsorship	- K'NEX Challenge/Experience		
	through	- Engineers Week		
	membership	- AreYouUpForIt.ie		
BT Young Scientist	Public and private	BT Young Scientist and Technology Exhibition	Unknown	Post-primary level
exhibition	sponsorship			
Science Gallery	Public and private	- Exhibitions	SFI, Trinity College,	Post-primary, third and fourth level, general
	sponsorship	- Workshops, lectures, debates	Wellcome Trust, and range of	public
			private donors	
Blackrock Castle	Public and private	- Cork Science Café	Unknown	Post-primary, third and fourth level, general
Observatory (BCO)	sponsorship	- COSMOS at the Castle		public
		- Film screenings		

Despite the proliferation of initiatives focussed on increasing student numbers in science, technology and engineering (SET), students disinterest in science continues in many European countries. The results of the Relevance of Science Education (ROSE) survey indicate that the majority of students do not wish to become a scientist or become employed in the technology sector (Matthews, 2007). These findings mirror similar studies across Europe and show that young people's interest in scientific careers is currently restricted to careers with an environmental, medical or health theme (Ibid). The major public engagement initiative in Ireland is the Discover Science and Engineering (DSE) programme which was established in 2003 to address falling numbers in physical science courses. An evaluation of its effectiveness was carried out in 2009 and the recommendations included the need for DSE initiatives to connect with students on topics relating to medicine, health and the environment as a way of attracting their interest in science generally (International Review Panel, 2009). These areas of science i.e. medical, health and environmental research, are similar in that they can have clear, identifiable outcomes and research in these area potentially is of broad benefit to society. A lesson learnt from this is that perhaps other areas of science would benefit from having their broader benefits and impacts made more explicit.

4.1.2 The limited reach of outreach

The Royal Society survey showed that institutional open days are the most common public engagement activity for researchers and that school teachers and students are the key targets for these initiatives (People Science and Policy, 2006). These activities are largely organised by staff with a specific focus on education and public outreach. While the expertise of outreach staff is acknowledged, this separation of researchers and outreach professionals in organising public engagement activities is problematic. A danger is that such approaches focus on the triumph and advance of science, and do not reflect on the broader impacts of science. Frodeman and Holbrook warn that "without equal consideration of the ethical, political, and cultural elements of science, the focus on education and outreach threatens not only to absolve scientists and engineers of the responsibility to integrate their research and education activities" but also turns efforts to establish outreach requirements for government sponsored research "into an advertisement for science and technology" (Frodeman and Holbrook, 2007, p. 30). At present, outreach remains the main focus of public engagement activities in Ireland. While the term outreach suggests a plethora of activities that engage and form links

with diverse audiences, this term is used in a much narrower sense by the agencies and individuals involved in public engagement in Ireland. As indicated in Table 4.2, Science Foundation Ireland (SFI) is involved in a number of public engagement activities. SFI's primary role is as a funder of strategic research and is focussed on areas of strategic interest such as ICT, biotechnology, energy, and nanotechnology. It is no surprise then to find that its primary focus as regards outreach is in enhancing science education in Ireland, and promoting science and technology careers amongst secondary school leavers. This focus is common to the initiatives listed in Table 4.2. Two initiatives however are notable in their efforts to broaden their 'outreach' activities to include dialogue based and experience-based activities. These are the Cork Science Café at Blackrock Castle Observatory, and the SFI funded Science Gallery at Trinity College Dublin.

The Science Café (or Café Scientifique) format facilitates public discussion about a scientific topic in an informal setting. A speaker is invited to talk on a topic for twenty minutes unaccompanied by PowerPoint slides, chalkboard, acetate sheets etc. The talk is targeted at a non-scientific audience and includes discussion of the broader impact of the speaker's research and the issues it raises or answers. A general audience discussion is facilitated featuring questions to the speaker and inter-audience discussion and debate. The Cork Science Café was established by the author in 2007 as a one-off public engagement event during Science Week. It proved such a popular activity that it was run as part of two subsequent Science Weeks, before finding a permanent and regular home in the Blackrock Castle Observatory in 2010. While this initiative at first glance looks like the deficit model revisited, its focus on peer to peer discussion means that lay-expertise and experiential knowledge is also acknowledged and can help inform the 'expert' presenter. It was the author's experience that the Science Café was very well attended by those working in research who appreciated having a social, informal forum to discuss science and research while also becoming exposed to other viewpoints on a topic.

The Science Gallery is an interactive exhibition centre at Trinity College Dublin which addresses the intersection of science, technology and the arts. It was established in 2008 by the SFI funded CRANN nanotechnology centre and Trinity College Dublin, with an aim of engaging the public in science and technology and particularly targets audiences

from 15-25 years of age. A diverse range of projects and exhibits are developed by issuing an open-call to scientists, designers, artists and engineers under a particular theme. A highly diverse Leonardo Group of individuals from the sciences, arts, business, government and social sectors are involved in brainstorming sessions around key themes in order to develop portfolios for possible Science Gallery exhibitions and activities. The submissions are reviewed by a group of curators and the submitters of the selected projects are invited to develop these projects further (Gorman, 2009). This open-call format enables interdisciplinary conversations and collaborations that create exciting results such as the INFECTIOUS exhibition which examined strategies for containing infection and looked at how diseases spread. Visitors to the Science Gallery were invited to participate in an authentic research experiment measuring the levels of a disease causing protein (MAL) in the Irish population³⁵. The Science Gallery has been particularly successful in attracting researcher participation with hundreds of different scientists becoming involved in the Gallery in the last years as curators of exhibitions, as project proposers, as speakers, debaters and experimenters amongst other roles. The Biorhythm exhibition in 2010 was the Science Gallery's most attended exhibit attracting 15,000 visitors in its first week. The success of the Science Gallery in terms of numbers of visitors has exceeded initial expectations by tenfold.

With the exception of a few initiatives such as the Science Café and Science Gallery, outreach in Ireland, as identified in a 2007 survey of outreach practitioners, sees "the deficit model as the dominant logic behind science communication" (Davison *et al.*, 2008, p. 28). Furthermore the survey identified a number of weaknesses in public engagement activities including a lack of focus on inattentive publics and also a lack of engagement of these activities with scientists and policy-makers. The recent evaluation of the Discover Science and Engineering (DSE) programme reiterates this point in recommending that outreach is broadened to include debate on topical issues relating to science and technology (International Review Panel, 2009).

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³⁵ MAL is a protein present in white blood cells which turns on the immune response to harmful bacteria and can help determine whether a person succumbs to diseases such as malaria (O'Neill, 2009).

4.2 Science communication and public engagement

Certain models of science may be more appropriate to be used at particular junctures, e.g. when faced with communicating a particular topic or when a particular goal or outcome is desired. Van der Auweraert (2005) argues the need for a 'blueprint' or framework to guide communication between scientists and the public and that different types of scientific knowledge should be communicated using different science communication models (van der Auweraert, 2005). The choice of model varies depending on different requirements for public involvement and ranges from a one-way transmission of information (PUS model) to the direct involvement of the public or stakeholders in related decision making processes. This framework borrows heavily from a similar framework proposed by Ortwin Renn in relation to risk management and suffers from a similar rigidity in relation to its "linking of risk characteristics (complexity, uncertainty, and ambiguity) and specific forms of discourse and dialogue" (Renn, 2006, p. 54). The question of who gets to decide on how knowledge is categorised is also problematic. The framework is useful however as a means of developing a communication exercise rather than as a more rigid description, and can help identify the appropriate communication response which could mean lower costs and time commitments for such initiatives.

This framework takes the form an escalator comprising of four steps (see Figure 4.1). The lower the step, the simpler the message to be communicated, i.e. the facts are largely agreed upon and reflect the current understanding, and the less of a requirement there is for public involvement in discussions relating to the topic. Conversely, as one moves up the steps the message to be communicated reflects greater uncertainty or more complex issues which require the inclusion of other considerations in addition to scientific knowledge e.g. ethical, moral and financial arguments. These issues require greater inclusion of the public or stakeholders in order to articulate the broad concerns relating to an issue to ensure the robustness of any related decision making process.

			PPS: Public
			Participation in science
		PES: Public Engagement	Actors:
		in Science	- scientific experts
	PAS: Public	Actors:	- specific target groups -
	Awareness of Science	- scientific experts	representatives of the
PUS: Public	Actors:	- specific target groups -	public
Understanding of	- scientific experts	representatives of the	- external experts
Science	- specific target groups	public	
Actors:			
- scientific experts			
Sender-predominance	Receiver-oriented	Expert/layperson	Partners
- inform	- context	- consulting	- dialogue
- one-way	- target group	- both ways	- open participation
- monologue	- needs, wishes	- closed participation	- mutual
- top-down	- feedback loops		- bottom-up
- mass-media			- local knowledge
No conflicts	Conflicts:	Conflicts:	Conflicts:
	- cognitive (incomplete	- cognitive	- cognitive
	or incorrect	- evaluative/ reflective	- evaluative/ reflective
	comprehension)		- prescriptive (different
			norms and values)

Figure 4.1: Science Communication Escalator (van der Auweraert, 2005)

The lowest step (as seen in Figure 4.1) is the Public Understanding of Science which involves one-way communication and may take the form of public lectures, popular science articles or books, science radio shows, science TV programmes etc. This form of communication is particularly suited to the transmission of simple messages i.e. where the facts are certain (or accurate at time of publication/ broadcast). The second step is Public Awareness of Science and the author argues that this communication model is suited to the transmission of more complex knowledge. While all science is by its nature complex, 'complex scientific problems' are described as problems where there is a difficulty in identifying and quantifying the causal links between different factors. Examples include understanding how a cellular system, ecosystem or climate system works. It is proposed by Renn (2006) that issues relating to complex scientific questions can be answered by initiatives that raise awareness of the complexity of certain decisions (Renn, 2006).

"Uncertainty" is described by Renn (2006) as being due to conflicts arising both at a cognitive and evaluative level e.g. disagreement over likelihood of an event happening (tipping points regarding global warming or likelihood of an asteroid impact on planet Earth), and current scientific knowledge is shown to be insufficient in political decision making. An example of this is the debate over perceived environmental risks arising from nanotechnology (which is a diverse area). Public engagement initiatives can help ensure that discussions include other viewpoints and other considerations such as ethical concerns (including the ethics of action vs. inaction). Ambiguous science is described by Renn (2006) as a situation where there can be multiple explanations for one set of currently existing data and thus there is conflict at a cognitive and reflective level at any particular point in time (Ibid). Further investigations may resolve such conflicts or may not. As the scientific process can be described as organised skepticism, scientists continually disagree amongst themselves as to what the correct explanation is for many phenomena for example the current debate over climate change and its impacts. Public participation exercises can ensure that other viewpoints and sources of knowledge are considered to broaden debate.

4.2.1 Motivating researchers to engage the public

Key actors in public engagement in science initiatives are members of the research community. Despite increased activity by this group in these initiatives in the past five years, the majority have limited involvement and this is despite respondents professing their support for public engagement as seen in the Wellcome/MORI and Royal Society surveys. The results of the Royal Society survey indicate that time pressures act as the major constraint upon researchers' ability to engage in science communication activities (People Science and Policy, 2006), however it is not clear whether this is a real constraint or rather an excuse used to mask other concerns i.e. that public communication is poorly regarded by peers or funding agencies, or a broader scepticism regarding what the purpose of science communication is. Poliakoff and Webb identified four factors that can be used to predict scientists' intention to participate in public engagement of science activities using an expanded version of Ajzen's theory of planned behaviour (Ajzen, 1991; Poliakoff and Webb, 2007). These factors are: past behaviour (extent of previous participation), attitude (whether they regard participating in public engagement activities as positive or otherwise), perceived behavioural control (whether they feel capable of participating), and subjective norms (how much they perceive their colleagues to be involved in public engagement activities).

In this PhD chapter, the findings of our survey of Irish researchers are analysed in terms of how practitioners view their involvement in science outreach and public engagement activities. Do they see such activities as helping inform an ignorant public (deficit model)? Do they see they see such activities as providing a forum for a two-way conversation between science and the public (dialogue model) or for enabling publics to participate in science (participation model) (Davison *et al.*, 2008; Trench, 2008). In analysing our research from such a perspectives it is possible to draw comparisons with the 2006 Royal Society survey on what motivates researchers to become involved in public engagement activities in the UK (People Science and Policy, 2006) and thus unpick what model of science communication is currently to the fore in Ireland and make recommendations regarding possible routes to improve science communication activities in Ireland.

4.3 Research Design

To determine the level of researcher involvement in science communication activities in Ireland, and to gain insight into the barriers to involvement in science communication, a diverse group of researchers in Ireland were surveyed in 2007. Over 550 responses were gathered. This survey in Ireland mirrors one in 2006 carried out by the Royal Society in the UK (People Science and Policy, 2006) which had a major impact on the development of the Beacons of Public Engagement funding programme in the UK.

The use of an identical survey in Ireland and the UK allows for a comparative analysis of science communication activities. It is intended that this research will provide recommendations on how barriers to public engagement can be overcome to involvement in public engagement activities by researchers and will be of use to policymakers and policy-implementing agencies in Ireland.

4.3.1 Objectives and relevance of study

The purpose of the survey was to examine the impediments and opportunities for researchers in Ireland to become involved in Science Communication activities and to develop a baseline measurement of the level of activity in Ireland in engaging the public in science and technology. The study involved an electronic survey of researchers in Ireland in universities, institutes of technology, and government research institutes.

The main objectives of this survey are as follows:

- To establish the relative importance of science communication to researchers in Ireland.
- To examine the amount and type of science communication activities undertaken by researchers in Ireland.
- To explore factors that may facilitate or inhibit science communication.
- To explore the extent to which researchers may wish to undertake further science communication.
- To provide evidence about how universities, other research institutions and funders can promote effective science communication.

4.3.2 Methodology

In order to survey all scientists and engineers in Ireland working in the public sector in Ireland, survey participants were recruited from all Higher Education Institutions (HEIs) and all the research centres in the Republic of Ireland. The UK survey required that these HEIs have at least 50 staff recorded as having a scientific or engineering research component to their job, no such requirement was necessary in Ireland due to the lower number of HEIs.

The description of researcher used was as someone whose job involves carrying out some degree of research. A similar definition is used by Forfás, the science policy office in Ireland, thus it was possible compare our survey respondents with national figures relating to research. All researchers who were not working in the natural or technological sciences were excluded from the survey and we differentiated between the different disciplines again using the same description as used by Forfás and by the creators of the Royal Society survey in the UK so that the surveys and national figures would be comparable (see Appendix E for details of the sample selection). Appendix D contains the questionnaire as it was presented verbatim to those surveyed.

The research offices in the various HEIs and research centres were contacted to ask them to participate in the survey and to seek their assistance in disseminating the survey. Most of the institutions and research centres agreed to participate on initial contact, while a few institutions required further contact and discussion to agree to

disseminate the survey. The next step was to identify the various departments and groups within the institutions and contact their secretaries to ask them to participate in the survey. This step was undertaken as the survey was sent out as an opt-in e-survey, and it was considered that direct contact from a familiar staff member may help ensure greater completion rates. The department/research group secretary also has a more up-to-date and complete email list for such contact.

The survey was distributed on the first of May 2007. Participants were sent an email invite to participate in the survey with a hyperlink to an Internet based version of the Survey MonkeyTM survey. The Science promotion groups as detailed about in Appendix E posted web notices about the survey or advertised the survey via their mailing list and newsletter. A reminder email by sent out to researchers via the HEI distributors on May 14th and a final notice sent on the 28th of May. The survey was extended by more than a week to facilitate participants who were travelling and it was finally closed on June 13th. Emails were sent out via the HEI research offices to prevent their being identified as spam. The emails were resent by secretaries in the various research departments to motivate department members to participate in the survey. In the case of bounced messages, the email was re-sent following a telephone call to the office in question.

4.4 Results

Forfás, the Irish policy and advisory board for enterprise, trade, science, technology and innovation, compiles yearly figures on the number of researchers in Ireland. The most recent figures at the time of conducting the survey were from 2005 and these have been used to measure the response rate to the survey. The Forfás figures indicate that there were roughly 18,000 researchers in the country in 2005. These figures can be further disaggregated into the various research areas which gives a final total of 6,753 researchers working in science and engineering. The survey was distributed to both the Higher Education sector and the Government sector as these researchers are in receipt of public money for funding their research. Full responses were received from 550 researchers which gives a response rate of 8%.

Despite the low response rate, the respondent profiles reflect the national figures on distribution of researchers per discipline (Table 4.3). Our respondent profile almost matches the national ratio for researchers of 43% female and 57% male (Forfás, 2004) with our respondents being comprised of 46% female to 54% male. Medical science is the one discipline where the number of respondents to our survey is much lower than national figures. Lecturers and postgraduate students are the most numerous respondents (27% and 26% respectively). The high number of postgraduate respondents shows a slight skew of the survey results towards this group. The recent national drive to increase the recruitment of PhD students into Science & Engineering (Department of Enterprise Trade and Employment, 2006) however means that these percentages better reflect the current research environment in Ireland.

Table 4.3: National figures relating to distribution of researchers per discipline compared with our respondent profile.

	Forfás:		UCC: researcher
	R & D survey 2005		Survey 2007
Higher Education &	# of researchers	% researchers	% researchers
Gov. Sector		per discipline	per discipline
Natural Sciences	3050	45	40
Engineering and	1828	27	31
Technology			
Medical Sciences	1518	23	9
Other (env. science)		5	20

4.4.1 Attitude towards public engagement and level of activity

Question 9 asks what the main reason is for scientists and engineers generally to engage with the non-specialist public with a selection of reasons to choose from. Respondents indicated that the main reason for them to engage with the public about their research was to ensure the public is better informed about science and technology (33%, 176). The second most important reason was to be accountable for the use of public funds (13%, 71) and the third most important reason was to raise awareness of science generally (11%, 61) (Table 4.4). Raising awareness of science generally was seen as more important than raising awareness of specific scientific subjects, while the suggested reason to contribute to discussions about the social and ethical issues that science can raise was considered as least important of the reasons considered (4%, 21).

Table 4.4: Ranking of main reason for respondent to engage with the public (n=538)

	# of	
Reasons	respondents	Ranking
To ensure the public is better informed about science and technology	176	1
To be accountable for the use of public funds	71	2
To raise awareness of science generally	61	3
To raise awareness about your subject	53	4
To contribute to public debates about science and scientific issues	52	5
To recruit students to your subject	45	6
To generate/stimulate additional funds for universities and colleges	41	7
To contribute to discussions about the social and ethical issues that	21	8
science can raise		

Question 8 asks how important it is that the respondent, in their current post, engages directly with the non-specialist public in relation to specified topics. The majority thought that the most important topic to engage the public with was the relevance of science to everyday life (44%, 236) (Figure 4.2). The second most important topic to engage the potential in is the potential benefits of your work to individuals/society (40%, 217) followed by the enjoyment and excitement of doing science (38%, 204). Respondents considered it least important to engage the public on areas of scientific uncertainty (20%, 107), areas for further research (20%, 107), or on policy and regulatory issues (18%, 93) (Figure 4.2).

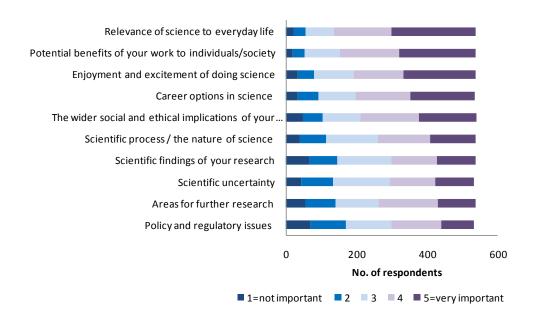


Figure 4.2: Respondent's ranking of how important it is for them to engage with the public on each of the suggested topics (n=540)

Question 2 asks which groups, from a specified list, the respondents felt it is most important to engage personally about their research. Respondents identified policy-makers and secondary schools kids and teachers as being the most important groups to engage and industry and business community as the third most important (Figure 4.3). Non-specialist journalists were considered the least important to engage.

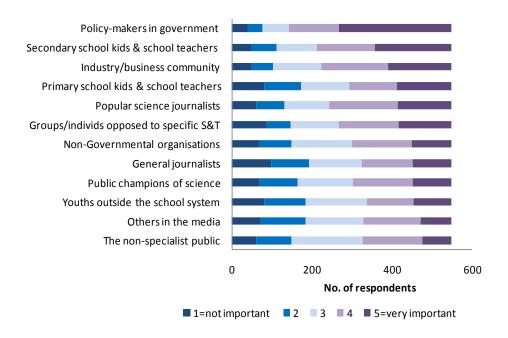


Figure 4.3: Respondent's ranking of how important it is for them to personally engage with the following groups (n=550)

Question 7 asks how many times in the past year the respondents have engaged in specified activities relating to public engagement with science. In terms of their own involvement, the respondents indicated the majority (68%, 214) had been involved in an institutional open day but this involvement was mostly a once off occurrence. A small number of respondents had more regular interactions with policy-makers (8%, 44) and school teachers or schools (7%, 40) working with these groups more than five time (Figure 4.4).

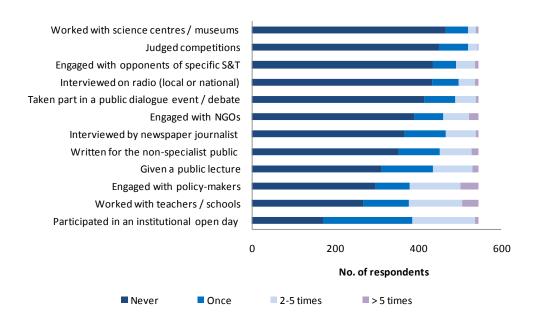


Figure 4.4: No. of times respondents have participated in science communication activity described in past 12 months (n=545)

Question 3 asks respondents to select from a specified list the groups they find it easiest to talk with about their research findings. Respondents considered popular science journalists to be the easiest group to communicate with (Table 4.5) and in an openended question cited relevance to own area and interest as being the main reason as to why this group was considered easiest to engage (Figure 4.5). Groups/Individuals opposed to specific sciences and technologies and 'others in the media' i.e. writers, documentary and other programme makers, were ranked lowest (Table 4.5).

Table 4.5: Groups ranked according to how easy they are to communicate with (n=547)

	# of	
Groups	respondents	Ranking
Popular science journalists	135	1
Secondary school kids & school teachers	85	2
None/don't know	77	3
Industry/business community	53	4
The non-specialist public	46	5
General journalists	42	6
Policy-makes in government	38	7
Non-governmental organisations	24	8
Primary school kids & school teachers	22	9
Young people outside of the school system	9	10
Pubic figures or celebrities who are champions of science	9	10
Groups/individuals opposed to specific S&T	4	11
Others in the media	3	12

The respondents were asked in an open-question, Question 4, why they identified the particular group as being easiest to talk to about their research. The majority of respondents indicated that the main reasons for the ease of communication was the level of interest, and prior knowledge of these audiences as well as the relevance of the topic (Figure 4.5). Also important, but to a lesser extent, was their relationship with the group i.e. whether the group was an end user, paymaster or had vested interests, and their ability to link up with the group.

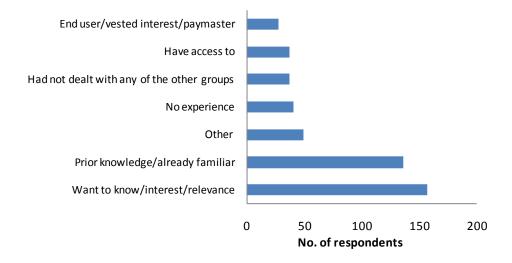


Figure 4.5: Respondents reasons as to why they considered certain groups easier to communicate with (n=498) (No experience refers to the fact that the respondent had not spoken about their research with any group; Other: Usually respondent described their previous experience here)

When asked in Question 5 who in a specified list of groups the respondent finds it hardest to talk with about their research findings, most respondents indicated that they were unsure or unaware of groups that would be most difficult to communicate with. The second highest ranking, in terms of difficulty in engaging, were groups or individuals opposed to specific sciences and technologies, followed by policy makers in government (Table 4.6).

Table 4.6: Groups ranked according to how hard they are to communicate with (n=540)

Groups	# of respondents	Ranking
None/don't know	189	1
Groups/individuals opposed to specific S&T	84	2
Policy-makers in government	65	3
The non-specialist public	53	4
General journalists	46	5
Youths outside the school system	28	6
Industry/business community	27	7
Primary school kids & school teachers	25	8
Pubic figures or celebrities who are champions of science	7	9
Popular science journalists	5	10
Secondary school kids & school teachers	5	10
Non-governmental organisations	4	11
Others in the media	2	12

When asked in an open-ended question, Question 6, why they chose a group as being the hardest to communicate with about their research findings, the main reasons given were the groups having a negative/blinkered viewpoint, the respondent having no experience of the group, and lack of understanding and interest of the group (Figure 4.6).

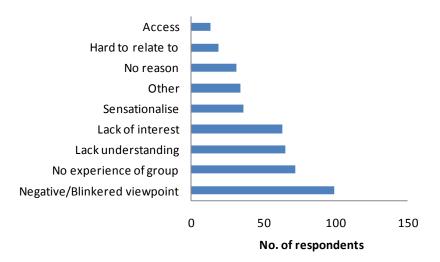


Figure 4.6: Reasons given by respondents as why they find groups hard to communicate with (n=438) (Other: respondents felt their research was not relevant to the various group or that they lacked the necessary skills to talk with the groups)

4.4.2 Public engagement intentions and motivations

Question 13 asks how important it is, in relation to other activities in their working life, that the respondents find time to engage with the non-specialist public. The respondents were split into three classes where almost the same number considered it either important or unimportant, followed by a smaller proportion being ambivalent regarding its importance (Figure 4.7). A third of respondents felt engagement was not very important, while a quarter of respondents felt it was important.

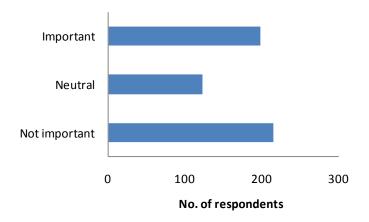


Figure 4.7: Indication from respondents of how important it is for them to engage the public regarding science and technology in relation to other work pressures (n=535).

When questioned further in Question 14 regarding the amount of time they would like to spend on engaging the public on Science and Technology, the majority of respondents indicated that they would like to spend more time on engagement activities (54%, 286) while a large proportion (38%, 204) felt they already spent enough time on public engagement activities (Figure 4.8). Only a fraction (0.03%) indicated that they should spend less time.

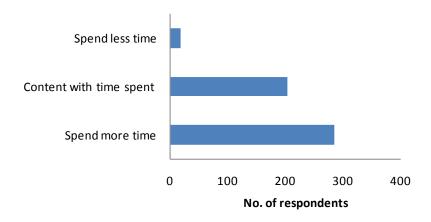


Figure 4.8: Respondents indicated the amount of time they would like to spend on engaging the public on Science and Technology (n=534)

When asked in an open-ended question, Question 20, what would encourage them personally to get involved in activities that engage the non-specialist public in science, respondents highlighted a wide range of factors that would motivate them in this regard. These included inter alia; public engagement infrastructure, time (general), increase profile of research and skills/training amongst many other factors (Figure 4.9).

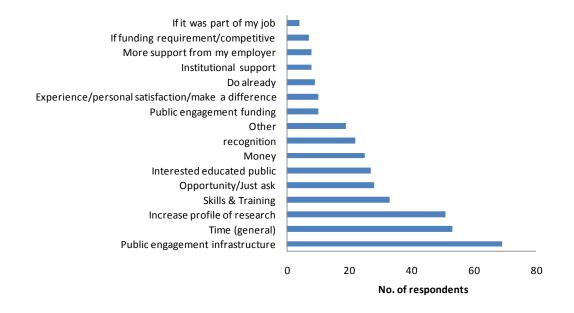


Figure 4.9: Respondents indicated what factors would motivate them to get involved in public engagement activities (n=397)

Respondents were asked to comment on a predefined list of statements made by people about engaging with the non-specialist public about science and technology. The responses to this question indicated that 84% (445) agreed with the statement "Funders of scientific research should help (i.e. funding, time) scientists to communicate with the non-specialist public". 83% (441) of surveyed researchers agreed with the statement "I would be happy to take part in a science engagement activity that was organised or run by someone else". 73% (384) of respondents agreed with the statement "Engaging the non-specialist public in science is personally rewarding". Respondents strongly disagreed with the following statements "There are no personal benefits for me in engaging with the non-specialist public" (67%, 356), "Scientists who communicate a lot are not well regarded by other scientists" (63%, 336), and "I don't think my research is interesting to the non-specialist public" (71%, 375) (Figure 4.10).

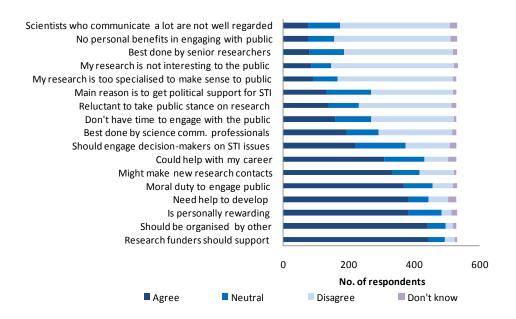


Figure 4.10: Respondents indicated what factors would motivate them to get involved in public engagement activities (n=534)

4.4.3 Opportunities and barriers to engagement

Question 22 asks what is preventing the researcher from getting (more) involved in activities that engage the non-specialist public in science used a specified list. The top three reasons as indicated in Figure 4.11 are "I need to spend more time on my research" (54%, 280), "I would have to do it in my own time" (38%, 198) and "I need to spend more time getting funding for my research" (29%, 148) The three reasons considered to be the least important are "I just don't want to" (6%, 31), "I feel that I am

encroaching on the institution's Press Office work/research" (5%, 27) and "Peer pressure" (1%, 7),

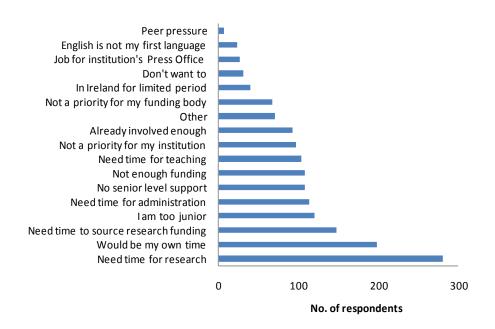


Figure 4.11: Obstacles stopping respondents from getting more involved in public engagement activities (n=518) (Other: Don't know how to get involved, have not been asked)

Question 11 asks what the respondent thinks is the main drawback to scientists and engineers engaging with the non-specialist public. The majority of the survey participants felt that there were no drawbacks to scientists and engineers engaging with the public (41%, 221), while 20% (109) felt that it took up time better spent on research, and 15% (82) felt that it can send out the wrong messages to the public. These concerns were reiterated with 8% (45) of respondents writing in the 'Other' section that time, lack of personal benefit, and fear of impact of engagement were the main drawbacks to such activities (Table 4.7).

Table 4.7: Ranking of drawbacks to researchers engaging with the public (n=537)

	# of	
Incentives	respondents	Ranking
There are no drawbacks	221	1
It takes up time that is better used on research	109	2
It can send out the wrong messages to the public	82	3
It makes them a target	55	4
Other (time, no personal benefit, fear of impact, inability of scientists to	45	5
communicate, misunderstanding by public)		
It takes up time that is better spent on other, non-research, activities	17	6
It makes them look bad in front of their peers	6	7
It diverts money from research projects	1	8
It diverts money from other, non-research, activities e.g. attracting	1	8
students into science		

Question 21 asks to what extent the respondent would be encouraged to get more involved in activities to engage the non-specialist public in science and engineering using a specified list of potential incentives. The top three choices in Figure 4.12 selected by respondents as encouraging them a great deal are "If my funding body recognised & measured science communication activities in research funding decisions" (43%, 221), "If my institution recognised & measured science communication activities in career promotion procedures" (42%, 220), and "If it brought money into my department or research team" (40%, 206). The lowest ranked choices in the same section, i.e. the respondent would be encouraged to a great extent, are "If my department or institution was recognised by an award or prize" (20, 105), "If my head of department / line manager were to give me more support and encouragement" (20%, 103), and "If there were awards and prizes for me as an individual or for my research team" (19%, 94).

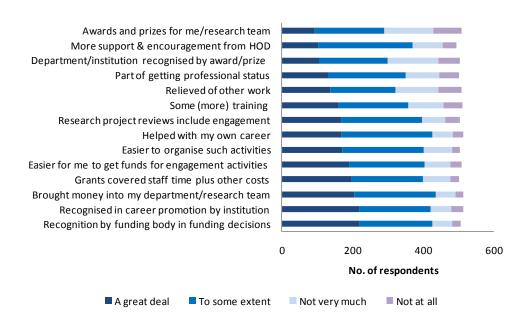


Figure 4.12: Respondents rank potential incentives that would encourage their involvement in public engagement activities (n=520)

When responses were combined under the categories 'would encourage a great deal' and 'would encourage to some extent' in relation to them becoming more involved in activities to engage the non-specialist public in science and engineering by a specified list of potential incentives, the top three choices are "If it brought more money into my department or research team", "If it helped with my own career", and "If my funding body recognised & measured science communication activities in research funding decisions" (Table 4.8).

Table 4.8: Ranking of incentives to encourage greater involvement in public engagement (n=520)

Incentives	# of respondents	Ranking
		1= A great deal &
If it brought money into my department or research team	436	to some extent
If it helped with my own career	428	2
If my funding body recognised & measured science communication	427	3
activities in research funding decisions		
If my institution recognised & measured science communication	422	4
activities in career promotion procedures.		
If it was easier for me to get funds for engagement activities	404	5
If grants for engagement covered staff time as well as other costs	401	6
If it was easier to organise such activities	401	6
If reviews of funded projects were changed to encompass	399	7
communication with the non-specialist public		

If my head of department / line manager were to give me more support	372	8
and encouragement		
If I had some (more) training	360	9
If it was part of getting professional status, such as chartered engineer	352	10
or membership of my professional body		
If I was relieved of other work	323	11
If my department or institution was recognised by an award or prize	301	12
If there were awards and prizes for me as an individual or for my	291	13
research team		

4.4.4 Support for researcher involvement

Question 23 asks if other members of the respondent's department take part in activities that engage the non-specialist public in science and technology. The respondents were split into three classes and 79% (407) indicated that members of their department are involved in activities to engage the public in science and technology (Figure 4.13).

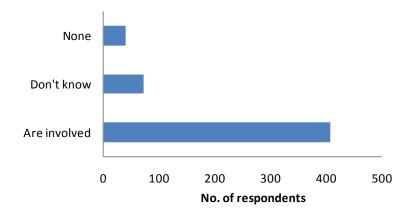


Figure 4.13: Amount of participation by other members of the department in public engagement activities (n=518)

Question 24 asks whether researchers in their department are generally supportive towards those who take part in activities that engage the non-specialist public in science and technology. The majority of respondents considered researchers in their department to be supportive ('very supportive' and 'fairly supportive' answers combined) towards those who take part in public engagement activities (57% 294) and 23% (121) considered their colleagues to be unsupportive towards those who take part in public engagement activities ('not particularly supportive' and 'not at all supportive' combined) (Figure 14.14)

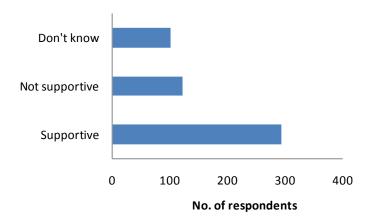


Figure 4.14: Perception of respondents on level of support from researchers in their department towards those who take part in public engagement activities (n=516)

Question 25 asks whether their institution is generally supportive towards researchers who take part in activities that engage the non-specialist public in science and technology. The majority of respondents considered their institution to be supportive ('very supportive' and 'fairly supportive' answers combined) towards researchers who take part in public engagement activities (54%, 276) while 21% (109) considered their institution not to be supportive ('not particularly supportive' and 'not at all supportive' combined) towards such researchers (Figure 4.15).

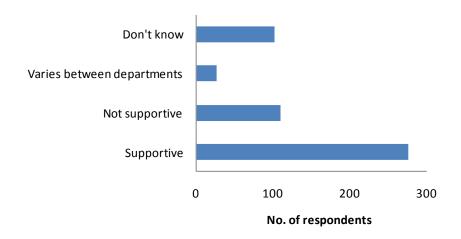


Figure 4.15: Perception of respondents on level of support from institution towards researchers who take part in public engagement activities (n=513)

When asked in Question 18 about how well equipped they feel themselves to engage with the non-specialist public about their research, the majority of respondents felt well equipped ('fairly well equipped' and 'very well equipped' combined) (62%, 326) to

engage with the public about their research (Figure 4.16), while 35% (186) felt they were not well equipped ('not very well equipped' and 'not at all equipped' combined)...

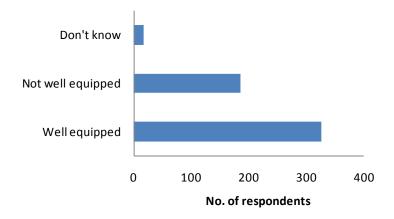


Figure 4.16: Respondents indicate how well equipped they feel they are to engage with the public about their research (n=529)

Question 17 asks how easy or difficult they think it is to get involved in science engagement activities for those who want to do so. A third of respondents (179) felt that it was easy ('very easy' and 'fairly easy' combined) to become involved in science communication activities, while 20% (112) felt that such involvement was difficult ('fairly difficult' and 'very difficult' combined). The majority (45%, 240) of respondents were unaware of the level of difficulty or ease of such involvement (Figure 4.17).

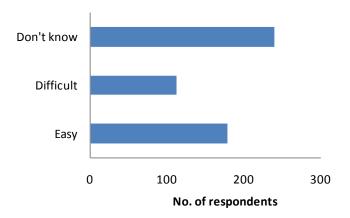


Figure 4.17: Respondents indicated their opinion on the ease of getting involved in science engagement activities (n=531)

When asked in Question 19 what training if any they have had in communicating science to the non-specialist public (which disregarding any teacher training) using a

specified list, the vast majority of respondents (60%, 318) had no prior training in communicating science to the non-specialist public (Figure 4.18).

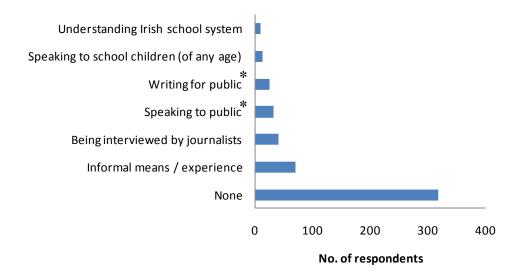


Figure 4.18: Respondents indicated the types of training they received in communicating science to the public (n=531) (Other: Communication courses)* public should read non-specialist public in the above figure.

4.4.5 Science Communication

The respondents are asked in Question 1 to describe in an open-ended question what the statement "Scientists are being asked to engage more with the non-specialist public" means to them. The majority of respondents described public engagement as meaning informing, explaining and promoting understanding (24%, 113). Communicating with or speaking to the public was the second highest response with 13% (61) of respondents giving this explanation (Table 4.9).

Table 4.9: Respondents' definition of what engaging more with non-specialist public means (n=480)

Description	% response (#)
informing, explaining and promoting understanding	24 (113)
Communicating with or speaking to the public, speaking in public lectures, shows	13 (61)
Implications, relevance, utility of research, value of research	12 (59)
Accountability, duty of public funded researchers	9 (43)
Good, worthwhile, important	8 (38)
Listening, understanding public, involving people in science, science based debates, science based decisions	7 (32)

Respondents who indicated that they wish to spend more time in engaging with the non-specialist public about science and technology (Figure 4.8) were asked in Question 15 to choose an explanation for this from a specified list. The main reason given by the survey respondents as to why they wish to engage more with the community is the normative one of "Scientists and engineers should engage more with the community" (35%, 105). Most respondents felt that they simply should engage more with the community (Figure 4.19). By contrast, working in a controversial area of science was less of a concern (5%, 15).

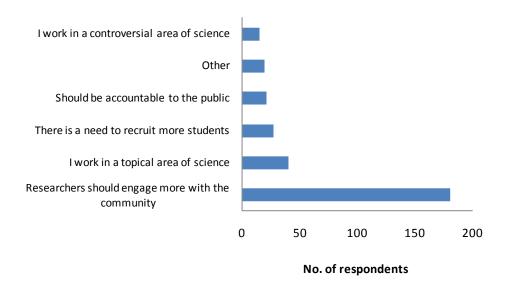


Figure 4.19: Respondents indicated that they wish to spend more time engaging with the public and choose the following choice as their explanation for why (n=303) (Other: raise awareness and interest in science, increase support for research)

4.5 Discussion

Public engagement initiatives can take a variety of forms, such as public consultations, science fairs, citizen juries, lecture series, and can serve a variety of purposes e.g. education, entertainment, promotion, awareness-raising, participation, information provision or extraction, consensus building etc. Public engagement initiatives in Higher Education Institutions in Ireland tend to focus on science promotion and outreach (Davison *et al.*, 2008). One reason for this focus for activities is the falling numbers of students applying for college courses based on science and technology. Other individuals, research groups and departments are involved in engagement activities such as sitting on advisory panels relating to environmental issues, writing articles to popularize science in the press, organizing open-days with patient groups to facilitate dialogue between a special interest group and researchers, etc. This diversity of action and purpose confuses the main purpose as to why researchers become involved in engagement activities but the research results in this chapter help us unpick these answers.

4.5.1 Attitude towards public engagement and level of activity

Why engage?

Firstly we wish to uncover the reasons as to why researchers engage with the public in relation to science and technology. In the closed-answer question with predefined responses, the most important reason given by the research community to engage the non-specialist public was to ensure the public was better informed about science and technology (33%, 176), followed by being accountable to the public for the use of public funds (13%, 71). The least important reasons were to stimulate funds for colleges/universities (8%, 41) and to contribute to ethical discussions about science (4%, 21) (Table 4.4). These responses are similar to responses from the UK Royal Society survey where the main reason given for engagement was to inform the public about science and technology (35%). However the two surveys differed over the selection of the least important reasons for engaging the public and UK respondents selected to contribute to ethical discussions about science (5%) and to recruit students (4%). This could suggest that independent of country, a majority of scientists are motivated to inform the public about science. The lack of interest of scientists in contributing to ethical discussions about science runs counter to advocacy for greater

discussion and public dialogue regarding science, ethics and society. One explanation for this is that researchers may favour science communication exercises more focussed on enhancing the public understanding or awareness of science e.g. outreach activities including school visits, public debates. These activities tend to be organised within institutions which allows the researcher to opt-in without a huge investment of time or effort (depending on the type of engagement). In contrast, contributing to ethical debates about science may involve greater time and energy inputs, may place the researcher on less firm footing with regard to their expertise or knowledge about an issue, or indeed may expose then to heated situations where they are faced with defending their position on an issue.

What about?

We next set out to determine what Irish researchers felt were the most important topics to engage the public with. When considering their own research, respondents felt the most important issues (ranked 4 or 5 on a scale of 1-5 i.e. combining 'very important' and 'important') to engage the public on was the relevance of science to everyday life (74%, 401), the potential benefit of their research to individuals or society (72%, 386), and the enjoyment and excitement of doing science (64%, 345) (Figure 4.2). Next in priority were promoting the career options in science (63%, 339) and communicating the wider social and ethical implications of your research findings for society (61%, 329). Interestingly, engaging with the public on policy and regulatory issues (32%, 171), the scientific findings of your research (27%, 146), areas for further research (26%, 141), and scientific uncertainty (25%, 134) were considered relatively unimportant (ranked 1 or 2 on the 1-5 scale, i.e. combining 'somewhat unimportant' and 'not important'). The UK Royal Society survey showed the same responses for the highest ranked answers (People Science and Policy, 2006).

The respondents' answers to this question give us an idea of their motivations in becoming involved in public engagement activities relating to science and technology. The responses could possibly suggest that they consider the public to be lacking in information and that engaging with the public may give them a greater appreciation of the relevance (and benefits) of scientific research. It could also support an interpretation that suggests a desire to attract greater numbers of students into science and to enhance the public perception of science (Nelkin, 1994; European Commission, 2005). Another

less benign reason may be that an increase in public appreciation in science and technology may also help secure future funding for science and technology R & D and prevent a public backlash against spending in this sector. Alternatively, the majority of scientists may consider that the public do not understand the contribution of science and technology to their everyday lives and that increasing the scientific literacy in this regard could be worthwhile. The desire by scientists to convey the excitement of doing scientific research could have altruistic or selfish motivations and further investigations would be necessary to unpack why scientists consider that communicating the excitement of science should be an important part of science communication. The muddled overlap between outreach and science communication could have confounding effects on scientist's perceptions of what they should be communicating about science. The questions on the content of science communication highlights a gap between the priorities of scientists and those engaged in advocacy to require scientists to have greater engagement with the public regarding policy and regulatory issues, the findings of scientific research, areas for further research and scientific uncertainty. Why does this gap exist? Are there control issues at play here on both sides?

Which targets/groups?

We set out to uncover which audiences researchers considered to be the most important to engage with, which audiences they had actually engaged with, and the purpose of this activity. The respondents indicated that the most important audiences for engagement (ranked 4 or 5 on a scale of 1-5) were policy makers in government (74%, 408), followed by secondary school students and school teachers (61%, 336) (Figure 4.3). The third highest ranked group is the business and industry community (60%, 326). The least important audiences (ranked 1 or 2 on the 1-5 scale) as identified by our survey respondents are non-specialist journalists (35%, 193), youths outside the school system (34%, 185), and others in the media such as writers and documentary makers (33%, 184). The UK survey showed the same responses for the most important and least important audiences with the addition of non-governmental organizations in the least important category (People Science and Policy, 2006).

The respondents' answers here contradict the results of Figure 4.2 which identified *engaging with the public on policy and regulatory issues* as being unimportant when respondents were asked to identify important topics to engage the public with. In

ranking policy makers in government the highest, the respondents give some insight into the science policy structure in Ireland. Researchers often are asked to contribute in consultations, Oireachtas (i.e. parliamentary) hearings, foresight exercises etc. The public, on the other hand, have less input into policy and regulatory issues and more often charge their elected representatives or representative bodies/groups with responding on their behalf. The selections made by the respondents in relation to which groups they consider it the most important to engage with suggest that researchers are quite strategic in their public engagement. The top ranked groups are important in terms of providing financial (business and industry) and political support (policy makers), as well as in helping reinvigorate the scientific community (secondary school students and teachers).

How to involve and how often?

Levels of actual engagement with the public in science and technology are quite low in Ireland if institutional open days are excluded from the sample. Less than a quarter of respondents reported having taken part in at least one science communication or public engagement activity in the past 12 months (Figure 4.4). Institutional open days were most popular with 68% (373) of respondents participating in these. The next most popular activities are giving a public lecture [23% (1123) once and 18% (97) 2-5 times] and working with teachers or schools [20% (110) once and 23% (127) 2-5 times]. A small number of respondents had more regular interactions with policy-makers (8%, 44) and with school teachers or schools (7%, 40) having engaged with these groups more than five time in the year. Unfortunately, the survey did not explore whether researchers were using electronic media or social media for science communication which may be an area for subsequent investigations. There is a much higher level of public engagement activity in the UK with 74% of respondents having taken part in at least one activity in the past year also excluding institutional open days. The survey reported an 18% increase in activity in the UK since an earlier survey by the Wellcome Trust in 2000. The most common form of engagement in the UK is the public lecture (40%) followed by engagement with policy makers (33%), working with schools (30%), writing for non-specialist publications (25%) and taking part in public dialogue (20%).

The popularity of researcher involvement in institutional open days can be attributed to a number of factors e.g. institutional requirement that each department contribute to the effort and use of attendance rotas to spread the time requirement across the staff, ease of access to engagement activity, feelings of self-efficacy as the engagement is linked to their own institution or research area, the provision of support from peers or their department, and peer/institutional pressure to be involved amongst other possible reasons. In Ireland, a small cohort of researchers is involved regularly with policymakers which suggests a potential imbalance in presenting the views of the broader research community to policy makers. This may reflect the 'who you know' culture of Irish politics whereby some scientists may cultivate relationships with policymakers and policymakers may only deal with scientists that they consider trustworthy from a political/policy perspective (i.e. are not loose cannons or leaks). The UK survey showed a positive correlation between the number of activities undertaken and the perceived importance of public engagement so participation may be seen to have a positive motivating influence on researcher involvement in public engagement activities (People Science and Policy, 2006).

Who are the future target audiences?

Past behaviour is a powerful indicator of future behaviour, particularly if a person has strong opinions as to the success or failure resulting from an action. We surveyed the researchers to uncover which groups they found the easiest and most difficult to engage with to understand better who could be a future target audience. While not all researchers are speaking from experience as only a quarter are regularly involved in engagement, their perception of such interactions could influence their decision on whether they will get involved in engaging these groups in the future. Our survey showed that the respondents considered popular science journalists to be the easiest group to communicate with (25%, 135) followed by secondary school kids and teachers (16%, 85) (Table 4.5). The reasons given for this are that the research being undertaken is of relevance and interest to both of these groups (Figure 4.5). *Groups/Individuals* opposed to specific sciences and technologies and others in the media i.e. writers, documentary and other programme makers, were ranked lowest. None/don't know was the third highest ranked answer in response to the request for the respondents to select from a specified list the groups they find it easiest to talk with about their research findings. The same responses, i.e. None/don't know and Groups/Individuals opposed to specific sciences and technologies were the highest ranked answers in response to the request for respondents to select from the list the group they find hardest to talk with

about their research findings (Table 4.6). Policy-makers in government are the third highest ranked group in terms of the respondent perception relating to talking with them about their research. The reasons given for choosing these groups was the negative/blinkered viewpoint of these groups, the fact that the respondent has no experience of the group, and the lack of understanding and interest of the group in their research (Figure 4.6)

The general lack of opinion regarding which groups are most difficult to communicate with may be due to the fact that most public engagement activities are demand-driven such as a journalist requiring information for a magazine article or Science fairs for school children. There are fewer opportunities for researchers to engage intentionally with groups who may not be receptive to their research. This may be due to a reluctance of the researchers to seek out such encounters due to their perception of these groups as having a negative/blinkered viewpoint (Figure 4.6). It is possible that many researchers see engagement with groups opposed to science and technology as a waste of valuable time, and may question the way groups opposed to science and technology frame such encounters or 'dialogue'. However any involvement of researchers in activities located in a public forum enable opponents of a particular type of research to air their views, as often happens at public lectures, but these oppositional groups are not necessarily the target audience for these activities. Other possible explanations for the lack of engagement with those who are opposed to particular types of science and technologies may be that both sides are polarised (entrenched) and see no benefit/rationale in engagement with each other, particularly if the advocacy objective is to influence the general public and/or policymakers rather than the proponents or opponents. The identification of policy makers as being difficult to communicate with regarding their research is interesting, particularly as this group are considered important to engage with. This gap in communication suggests the potential for novel methods to bring these two groups together e.g. researchers and policy makers. One example of such an initiative is the 'Bacon & Egg-heads³⁶' scheme in Canada which brings together members of parliament with experts from the fields of science and engineering.

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³⁶ See PAGSE: The Partnership Group for Science and Engineering website for more information on this scheme. Go to: www.pagse.org/en/breakfasts.htm

4.5.2 Public engagement intentions and motivations

We set out to ascertain the intention of researchers in Ireland in relation to their role in engaging the public about science and technology. When faced with other work pressures, 37% (198) of surveyed researchers thought that it was important to find time to engage the public (Figure 4.7). However, 41% (215) of respondents felt that finding time for such activities in the face of other work commitments was not important. Time pressures most definitely can counter researchers' intentions to become involved in public engagement activities. Despite the mixed feelings expressed above about the importance of engagement, 54% (286) of surveyed researchers wished to spend more time on public engagement activities (Figure 4.8). 38% (204) of respondents were content with the amount of time they spend on public engagement already. Very few of the researchers surveyed (3%, 17) wished to undertake less public engagement activity, suggesting that there is general support among researchers for involvement in public engagement activities.

We set out to unpick what factors would motivate scientists and engineers to become more involved in public engagement activities relating to science and technology. In an open ended question survey participants identified motivating factors which ranged from public engagement infrastructure, time (general), increase profile of research and skills/training amongst many other factors (Figure 4.9) and the responses were grouped together. The first group of responses relate to the researchers' beliefs of self-efficacy³⁷ and what supports should be given to encourage involvement e.g. provision of public engagement infrastructure (17%, 69), provision of training (8%, 33), or simply being asked to participate (7%, 28). The second group relate to external constraints that might be experienced by the researcher e.g. time (14%, 53), or money (6%, 25). The third group relate to subjective norms³⁸ and how a positive response to engagement may encourage further participation e.g. engagement increases the profile of research (13%, 51), engagement leads to an interested public (7%, 27), or engagement ensures recognition by peers (6%, 22). It is worth noting also that factors such as engagement being part of one's job or having public engagement as a requirement of funding would not especially motivate them to become involved in activities that engage the non-

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³⁷ Self-efficacy is the belief that one is capable of performing in a certain manner to attain certain goals.

³⁸ Subjective norms relate to the influence of people within a social environment on a person's behavioural intentions.

specialist public in science in comparison to factors such as infrastructure provision, dedicated time, increasing their profile and the development of related skills/training. These responses suggest that researchers require specific and tangible supports to motivate them to become involved in public engagement activities.

We asked researchers to indicate their agreement or disagreement with a number of comments made about science communication. The highest ranked answers relate to organisational issues i.e. research funding agencies should help scientists to communicate, researchers would take part in activities organised by someone else, or researchers would need help in organising these activities (Figure 4.10). The next highest ranked answers relate to the perceived benefits of engaging the public i.e. researchers would find such activity personally rewarding, respondents feel that scientists have a moral duty to engage the public about the social or ethical implications of their research. The responses to both questions indicate that respondents would require additional resources such as funding, time allocation, training, infrastructure etc to facilitate their involvement, and also that researcher recruitment strategies by research funding bodies should highlight the perceived personal and societal benefits of engaging the public³⁹.

4.5.3 Opportunities and barriers to engagement

The majority of respondents identified the need for public engagement in science and technology and we set out to identify the main barriers to researcher involvement and to identify what supports and incentives would need to be put in place to remove or lower these barriers. In a closed-response question, half of the researchers surveyed (280) selected *I need to spend more time on my research* as the main reason stopping them from being more involved in science communication and public engagement activities (Figure 4.11). Similarly when asked to indicate the main drawback to engaging with the public, 20% of respondents (198) chose the response *It takes up time better spent on research*. The majority felt however that there was no drawback (41%, 221); 15% (82) selected *It can send out the wrong messages to the public* (although it was not specified

³⁹ The UK Research Councils have recently published a booklet entitled *What's in it for me? The benefits of public engagement for researchers*, which highlights the benefits of involvement (Research Councils UK, 2010).

as to what these messages might be); and 10% (55) selected the response *It makes them* (the researcher) *a target* (Table 4.7). Bringing more money into the department was the top incentive for such involvement with 84% (436) of respondents saying it would encourage them a great deal or to some extent to undertake more public engagement (Table 4.8). The recognition of such activities by funding bodies in making funding decisions (82%, 427) as well as recognition of science communication activities in career promotion procedures (81%, 422) were also important for a large proportion of respondents (Figure 4.12). Hence financial and resource (time) commitments were seen as the major barriers and incentives that should be focussed on for increasing science communication. It worth investigating also what was meant by 'it can send out the wrong messages to the public' in relation to the respondents ranking of what they consider to be the main drawbacks for scientists and engineers engaging with the non-specialist public as this was the third highest ranked response (15%, 82).

The barriers to researcher involvement in public engagement activities are not insurmountable and there are a number of practical steps that could be taken such as the development of training modules for scientists and the changing of grant applications to require public engagement activities. Both of these steps have financial and resource allocation implications and hence institutions and funding agencies would be required to divert existing resources towards these activities. In addition, the time constraint barrier has resource implications as diversion of researchers time to science communication will mean that other existing activities would have to be sacrificed. In such a context, the cost-benefits of science communication become an issue, and while outreach activities generate revenue/resources (allowance per student recruited), the resource payback from science communication is harder to measure and more nebulous.

Several Higher Education Institutes in Ireland have already tried to address some of the barriers/incentives and the national "Science for All" competition attracts a wide array of postgraduate researchers who are willing and interested in developing their communication skills by presenting their research to the public. Some funding agencies also require outreach activities as a proviso to receiving a grant e.g. Science Foundation Ireland and its Centres for Excellence grants. The Science Gallery is a notable example that has successfully attracted *free gratis* researcher involvement in its activities and which has had 550,000 visitors since its inception. Similar initiatives that focus on

broader themes and supporting creativity, innovation and interdisciplinary collaboration, i.e. artists, actors, musicians, dancers as well as researchers, should be encouraged.

4.5.4 Support for researcher involvement

A key factor that determines people's involvement in activities is the degree to which they feel able to perform a particular activity. This feeling of self-efficacy in public engagement may relate to the level of training they have in communicating their research or may also relate to the support being offered by their colleagues or institutions in relation to their participation in these activities. An additional motivating factor could be whether or not one's colleagues are involved in such activities already, which is known as a descriptive norm as it relates to perceptions of how other people behave rather than on how that behaviour is viewed.

The surveyed researchers indicated that in the majority of cases (78%, 407) members of their department are already involved in public engagement activities (Figure 4.13). Fellow researchers were considered to be supportive of such activities (54%, 294) (Figure 4.14) as were the institutions housing the researcher (54%, 276) (Figure 4.15). The majority of survey respondents felt well equipped (62%, 326) to engage with the public about their research (4.16). However, there seems to be a lack of awareness of how to get involved in such activities with 45% (240) of respondents being unsure as to how easy or how difficult it was to become involved (Figure 4.17). Also formal training was seen to be lacking as 60% (318) of researchers surveyed have had no media, communications or public engagement training, or their training was largely informal or based on personal experience (13%, 69) (Figure 4.18). These responses suggest that the researchers surveyed feel able to engage in such activities due to the support of the colleagues and employers and despite any formal training relating to engagement activities. It would seem that the bottleneck in encouraging researcher involvement occurs higher up the chain with funding agencies and institutional incentive structures not being seen to support engagement activities. The Royal Society survey showed similar results regarding the training of scientists and engineers relating to science communication activities (People Science and Policy, 2006).

4.5.5 Science Communication

When scientists were asked to define in their own terms what engaging with the nonspecialist public meant to them, the dominant answer was to explain and promote public understanding of science (24%, 113), followed by communicating with the public, giving a public lecture (13%, 61), highlighting the implications, relevance and value of science (12%, 59), and being accountable to the public (9%, 43). These different answers reflect different models for communicating science or different purposes for the communication. The two highest ranked responses relate predominantly to the deficit or linear model of science communication also known as the Public Understanding of Science (PUS) model⁴⁰ (The Royal Society, 1985). In this model a deficient public need to be filled with scientific knowledge in order to assuage their distrust of science and to garner their support for science. The next two responses highlighting the implications, relevance and value of science and being accountable to the public are focussed on the purpose of engagement rather than the process. The former makes the argument that as scientific research yields useful products, processes and findings, such usefulness must be highlighted to the public. However the reasons why such usefulness must be highlighted to the public remains elusive as it could be (a) to encourage greater public support for science; (b) to increase scientific literacy of the public; (c) concern that the public is unaware of what science and technology can offer to improve human livelihoods or (d) other reasons. The second response regarding accountability to the public relates to the fact that science is significantly funded by public monies and thus there is an obligation on scientists to report back to the public and justify such expenditure. This way of thinking about communicating science relates to the Public Awareness of Science (PAS) model for communicating science. The PAS model recognizes the complexity of scientific research and that communications need to be targeted to specific audiences to facilitate understanding (van der Auweraert, 2005). Interestingly, definitions that relate to the Public Engagement in Science (PES) model or the Public Participation in Science (PPS) model are less common in our survey with only 7% of respondents considering the term to mean Listening to and understanding

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⁴⁰ The term 'Public Understanding of Science' gained its current usage, and its identification as an distinct area for research and enquiry, in 1985 following the publication of the Royal Society report, which is often named the Bodmer report after its lead author, Sir Walter Bodmer. This report suggested that better public understanding of science would lead to greater public support for science and in turn lead to greater scientific innovation with a knock on effect on the nation's economic success (The Royal Society, 1985).

the public (PES), involving people in science or in science based decisions (PPS). These findings would suggest that the majority of researchers in Ireland currently view engagement activities as being aligned with the PUS and PAS models of science communication.

In our survey 60% (181, n= 247) of respondents hold the normative idea that scientists and engineers should engage more with the community. This support for engagement activities is encouraging however it is worth investigating further (a) what form this communication might take and (b) its purpose, in order to identify suitable approaches to public engagement. Scholars of Science and Technology Studies (STS) have shown that rather than increasing support for science, exercises to increase public understanding of science can have the opposite effect and can help alienate the public further and create disinterest and ill-will towards science (Wynne, 1995; Logan, 2001). The notion that the scientific community is accountable to the public is ranked much higher as an answer in our Irish researcher survey than in the UK Royal Society survey, (9% in Ireland which is the 4th highest answer) and 7% in the UK which is the 9th answer). In the UK survey support for listening to the public or increasing public participation in science, i.e. the democratic model of science communication, is more prevalent, UK (13%) and Ireland (7%). The response rate to this question regarding public participation however was quite poor in our survey with less than half of the respondents answering the question. It is difficult to draw strong conclusions from these findings due to the lowered response rate. The tendency towards the use of communication strategies based on increasing public understanding or public awareness of science however results mirror results from a survey of outreach strategies in Ireland which showed the predominant use of the deficit model of science communication in the outreach activities (Davison et al., 2008).

4.6 Conclusions and recommendations

The research findings indicate that the majority of respondent scientists and engineers in Ireland (54%) wish to spend more time engaging with the public on science and technology. Despite this expressed desire, the level of engagement activity in Ireland is much lower than in the UK with only a quarter of researchers involved regularly in activities in Ireland versus 74% in the UK. The difference may be due in part to new funding mechanisms in the UK to encourage public engagement and also the increased importance placed on such activities by funding bodies in the UK.

The respondents in our survey indicated that the majority feel accountable to the public due to the recent large public investment in science and this is a motivating factor for getting involved in engagement activities. The respondents feel they *ought* to engage the public in science and technology. This would suggest that there is a good "supply-side" opportunity here to put public engagement requirements in place that do not add additional workloads to Irish scientists and engineers. Perhaps not all scientists should be required to be involved in such activities, and funding mechanisms and career advancement measures should reflect differences in ability and interest.

4.6.1 Barriers to researcher involvement

Lack of time was identified as being the main barrier to involvement in public engagement activities in Ireland. If scientists and engineers in the UK have similar time demands, it is difficult to understand why there is more than four times the level of public engagement activity occurring there. One explanation for this is that the Irish system is not mature in terms of support systems for science and engineering. In addition to a lack of time there is also a lack of institutional support for such activities in Ireland with little money (i.e. to cover the costs of labour time, facilities, substitution of time lost in terms of lecturing or research etc) assigned towards public engagement activities. The initiatives that are in place are directed towards secondary school student recruitment into science (in particular specific scientific disciplines) or increasing student interest in science. The broader public are largely left out of these outreach exercises, although it is not clear whether (or who in) the public would want to engage in such outreach exercises and the cost of democratic participation of the public in outreach activities would have to be covered also (in both direct and opportunity costs). Researchers also identified the lack of opportunity for them to engage with other groups

in society other than secondary schools and industry groups with which they have had an association traditionally. There is a general lack of awareness about engagement activities amongst researchers and this is an additional barrier towards engagement. How can one become involved in an activity if you are not aware of it? Equally how is it possible that scientists and engineers remain unaware of engagement activities relating science and technology, as surely they would be a target group for such participation in or leading such activities?

Investment in scientific and technological research and development in Ireland is promoted for the development of knowledge economy and the aspiration that knowledge products and services arising from R & D will lead to increased economic and social prosperity. At present in Ireland, there is less emphasis placed on the societal and cultural impacts of these knowledge products or on encouraging dialogue about science.

4.6.2 Opportunities for researcher involvement

One theory of planned behaviour identifies three main factors that influence behaviour (Ajzen, 1991). These are attitude towards a behaviour, a person's perceived behavioural control or belief that they are capable to engage in such behaviour, and subjective norms or perceptions of peer approval of a behaviour (op cit.). Our survey respondents displayed a positive attitude towards engaging in research, they were confident in their ability to be involved in such activities despite a lack of formal training, and they described a largely supportive peer group. Why then are public engagement activities not more common in Ireland?

This thesis chapter has identified a number of steps that can be taken to help address this deficit.

4.6.3 Recommendations

1: Cost benefit analyses of science communication and engagement initiatives

The weak and shallow extent of science communication and engagement activities in Ireland indicates that funding agencies and institutions (e.g. universities, research institutes) do not consider science communication and engagement initiatives an important investment in terms of resources deployed. There is more activity on outreach

because it generates income via recruitment of students. However, broader public engagement and public dialogue activities are more difficult to assess in terms of benefits realised per unit cost deployed (time, salary, institutional resources etc).

It is recommended that all publicly funded science communication and engagement activities be subject to long term monitoring and evaluation in order to determine what the benefits are that can be derived from different cost/resource outlays and to which groups such benefits accrue.

2: Current outreach activities to be evaluated and improved

The majority of respondents' involvement in public engagement is in institutional open days with school children. The main purpose of these events is to encourage students into science and engineering, yet annual Central Applications Office (CAO) figures show that there is decreased interest in scientific courses.

It is recommended that all publicly funded outreach activities be audited (and subject to continual monitoring and evaluation, including follow-up surveys of effectiveness) by the relevant funders/funding agencies or by the office of the Chief Scientific Adviser to identify the most effective mechanisms for achieving these goals. Perhaps parents and guidance councillors, or focus groups of children to ascertain peereffects are the more appropriate targets.

3: Clarification of the term public engagement

The term public engagement is ambiguous as is much of the current language relating to communicating science. There is a need to define what is meant by the term and also to identify what impacts are desired from engagement activities. Previous and ongoing science communication attempts are being counter-productive with linear, top-down information relays leading to increased public distrust of and disconnect with science.

It is recommended that a model (or models) of good practice in public engagement regarding science and technology be developed to identify what needs to be considered prior to beginning such an exercise, what methods are most effective for reaching and engaging particular audiences and how might researchers become involved in such activities.

4: Training in public engagement for scientists and engineers

The survey showed a deficit in science communication training for the Irish research community.

It is recommended that science communication training modules be devised for students and research staff and that participation in these training sessions be recognised and rewarded (in a tangible manner e.g. promotion, resource allocation etc) by departments and institutional heads.

5: Identify new groups to engage

The majority of respondents felt that school children and policymakers were the most important people to engage with in relation to science and technology and they felt that the general public were less important. There are many stakeholder groups with an interest in engaging with researchers e.g. farmers groups, patient groups, environmental groups, commuters, local authorities etc, but they are unable to link up with research communities to their mutual benefit.

It is recommended that stakeholders groups be investigated as potential public engagement targets and institutional and departmental action plans be devised on how to best reach a wider range of groups and facilitate engagement.

6: Dedicated public engagement staff

While respondents were interested in becoming involved in public engagement activities, the majority were unaware of how to participate in such events and were reluctant due to time pressures to take on organising events themselves. Clearly there is an opportunity to involve researchers in public engagement activities, but a support system is required to facilitate this.

We recommend that institutional budgets be redeployed to allow departments and research centres to hire staff to organise and run engagement activities as well as working with staff to develop their communication skills for these events. This may require a cut-back in existing educational and research provision to allow for a

redeployment of resources. Where possible, researcher involvement should be at the early stages of developing an engagement plan rather than as facilitators on the day.

7: Create policies to encourage public engagement activities

The current research climate sees researchers under major time pressure to conduct research, to source funding on a recurrent basis, to make links with industry, to inform policy amongst many other pressures on time and resources. Involvement in public engagement activities, whilst considered very necessary, would create another time pressure. There is a need for institutional backing and funding agency recognition for researchers who become involved or increase their involvement in these activities.

It is recommended that funding agencies alter their scoring system for grant proposals to encourage involvement in public engagement activities. Not all scientists should be involved in such activities, but equally it is necessary for some research areas to be more vocal than others. We recommend similarly that institutions include involvement in public engagement as a criterion for progressing through a PhD or for career advancement.

8: Forum for engaging with opponents

Respondents indicated that opponents of a particular area of research or applications arising from such research were the most difficult group to engage. The reasons given are that these groups have a negative or blinkered view of science. The public opposition to GM crops generated by environmental groups in the 1990s in Europe shows the influence of certain groups on public opinion. There is a definite need to engage with oppositional groups in order to share knowledge and help inform science policy to make it understandable and perhaps acceptable to the majority.

It is recommended that a forum be created at national level to facilitate debates and discussion on science and society topics considered risky or uncertain. The Danish Board of Technology assessment is one example of how this might be arranged.

9: Funding mechanisms for public engagement exercises

Public engagement activities are not without their cost. Clearly there is a need for dedicated and sustained funding to ensure departments, research institutes etc can

structure a support system and finance a range of activities to ensure the public are engaged in science and technology topics.

It is recommended that funding agencies, government departments and Institutions of Higher Education coordinate to create funding mechanisms for public engagement activities regarding science communication. Conflict over new technologies: shaping frames and perceptions
The biosciences have always been a discursive battleground for many issues
that divide social, religious and ethical opinions. In some cases, such as the use of GM
technology in food and agriculture, proponents and opponents positions have become so
entrenched that the task of finding a mutually agreeable resolution remains difficult.
Rather than a novel occurrence, conflict over new technologies, discoveries and
products has a lengthy history paralleling the history of science and technology.
Nanotechnology, an example of an emerging technology, is the focus of this chapter
and the level of opposition or support for nanotechnology is investigated as reflected
amongst the YouTube user community. The response to nanotechnology as evidenced
from YouTube posts will then be considered in relation to conflict resolution based
approaches for managing conflict trajectories of new or emerging technologies.

"Debates over biotechnology are part of a long history of social discourse over new products. Claims about the promise of new technology are at times greeted with skepticism, vilification or outright opposition - often dominated by slander, innuendo and misinformation. Even some of the most ubiquitous products endured centuries of persecution" (Juma, 2003, p. 29). An example of such a conflict was public opposition to coffee (Ukers, 1922). Despite being introduced initially to Western countries by the clergy and the medical profession, coffee was subsequently denounced in the 17th Century by the same groups. As a result, coffee houses were forced to close across England, Sweden, Germany and France. The main reason for this was that coffee houses provided arenas for dissenting voices to be raised which threatened the ruling class of the time (Ukers, 1922). Margarine was another product to face mass protest and incurred its own tax for forty years in order to pacify the dairy sector in the US. Paradoxically, not all new products suffer the same fate. As seen in the history of biotechnology, products derived from organisms for the improvement of medical processes were seemingly acceptable 41 as were the manufacture of fermentation-derived

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⁴¹ While there may be a current perception that use of gene technology in medicine always had support this is not the case. In the 1980s the Green movement and Green Party Environment Minister Joschka in Germany was fundamentally opposed to the use of GM in medicine (e.g. production of recombinant insulin by Hoeschst was blocked for 14 years until 1988). Pressure by patient groups who sought use of GM to develop therapies and who were opposed to misrepresentation by anti-GM groups (including the Green movement) subsequently led to the German Green Party reversing their opposition to use of GM in medicine and human health.

products using live organisms such as in beer, cheese and probiotic production. The acceptance of technologies can depend on whether they are perceived as new or old technologies and can lead to paradoxical situations where groups call for less regulations on dangerous herbal or alternative health remedies while calling for more regulations on more stringently assessed technologies or products derived from modern day science.

5.1 Identifying and addressing risks of new technologies

Issues relating to science and technology can often relate more to people's perceptions of a technology, application or scientific finding and how it resonates with their value system rather than the scientific process or product itself. Efforts have been made in the field of risk communication to identify the causes of aversion to particular technologies and developed the following criteria to predict public response (Slovic, 2002). In one typology, potential hazards are measured on two axes with the magnitude of the risk or 'dread' on one axis and its controllability on the other, thus risks considered to be involuntary and potentially catastrophic are perceived as being worse than those that arise by personal choice where the consequences are known (Slovic, 2002). This may help to explain why people will consider activities such as smoking or driving recklessly as being more acceptable risks, than the risks arising from the development of new technologies even though the former are more likely to lead to their future demise (or the demise of others). Studies have shown that the public are more accepting of biotechnological applications such as cloning of human cells and tissues and genetic testing for inherited disease if they can show clear medical benefits for the diagnosis and treatment of diseases (Gaskell et al., 2003). Similarly, support for agricultural biotechnology is highest when the potential benefits are framed in terms of human health (Sturgis et al., 2005). However, applying the same technologies in a different context does not elicit the same response, and in fact it can lead to a completely opposite response e.g. public response to human cloning (Human Genetics Commission, 2001). Peter Sandman, the risk communication scholar, explains risk perception using the formula $risk\ perception = hazard + outrage$. Hazard is described as the magnitude of the risk multiplied by the probability of it occurring. Outrage is a much more subjective measure and refers to how (at any point in time) the public perceives or responds to a risk and this helps illustrate the disconnect between expert

perception of risk and the perception of risk by different members of the public (Sandman, 1993).

Risk assessment focuses on rational calculations of risks. Despite the use of participatory mechanisms in risk assessment, current methods of risk assessment analysis limit participation in debates over new technologies as it means that other questions may not be asked such as who has ownership of the technology and who will be its main beneficiary (Wilsdon and Willis, 2004). Such questions are addressed more by technology assessment which is the study and evaluation of new technologies, particularly regarding their social and economic impact (Mohr, 1999). Technology assessment is not risk assessment, but makes assessments of possible social and economic risks associated with particular science and technology sectors or applications.

5.1.1 Public involvement in deliberations over new technologies

Public involvement in debates and discussions about new technologies is frequently limited to consultation where the public is cast in the role of the consumer of technologies. However this is not the case worldwide as the public has taken a decidedly more participative turn in debates elsewhere about science and technology, examples being technology assessment exercises in the US and Denmark.

Technology Assessment arose in the US as a method for addressing controversies over new technologies in the 1970s and aimed to do so by inviting public consultation (Joss, 2002). The Office of Technology Assessment (OTA) at the US Congress analysed research activities and findings and provided this information and suggested political options to decision-makers; to "speak truth to power" (Klüver *et al.*, 2002, p. 15). Despite TA showing links early on with wider public concerns, it soon lost this public focus and "developed into an expert-driven tool of policy analysis, with little resonance beyond congressional politics and the expert community" (Joss, 2002, p. 222). Participatory technology assessment (Bubela *et al.*, 2009) was established in Europe in the 1980s with the aim of finding more optimal solutions through participatory mechanisms. In addition to providing knowledge and options to decision-makers, PTA

⁴²See the 'Honest Broker' for a discussion of the role of scientists in political debates and policy formation and the options for consideration by scientists (Pielke, 2007).

processes also facilitate dialogue between all stakeholders i.e. politicians, experts, and the public. New developments in biotechnology and the controversy they sparked led to the inclusion of participatory methods in Technology Assessment initiatives. One PTA tool is the consensus conference, where diverse groups of citizens (stakeholders) are brought together over three or four days to discuss a particular topic with testimony from selected experts. The consensus conference ends with the group issuing a consensus report on the deliberations. PTA processes are meant to be complementary to classical TA and are a means of better "appropriating technology to the needs and expectations of society" (Klüver et al., 2002, p. 170). Consensus conferences have limitations that can derive from the process by which they are conducted (e.g. selection of participants, framing of questions, composition of juries etc) whereby a lot of power rests in the hands of those who design, draft and finalise the consensus outputs (e.g. the report and recommendations) and hence consensus conferences are very similar in process to any form of negotiation of a new law or policy which results in a compromise text that can be considered acceptable to most of the participants, but does not typically reflect the proposals of any one sector or individual.

Arguments for increased public participation in the governance of science can be seen as arising from the fields of technology assessment (Joss, 2002) and risk assessment (Kleinman, 2000; Wilsdon and Willis, 2004). While exercises such as consensus conferences have been utilised in a variety of countries e.g. plant biotechnology consensus conferences in the UK and internationally, ozone consensus conference in Austria (Klüver et al., 2002), these are very much once-off efforts and have been criticised over their lack of political clout as the findings do not always reach policy makers (Jones, 2006). This may be due to perceptions by policymakers that those who organise consensus conferences and outputs have their own pre-determined agendas and may be using the consensus conferences as a Trojan horse to relay their own recommendations. The policy relevance of any consensus conference will relate to the level of engagement and control that policymakers have over the process. Hence it is not surprising that ad hoc self appointed consensus conferences have little policy clout. Recognising this, the 2002 EUROPTA project Participatory Methods in Technology Assessment and Technology Decision Making indicated that participatory TA should be used to facilitate public discourse and the forming of political opinion on science and technology and "participants should not expect to get a decision making power-base

from participatory TA, unless the existing power-structure is represented among the participants" (Klüver *et al.*, 2002, p.12).

Are exercises to increase public participation in science and technology little more than talking-shops in this case with minimal impact on decisions? Previous attempts to mitigate public distrust of science and technology were based on the assumption of there being a public deficiency in knowledge about science which led to the rejection or opposition to these new technologies (Wynne, 1995). The task was then placed upon the scientific community, policy makers and regulators to increase public understanding of science and thereby hopefully increase the public acceptability of new technologies and new directions in scientific research. However, greater awareness of the developments in science did not lead to greater acceptance of science; in fact the converse happens where increased knowledge led to increased scepticism and suspicion about science (Human Genetics Commission, 2001; Evans and Plows, 2005). This 'deficit model' also fails to recognise that knowledge is one of a myriad of influences that guide an individual's decision making, and that understanding of "the 'patronage, organisation and control' operating in and around science and the scientific community" (Sturgis and Allum, 2004) often has a far stronger impact. More emphasis is now being placed on early engagement of stakeholders in dialogues about the trajectories of discoveries and new technologies rather than at the latter stage such as happens in PTA and risk assessment.

5.1.2 The governance of science

In government policymaking it is not always clear to outsiders how decisions are reached or who is involved in the final decision making process. This is also apparent in science policy making. The global nature of scientific discoveries "makes it difficult for the politicians of any one country to have a veto on the development of some technology that their constituents find unappealing. "In fact, this is one of the features of science and technology that people find most shocking - scientists and policy-makers can seem as powerless as the public themselves. No one seems to know whose hands are on the steering wheel" (Jones, 2006, p. 263). This can be said about any policy area however and it is not possible to assess all possible impacts of a given policy. The direction of publicly funded research can be influenced to a certain extent by policy makers, business leaders, lobby groups, and representative bodies like patient groups.

However science is not easily directed from above. It is often not clear who should listen and respond to issues (whether pro or anti) being voiced in relation to particular research trajectories. Indeed, it is often not clear what the benefit could be from greater engagement (e.g. listening and dialogue) of different members of the public regarding research trajectories in science and technology.

Public consultation regarding applied science, as discussed earlier, is often a late stage process and usually takes place at the end of the innovation process through market research when a new product, application or research finding is being made available or being deployed. There have been increased calls made for earlier public engagement in this process. Current science communication efforts with regard to nanotechnology are placing significant emphasis on engaging the public in discussions over its uses and potential benefits and risks. Nanotechnology is an "umbrella term for describing research and technology development that allows for the manipulation and control of materials at the atomic or molecular levels in order to build novel structures and devices" (Cobb, 2005, p. 221). In the UK a 2004 report recommended that a debate take place about the future of nanotechnology "before deeply entrenched or polarised positions appear" (The Royal Society and The Royal Academy of Engineering, 2004, p. 67). There followed numerous public engagement activities on the topic 43 and despite initial worries, nanotechnology has not yet ignited the public as GM did. This may reflect that much nanotechnology research is at an early stage with very few nanotechnology products having yet been sold or deployed in society. Politically powerful anti-technology/corporate lobby groups such as Greenpeace, ETC, Soil Association, Friends of the Earth, and Green parties internationally are currently opposed to nanotechnology research and development with significant efforts underway to realise an international moratorium on nanotechnology deployment in society⁴⁴.

Too early an engagement can mean that a nascent technology is held under scrutiny before there is any evidence to support claims relating to its benefits or risks. In the case

⁴³ For details see (Gavelin, 2007, Stilgoe, 2007, Scheufele, 2007, David, 2008).

Examples of the communication strategies employed by these lobby groups include the following: (International Center for Technology Assessment, 2007; Johnston et al., 2007). The frame used in relation to nanotechnology by two particularly oppositional groups is evident in the following websites: www.etcgroup.org/en/issues/nanotechnology; www.greenparty.org.uk/articles/56.html

of nanotechnology the public are currently largely uninterested (or unaware) in the topic (European Commission, 2005; Research Councils UK, 2008) which could be interpreted as too early an engagement or as "a failure for those working on public engagement" (Jones, 2006, p. 262).

5.2 Understanding Conflict

Where does the initial disquiet arise from in relation to nanotechnology (or other technologies) and how should we interpret current expressions of intolerance or tolerance to this growing branch of technology? While Noam Chomsky asked the question whether consent is being manufactured (Herman and Chomsky, 2002), in the case of new technologies it may also be questioned whether dissent is being manufactured (and successfully amplified via the internet). Nonetheless, conflict is a regular accompaniment to new technologies and there are features common to all conflicts that can be investigated and considered when deciding upon possible approaches to addressing and mitigating conflict.

5.2.1 Defining conflict

Conflict is a state of discord between two or more parties caused by the actual or perceived opposition of needs, values and interests. In one typology Mayer (2000) describes conflict as being comprised of three dimensions: cognitive (perception), emotional (feeling), and behavioural (action) (Figure 5.1). The cognitive dimension can have subjective or objective elements associated with it but this dimension ultimately relates to the "belief or understanding that one's own needs, interests, wants, or values are incompatible with someone else's" (Mayer, 2000, p. 3). The emotional dimension relates to a person's personal reaction to a situation and this may signal the presence of conflict. Indicative feelings may include sadness, anger, hopelessness, fear, frustration, bitterness or a mixture of some or all of these. The behavioural dimension relates to the actions that a person chooses in order to express their feelings and ensure that they get their needs met, but these may clash with another's chosen actions. In a Western cultural context at least⁴⁵, it is necessary to address all three dimensions in order to forge a lasting resolution to a conflict.

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⁴⁵ Conflict resolution is highly culture specific and approaches need to be tailored towards different cultures.

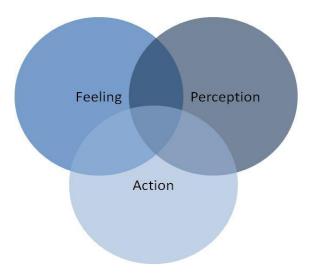


Figure 5.1: The three dimensions to a Conflict

The cognitive dimension is the most pertinent with regard to the public reaction to new technologies i.e. they have incompatible needs and interests, but behaviours can change over time as can emotions and these can combine and reinforce each other and help escalate or prolong a conflict (Centre for Conflict Resolution, 2005).

A first step towards resolving a conflict lies in gaining an understanding of where it has arisen. Mayer's 'Wheel of Conflict' (Figure 5.2) aids our understanding of the sources of conflict and he places human need and the importance of having one's needs met at the centre of the wheel. Spinning out from the centre are five main sources of conflict, i.e. communication, emotions, values, structures and history, and these impact on how a person's needs are experienced and developed (Mayer, 2000). Conflict can arise due to poor communication skills leading to a misinterpretation of situations. Emotions can help fuel a conflict and conflict is further increased if a person considers their core values and beliefs to be under threat. Structures provide the context for a conflict, but as structures are embedded within societies or relationships, they are often difficult to identify (Fast, 2002). Structures can impact on a group's access to resources and can influence the way it makes decisions or communicates in general. Many conflicts have historical roots which can lead to recurring conflict. The 'Wheel of Conflict' proves most useful in examining complex conflicts as it allows partial examination of the causes of a conflict rather than attempting to make sense of the entire conflict. Early intervention is important however as a conflict increases in complexity as it continues (Centre for Conflict Resolution, 2005).

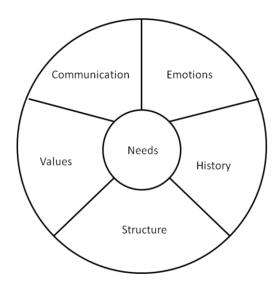


Figure 5.2: Wheel of Conflict (Mayer, 2000)

If we consider the sources of conflict from a knowledge deficit perspective, biosciences-related conflicts would seem to be based on a miscommunication between parties which then elicits an emotional reaction. This miscommunication can be unintentional and potentially arise from cultural differences (Avruch, 2002) or may be deliberate and used to create conflict and suggest a particular viewpoint (Galam, 2010). Some studies on public responses to GM technology however indicate that people are more concerned with structures and values in relation to GM (Marris, 2001; Weisenfeld, 2003; Horlick-Jones, 2004). It is necessary to gather empirical evidence to support any claims regarding the root causes of a conflict as it is easy to misinterpret situations based on one's own presumptions and particular perspective. The structural causes of conflict must be addressed particularly as otherwise resolution efforts may have the opposite effect and actually strengthen oppressive structures, therefore diminishing the possibilities for transformation⁴⁶ (Galtung, 2000). Once the sources of conflict are identified (which for many biosciences related conflicts is an ever evolving/expanding tableaux of possible issues which conflict can hinge around), how then can conflict be addressed and what are the best methods for ensuring lasting and harmonious resolution?

5.2.2 Steps towards resolution

Rubin, Pruitt, and Kim (1994) suggest that there are five basic conflict strategies. These are contention, problem solving, yielding, withdrawal and inaction. A strategy is chosen

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⁴⁶ Transformation is viewed as a long term version of conflict resolution which is focussed on resolving the structural, relational and cultural dimensions of a conflict (Centre for Conflict Resolution, 2005).

based on a party's aspirations as to what they can achieve and their perceptions of the other party's level of aspiration (Rubin *et al.*, 1994). Thus, a party will choose inaction if they are not particularly concerned about themselves or the other party in relation to the conflict. A party will choose a problem solving strategy if their concern for the outcome of the conflict is high both for themselves and the other party. The Thomas-Kilmann conflict mode instrument (Figure 5.3) examines the strategies which an individual or group involved in a conflict intend to use in order to satisfy their own and the other's goals. This is measured along two dimensions, assertiveness (satisfying one's own concerns) and cooperativeness (satisfying another's concerns) (Kilmann and Thomas, 1977; Thomas, 1992).

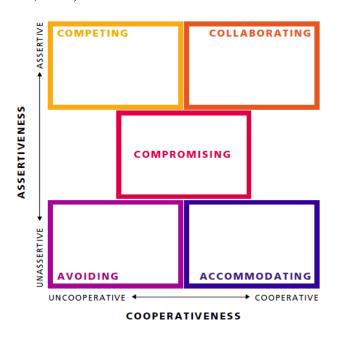


Figure 5.3: Thomas-Kilmann Conflict Mode Instrument

Most people have a preferred conflict management style but different situations may call for different ways of managing a conflict. For example if winning is more important than maintaining relationships the competitive style might be more suitable, while an accommodating style would best suit a situation where winning is not important, but maintaining relations is or ensuring that 'the favour' can be called upon in a future interaction. The time frame within which one is working also impacts on the conflict management style chosen, e.g. collaboration may not be possible in a short time frame but this would be the optimum style to pursue for lasting conflict resolution. The approaches chosen for managing a conflict as well as the methods used to manage or resolve a conflict are determined by how it is perceived (Avruch and Black, 1993; Avruch, 2002) and culture plays a large part in this. For example parties to a conflict

may perceive that particular resources are scare, but it is the surrounding culture that places a value on these resources.

Conflict resolution involves investigating the positions held by conflicting groups and their underlying needs and interests. There is a distinction drawn between needs and interests with the former seen as being a deeper, enduring requirement, and the latter seen as more superficial and transitory (Mayer, 2000). Mayer sees interests as being part of a continuum of needs which begin with basic needs centered on survival and moves through to identity-based needs such as the need for community. The position taken or demands made by a group are often irresolvable but the interests and needs may be easier to reconcile. One example of this is the seemingly intractable conflict between proponents and opponents of GM foods. Both groups continue to argue back and forth based on their positions. Yet a focus on needs and interests could in theory allow for some common ground to be forged between both sides e.g. on their common concerns regarding food security and agricultural sustainability. Such basic needs are common however to both groups and would suggest a starting point for dialogue. In the case of groups in opposing positions relating to GM such dialogue might as a starting focus on issues regarding the safety of GM products.

The ultimate goal of conflict resolution is to remove the underlying causes of a conflict and to re-establish relationships between the warring groups. There are a number of techniques available to resolve a particular conflict according to the power relationships at play in the conflict. These techniques include negotiation, mediation, conciliation, facilitation and problem-solving (Centre for Conflict Resolution, 2005). Negotiation involves direct communication between conflicting groups in order to resolve the conflict and reach a mutually agreeable solution. Mediation requires the involvement of an impartial third party, the mediator, and can result in compromise. Conciliation is similar to mediation but the mediator plays a lesser role in encouraging parties to begin negotiations. Problem-solving involves a third party who brings conflicting groups together so that they can reconsider their relationship and situation in order to find creative, win-win outcomes. This final technique relates to the collaboration management style mentioned in the Thomas-Kilmann Conflict Mode Instrument described in Figure 5.3.

When seeking to address conflict, we need to understand its causes, the strategies employed by the groups or individuals involved and their interests and needs in order to identify the best method to employ. Cultural influences may interfere with resolution efforts as might the frames used to by individuals, groups or indeed the media to provide the conflict with context.

5.2.3 Barriers to resolution: culture, framing and the media

Cultural factors do not create conflict per se (Avruch, 2002); they help shape our perceptions of what a conflict is about, our attitudes and behaviours during a conflict, and ultimately influence the outcomes of the conflict. Avruch and Black (1993) describe culture as "a grammar for the production and structuring of meaningful action" (Avruch and Black, 1993, p. 132). Thus it is necessary to understand the cultural influences that give meaning to a particular behaviour in order to understand the behaviours evident in parties involved in a conflict. When these parties come from different cultures, it is crucial that the third party responds to these differences and undertake cultural analysis. While many cultural elements seem normal or commonsense to its fellow members they may seem strange, irrational and shocking to non-members. For example scientists working in the field of biotechnology may consider public reaction to GM food to be irrational or the result of influence by other groups such as environmental NGOs or special interest groups. In this belief however they fail to see that these reactions may arise from some sectors of the public having an alternative rationality which they consider completely logical given their particular cultural viewpoint (Avruch, 2002). Scientists in this case are themselves influenced by their own professional culture, experience and the scientific evidence upon which their views are formed. Cultural analysis can be a difficult and lengthy endeavour which involves a 'thick description', an interpretation of the interpretation, of how each other's cultural lens may be influencing their decision making (Avruch and Black, 1993).

The framing of a conflict can also delay its resolution. Much like culture, framing helps people make sense of a conflict by providing it with context and indicating its relevance and showing how it resonates with core values. As described by Nisbet and Mooney (2007), frames "allow citizens to rapidly identify why an issues matters, who might be responsible, and what should be done" (Nisbet and Mooney, 2007, p. 56). Thus a frame

can have a dramatic influence on the source of conflict, i.e. emotions, and values, and may help escalate a situation. An article on the use of GM technology may highlight its health benefits/risks, e.g. adding vitamin A to rice to address micronutrient deficiencies, or its health risks e.g. possibility of allergic reaction. Scheufele identifies most people as 'cognitive misers' (Scheufele, 2006, p. 21) who in absence of sufficient motivation to pay attention to debates either use shortcuts or 'rule of thumb'/ heuristics to inform their decisions. In using shortcuts they only collect as much information as deemed necessary to enable them to form an opinion on an issue rather than putting large amounts of time and energy into sifting through quantities of information. If this is the case it suggests there are inherent limitations to public "lay" participation as an adjunct to professional science-based enquiry whose role it is to analyse information on much larger scales and in greater depth than can be conducted by most lay persons.

Heuristics relates to knowledge gained by experience and includes the frames used by the information provider as well as perceptions about their trustworthiness. In times of conflict, there is often insufficient time to become fully aware of all the issues and all the information relating to the conflict situation, thus heuristics and framing play an important role in shaping opinion. Many processes of conflict resolution include one or more stages during which there is a deliberate reconsideration of existing frames (Vraneski and Richter, 2002). Tracing theses frames can be a starting point for identifying entry points for conflict resolution strategies.

The Western media (fed by lobby groups, including politicians) particularly plays a large framing role by signalling which issue is important and by suggesting how an issue could be interpreted (Scheufele, 2006). Merely reporting on a conflict can help escalate it as it brings it to public attention (Baumann and Siegbert, 1993), but the careful use of frames and the regular reframing of a story can ensure that the duration of a debate or conflict can be significantly extended. The media coverage of GM technologies in the UK during the late 1990s serves as an example for this. During this

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⁴⁷The notion of 'motivated tacticians' has begun to replace the idea of the 'cognitive miser' as the preferred theory in the field of social perception. 'Motivated tacticians' tend to be more thoughtful and considered when processing information and do so under particular motivations i.e. values, desired goals and needs, while they may rely on shortcuts such as biases, stereotypes and categorising in other situations (Fiske, 2004).

period a handful of journalists attracted the attention of the UK public to the issue of GM foods and kept public attention on this topic through the judicious choice of frames for the stories (Viella-Vila and Costa-Font, 2008).

5.2.4 Conflict as revolution

Although many people and cultures regard conflict as a negative experience, the good news is that it need not be. Conflict is an intrinsic and inevitable aspect of life and often a catalyst for beneficial change. Within the field of conflict resolution the main aim is not to eliminate all conflict, which would be impossible and probably damaging, but to transform violent (or destructive) conflicts into processes of peaceful (or constructive) social change. Indeed the careful management of small conflicts serves to provide a constant release of pressure and helps avoid larger social catastrophe (Coser, 1956). Conflict is a dynamic process in which the elements of a conflict change and influence each other and can lead to the reorganization of structures and reconsideration of behaviours and attitudes. Conflict does not arise per se due to problems with the technology itself but rather from a myriad of competing factors described above. Conflict resolution efforts serve to identify potential junctures for the beginning of discussions on current conflicts and a means towards minimising conflict in relation to future technologies.

5.2.5 Conflict prevention – the case of Nanotechnology

Nanotechnology emerged as a focus of public interest and concern in the UK in 2003 and the growing media focus on the topic led to the UK government commissioning a study on nanotechnology. This study involved two public engagement exercises and its aim was to uncover the hopes and concerns that the UK publics may have about nanotechnology. The report that emerged from the study recommended that a debate on the future of nanotechnologies be undertaken to inform decisions on their development and before positions on the topic became entrenched (The Royal Society and The Royal Academy of Engineering, 2004). On many topics (technology included) there are persistent calls for a "debate" without any specifics proffered on the objective of the debate, who should debate, how the debate would be organised, what the timeframe of the debate should be or what should be the outputs of the debate. There is much need to clarify what is meant by the term debate in the context of science communication and engagement.

Following the Royal Society recommendations, a series of public engagement activities have been organized in the UK around the topic of nanotechnology while similar initiatives have taken place in the US, Germany, France, Ireland and other countries. A report from the Nanotechnology Engagement Group in the UK gives a broad overview of the lessons learned from engagement activities in the UK and elsewhere. These initiatives provide examples of upstream engagement (Wilsdon and Willis, 2004) and seem to look to broaden stakeholder input into decision making at the early stages of a technology being researched and well before its conversion into a usable product. The report from the NEG shows that while the public are largely supportive of the potential beneficial outputs of nanotechnology in the field of renewable energy and medicine, there are concerns over the potential safety issues associated with nanotechnology as well as concern over the control and regulation of the new technology (Gavelin, 2007).

The principle argument for broader public input is that the public(s) should have sufficient knowledge in order to be able to make informed decisions e.g. on whether to have a child vaccinated against MMR, on which household products are least damaging to the environment etc. The secondary argument is that research is funded by the tax-payer (i.e. the public), thus it is incumbent upon the researcher to be transparent and open about the type of research he/she is carrying out and the possible future applications of this research to show that public money is being well spent.

Nanotechnology has been identified by the UK's Royal Society and others as a potential cause of conflict (The Royal Society and the Royal Academy of Engineering, 2004) and is comprised of two of the dimensions described by Mayers i.e. cognitive and emotional dimensions. The sources of a potential conflict over nanotechnology, as determined using Mayers' 'Wheel of conflict', are largely structural as this technology and its applications have been embraced by industry with attendant concerns regarding regulation and trust. In tandem with scientific discovery and product development in this area is a concerted effort to engage with the public on the topic and address concerns as and when they arise which may help offset potential conflict.

5.3 Research Design

Nanotechnology has appeared at an interesting time when there is broader debate on who should participate in decision making about science and technology and on how this participation might take place. The scale of investment of government and industry into nanotechnology worldwide is considerable. The US alone has ring-fenced a budget of \$3.63 billion over four years for the National Nanotechnology Initiative. Other countries who are investing heavily in nanotechnology are Germany, Japan, South Korea, and, more recently, China⁴⁸.

As an enabling technology with broad economic potential, nanotechnology yields products and applications that can be used in such diverse areas as medicine, pharmaceuticals, environmental engineering, construction, and agri-food. Economic potential is only one aspect of this field of research and it is less clear as to what the social, health, environmental, ethical and legal implications will be. These questions require answers from scientific experts but also will require inputs from a broader range of stakeholders including politicians, ethical advisors, regulators, philosophers, environmentalists, patient groups, consumers' associations etc.

5.3.1 Objectives and relevance of nanotechnology study

This chapter investigates the potential for techniques from the field of conflict resolution to be used in dealing with conflict over technologies. It also looks at the measures being taken currently to engage the public in the early stages of a technology, in this case nanotechnology, and looks at general public awareness and attitudes on this nascent technology.

The convergence of the internet with web 2.0 technologies has redrawn the landscape for communication on science and technology. One-to-one or one-to-many conversations have expanded so that many can engage many in non-synchronous, interactive conversations that can take the form of audio and video recordings, written communiqué, and animated interactions to name but a few. Social media, i.e. media designed to be spread by social interaction, facilitate the sharing of ideas, experiences

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⁴⁸ See www.nanotechnologydevelopment.com/investment/nanotechnology-investment-worldwide.html for more details on worldwide investment in nanotechnology.

and information while also enabling the extension of informal personal networks. Conversations about new technologies and scientific discoveries abound in this online space with perspectives ranging from instant acceptance, to measured concern, and outright rejection.

While many studies have measured the media's ability to amplify public perceptions of risk in relation to new technologies and discoveries, there has been a dearth of research into the influence of informal personal networks, the *second channel*, on the same (Kasperson *et al.*, 1988). Research commissioned by the Society of New Communications Research has shown that social networks are increasingly being used to inform decision making with the professionals surveyed using these networks for gathering peer referrals and opinions (Bulmer and DiMauro, 2009).

YouTube is a video sharing social media tool with over 100 million monthly viewers and more than 150,000 videos uploaded per day. It first debuted in December 2005 and experienced meteoric growth due largely to the fact that YouTube content can be embedded anywhere from blogs, to web pages and on social networking sites. In this study we examined the opinions expressed about nanotechnology and the frames used through watching and analysing videos posted on YouTube over a one year period.

5.3.2 Methodology

The YouTube video public database was searched using the term 'nanotechnology' and videos were analysed one year back from the date of the study, February 2008. The videos were downloaded and stored as flash video files. All data relating to their categorisation, rating, number of views was captured at the time. The full sample of videos was studied to remove duplications, non-English submissions and any erroneous entries. The content of the final sample was then analysed to identify the message being relayed in relation to nanotechnology.

5.4 Results

Using the search term nanotechnology, 308 videos were returned from our search of YouTube which included all videos posted on the topic over a one year period from the posting of the first video in February 2007. Of the 308 videos returned, seventeen were non-English videos, six videos were repeated once and one video was repeated six times. Once these were removed our sample size was reduced to 280 videos. The videos were watched and analysed to identify whether the content was positive towards nanotechnology, negative towards nanotechnology, or ambiguous i.e. containing both positive and negative messages. These categories mirrored those used in a 2007 study on *YouTube as a source of information on immunization* (Keelan, 2007). A high proportion of the videos (91) used the term nanotechnology as a descriptor, e.g. iPod Nano, and the content was not deemed to provide a positive, negative or ambiguous message and these videos were given their own category.

5.4.1 Public opinion on nanotechnology

Once the videos were categorised, we then began an analysis of the videos to determine characteristics which are detailed in Table 5.1.

Table 5.1: Analysis of YouTube videos returned using search term nanotechnology (n=308, 280)

Categorisation	# videos	Mean Clip length (min)	Mean View counts	Mean Viewers' reviews (stars 1-5)
Positive	154 (55%)	4.31	2868	2.87
Negative	22 (8%)	3.07	1378	3.23
Ambiguous	13 (5%)	5.37	754	3.33
Descriptor	91 (32%)	1.90	558	2.19
Mean values		3.75	2777	2.7

As of February 2008, the majority of the videos returned from YouTube during the time period were largely positive in their reference to nanotechnologies and focussed on the beneficial products that may arise from this research as well as the potential for innovations in this area to lead to job creation and to invigorate the economy (Table 5.1). The 8% of videos that referred to nanotechnology in a negative sense were mostly dystopian animations of what might happen if nanomolecules are released into nature.

The most highly viewed videos featured a positive viewpoint on Nanotechnology with the three most highly viewed videos attracting 151,132 views, 48,096 views, and 33,822 views respectively. The highest viewed video was created by University students which was ten minutes in length and resembled a news segment. The same video was posted six times on YouTube in a similar format but the first of these videos attracted the most views. The video had a consistently high star rating with an average of four and a half out of five.

The most highly rated 'negative' video attracted 9,499 views and had a star rating of two and a half. The video was an animated cartoon featuring nanorobots running riot and lasted three minutes. The videos in the ambiguous content group had a similarly low viewing count with the highest viewed video only attracting 3,297 views. This video was part of a three part TV programme featuring a teenage cast using nanotechnology for time travel. Each clip lasted under ten minutes and received a five star rating from its audience. The videos identified as 'descriptors' typically had a lower number of views than any of the other groups. The highest viewed video attracted 9,861 views, was rated four and a half stars, ran for forty seconds and was an educational video on wiring.

5.4.2 Framing of nanotechnology

People using YouTube to upload and host their videos can chose from one of thirteen different categories to identify the content of their video and these categories are provided by the site. *Science & Technology* was the most populated category chosen to describe the videos in our sample followed by the categories *How to & Style, News & Politics*, and *Film & Animation* (Figure 5.4).

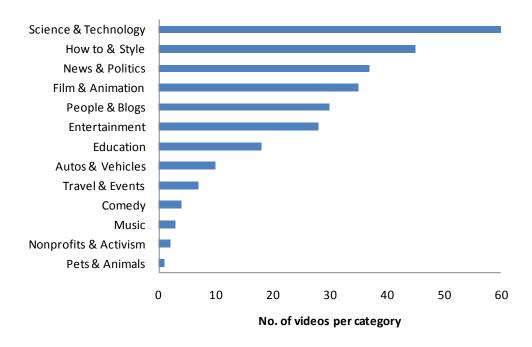


Figure 5.4: Number of videos per category type from full sample (n=280)

In comparison to the full sample, the biggest proportion of the positive content videos were placed in the *How to & Style* category reflecting the number of videos that focus on the products arising from nanotechnology research (Figure 5.5) such as glass windows that do not streak, stain resistant fabrics etc.

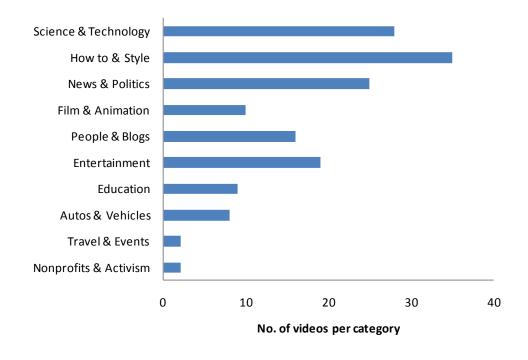


Figure 5.5: Number of videos per category type from positive sample (n=154)

The majority of negative videos are dystopian animations (Figure 5.6) or categorised as *News & Politics*.

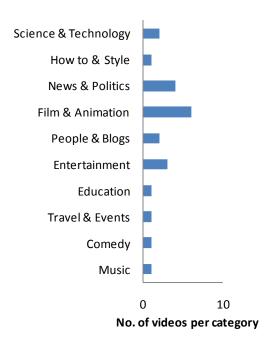


Figure 5.6: Number of videos per category type from negative sample (n=22)

The ambiguous sample was quite small with an almost even spread over category types (Figure 5.7).

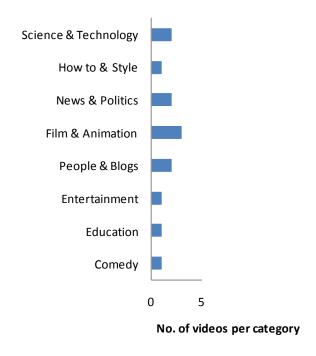


Figure 5.7: Number of videos per category type from ambiguous sample (n=13)

The descriptor sample includes a number of videos displaying machinery involved in photolithography or software used for visualising nanomolecules and similar videos which is reflected in the tendency for these videos to be categorised as *Science & Technology* (Figure 5.8).

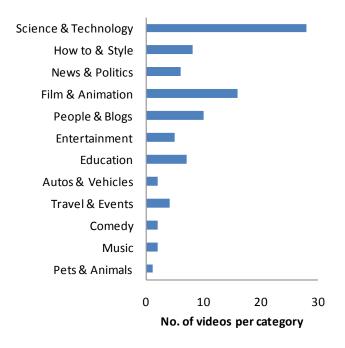


Figure 5.8: Number of videos per category type from descriptor sample (n=91)

When a comparison is made between all four categories we see a similar large number of descriptor and positive videos sharing the same categorisation i.e. *Science & Technology* (Figure 5.9). It is hard to make sense of these numbers as the sample of negative and ambiguous videos are very small in comparison to the positive sample.

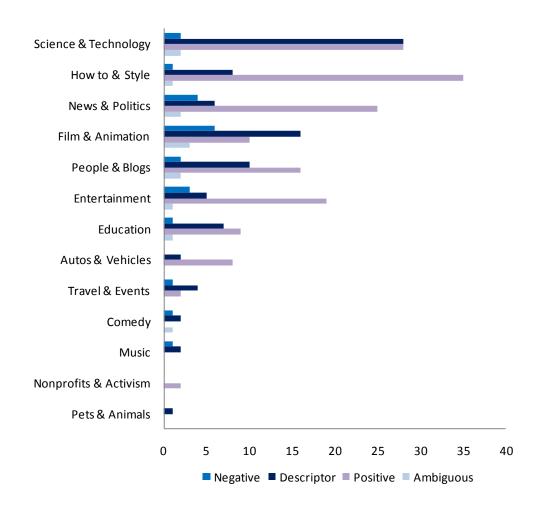


Figure 5.9: Comparative overlay of four video categories (n=280)

5.5 Discussion

The above data would suggest that overall interest in Nanotechnology as of February 2008 by YouTube users is quite low as evidenced from the small number of videos posted on the topic over a one year period especially when you consider that more than 150,000 videos are posted on YouTube daily.

The investigation indicates that the term nanotechnology has begun to be used increasingly as a descriptor or marketing term, e.g. a component in skin care products. These YouTube findings echo other research which shows a low level of public awareness of nanotechnology currently (Currall, 2009; Corley and Scheufele, 2010).

In the YouTube sample studied, nanotechnology tends to be identified with the *Science & Technology* or *How to & Style* categories. These are two of the thirteen individual categories given to choose from when tagging the video for uploading. These category choices can be considered as frames for the videos as these are the terms used to identify a particular video when searched for using the YouTube search function. It would seem from the above results that nanotechnology was framed in 2008 in positive terms as a new scientific enterprise and as the component of or contributor towards novel, useful products.

Interestingly, there are much fewer examples of films and animations relating to Nanotechnology in the 'positive' sample, but this is the category most favoured in the 'negative' and 'ambiguous' samples. When these animations and films were studied they were seen to be set in a dystopian future where the products of nanotechnology wrecked havoc in the world. This suggests that a rival interpretation of nanotechnology is as an uncontrollable potentially catastrophic risk. The frames chosen in the YouTube nanotechnology videos confirm broader research findings that nanotechnology is an emergent topic which is not yet of interest or of great concern to the wider public. Instead, it is a topic for futuristic imaginings or is associated with scientific endeavour and product innovation.

5.5.1 Public opinion on nanotechnology

Despite the identification of nanotechnology in the media as the next potential flash point, the public response has been largely positive towards this technology despite (or

possibly due to) a general lack of factual knowledge on the topic. A 2004 survey by Cobb and Macoubrie in the US revealed that the public reaction is generally positive towards nanotechnology and that, while they do not presume benefits, they expect there to be more benefits than risks associated with it (Cobb and Macoubrie, 2004). The same survey showed however that more than 80% of the respondents had had heard very little about the topic. A later study from Cobb in 2005 has shown that a large amount of the survey respondents are ambivalent towards nanotechnology (more than 40%) with only a small amount more indicating a positive reaction (Cobb, 2005). Results from similar European studies show that there is a positive public reaction generally, but that the public lack knowledge on the topic (The Royal Society and the Royal Academy of Engineering, 2004; Shovelin and Trench, 2007).

Is nanotechnology thus a topic with low potential to spark off public controversy? The dearth of public awareness of the topic makes it difficult to engage the public in discussions of potential benefits and hazards arising from these new technologies. How can the public articulate concerns or support in relation to a technology it is meeting for the first time? Zaller (1992) argues that the lay public does not have well formed opinions on most issues which are not of immediate salience or relevance to their everyday life and livelihood (Zaller, 1992). Opinions and perceptions are instead, he argues, shaped by the media and the efforts of other stakeholders including NGOs.

The analysis of YouTube videos posted on the topic of nanotechnology in the one year period showed that 55% of the videos showed positive content while 32% used nanotechnology as a descriptor with no real indication of a positive or negative slant. These results correspond with wider studies into public attitudes towards nanotechnology which is largely positive (Kahan, 2009; Pidgeon *et al.*, 2009).

5.5.2 Framing of nanotechnology

One possible way of influencing public opinion on new topics is in the use of frames. The frames applied to an issue or topic enable us to organise information on the topic (Vraneski and Richter, 2002) and can be used to influence opinions by highlighting some aspects of the issue thus promoting a particular interpretation (Cobb, 2005). Frames are used by the media to add interest to stories and indicate a particular interpretation of an issue which may be useful when a person has little information about a topic or lacks the interest to form their own opinion (Scheufele, 2006). Research

by Scheufele and Lewenstein suggests that the media currently is emphasising the beneficial aspects of nanotechnology thus providing a positive frame which indirectly influences public attitude (Scheufele and Lewenstein, 2005). A recent analysis of media frames used in the UK shows a preference towards framing in terms of business/economics or scientific discovery (Anderson, 2005).

The YouTube video sample showed that the majority of videos focused on the potential benefits arising from nanotechnology mentioning new products and the positive economic impacts (85 of the 154 positive sample). Videos displaying a negative focus on nanotechnology highlighted the potential risks of these technologies and used a science fiction frame showing an animated futuristic dystopian setting, but this frame was much less prevalent overall (six videos in total). Recent research has shown an increase in health-related queries relating to nanotechnology as evidenced from analysis of Google search trends. This shows a shift away from searches linking nanotechnology and economic possibilities (Ladwig et al., 2010). The search engine research is supported by an additional study which examined people's mental cognitions of nanotechnology. Those surveyed were predominantly seen to associate nanotechnology with the medical field (Cacciatore et al., 2010). This association with the medical field is problematic as it may lead to a permanent link in people's minds between nanotechnology and health which could prove disastrous should these stories take a negative turn. As mentioned earlier, nanotechnology is an enabling technology that impacts upon a number of fields including health research and medicine.

Frames however will only have an impact if "they resonate with underlying audience schemata" (Scheufele, 2006, p. 23) i.e. their beliefs, values, and levels of trust in those providing the information or developing the technology. These schemata are acquired through socialisation or other forms of social learning. Thus there is a need for audience analysis to be undertaken and to identify the most suitable frame prior to creating and disseminating a message. Trust in the information provider becomes a key influence in determining public perceptions of a new technology in times of uncertainty (Slovic, 1999; Stebbing, 2009) and is linked to a belief in the accuracy of the information being provided, the competence of the information provider, and their concern for public welfare (Slovic, 1999; Frewer, 2003). Numerous studies have shown that public trust in scientists remains high (European Commission, 2005) however this trust diminishes

when societal leaders present different viewpoints on an issue. This leads to a frame contest between societal leaders and scientists/regulators and one frame may gain more influence because it resonates more with popular culture or if the viewpoint is encouraged by elites (Nisbet and Scheufele, 2009). What then causes people to form a strong opinion on or change their opinion about an emerging technology?

5.5.3 Influencing public perceptions of nanotechnology

Research into public perception on nanotechnology is emerging and has moved from descriptive studies of current attitudes towards and knowledge of nanotechnology, towards theoretical models on the factors that influence public perceptions and attitudes (Currall, 2009). Kahan et al examined the impact of a person's value system on their response to new information or new technologies. This analysis is based on the culturalcognition hypothesis which refers to the "tendency of people to base their factual beliefs about the risks and benefits of a putatively dangerous activity on their cultural appraisals of these activities" (Kahan et al., 2009, p. 87). People with an egalitarian and communitarian worldview perceive nanotechnology to be less beneficial and more risky while those with a hierarchical and individualist worldview have the opposite perception. Equally people tend to seek out information in a biased fashion which can help reinforce their personal viewpoint e.g. those with a pro-technology viewpoint are more likely to be exposed to information about nanotechnology and also would be more likely to see this information as positive. Despite greater access to quality information on science, knowledge about science remains low as only a small audience is attentive to this information and the fragmentation of the media means that the public are not exposed to science information unless they purposefully seek it out (Genome Prairie, 2005).

There is a clear need to engage citizens in discussions about the development of new knowledge and new technologies, but if biases towards particular viewpoints are so prevalent then what is the point of such engagement exercises? Efforts to engage the public in discussions about nanotechnology have been ongoing since the turn of the last decade, but the effect rather than increased awareness of the topic is a broadening gap between publics based on their educational level (Corley and Scheufele, 2010). On one side of this gap are the well-educated and information rich while on the other side are those with little or no formal education who lack information about these new

technologies. How can this second group be expected to make informed consumer and policy choices? Is it possible to close these knowledge gaps and how is this best achieved? Perhaps the role of the public is to remain uninterested thus ensuring that public engagement exercises truly capture the viewpoint of the broader public and not the particular viewpoint of an interested minority (Evans and Plows, 2007). "It is only those who are non-experts with respect to the science in question who can authentically represent the lay perspective implied in calls for the democratisation of science" (Evans and Kotchetkova, 2009, p. 830).

In addition to the producers of a technology, there are many other stakeholders who stand to benefit economically from steering the debate on nanotechnology. NGOs and special interest groups tend to focus on issues that resonate well with the broader public thus ensuring greater public support and maximising fund-raising and membership possibilities (Bernauer and Caduff, 2004). It is not clear however whether NGOs and special interest groups are responding to public concerns and creating a spiral of increased awareness and focus on issues relating to a new technology and hence greater concern, or rather are themselves the initiators of controversy over an issue. Political parties also may develop strong stances against or in favour of a particular technology as a way of garnering public support. Scientists and technologists have been slow to enter this arena i.e. framing debates on nanotechnology, but may have the most to gain or the most to lose by not participating (Nisbet and Mooney, 2007)

5.6 Conclusions and recommendations

Conflict can be described as arising from the perceived opposition of needs, values and interests. These perceptions can be due to the clever framing of the issue by stakeholders to highlight or suggest a particular interpretation or viewpoint. However, it is not easy to alter or influence the perceptual filters that people use particularly when engaging with science and technology. People will act as *cognitive misers* in how they form opinions if they lack the motivation to pay attention to debates surrounding a topic. Instead they rely on cognitive shortcuts, experiential associations and emotions. The motivations to use increased cognitive resources include the intended outcome or goal, the influence of culture and values (e.g. whether individualistic or communitarian) and the relevance of the information (Fiske, 2004). These motivations can be considered powerful frames also for encouraging public engagement with science. The purpose of framing should not be to manipulate opinion rather to "promote dialogue, learning and social connections and that allow citizens to recognize points of agreement while also understanding the roots of dissent (Nisbet and Scheufele, 2009, p. 1771).

5.6.1 Barriers to shaping public perceptions

Nanotechnology has been identified as the next potential flashpoint over science and technology, but this does not seem yet to be the case (Kahan, 2009). This may be due to early downstream engagement by scientists and other stakeholders with the public on the topic or perhaps it is due to how nanotechnology is being framed by the media and other stakeholders as being of great potential benefit. Other reasons could simply include the fact that most nanotechnology research is at an early stage with limited nanotechnology products in existence or being deployed/sold commercially. Hence, it may be simply too early for opposition to nanotechnology products to gain traction by those seeking a moratorium on nanotechnology research. The long march to engendering societal opposition to technologies can take decades which is also the timescale for policy developments. In September 2010, the Belgian European Union (EU) Presidency indicated that it is proposing to create a specific register for nanomaterials under the EU's REACH (Registration, Evaluation, Authorisation and Restriction of Chemical substances) regulation, while also making it mandatory to label their presence in consumer products. This policy solution may prevent against a moratorium on nanomaterials which may have been requested if the precautionary principle is invoked

as the risk of these materials in terms of human health and environmental impact have not been determined.

In this regulatory context, rival frames are only now just beginning to emerge, such as nanotechnology being the asbestos of tomorrow and 'nano is nature'. The frame 'asbestos of tomorrow' is problematic in that it suggests a limited way of interpreting nanotechnology and strengthens the case for a strict use of the precautionary principle in nanotechnology regulation. The frame 'nano is nature' has been used primarily by European companies to encourage a benign view of nanotechnology but similarly this disregards debate surrounding nanotechnology. In the absence of public interest in and awareness of issues relating to nanotechnology a gulf exists which gives scientists and technologists or opposing stakeholders the opportunity to carve frames to shape future debate on the topic.

The conflict resolution tools described in this chapter can be used by parties to a conflict to identify possible junctures for addressing a conflict in order to emerge from it unscathed. In the case of nanotechnology however this intervention is currently premature but may be warranted in the years ahead. Perhaps rather than heading off potential conflict on the topic, it may be more advantageous and constructive for the benign development of nanotechnologies to allow the flames to be fanned a little and allow debate and counter-debate to occur on the topic. This would be likely to increase people's interest in and awareness of the topic. In this scenario, conflict is not always a negative occurrence and can be a powerful tool for education and social change. In this case conflict over nanotechnology could help encourage a dialogue about the future directions of science and technology as a form of social barometer for scientific innovation.

5.6.2 Opportunities for engaging the public

The YouTube video analysis shows that the public response to nanotechnology is largely positive, but this needs to be interpreted in light of the evidence of a low level of public awareness of the emerging technology. The question remains as to how the

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⁴⁹ The 'nano is nature' frame has been used to describe materials created using nanofibres, e.g. non-absorbent table cloths, napkins and umbrellas, which are compared to the natural ability of plant leaves and flowers to repel water and dirt.

broader public can be engaged with in relation to this topic and whether efforts to raise awareness of, interest in or desire for increased dialogue or debate on the topic are premature.

One criticism voiced by Brian Wynne in relation to participation or engagement activities is that they tend to resemble risk management exercises and are less interested in gathering public opinion rather in discouraging or sidestepping public disquiet (Wynne, 2006). Douridé argues that public participation initiatives are seen by some scientists as a type of diagnostic instrument to guide the development of their message on a particular topic (Durodie, 2003). This view is countered by studies showing that scientists' intentions to participate in public engagement activities are predicated on feelings of capacity to participate, perceptions of whether participation is positive or negative, and their previous levels of participation (Poliakoff and Webb, 2007). Nonetheless, the aspiration of public engagement of science has been conceptualised as a dialogue leading to socially robust knowledge (Nowotny *et al.*, 2001) and clearly the delivery of public engagement activities is problematic.

One way to address this criticism of public engagement activities might be in developing engagement exercises that are not policy focussed (i.e. goal oriented) but rather interested in sharing viewpoints on a particular issue. In such scenarios there is less focus on consensus thus circumventing the polarisation that occurs in such activities and allowing a multitude of positions to be explored. The purpose of non-policy dialogue instead is on social learning and the articulation of different viewpoints (Limoges, 1993). Care is required however to ensure that there is symmetry across learning hierarchies and expertises and that all participants contribute to discussions on what content should be discussed in relation to an issue as well as the identification of what issues should be discussed in the first instance (Davies *et al.*, 2009). This initiative could be complementary to typical deliberative forums which allow interested stakeholders to discuss potential policy solutions to issues relating to a new technology.

Practical considerations such as costs, recruitment issues and time investment may dissuade against this non-policy focussed activity; however there are for where such debate could be encouraged. These include Higher Education Institutions, museums, libraries and other traditional and novel arenas for public engagement. One example is

the Science Gallery (Ireland) which invites scientists, artists, musicians and the general public to submit ideas for exhibits with a particular focus that resonates with broader societal issues e.g. INFECTIOUS, BIORYTHM, HUMAN+. The successful submissions are developed into an exhibit by a multidisciplinary group thus allowing the disparate groups to discuss and debate their ideas. Similar initiatives have the potential to encourage discussion between scientists and the wider public and could be supported at a local level by municipal councils. Nisbet and Scheufele highlight the need for localized communication efforts in order to provide information on "adapting to climate change or managing the localized implications of emerging technologies such as nanotechnology" (Nisbet and Scheufele, 2009, p. 1775) which supports the reasoning for local councils to become involved in these initiatives.

5.6.3 Recommendations

- 1: There is a need to analyse how different groups filter or interpret technological or scientific information when it reaches them given their personal value systems and beliefs.
- 2: Science communication efforts should begin with an appraisal of the intended recipients' values, their current understanding on the topic, their perspectives on the subject and how these have arisen, their social and cultural context and their preferred media and information sources.
- 3: Guided by such research, engagement exercises should be tailored to publics from different backgrounds, including educational backgrounds and ages, and different interests/motives. Similarly communications should be tailored to the requirements of these diverse groups so that the communication resonates best with their inner schemata, i.e. the internal cognitive frameworks by which we perceive and respond to different situations or information. These initiatives should utilise a myriad of different media to ensure as broad an audience as possible is reached.
- 4: The purpose of framing an issue should not be sell science (Nelkin, 1994) rather different frames should be used to promote dialogue, and foster social learning so that citizens recognise points of agreement and disagreement.
- 5: Researchers, regulators, policy makers and funding agencies should participate in upstream engagement activities. As well as allowing broader public concerns to be identified early on, such engagement will also ensure that these groups help frame a

potential debate rather being forced to respond to a debate as framed by other groups (Hotchkiss, 2001).

6: A dual engagement could be considered where deliberative forums are organised to enable interested publics to help inform policy decisions and the development of a new technology, thus ensuring science becomes more socially robust. The second engagement initiative would not be focussed on informing policy rather would encourage general discussion on the topic so that all positions and perceptions are put forward and equal consideration be given to expert and non-expert knowledge to ensure symmetrical learning of each other's viewpoints.

7: Research should be undertaken to examine the potential use of social networks for amplifying individual perceptions on a topic and tracing their ability to influence public opinion.

5.6.3 Future research

As indicated in Chapter 3, the author is engaged in a four year project with the UCC Science Shop entitled *The Public Engagement with Research and Research Engagement with Society (PERARES)*. Nanotechnology is one focus of this project and a transnational debate on Nanotechnology will be organised for early 2011, the purpose of which is to identify research questions relating to this topic area and to feed these back to the partner institutions and national funding bodies and indentify and encourage potential research projects on the topic. It is the intention of the author to use the findings of this chapter as a baseline study and to engage with the PERARES project to progress these ideas and research questions in early 2011 at which juncture there may be increased public engagement in dialogue relating to nanotechnology.

Overall Conclusions

The governance of science, technology and innovation, or STI, has become a topic of increased scrutiny in the last few years and, rather than observing a crisis of trust in science, it seems that concerns instead are centred on questions of legitimacy, transparency and accountability in relation to policy decision making regarding STI (Wilsdon *et al.*, 2005). There is a need to develop governance mechanisms that align better with democratic values of representation and participation (Lidskog and Elander, 2007) and this PhD dissertation highlights some mechanisms that may facilitate this.

The research undertaken in developing this PhD thesis explores two particular areas i.e. mechanisms to facilitate the co-production of knowledge (Chapters 2 and 3) and initiatives to support public engagement in deliberations relating to science and technology (Chapters 4 and 5).

6.1 Co-production of knowledge

To better address complex problems there is a need for the inclusion of other viewpoints and expertise to strengthen the contribution from scientific knowledge. Scientific and technological communities no longer are the main producers of knowledge and increasingly research is conducted in other areas of relevance. The Science Shop model is one method for the co-production of knowledge and ensures that research being produced answers expressed local concerns. Experience-based experts such as patient groups can have a vital role also in research. They can highlight priorities regarding novel applications or research trajectories at an early stage thus ensuring that the end product or outcome is more acceptable and suitable to consumers and the broader public. They also play a key advocacy role and can ensure increased government funding for particular research or highlight regulatory issues that might prevent against the development of particular treatments e.g. as advocates of stem cell research. There is some danger that patient groups could steer decisions in a selfish manner (but this is no different than being a self-help group) or that they are 'astroturf'

organisations⁵⁰ and thus they should be one of many voices heard in a broad consultation.

6.2 Public engagement in STI deliberations

Public Engagement in Science, PES, is a term used in reference to a number of different initiatives that involve the public in deliberations concerning science and technology. These initiatives emphasise dialogue with stakeholders, and stakeholder participation in decision making processes; thus PES is considered a democratic model for science communication. Although this model is advocated in science communication activities, it is rarely used in practice. Instead communicators revert to the much maligned 'deficit model' which involves the linear transmission of information to the public and provides little capacity for feedback or the consideration of other viewpoints other than those of the scientific and technological community.

PES initiatives can also suffer an overemphasis on the process rather than on outcomes. Oftentimes engaging the public is seen as an end in itself and an example of democracy in action. However, engagements that lead to impacts could take the form of public inputs that inform policy making or influence research funding priority setting. Researcher involvement is key to the success of public engagement initiatives as it ensures the closing of the one of the feedback loops and, in the case of the Science Shop model, it can broaden researchers' awareness of societal research needs and concerns. Public engagement is often a question of motivation both in terms of motivating researchers to become involved in these initiatives and in terms of encouraging public interest in and engagement with scientific and technological topics. The final research chapter of this PhD thesis, chapter five, identifies ways to shape frames and public perceptions in order to encourage public involvement and interest in deliberations concerning new technologies. Overall, this PhD thesis asks the question as to whether the democratic model of science communication can influence scientific, innovation and technological trajectories. The answer is yes in theory and maybe in practise, but it is clear that there are a number of institutional supports that would be required to facilitate this happening.

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⁵⁰ Astro-turfing occurs when companies or NGOs influence deliberations through the provision of supposedly 'grassroots' patient representatives who instead represent the perspective or advocate for the position of the company or NGO.

6.3 Recommendations and suggestions for further research

Specific recommendations are made in each research chapter on how to enhance particular activities and initiatives to encourage broader public engagement and participation in relation to scientific and technological issues. In the below tables these recommendations are synthesised, and areas for future research are identified.

6.3.1 Public inputs into STI policy setting

Create national initiatives to support broader public inputs into policy setting

Required steps:

- 1: Encourage funding agencies to link with special interest groups such as patient groups to develop cohesive policy on health and biomedical R & D and to encourage their involvement in the early stages of policy development. The use of deliberative exercises may facilitate this e.g. a consensus conferences amongst interested stakeholders regarding a particular aspect of health and biomedical research. The Office of the Chief Scientific Adviser in Ireland might play a role also in facilitating these deliberative exercises.
- 2: Policy development agencies or departments could modify policy consultation exercises to ensure that a larger number of interest groups are able to participate whether through awareness raising, through organising online consultative exercises to enable participation of time and resource poor organisations or through the provision of supports and funding to umbrella organisations e.g. the Medical Research Charities Group, to enable them to support patient group involvement in such consultations.
- 3: Local councils and local Higher Education Institutions (HEIs) could provide support and funding for community based research (CBR) initiatives such as the Science Shop model. This would facilitate the co-development of knowledge, particularly if support is provided for collaborative participatory research projects with Civil Society Organisations (CSOs) on topics relating to expressed local needs and concerns. There are a number of projects in place in HEIs around Ireland that are focussed on CBR e.g. Community Knowledge Initiative in NUI

Galway, but these initiatives would need to be embedded within the HEIs to ensure their sustained support and continuation.

6.3.2 Public engagement initiatives

Provide supports and incentivise stakeholder involvement in public engagement initiatives i.e. both researchers and the public

Required steps:

- 1: Provide researcher communication training to facilitate reframing of information to suit particular audiences. This should include the provision of modules to develop awareness of alternative cultural contexts and viewpoints on knowledge. An example of this is the module on *Unravelling Complexity* provided by the Australian National University. This module involves a series of lectures across disciplines on topics that highlight the complexity of modern problems. For example a recent focus of this module was on the topic *Collapse*. The module included presentations from a mathematician on chaos theory and fractals, from a historian on what caused the Roman empire to endure while other empires collapsed, and from an economist on the economic downturn. The interdisciplinary nature of the talks highlights the obfuscations caused by disciplinary boundaries i.e. what was considered complex or difficult in one setting is considered commonplace or unproblematic in another thus highlighting how different rationalities and cultural viewpoints can lead to different responses or understandings (Avruch, 2002).
- 2: Broaden outreach activities to include engagement with wider community and place increased emphasis on social learning. This might include having research departments become involved in Youth Science-Cafés in secondary or primary school. These Cafés would have the same format as the adult version facilitating debate about issues and topics arising from the expert's talk. Extra supports such as allowing secondary or primary school students to ask questions in groups and make participation count towards in-class assessment for example could help encourage student participation. Similarly participating researchers should have their involvement in outreach be recognised either through the provision of credits or as part of a general course of public

engagement and outreach required of all research masters students, PhD students and staff undertaking professional development courses.

- 3: Funding agencies could include a public engagement requirement when awarding grants and similarly HEIs could support researcher involvement through the recognition of staff involvement in public engagement activities in promotions and in identifying workloads. This could include support for bottom-up approaches to research such as the Science Shop models. Government programmes such as *Discover Science and Engineering* already support innovative activities to engage school children in science and technology but these suffer from lack of engagement with the broader research community and an over-emphasis on the promotion of science and encouraging scientific careers. Funding support for projects that engage the broader community could also be provided at both local and national level.
- 4: Public engagement initiatives should be informed by best practice and a funding stream developed to encourage research into the impact of public engagement activities (as well as cost benefit analysis of these initiatives conducted). This suggestion for measuring impact follows the model of the scholarship of teaching and learning where HEI lecturers are encouraged to research their own teaching and can publish in related international journals and help foster scholarly development in this area. The Science Shop model would benefit from a similar scholarly approach by conducting longitudinal studies on the impact of involvement in Science Shop projects on students, HEIs, research communities and CSOs.

6.3.3 Framing and disseminating

Encourage technological citizenship through careful framing and broad dissemination of information on issues relating to STI

Required steps:

1: The use of democratic models for science communication can help ensure that the technological citizens' access to knowledge and to participate in discussions and debates relating to STI are facilitated. However, it is difficult to encourage the broader populace to carry out the responsibilities assigned to them in return for the rights conferred (i.e. to achieve technological literacy and engage with current problems). Public engagement exercises need to be tailored to particular audiences to attract their interest and attention. Research should be conducted nationally to identify the perspectives, preferred media sources, current understandings and cultural contexts of desired audiences. The results of this research could feedback into and held sculpt future engagement activities.

- 2: There is a need to explore different media streams for engaging audiences. Social networking and Web 2.0 interfaces might be appropriate sites for initiatives that encourage debate and discussion about science, technology and innovation. These initiatives could take the form of social learning initiatives with an emphasis on talking across hierarchies of expertise and incorporating a plethora of viewpoints. These talking shops would be complimentary to more formal deliberation exercises that are linked with policy decision making.
- 3: One concept of active citizenship is as "participation in civil society, community and/or political life, characterised by mutual respect and non-violence and in accordance with human rights and democracy" (Hoskins, 2006, p. 4) and could be reformulated to place an emphasis also on developing information literacy across all disciplines. This would enable citizens to rapidly locate useful information and to determine the trustworthiness of the sources and the validity of the claims. Information literacy is a key competence to be fostered as societies become more dependent on technology and could be stated as a public goal.

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Appendix A: Health and Patient group survey questions

Purpose of Survey

The objective of this survey is to gain a better understanding of the **mechanisms and extent** to which health and patient groups can be more actively involved in **decision-making and priority setting** for biomedical research & development (R & D) in Ireland. This research is part of a broader IRCHSS (Irish Research Council for the Humanities & Social Sciences) project aiming to identify practical models and good practices for engaging a broader range of stakeholders in policy and funding decisions regarding scientific R & D innovation priorities in Ireland.

Output of Survey

The findings of the survey will be synthesised in a draft discussion document containing inter alia: **good practices identified**, and **recommendations** from the health and patient group communities for possible improvements in **priority-setting and stakeholder engagement mechanisms** for biomedical R & D in Ireland.

This draft discussion document will be re-circulated to all stakeholders contacted for further comment and inputs prior to finalisation. The final document will then be circulated to research funding bodies, government departments, biomedical researchers, health groups and patient groups with the aim of encouraging **greater stakeholder input** into decisions about funding and priority setting decisions for biomedical R & D.

The information contained in this survey will be treated as **confidential**.

There are 4 sections to this survey, each containing 15-20 short questions. Thank you in advance for your participation.

Section A: Involvement in Decision making and priority setting for R & D

Part 1: Involvement in Research 1. Does your organisation have a mission statement? Yes No Don't know If yes, please state here: 2. Does your group/organisation fund research & development into your disease/syndrome of interest? Yes No Don't know Planned for the future (5 years) If no, why not?

	Main activity	One of several activities	Very minor	None	Don't know
Advocacy/ lobbying					
Health Research					
Patient care/support					
Health promotion					
□ Yes □ No					
□ Planned for the fut If no, why not? 5. Does your organis □ Yes □ No		t important	to fund biomed	ical researc	ch in Irelai
□ Don't know □ Planned for the fut If no, why not? 5. Does your organis □ Yes □ No □ Don't know If no, why not?		t important	to fund biomed	ical researc	ch in Irelai
□ Planned for the fut If no, why not? 5. Does your organis □ Yes □ No □ Don't know	sation consider i			ical researc	ch in Irelai
☐ Planned for the fut If no, why not? 5. Does your organis ☐ Yes ☐ No ☐ Don't know If no, why not? Section A: (Part 1: 6. How much does y	sation consider i	in Research	cntd)		
☐ Planned for the fut If no, why not? 5. Does your organis ☐ Yes ☐ No ☐ Don't know If no, why not? Section A: (Part 1: 6. How much does y	sation consider i	in Research n spend on b	cntd)		
☐ Planned for the fut If no, why not? 5. Does your organis ☐ Yes ☐ No ☐ Don't know If no, why not? Section A: (Part 1: 6. How much does y (€)?	sation consider i	in Research n spend on b	cntd) iomedical R & 3	D funding J	
☐ Planned for the fut If no, why not? 5. Does your organis ☐ Yes ☐ No ☐ Don't know If no, why not? Section A: (Part 1: 6. How much does y (€)? ☐ None	sation consider i	in Research n spend on b	cntd) iomedical R & 3	D funding p	

8. Approximately how much (% of budget or actual figure) is spent annually by your organisation on the following types of research (please indicate below for each type):

Basic/fundamental research*	
Applied research**	
Disease management***	
Patient & palliative care	
Epidemiology studies	
Clinical trials	

Other, please indicate:

9. Biomedical research can be expensive. Does your organisation have the resources to fund biomedical research costs such as the following:

Tulia Sioliicaicai i est	car car copes	buch up the for	10 11 111g.		
	All	Part	None	Don't know	
Labour*					
Equipment					
Consumables**					

^{*} Post Grad student costs €25,000 inc. fees, Post Doc researcher costs €50,000 inc. PRSI and pension contributions

10: Have you biomedical research links with any of the following groups in Ireland?

,	Yes*	No	Don't know	Planned for the future (5 years)
Research Institutes				
Hospitals				
Companies				
Universities and ITs				

^{*} If yes, please read following classification guide before answering question 11

Classifying patient-group participation in biomedical R & D

Biggs (1989) identified four levels of participation in farming research: contract, consultative, collaborative and collegial. These levels represent the extent and type of participation and can be used in this case to examine patient-group participation in biomedical R & D.

Participation can be:

Contractual: researcher uses the facilities or resources of the patient groups and sufferers to carry out his or her research

^{*} understanding cell or molecular mechanisms

^{**} development of therapeutics

^{***} development of treatment regimes

^{**}Consumables cost €15,000 - €20,000 per person per year

Consultative: researcher consults the patient groups to identify problems and then find solutions. Patient groups play a fairly passive role

Collaborative: researcher and the patient groups work together in the design and carrying out of the research, and discuss the implementation continuously.

Collegiate: patient groups play a major role in designing the research, defining the methods, analysing and interpreting the data, and implementing the outcomes.

11: Please classify your level of involvement with the following groups (more than one answer is possible)

(more than one answer is possible)							
	Contract	Consult	Collaborate	Collegial			
Research Institutes							
Hospitals							
Companies							
Universities and ITs							
None of the above							

12: Have you biomedical research links with any of the following groups outside Ireland (in the EU)?

(111 1110 22 0) 1				
	Yes*	No	Don't know	Planned for the future (5 years)
Research Institutes				
Hospitals				
Companies				
Universities and ITs				

13: If yes, please give details:

14: Have you biomedical research links with any of the following groups in countries outside of EU member states?

	Yes*	No	Don't know	Planned for the future (5 years)
Research Institutes				
Hospitals				
Companies				
Universities and ITs				

15: If yes, please give details:

Section A: (Part 2: Funding of organisation and research)

16: What is your organisation's/group	p's over	all an	nual b	udget (€))?		
□ €0 - €100,000		□ €100,001 - €250,000					
□ €250,001 - €500,000		□ €500,001 - €1 million					
□ €1,000,001 - €5 million		□ €5,000,001 - €10 million					
☐ Greater than €10million		□ Don't know					
17. Please estimate what percentage or research and development (average or	•			et is sper	nt on bio	omedica	l
□ 0-2%		□ 2.1	-5%				
□ 5.1-10%		□ >1	0%				
□ None			n't kno)W			
18: Approximately what % of your bu	udget c	omes f	from th	ne follow	ing sou	rces?	
Government*							
Private Industry**							
Private Donations***							
Membership fees							
Other, please indicate							
* grants							
** pharmaceutical companies, food groups							
*** fund-raising, benevolence funds, sponso	orship (n	ot indu	ıstry), pe	ension fur	nds		
19. Please rank in order of importanc income (tick all that apply):	e (1 = n	nost ir	nporta	nt) your	sources	s of over	all
			1	2	3	4	5
Fund-raising (e.g. from public)							
Membership fees							
Health Research Board grant							
Dept of Health and Children grant							
National Lottery grant							
Local government grants							
EU grants							
Welcome Trust							
Pharmaceutical Industry funding							

Food Industry funding

Non-governmental organisations

21. Are you aware of the level of government funding on your disease of interest?
□ Yes
□ No
22. Please rate the level of Irish government funding on biomedical research of your disease of interest:
□ High
□ Sufficient
□ Low
□ None
□ Don't know
23. If you answered "low or none" above, is there a need to increase Irish government funding on biomedical R & D related to your disease of interest?
□ Yes
□ No
□ Don't know
If answered, please list any barriers that prevent increased funding
24. If you answered "sufficient or high" above, are there opportunities for further Irish government spending in this area?
□ Yes
□ No
□ Don't know
If answered yes, please identify the opportunities
25. What % of your overall budget is received from these sources (please indicate below)?
Fund-raising (e.g. from public)
Membership fees
Health Res arch Board
Dept. of Health and Children grants
National Lottery grants
Local government grants

20: Other, please indicate

EU grants

Wellcome Trust	
Pharmaceutical Industry funding	
Food Industry funding	
Non-governmental organisations	
Other, please indicate	
Section A: (Part 3: R & D Needs assessn	nent & prioritisation)
26. Does your group/organisation have a med in terms of research & development?	chanism for assessing the needs of patients
□ Yes	
□ No	
□ Don't know	
□ Planned for the future (5 years)	
27. If answered yes to above, please provide out.	details on how these assessments are carried
28. If answered no to above, would such an a explain your answer)	assessment mechanism be desirable (please
29. Does your group/organisation have a medin terms of research & development?	chanism for <i>prioritising</i> the needs of patients
□ Yes	
□ No	
□ Don't know	
☐ Planned for the future (5 years)	
30. If answered yes to above, please provide	details on how this prioritisation occurs
31. If answered no to above, would such a prexplain your answer)	rioritisation mechanism be desirable (please
32. Which members of your group/organisat of patients in terms of research & developme	<u> </u>
☐ Biomedical Researchers	
☐ Medical Doctors (physicians)	
☐ CEO/Director of Patient group	

☐ Patient representatives						
□ Patients						
□ Nurses						
□ Carers						
☐ Industry representatives						
☐ Government officials						
Other (please specify)						
33. Which members of your group/organisation of patients in terms of research & development		respons	ible for	prioriti	ising th	e needs
☐ Biomedical Researchers						
☐ Medical Doctors (physicians)						
☐ CEO/Director of Patient group						
□ Patient representatives						
□ Patients						
□ Nurses						
□ Carers						
☐ Industry representatives						
☐ Government officials						
Other (please specify)						
34. Please describe below how the research private with regard to funding.35. Who makes these decisions? Rank according influential (more than one answer possible).						
	1	2	3	4	5	N/A
Biomedical Researchers						
Medical Doctors (physicians)						
CEO/Director of Patient group						
Patient representatives						
Patients						
Nurses						
Carers						

Industry representatives

Government officials

37. Do you have mechanisms in planted by your organisation?	lace to monito	or/evaluate t	he effectiveness of research
□ Yes			
□ No			
□ Don't know			
☐ Planned for the future (5 years)			
38. If answered yes to above, plea	se describe th	e mechanisr	ns
39. If answered no to above, is the	ere a need for	such mecha	nisms?
40. Do you have mechanisms in pl funded by <i>other organisations</i> (in			
□ Yes			
□ No			
□ Don't know			
☐ Planned for the future (5 years)			
	1 9 41		
41. Is answered yes to above, plea	se describe th	e mecnanisi	ns
42. If answered no to above, is the	ere any need f	or such a m	echanism?
Section A: (Part 4: Communication)	ation of R &	D needs &	priorities)
43. Does your group have any for any of the following R & D funding		m for comn	nunicating R & D needs to
any or one ronowing it to D runain	Yes	No	Don't know
Health Research Board			
Wellcome Trust			
Science Foundation Ireland			
Dept. of Health and Children			
Pharmaceutical companies			
Food Industry			
44. Other, please indicate			

36. Other, please indicate who else makes the decisions.

45. If answered yes to above question:					
(a) give details about this mechanism (indicating which funding body)					
(b) list the most effective mechanisms for communicating R & D needs to funding bodies					
46. Does your group/organisation have a formal mechanism for communicating R & D needs to researchers in:					
	Yes	No	Don't know		
Hospitals					
Universities and ITs					
Pharma companies					
Food Industry					
Research Institutes					
47. Other, please indicate					
48. If answered yes to above:					
(a) give details about this mechan	ism (indicati	ing which type	e of Institutions)		
(b) list the most effective mechani these Institutions	isms for com	municating R	& D needs to researchers in		
49. In your opinion is there a need for mechanisms to communicate the R & D needs of patients?					
□ Yes					
□ No					
□ Don't know					
50. If you answered yes above, please describe what type of mechanism would be suitable.					
You have reached the half-way mark, please continue until the end					
Section B: Description of your organisation					
Part 1: Disease Focus					
51. Please indicate below which disease(s) or syndrome(s) your organisation is concerned with. (If more than one disease is focussed on then, please answer here for principal disease and add further comments below).					

52. What is the incidence* of the disease(s) or syndrome(s) in Ireland?

53.	What is the	prevalence*	of the	disease(s) or s	vndrome(s)) in	Ireland?

54. What is the annual mortality rate from this disease in Ireland?

55. What is the estimated annual cost of care for an individual with this disease in Ireland?

56. Please provide parallel information here for other disease(s) that your organisation is focussed on: (e.g. incidence, prevalence, mortality rate, cost to health care etc).

Section B: (Part 2: Structure of group/organisation)

57. What number of staff are:

	1-4	5-9	10-14	15-19	20+	Don't know
Full-time						
Part-time						
Voluntary						

58. Please estimate the percentage of full-time staff involved in the following functions:

co. I lease estimate the percentage of fair	mie stan myorvea in the ronowing runctions.
Administration	
Fund-raising	
Management	
Communications & Awareness raising	
Research-related	
Support services	
Accounting	
Information technology	
Other, please indicate	

59. Please estimate the percentage of part-time staff involved in the following functions:

Administration	
Fund-raising	
Management	
Communications & Awareness raising	
Research-related	
Support services	

^{*} rate at which new occurrences of a disease or syndrome appear in the population

^{**} the proportion of individuals in a population with a disease or syndrome

	-			
Accounting				
Information technology				
Other, please indicate				
60. Please describe the management structure of the group/organisation:				
61. Does the organisation/group have a Boar	rd of management?			
□ Yes	d of management.			
□ No				
□ Don't know				
□ Planned for the future (5 years)				
62. If answered yes to above question, how rare present on the board?	nany individuals from the following groups			
Biomedical Researchers				
(Research Group Leaders)				
Medical Doctors (Physicians)				
Patient representatives				
Patients				
Nurses				
Carers				
Industry representatives	+			
Government official	+			
Lay persons Legal representatives				
Other, please indicate	1			
Other, piease indicate				
63. What are the main mechanisms by which organisation/group are accountable to the n	<u>e</u>			
Section B: (Part 3: Research & Funding	Policies)			
64. What is your organisation's policy in rel company) funding?	ation to private sector (e.g. pharma			
☐ Have best practice guide				
☐ Have policy in place				
□ Considering policy				
□ No policy in place				
□ Don't know				

Other (please specify)
65. What is your organisation's policy in relation to public sector (e.g. government) funding?
☐ Have best practice guide
☐ Have policy in place
□ Considering policy
□ No policy in place
□ Don't know
Other (please specify)
66. Does your organisation have any policies on intellectual property rights in biomedical research of relevance to your disease focus?
□ Yes
\square No
□ Don't know
□ Planned for the future (5 years)
67. If answered yes to above question, please provide details here:
Section C: Outreach and awareness raising
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease?
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? □ Yes
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? □ Yes □ No
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? □ Yes □ No □ Don't know
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? □ Yes □ No □ Don't know
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? Yes No Don't know Planned for the future (5 years)
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? Yes No Don't know Planned for the future (5 years) 69. If answered yes above, for what purpose?
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? ☐ Yes ☐ No ☐ Don't know ☐ Planned for the future (5 years) 69. If answered yes above, for what purpose? 70. If answered no above, why not?
Section C: Outreach and awareness raising Part 1: Science communication and outreach 68. Does your organisation monitor recent advances in science and technology of relevance to your disease? Yes No Don't know Planned for the future (5 years) 69. If answered yes above, for what purpose? 70. If answered no above, why not? 71. Does your organisation utilise a strategy for communicating new research findings?

□ Planned for the future (5 years)
If yes, please give details of this:
72. Please indicate to which of the following groups your organisation communicates new research findings: (tick all that apply)
□ media/journalists
□ members
□ patients
□ carers
□ general public
□ health officials
□ politicians
□ researchers
□ medical doctors (physicians)
□ funding bodies
Other (please specify)
73. What is the purpose of this communication?
73. What is the purpose of this communication?74. How do you communicate your research findings?
74. How do you communicate your research findings?
74. How do you communicate your research findings? □ press releases
74. How do you communicate your research findings? □ press releases □ scientific papers
74. How do you communicate your research findings? □ press releases □ scientific papers □ media interviews
74. How do you communicate your research findings? □ press releases □ scientific papers □ media interviews □ newsletter
74. How do you communicate your research findings? □ press releases □ scientific papers □ media interviews □ newsletter □ meetings
74. How do you communicate your research findings? □ press releases □ scientific papers □ media interviews □ newsletter □ meetings □ website
74. How do you communicate your research findings? press releases scientific papers media interviews newsletter meetings website conferences Other (please specify) Section C: (Part 2: Representation on National Committees) 75. Is your organisation a member of any national committees on policy in biomedical R & D funding in Ireland?
74. How do you communicate your research findings? press releases scientific papers media interviews newsletter meetings website conferences Other (please specify) Section C: (Part 2: Representation on National Committees) 75. Is your organisation a member of any national committees on policy in biomedical R

□ Don't know					
76. If answered yes to above question, please indicate which committees					
77. If answered no, please indicate which committees you would like to participate in					
78. Are there any barriers towards becom	ing in	volved	l in such c	ommittees?	
□ Yes					
□ No					
□ Don't know					
If answered yes to above, what are they?					
79. Is your organisation a member of any & D funding in Europe?	nation	nal cor	nmittees o	n policy in biomedical R	
□ Yes					
□ No					
□ Don't know					
☐ Planned for the future (5 years)	□ Planned for the future (5 years)				
80. If answered yes to above question, please indicate which committees					
81. If answered no, please indicate which o	commi	ittees	you would	like to participate in	
82. Are there barriers present towards gain	ining a	access	to such co	ommittees in Europe?	
□ Yes					
□ No					
□ Don't know					
If answered yes to above, what are they?					
83. Which of the following organisations drepresentation in?	loes yo	our gr	oup/organ	isation have active	
	Yes	No	Don't know	Planned for the future (5 ears)	
Medical Research Charities (MRC)					
Irish Platform for Patients Organisations, Science and Industry (IPPOSI)					

Irish Patients' Association (IPA)

European Platform for Patients Organisations,

Science and Industry (EPPOSI)				
Working Group with Patients' & Consumers' Organisations (EMEA/CHMP)				
European Patients' Forum (EPF)				
International Alliance of Patients' Organizations (IAPO)				
84. Other, please indicate				
85. If answered yes to above, please descrimembers on the board.	be your ass	sociation e.	g. collaborators,	
Final questions coming up, please cont	inue until	the end		
Section D: Profile of Respondent				
86. Please indicate the name of your organ	nisation bel	ow:		
87. What is your primary role within this organisation (Please tick as many as applicable)?				
88. Are you a membership based organisation?				
89. If answered yes to above question, approximately how many members do you have?				
90. Does your organisation have links with	n a similar l	European	organisation?	
□ Yes				
□ No				
□ Don't know				
91. If answered yes to above question, please provide the name and website of this organisation, and briefly describe the nature of your involvement				
92. Does your organisation have links with	n a similar i	nternation	nal organisation?	
□ Yes				
□ No				
□ Don't know				

- 93. If answered yes to above, please provide the name and website of this organisation, and briefly describe the level of your involvement.
- 94. Please feel free to provide any final comments on how your organisation and other similar organisations could better represent the R & D needs of the patients/sufferers

with the disease so that biomedical R & D can better target their needs.

95. Please leave suggestions here of the names & e-mail addresses of others who should be contacted for this survey:

Thank you very much for your participation. Your inputs are very important to us and will be treated with strictest confidence.

Appendix B: Sample group: Health and Patient group survey

Adelaide and Meath Hospital	Endometriosis Association of Ireland
AIDs Care Education and Training	Erbs Palsy Association of Ireland
Alpha One Foundation	Europa Donna Ireland, The Irish Breast Cancer
Alzheimer Society of Ireland	Campaign
Ankylosing Spondylitis Association of Ireland	Fight for sight
ARC Cancer Support Centre	Fighting Blindness
Arthritis Foundation of Ireland	Friedreich's Ataxia Society of Ireland
Arthrogryposis Association of Ireland	Gay Health Network
ASH Ireland	GROW- Mental health organisation
ASPIRE Asperger Syndrome Association	HADD Family support group
Asthma Society of Ireland	Headway Ireland
AWARE (Mental Health)	Heart Children Ireland
Bodywhys	Huntingtons Disease Association of Ireland
Brain Research	Institute of Public Health
Brainwave: the Irish epilepsy association	Irish Advocacy Network
CAIRDE	Irish Ants -Syringomyelia Self Help Group
Cancer Research Ireland	Irish Association for Spina Bifida and Hydrocephalus
Children in Hospital	Irish Cancer Society
Children's Leukaemia Research project	Irish Cardiomyopathy Support Group
Children's Medical & Research Foundation	Irish Chronic Pain Association
CoAction West Cork	Irish Deaf Society
Coeliac Society of Ireland	Irish Family Heart Association
Cork Cancer Research Centre	Irish Family Planning Association
Cri du Chat Syndrome Support Group	Irish Fragile X Society
CROI - West of Ireland Cardiology Foundation	Irish Glaucoma Association
Cystic Fibrosis Association of Ireland	Irish Haemochromatosis Association
Cystinosis Foundation Ireland	Irish Haemophilia Society
DEBRA Ireland	Irish Heart Foundation
DELTA/Detect Project	Irish Kidney Association
Dementia Services Information and Development Centre	Irish Lupus Support Group
Diabetes Federation of Ireland	Irish ME/CFS Support Group
Down Syndrome Ireland	Irish Motor Neurone Disease Association
Dublin AIDs Alliance	Irish Mucopolysaccharide Society
Dyslexia Association of Ireland	Irish National Council of ADHD/HKD Support
Dyspraxia Association	Groups
Dystonia Ireland	Irish Osteoporosis Society
2 journa nomia	Irish Patient's Association

Ehlers-Danlos Syndrome Support Group

Irish Prader – Willi Syndrome Support Group

Irish Raynaud's and Scleroderma Society

Irish Society for Colitis and Crohn's disease

Irish Society for Mucopolysaccharide Diseases

Irish Society for Rheumatology

Irish Stammering Association

Irish Stillbirth and Neonatal Death Society

Irish Sudden Infant Death Association

Marfan Research Foundation

Mater Foundation

Medical Research Charities Group

Meningitis Research Foundation

Meningitis Trust

Mental Health Ireland

Migraine Association of Ireland

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

Myaesthenia Gravis Association

National Breast Cancer Research Institute

National Campaign for Homelessness

National Centre for Inherited Metabolic

National Council on Aging and Older People

National Disability Authority

National Suicide Research Foundation

National Youth Health Programme

Neurofibromatosis Association of Ireland

Neurological Alliance of Ireland

Parkinson's Association of Ireland

PCOS Ireland: The Poly cystic ovary syndrome association of Ireland

Peter Bradley Foundation

Post Polio Support Group

Primary Immunodeficiency Association of Ireland

Public Health Alliance

Reach- the Association for Children with Hand or Arm Deficiency

Research & Education Foundation Sligo General Hospital

Research Institute for a Tobacco Free Society

RETT Syndrome

Schizophrenia Ireland

SOFT Ireland (Trisomy 13/18)

SOTOS Syndrome

Suicide Prevention office

Tallaght Homeless Advice Unit

Tourette Syndrome Association of Ireland

Transverse Myelitis Association

Unique Ireland

Volunteer Stroke Scheme

Williams Syndrome Association of Ireland

Woman's Health Council

Appendix C: Science Shop survey questions

Background to the Survey

What is a Science Shop?

Science shops -- despite the name -- are not retail outlets. Instead, a community group with a problem or question can approach their local university 'science shop', which would then arrange for students and researchers to undertake research that tackles the problem.

Examples of past Science Shop research projects:

- Biodiversity assessment of sand dunes to chart the influence of climate change and inform preservation strategies
- Literature review on the effectiveness of laser use in treating psoriasis
- Measurement of toxicity of chemicals being released by near-by factory
- Examination of whether the use of certain medicines increased one's sensitivity to light. The results were used to inform a campaign on sun-bed safety.

Science Shops have been in existence in universities since the early 70s and the network is rapidly growing, with Science Shops now located within Universities and research institutions across Europe and Northern America. Science Shops are now emerging in Dublin City University, National University of Ireland, Galway and University College Cork.

Purpose of Survey

While Science Shops are involved in all types of research, including environmental, biological, chemical and engineering research, at present there is a tendency for Science Shops to be more active in social and economic research.

We wish to investigate the opportunities and obstacles towards establishing of a Science Shop within the School of Science, Engineering and Food Science.

Output of Survey

Your answers will be used in finalising a PhD thesis chapter on:

"Science Shops and their potential for increasing local public inputs into Science and Technology research".

1. Were you previously aware of Science Shops or similar initiatives?

Awareness of the Science Shop initiative

your group: □ Yes
2. Do you think that community driven-research questions could be considered within your group?
Science Shops allow local communities to pose questions to researchers in university that combe researched as a collaborative effort between the local community group and the researcher/research group.
If answered similar initiatives, please explain:
□ No
□ Yes
• •

4. What would be the best approach for resourcing a Science Shop facilitated research project? Please give your suggestions below.

Opportunities and Obstacles

5. To what extent would you personally be encouraged to get involved in a Science Shop initiative by each of the following? Please answer for all choices.

1= A great deal, 2= To some extent, 3= Not very much, 4= Not at all, 5= Don't know

	1	2	3	4	5
Efficient support system for managing* the project					
Efficient support system for managing interactions with the local group					
Partial funding support to carry out the research					
Full funding support to carry out the research					
Assistance with supervision** of project by Science Shop staff					
Recognition for involvement in such projects (impact on career advancement)					
Awards for students involved in Science Shop projects					
Engaging with local groups in research they consider relevant					

^{*} managing administration relating to the project

What else would encourage you personally to get involved with the Science Shop?

6. To what extent would the following discourage you from getting involved in a Science Shop initiative? Please answer for all choices.

^{**} overseeing of research being conducted and ensuring adherence to schedule

1= A great deal, 2= To some extent, 3= Not very much, 4= Not at all, 5= Don't know

	1	2	3	4	5
Lack of time to manage such a project					
Lack of resources to carry out research					
Personal lack of interest in locally-driven research					
Undergraduate students lack of interest in these projects					
Researchers (e.g. postgrad, postdoc) lack of interest in these projects					
My lab is conducting research that would not be applicable to groups in the local community					
Ownership of research results (e.g. Intellectual Property) concerns					

What else might discourage you personally from getting involved with the Science Shop?

7. Please indicate below whether you agree or disagree with each of the following comments regarding a Science Shop. *Please provide an answer for each statement.*

1= Disagree, 2= Somewhat disagree, 3= Neither agree nor disagree, 4= Somewhat agree, 5= Agree

	1	2	3	4	5
Focussing on locally-driven research questions is a waste of research time for undergraduate students					
Focussing on locally-driven research questions is a waste of research time for researchers					
Students/researchers would benefit by being involved in research relating to locally relevant problems					
Science Shop initiative would make members and groups in the local community more appreciative of SEFs research					
Science Shop initiative would make science more attractive to future students from the local community					
Science Shop initiative is of little real benefit to local groups as it doesn't enable long-term research					
Science Shop initiative would improve students' research skills					

Please leave any comments, advice or questions you have in relation to a Science Shop operating in SEFS below.

Please write your name and email address here if you wish to be contacted directly:

Appendix D: Factors affecting Science Communication: Survey of Scientists and Engineers

Rationale

There are increasing calls by the non-scientific community for scientists and engineers to more widely engage in science communication activities with schools, the public, industry, politicians and broader civil society groups to communicate and explain their research findings.

However, there has been little analysis of Irish scientists and engineers' perceptions and views on the rationale, value and effective means of science communication.

A University College Cork research team has received funding from the Irish Research Council for the Humanities and Social Sciences to explore models of science communication in Ireland. Professor Charles Spillane and Catherine O'Mahony of University College Cork are leading the study in collaboration with the Royal Irish Academy (RIA)¹.

As part of this study we are conducting a national survey of science communication in Ireland which closely mirrors similar survey exercises recently conducted by the Royal Society in the UK (link to report). We wish to invite you to participate in this survey. You have been selected using robust sampling procedures and it is important that you personally reply with your views and opinions. Your replies will be anonymised and treated in the strictest confidence. Nothing that any individual says will be attributed in the final report or passed on to the funders or anyone else. Towards the end of the questionnaire you will be asked some questions about yourself so that we can compare the results for different groups of scientists (e.g. based on age, gender, discipline etc).

Please contact Catherine O'Mahony at 021 4901425 or email catherine.omahony@ucc.ie if you have any questions in relation to this survey.

1: The RIA is the academy for the sciences and humanities for the whole of Ireland and seeks to promote excellence in scholarship, recognise achievements in learning, direct research programmes, reflect upon, advise and contribute to public debate and public policy formation on issues of major interest in science, technology and culture.

Survey Ouestions

1. Scientists are being asked to engage more with the non-specialist public. What, if anything does this mean to you? Please write below:

2. How important do you feel it is that you personally, in your current post, directly engage with the following groups about your research? Please rate importance on a scale of 1 to 5, where 1 is not important and 5 is very important.

	1	2	3	4	5
General journalists (i.e. in press, TV and radio)					
Popular science journalists (e.g. in Science Spin, New Scientist)					
Others in the media such as writers, documentary and other programme makers					
Primary school kids & school teachers					
Secondary school kids & school teachers					
Young people outside of the school system					
Policy-makers in government (politicians, civil servants)					
Industry/business community (other than where directly concerned with funding your research)					

The non-specialist public (e.g. those working or studying in unrelated field)			
Non-Governmental organisations (NGOs) e.g. farmers groups, environmental groups, welfare groups			
Public figures or celebrities who are champions of science			
Groups/individuals opposed to specific sciences and technologies			

3. Which of these groups do you find it easiest to talk with about your research findings?
□ General journalists (i.e. in press, TV and radio)
□ Popular science journalists (e.g. in Science Spin, New Scientist)
□ Others in the media such as writers, documentary and other programme makers
□ Primary school kids & school teachers
□ Secondary school kids & school teachers
□ Young people outside of the school system
□ Policy-makers in government (politicians, civil servants)
□ Industry/business community (other than where directly concerned with funding your research)
□ The non-specialist public (e.g. those working or studying in unrelated field)
□ Non-Governmental organisations (NGOs) e.g. farmers groups, environmental groups, welfare groups
□ Public figures or celebrities who are champions of science
□ Groups/individuals opposed to specific sciences and technologies
□ None/ Don't know
4. Why do you say that? Please write below.5. Which of the following groups do you find it hardest to talk with about your research
findings?
☐ General journalists (i.e. in press, TV and radio)
□ Popular science journalists (e.g. in Science Spin, New Scientist)
□ Others in the media such as writers, documentary and other programme makers
□ Primary school kids & school teachers
□ Secondary school kids & school teachers
□ Young people outside of the school system
□ Policy-makers in government (politicians, civil servants)
□ Industry/business community (other than where directly concerned with funding your research)
□ The non-specialist public (e.g. those working or studying in unrelated field)
□ Non-Governmental organisations (NGOs) e.g. farmers groups, environmental groups, welfare groups
□ Public figures or celebrities who are champions of science

$\hfill \Box$ Groups/individuals opposed to specific sciences and technologies	es
□ None/ Don't know	

6. Why do you say that? Please write below.

7. Thinking about public engagement with, and communication about, science, roughly how many times in the past 12 months have you done each of the following? 1= None,

2=Once, 3=2-3 times, 4=4-5 times, 5=5 times

1	2	3	4	5
	1		1 2 3	1 2 3 4

For the remainder of the questionnaire, we will be talking about communication and engagement with the non-specialist public only. By this we mean adults with no specialist knowledge or, or training in, science.

8. How important do you think it is that you personally, in your current post, engage directly with the non-specialist adult public on each of the following?

Please rate importance on a scale of 1 to 5, where 1 is not important and 5 is important.

	1	2	3	4	5
The scientific findings of your research					
Areas for further research					
Policy and regulatory issues					
The wider social and ethical implications of your research findings for society					
The potential benefits of your work to individuals/society					
The scientific process / the nature of science					
Scientific uncertainty					
The enjoyment and excitement of doing science					
The relevance of science to everyday life					
The career options in science					

engineers generally to engage with the non-specialist public?
☐ To be accountable for the use of public funds
□ To contribute to public debates about science and scientific issues
□ To contribute to discussions about the social and ethical issues science can raise
□ To generate / stimulate additional funds for universities and colleges
☐ To recruit students to your subject
□ To ensure the public is better informed about science and technology
☐ To raise awareness about your subject
☐ To raise awareness of science generally
□ There are no reasons to engage with these groups (GO TO QUESTION 11)
□ Other, please specify
10. Looking at the list below, what do you think is the second most important reason for scientists and engineers generally to engage with the non specialist public?
☐ To be accountable for the use of public funds
□ To contribute to public debates about science and scientific issues
□ To contribute to discussions about the social and ethical issues science can raise
□ To generate / stimulate additional funds for universities and colleges
□ To recruit students to your subject
□ To ensure the public is better informed about science and technology
□ To raise awareness about your subject
☐ To raise awareness of science generally
□ There are no reasons to engage with these groups (GO TO QUESTION 11)
□ Other, please specify
11. Looking at the list below, what do you think is the main drawback to scientists and engineers generally engaging with the non-specialist public?
☐ It makes them look bad in front of their peers
☐ It makes them a target
☐ It can send out the wrong messages to the public
☐ It diverts money from research projects
□ It diverts money from other, non-research, activities (e.g. attracting students into science)
☐ It takes up time that is better used on research
$\ \square$ It takes up time that is better used on other, non-research, activities
□ There are no drawbacks to engaging with any of these groups (GO TO QUESTION 13)
□ Other, please specify

. Looking at the list below, what do you think is the main reason for scientists and

12. Looking at the list below, what do you think is the second main drawback to scientists and engineers engaging with the non-specialist public?
☐ It makes them look bad in front of their peers
☐ It makes them a target
☐ It can send out the wrong messages to the public
☐ It diverts money from research projects
☐ It diverts money from other, non-research, activities (e.g. attracting students into science)
☐ It takes up time that is better used on research
☐ It takes up time that is better used on other, non-research, activities
☐ There are no drawbacks to engaging with any of these groups
□ Other, please specify
13. In relation to the other things you have to do in your working life, how important is it to you that you find time to engage with the non-specialist public?
□ Not at all important
□ Not very important
□ Equally important
□ Fairly important
□ Very important
14. Would you like to spend more time, less time, or about the same amount of time as you do now engaging with the non-specialist public about science and technology?
□ I would like to spend more time (GO TO QUESTION 15)
□ I am content with the amount of time I spend on this now (GO TO QUESTION 16)
□ I would like to spend less time (GO TO QUESTION 16)
□ Don't know (GO TO QUESTION 16)
15. You answered that you wish to spend more time engaging with the non-specialist public about science & technology. Please choose one of the following explanations for your answer if relevant.
□ Scientists and engineers should engage more with the community
□ I work in a topical area of science
□ I work in a controversial area of science
☐ There is a need to recruit more students
☐ Scientists and engineers need to be more accountable to the public
□ Scientists and engineers should engage more with the community
□ Other, please specify:

16. Below are some things people have said about engaging with the non-specialist public about science and technology. Please indicate whether you agree or disagree for each statement.

 $1=Strongly\ agree,\ 2=Disagree,\ 3=Neither\ agree\ nor\ disagree,\ 4=Disagree,\ 5=Strongly\ disagree,\ 6=Don't\ know$

	1	2	3	4	5	6
Scientists who communicate a lot are not well regarded by						
other scientists						
Engaging with the non-specialist public might help						
researchers make new contacts for their research						
Funders of scientific research should help (i.e. funding, time)						
scientists to communicate with the non-specialist public						
Scientists have a moral duty to engage with the non-specialist						
public about the social and ethical implications of their						
research						
I don't think my research is interesting to the non-specialist						
public						
The main reason to engage with the non-specialist public is to						
get their political support for science and engineering						
I simply don't have time to engage with the non-specialist						
public						
I would not want to be forced to take a public stance on the						
issues raised by my research						
Engagement with the non-specialist public is best done by						
trained science communication professionals						
Engaging the non-specialist public in science is personally						
rewarding						
My research is too specialised to make sense to the non-						
specialist public						
I would need help (funding, time) to develop a science						
engagement project						
I would be happy to take part in a science engagement						
activity that was organised or run by someone else						
Public engagement could help with my career						
Engaging with the non-specialist public is best done by		t				
senior researchers						
There are no personal benefits for me in engaging with the						
non-specialist public						
It would make more sense to engage with decision-makers in						
society on science and technology issues (e.g. politicians,						
representatives of business and civil society groups, opinion-						
formers etc)						
	l	<u> </u>	<u> </u>	1	l	

17. How easy or difficult do you think it is to get involved in science engagement activities for those who want to do so?

Very easy
Very difficult
Don't know / Can't say
Fairly easy
Fairly important

public about your research?
□ Very well equipped
□ Fairly well equipped
□ Not very well equipped
□ Not at all equipped
□ Don't know
19. What training, if any, have you had in communicating science to the non-specialist public? Do not include any teaching training you may have had.
□ None
□ Media training on being interviewed by journalists
□ Training in writing for the non-specialist public
□ Training in speaking to the non-specialist public
□ Training in understanding the Irish school education system
□ Training in speaking to school children (of any age)
□ Other informal means / experience
□ Other, please specify:

20. What would encourage you personally to get involved in activities that engage the non-specialist public in science? Please write below.

21. To what extent would you personally be encouraged to get more involved in activities to engage the non-specialist public in science and engineering by each of the following?

1=A great deal. 2= To some extent, 3=Not very much, 4=Not at all, 5=Don't know

	1	2	3	4	5
If my head of department / line manager were to give me more support and encouragement					
If there were awards and prizes for me as an individual or for my research team					
If it was part of getting professional status, such as chartered engineer or membership of my professional body					
If it helped with my own career					
If I was relieved of other work					
If reviews of funded projects were changed to encompass communication with the non-specialist public					
If my department or institution was recognised by an award or prize					
If it brought money into my department or research team					

If it was easier for me to get funds for engagement activities			
If grants for engagement covered staff time as well as other costs			
If it was easier to organise such activities			
If I had some (more) training			
If my institution recognised & measured science communication activities in career promotion procedures			
If my funding body recognised & measured science communication activities in research funding decisions			

22. What is stopping you from getting (more) involved in activities that engage the non-specialist public in science? Please mark all that apply.
□ I am already involved enough
□ I am too junior
□ I am only in Ireland for a limited period
□ English is not my first language
□ I feel that I am encroaching on the institution's Press Office work/research
□ There is no senior level support
□ There is not enough funding
□ I need to spend more time on my research
□ I need to spend more time teaching
□ I need to spend more time on administration
$\ \square$ I need to spend more time getting funding for my research
□ I would have to do it in my own time
□ Peer pressure
□ I just don't want to
□ This is not a priority for my institution
□ This is not a priority for my funding body
□ Other, please specify:
23. Do other members of your department take part in activities that engage the non-specialist public in science and technology?
□ Yes, most of them
□ Yes, some of them
□ Yes, one or two of them
□ None of them

□ Don't know

24. Are the researchers in your department generally suppart in activities that engage the non-specialist public in s	-				o take
□ Yes, very supportive					
□ Yes, fairly supportive					
□ Not particularly supportive					
□ Not at all supportive					
□ Don't know					
25. Is your institution generally supportive towards resea activities to engage the non-specialist public in science an			_	rt in	
□ Yes, very supportive					
☐ Yes, fairly supportive					
□ Not particularly supportive					
□ Not at all supportive					
☐ It varies between departments					
□ Don't know					
spend on science communication activities? Please rate your answer on a scale of 1 to 5, where 1 is least	t time and	d 5 is 1	nost ti	me.	
	1	2	3	4	5
Full Professor or Chair					
Associate Professor					
Senior lecturer					
Lecturer					
Principal Investigator/Group Leader					
Research Technician					
Research Assistant					
Postdoctoral researcher					
Postgraduate researcher (e.g. PhD, MSc, MA)					
Undergraduate student					
Overview of Respondent					
In order for us to understand the views of different types of r something about yourself. All replies will be treated in the st	-	-		ll us	
27. Which of the below titles best describes your current	nosition	?			
	position				
□ Full Professor or Chair	position				
□ Full Professor or Chair □ Associate Professor	position				
	position				

□ Principal investigator/Group Leader
□ Research Technician
□ Research Assistant
□ Postdoctoral researcher
□ Postgraduate researcher (e.g. PhD, MSc, MA)
□ Undergraduate student
□ Other, please specify:
20 W
28. Working status
□ Working full-time (>35 hours per week) □ Working port time (<25 hours per week)
□ Working part-time (<35 hours per week)
□ Unemployed □ Other places specify:
☐ Other, please specify:
29. Which activity best describes your main role at your institution?
□ Research (including clinical research)
□ Research and teaching
□ Teaching only
□ Clinical work only
□ Management/ administration
30. From the list below, which discipline most closely describes your current area of research interest?
□ Clinical medicine (including dentistry)
□ Non-clinical bioscience (including medical, psychology, veterinary, agricultural)
□ Engineering / engineering sciences (including IT)
□ Chemical / chemical engineering
□ Physics (including materials sciences) and astronomy
□ Mathematics
□ Environmental sciences (including earth and marine sciences)
□ Other, please specify:
31. Do you think your research has implications for society?
□ Yes
□ No
□ Don't know / Not sure

32. Do you think your research has implications for policy-makers and regulators?
□ Yes
\square No
□ Don't know / Not sure
33. What is the principal source of funding for your research? Are you wholly or principally funded by:
□ Research council (IRCSET/IRCHSS)
□ Government Department
□ Science Foundation Ireland
□ Enterprise Ireland
□ Health Research Board
□ Environmental Protection Agency
□ Higher Education Funding Council
□ EU Research
□ Wellcome Trust
□ Local government
□ Charity
□ Industry
□ Other, please specify:
34. To the nearest year, how long have you been working in scientific research, whether in academia or elsewhere? If less than six months enter 0, if more than six months but less than a year enter 1.
35. What was your age last birthday?
36. Are you:
□ Male
□ Female
37. What is your nationality?
□ Irish-English
□ Irish-American
□ Irish-European
□ Irish-Other
\Box UK

□ France
□ Germany
□ Other EU nationality
□ Other European nationality
\Box USA
□ Africa
□ Asia
□ Other nationalities
□ Multi-nationality
□ No nationality
□ Not stated
□ Other, please specify:
38. Is English your first language?
□ Yes
\square No
39. Do you intend to work in Ireland in the long term?
□ Yes
□ No
□ Don't know
Thank you for giving up your time to complete this survey. Your views will be treated in confidence, and we will not pass individual comments back to the Royal Irish Academy. Over the coming months, we would like to talk to some of the survey respondents in more depth about their views. If you are willing to be contacted for a short interview by telephone or in person, please enter your contact details below.
40. Please provide us with the following details
Your email:
Your name:
Tour telephone no:

Appendix E: Sample selection for survey of Scientists and Engineers

Disciplines included in the survey sample

Scientific and technological research was disaggregated into the following areas in line with Forfás research categories for research thus enabling comparison with national figures.

Table 4.10: Description of disciplinary boundaries in natural and technological sciences

Disciplines
Clinical medicine (including dentistry)
Non clinical bioscience (including psychology, veterinary, agriculture)
Engineering / engineering sciences (including IT)
Chemistry / chemical engineering
Physics (including materials sciences) and astronomy
Mathematics
Environmental sciences (including earth and marine sciences)

Higher Education Institutions (HEIs) included in sample

All of the Higher Education Institutions in Ireland were contacted in relation to the survey. This sample was comprised of eight Universities and fourteen Institutes of Technology (Table 4.11).

Table 4.11: Higher Education Institutions in Ireland

Higher Education Institute	Initials
National University of Ireland Galway	NUIG
National University of Ireland Maynooth	NUIM
Dublin City University	DCU
Royal College of Surgeons	RCSI
Trinity College Dublin	TCD
University College Cork	UCC
University College Dublin	UCD
University of Limerick	UL
Athlone Institute of Technology	AIT
Cork Institute of Technology	CIT
Dublin Institute of Technology	DIT
Dundalk Institute of Technology	DKIT

Galway/Mayo Institute of Technology	GMIT
Dun Laoghaire Institute of Art, Design & Technology	IADT
Carlow Institute of Technology	IT Carlow
Sligo Institute of Technology	IT Sligo
Tallaght Institute of Technology	IT Tallaght
Tralee Institute of Technology	ITT
Limerick Institute of Technology	LIT
Letterkenny Institute of Technology	LYIT
Waterford Institute of Technology	WIT
Blanchardstown Institute of Technology	ITB

Research Institutes included in sample

(1) Teagasc: Irish Agriculture and Food Development Authority

Teagasc, the Irish Agriculture and Food Development Authority, is comprised of nine research centres located around the country, each of which is focused on specific research interests (Table 4.12). The primary purpose of Teagasc is to provide "integrated research, advisory and training services to the agriculture and food industry and rural communities" (Teagasc, 2010). All nine centres were contacted and Heads of Department/Centre were asked to disseminate the survey to researchers within the different centres.

Table 4.12: Teagasc research centres

Research Centre	Focus
Teagasc Moorepark, Cork	Dairy Products Research
Teagasc Athenry, Galway	Animal Reproduction & Rural Economy
Teaguse 7 themy, Garway	Research
Teagasc Dunsany, Meath	Beef Research
Teagasc Johnstown Castle, Wexford	Environment Research
Teagasc Kinsealy, Dublin	Horticulture and Farm Forestry Research
Teagasc Oakpark, Carlow	Arable Crop Research
Teagasc Ashtown, Dublin	Food Research
Teagasc Kilmaley, Clare	Farm Research
Teagasc Leenane, Mayo	Hill Sheep Research

(2) Irish Marine Institute

The Marine Institute is the national agency responsible for Marine Research,
Technology Development and Innovation (RTDI). It is located primarily at Oranmore

in Galway but has regional offices in Dublin and Mayo. The purpose of the Marine Institute is to "assess and realise the economic potential of Ireland's 220 million acre marine resource; promote the sustainable development of marine industry through strategic funding programmes and essential scientific services; and safeguard the Irish marine environment through research and environmental monitoring" (Marine Institute, 2010). The Institute is divided into seven service teams and the head of each team was contacted in relation to the survey.

Funding agencies included in sample

There are sixteen organisations/departments that are involved in funding research in Ireland. We contacted all sixteen in order to enlist the participation of the grant holders in the survey (Table 4.13).

Table 4.13: Funding agencies in Ireland

Organisation/Department	Focus
National Council for Forest Research and	Forestry research
Development (COFORD)	
Science Foundation Ireland (SFI)	Biotech & ICT research
Health Research Board (HRB)	Health Research
Higher Education Authority (HEA)	Planning for higher education & science
Irish Research Council (IRCHSS)	Humanities and social sciences research
Irish Research Council (IRCSET)	science, engineering & technology research
Environmental Protection Agency (EPA)	Environmental protection
Industrial Development Agency (IDA)	Secure overseas investment
Enterprise Ireland (EI)	Develop national industry
Dept of Enterprise, Trade and Employment	Scientific research
(DETE)	
Dept of Agriculture and Food (DAF)	Agri-food research
Department of Education and Science (DES)	Scientific research
Department of Health (DOH)	Health research
Department of the Environment (DOE)	Environmental research
Sustainable Energy Ireland	Energy research
Cancer Research Ireland	Cancer research

Appendix F: Promotion of survey of Scientists and Engineers

Several organisations are involved in promoting science and research in Ireland at the time of carrying out the survey and we asked for these organisations to help promote participation in the survey amongst researchers in Ireland (Table 4.14). The HEIs, research centres and funding agencies contacted to request the participation of their researchers in the survey also helped promote participation.

Table 4.14: Science and research promotion organisation in Ireland

Organisation	Description
Expertise Ireland	Online expertise database for researchers
The Alchemist Café	Forum for informal presentations on and discussion about scientific issues
Science Spin	National magazine on topics relating to science and technology
Cancer Research Ireland	Produce monthly newsletter for subscribers
Environmental sciences	Electronic forum for discussion and alerts
association of Ireland	
Research Staff association	Present in TCD, UCC, NUIG and UCD
Engineers Ireland	Professional body representing engineers
Royal Irish Academy	Academy for the sciences and humanities in Ireland
TREO group	Third level research, education and outreach
Discover Science & engineering	Programme to promote science and engineering
Steps to Engineering	Science, Technology and Engineering programme for schools
SEED ART SCIENCE	Group developing creative projects connecting art and science
Irish Universities Association	Representative body for seven universities