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Virtual Reality, Gamification, and Mobile Multimedia for Cystic Fibrosis Education and Management

Tamara Vagg



A thesis submitted to the National University of Ireland, Cork
in fulfillment of the requirements for the degree of
Doctor of Philosophy in the faculty of Science

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Research Supervisor Dr. Sabin Tabirca

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Abstract

Cystic Fibrosis (CF) is a rare condition and is the most common life-limiting genetic disease affecting Caucasians; and Ireland has the highest occurrence of this condition in the world. As CF is a rare disease, common conditions and diseases such as asthma, diabetes, and heart disease are given precedence by researchers and practitioners who design and implement multimedia solutions. As life expectancy for CF patients is expected to rise, it is postulated that the development of multimedia interventions may aid CF adults in the management of their disease. This research, therefore, aims to investigate if and how the use of multimedia can be of benefit to Cystic Fibrosis knowledge and education. To achieve this, a systematic scoping literature review was conducted which yielded 12 manuscripts. From these papers it was observed that there is paucity in available multimedia for medical professionals, games for CF adults, and management applications for CF adults. These three observations serve as the objectives of each Chapter within the thesis. Each Chapter begins by investigating the observation further before designing and implementing a multimedia solution. The results of this research produced a 3D interactive virtual reality tool for medical professionals, a general mHealth design and development pipeline/framework, a serious game with data analysis system for CF adults, three e-learning tools for CF adults, and a CF patient passport app. All multimedia solutions were evaluated with their target audience, and each result is presented. This research concludes that multimedia can be of benefit to the education and management of Cystic Fibrosis. Feedback from testing with both medical professionals and CF adults demonstrates that these cohorts indeed want these multimedia solutions and find them beneficial. However, further investigation and research is required to evaluate the benefits these solutions have. Therefore this thesis also identifies further areas of interest and makes recommendations for future research.

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"If I have seen further it is by standing on the shoulders of giants"
– Isaac Newton

This research and subsequent thesis could not have come into fruition without the ongoing support, wisdom and friendship of numerous amazing people. The words written in this section are to acknowledge these people, but do not come close to the gratitude I have.

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Thank you all for everything.

Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institution of learning.

Signed:
Tamara Vagg

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Acronyms

2D Two-dimensional.

3D Three-dimensional.

ACBT Active Cycle of Breathing Technique.

ACM Association of Computing Machinery.

AD Autogenic Drainage.

AES Advanced Encryption Standard.

AR Augmented Reality.

BMI Body Mass Index.

CD-ROM Compact Disc Read-Only Memory.

CF Cystic Fibrosis.

CFMATTERS Cystic Fibrosis Microbiome-determined Antimicrobial Therapy Trial in Exacerbations: Results Stratified.

CFTR Cystic Fibrosis Transmembrane Conductance Regulator.

COPD Chronic Obstructive Pulmonary Disease.

CSS Cascading Style Sheets.

DCR Digital Camera Raw.

DCR Digital Camera Raw.

DK2 Development Kit 2.

DPA Data Protection Act.

e-Health Electronic Health.

e-Learning Electronic Learning.

EC European Conformity.

eHealth Electronic Health.

eLearning Electronic Learning.

EMR Electronic Medical Record.

ESG Electronic Support Group.

EU European Union.

FAQ Frequently Asked Questions.

FBX Filmbox.

FCC Federal Communication Commission.

FDA Food and Drug Administration.

FPS Frames-per second.

FTC Federal Trade Commission.

HCM Human Centered Multimedia.

HIPAA Health Insurance Portability and Accountability Act.

HMD Head-Mounted Display.

HSE Health Service Executive.

HTC High Tech Computer Business.

HTML5 Hyper-Text Markup Language 5.

IBD Inflammatory Bowel Disease.

ICT Information and Communications Technology.

IV Interactive Visit.

LCP Life Course Perspective.

M-Learning Mobile Learning.

MCQ Multiple Choice Questionnaire.

MERLOT Multimedia Educational Resource for Learning and Online Teaching.

mHealth Mobile Health.

mLearning Mobile Learning.

MUI Mobile User Interface.

NASA TLX NASA Task Load Index.

NQF National Quality Forum.

PC Personal Computer.

PEP Positive Expiratory Pressure.

PNG Portable Network Graphics.

PPT Microsoft Power Point.

PwC Price Waterhouse Coopers.

QOL Quality of Life.

SMS Short Message Service.

SWF Small Web Format.

T1D Type 1 Diabetes.

UE4 Unreal Engine 4.

UI User Interface.

UML Unified Modeling Language.

UX User Experience.

VR Virtual Reality.

VRE Virtual Reality Environment.

WHO World Health Organisation.

Chapter 1

Introduction

"Computer Science is no more about computers than astronomy is about telescopes"

– Edsger W. Dijkstra

This chapter will begin by introducing Cystic Fibrosis before discussing the role multimedia has in medicine. By doing so, this chapter aims to provide context and rationale to the origin of this research and its significance. The chapter will then describe the aims and objectives of this research as well as its outcomes. The chapter will then provide an outline of the remaining chapters structures before describing the writing style used in this thesis. Chapter 2 will then draw upon the rational, aims, and objectives before presenting the results of a systematic scoping literature review.

1.1 Cystic Fibrosis

Cystic Fibrosis (CF) is the most common life limiting genetic disease affecting Caucasians in the world. CF is caused by a mutation in the CF gene, this gene is responsible for the creation of a protein known as Cystic Fibrosis Transmembrane Conductance Regulator (CFTR). However, due to this gene mutation, abnormal CFTR proteins are produced which disrupts or inhibits the transmission of salt and water in chloride channels of the cells. Subsequently the body over produces a thick and sticky mucus. The mucus affects many organs within the human body, primarily the lungs and digestive system. If the mucus is not managed, it

may lead to life threatening lung infections and the prevention of food absorption. To manage this disease patients must adhere to many rigorous therapies such as airway clearance physiotherapy, antibiotics, diet, and exercise. However, compliance to these therapies is often low. Which presents the question; are there interventions that can help this cohort in the management of their disease, and could multimedia play a part? Currently, the predicted median age of survival in Ireland is early to mid thirties. However, life expectancy for these patients is rising with some patients predicted to live to retirement age. Currently, 55% of the Irish CF population are aged 18 years old or older. Through this research it is identified that there is a paucity in available multimedia for this cohort, and that currently available multimedia is more generally focused towards CF pediatrics and adolescents. Ireland has the highest prevalence of CF in the world and affects approximately 1,200 patients. Furthermore, Irish CF patients have among some of the most severe strains of this genetic disease. Considering this, Ireland has the potential to lead in the research and development of educational multimedia for cystic fibrosis.

1.2 Multimedia for Cystic Fibrosis

In recent years, the rapid proliferation of Information and Communications Technology (ICT) has produced many intelligent, powerful, and affordable consumer devices. Providing the average user with persistent and convenient access to computationally powerful devices. Furthermore, technological advancements have lead to the minimising of hardware size while increasing hardware potential and information storage. This has allowed for the development of advanced devices such as smartphones, tablets, high-powered personal computers, and virtual reality headsets. This hardware acceleration facilitates rich graphical media such as interactive Three-dimensional (3D) environments, advanced visualisation, Virtual Reality, and Augmented Reality. In addition, many of the aforementioned graphically advanced media can now be deployed over the web thanks to the advent of Hyper-Text Markup Language 5 (HTML5).

By reducing the size of these devices and increasing their mobility and connectivity (smartphone, tablet), unique opportunities are available to collect, share and communicate information and data; therefore, making it easier to disseminate, communicate and inform. These advancements in ICT and communication

further enhance the capabilities of multimedia used for education. Multimedia can and is being used more and more advantageously in the medical and healthcare industry. Such practices include the management of long term diseases and the education of medicine and health. Multimedia is employed for these tasks due to the aforementioned reasons and also its ability to engage users effectively. Examples of where multimedia have been used effectively in medicine can be seen in the care and management of long term or prevalent conditions such as diabetes, asthma, cancers, and heart disease. Often multimedia is employed for interactive 3D or virtual reality tools for the education of medical professionals. Likewise it can be used to track patient data outside of a hospital; providing further insight into the patient's condition. This can also encourage the patient to be proactive in their illness management. Moreover, this advanced multimedia can allow for communication and support between patients and increase apomediation between patients, and healthcare professionals.

Cystic fibrosis is a rare, life-limiting condition with no cure and must be strictly managed. However, precedence for multimedia development is often given to other respiratory diseases that occur in patients more frequently; such as Asthma, Lung Cancer and Chronic Obstructive Pulmonary Disease (COPD). For example, medical/health smartphone apps, educational websites, games, educational animations *etc.* Due to this, it is not clear to what extent multimedia can be adopted for an orphan lung disease such as cystic fibrosis, or the potential benefits it could have for patients and medical professionals alike. Furthermore, there appears to be limited research groups which develop multimedia for the management and education of cystic fibrosis.

The CFMATTERS research group is a collaborative project funded by the European Union under the 7th Framework Programme under grant agreement n° 603038 [1]. This project evaluates the use of microbiome directed treatments compared to standard therapies for CF patients experiencing respiratory infections. CFMATTERS also aims to disseminate the results of this trial while simultaneously producing engaging educational multimedia to benefit those affected by and working with CF. Considering the advancements in ICT and its adoption in the medical and healthcare industry, this research will investigate the potential and impact multimedia could have for CF. The aims and objectives of this research are further described in the next section.

1.3 Aims and Objectives

The aim of this research is to identify the areas in which multimedia can benefit CF patients and medical professionals. To identify these areas, a scoping systematic literature review is conducted. Based on these findings, this thesis develops interventions and evaluates their potential effects with their target audience. The objectives of this research are as described:

- To propose a conceptual pipeline which consolidates regulations as well as researchers considerations for the development of mHealth applications.
- To develop an interactive 3D educational tool for medical professionals that can also be used on multiple platforms such as the web, standalone application, and Virtual Reality headset.
- To develop a serious game for mobile based on the mHealth pipeline with web based data analysis system; to engage CF patients with their physiotherapy and record medical data.
- To develop a multimedia intervention for CF patients education and management of their condition.

1.4 Thesis Outcomes

During the research and development of this thesis, several outcomes have emerged in the form of peer reviewed publications and multimedia tools for Cystic Fibrosis. These outcomes are described further in this section.

1.4.1 Peer Reviewed Publications

Conference

- T. Vagg, C. Fleming, M. McCarthy, B. Plant, and S. Tabirca, "Patient e-learning tools for adults with cystic fibrosis", in *Proceedings of the International Scientific Conference eLearning and Software for Education*, Carol I National Defence University Publishing House, 2018.
- T. Vagg, C. Shortt, C. Hickey, J. Eustace, B. Plant, and S. Tabirca, "A mhealth patient passport for adult cystic fibrosis patients", in *Proceedings*

of the International Conference on Wireless Mobile Communication and Healthcare (MobiHealth), European Alliance for Innovation, 2017.

- T. Vagg, Y. Y. Tan, J. Eustace, B. Plant, and S. Tabirca, "A serious mobile game app for adults with cystic fibrosis", in *Proceedings of The 7th Irish Conference on Game-Based Learning (IGBL2017)*, Irish Conference on Game-Based Learning, 2017.

- T. Vagg, S. Tabirca, J. Eustace, and B. Plant, "A review of educational content for adults with cystic fibrosis", in *The International Scientific Conference eLearning and Software for Education*, vol. 2, pp. 225 – 233, Carol I National Defence University Publishing House, 2017.

- T. Vagg, B. J. Plant, and S. Tabirca, "A general mhealth design pipeline", in *Proceedings of the 14th International Conference on Advances in Mobile Computing and Multi Media*, pp. 190 – 194, ACM, 2016.

- Y. Y. Tan, S. Tabirca, B. J. Plant, and T. Vagg, "Using a mobile game application to monitor well-being data for patients with cystic fibrosis", in Proceedings of the 14th International Conference on Advances in Mobile Computing and Multi Media, pp. 195 – 198, ACM, 2016.

- T. Vagg, N. Ronan, J. Eustace, B. Plant, and S. Tabirca, "A cystic fibrosis virtual reality gamified experience for medical students", in *Proceedings of The 6th Irish Conference on Game-Based Learning (IGBL2016)*, pp. 93 – 99, Irish Conference on Game-Based Learning, 2016.

- T. Vagg, S. Tabirca, N. Ronan, B. J. Plant, and J. Eustace, "A web-based 3d lung anatomy learning environment using gamification", in *The International Scientific Conference eLearning and Software for Education*, vol. 1, pp. 556 – 560, Carol I National Defence University Publishing House, 2016.

- T. Vagg, B. J. Plant, and S. Tabirca, "A multi-platform interactive 3d educational application for bronchoscopy & bronchial anatomy", in *eProceedings 18th International Conference on Medical Image Computing and Computer Assisted Interventions, Workshop on Interactive Medical Image Computing (IMIC)*, Technische Universitat Munchen, 2015.

- T. Vagg, B. J. Plant, and S. Tabirca, "Interactive bronchial tree e-learning environment", in *Proceedings of 7th International Conference on Education and New Learning Technologies*, pp. 7151 – 7158, IATED, 2015.

Abstracts

- Y. Y. Tan, S. Tabirca, J. A. Eustace, B. J. Plant, and T. Vagg, "A mhealth app with game for adult cystic fibrosis patients", in *New Horizons in Medical Research*, p. 92, School of Medicine Research & Postgraduate Affairs Committee University College Cork, 2016.

- T. Vagg, B. J. Plant, N. Ronan, J. A. Eustace, and S. Tabirca, "Using immersive virtual reality for medical education; a case study for cystic fibrosis", in *INFANT Centre Research Day*, The Irish Centre for Fetal and Neonatal Translational Research (INFANT), 2016.

- T. Vagg, N. Ronan, B. J. Plant, and S. Tabirca, "An interactive virtual reality game-based educational application for cystic fibrosis", in *Proceedings of Picteilin 2016 Creative Media Conference*, p. 25 – 25, Dundalk Institute of Technology, 2016.

1.4.2 Cystic Fibrosis Multimedia

Each chapter of this thesis develops a multimedia education or engagement tool to benefit those working for and affected by CF. These multimedia tools are listed below:

- "A General mHealth Design Pipeline": This is a theoretical framework outlining considerations for designers and developers of mHealth apps.

- "The Lung Experience": a system which allows for visualisation, exploration, and active learning through a 3D bronchial tree structure. This system has been deployed to web based platforms, stand alone executables, and virtual reality head mounted displays. Three tools have been created using this framework to benefit medical professionals knowledge of bronchial anatomy and CF. This educational multimedia can also be used by CF patients and for outreach purposes.

- "Biofeedback Game and Web Analysis Tool": a multimedia system comprising of two parts. The first is a serious game smartphone app targeted at CF adults which requires the user to blow into the device microphone to interact with the game. All data recorded via this game is then stored and analysed in a web tool, the second component of this system. The web tool can be accessed by medical professionals via a secure login and allows these professionals to view data collected from the patient both graphically and in a table format. The web tool analyses the patients data for possible exacerbations under three criteria. If any of these criteria are met, an SMS alert is sent to the patient. This alert criteria is customisable on a per patient basis for a more individualised approach to their care.

- "Patient Education Web Tools": Three web tools were developed that target CF adults. These web tools describe pertinent information for a Bronchoscopy, Gastrostomy Tube, and Portacath. Videos, animations, Two-dimensional (2D) images and photos were all created and validated by a CF multidisciplinary team. These web tools are accessible by patients via personal devices and bedside tablets within the Cork University Hospital.

- "A CF Patient Passport App": The final multimedia contribution includes a smartphone patient passport app for CF adults. This app allows patients to store their basic medical information so that they can receive care when travelling abroad and between CF centres. The app will also encourage CF adults to record their own health data making them a more active participant in their care.

1.5 Thesis Outline

The thesis is structured as follows:

Chapter 2: Scoping Literature Review
Chapter 2 begins by briefly discussing what multimedia is and the areas it encompasses. The chapter also outlines who the key stakeholders are in educational multimedia for the medical discipline. The chapter will progress further to source available literature pertaining to multimedia educational interventions for patients with cystic fibrosis and medical professionals via a systematic scoping

literature review. This literature will then be investigated to identify areas in which multimedia interventions may be best served in this realm. The chapter will then outline these observations before drawing its final conclusion.

Chapter 3: A General mHealth Design Pipeline.
An introduction to mHealth is presented and a proposed design pipeline is then outlined. The chapter then reports the results of a survey which aims to evaluate patients attitudes towards mHealth apps. This pipeline and patient survey provide insights for Chapter 5 and Chapter 6 which both present an mHealth intervention.

Chapter 4: The Lung Experience.
This chapter will first define an issue identified in Chapter 2, which is the lack of CF educational material for medical professionals. The chapter will then further investigate this issue by discussing found literature and multimedia based educational programs. Based on the findings, the results of a student survey, and discussions with the CF multidisciplinary healthcare team in the Cork University Hospital, the chapter also aims to develop a gamified 3D exploration system. The first tool created based on this system targets bronchial anatomy; the second tool targets Cystic Fibrosis. The system is then used to create a Virtual Reality CF lung which was then evaluated by eight medical students. The results of this study and the systems application for CF patients are then discussed.

Chapter 5: Biofeedback Game and Data Analysis System.
This chapter begins by contextualising the findings of the literature review and how they have influenced the development of the tools presented in this chapter. Similar to the 3D gamified exploration tool discussed in Chapter 4 games are also incorporated to educational interventions as discussed in the literature review. The chapter defines "Serious Games" and outlines those currently available for CF children. The culminating output from this process is a serious game application for smartphone that utilises blow data captured via the microphone. As the app is developed for a smartphone platform it is considered to be an mHealth application and thus follows the pipeline as detailed in Chapter 3. Data from the smartphone game is then sent to an external server which is accessible to medical professionals via a web tool. This data can be analysed for possible exacerbations

under three criteria which are customisable per patient. If any of the criteria are met, an SMS alert is sent to the patient. This serious game and web analysis tool is then tested with three CF adults and the results discussed.

Chapter 6: Patient Education; e-Learning and CF Management
This chapter again draws upon the literature review findings in Chapter 2, but instead focuses on patient education and engagement. The identified manuscripts primarily target their interventions for CF paediatrics and adolescents on a web based platform. Thus, this chapter begins by identifying the paucity of available content for CF adults and the aging CF adult. Hence, the development of three educational web tools with built in interaction trackers are presented. These web based tools are available to CF patients via personal devices and bedside tablets situated in the hospital. The resulting interaction data generated via the website trackers are then discussed. It was found that these tools, although they show promise, are not interacted with frequently by CF patients. Therefore, other more accessible platforms are considered, such as smartphone apps; as outlined in Chapter 5. The development of a "CF Patient Passport" mHealth app which incorporates the pipeline as outlined in Chapter 3 is then discussed. The chapter then provides details on a pilot study conducted with five CF adults.

Chapter 7: Conclusion and Future Work.
Chapter 7 is the final chapter in this thesis, and presents an overview of this research while highlighting its contributions to the field. After this overview, the final conclusions are then drawn. The chapter moves on to discuss the limitations of the research and suggests future works for this research area.

1.6 Thesis Writing Style

The objective of this research is to investigate the use of a technical medium such as multimedia for the medical and healthcare discipline, specifically CF. Subsequently, this research aims to define those gaps identified from the literature review and report on the proposed interventions' design, development, implementation, and evaluation. This will be done using neutral language which is predominantly non-technical so that it can be understood by practitioners of both computer science and medicine. Similarly, as the fundamental focus for

this research is the development of such multimedia for the benefit of the patient and medical professionals; the design process and its evaluation is principally discussed in each chapter, rather than the technical aspects of the application development. Furthermore, the significance of this thesis and its contribution is not in the technical adaptation of the multimedia content or advancement in technology; but in its purpose, ambition, and objective. The intention for this writing style is that it will be understood and interpreted effectively by both medical professionals with an interest in ICT; and ICT professionals with an interest in the development of multimedia content or systems for those affected by or working with patients of long term conditions. In addition, this non-technical approach to writing is intended to increase the clarity of the contributions, considerations, and suggestions for future work so that it may be applied in research for other long term conditions or any related research fields. Further explanation and detail of the technical implementation and development of these multimedia interventions can be found in the aforementioned publications.

Chapter 2

Scoping Literature Review

The objective of this research, as described in the previous chapter, is to contribute multimedia to the subject of CF. For example, interventions for those affected by CF, those who care and support CF, or for researchers in the field. To identify areas where such a multimedia intervention can be of benefit, this chapter conducts a systematic scoping literature review. The significant contributions produced from this chapter are the observations made in and by the yielded manuscripts. These observations highlight opportunities which are the fundamental focus of all following chapters. The research which supports the contributions of this Chapter include: "A review of educational interventions for Adults with Cystic Fibrosis" [2].

2.1 Background

Multimedia is described by Vaughan *et al.* as *"Any combination of text, art, sound, animation, and video delivered to you by computer or other electronic or digitally manipulated means. It is richly presented sensation. When you weave together the sensual elements of multimedia—dazzling pictures and animations, engaging sounds, compelling video clips, and raw textual information—you can electrify the thought and action centers of people's minds. When you give them interactive control of the process, they can be enchanted."* [3]. Multimedia is not a new or young discipline and is a well established field [4]. However, the definition of multimedia can evolve and can be further refined across disciplines, holding different meaning in various contexts [5]. Focusing on multimedia in the area of Computer Science, Hugo *et al.* describes multimedia as the ability to

put into practice multiple technologies at once [6]. Similarly, Newton delineates multimedia as a combination of media used to communicate information from two users through their machines [7]. Bornman *et al.* incorporates the aforementioned definitions and summarises by characterising multimedia as the combining of standard data processing with graphics, animation, sound and video [6]. These definitions have overlapping themes which can be encapsulated through the Oxford dictionary definition of Multimedia: *"using more than one medium of expression or communication."* [8].

Although not divulged in the previous definitions, multimedia can also contrast with general media as it is not just the rudimentary displaying of information through multiple mediums. Interactivity is often included under the definition of multimedia. Allowing the user full control over the content and the time in which it is displayed, paused, stopped, started *etc.* is defined as Interactive-Media, which is often used synonymously with multimedia.

2.1.1 Multimedia Categories

Multimedia plays an important component in much of daily life [4]. Subsequently this has led to the proliferation of a variety of multimedia research [4]. Tsai *et al.* extracted, analysed, and categorised multimedia using multiple Association of Computing Machinery (ACM) multimedia conference proceedings [9]. These categories include the following:

- *Content:* refers to the study and creation of multimedia content including, but not limited to, videos, images and learning materials.
- *Applications:* includes multimedia apps for authoring, searching, and analysing content. This category also encompasses the development of new interactive multimedia apps.
- *Systems:* generally concerned with hardware research, content distribution, adaptability and scalability, and 3D systems.
- *Human Centered Multimedia (HCM):* is related to enriching multimedia applications, improving user experiences and interactivity with multimedia content, and social media research.
- *Art:* encompasses multimedia art in contemporary culture, interactive art installations, and emerging art mediums.

Of these categories, *Content* was found to be the most popular [9]. Similarly, this research is predominantly concerned with the *Content* and *Application* categories of multimedia for cystic fibrosis. Keywords pertaining to these categories will be employed in the formulation of a search string, which is discussed further in the following subsections.

2.1.2 Multimedia End Users

It is generally understood that multiple mediums of communication such as audio, graphics, animation, text, and video are required for the creation of multimedia applications. The user or recipient is also integral to any development process. Due to its high impact, multimedia is generally used for entertainment, commercial/sales, education/training, and journalism, among others. Focusing on education and training, the key stakeholders are the students/trainees and teacher/-trainer. However, when investigating multimedia and education in medicine, further stakeholders are introduced; such as the patient, caregivers, parents and the general public.

2.1.3 Multimedia and Medicine

The proliferation and evolution of multimedia to interactive media has allowed many industries to take advantage of its benefits in various educational platforms. Specifically relating to medicine, interactive multimedia allows complex scientific and medical aspects to be disseminated at the end user's own pace (by simple stop, start, and pause mechanisms). Interactive multimedia can provide active learning experiences which are considered indispensable in medical education [10]. This active learning experience can be applied to health care professionals, students, patients, the patients families, in addition to the general public. Therefore, it can be considered that patients and healthcare professionals/students are the key stakeholders to medical multimedia.

Healthcare Professionals/ Students

The use of interactive multimedia in education for health care professionals and students can be considered beneficial when used in addition to traditional methods. One such example includes the manipulation, rotation, scaling, exploration

and viewing of 3D models, such as organs. Traditionally, health care professionals view these organs either in an anatomy laboratory or by viewing cadaverous specimens. Such teaching sessions are often scheduled and cannot be accessed outside of these hours. Outside of these organised teaching sessions, students are often restricted to 2D or 3D illustrations or photos. Hence, interactive 3D multimedia anatomy tools serve as a solution outside of laboratory hours [11]. These tools allow students to progress through content at their own pace, without any restriction on time. Additionally, the student can revisit the educational content as often as they require. Interactive multimedia can also be used as an effective alternative to otherwise costly or consequential learning exercises.

Patients

Similar to the previous section discussing interactive multimedia for students and healthcare professionals, abstract medical concepts can be visualised to help understand and describe conditions and complications to patients. Examples of these include the use of 3D animations, 2D animations, and videos [12]. However, interactive multimedia is more commonly used as a supplementary health care tool. These tools can be used to aid in the management of condition symptoms, therapies, knowledge, and communication with the larger health care team.

2.2 Literature Review

There are various literature review methods available. This chapter will focus on a scoping literature review that employs a framework as described by Arksey *et. al* [13]. In this framework five key stages are required to conduct such a review. These stages include 1) Identifying a research questions/objective, 2) Identifying relevant studies, 3) Study selection, 4) Charting data, 5) Collating, summarizing, and reporting the results [13]. The following subsections will outline each of these stages.

2.2.1 Stage 1: Identifying a Research Objective

Objective:
As cystic fibrosis is an uncommon disease, it can therefore be postulated that the available multimedia resources are sparse. As such there is no restriction on

multimedia platform, content or intervention. Instead the primary focus of this scoping review is threefold:

1. Locate areas where multimedia has been used for cystic fibrosis education.
2. Identify the stakeholders targeted and not targeted by this research.
3. Establish areas where multimedia can be better used for cystic fibrosis visualisation and education.

2.2.2 Stage 2: Identifying Relevant Studies

Inclusion Criteria

To achieve the above objective, manuscripts that specifically discuss the development or the evaluation of CF multimedia content are included. Papers that discuss the creation or evaluation of multimedia for a range of chronic conditions which includes CF are also included. Similarly, literature reviews that focus specifically on CF multimedia are included; whereas, literature reviews that include multimedia for chronic conditions, in which CF may be a small subpart, are excluded. To be included, manuscripts must be written in English or be available in English. There is no timeline restriction enforced on this literature review as multimedia technology and the years in which CF research is available will infer this.

Search Strategy

At the beginning of this chapter multimedia is described as comprising of multiple mediums. These mediums include graphics, animation, sound, and video. These mediums can then be further expanded into search terms which can be used as part of a search string. Predominantly visual media is further described by the following terms: “3D”, “2D”, “Virtual Reality”, “Augmented Reality”, “Games”. This search string can also be further refined when considering multimedia platforms, such as the world wide web, computer, tablet and mobile. These platforms can also infer specific multimedia delivery methods, such as Electronic Learning (e-Learning) and Mobile Learning (mLearning). Additionally, when coupling these platforms with the medical industry further search terms arise such as Mobile Health (mHealth), serious games, and Electronic Health (eHealth).

The databases utilised for this scoping review include: ITHAKA JSTOR, PubMed NCBI, Elsevier Scopus, Elsevier Science Direct, and the Web of Science. These databases were chosen due to the number of disciplines in which it indexes. The complete search string used for this study is as follows:
"Cystic Fibrosis" AND "Education" AND ("multimedia", OR "mHealth", OR "serious games", OR "eHealth", OR "eLearning", OR, "mLearning", OR "3D", OR "2D", OR "Virtual Reality", OR "Augmented Reality", OR "simulation").
This string is then modified respective to each database to yield more relevant results. For example some databases would implement these boolean terms in a slightly different syntax.

Outline of Citation and Results Management

All manuscripts located through the previously outlined databases are downloaded in a BibTex format and imported into Mendeley Reference Management Software version 1.17.8 [14]. This software was chosen for its facility to store large quantities of BibTex files and its at a glance service which allows you to preview titles, authors, abstract and keywords without the need to download full papers. The findings for each database are stored in separate folders and duplicated for each stage of the refinement process. The quantity of papers for each stage of this refinement process is then stored in Microsoft Excel [15].

2.2.3 Stage 3: Study Selection

Title and Keyword Screening:
This is the first of the refinement process. During this stage all titles and available keywords are read. Any manuscripts considered to be irrelevant are subsequently removed. Criteria that would result in a paper being removed include those that do not utilise multimedia for education or management and those that do not use multimedia for CF. If it is not possible to determine if the manuscript is irrelevant, it is retained.

Abstract Screening:
After the title and keyword screening, the abstracts for the remaining papers are then read. At this stage papers that are deemed ineligible or irrelevant are

removed. If it is unclear from the abstract whether the paper is relevant or irrelevant to this research, it is not removed and is instead passed to the next stage of the screening.

Introduction Screening:
Following the abstract screening, the introduction or first main section is read for the remaining manuscripts. This introduction or first section should describe the primary objectives of the research and the proposed multimedia intervention. Hence by reading this section, it can be determined whether or not these papers are irrelevant. If further clarity is required before removing the manuscript, the paper is read in its entirety. After this final screening technique, the remaining literature is then reviewed and reported on. The characterisation of data that is of interest to this research is discussed in the proceeding section.

2.2.4 Stage 4: Charting the Data

Data Characterisation After the refinement screening, the resulting papers are read in full and evaluated under various topics. The data of interest to this study will then be recorded into a Microsoft Excel sheet and then characterised under General Information, Multimedia Content, End User, Results, Conclusion and Limitations.

1. General information in the manuscript includes data such as author, title, year published, publication type, and discipline of publisher.

2. Multimedia content refers to the multimedia utilised within the paper and the platform on which it is disseminated.

3. The end user in this case refers specifically to the intended audience, or those to which the communication is targeted.

4. Results refers to any testing that was performed in the manuscript. As these manuscripts are not refined to a publication type, such as review, descriptive, or original research, the results category is unique to the final manuscript reviewed. If any testing is recorded in the manuscript, this data is also recorded under this section.

5. Data that is characterised under conclusions will be drawn directly from those reported by the authors of the manuscripts.

6. Lastly, any limitations denoted throughout the paper by the authors with reference to any of the above data characteristics will be recorded. An example of such data would include limitations of the study, testing or multimedia content and/or platform.

2.2.5 Stage 5: Collating, Summarizing, Reporting the Results

The title, author, year of publication, publisher, paper type, and publisher discipline along with the data of interest to this study as mentioned in Section 2.2.4 is then compiled into a Microsoft Excel document.

2.3 Results

The search strategy utilised in this literature review resulted in 1566 manuscripts. PubMed yielded 469 results, Web of Science yielded two manuscript, JSTOR produced 670 papers, and Science Direct yielded 57 manuscripts. These manuscripts are then subjected to the refinement process as outlined in Section 2.2.3.

2.3.1 Title and Keyword Screening

This refinement stage resulted in the removal of 1,246 manuscripts. The remaining 320 are apportioned across the databases as follows: PubMed (300), Web of Science (2), JSTOR (9), Scopus (10), and Sciencedirect (0). During this process there was a substantial quantity of papers removed as they were predominantly unrelated or irrelevant. Examples of papers that were deemed as irrelevant by their title alone include: "Toxicological effects of veterinary medicinal products in humans" [16] and "Guidelines for the use and interpretation of assays for monitoring autophagy (3rd edition)" [17]. Most notably, the vast removal of papers from JSTOR was due to the amount of ambiguous materials published in a journal or proceedings. Such as those publishing materials labelled as "Front Matter" and "Back Matter".

2.3.2 Abstract Screening

Twenty eight papers remained after this stage and those remaining manuscripts are distributed across the databases as follows: PubMed (15), Web of Science (2), JSTOR (4) and Scopus (7). Many of the papers that were not excluded during the title Screening can be attributed to vague titles that do not make clear if a multimedia intervention was utilised in the study. This is then clarified during the abstract screening with the papers being subsequently removed. Examples of such papers include: "Prevalence of Medical Technology Assistance among Children in Massachusetts in 1987 and 1990" [18]. In which this paper discusses the use of medical devices as part of pediatric care.

2.3.3 Introduction Screening

This stage resulted in 15 manuscripts, which were then printed for review. The primary cause for removal of manuscripts is attributed to ambiguous wording such as "Program" and "Intervention", which does not explicitly define the type of program such as face to face or multimedia based. An example of such a paper includes "Continuing Education Activity Sponsored by CDC: Newborn Screening for Cystic Fibrosis: Evaluation of Benefits and Risks and Recommendations for State Newborn Screening Programs" [19].

2.4 Final Manuscripts

The final 15 papers were then reviewed in their entirety. At this stage three papers were removed as their is no discussion of multimedia content. For example "Quality of cystic fibrosis information on Italian websites". This article investigates the quality of the textual information available on Italian cystic fibrosis websites. It does not discuss the development, utilisation or types of multimedia that are available through these websites. A graph of the quantity of manuscripts after each refinement criteria can be seen in Figure 2.1.

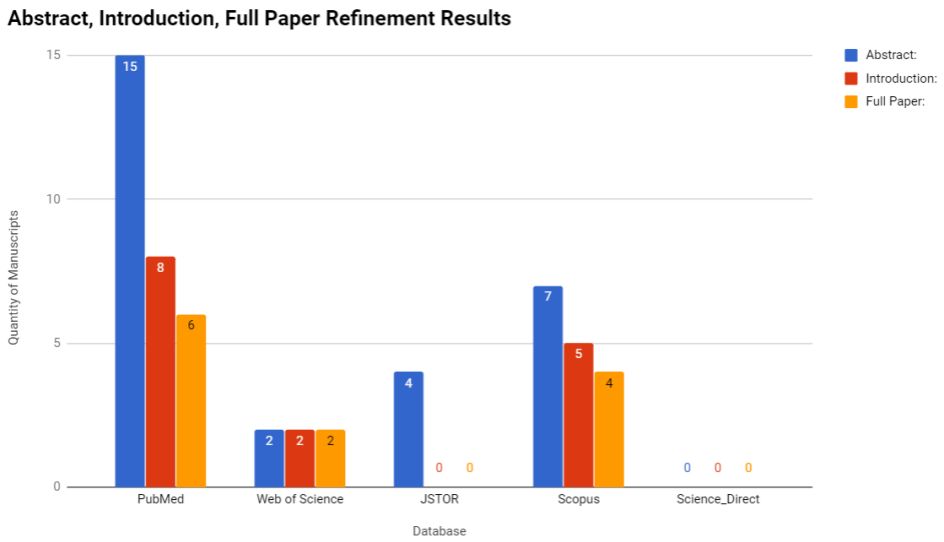


Figure 2.1: Manuscript Refinement Results.

2.4.1 Manuscript Data

The majority of the final manuscripts are Journal Articles. Only two manuscripts are published in conference proceedings and one as a poster. One manuscript was published in a technology focused journal, another published in an interdisciplinary technology and medical journal, and the remaining published in medical journals. The oldest manuscript is published in 2001 and the most recent published in 2015. This descriptive information can be seen in the proceeding Table 2.1.

Table 2.1: Descriptive Information for Final Manuscripts.

Paper Title	Authors	Year	Type	Publisher	Discipline
Simulation-Based Education: Improving Evidence-Based Decisions For Cystic Fibrosis Management	Mehta N, Capparelli C	2014	Poster	Pediatric pulmonology	Medicine
Hopkins Teen Central: Assessment of an internet-based support system for children with cystic fibrosis	Johnson, Kevin B., Russell D. Ravert, and Andrea Everton	2001	Journal Article	Pediatrics	Medicine
Betterland: an interactive cd-rom guide for children with cystic fibrosis.	Duff A, Ball R, Wolfe S, Blyth H, Brownlee K	2006	Journal Article	Paediatric nursing	Medicine
Cell phone intervention to improve adherence: cystic fibrosis care team, patient, and parent perspectives.	Marciel K, Saiman L, Quittell L, Dawkins K, Quittner A	2010	Journal Article	Pediatric pulmonology	Medicine
Preparing adolescents with chronic disease for transition to adult care: a technology program	Huang J, Terrones L, Tompane T, Dillon L, Pian M, Gottschalk M, Norman G, Bartholomew L	2014	Journal Article	Pediatrics	Medicine
The development and implementation of an interdisciplinary on-line academic course using a life course perspective	Anderson L, Schroth M, Marcus M, Becker C, Pfeil D, Yngsdal-Krenz R, Silvis D, Drier C, Marshall H	2014	Journal Article	Maternal and child health journal	Medicine
Pilot evaluation of web enabled symptom monitoring in cystic fibrosis	Roehrer E, Cummings E, Beggs S, Turner P, Hauser J, Micallef N, Ellis L, Reid D	2013	Journal Article	Informatics for Health and Social Care	Medicine
Pain, coping, and disability in adolescents and young adults with cystic fibrosis: a Web-based study.	Hubbard P, Broome M, Antia L	2005	Journal Article	Pediatric nursing	Medicine
Moving on: Use of computer games during transitional care for young people with long term medical conditions	Wilson A, McDonagh J	2012	Conference	European Conference on Games-based Learning	Technical
Web-based intervention for nutritional management in cystic fibrosis: Development, usability, and pilot trial	Stark L, Opipari-Arrigan L, Filigno S, Simon S, Leonard A, Mogayzel P, Rausch J, Zion C, Powers S	2015	Journal Article	Journal of Pediatric Psychology	Medicine
An interactive computer program can effectively educate potential users of cystic fibrosis carrier tests.	Castellani C, Perobelli S, Bianchi V, Seia M, Melotti P, Zanolla L, Assael B, Lalatta F	2011	Journal Article	American journal of medical genetics. Part A	Medicine
Enhancing self-efficacy for self-management in people with cystic fibrosis	Cummings E, Hauser J, Cameron-Tucker H, Fitzpatrick P, Jessup M, Walters E.H, Reid D.W, Turner P	2011	Conference	Studies in Health Technology and Informatics	Technical, Medicine

2.4.2 Manuscript Summary

Following on from the Table outlining the details of each manuscript, this section will provide a short summary of each manuscript before drawing some critical observations.

Simulation-Based Education: Improving Evidence-Based Decisions For Cystic Fibrosis Management [20]. The authors of this paper developed a web-based patient simulator to teach pulmonologists and infectious disease specialists about CF infection management guidelines. This interactive web application replicated patient cases that involved the pulmonologist and/or infectious disease specialist to choose the correct lab test, procedure, drug, and diagnosis. This tool incorporated images, text and simulated patient files. A sample of 95 pulmonologists and infectious disease specialists were recruited and subjected to the web-based intervention. The results of this study found significant improvements in several patient management areas such as identification of acute exacerbation related to CF, improvement in correctly ordering therapy for some staphylococcus aures infection, and improvement in counselling for infection control.

Hopkins Teen Central: Assessment of an Internet-Based Support System for Children with Cystic Fibrosis [21]. CF patients are actively discouraged from contact with one another due to the possibility of cross infection. Hence, this research aimed to evaluate the use of an Electronic Support Group (ESG) for CF adolescents over the web. The web based tool included many other features such as a Graffiti wall, Diary, Message Board, Knowledge based Games, and the ability to socialise with other adolescent CF patients through email. Eighteen adolescents between 13-18 evaluated the tool by completing a pre and post CF education quiz and provided feedback regarding the tool and their usage. It was found that the participants visited the web tool on average four times a month and emailed one another on average once a week. There was no significant difference in knowledge gain evaluated in the pre and post quiz, however there was an increase in perceived knowledge. It was also found that the participants believed that they had more relatable friends. To note, this paper is the oldest of the final 12 reviewed and as such internet accessibility was limited. The authors made efforts to provide all participants with an internet connection

through a Microsoft WebTV. However, it is noted in the paper that the WebTV posed some technical difficulties which contributed to the minimal site visitation. Similarly the reliance on a dial up connection which required a phone line also posed many family logistic issues with connecting to the internet. The study concluded that the proposed ESG shows much promise for adolescents' social involvement with peers and staff members.

Betterland: an Interactive CD-ROM Guide for Children with Cystic Fibrosis [22]. Similar to the previous paper, the authors of Betterland created this Compact Disc Read-Only Memory (CD-ROM) game as a result of the segregation of CF patients due to cross infection. This interactive game CD-ROM was aimed at improving CF pediatrics knowledge and understanding of treatments and painful procedures. The multimedia content was interactive and incorporates graphics, animations, games, audio, and film. The games were presented in a carnival mini-game style where the patient can come to a carnival stall and participate in an educational mini-game. Some games are quiz-based, others are created to enhance therapy techniques and breathing exercises. One particular game requires the user to take a deep breath and to focus their exhale on a moveable target on the screen. To note, an audio narrative instructs the child when to inhale and exhale so that the animations are timed correctly, as the CD-ROM is not capable of processing a blow/exhale from external hardware. For games that are targeted at painful procedures, the CD-ROM also incorporates *film models*; which involves film footage of a child undergoing the painful procedure, such as an injection and enunciating coping mechanisms. The authors did not report any evaluation in this paper, instead the authors outline the features of Betterland and where it is currently being incorporated into the healthcare system; specifically nurse-ied, Moving to High School (MotHS) program, as well as some CF multidisciplinary teams. The authors also provided information on how to purchase a copy of the Betterland CD-ROM.

Cell Phone Intervention to Improve Adherence: Cystic Fibrosis Care Team, Patient, and Parent Perspectives [23]. This study is designed to aid CF adolescents' therapy compliance. To do so, the authors developed a web enabled cell phone: CFFONE. The intervention content is categorised into five areas; CF information, care management, social networking, entertainment, and

communication. Similar to the other manuscripts discussed thus far, this intervention also incorporates games, music, quizzes, and puzzles. However, these media are harnessed to provide a distraction during treatments. As mentioned, one area of focus in this intervention is social networking, similar to the Hopkins Teen Central [21] intervention. To achieve this, the intervention allows for sharing of media, including videos and pictures, as well as a message board. Other features unique to this paper included personalised calendars which can send Short Message Service (SMS) reminders for treatments and appointments; and an interactive chatbot, which simulates a conversation by responding with predefined messages stored in a database. The authors of this paper subjected the intervention to testing with 12 CF adolescents, six CF adults, 17 CF professionals, 12 parents, and eight technical experts. The results found that the CF adolescents, CF adults, and parents regarded the CFFONE as likely to improve therapy adherence. The technical experts concluded that the intervention in its current state was appropriate for any age. To note, CF participants of the study found no difficulty in utilising the main features of the social network. However, there was confusion with how to use the profile page, and a small minority were unable to use the video and game features. All those who completed the usability survey strongly agreed that the user interface was intuitive and resulted in users locating CF information easily.

Preparing Adolescents with Chronic Disease for Transition to Adult Care: a Technology Program [24]. Unlike the previous papers, this manuscript did not focus on cystic fibrosis explicitly, but instead investigated CF in conjunction with Inflammatory Bowel Disease (IBD) and Type 1 Diabetes (T1D). Similar to Johnson *et al.* [21] and Cummings *et al.* [25] this paper was targeted towards adolescents; however, it instead focused on preparing these adolescents to transition to adult care. The paper presented a two part technical intervention. The first was a web based educational tool where adolescents can receive weekly disease management education material, lifestyle tips, and communication skills. The multimedia used within this site included images, figures and text. The second part of this intervention involved SMS reminders sent to the participants to notify them of new educational materials on the website. An SMS was also sent to follow up on the participant's understanding of the content. The patients were also given access to an SMS portal which allowed the adolescents

to send personalised messages concerning their health to the healthcare team. To evaluate the intervention the authors conducted a randomized clinical trial over eight months with 81 participants aged between 12 and 20. The study group (referred to as MD2ME) received the intervention for two months followed by a six month review period. The control group received similar educational material via the mail. Baseline data regarding health related self efficacy, disease management, and health assessments were recorded pre-intervention and followed up at month two and month eight. The results of this study found that recipients in the MD2ME intervention demonstrated significant improvements in health related self efficacy, disease management, and health assessment compared to the control group. The authors concluded that this intervention was a low cost and easily distributed solution that may be of benefit to adolescents transitioning to adult care.

The Development and Implementation of an Interdisciplinary On-Line Academic Course Using a Life Course Perspective [26]. Similar to the paper authored by Mehta *et al.* this paper discussed an intervention for students and not patients. An online course was developed for graduate students and postgraduate professionals. The training course was titled *"Interdisciplinary Care of Children with Special Health Care Needs"* which is developed based on the Life Course Perspective (LCP) conceptual framework. The framework foundation focused on the premise that health and disease can change in an individual over time, based on numerous factors. To achieve this, the authors created a number of online medias including recorded lectures, text, and case study videos which were focused on a child with CF. The case study videos were developed from the experience of the CF multidisciplinary team and follows a child and their family. The video followed them from diagnosis at two weeks old to their transition to adult care at 18 years old. Three videos were created for this case study which focused on the health care team, respecting family and culture, and transitioning to adult care. Nineteen students were recruited into the course; however, only nine returned feedback and evaluation of the course. From the student evaluation, the course was found to benefit student learning. The students also reported that they will use the newly acquired skills in future practice. The authors concluded that the LCP framework is successful in course design and can appropriately serve the students learning needs.

Pilot Evaluation of Web Enabled Symptom Monitoring in Cystic Fibrosis [27]. Similar to the other five papers reviewed, the multimedia in this intervention was presented on a web based platform. The intervention created was developed to enhance CF patients self management and communication skills with the added benefit of improving access to CF educational material. The intervention was not limited to any age range and instead evaluates its effect on CF patients from 19 months to 57 years old and their families. The web tool also included a symptom diary which posed a series of questions including mood, appetite, and sputum volume. The questions were presented in a Multiple Choice Questionnaire (MCQ) format and implemented images instead of text for each possible answer. Users could enter data into their mood diary which is initially set to be viewed only by the patient. However, the patient could choose to share this information with mentors, caregivers, or health care team members. The web tool also contained textual education material, links to external resources and contact details. Usability data pertaining to the websites perceived usefulness was collected from 15 CF patients (five pediatrics, five adolescents, and five adults). Data from semi structured interviews, surveys, and health outcomes were collected pre and post web intervention. Initially the participants believed that the web diary would be of more benefit to peers rather than their own self monitoring. However, this changed at the end of the study where users reported that although the diary did not change how they managed their CF, it did make them more aware of their own symptoms. The authors concluded that further research is required to understand the effect web based interventions have on CF self management and perceptions of their own condition.

Pain, Coping, and Disability in Adolescents and Young Adults with Cystic Fibrosis: a Web-Based Study [28]. Again, this ICT based intervention was created for a web based platform. Although, unlike the other studies, this manuscript exclusively investigated pain and coping mechanisms for CF adolescents and young adults. To investigate this, the authors created an educational website focused on pain and the communication of pain to the health care team. The website also encompassed three surveys; demographic, pain disability, and coping with pain. To note the emphasis of this paper was on the the surveys and data collected, the educational website was subsidiary to the study and was created as a means to collect survey data. The authors did not elaborate on the

multimedia incorporated into this web tool. Participants were recruited through the website, which yielded 18 patients. This study found that approximately half of the participants reported moderate pain lasting two hours on a daily basis. The most common strategies to cope with pain were found to be problem solving, acceptance and self encouragement. The conclusion of the authors was that pain management continues to be problematic for some young adults with CF, which can serve as a foundation for future research in this area. The authors did not provide any conclusions on the web based tool.

Moving On: Use of Computer Games During Transitional Care for Young People with Long Term Medical Conditions [29]. As found previously with the other reviewed papers [24] the authors have identified that many adolescents with chronic conditions feel unprepared when transitioning to adult care. This paper reviews the impact of serious games that target self efficacy, education, adherence, and treatment for adolescents with chronic conditions. These results are then extrapolated and discussed as a method of improving the transition to adult care for these young adults. The chronic conditions considered in this review are cancer, asthma, cystic fibrosis, diabetes, depression, smoking prevention, and weight management. For CF, the authors reviewed a game targeted at CF patients between 7-17 years old called "Creep Frontier" [30]. The purpose of this game was to improve breath awareness and uses breath biofeedback data to control sprite movements. The reports of the Creep Frontier study found a positive effect among its CF participants. The authors of this paper comment that the games reviewed are often too disease specific which causes difficulty in transferring their successful methods to other chronic conditions. However the authors conclude with recommendations for games specific to adolescents transferring to adult care with reference to the possible barriers with acceptance and uptake among these populations.

Web-Based Intervention for Nutritional Management in Cystic Fibrosis: Development, Usability, and Pilot Trial [31]. This manuscript was published in 2015, making it the most recent of all the papers. Similar to the other papers, the authors use a web based platform to disseminate their *BeInCharge* (BIC) nutritional management intervention. The authors' reported standard nutritional care for CF children aged between 4-9 years old requires a parent to complete educational courses in the hospital, some parents also keep calorie diaries

for their children. The proposed intervention instead presented this educational content to the users over the web via videos, text, and audio. The intervention also included a calorie counter app. The manuscript reported usability data from the five mothers of CF children; the feedback of which was then implemented before a randomised trial with ten mothers of CF children. In the randomised trial, five mothers were given the web based intervention and the remaining five received standard care. The usability data found areas which required attention such as wording and technical issues. This data also reported that the mothers found the intervention to be less stressful than standard care. The participants also regarded the app as clear and easy to navigate. The results of the pilot trial found that children with mothers in the web based intervention experienced an increase in Body Mass Index (BMI) as well as achieving their calorie goal. The authors conclude that there are limitations to the study and further research is required to further assess the effect of a web-based intervention; however, the data reported in this trial shows promising results for increasing weight gain in children with CF.

An Interactive Computer Program can Effectively Educate Potential Users of Cystic Fibrosis Carrier Tests [32]. Unlike all the papers included in this review, this paper aims its focus on carrier testing for CF and not the CF population. The authors of this paper develop an interactive computer program that is comprised of three sections; general features of CF, genetic features of CF, and genetic test of CF. These sections all utilise the following media: audio, images, animation and MCQ. To evaluate the effectiveness of this interactive program the authors recruited 44 participants who were undergoing assisted reproduction, and randomly assigned the participants to either the interactive computer program or standard genetic counseling. All participants were given a pre and post questionnaire to measure improvements in understanding. The results of this questionnaire showed a statistically significant increase in knowledge in both the intervention and standard care group. The authors conclude that the interactive computer program is as effective as standard care. However, it should not substitute these genetic counselling sessions as the counselors offer more knowledge and support which is outside of the scope of this program. Therefore, the authors advise that interactive computer programs can be used to assist or complement standard care.

Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis [25]. Cummings *et al.* focus on self efficacy, self management and Quality of Life (QOL) in their web and mobile based intervention. The intervention is designed to be used specifically by CF adolescents and adults. To determine the beneficial effect of this intervention, the authors randomised 19 participants into three study groups. Group one served as the control group and received standard care. Group two were provided access to a self efficacy program under guidance of a mentor. Group three received the same exposure as group two; however, they also receive access to a web-based application which allows the participant to record and view graphical interpretations of daily symptoms and QOL data that is entered via the website or by SMS. For those receiving mentorship, trained health professionals were given the ability to log onto the webtool to review recorded data from their mentee and contact the participant via telephone to discuss or revise action plans and goals as necessary. Qualitative data pertaining to this study was collected via recorded interviews at the end of the six month intervention. The results of this study found that although participants regarded the web and phone based intervention as useful and provided the ability to monitor changes in their own symptoms, usage of the intervention reduced over time. However the authors note that the intervention provides a feasible solution to geographical dispersed population. The authors also noted that the majority of the CF adolescent and adult population are confident with web and mobile phone technology. Both Group 2 and 3 demonstrated an increase in self efficacy, although the authors note that it is unclear if the application subjected to Group 3 provided any additional benefits beyond supporting the mentoring intervention subjected to both groups.

2.5 Evaluation and Observations of the Final Manuscripts

The final 12 manuscript titles, target population, educational topic, platform, and the included multimedia are presented in Table 2.2. During the screening process a substantial quantity of ineligible manuscripts were found and removed which explored various interventions, problems and solutions to CF adolescents transitioning to adult care that did not discuss any multimedia. This theme continues with two of the final manuscripts discussed in this study [24, 29]. For

a time, CF was considered to be a pediatric disease; however, life expectancy for this cohort has grown. The large amount of published research investigating CF children transitioning to adult care may be attributed to this change in life expectancy. The research presented by Anderson *et al.* [26] is not targeted at CF patients and is instead targeted at students. Interestingly, although the course is targeted at students it again revisits the theme of CF children transitioning to adult care.

Of the 12 final manuscripts only two investigated one aspect of CF education for students and healthcare professionals [20, 26]. This may be an indicator that medical professionals do not struggle with CF educational aspects, or it may be attributed to CF being an orphan lung disease and is instead treated as a sub-topic or case study of a much larger curriculum. For students preparing to become respiratory specialists, CF is one of many respiratory diseases that must be studied and is acute in comparison to the likes of asthma and COPD. Likewise, for those healthcare professionals who must study many medical topics with some aspect of CF healthcare, specific CF educational tools may prove as a beneficial means for refresher training/education. This may be the case in two of the papers reviewed in this literature review. Mehta *et al.* present a web based patient simulator to exemplify use cases for CF infection management guidelines to pulmonologists and infection control specialists [20]. This is perhaps one of many infection management guidelines healthcare professionals must practice; however, it is the main focus of the research. Whereas in the research intervention presented by Anderson *et al.* CF is used as a case study for a much larger curriculum, focusing on children with special healthcare needs [26]. In both papers, the authors concluded that these tools showed a significant increase in knowledge and improved confidence. Considering the promising results these papers demonstrate and the lack of research found for CF education for healthcare professionals, this demonstrates the need for explicit CF multimedia education tools.

Another common theme identified in these papers is the use of social networking elements such as SMS, email, phone call, message board, chatbot, and ESG. Due to cross infection, CF patients are actively discouraged from face-to-face gatherings; as such it can be considered that CF patients may feel like an isolated cohort. The authors of three manuscripts [21, 23, 24] identify this issue and subsequently implement a technology based communication solution for these

patients. The mobile phone intervention as presented by Marciel *et al.* notes the importance of social support among CF patients; however, it harnesses this concept to motivate users to improve therapy adherence [23]. For some studies the social communication elements are a secondary feature to the overall intervention [23, 24]; however for, Johnson *et al.* this is the primary evaluation [21]. The research conducted by Johnson *et al.* is the oldest paper located in this literature review [21]. The authors describe many technical difficulties in the paper such as the reliance on dial-up connections and the family phone not being in-use to log on to the educational and social tool. However, despite these reported issues, participants continued to use the tool to communicate with peers. No other papers found in this scoping literature review primarily focus on social networking for CF patients. This may be a product of the rapid growth of various websites since 2001; including social media, social networks, and forums. In a study conducted by Kirk *et al.* the authors reviewed common CF Web Forums and analysed the forum postings for content and conversation themes and types [33]. The study found that CF patients and their families commonly use forums to discuss various topics; resulting in these online support groups acting as a supplementary aid to professional support for self management. It was also found that these forums enabled CF patients and their families to share experiences and strategies for living with CF. Moreover, it aided these patients in developing communication skills with healthcare professionals [33]. The development of these forums and their increase of use may be indicative that CF patients no longer feel like an isolated cohort and perhaps development and research of multimedia tools capable of social networking is no longer required. Alternatively due to improvements in technology, multimedia could perhaps promote online social interactions further and provide additional features to enhance the social experience.

Another common research topic noted in the refinement process is CF carrier screening. Predominantly, these papers advised the need for testing and the implementation of screening into care. Only one paper found in this literature review addressed this topic with their interactive tool. Castellani *et al.* [32] present an interactive educational tool to disseminate to potential parents the general and genetic features of genetic testing. The authors found that the tool was as effective as standard care received via a genetic counsellor, however they believe that it should be utilised in parallel and not as an alternative to standard care.

Table 2.2: Focus and Medium of Final Manuscripts.

Paper Title	**Focus**	**Multimedia**	**Platform**	**Users**
Simulation-Based Education: Improving Evidence-Based Decisions For Cystic Fibrosis Management	CF infection management guidelines	images, text, patient files	Web	Pulmonologists and Infectious Disease Specialists
Hopkins Teen Central: Assessment of an internet-based support system for children with cystic fibrosis	Electronic Support Group	Graffiti Wall, Diary, Message Board, Knowledge based Games, Social elements	Web	CF Adolescents
Betterland: an interactive cd-rom guide for children with cystic fibrosis.	Knowledge and understanding of treatments and painful procedures	Graphics, Animations, Games, Audio, Film	CD-ROM	CF Pediatrics
Cell phone intervention to improve adherence: cystic fibrosis care team, patient, and parent perspectives.	Therapy Adherence	Games, Music, Quizzes and puzzles, Text, Images, Video, Personalised Calendars, Interactive Chatbot	Web Enabled Mobile Phone	CF Adolescents
Preparing adolescents with chronic disease for transition to adult care: a technology program	Transition to Adult Care for Chronic Conditions	Images, Figures, Text, SMS	Web and Mobile	CF, IBD, T1D Adolescents
The development and implementation of an interdisciplinary on-line academic course using a life course perspective	Interdisciplinary Care of Children with Special Health Care Needs	Recorded Lectures, Text, Videos	Web	Graduate Students and Postgraduate Professionals
Pilot evaluation of web enabled symptom monitoring in cystic fibrosis	Symptom Monitoring	Text, Picture Based MCQ, Mood Diary	Web	All CF Patients and Their Families
Pain, coping, and disability in adolescents and young adults with cystic fibrosis: a Web-based study.	Pain and Coping Mechanisms	Text, Images, Surveys	Web	CF Adolescents and Young Adults
Moving on: Use of computer games during transitional care for young people with long term medical conditions	Transition to Adult Care for Chronic Conditions	Games	Game	Asthma, CF, Diabetes, Depression, Cancer Adolescents
Web-based intervention for nutritional management in cystic fibrosis: Development, usability, and pilot trial	Nutritional Management	Videos, Text, Audio, Calorie Counter App	Web and App	Mothers of CF children aged 4-9 years old
An interactive computer program can effectively educate potential users of cystic fibrosis carrier tests.	CF Carrier Tests	Audio, Images, Animations, MCQ	Interactive computer program	Persons who do not have CF
Enhancing self-efficacy for self-management in people with cystic fibrosis	Self efficacy, self management, Quality of Life	Daily symptom diary, text, graphs	Web and Mobile	CF adolescents and Adults

Nine of the final papers produced interventions for a web based platform exclusively or in addition to a mobile application [20, 21, 23–28, 31]. In most cases the authors noted their choice to use the web based platform due to it being considered as the most accessible and cost effective solution: *"Internet treatment delivery provides an excellent alternative, addressing access barriers, circumventing problems of limited providers, geography, time, and costs, and offering great potential for dissemination of interventions."* [31]. One paper specifically sites the web as an effective means to recruit participants and retrieve data quickly and efficiently: *"Using the internet allows researchers potential access to a larger sample size. Another advantage is the decreased amount of time it takes to receive data"* [28]. For the studies utilising mobile phone technology in addition to web, those authors regard mobile phone technology as innovative, with unique opportunities: *"New technologies may provide a unique opportunity to deliver effective adherence interventions while promoting safe social interactions and peer support"* [23].

It's perhaps unsurprising that so many of the papers reviewed used a web platform to disseminate their intervention considering the rapid adoption and use of the internet. In 2002 it was reported that advancements in internet technologies has lead to the world wide web and social media becoming the first information source for many patients [34]. A survey conducted in 2012 found that 72% of participants procure healthcare information via the internet [35]. This trend could be ever increasing as in 2014 a study conducted in the US found that 87% of American adults use the internet [36]. This is a similar finding with the Irish population in 2015 showing 82% of Irish citizens use the internet frequently [37]. There is a similar exponential growth in the quantity of smartphone users in Ireland, from 39% of the population owning a smartphone in 2012 to 70% in 2015 [38]. Kessels *et al.* found that between 40% and 80% of the healthcare information communicated to patients by healthcare practitioners and professionals is forgotten immediately [39]. With this increase of accessibility and usage, the web can be considered a feasible solution to the communication of healthcare information.

Seven of the nine papers which use a web platform propose their multimedia intervention for patients. In the field of Patient Education, patient engagement, and individualised care is often regarded as a key aspect to its success. This can be seen in the research reviewed by Stark *et al.* where the authors provided a

mobile app to mothers of CF patients to record calorie intake [31]. In allowing the participants to view their personal calorie intake along with calories for certain foods, there was a significant increase in BMI. Considering the effects individualised care could potentially have on CF education and management, perhaps the monitoring and recording of other CF medical data could also be of benefit. However, this information could perhaps be produced in a more engaging manner such as games.

Three of the manuscripts from the literature review incorporate games as a feature of the overall research intervention [21–23]. In the case of Johnson *et al.* the games are knowledge based and are used to increase knowledge among patients [21]. The other games developed by Duff *et al.* are used to improve breathing exercises and involve CF pediatrics blowing at a screen [22]. To note, the game does not utilise any biofeedback data and instead narrates the user to blow at the screen while playing synchronised animations. The last paper which implements a game does so as a way to distract CF adolescents during therapies [23]. In the case of [21, 22], the games involve some form of CF focused information. Whereas the games included by Marciel *et al.* have no relationship to CF information [23].

One other paper found in this scoping review also discusses the use of games for chronic conditions. However, it does not present a developed application, but instead reviews the current games available in the field and what features could be modified for use specifically to aid adolescents transitioning into adult care [29]; a common theme to some of the papers found in this review. Wilson *et al.* reviews several games for adolescents with chronic conditions including cancer, diabetes, CF, asthma, and depression. The game reviewed for CF (Creep Frontier) was developed by Bingham *et al.* and is not focused on adolescents transitioning, but instead aims to improve CF pediatrics breathing techniques by using a digital spirometer to control sprite movements [30]. This is perhaps a similar goal to some of the games available in Betterland [22]. The authors of the Creep Frontier game concluded that this game can improve CF pediatrics breath awareness [30]. The emergence of this engaging and effective approach to breathing exercises may also show promise with CF adults; however, this is not expressed by the authors. Similar to the game presented by Bingham *et al.* [30] the games used by the other three manuscripts [21–23] in this literature review are also targeted at CF adolescents and pediatrics, but not CF adults. This is perhaps due to games

often being perceived for children and not for adults. However games developed for a smartphone have proved to engage a larger population without restriction on demographics or gender [40, 41]. In addition to this, the average age for the Irish population who play games is between 30 or 31 [40, 41]. With this in mind, it may be possible that biofeedback games could be of interest to CF adults as well as CF pediatrics and CF adolescents.

Two of the nine web based papers were targeted towards medical and healthcare students and professionals and were published in 2014 [20, 26]. Another media that could again be considered to be more engaging is games. A survey that was completed with two medical schools with 217 medical students in 2010 found that 98% of students like the idea of using technology to enhance their learning [42]. It was also found that 96% of respondents felt that technology should be better used in education. The respondents also believed that games have the potential for educational value (80%). Building on this, 97% of the participants agreed to play an educational game if it was fun, furthermore 77% agreed if it helped to accomplish an important task or goal. Lastly, 90% of the respondents confirmed that they would play a serious educational game if it helped improve or develop skills in patient interaction [42]. However, a systematic review of 26 educational games for medical students found that there is not sufficient evidence to confirm or refute the ability of serious games in medical education [43]. During 2014, when the papers were published, HTML5 was being fully implemented which provides extended functionality and more User Interface (UI) elements to browsers such as 3D rendering and drag-drop functionality. Despite this, none of the papers targeting healthcare professionals incorporate any of these extended functionalities. It may also be speculated that perhaps at this time other more visual enriching platforms, such as 3D software, simulation tools, virtual reality and augmented reality, could be more engaging for the student. In the case of 3D rendering, 3D simulation and virtual reality, all are achievable in a browser.

For a time, CF was considered to be a pediatric disease; however, this has now changed and it is predicted that some patients will live to retirement age [44]. Additionally, it is anticipated that there will be a considerable growth in the number of adult CF patients [45]. In a recent study, longitudinal data from 34 cystic fibrosis registries were analysed. From this analysis it is predicted that Ireland, along with 15 other countries, will experience an increase of approximately 75% of the adult CF population and 20% in the CF pediatric population by 2025 [45].

From this, it can be postulated that multimedia research for CF would focus on this new aging population. Of the final 12 papers, nine are targeted at CF patients [21–25,27–29,31]. None of the papers are targeted at CF adults only; instead, three of the nine are geared to adolescents and adults [25,28] or CF patients and their families [27]. As the majority of CF adults have been diagnosed from birth and subsequently managing their condition for a number of years; they can be considered a knowledgeable cohort and this may attribute to the small number of yielded manuscripts targeting the adult CF population. This was investigated further by Vagg *et al.* who sought to review the available literature pertaining to adult CF education [2]. This review yielded eight manuscripts which focused on educational interventions and concerns for CF adults or CF adults in addition to another CF cohort, such as CF pediatrics. Of the eight papers, four focused on CF adults only, with only one paper producing an intervention. This intervention was not ICT based and did not include any multimedia content; instead, it utilised traditional educational methods [46]. The authors conclude that there continues to be knowledge gaps among the adult CF population and there is a paucity in research into this area. The authors also advise that as the survival age increases for this population further research and educational interventions are required to meet the emerging needs of the aging adult CF population [2].

Most of the papers reviewed also noted a common lack of studies for the use of ICT tools to aid some aspect of CF: "*To date there are few published studies of the use of ICT tools to aid care delivery and self management in CF*" [27]. In the case of one web based intervention, the authors referenced one of the other papers found in this review, *"Although a web-enabled iPhone that allowed access to educational material was recently trialled with success"* [27], *"Recently, an educational intervention utilizing an interactive CD-Rom for children with CF was shown to remediate gaps in knowledge and increase coping skills"* [23]. Similarly, two of the papers share the same authors and is considered continued research [25, 32] *"Previous research conducted with this group provided the rationale for the conceptualisation of a comprehensive self-management support system"* [32], perhaps demonstrating the lack of multimedia interventions utilised in studies for CF.

Furthermore, of the final 12 manuscripts, two were written by CF clinics based in Tasmania [25, 27]. The research location is regarded as relevant by all authors as Tasmania has the second highest incidence of CF in the world: *"In*

the current research this is particularly relevant as the location, Tasmania, has the second highest incidence of CF in the world." [27]. As Ireland has the highest incidence of CF, it can be postulated that more ICT based interventions should be produced. However, none of the research of the final twelve manuscripts was conducted within Ireland.

The scoping literature review conducted in this Chapter has highlighted gaps in the available CF multimedia content. As such, these gaps form the foundation for each chapter's research objective and agenda. To further investigate these found gaps, each proceeding chapter will conduct a shorter and more refined literature review to inform the chapter's research and multimedia development.

2.6 Comparison to Other Chronic Conditions

This chapter has focused predominantly on the multimedia for CF to gain an understanding of what is currently available for patients and medical professionals alike. However this section briefly compares these found CF-focused multimedia against multimedia for other chronic conditions. The chronic conditions chosen for this are Asthma,T1D, and Rheumatoid Arthritis (RA). To locate relevant material, the aforementioned search string discussed in Section 2.2.2 is modified slightly, whereby cystic fibrosis is replaced with each condition respectively and then entered into Google Scholar. Google Scholar is chosen as the search engine as it has access to many databases including those implemented for this chapter's systematic literature review. The first three relevant manuscripts (following the same inclusion criteria as Section 2.2.2) are then investigated.

The publication year range for these found papers are 2000-2016, which is similar to the found CF multimedia papers (2001-2015). Therefore it can be postulated that similar technologies and devices may be seen through the found chronic condition manuscripts. Firstly it is noted that there is a similar tendency for these medical-multimedia platforms to be developed for the web platform, with four of the found manuscripts evaluating or developing web-based applications [47–50]. Likewise, two manuscripts focus on mobile apps [51, 52] and a further two developing for standalone computer applications [53,54]. Whereas McPherson *et al.* discuss general multimedia and its application to asthma education [55]. All nine manuscripts focus on multimedia for patients, no manuscript reports multimedia for medical professionals in their respective areas.

Firstly, it is worth noting that, similar to the CF manuscripts, the found chronic condition manuscripts report mixed findings with the use of multimedia for education and management. Five manuscripts report that multimedia benefited patients in some form [47–50, 55]. One manuscript, although it describes users as having an increased perceived knowledge of their condition, also advises that the multimedia experienced less use in comparison to traditional methods [53]. While another manuscript reports that the presented multimedia intervention did not have any improvements over traditional written materials [54].

Similar to the CF focused multimedia, the majority of the found chronic condition manuscripts focus their intervention towards children and adolescents [47–49, 54, 55]. Three other papers also evaluated their multimedia with the target audience, however two papers did not specify the age range of the study participants [51,53], and one only specified the mean age of the participants (57.95 years, n=155) [50]. McPherson *et. al* further elaborate on why multimedia may be used so often for paediatric education [55]. In their manuscript they describe multimedia being a familiar technology that is interesting to children [55].

One found manuscript among the chronic conditions develops a web-based intervention for children with T1D transitioning to adolescence [48]. The authors of this paper conclude that delivering behavioural and educational interventions via the web is effective in improving outcomes for these children [48]. Although transitioning is also a focal point for some CF manuscripts [24,29], the CF manuscripts focus more on transitioning to adult care as opposed to adolescence.

Similar to the CF manuscripts, social networking and social media are also discussed in four of the chronic condition manuscripts. Geuens *et al.* review 28 apps targeting RA to investigate their use of persuasive principles. The authors conclude that social support was the least used persuasive principle and future apps for RA would benefit from the implementation of social networks and media [52]. In the case of [51] the authors only report the use of social media such as Facebook to keep in contact with study participants. However, [49] and [50] specifically describe the use of social support to assist in improving self management and education, similar to the CF manuscripts [21, 23, 56].

Three manuscripts also describe or discuss games for education [50, 54, 55]. McPherson et al. again discuss the advantages of games for paediatric asthma education, such as captivating and engaging its audience [55]. Again, Homer *et*

al. discusses games in the context of children with asthma [54]. This manuscript describes the development and evaluation of a game focusing on management education, and reports that this game did not produce any greater or lesser improvement than traditional written methods. However the participants reported enjoying the game more [54]. These two asthma papers are similar to the findings of the CF manuscripts, where games are employed for educational purposes with children [21–23]. However, unlike the CF manuscripts, one of the found RA papers describes a gamified web-based experience that is used by adults in addition to children [50]. Allam *et al.* advise this choice to incorporate gamified elements into the educational web tool was to encourage and motivate users to use the platform. The gamification elements in this paper focus predominantly on a reward scheme, whereby users are rewarded with points, badges and medals each time they complete a quiz, explore/read articles, and contribute in chat rooms. The web tool also contained a leaderboard of the top five users. Overall the authors conclude that the web-based gamified education tool had more positive outcomes compared to intervention groups [50].

This small comparison highlights several findings. The first is that multimedia is used for the education and management of chronic conditions effectively. The second is that the found CF manuscripts have similar themes, technologies, and multimedia to that of the found chronic condition manuscripts. Similar to both CF and other chronic condition manuscripts, there is a paucity of multimedia for medical professionals and adults. Likewise, social media and games, although not common, are still used. Some themes were more unique to CF, such as the focus on transitioning to adult care. However, multimedia for patient education appears to be a large commonality. Although the quantity of CF available multimedia can not match that of more common chronic conditions (such as Asthma), it appears that it is targeting what appear to be important themes while using current technology. However, multimedia can target other integral areas for CF patients and professionals alike, which will be further examined in the proceeding chapters.

2.7 Summary

The purpose of this systematic scoping literature review was to first evaluate the current available educational multimedia that focuses on CF. From this evaluation, this chapter then discerns gaps in the found literature. The first noteworthy observation found in the literature review is the paucity of available manuscripts. Although the scoping review yielded a large quantity of papers in its first refinement stage, these papers were later deemed irrelevant, leaving only 12 applicable papers. On further inspection several common themes and gaps were identified. Firstly, only two manuscripts concern themselves with the education of medical professionals. There is also a general lack of visual content for these two manuscripts. Nine papers target their proposed multimedia intervention towards CF patients. A common media found throughout these papers was that of CF games. More frequently, these games were used as a distraction or social component. However, only some of the utilised games attempted to benefit CF education through quizzes or puzzles. Moreover, two manuscripts briefly invoke concepts reminiscent of serious games without pursuing them as part of their intervention. In all cases, these games were for the primary attention of CF paediatrics and adolescents. This exclusion of CF adults is a common theme found throughout the manuscripts focused on CF patients. Three manuscripts pertaining to multimedia for Asthma, T1D, and RA were also analysed and compared against the found CF multimedia papers. The comparison highlights that the found chronic condition manuscripts have similar themes, technologies, and multimedia to that of the CF manuscripts. However, there was a larger quantity of papers for the other chronic conditions when compared to the CF manuscripts. It is acknowledged that a larger literature review may have identified more manuscripts and gaps, and is therefore suggested for future works. Whereby the researcher conducts a larger literature review which includes other chronic conditions to compare and inform the research further. This lack of educational intervention for medical professionals and CF adults was also an identified gap in the chronic conditions, and formulates the premise of the proceeding chapters. Chapter 4, 5, and 6 discuss the design, development and evaluation of multimedia for cystic fibrosis. Chapter 5, and 6, specifically develop this multimedia for a smartphone platform in the form of an mHealth application. However while developing these multimedia it was found that there is no currently available pipeline outlining the considerations for designing and developing such an application. Hence, this

research designed such a conceptual pipeline, which is discussed first in Chapter 3.

Chapter 3

A General mHealth Design Pipeline

The previous chapter outlines some of the identified gaps where multimedia can be used for cystic fibrosis medical professionals and patients. The proceeding chapters discuss the design, development, and evaluation of such multimedia. Chapter 5 and 6 specifically design these interventions for CF patients on a smartphone device. By deploying the app onto a smartphone, the intervention can be considered as an mHealth app. Subsequently, this chapter outlines a "General mHealth Design Pipeline" to support the development of mHealth applications from the research and experience of Chapter 5 and 6. This chapter is discussed first as it is a theoretical pipeline where-as the remaining chapters are more technical driven. This delineation is made to contextualise the pipeline in the proceeding chapters. Chapters 5 and 6 will build upon this pipeline by discussing its implementation into the development process of a serious game and patient passport. The significant contribution of this chapter is an mHealth design pipeline which consolidates intricate elements and considerations presented by researchers and governmental departments into one concise set of guidelines. The manuscript published to support this chapter is "A General mHealth Design Pipeline" [57].

3.1 eHealth and mHealth

Advancements in information and communication technologies have led to their innovative incorporation into medicine and health; this is defined by the World Health Organisation (WHO) as eHealth [58]. The incorporation has since been

adapted for the proliferation of mobile technologies, and has formed a branch of eHealth known as mHealth. Mobile Health or mHealth refers specifically to the use of mobile technologies and apps developed for smartphone and tablet that are utilised to benefit the medical and health industry [59]. Such uses for these apps include; improving communication between a patient and medical staff, collecting patient data to aid in prognosis and diagnosis, and generally assisting in the management of long term conditions. Smartphone devices in conjunction with connection to the internet provide unique opportunities to enhance disease management by extending interventions outside of a hospital setting. It is believed that in 2015, 500 million people were using mHealth apps [60]. The mHealth market report published by Research2Guidance found that in 2014, 100,000 mHealth apps were listed on leading App Stores [61]. 808 of these apps were then extracted and analysed. The most frequent mHealth app types consisted of Fitness at 30.9% and Medical reference apps at 16.6%. Other mHealth apps within this group included medical condition management apps (6.6%), compliance apps (1.6%), and diagnostic apps (1.4%) [61]. Mobile devices have also been found to be popular among medical experts. A study conducted by "Manhattan Research – Google Physician Channel Adoption Study", found that 54% of physicians surveyed use a tablet device in the workplace, and 84% of physicians use a smartphone in the workplace [62].

Other research into mHealth apps has concluded that these apps enhance and benefit both practitioner and patient [63, 64]. However, mHealth apps and their ever growing popularity pose many risks to patients, including data security and data protection. In a study conducted by Sunyaev *et al.*, it was found that only 30.5% (n=600) of the most popular mHealth apps on app stores had privacy policies [65]. To address these and other concerns, regulations have been enforced by governing bodies and representatives, such as the European Union (EU) and the Food and Drug Administration (FDA) in the United States of America (USA) [66–70]. In conjunction with these regulations, other factors exist that have not yet been enforced into any directive. As such, the research presented in this chapter will first create a comprehensive mHealth design pipeline intended for use by designers, developers, and medical professionals. The pipeline aims to outline the required components for developing a mHealth app to provide a better understanding of the development process. Subsequently, it is anticipated that the pipeline will improve mHealth app quality and increase app store success.

3.2 mHealth Pipeline Insights

One of the many factors to be considered while developing an mHealth app is a regulation checklist or development strategy. Price Waterhouse Coopers (PwC) published a report in 2012 providing a general checklist for global regulatory considerations for mHealth developers [71]. Although this publication provides a checklist essential to distributing mHealth apps on the market, it does not provide further details into content development strategies. Buijink *et al.* introduces strategies which aim to enhance the development process through evidence based content, while simultaneously retaining mHealth's "open" nature [72]. To note, Buijink *et al.* describes mHealth's "open" nature as the freedom to develop mHealth apps and make them widely available. This demands an additional consideration to the design pipeline: for example the balance of regulation restriction to maintain openness.

Another intrinsic component to the development of mHealth apps is the user interface (UI or MUI in the case of Mobile User Interface). A patient and practitioner may have disparate requirements for the MUI. Additionally, if the MUI is not appealing or suitable to the need of the users, the mHealth app may have negative results and poor penetration into the market. For more specific mHealth uses, the app may require the ability to adapt its user interface to its surroundings based on multiple variables and factors. The lack of adaptable MUIs has also been recognized by the World Health Organisation (WHO) as an issue which requires addressing [73]. Hence, a MUI is a necessary factor in the development process as the developer must correctly assess if an adaptive MUI is required, and subsequently implement. Alnanih *et al.* presents research which informs a proposed context-based and rule-based approach to adaptive MUI design [74]. Such an approach could be considered for use when designing the MUI, as early tests indicate the adaptable system is superior in its effectiveness and task navigation, and in turn reduces the cognitive load demand on its user.

Finally, the issue of data security with any data which is recorded, stored, or transmitted is an imperative consideration when developing an mHealth app. Depending on what actions are performed on the data, one or multiple techniques may need to be incorporated. Sorber *et al.* present a solution to this in the form of Amulet [75]: a security architecture for mHealth apps. Amulet proposes the use of a purpose-designed mHealth device which operates independent of the patient's mobile phone, but is attached to the patient. The proposed device allows for an

additional barrier of security in mHealth systems, and could be incorporated as a technique to ensure the security of user data.

3.3 Pipeline Structure

From the previous section, it can be acknowledged that there have been published guidelines and literature on essential components from industry and researchers for the development of mHealth apps. They have focused on many imperative aspects that have yet to be incorporated into official regulations. Moreover, these development components and government regulations have yet to be compiled into one instructional body. This pipeline has been divided into four sub-categories and is outlined in Figure 3.1. A developer or designer may also wish to incorporate other principles such as PwC's "Six Principles for successful mHealth" [71]. Other important areas for consideration throughout include Sundin *et al.* six failure modes [76] and multidisciplinary approach such as design thinking in a mobile health context as discussed by Eckman *et al.* [77].

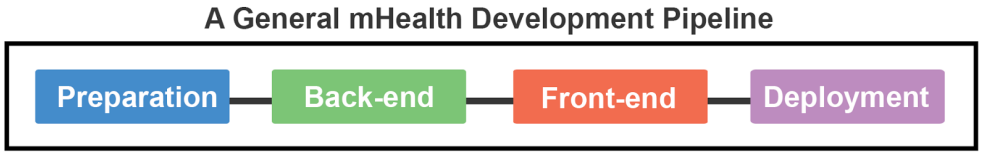


Figure 3.1: A schema of the proposed pipeline.

3.3.1 Preparation

This section outlines the methodology applied in preparing the mHealth app, such as identifying the issue, devising a solution, and identifying the target market. The components of this subsection can be seen in Figure 3.2.

Purpose:

Before embarking on such a project, the development team should form a written report or plan, outlining the purpose of the app and how it shall benefit both patients and medical/clinical staff. It is important at this stage that equal amounts of insights (50/50 co-design) are gathered from both patients and medical professionals. Although mHealth applications are predominantly targeted at patients, medical professionals are also secondary users of mHealth applications as they

too can interact with or use the app in some form, for example viewing recorded data, or implementing the app into the current healthcare scheme. It can be argued that both users (patients and medical professionals) may have different objectives and aims for the mHealth application which need to be married into one cohesive design. For example, medical professionals may design an mHealth application which can generate more data to be used as part of monitoring/-managing a condition, however it is not designed to be implemented into the demands of a patient lifestyle or is not seen as beneficial by a patient. Similarly a patient may have particular opinions on what an mHealth app should do, but this may not necessarily prove any use to medical professionals, or may not be possible to implement into the current healthcare system, or may perhaps be harmful to a patient's physical or mental health. For these reasons it is strongly suggested that both medical professionals and patients provide equal insight into the mHealth app to ensure its usefulness and desirability. At this stage patient advocates or representatives can also review this written report. Once it is considered a plausible and beneficial concept, the report can also be used as evidence or means of recruitment for stakeholders or funders. It is recommended that the report also include:

- A definition of its purpose and the issue to be solved.
- Proposed benefits (to avoid "scatter shot" approaches that often fail) [78].
- Penetration plan/Adoption plan for dissemination.
- In the event of data collection, all intentions for how this information is to be treated or analyzed.
- A Privacy Policy.

It is also recommended that preliminary data are documented in the report to validate the purpose of the mHealth app. Such data can include a needs assessment questionnaire or patient interviews. The following two stages (Back-end and Front-end) should also incorporate continuous consultation with a medical expert or patient.

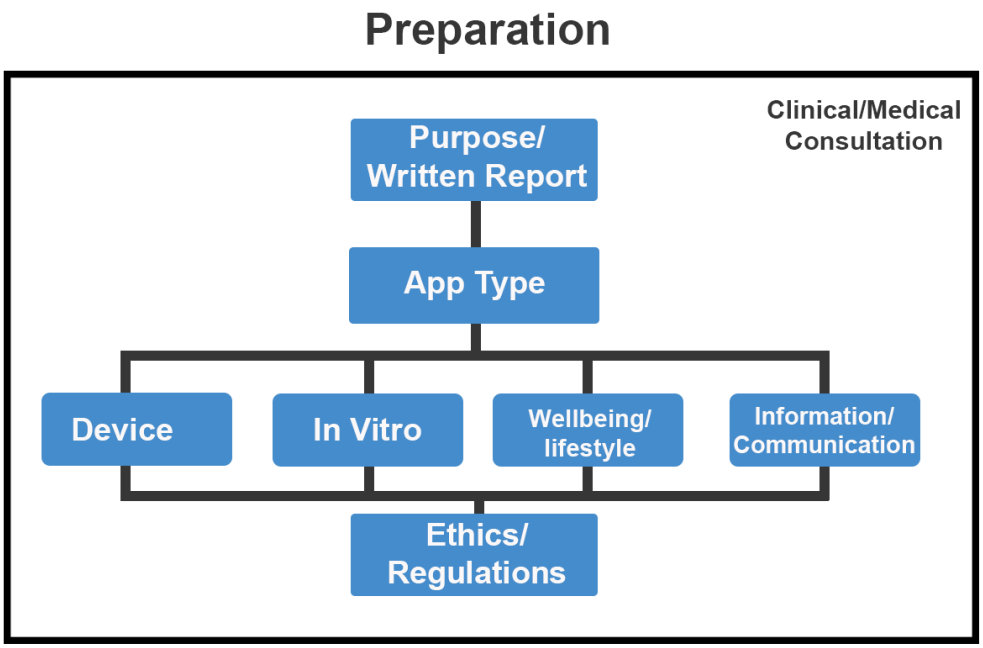


Figure 3.2: Preparation sub-category.

Application Type:

From the written plan mentioned previously, the development team should have a clear definition of their app and which type it falls under *i.e.* In Vitro, Device, Wellbeing/Lifestyle, and information or communication. In Vitro apps are mHealth apps which can collect, transmit, or plot medical data [68]. However, if the medical data collected are combined with a patient's physiological data for diagnostic/treatment purposes or to generate immediate decision making via alerts, the mHealth app is considered to be a medical Device. An mHealth app may also be considered as a device if it is coupled with an external device for the aforementioned task [68]. Lifestyle/wellbeing mHealth apps are those intended to maintain or improve QOL, health behaviours, and wellbeing of individuals [68]. Whereas Communication or Information apps are generally used to motivate the user to perform or adhere to their personal health care or a healthy lifestyle. Such apps include medication reminders, dietary recommendations, or medical information [68]. This delimitation is crucial in the design and development pipeline, as governing bodies have set directives and regulations on each [68, 70]. Likewise, other components of this pipeline such as security and user experience require different considerations and conformities.

Ethics/Regulations:

If the mHealth app is created for or as part of a research organisation, the written report outlining the app and its purpose should be submitted to the organization's ethical committee for review. The developers should then analyze and assess the most appropriate market to deploy the mHealth app and conform to the regulations set out for the app type by this market; for example EU directives or FDA regulations. To note, these regulatory bodies may uphold many acts for different components outlined in this framework, and the appropriate act must be considered throughout each section.

3.3.2 Back-End

This subsection describes the considerations that must be made for the delivery, recording, transmission, and storage of data and information. As some data are personal to the patient and their health, ramifications at this level have the highest potential for threat. Due to this, it is suggested that these sections also involve the consultation of a technical expert in the field of security. An overview of this subsection can be seen in Figure 3.3.

Dialogue Validation:

It has been found that the reading level and wording of available medical literature is not appropriate for some patients [79]. Subsequently, information is not communicated adequately and may lead to confusion or intimidation for the patient [79, 80]. This may also result in poor market penetration. To accomplish such dialogue validation, developers may require preliminary research into the reading levels of their target audience, with continuous reading level tests and patient tests to confirm their compatibility. Additionally, developers and designers may require the employment of literacy agencies to review the intended content. Other solutions include the validation of dialogue with members of the health care team who interface and communicate this information regularly.

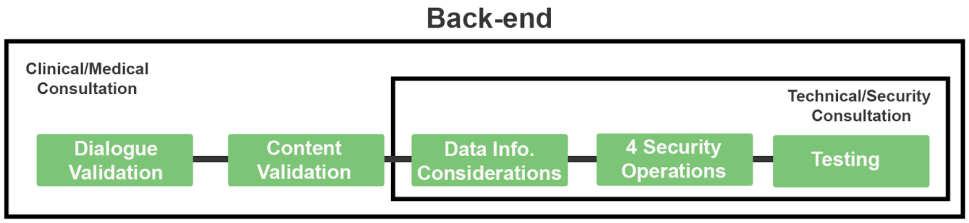


Figure 3.3: Back-end sub-category.

Content Validation:

Textual information contained within mHealth apps have been noted among researchers as requiring validation as a necessity [72]. As stated previously, many of the stages within the framework pipeline have need for a consulting medical expert. As such, this expert should provide validation of medical information. Imagery that is not for schematic purposes should also be validated among members of the target audience to analyse if the imagery is in keeping with the textual information message.

Data Information Requirements:

This area refers to how the user is notified of the developers' intentions for the data that is being collected. Specifically, there are three points of interest:

- *Intentions:* The developer must clearly state if and what data will be collected through this app and if the app will access other data stored on the device. They must also detail what actions will be carried out on this data and the personnel authorised to examine the data.
- *Transparency:* After the intentions are clearly defined, the app should provide an opt-out service to the patient.
- *Data Protection Act (DPA):* If information concerning a patient is to be stored, the developers should provide the facility for the patient to request and review all information stored.

Data and Data Analysis:

A common issue encountered with the design of mHealth data collection apps is that they are often "closed". Meaning that data collected are formatted specifically for the app and are then "siloed"; thus, limiting the potential of the app [80].

For this reason, it is essential that the data and their types are considered when developing an mHealth application. As a solution for this, some researchers suggest the implementation of an open architecture approach [80]. The concept of an open architecture varies between domains. In the context of mHealth apps, the design of the mobile app and server side technologies would consist of reusable modules wherever possible. These modules can be swapped, updated and incorporated easily. For example, such an architecture would allow open components (or modules) for data storage. This would result in many mHealth application recording a standard of data which is meaningful across different mHealth apps.

Four Security Operations:

There are many security operations to be considered when developing or designing a mHealth app. This pipeline identifies four pertinent areas:

- *Local Storage:* Security precautions should be undertaken to ensure that in the event of the smartphone or an assistive medical device becoming lost or stolen, personal information stored locally through the mHealth app cannot be accessed. This is essential for those apps that require patients to fill out personal diaries or that creates a patient profile that can be accessed on the device.

- *Transmission:* Some mHealth apps receive and send data to external databases. This data can be inconsequential, such as news in medicine or care information. However, other data can be of risk to both patient and care staff if intercepted; such as the patient's personal information or data being recorded as part of a study. Safeguards should be implemented to ensure that any data being transmitted from or to the mHealth app is secure and not interceptable by any third parties.

- *External Storage:* All data that are to be stored in external databases must also be equipped with cautionary security measures.

- *Viewing Authorisation:* In cases where the stored data will be analysed or viewed by personnel, the platform utilised for this should be set up with security measures. Those personnel should also undergo authorisation to certify that this information is kept secure.

Testing:

During this development phase, continuous testing should be implemented to ensure that the methods chosen are proficient for the security needs outlined above, among others. Such testing includes "Stress Testing" to ensure that the mHealth app functions correctly and that data is not exposed incorrectly. For example, without the app being first authenticated by a password. More rigorous testing can then be performed on both local and external storage to ensure that data cannot be accessed via third party sources. Developers may also consider using various encryption techniques during this stress testing.

3.3.3 Front-End

This section will summarise fields that must be considered in front-end development. Allocating time within the design pipeline to correctly address these areas will benefit both patient adoption and satisfaction among patients and practitioners. To note, the app type will serve as a prerequisite to the following subsections. This subcategory is illustrated in Figure 3.4. It should be noted that for explaination purposes UI and UX have been separated in the proceeding sections, however both UI and UX overlap enormously and can be quite fluid.

UI or MUI:

The UI or MUI requires a suitable strategy for the users needs. The mHealth developers should consider the assimilation of an adaptive UI design model [74] among others. Adaptive UIs can be focused on one of two areas, Adaptive Navigation or Adaptive Presentation. Adaptive Navigation aims to direct a user to specific information or a specific goal by altering the app navigation based on varying factors. Similarly, Adaptive Presentation alters the information being presented based on external factors [74]. Examples of factors for both Adaptive Navigation and Adaptive Presentation include environment or user expertise.

User Experience (UX):

UX for mHealth apps is vital to patient adoption and for continued use. To enhance UX, the developer should manoeuvre the app so that it is seamless with the lifestyle or demands of the target audience. This is also true for situations where an external device is used in tandem with the mHealth app. Technologies

such as this should also be seamless and not stand out as a medical device, and may require coupling or disguising with other devices such as a watch.

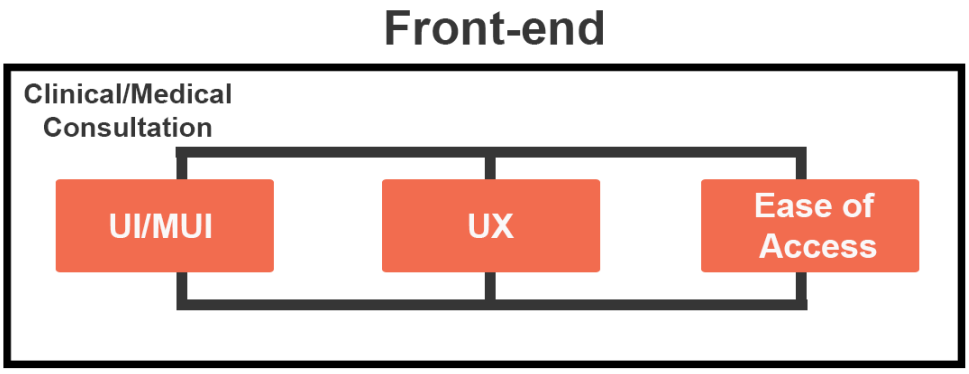


Figure 3.4: Front-end sub-category.

Vulnerable Cohort Considerations:

This refers to considerations that must be made when developing a system targeted at patients for whom non-standard solutions may be required. These kinds of considerations are specific to each mHealth app, but can include the blind, the deaf, those with limited mobility or learning difficulties, social context, cultural context, and age.

3.3.4 Deployment

This final subsection outlines the process of completing and deploying the app. At this stage, the medical expert is no longer required as a consultant. However, consideration should be given to documenting the consultant as an author or developer as it validates and authenticates the content within the application. Hereafter, it may be appropriate to consult with a marketing expert. An outline of this sub-category can be seen in Figure 3.5.

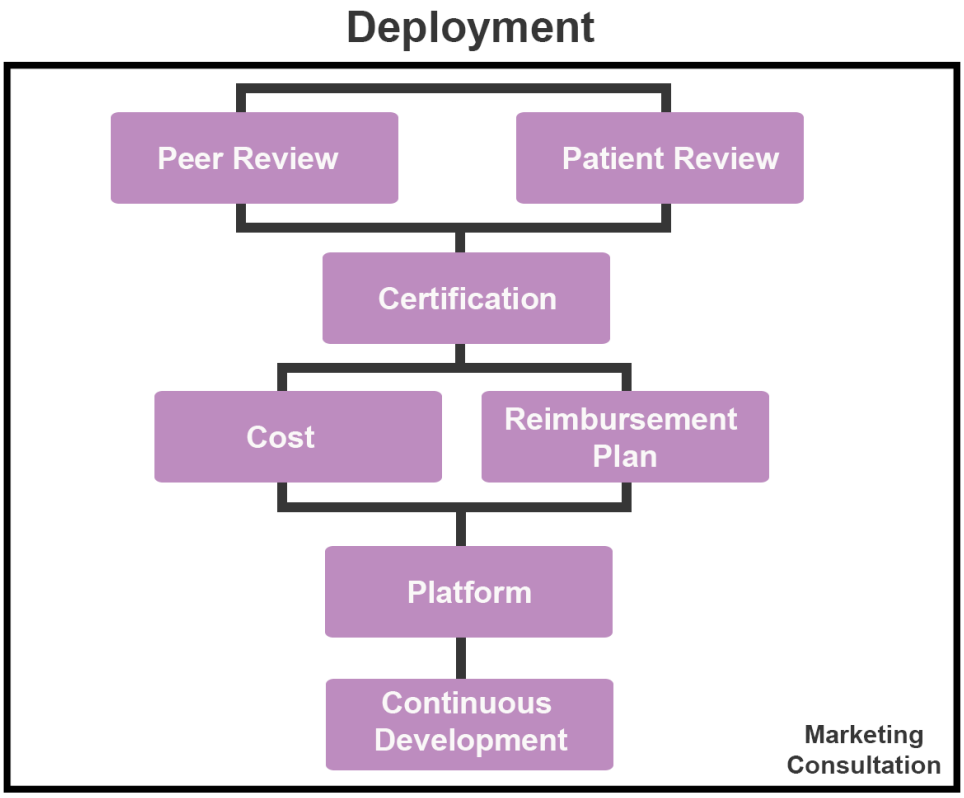


Figure 3.5: Deployment sub-category.

Peer Review:

Although there are review processes put in place at each app store, there is no medical peer review infrastructure put in place. External peer review remains an imperative component of the deployment process and as such other solutions must be considered. For instance, websites have been formed by medical experts for the purpose of reviewing and recommending mHealth apps [81]. Another option would be to submit the app to a reputable journal for peer review from its database of mHealth experts, such as The Journal of Medical Internet Research [82], among others.

Patient Review:

The mHealth app should also be submitted to a group of patients or to a patient organisation for review in parallel to the peer review. As peers would focus primarily on the content, functionality and security; this patient review would focus on desirability, usability and plausibility.

Certification:

Developers and designers should be encouraged to authenticate the mHealth app through certification. Such certification may include but is not limited to, European Conformity (EC) or Health Insurance Portability and Accountability Act (HIPAA) compliancy. Again it is essential to know the app type for this certification, especially in the USA where apps are submitted to different governing bodies such as the FDA, Federal Communication Commission (FCC) and Federal Trade Commission (FTC) depending on their type.

Cost:

If the developers and authors of the mHealth app decide to charge for the app, they should also consider consumer rights and other such policies. Likewise if the developers choose not to charge for the mHealth app, they should consider respective e-commerce policies to the specific market. Countries and regions may also have specific consumer or commerce policies which will also need to be considered.

Reimbursement Plan:

As mHealth apps become more popular they may become increasingly more important to a patient's health. For paid mHealth apps, future considerations include medical subsidiaries such as health insurance, public health or long term illness plans. These medical subsidiaries may be used for the payment of these apps, or perhaps the cost should be waived in some instances with the appropriate documentation.

Platform:

There are multiple delivery platforms for consideration. The developers may choose one or more of these depending on the patient's needs and requirements. These platforms include an app store, website, library, and journal database.

Continuous Development:

Once the app has been successfully published to a platform, continuous development will be required to ensure that the mHealth app stays current with security

measures and regulations.

The above pipeline summarises general components required in the development of an app while suggesting research into architectures for each component. This generality is to accommodate for various app types which may need to focus on some or all of these components. This generality also allows for changes in market regulations which are continuously being established and updated, and allow leeway for implementing additional legal requirements invoked at an international and organisational level. Additionally, by keeping this general approach, the only restrictive requirements are as presented in the respective regulations. In this way, it is envisaged that the developers and designers innovation will not be hindered. It is anticipated that by incorporating this general framework, developers will be aware of integral components in the design pipeline as well as areas which require regulation adherence. Consequently, this is anticipated to result in a clearer development framework, which can accommodate for innovation and the continuum of benefits to both patients and medical/health experts in the mHealth industry.

3.4 Patient mHealth Survey

As previously mentioned, the following two chapters will discuss the rationale and development of an mHealth app for CF adults. Therefore, in keeping with the mHealth design pipeline as presented in this research, a survey is conducted with CF adult patients from the Cork University Hospital to include their insights before developing a written report with medical professionals. To evaluate if CF adults would find an mHealth app beneficial and to determine what aspect of patient education and patient management that is of interest to CF adult patients, an 18-part multiple choice survey (see Appendix D) was created and validated over a series of three formal meetings with the Cork CF multidisciplinary team (see description 4.2.3). Participation in this survey was voluntary, and the inclusion criteria for this survey was that participants were 18 years old or older and owned a smartphone. Surveys were offered to all patients attending their designated outpatient appointment over a four week period at the CF Day Ward in Cork University Hospital. Ethical approval for this survey is obtained via the Clinical Research Ethics Committee in University College Cork. During

the study period, 49 eligible patients completed the survey; no patients opted-not to complete the survey. The collected survey data was anonymised, and the only clinical information collected in this survey was that the participants have CF and are attending the Cork CF centre. The results of these reported attitudes towards mHealth applications are further described in section 3.4.1.

3.4.1 Survey Results

A total of 49 completed surveys were analysed. Of the 49 participants, 55% of respondents use an Android smartphone and 40% use an iPhone. It was reported that 38% of participants have a mHealth app installed on their smartphone device such as exercise trackers or calorie counters; however, only 10% (n=5) know of or are aware of an app which targets CF. Those CF focused mHealth apps identified by the participants are "CF MedCare", "My Fitness Pal", "CFMATTERS STUDY INFO", and "CF View". Two of the five participants reported having a CF app installed on their phone (CF View and CF MedCare). The remaining 44 participants who do not know of any CF apps or have a CF app installed were then asked to explain their answer. Of the 44 participants, 20 patients reported being unaware of the existence of CF apps; *"I don't think there is one",* and three advised that they are not interested in a CF app; *"Not Interested".*

The participants are also given the option to choose multiple aspects of their CF that they would like targeted by a CF mHealth app. To note, the participants could choose as many of these options as applicable. It was found that "New Research Developments" (55%), "Medication" (55%), and "Physiotherapy" (47.5%) are the areas of most interest to the participants, followed by "Diet" (42.50%), "Monitoring" (40%), "Social Networks" (40%), "Self-Psychological Help" (37.50%), "News" (32.50%), "Education" (27.50%), and "Management" (20%). One patient reported "None" for this question.

Further questions were presented regarding specific features within mHealth applications. 85% of participants agreed that they would like to receive notifications from the app, such as reminders to take medication or next clinical appointment. When asked would the participant play a game to support their CF, the results were more dispersed; 32.65% agreed they would play a game, 34.69% reported they would not and 30.61% were unsure. This maybe due to the vagueness of the question as no example or further explanation was provided. Ten of the 49 participants reported as being part of a clinical trial currently or

in the past. Six of these 10 participants reported that an mHealth application would have been of use to this trial for data collection or self reporting.

A series of questions regarding the collection of personal medical data was then presented. When asked if their CF medical information, such as genotype and medical history, is difficult to remember, 32.65% of participants regarded this information as difficult and 42% regarded this information as easy to remember. 26.5% of participants agreed they would record their medical information in a mHealth app, 46.9% agreed they would store this information if the mHealth app is password protected and 16% (n=8) agreed they would if the mHealth app is password protected and does not have access to the internet. One participant reported being unsure to recording their medical data. Each participant was then given the option to further explain their reasoning for choosing their security preference. These results are listed below.

- Yes: If password protected
  - *Security is priority*
  - *Only available to me and no online servers*
  - *Privacy Matters*
  - *As long as it is stored on a secure database*
- Yes: If password protected and does not connect to the internet
  - *It would be very helpful/useful to store the data for myself but I would be cautious about who else could access it*
  - *It is personal information and so it would need to be very secure*
  - *It is personal and private info*
- Unsure
  - *Security Issue*

To note, two additional answers were submitted for "Yes: If password protected"; however, these answers were specific to the perceived usefulness of such an mHealth application and not their rationale for their security preference and hence negated from the above list. The two submitted answers include: *"Handy if required when travelling/emergencies"* and *"It would help to track what might*

*have been working at the time to maintain lung function (*e.g. *meds/physio)".* In a follow up question specific to the usefulness of such an application, 87.5% of participants reported that they would find it beneficial to have access to their medical data through an mHealth app. Of the 49 participants 67.35% agreed that an mHealth app that recorded their medical data would be useful and 61.22% confirmed they would use an app to record this data.

Two questions were also posed regarding travel and admission to the accident and emergency department in a hospital to determine scenarios in which the recording of medical information would be of benefit. 75.5% of participants reported having gone travelling outside of Ireland and only 12 participants have had to visit a hospital emergency room due their CF. When the participants were asked "would they use a CF mHealth app if created", 67.5% said yes; however, 27.5% were unsure.

Lastly, the participants were given the option to share what they felt a CF mHealth app should target. 23 participants suggested mHealth apps which can be categorised under three headings; Management, Support, and Information. Sixteen participants suggested management apps to track and store their medical information to aid in self management of the condition. Examples of this category include *"Medication taken/taking"* and *"Medical Info i.e weight lung fx exercise + diet plans".* Six participants suggested apps that can access medical information such as drug names and new treatments or research. An example of this category includes *"Proper medical names of meds"* and *"New treatments".* Lastly, five participants suggest apps which can allow for support among CF patients, similar to social networks; *"Experience/Information sharing between other patients".*

3.4.2 Survey Discussion

The data collected in this survey is qualitative and as such, no statistical tests were performed. Instead, the survey results provided in the previous section outline descriptive statistics from the 49 collected surveys. Due to the inclusion criteria, there is a potential age bias (>18), however, this refinement was made as it represents the adult CF populations opinion. Individual participant ages are not recorded, and as such this is acknowledged as a limitation, as there is a potential for mHealth preferences to vary with age. Additionally, ownership of a smartphone is a prerequisite, as the survey sought the opinion of current smartphone users with contemporary experience and knowledge of apps. No

identifiable information is collected from this cohort; that is, the survey does not require any demographic or medical information. Due to this, the gender, age groups, and socio-economic class of these participants are unknown and cannot be correlated; this is acknowledged as a limitation of the study. The purpose of the survey was to gather general information pertaining to patient attitudes, and consequently provide insights into the features and app types of interest to CF adults. The mHealth applications developed as part of Chapter 5 and 6 are informed by the literature review conducted in Chapter 2 and include insights from the aforementioned survey results.

Firstly, it is noted that slightly more patients own an Android device; however, the number of iPhone owners was still high. The first observation to note from the survey results is the paucity in awareness of CF apps. Only five patients reported being aware of CF mHealth apps, and only two patients have these apps installed. When questioned further this seemed to be primarily due to being unaware of such apps; *"I don't think there is any"*. However despite this lack of awareness, the CF adult participants still demonstrated interest and expectations on what a CF app should focus on. New Research Developments, Medication, and Physiotherapy focused apps were of the most interest to these participants. Additionally, tracking medical data and receiving alerts or reminders were the most popular features.

It is important to note that the participants demonstrated concerns regarding data security and as such any mHealth app created for these patients will need to be fully transparent *i.e* full disclosure on what data is being collected, who is it being used/viewed by, and the security measures in place.

3.5 Summary

In this chapter a General mHealth Design Pipeline is discussed, which to the researchers knowledge, is the first of its kind. The aim of this pipeline is to provide considerations to both developers and designers of mHealth applications. mHealth solutions are becoming increasingly popular with the medical industry and app developers, and as this proliferates areas of concern and consideration also arise. While formalising this pipeline, particular attention was taken to consider the perspective of users/patients and medical professionals. Firstly, it was observed that although most mHealth applications primarily target patients,

medical professionals are often secondary users as they may view/use the data gathered through the applications. Moreover, it is identified that the mHealth apps medical professionals deem to be of value to patients, often may not be. Likewise, what a patient may deem as beneficial to their care may not have any implementation medically. Therefore, contrary to other reports, this research suggests that user input should be received equally from a medical professional and patient (50/50). Another point to note is the recurring concern of data ownership and intentions. This concern was not only identified through the found research but also discussed at many open-forums such as conferences, and general assemblies. It has been claimed that most users understand that their data is being recorded, and are not concerned about what is happening to that data. However, in light of recent events surrounding Facebook and data [83], this may change. This data concern has yet to be fully addressed in government regulations (currently under discussion), and this pipeline does not discuss who is the owner of any collected data. However this pipeline argues that all intentions should be fully transparent. That is, all intentions for data that is being collected, stored, and analysed, viewed must be communicated to the user. If any of these factors change (such as data being analyzed for new purposes or to detect new symptoms) this too should be communicated to the user. However, both these arguments may be debated among mHealth developers, medical professionals, and patients and requires further testing and validation to confirm these findings. For the purpose of this research, this mHealth design pipeline will be incorporated into the design of a serious game intervention in Chapter 5 and a CF passport in Chapter 6. To further inform these interventions a short qualitative survey to evaluate CF adults attitudes towards mHealth applications was conducted. The proceeding patient-focused chapters will develop these mHealth apps with the continued consultation of the CF multidisciplinary team while also drawing upon insights from the surveys results.

Chapter 4

The Lung Experience

In this chapter a cross-platform, interactive, gamified framework to help explain CF is presented. To note, this framework could also be modified to support a wide variety of medical concepts. This chapter also incorporates the findings of the literature review conducted in Chapter 2. In particular, the observed lack of educational mediums to support medical students. The development and implementation of this gamified educational framework is discussed including user interactions, user interface, 3D models, and educational content. This chapter also evaluates the usefulness of a virtual reality system for medical students with promising results. This chapter extends the works published by Vagg *et al.* in [84–89]. The significant contribution of this chapter is the three educational multimedia applications created for medical professionals. These applications all address issues with the current state of multimedia available for their respective topics. These tools provide a visually rich educational environment which was found to be lacking as indicated through the reviewed literature. In addition to this, it contributes a 3D virtual environment that replicates a bronchoscopy simulator for medical professionals via an accessible platform such as the web.

4.1 Introduction

The literature review conducted in Chapter 2, yielded two manuscripts focusing on educating health care and medical professionals for various topics concerning CF [20, 26]. However, the research presented by Anderson *et al.* used CF as a case study for a more generalised topic [26]. The educational aspect covered by these two manuscript included CF infection management [20] and care of children

with special health care needs, including CF [26]. The intervention as presented by Mehta *et al.* uses static multimedia materials such as images and text [20], whereas Anderson *et al.* implements animating material such as recorded lectures and videos in addition to text [26]. It is evident from Chapter 2 that there is a paucity in CF educational interventions for medical professionals. This is investigated further to determine: 1) Current educational material available, 2) The level of interactivity, 3) What Multimedia is used, and 4) Topics or areas that have not yet been explored.

Both interventions from Chapter 2 are developed for the web as this is more accessible and convenient for students and medical professionals alike. A common and popular open-source E-Learning portal called, Multimedia Educational Resource for Learning and Online Teaching (MERLOT) [90] is scrutinized further. Those resources which used CF as an example for a more generalised area are not included.

MERLOT yielded ten results in total, but only three are applicable to this research. Of the remaining seven results, two are considered irrelevant, two are used as advertisements for an online course in which the user must be registered, and three contain broken links or the content is no longer available. The three relevant results are summarised in Table 4.1 below, and then comparatively discussed further paying particular attention to user interactivity.

Table 4.1: Educational resource summary.

Resource Title	**Authors**	**Audience**	**Format**
"Cystic Fibrosis Interactive Punnet Square" [91]	Unknown Author *Uploaded by Jim Bidlack in 2013*	High School, College General Ed and College Lower Division	Digital Camera Raw (DCR)
"M2 Respiratory - Cystic Fibrosis" [92]	Open Michigan in 2012	College General Ed, College Lower Division, College Upper Division, Graduate School, and Professionals	Microsoft Power Point (PPT)
"Understanding the Problem-Cystic Fibrosis" [93]	Jim Bidlack in 2013	High School, College General Ed, College Lower Division, College Upper Division	Small Web Format (SWF)

The first tool uses a punnet square, which is a graphical means to calculate the probability of inheriting a specific trait or gene. This tool allows the user to interact with the punnet square by dragging and dropping the male and female parents and individually marking them as carriers. The user can then select

grids on the square to view the probability of a child being born with CF from these parents. This intervention incorporates audio, images and drag and drop functionality and is downloadable as a .DCR file [91].

The second resource located on MERLOT is the "M2 Respiratory - Cystic Fibrosis". This intervention introduces and explains CF genetics, how to diagnose the disease and its treatments. Again, similar to the Punnet Square, this resource is downloadable as a PPT (Powerpoint Presentation). It includes static multimedia material such as text, images, and charts. Much of the content in this presentation is displayed in a bullet point format and is often vague. For this reason, it can be considered that the presentation was designed for narration, however no audio is included [92].

The next resource (Understanding the Problem-Cystic Fibrosis) [93] is available as a downloadable SWF file (Small Web Format), a file format which is no longer supported by browsers and considered deprecated. This resource introduces CF genetics, their effects at a cellular level, and how gene therapy could aid in repairing these faulty genes. The content is presented by using 2D images, 2D animations and text. The information and multimedia content is displayed at the user's pace via the pressing of forward and back buttons.

Although few resources were identified in MERLOT, observations and development considerations can still be drawn. These observations are discussed further in the following section.

4.1.1 Initial Observations

Three core observations can be made from the two manuscripts and three open-source applications. Firstly all found resources offer limited interactivity (if any); often restricted to video controls. Modern web standards include support for far more interactive applications ranging from interactive 3D rendering to more complex interactivity such as feedback from device orientation.

Secondly, there is an overall lack of visual material. Where material is available, the predominant media used is text as-well-as photos, images or videos. In addition, the MERLOT visual resources often appear more stylised and were anatomically incorrect. This is perhaps attributed to the limited media available that can be viewed without specialised softwares. Another factor that may have contributed to the development of 2D media is perhaps to accommodate for the target audience as listed on MERLOT. In all cases the material is registered as

applicable for second level, third level, and postgraduate students.

The third observation is that all found resources require proprietary software. For example, the found resources are only available as .SWF, .DCR, and .PPT, which requires Adobe Flash, Adobe Photoshop, and Microsoft Power Point respectively. Thus, reducing the reach and applicability of the resource. Whereas, if the educational multimedia was deployed over the web, further and more intuitive interaction can be achieved. This is discussed further in the next section.

From these observations it can be postulated that a CF specific educational resource that is both visually rich and highly interactive is not currently available. CF affects many organs and cells throughout the human body, with symptoms that are internalised and require medical scanning or imaging for viewing. Considering this, the visualisation and interactivity of an organ or organs affected by CF may reify these difficult concepts for medical students and medical professionals.

Interactivity offered by modern web standards

In this subsection, a technical overview of the interactivity offered by modern web standards based on those outlined by the World Wide Web Consortium (W3C) [94] is presented. The introduction of the HTML5 standard in October 2014 expanded the potential of modern web browsers to support features normally only found in native desktop applications. Modern browsers are capable of providing highly functional, interactive, and extremely accessible applications that can supplement or replace traditional desktop applications. An overview of the modern web standards that provide this functionality are summarised in Table 4.2.

Table 4.2: Summary of interactivity offered by modern web standards.

Feature	**Technology**	**Availability**
Application layout, structure, user interface, and style	HTML, CSS	Supported by all common browsers on most platforms
User interactions, geolocation, mobile widgets, and interactive documents through scripting	Javascript, Javascript APIs	Supported by all common browsers on most platforms
Audio and video playing and authoring	HTML, SVG, SMIL, Javascript	Supported by modern browsers on most platforms
Graphics, images, and games	HTML, Javascript, PNG, SVG, Canvas API	Supported by all common browsers on most platforms
3D graphics, 3D visualisation, Virtual Reality, and 3D interactivity	WebGL, Three.js, Vulcan, 3D Game Engines	Supported by all common browsers on most platforms

4.2 Student Attitudes Towards Multimedia

From the investigation of online multimedia repositories, it can be seen that there is limited educational media for CF. This could be attributed to a number of factors, such as CF being an orphan lung disease and as such not taking precedence for respiratory disease multimedia. This may also be due to an absence of ICT skills among medical professionals to develop this multimedia, or possibly a lack of interest from medical students. However, research conducted into the learning styles of medical students suggests that they may benefit from the use of educational multimedia.

In most cases, research concerned with the learning styles of medical students use the Visual Aural Read or Write Kinesthestic (VARK) learning styles questionnaire and guide [95]. Amini *et al.* found from their research with 90 medical students that generally the students were visual learners [96]. This contrasts with Lujan *et al.*, who used this questionnaire with 166 first year medical students and found that the majority of students were kinesthetic learners and thus preferred to use all their senses such as touch, hearing, smell, taste, and sight [97]. The authors also found that 63.3% of students preferred multiple modes of presentation, *e.g.* visual and auditory. This is a similar finding to Baykan *et al.* who

again used the VARK survey, with 155 first year medical students [98]. The authors again found that these students were predominantly kinesthetic learners and again preferred multiple modes of presentation. The authors also conclude that no significant difference was found between genders [98]. Overall these manuscripts demonstrate a tendency for medical students to be kinesthetic learners who prefer multiple modes of presentation. These findings suggest that multimedia such as e-learning, simulators, virtual reality and augmented reality could engage medical students and aid in their learning; as they appeal to many senses (kinesthetic) and provide multiple modes of information presentation.

Considering the outcome of the aforementioned research, this chapter will first seek to identify the attitudes of medical and healthcare students towards multimedia. To achieve this, a MCQ (multiple choice questionnaire) comprising of 23 questions was created (Appendix A). This survey was created in collaboration with a researcher at University College Cork investigating Interventions for Anatomy Education. The survey questions focus on several topics which include:

1. Learning Style Indicator
2. Device Usage
3. Interests in Technology
4. Multimedia Familiarity
5. Perception of Multimedia Services in the University
6. Attitudes Towards Multimedia
7. Multimedia Usage

This survey was made available online, and the results were stored in a Microsoft Excel Workbook. Ethical approval for this study was received by the Social Research Ethics Committee in University College Cork. To recruit participants, an email was sent to all undergraduate and postgraduate students registered in a health or medical discipline in the University College Cork. CF patients are supported and cared for by a CF multidisciplinary team consisting of nurses, dieticians, respiratory specialists, respiratory consultants, respiratory technicians and physiotherapists. Therefore, by inviting all medical and health

students, insights into attitudes towards multimedia from the perspective of multiple disciplines can be achieved. Moreover, this may identify whether the attitudes of these medical and healthcare students towards multimedia change as they progress through their degree. The web survey was made available for six months. Participation in this study was voluntary and all data collected was pseudoanonymised.

4.2.1 Results

During the six month availability of the survey, the survey was completed by 157 students. Of these 157 students, 83 were medical students, 47 were dental, and 21 were from nursing. 74 students were in the first year of their medical or health degree, 60 were in the second year, six were in their third year, seven were in their fourth year, six were in the fifth year, and four were research postgraduates. 57 respondents were male and the remaining 100 were female. Due to the high amount of female respondents there is the possibility of gender bias. As no gender bias was found from the research into learning styles in the previous section, it is anticipated that a similar result will be seen here. The possibility for gender bias must still be acknowledged and as such, should be considered a potential limitation of this survey.

For the learning styles indicator question, students were given five statements regarding their memory. They were then asked to rank the statements from 1 to 5 (1 being the least value and 5 being the highest) according to the statements' relevance to the student. Students regarded things they "practice or do" as the most memorable (47%). This was followed by things that they write after reading (39%), things they see or watch (33%), things they read (25%), and things they hear (35%). This question also encompasses a multimodal element, whereby students were asked to comparatively rank three scenarios in terms of how well they remember the content from 1-3 (1 being remembered the least and 3 being remembered the most). The results of this can be seen in Table 4.3. From the results, it can be seen that students remembered the least from Reading notes while listening to a lecture and remembered the most from watching video with audio.

Table 4.3: Learning Style Indicator.

Ranking (1-3)	**Watching video with audio**	**Reading lecture notes and looking at images**	**Reading notes while listening to a lecture**
Remember Least (1)	18.58%	19.46%	52.21%
Remember Some (2)	30.97%	50.44%	27.43%
Remember Most (3)	50.44%	30.08%	20.35%

As part of the device usage questions, the students were first asked to select the devices they currently own or have owned in the past. They were then asked to rate their experience of these devices from 1- 5 (1 being an unpleasant experience and 5 being pleasant), the results of which can be seen Table 4.4 below. The first two rows represent the number of students who selected each option. The percentage values for user experience in the remaining three rows is calculated based on those who reported owning the device. Overall, it can be seen that Smartphone, Laptop, and Desktop are the students' most frequently owned devices. In each case, students tend to rate their experiences positively. However, it can be clearly seen that Smartphones and Laptops are the most prefered devices among students.

Table 4.4: Student Reported Device Usage.

	Smartphone	**Desktop**	**Laptop**	**Notebook**	**Tablet/iPad**	**Game Console**
Own	153	102	148	60	89	69
Use Frequently (daily/weekly)	140	37	135	38	40	14
Unpleasant Experience (1-2)	1.3%	12.74%	2.02%	15%	10.11%	13.04%
Neutral (3)	7.84%	34.34%	6.08%	16.66%	24.71%	27.53%
Pleasant (4-5)	90.84%	52.9%	91%	68.33%	65.16%	59.42%

The students were next asked to rate four statements about their interests in technology from 1-5 (1 being strongly disagree and 5 being strongly agree). From these questions it was found that students tended to agree that they have an interest in technology (58.59%) and do not find technology intimidating (51.2%). However, the students had a more varied response to whether technology was frustrating for them, with 40.76% disagreeing and 33.75% agreeing. A similar distribution was seen in the final question of this section whereby users rate how up to date they attempt to stay with advances in technology, 29.9% of participants responded that they do not, 38.85% attempt to keep up to date, and 31.84% neither agree nor disagree that they keep up with technology.

Several likert questions regarding the students' confidence with multimedia were also asked, and ranged from 1-5 (1 being the lowest and 5 being the highest). These questions found that the students are confident with:

- using a computer to search for educational multimedia online (76.92%)
- maneuvering/rotating 3D models on a smartphone (60.52%)
- maneuvering/rotating 3D models on a laptop or personal computer (60.89%)

To gauge multimedia familiarity, students were provided with a table of common multimedia interventions and asked to select the multimedia they are most familiar with, that they have used during any point of their study, and what multimedia they want to see more of in health and medical education. The results are displayed in Table 4.5. The first column lists multimedia interventions, with the second representing the number of users who reported being familiar with the intervention. The final two columns represent the percentage of familiarised students who reported using this intervention and wanting more of this multimedia to support their learning.

Table 4.5: A breakdown of medical students familiarity, usage and need with multimedia.

	Familiar With	**Used During Study**	**Want To See more of in Education**
E-Learning	117	64.96%	43.59%
Interactive 3D	112	44.64%	65.18%
3D animations	123	47.15%	66.67%
2D animations	108	72.22%	31.48%
Simulators	104	29.81%	64.42%
Virtual Reality	103	11.65%	49.51%
Augmented Reality	75	9.33%	50.67%
Mobile Apps	123	49.59%	45.53%
Game Based Learning	96	23.96%	45.83%
3D Websites	81	29.63%	50.62%

During further questioning regarding their multimedia usage and familiarity, 51.97% of students reported educational multimedia as being easy to locate. 98.07% of the participants reported watching educational animations, and 97.45% have actively searched for educational animations. 70.7% also reported using a 3D educational tool, such as a 3D website. It was also found that 45.22% of students have used educational games to support their learning and 52.9% enjoy

learning with games; however, only 13.37% currently own an educational game. In contrast, a high number of students (64.51%) have an educational app installed on their phone. Virtual Reality (7%), Simulators (7%), and Augmented Reality (11%) were found to be the least utilised multimedia interventions, however all participants who reported using these interventions also considered the multimedia to be beneficial to their learning.

Following this, the participants were asked a series of True or False questions regarding their opinion on educational multimedia. From these questions, it was found that 84% agreed they would search for additional visual content such as videos, animations, images online or via a smartphone when revising or studying. However, 52.63% of students believe that educational multimedia is expensive. Similar to their interest in searching for multimedia content, 78.54% agreed they would look for text based content such as research papers when studying or revising.

Next, the students were asked to rate from 1-5 (1 being disagree and 5 agree) whether they believed their University has sufficient multimedia to support their learning. Of the respondents, 22.07% felt that the university did not, 42.85% were unsure, and 35.06% feel there was sufficient multimedia. Again, this results shows a distribution of opinions, with a tendency to agree. 69.97% of students agreed they would like to utilise more multimedia interventions and content to support their learning, and 70.51% agree that multimedia for education is engaging. Likewise, 72.43% agreed that interactive multimedia is a good resource for practical learning and 74.83% agree that it is important for educational multimedia to be interactive in some way. Similarly, 73.07% agree that multimedia can help them garner a better understanding of topics which were covered in a class or lecture. When asked if the students preferred multimedia to textbooks, 46.15% of students agreed that they did, while 26.28% were unsure. The students were then asked if they prefer 2D or 3D multimedia. This question showed that 57.79% of students prefer 3D multimedia, and 29.22% were unsure.

When asked if students find multimedia to be as good as a class or lecture, 33.33% of students neither agreed nor disagreed, while 39.1% agreed; however, 59.61% reported that they prefer lectures over multimedia content. Finally, the students were presented with six statements and asked to choose which option more accurately reflects why they do not use multimedia. The results of this can be seen in Table 4.6.

Table 4.6: Reasons why students do not use multimedia.

Option	Frequency
I like traditional learning with textbooks, diagrams and lecture notes	60.15%
Advances in technology intimidate me	5.46%
I cannot understand 3D or VR	3.12%
I dont have the time for using technology while studying	11.71%
There is no multimedia resources available to benefit my learning	17.96%
I had a bad experience with multimedia learning	1.56%

4.2.2 Discussion

The results of this survey suggest that medical and healthcare students prefer traditional teaching methods to educational multimedia, and believe that multimedia cannot replace these traditional teaching methods. However, the students also believe that interactive multimedia is a feasible resource for practical learning. This mechanism was found to be both favorable and effective by students who answered the learning style indicator question, and is reflective of the learning style preference found in previously discussed studies. The participants also regard multimedia as complimentary to their learning and often seek multimedia to support or further explain difficult concepts encountered during their study.

In addition to this, it can be seen that this particular student population do not appear to be intimidated by technology and use smartphones and laptops regularly. These students also report being confident at sourcing and interacting with multimedia. From the multimedia familiarity table it can be seen that these medical health students are most familiar with 3D animations and educational smartphone apps. They appear to be the least familiar with Augmented Reality (AR) and 3D websites. It was also found that students use e-Learning tools and 2D animations more frequently than other multimedia during the course of their study. Interestingly, students also reported being the least interested in the development of more 2D animations to support learning, perhaps due to the high availability of this resource. Finally, students expressed the most interest in seeing 3D animations, Interactive 3D, and Simulators incorporated to support their studies in the future.

The results of this survey are limited due to the number of participants and possible gender bias; however, general observations can be drawn to inform the development of a CF multimedia intervention for medical students and professionals. Specifically, it was found that medical and health students prefer practical

learning and regard interactive multimedia as a plausible intervention for practical learning. The multimedia of most interest to these students appears to be 3D animations, Interactive 3D, and Simulators. These findings are considered and discussed further with the CF multidisciplinary team.

4.2.3 CF Multidisciplinary Team Discussion

CF clinical care is driven by a multidisciplinary team approach. This team normally comprises of a mixture of healthcare professionals with varied skill sets to support this multisystem condition. Ordinarily, a CF multidisciplinary team comprises of a CF nurse specialist (designated and working fulltime in CF care), CF physiotherapist (designated and working fulltime in CF care), and CF dietician (designated and working fulltime in CF care). The team is supported by a respiratory technician (with a commitment to CF) and psychologist (can be full time ideally). This group is medically lead by a respiratory physician with a special interest (fulltime or partime) in CF, and supported by a specialist registrar and/or research registrar in lung diseases [99].

The Cork University Hospital adult CF multidisciplinary team comprises of: three CF nurse specialists (>30 years collective fulltime experience in CF care), one dietician (>10 years full time experience in adult and paediatric CF care) one senior physiotherapist (>5 years full time experience CF care), one respiratory technician (>20 years full time experience), and one CF consultant with 10 years as the director of the Cork unit and 10 years experience in other leading centres both nationally (Ireland's largest CF centre - St Vincent's Hospital) and internationally (United States leading Therapeutics Development Network - University of Washington Medical Centre).

This multidisciplinary team supports the second largest CF centre in Ireland with over 180 adult CF patients. The Cork CF multidisciplinary team are also an international leader in CF best practices and currently leading CFMATTERS; an international multicenter consortium exploring antibiotic therapies in CF [1].

A series of five formal meetings were arranged with the multidisciplinary team in totality to discuss the results and findings of the medical and health students attitudes towards multimedia for learning survey. This meeting also facilitated robust discussions to scope possible directions followed with designated approaches.

It was highlighted during this meeting that there is an evident lack of visual content available on multimedia repositories. Additionally medical and health students have the most interest in interactive 3D, 3D animations, and simulators to support their learning. From these insights it is agreed that this research should target the visualisation and simulation of fundamental concepts pertaining to the health and care of CF. This intervention will do so by visualising such concepts using interactive 3D. From this criteria, it is agreed to focus on the effects of CF on the human lung. The reasoning for this is due to the structure of the delivered material and the complexity of the human bronchial tree structure.

In University College Cork, medical students study human anatomy during their first and second years. The remaining three years of the undergraduate degree are then spent on clinical attachments, with refresher classes and training on human anatomy. If the student chooses to further train as a respiratory specialist, there is a further minimum of three years of general training, before commencing specialist training. Therefore, there can be approximately six to eight years between the study of human anatomy and performing of bronchoscopies. A bronchoscopy is a procedure where by a small scope (bronchoscope) is inserted into the human lungs for medical purposes such as diagnosis, prognosis, and sample collection. The first and second year anatomy study encompasses 3D plastic models, 2D image, videos, animations, and the demonstration of an animal lung such as a pig lung. While training as a respiratory specialist, the postgraduate must perform a bronchoscopy on a living patient with a time constraint so as to prevent unnecessary discomfort to the patient. In addition to this pressure, a novice bronchoscopist must identify regions within the tree structure for a correct evaluation without the use of any orientation or navigation indicators. Bronchoscopies are performed frequently on CF patients to monitor lung function and lung health. Subsequently, a system which can visualise the internal lung anatomy of both a healthy and CF lung can be of benefit to novice bronchoscopists, medical students, and medical professionals. The proceeding section will investigate the available visualisation tools for bronchoscopists.

4.3 Review of Current Simulators

Slinger *et al.* believes that institutions that are involved in lung surgery and procedures should develop a simulator to enhance the skills and knowledge of

residents, fellows, and staff members [100]. Furthermore, it has been found in previous studies that these simulators can benefit the speed and quantity of the bronchial regions being identified [101–105]. These simulators have also proven to benefit the motor skills required to navigate and control the bronchoscope [102, 104–106]. They also include additional features to benefit the user, such as a map, various lung models, and multiple lung conditions. However, due to the simulators size, hardware reliance, and cost, these tools are often inaccessible to students for self directed study outside of allocated or appointed training hours. In some cases the simulators also require a tutor to further guide the trainee [102]. Ost *et al.* reported that the incorporation of the tutor had a positive effect on the trainees' learning outcomes. However, this is perhaps unfeasible for all training scenarios.

Considering the benefits of a bronchoscopy simulator, its cost, and limited accessibility, a pragmatic solution may be found in the development of a *lightweight* simulator that is easily accessible and created at a reduced cost. Although this proposed simulator could be considered as a lightweight imitation, it should still allow the user to explore and view the internal bronchial structure freely. Furthermore, the tool should replicate some responsibilities of the tutor, as seen in [102], such as providing information on each segment and guidance on how to locate these areas. Similarly, the tool could also provide an environment which tests the user on their knowledge to further enhance the learning experience. A lightweight simulator could potentially be found as a web or smartphone application due to the accessibility of the platforms. The proceeding section will review existing lightweight simulators found via these platforms. To further inform the design of a lightweight simulator for visualising and educating medical students on bronchial anatomy along with the effects of CF on a human lung, the found simulators will be investigated with reference to their Features, Accessibility and UI. An image of the found lightweight simulators can be seen in Figure 4.1.

4.3.1 Thoracic Anesthesia Bronchoscopy Simulator

This open-source web based bronchoscopy simulator was created using Adobe Flash by Kanellakos *et. al.* of the Toronto General Hospital [107]. Before entering the simulator, users are encouraged to test current knowledge of bronchoscopies via the pre-test questionnaire. Once ready the user can then explore the simulator, which contains: a labeled schema map for navigation, a main view

which contains real video footage of the procedure, set rail navigation (along a predefined path) explorable via arrows within the simulator, and an information panel (which replaces the map to provide textual information of a selected area). When complete the user can then re-attempt the knowledge questionnaire. Feedback concerning knowledge gaps and areas of improvement is then provided to the user. The developers of this application, evaluated the system with 2,000 participants via a pre and post knowledge based questionnaire. The results of this study were then presented at the 2011 Society for Airway Management meeting. It was found that the average scores of the questionnaire increased by 30% along with user confidence; however, the average score remained low at 56%. The creators of the application suggest areas to improve the simulator, such as real-time simulation elements and didactic teaching [108].

4.3.2 iBronch

iBronch is an iPad application which allows the user to control the delivery of a bronchoscopy video by selecting areas of interest using a map of the bronchi [109]. Once the user selects a bronchiole, a bronchoscope video is displayed next to the map. This video then visualises the bronchoscope's journey to the selected area. The user can also choose to close the map and watch the video full screen. The UI found in this tool is minimal. Unlike the Thoracic Anesthesia Simulator, this app dedicates a larger proportion of the screen to the map, with a much smaller viewport for displaying the corresponding video. Moreover, this simulator does not include any supplementary multimedia, such as textual information, as seen in the previously reviewed simulator. To access the application, the user must have a compatible device and pay the small fee of $0.99. Arguably, both iBronch and the larger simulators are cost and equipment reliant. However, the cost and device requirements for the iBronch are considerably less demanding and subsequently more achievable.

4.3.3 BronchoGuide

BronchoGuide was created by Olympus; a global manufacturer of digital and optical equipment for the healthcare sector [110]. Unlike the Thoracic Anesthesia Simulator, the BronchoGuide is not web-based and does not include a self assessment environment. Instead, this application is available on both the iOS

App Store and Android Google Play Store. Its features include a main menu which can direct the user to a video of the procedure, a demo on the features of the application, and the navigation environment. Similar to the Thoracic Anesthesia Bronchoscopy Simulator, this application includes a labelled 2D map of the bronchial tree, a real video of the procedure with overlaid arrows to accommodate for rail navigation, and an information panel which provides text of the area selected, along with a list of previous areas visited during navigation. This application also provides a novel feature, which allows for the map to be enlarged and areas of the 2D map to instead be selected, showing still images inside the selected area in a small panel in the top left.

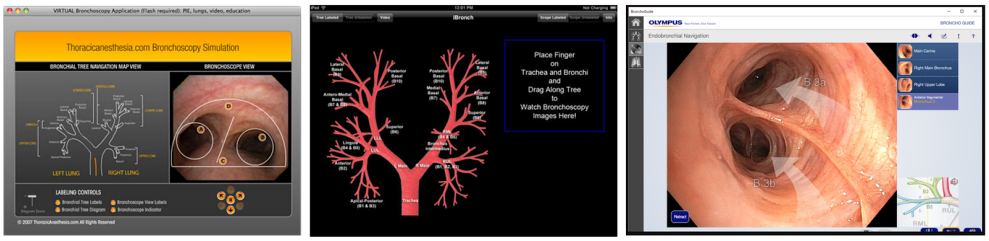


Figure 4.1: Thoracic Anesthesia, iBronch, BronchoGuide Simulators.

4.3.4 Observations

Of the three found lightweight simulators, two are deployed as a smartphone app [109, 110] and one is deployed for web [107]. The two smartphone apps contain less features and educational content to that of the web based simulator. All three simulators use controlled delivery of real footage of a bronchoscopy through the use of arrows overlaid on the video, or touching a map. In this way, none of the users can freely explore the bronchial anatomy and instead rely on a set navigation or rail navigation. Furthermore, only the Thoracic Anesthesia simulator included additional educational multimedia such as text, images, and quiz environment. Additionally, this simulator is the only tool that attempts to evaluate the application with medical students [107]. It was found from this study that the web based simulator demonstrated an increase in knowledge; however, the average score remained low and it is subsequently suggested by the authors to include didactic teaching and real-time simulation elements. Therefore, this feedback is considered for this chapter's multimedia application. The features of interest to this research include real-time simulation instead of video footage, a map (as it is a common and favorable feature across the reviewed simulators),

and other educational multimedia (text, images, and videos). The inclusion of these features in the design of the proposed system is discussed further in the following section.

4.4 Design

The main visual and orientation features listed in the previous section, such as rail navigation, maps and the use of demos, are similar to that of elements found in games for education. As such, conceptual frameworks, more commonly found in the creation of games are included in the design of this educational tool [84]. For this the Unreal Engine 4 (UE4) [111] game engine is utilised as it is optimized for large-scale projects with complex mechanics, high performance, strong dynamic lighting and aesthetics. The use of a game engine will also accommodate for the inclusion of gamification techniques, which has proven beneficial in many areas of the medical pedagogy [112]. Furthermore, medical students have confirmed their interest in medical games as an educational intervention. A survey conducted with over 200 medical students in 2010 concluded that 97% of medical students would use the game if it is fun, 77% if it helped to accomplish an important goal, and 90% if it helped to develop skills in patient interaction [42]. Moreover, the completed application executable can be published for multiple platforms including Windows, MacOS, Linux, Android, iOS, and HTML5 (web). This chapter will introduce three tools created for medical students, each tool utilises the same framework and design. This design comprises of two main categories, which are the environment and logic. Environment includes three subcategories: visual support, navigation, and interface [87].

- *Visual Support* extends to many aspects of the application. Primarily this category focuses on the inclusion of a 3D bronchial structure to accommodate for self navigation and a 2D map for orientation support. The map also includes a zoom feature. As the main view utilises a 3D synthetic model, secondary multimedia content is included for further understanding at each interest point. Such multimedia content includes video, animation, image, and audio.

- *Navigation* encompasses how the user will explore the environment. Related works discussed in the previous section utilises a rail navigation for the

user to explore the anatomical bronchial structure. This can perhaps be attributed to the reliance on video footage of a bronchoscopy procedure which does not allow the user to freely explore the environment. In contrast to this, self navigation is incorporated into the proposed system.

- *Interface* relates to the UI within the application. It comprises of an information panel and a main view panel. The main view displays the exploration environment of the internal 3D bronchial tree to the user. The information panel presents information on the current area along with any necessary instruction when the user collides with an interest point (discussed in the next paragraph). The information panel also includes an interest point counter and timer.

The next category is logic, which refers to the mechanics within the application and is again sub-categorized into interest points and task/objectives.

- *Interest points:* A technique more frequently found in first person games to highlight an area of interest or of further instruction to the user. This concept has been modified and re-appropriated for use in this application. The interest points in this system denote an area of interest to the user which when approached will display textual information, additional multimedia, or quiz questions.

- *Task/Objectives:* The lightweight simulators reviewed in Section 4.3 appear to focus on an overall objective such as self learning or familiarisation of the internal bronchial tree structure. However, there does not appear to be any set user tasks or objectives within these applications. This system has been created with the consideration of tasks which can differ per each educational tool. Such tasks include the user locating all the visual segments or interest points within a set time frame, completing the quiz at each interest point, reducing the mucus *etc.*

As the proposed tool includes free navigation, a 3D model, textual information and other multimedia, there is the risk for too much information or stimulus to overload the user's working memory. This can obstruct the user's learning experience and result in no change in knowledge. For this reason, this system considers the effects of germane, intrinsic, and extraneous cognitive load. Intrinsic cognitive load is affected by the number of interest points and the activity

or task required by the user at each point. Extraneous cognitive load is affected by the way in which the educational material is presented, such as the multimedia content, 3D model, and UI. If intrinsic or extraneous cognitive capacity are overloaded, this could interfere with the construction and automation of schemas. This construction and automation is referred to as germane cognitive load [113]. The instruction or task (intrinsic) can be managed by adjusting the manner in which the educational material is presented (extraneous). Therefore, categorising the system into its environment and logic and related sub-categories allows for greater manipulation of these cognitive loads [113]. The relationship of the system's sub-categories and the cognitive load they affect can be viewed in Figure 4.2. In this figure, the sub-categories are placed on the left with each cognitive load on the right. All subcategories under environment (interface, navigation, visual support) directly affect the way in which the educational material is affected (extraneous cognitive load). Similarly the sub-categories under logic (task/objectives, interest points) contribute to the difficulty of the learning task (intrinsic cognitive load) and may be managed for a better learning outcome. The relationship between the educational content (extraneous) and the task/objective (intrinsic) plays a key part in the development and automation of schemas (germane cognitive load). All of which affects the results of the learning outcome. Managing cognitive load is achieved by implementing the low to high- fidelity strategy, as outlined by Merrienboer *et al.* In this strategy, the learner begins with low fidelity environments; for example paper based. The learner then progresses to a computer simulation (medium fidelity), before moving onto a larger simulation such as actors (high fidelity), and finally real patients [114]. With this in mind and in an effort to reduce intrinsic cognitive load, the tool is targeted towards those students and professionals who have some prior knowledge of low fidelity simulations and are progressing to a medium fidelity computer simulation. Similarly, Merrienboer *et al.* also provide suggestions to balance extraneous cognitive load such as the Goal free principle [114]. In this principle the developer should replace conventional tasks with non-specific tasks [114]. Therefore the task or objective of the tool is designed so that it is non-specific, *i.e* identifying all the interest points as opposed to locating each interest point in a predefined order.

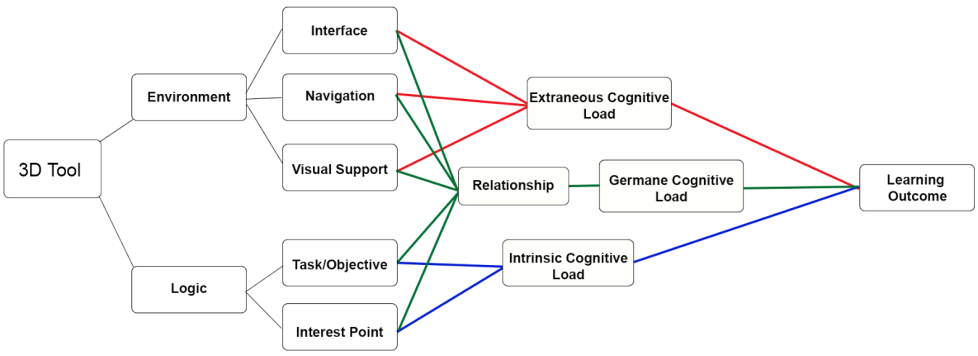


Figure 4.2: The sub-categories within this systems design and their relationship with intrinsic, extraneous, and germane cognitive load.

All textual information for the proposed system is developed by respiratory consultants in the Cork University Hospital. Textual content specific to CF is then reviewed by the CF multidisciplinary team and edited where necessary. Information pertaining to bronchial anatomy is then reviewed by senior consultants who perform bronchoscopies frequently. Any multimedia, such as images and animations, are reviewed by both respiratory consultants and the CF multidisciplinary team.

4.5 Framework Implementation

The proposed system framework is used in the creation of three separate tools. The overall framework is discussed in the following subsections. Specific features pertaining to the three tools are discussed for each respectively in Section 4.6, Section 4.7, and Section 4.9.

4.5.1 3D Model Methodology

The internal bronchial structure is created as a static mesh object in the 3D modelling software Blender version 2.73 [115]; based on schematic diagrams found in the bronchoscopy ward of Cork University Hospital. The bronchial architecture and cartilage rings are created as one solid model by converging and manipulating basic cylindrical meshes applied with a boolean modifier to remove intersecting faces. Additional faces are created to bridge edge loops of the mesh and fuse the limbs of the bronchiole to the main body of the tree structure. Where possible, nearby vertices are joined to limit scattering of points and ensure "water-tight"

edges at the bases of conjoining limbs. Once the main structure is complete, the model's vertices are subject to a manipulation process known as "sculpting", which allows for the vertices of the mesh to be manipulated using the metaphor of clay sculpture. The sculpting is used to amplify the curvature of the bronchiole arms, smooth sections of uneven vertices, and manipulate the space between the cartilage rings on the main sections of the tree. This process is also accompanied by a subdivision surface modifier so the curves and edges of the structure appear smooth, minimizing blockiness and increasing the organic look throughout the mesh. The model is then presented to respiratory specialists for feedback and validation. Web browsers that support HTML5 use Web Graphics Library (WebGL) for the rendering of 3D content, hence the bronchial model is apportioned into separate meshes so that each does not exceed 65,000 vertices, the maximum vertex count for a model on web [116]. As the lungs surround the heart, two bronchiole pipes will pulsate. This is often used as an identifier for bronchoscopisits when exploring a human lung. As such the two areas which surround the heart are applied with a shape keys animation to reproduce this pulsation. A shape keys animation is a Blender specific animation that does not require a rig or skeleton and instead records transformed vertice points [117]. This approach is also adopted for the cough animation used as part of the CF educational content. The individual segments of the bronchiole model are then exported as proprietary Filmbox (FBX) models as this format allows for shape key animations to be retained.

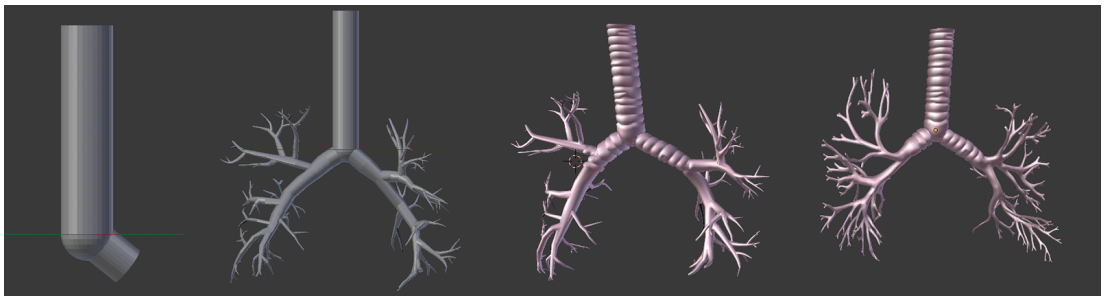


Figure 4.3: The creation of the 3D Bronchial model.

4.5.2 Environment

The completed FBX models are imported into a new, empty UE4 project version 4.7.6 [111]. The virtual environment is created by placing the completed objects into the 3D scene and performing affine transformations until the model is large

enough to enclose the player controller and ensure there is sufficient space to facilitate movement and exploration. By default the internal faces of a mesh are not visible; to resolve this a two-sided material is applied to the model. Due to the nature of object collision presets in the UE4 environment, a user is unable to move within the interior of a cylindrical model as it is automatically applied with a box collision model. Therefore, default collision is removed from the 3D mesh. The model properties are then altered to register the object as a "Double sided" geometry. Once this is done, the collision complexity is then set to "Use complex Collision as Simple". By doing this, the complexity collision calculates collision for each polygon. Thus, allowing the user to travel through the internal structure of the model. Collision is then detected by the user overlapping with the internal polygons of the model.

To build the mucus walls in the cystic fibrosis environment, a copy of the bronchiole mesh that has had sections removed in Blender is brought into the scene and applied with a mucus material. The mucus material is created in UE4's built-in material editor and uses a sine-controlled panning function to animate layered normal textures as a mask across a combination of blended base colours. Therefore, the mucus material is animating to give the appearance of movement, similar to a cillia beat. The lighting of the environment is achieved by first removing all global illumination and including only local lighting inside areas of the model to reflect how illumination occurs when performing the bronchoscopy. Finally, a 3D model representing the letter "i" is applied with an emissive material. This model is used to signify an interest point and is included in various bronchial segments in the bronchial structure.

The navigation method used for this environment is the default player pawn navigation, which utilises common computer inputs such as the mouse and keyboard. This navigation allows the user to control forward, backward, left and right movements with W, A, S, and D on their keyboard, it also allows the user to control yaw and pitch movements with the mouse.

The models with shape key animations are imported to UE4 with morph targets. By doing this the shape key animation can be targeted and animated via a timeline. On the "Begin Play" event, the pulsating morph target is accessed and played via a looping timeline. Thus, the walls of the respective bronchi models pulsate while the user explores the environment.

4.5.3 UI Design

The user interface is constructed in UE4's built-in tool, Unreal Motion Graphic (UMG). The tool provides the facility for creating 2D interfaces that accommodates for control or display of information inside the virtual environment. The user interface widget is dynamically spawned and attached to the main viewport as an overlay once simulation begins. At this time, control of the mouse is given to the navigation; however, the user can chose to right-click at any time to show the mouse cursor and interact with the interface, returning to navigation by right-clicking again. The interface includes one right hand panel, which is separated into three tabs, 1) Textual information, 2) Controls, and 3) Map. The content supplied in the controls tab does not change. Likewise, the content found in the map tab does not change, instead the user location within the app is updated dynamically with the user's movement. The content found in the textual information tab changes during each overlap with an interest point, this is so that only relevant information to the bronchial segment is displayed. The right hand panel also contains a timer and interest point counter. The interest point counter receives its value from a variable which is incremented on each overlap with a new interest point. In the same panel, a counter receives real-time seconds from Blueprints every frame.

4.5.4 Logic

All the logic governing the mechanics and interaction in the simulator is scripted using Blueprint nodes. The main functionality relies on the activation of interest points. Each interest point is governed by a bounding box, which is invisible in the environment. Once the user enters the bounding box of an interest point the UI is populated with relevant educational content. Separate bounding boxes also exist to dynamically determine the audio file that is played in certain areas of the bronchial model. Specifically, for CF tools, wheezing can be heard in the upper areas of the bronchial structure and crackles can be heard in the lower lobes. The behaviour of the mini-map is governed by a combination of dynamic material editing and player camera tracking. During each frame, a camera located high above the player checks the player's X and Y location and adapts accordingly. The view of the camera is transferred to a 2D material applied to a 2D render target at a fixed size, which resides inside the info panel on the UI. The user's

location is marked by a pulsing green point.

4.6 The Lung Anatomy Quiz

The first tool created using the aforementioned system was the "Lung Anatomy Quiz" [85]. This tool is created specifically to address bronchial anatomy for novice bronchoscopists and medical professionals. The tool can also be used as a practical learning tool in the foundation years of a medical degree. The Lung Anatomy Quiz utilises the framework as described in the previous section. However, it encompasses both a learning and quiz environment.

Once the user opens the application they are presented with a menu providing instruction on the controls and how to locate information via the interest points. From this menu the user can then choose the learning or quiz environment. If the user chooses the learning environment, interest points display textual information in addition to any complimentary multimedia. Once the user has located all interest points, a home button will appear in the right panel. This home button will return the user to the original menu as seen on starting the application. If the user chooses the quiz environment, the textual information tab is removed from the right hand panel. On colliding with the interest point, a question regarding this area of the bronchial structure is now presented to the user. Each interest point contains a list of questions and corresponding answers which is chosen at random during the overlap event. This is to ensure variety in the quiz and that any knowledge gained is not specific to the tool. On completing the last quiz question the user is then given the option to progress to the feedback screen. This screen contains a quiz score, a list of the questions, and the submitted answers. If the answer is incorrect, the correct answer is then listed. The feedback screen also contains an image of the bronchial model and interest points; the image is then overlaid with green ticks for a correct answer or red crosses for an incorrect answer respectively. This is to allow the user to visualise the areas of the bronchial anatomy, which may require more focus. The lung anatomy quiz and these four stages can be seen in Figure 4.4.

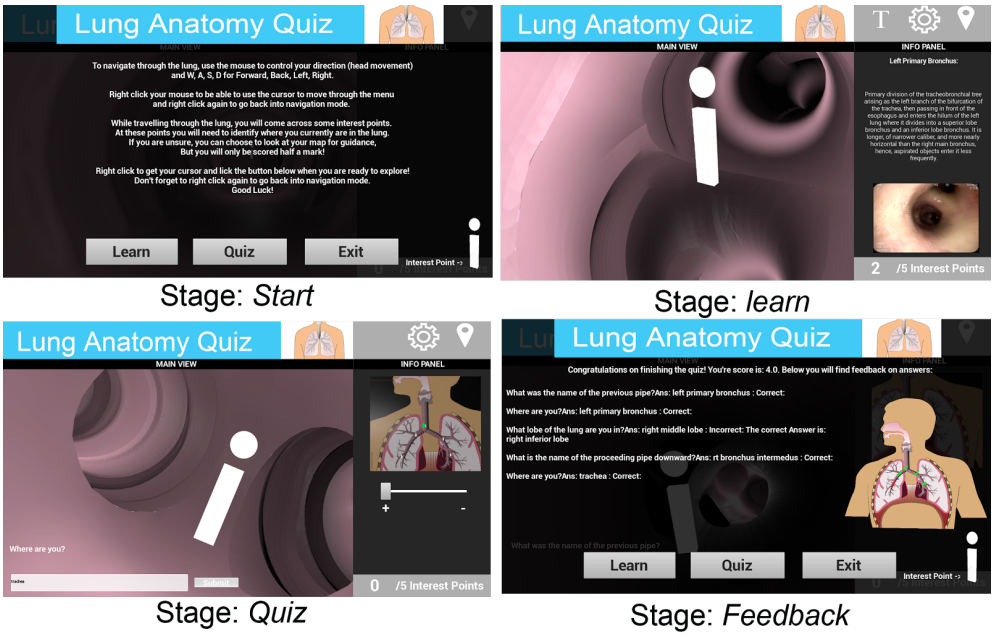


Figure 4.4: An image showing the four game states *Start, Learn, Quiz, and Feedback*.

4.7 Travel Through a CF Lung

The second tool, which uses this framework, is created specifically for CF and is called "Travel Through a CF Lung" [86]. This CF focused application can be seen in Figure 4.5. The primary objective of this tool is to allow the user to view the internal bronchial structure while learning about the effects CF has on the human lungs, treatments, and microbiota. Due to this, lung anatomy is a secondary learning objective and is inferred whilst the user travels through the model. Unlike the Lung Anatomy Quiz, this tool does not include a quiz environment. In addition to the pulsation animation this system also uses a cough and inhaled antibiotics environment animation. These actions are triggered by the user; allowing them to interact and manipulate their surroundings.

For the Travel Through a CF Lung application, the interest points are populated with textual and multimedia content specific to CF. One interest point positioned in the upper right bronchi describes the different medications a CF patient must adhere to, such as inhaled antibiotics. After this interest point, the user is unable to proceed to the lower bronchi as the passage is clogged by mucus; therefore, the user must initiate inhaled antibiotics by pressing "G" on their keyboard. Pressing this key triggers an event listener which is bound to

a spawn volume positioned at the top of bronchial structure. Once the event is triggered the volume spawns small spherical 3D objects known as meshes. The meshes are applied with a semi transparent white material; giving the appearance of inhaled antibiotics. The spherical objects are generated for as long as the key (G) is pressed. These antibiotic objects travel down the bronchial structure via a predefined path described using a timeline node and animation curves. When the objects collide with the mucus plug, the mucus model is then removed so that the user can progress forward to the next interest point.

Similarly, another interest point positioned in the upper left bronchi is associated with a user controlled animation. The interest point describes the various breathing techniques a CF patient must adhere to in order to clear the mucus in their lungs. The user can then press "F" on their keyboard to view a cough in the current bronchi. This is achieved by again utilising a shape key animation which is imported as a morph target. Once the user presses the key, the animation is played via a time line once only.

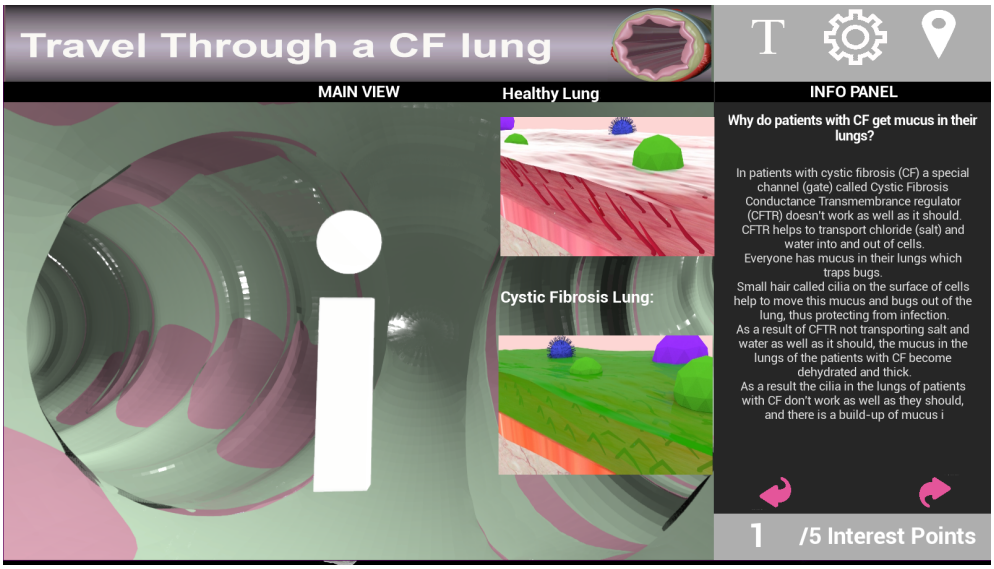


Figure 4.5: An image of the Travel Through a CF Lung application.

4.8 Evaluation

Both the Lung Anatomy Quiz and the Travel Through a CF Lung were evaluated via a performance stress test [86] and usability study [87]. The evaluation and results of these tests are as described in the following evaluation sub-sections.

4.8.1 Stress Test

To assess the accessibility of the applications, both tools are compiled as Windows 64bit, Mac OS 64bit and HTML5 (web) packages. The executables' performance is then tested using five computers with various specifications on both Windows and Mac operating systems. The machines range between 4GB to 10GB RAM, with Dual or Quad core processors, and GPUs with between 256MB and 2GB. The machine specifications and results are displayed in Table 4.7.

Table 4.7: Performance results following stress test of the framework.

Machine:	Desktop 1	Desktop 2	Desktop 3	Laptop 1	Laptop 2
OS:	Windows 7 64bit	Mac OS Yosemite	Mac OS Yosemite	Windows 8.1 64bit	Windows 8.1 64bit
CPU:	Intel i3 3.5GHz Quad Core	2x Intel Xeon 2.26 GHz Quad Core	Intel Core 2 Duo 2.6GHz Dual Core	AMD A10-4600M 4 GHz Quad Core	Intel Core i7 4GHz Quad Core
RAM:	4GB DDR3	10GB DDR3	8GB DDR3	8GB DDR3	8GB DDR4
GPU:	GTX760 2GB	GT120 512MB	GeForce 9400 256MB	Radeon HD 7970M 2GB	GT650m 2GB
FPS:	140	8	3.7	97	33.5
Frame time:	7.1ms	118.5ms	238 ms	9ms	28.1ms
Game time:	1.8ms	3.5ms	3.5ms	3.5ms	1.8ms
Draw time:	1.5ms	70ms	240ms	5ms	28.1ms
HTML FPS:	60	35	21	60	60

When running the simulator through a native executable, it can be determined by the GPU-related frames per second and frame time results that the simulator performs more optimally on machines with higher-end graphics capabilities/cards, reaching between 97 - 140 Frames-per second (FPS). It also shows that the higher-end graphic aid in freeing up the Central Processing Unit (CPU), keeping the CPU-related game-time and draw-time low, ranging between 1.5ms - 5ms, and preventing bottlenecks. The performance of the tool appears to be unaffected by the operating system and RAM in each case; however, it is heavily affected by the power of the Graphics Processing Unit (GPU). This could prove problematic as the lowest acceptable frame rate for this simulator is 20 FPS, and not all consumer computers will meet this requirement.

A distinct change can be observed on the HTML5 platform however; where on the lower-spec machines, the FPS is four to five times higher compared to that of the native executable. This demonstrates a promising result for the use of web technologies as a dissemination option over native applications. From these

results it can be suggested that the tool, at this stage, would require the following minimal technical machine specifications to run adequately on the HTML5 platform: Windows or Mac OS, Dual Core 2.6GHz+ CPU, 256MB GPU, 4GB+ RAM. With the use of the native executable, it would also be suggested that the user have basic computer literacy skills. Such as downloading and opening an application, accompanied with basic computer input or motor skills such as the keyboard and mouse to explore the tool. However, hosting the tool on the HTML5 platform eliminates the need for download and installation, and instead only requires basic web literacy from the user [87].

4.8.2 System Performance Evaluation

The user interface for the proposed application was tested using two approaches: Usability Testing, and a Heuristic Walkthrough. Both applications were populated with five interest points, which included textual content and additional multimedia. The applications are then presented as a Windows executable to 15 postgraduate students completing a PhD or MSc in computer science or interactive media. To note for the purposes of testing, computer science and interactive media students are chosen over the intended audience due to their knowledge and former experience of these testing methods. However, it is anticipated that once the integrity and pedagogical structure of this application have been validated, it can then be tested with medical students, novice bronchoscopists, and junior respiratory specialists.

Heuristic Walkthrough Methodology and Results

Nielsen *et al.* commend heuristic evaluation as it can be applied early in the development process [118]. Considering the infancy of the system, heuristic walkthroughs are the first testing method to be introduced to the participants. Each participant is met with an invigilator who outlines the controls before introducing the participant task. The user is requested to locate all five interest points and to follow the instruction provided in the right panel. Once the user has located all interest points, the time taken is noted. The participant is then asked questions regarding the clarity of the instruction provided at the interest point. Following this, the participant is advised of the intended purpose of the system. The participants are then given the opportunity to develop their own tasks and navigate

freely through the application without constraints. After which the user is asked to provide feedback on the application dialogue and instruction.

On average it took the students 227.86 seconds to locate all five interest points. Interestingly, although each student is able to locate all five interest points, not all were able to complete the task instructed in the information panel. Thirteen of the fifteen users were able to open the image when prompted and only eleven of fifteen users understood to input text when interacting with the quiz interest points. Further to this, a large portion of the participants ($n = 12$) confirmed that they would play games in their spare time; however, a small portion ($n = 3$) of these users play console games as opposed to PC/Mac and are unfamiliar with the navigation utilised in the application. Adding to this, the participants who described themselves as unfamiliar with PC/Mac games were unable to complete the task at all five interest points. The majority of feedback received regarding the instruction and dialogue of the application focused mainly on dialogue aesthetics with one user suggesting that *"video, image, and audio should be caps so it's easier to see"*. To note, in order for the participants to open the additional multimedia they must click a button with in the UI. Considering the issues identified with these buttons, they are removed for future iterations of these tools. Instead, the additional multimedia is displayed in the UI along with the textual information. Other feedback received was focused on supplementary instructions such as a help button with instructions on what to do in the event the media will not open or play.

Usability Testing Methodology and Result

As the participant is now familiar with the system, the user is then presented with a usability questionnaire to evaluate the interaction, perception and performance of the application. This test is segmented into four three-part questions, Performance, Simplicity, Presentation, and Perceived Quality. These categories were incorporated into the questionnaire as they are suggested for consideration as part of the Unified Modeling Language (UML) user interface testing method [119]. All questions from this feedback form are answered via a Likert scale from 1 to 5, with 1 being the lowest possible value and 5 being the highest. The questions used in the usability questionnaire are listed below along with the wording on the Likert scale.

1. Performance (rated from 1-5, 1= Not Acceptable, 3 = Acceptable, 5 = Exceed Expectation):
   (a) Please rate the length of time it took to open the application
   (b) Please rate the time it took to perform functions or requests (*e.g.* open and play a video)
   (c) Please rate the overall application performance
2. Simplicity (rated from 1-5, 1 = Not Simple, 3 = Simple, 5 = Very Simple):
   (a) Please rate the impact the quantity of inputs had on simplicity (*e.g.* mouse, keyboard)
   (b) Please rate the impact the number of UI elements had on the simplicity (*e.g* buttons, sliders)
   (c) Please rate the overall simplicity of the application
3. Presentation (rated from 1-5, 1= Not Acceptable, 3 = Acceptable, 5 = Exceed Expectation):
   (a) Please rate the colours and layout used
   (b) Please rate the use of metaphors for the buttons (*e.g.* camera icon to see images)
   (c) Please rate the overall the application presentation
4. Perceived Quality (rated from 1-5, 1= Poor Quality, 3 = Acceptable, 5 = Good Quality):
   (a) Please rate the quality of the media elements used
   (b) Please rate the quality of feedback presented by the application (*e.g.* text box)
   (c) Please rate the overall application quality

Once the questionnaire form is complete the participants are then asked to complete the NASA TLX (Task Load Index) [120] (Appendix B). The TLX was created by the Human Performance Research Group at NASA is also one of the most rigorously tested questionnaires available. The TLX was developed over three years which involved more than 40 laboratory, simulation, and inflight experiments [121]. The NASA TLX is a subjective multiple choice questionnaire

that rates perceived workload in order to assess a task [120]. Hence, this questionnaire is implemented to evaluate the user's perceived workload. The TLX questionnaire includes six questions which are answered via a Likert scale from 1 (very low) to 20 (very high).The TLX questionnaire includes six questions which are answered via a Likert scale from 1 (very low) to 20 (very high), see Figure 4.7.

Although a small portion of the users were unable to complete all the tasks the usability questionnaire was scored highly. The highest ($n = 4.26$) scoring question was Q1.A which was the length of time it took for the application to open. The lowest ($n = 3.3$) scoring question was Q3.A, which focused on design layout and application colours. Post analysis on the feedback accompanying the lower scores reveal that users on average are happy with the application layout. However, they were unimpressed with the colours used. Some feedback included *"use complementary colours"* and *"overall I am very happy with the layout, but the colours could be more contrasting"*. The results of these questionnaires can be seen in Figure 4.6. At the end of this questionnaire, the users were given the option to provide general feedback for the application. Five users supplied general feedback while nine users supplied feedback on the dialogue and instruction. The general feedback received focused on additional navigation techniques: *"maybe some markers on the map and in model to plan routes", "got a bit lost at times and wasn't certain if I had already visited an area. A breadcrumb trail to show this would be beneficial"*. The questionnaire results can also be broken down further into the rating among question category. The presentation category scored the highest average ($n = 4.25$), followed by simplicity ($n = 3.95$), presentation ($n = 3.86$), and perceived quality ($n = 3.81$).

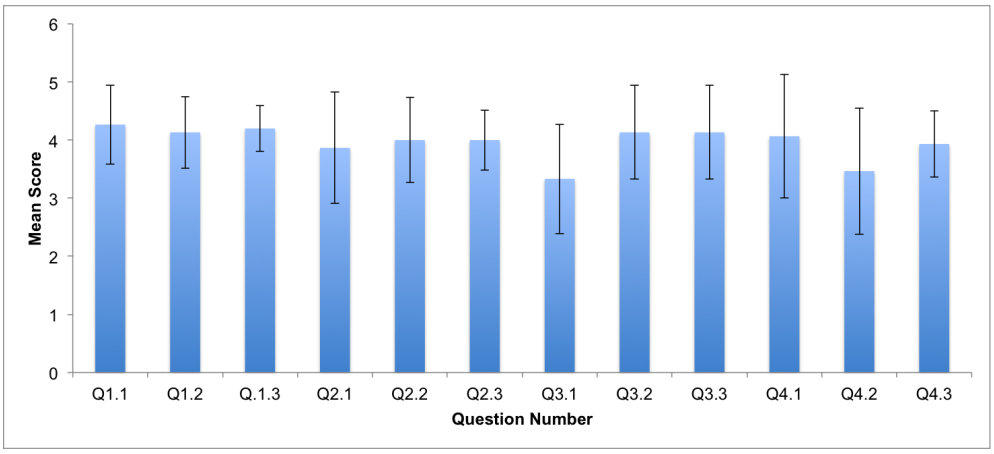


Figure 4.6: Usability Questionnaire Results.

The results of the NASA Task Load Index can be seen in Figure 4.7. The results of the user perceived workload gathered by the NASA TLX reveal that mental demand for the application was the highest scoring ($n = 9.4$ scale from very low to very high). This could again be attributed to the chosen user inputs as those participants who ranked highly for the mental demand are also the users who do not play games on PC/Mac. Physical demand was ranked low at $n = 3.53$ (scale from very low to very high). However when the users were asked to rank how hurried or rushed they felt the pace of the task was (temporal demand), there was a slight increase ($n = 6.53$), this may be attributed to the timer which was displayed in the bottom right hand corner of the lung anatomy tool window. For question four, the users were asked to rank how successful they were at completing the task (performance) from perfect - failure. The average score for this question was 3.73, indicating that participants felt successful in completing the outlined task/objective. Participants also reported that they did not find the task difficult to accomplish ($n = 6$ on a scale from very low to very high) in question five "Effort". In the he final question, question six, frustration was scored the lowest ($n = 3.46$). Overall, these results show that participants felt that they could achieve the objective and did not regard it as difficult. Likewise they did not feel rushed or frustrated when completing the task, although they reported a high mental demand. These results show promise in the application of the system with medical students as it is anticipated that they too will not feel frustrated when performing the task and can also feel like they can accomplish the task accurately.

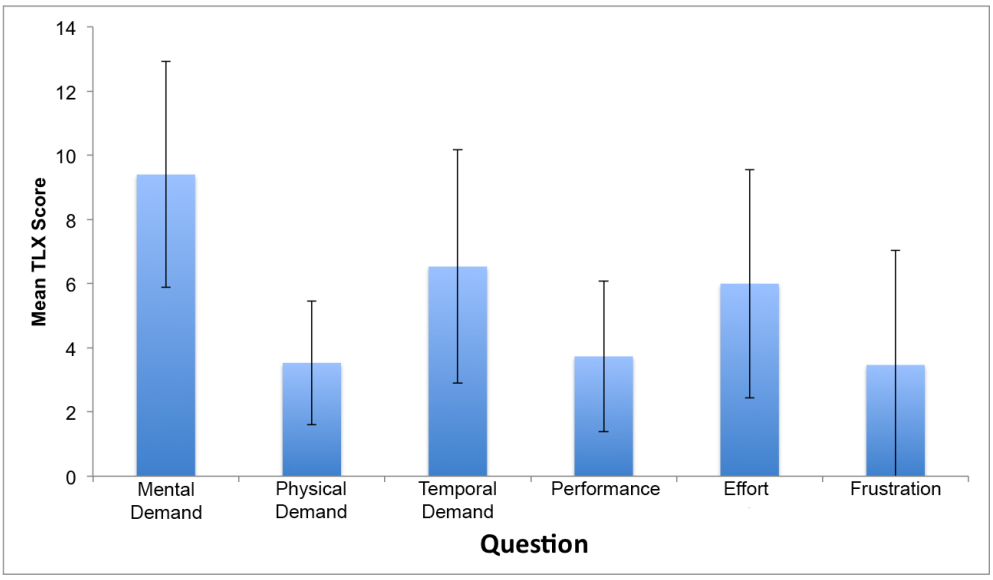


Figure 4.7: NASA Task Load Index Results.

4.9 Further Enhancing Visualisation With VR

The previous tools are developed so that they can be accessed easily by medical students. The applications allow the student to explore a 3D environment freely, which is not possible in currently available lightweight simulators. However despite these benefits, the visualisation of the bronchial tree cannot match that of real video footage. Similarly, these tools cannot match the practical learning application of larger simulators. The aforementioned framework used to create these tools generates a virtual reality (VR) environment to explore and interact with the 3D model. The Oxford Dictionary defines virtual reality as *"computer-generated simulation of a three-dimensional image or environment that can be interacted with in a seemingly real or physical way by a person using special electronic equipment, such as a helmet with a screen inside or gloves fitted with sensors"* [8]. With this definition in mind, it can be considered that the VR environment developed thus far for bronchial anatomy and CF content can be further enhanced with VR peripherals such as a Head-Mounted Display (HMD). This enhancement may improve the experience of the system and the visualisation component; which may prove more beneficial to the intended medical professionals. Hence, the incorporation of a VR HMD is explored.

Recent research expansion into virtual reality educational applications and software have proven effective for teaching complex or abstract concepts [122].

The affordances of VR have also been translated to the medical industry with positive results [123]. A recent project by INVIVO Communications shows that exposure to computer generated 3D medical models in a virtual environment with 360 degree of freedom using the Oculus Rift is engaging among medical professionals and consultants [124]. Other medical VR examples include the collaborative project between Rémi Rousseau and the MOVEO Foundation [125], which utilise a HMD and 360 degree video recordings, to allow students to watch surgical procedures from the surgeon's first person perspective. As these video recordings are 360 degrees, the student has the freedom to look around the theater to observe the activities of the entire surgical team. Another use for VR in medical education can be seen in the "World of Comenius" project [126], where the user wears a HMD and interacts with a 3D anatomical educational model through touching and grabbing individual components. The user can also teleport to a 3D animation of a blood vessel or brain tissue, depending on the anatomical areas uncovered.

Considering the practical benefits of VR for medical professionals, the "Travel Through a CF Lung" tool is enhanced and deployed for a VR HMD. To accommodate for this new platform, minor adaptations are made to the framework. These modifications and VR HMDs are discussed further below. The final VR CF tool is hence referred to as the "Lung Experience".

4.9.1 Oculus Rift Development Kit 2

During the initial development stages of the Lung Experience the only available HMD was the second Oculus Rift Development Kit 2 (DK2) [127]. This HMD is compatible with the software used to create the previous tools, UE4. This kit targets a seated experience and includes a six degrees of freedom HMD with infrared sensors situated on the front panel. These sensors communicate with a tracking camera situated above the computer monitor. However, this kit does not include an input device.

The player pawn spawner is removed from the bronchial structure and instead placed in a separate self contained room with a single interest point. On starting the simulation the user can move around in this room and become accustomed to the controls and headset. Once the user overlaps with the interest point, a widget is displayed providing further information on controls and objectives. The user can then select the appropriate control to teleport to the model and explore

the bronchial structure.

As the user will experience the environment through the DK2 HMD, the UI cannot be overlaid to the main viewport as doing so will cause the user's eyes to converge. To resolve this the UI and associated content is taken and reappropriated as a widget in the environment. Subsequently the 3D "i" representing the interest point is hidden and the widget is then dynamically spawned during overlap events. This new widget contains both the educational content, mini map and additional multimedia.

As the user is wearing a HMD they are unable to see the positioning of their hands on the keyboard. As such the original W, A, S, D keys on the user's keyboard are no longer sufficient for the player navigation. Therefore, an Xbox 360 arcade pad is instead implemented, as the user can hold the joystick and feel the large tactile buttons on the pad. To achieve this, some minor changes are made so as to accommodate for the new input. The user can control pitch, roll, and yaw via head movements while wearing the HMD. Forward, back, left, and right movements are determined via the joystick on the arcade pad. An issue encountered with this setup is that both arcade pad and HMD are tethered and thus the user will be unable to rotate 180 degrees to turn around. Hence, the left trigger (LT) and right trigger (RT) buttons are also assigned yaw movements to the left and right respectively. By pressing these buttons, the users yaw is slowly altered so as not to cause sickness, but also allow the user to turn around. The remaining buttons on the arcade pad are then assigned to user interactions which are; teleporting, coughing, and producing inhaled antibiotics. This system is then informally demonstrated to computer science students which can be seen in Figure 4.8.

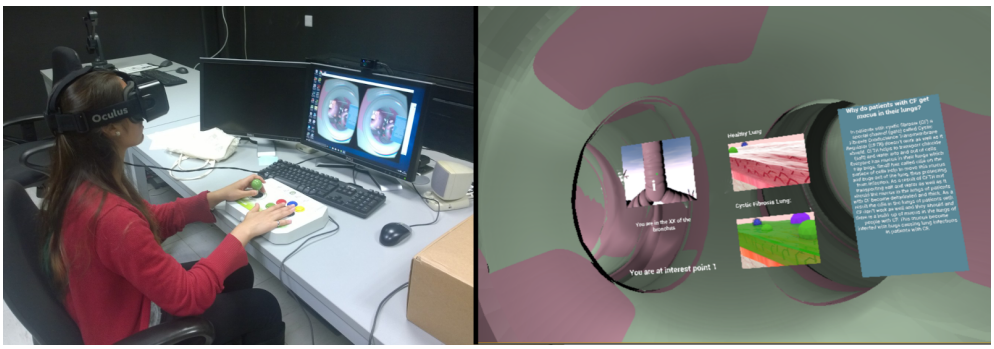


Figure 4.8: Stereoscopic view of environment and non stereoscopic view.

A pluralistic walkthrough is conducted with a group of five students to record

qualitative data that evaluates the end-user's perceived usefulness of the environment [128]. A pluralistic walkthrough was implemented for this task as it is predominantly used for early design evaluations, and it can be conducted quickly. Unlike heuristic walkthroughs which require multiple run-throughs, pluralistic walkthroughs can be complete in a single run-through [128]. During this evaluation the users are introduced to the controls and primed for use of the VR HMD [129]. The decision is made to enrol only five students for this study as this is preliminary stress testing. The users are given three tasks to perform during the pluralistic walkthrough. The first task is to locate all the interest points within the lung. Once this is accomplished, the users are asked to read all the information available on the interface. Lastly, the users are requested to complete the environment interactions displayed at each interest point. While using the HMD and exploring the environment, data is collected about the users' interactions and behaviours through observation. Each user is asked to "think aloud" their experience during this evaluation. It is observed that the users spent the most time at task one (approx $<$ 3 min). From the comments made by the users, this is due to the user continuing to adjust to the use of head movement to navigate. However, this is no longer an issue by task three, as the user had quickly adapted to the new control mechanism. During task two, four of the five users experienced difficulty reading the textual information but experienced no issue when viewing an animation or image. This appears to be a repercussion of the angle in which the user is looking at the text, as in some cases it may appear blurry. The users are then prompted to adjust their position to view the text, which took one or two attempts. After this, the user is able to read the text without any further issues. For the final task, all users are able to locate all the interactions and activate them with ease by using the gamepad. After the third task is complete the users are provided time to explore and interact with the game experience while continuing to speak aloud any feedback they may have. Generally, the feedback received from the students was positive. It is regarded as fun and interesting, which promoted exploration, and motivated users to continue engaging with the experience until they had interacted with most or all of the available content. However, it is found that there are some minor issues, which can be attributed to the developmental nature of the hardware. If used for long periods of time, the stereoscopic screens in the headset can become blurry. Often if the user turned more than 120 degrees in either direction, the tracking would

experience some latency and three of the five users reported feelings of nausea as a result. During the informal testing, various consumer HMDs became available. As such it is agreed to move the system to a more refined headset, for this purpose the HTC Vive is chosen.

4.9.2 HTC Vive

The HTC Vive [130] is one of the first official consumer graded HMD products. This headset has evolved from the technology seen in the DK2 and includes two infrared light houses to track the user's movement and two hand held wireless controllers which are visualised and tracked in the VR environment. The HTC Vive provides the facility for room scale experiences and standing experiences. Above all the hardware capabilities of the Vive exceed the DK2, providing better tracking and graphics and thus limiting the potential of nausea.

As the previous Lung Experience Tool is created to be deployed onto a HMD, minimal changes are required. The main modification made to the previous DK2 Lung Experience is the use of the HTC user inputs. The Vive controller touch pad can also be pressed to trigger events. To take advantage of this, a custom texture is created for the controller which now includes large coloured circles to identify the user interaction buttons (see Figure 4.9). The left controller trigger is used to move the player backwards and the right controller allows the user to travel forward. The additional buttons, which allowed the user to modify their yaw position, are no longer required due to the infrared lighthouses. The DK2 tracking camera is ordinarily situated on top of a computer monitor/laptop screen. As such the camera is unable to track the user correctly when facing opposite the camera. However, the HTC Vive lighthouses are positioned less than 5 metres apart in either corner of the VR experience space. The lighthouses then face opposite one another above the user pointing down. Subsequently, the user can now rotate with 360 degrees in the real world and be accurately tracked and updated in the VR environment.

The last change made to the Lung Experience is the environment mucus. Previously, 3D models are imported and positioned in the environment. These models and all others that do not serve a purpose for user interaction or the blocking of smaller bronchioles are removed. Instead, a "Mesh Paint" approach is utilised. Mesh Paint incorporates a pair of materials, such as the pink bronchiole material and the animated mucus material. The first material is used as the

primary facet on the the 3D model, the second material is then painted directly onto vertices applied with the Mesh Paint. Therefore, the mucus model is painted directly onto the bronchiole structure to give the appearance of thick mucus. The vertex painting can be seen in Figure 4.9.



Figure 4.9: The HTC controllers and Mesh Painted Mucus.

This tool is then demonstrated to CF consultants and respiratory specialists. It is agreed that the new Lung Experience performs better than its predecessor and did not induce any feelings of nausea among the group. It is also agreed that the Lung Experience shows promise as a practical learning and visualisation tool for medical students. Currently in Ireland, medical students in the final three years of their medical degree undergo work placement in various wards of a university hospital, known as attachments. During these attachments, students are assigned to a consultant and may attend clinical appointments and consultations. The students are also given time to attend additional lectures and seminars in both the University and Hospital. Time is also allocated for self directed study which is often conducted via traditional methods. Therefore, it is suggested by the consultants and respiratory specialists that the Lung Experience can be of benefit to students for self directed study while attending respiratory attachments as this VR learning tool may complement their practical attachment learning. It is suggested that the tool could also be set up in a study area so that it can be used by the students freely.

Medical Student Study Methodology and Results

Following this suggestion, the desirability and usefulness of the Lung Experience is evaluated. During a meeting amongst the Cork University Hospital CF Multidisciplinary Team and two members of the University College Cork Computer Science department, a study outline is agreed upon by consensus. A ten part questionnaire is developed by the CF Multidisciplinary team based on the available content in the Lung Experience (Appendix C). The corresponding answers are also agreed upon in this way. To determine if any knowledge gain is acquired by the students, this questionnaire is presented to the user before and after entering the VR environment. The user will be asked to locate all interest points and read/view the available textual information and multimedia content or interact with the environment based on the instruction provided. Furthermore, so as to determine if this tool is desirable to the medical students, four additional questions are added to the post questionnaire. These questions are listed below:

1. How useful did you find the virtual reality experience?
2. How likely are you to use a virtual reality experience for your education in future?
3. Do you think a virtual reality experience would be useful during attachments?
    a. "Please explain your answer:"
4. Do you think virtual reality complements lecture based learning and clinical attachment learning?

The first three questions use a Likert scale with 1 being the lowest possible value and 5 being the highest. Question four is presented as a multiple choice question where the users can choose either "Yes", "No", or "Unsure". The Lung Experience is then assembled in the Cork University Hospital for evaluation by medical students. This evaluation does not include a control group or comparison to other learning method as the primary objective is to determine if the Lung Experience can be of benefit and if it is desirable. However, future studies may further examine the benefit of the Lung Experience through a comparative study.

Ethical approval for this study is granted via the Social Research Ethics Committee at University College Cork. Participation in the study is optional and all

participants can retract submitted data by emailing a member of the research group. During attachments, students are separated into small groups of two or three and rotate among wards/departments every second week. Students attending University College Cork who are currently undergoing respiratory attachments are invited to partake in the study. The participant is then given an information sheet and provided with informed consent.



Figure 4.10: A fourth year medical student taking part in the Lung Experience study.

Eight students were approached over the course of one semester and agreed to take part in the study. Of the eight students five were currently completing their 4th year and three were completing their 5th year. During the study the users are given the option to stand in the room or sit in a rotating chair while wearing the HMD. Participants are also advised that they can take off the headset at any stage should they feel uncomfortable or nauseous. All participants answered the questionnaires fully and successfully located all interest points. The answered questionnaires are then marked and reviewed by two members of the research group before being brought to the CF Multidisciplinary team for validation. The marking scheme and allocated marks are then agreed upon by consensus. The results of the knowledge based questions can be seen below in Table 4.8.

Table 4.8: Results of the pre and post questionnaire.

Student:	1	2	3	4	5	6	7	8
Pre Questionnaire Results	48%	22%	22%	48%	39%	35%	13%	26%
Post Questionnaire Results	78%	73%	73%	91%	70%	43%	61%	48%

From Table 4.8 it can be seen that all participants scored higher in the post questionnaire, perhaps signifying some knowledge gain. Participants 2 and 3 scored the second lowest in the pre questionnaire (22%) and acquired 73% in the post questionnaire, which is the highest difference among the pre and post questionnaire results (51%). Participant 6 scored the lowest (43%) in the post questionnaire which shows an increase of 8% from the pre questionnaire; the lowest observable difference in the pre and post scores. The average pre questionnaire score is 31.6%, the average post score is 67%, and the average increase is 35.5%, these findings are similar to that of the Thoracic Anesthesia Simulator [107]. The developers of the Thoracic Anesthesia simulator found an increase in knowledge of 30%, where as the Lung Experience demonstrates an increase of 35.5%. Similarly the average score achieved in the post questionnaire for the Thoracic anesthesia is 56% where as the Lung Experience shows an average of 67%. Although the number of participants are significantly less than that of the Thoracic Anesthesia, the results found among this small group shows a positive pattern demonstrating the potential impact of this VR simulator. Furthermore, the results of the four desirability questions proves that medical students want such tools as part of their learning. The results of these questions are displayed in Table 4.9.

Table 4.9: Results of desirability focused questions in post questionnaire (VRE = Virtual Reality Experience).

Student:	1	2	3	4	5	6	7	8
How useful did you find the VRE*?	5	4	4	4	5	4	4	5
How likely are you to use VR for education in future	5	4	5	5	5	5	2	4
Do you think the VRE* would be useful during attachments?	5	5	5	5	5	5	3	4
Do you think VR compliments lectures and clinical attachments?	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes

The first three questions in the Table are rated via a Likert scale with 1 being the lowest possible value and 5 being the highest. All participants regarded the Lung Experience as useful scoring it a value of either 4 or 5. Five participants submitted a value of 5 for the likelihood of using VR for education in future and two participants scored this question a 4. When asked would the VR experience be useful for attachments, six participants scored a 5 and one scored a 4. Similarly seven participants agreed that VR compliments lectures and clinical attachments. To note participant seven scored the lowest for questions two and

three. Although this participant considered the Lung Experience useful he/she will not use VR in future for education and is unsure if VR environments are useful during attachments. Likewise, this participant also advises that they are uncertain if VR compliments lectures and attachments. To note, participant seven is the only participant who felt nauseous while using the experience, but regarded the symptoms as mild and chose to continue using the system. This is further reflected in their submission for question three when asked to further explain their answer:

"unsure of its benefits. Simple reading of slides is difficult in VR due to text out of focus and slight nausea. A more interactive experience displaying lung pathology maybe of more benefit i.e channel defect, mucus plugs etc."

From this it can be seen that although participant seven found reading the text difficult, they suggest a possible scenario where VR may be of more benefit to medical education in future. This implies that the user is not entirely averse to the use of VR in medical education. The remaining participants submitted answers for question three demonstrate that the students found the tool to be engaging and complimentary to their respiratory attachments. These submitted answers are as follows:

Student 1: *It helps improve your understanding of common conditions and highlights what you need to know (key points).*

Student 2: *interactive and interesting learning medium.*

Student 3: *helps explain pathophysiology much better. makes learning fun.*

Student 4: *it's good fun and there's probably lots of topics you could use it for.*

Student 5: *very good and engaging. useful for visualising areas and the interaction keeps you focused. Would be useful for areas that are hard to see/ demonstrate clinically.*

Student 8: *if used to explain physiological concepts.*

This study highlights two findings: the first is the utility of an educational VR tool for practical learning. The second finding is a potential pitfall, as it was found that the VR Lung Experience may induce feelings of nausea. In the aforementioned pilot study, Participant 7 experiences some of the largest knowledge gain using the tool; however, the participant is dismissive of using it in future

due to feeling nauseous during the experience.

Nausea is a known pitfall of VR. It can be caused by users feeling as though they are moving (self-motion) through visual stimulus, without the additional senses which normally indicate body movement. There are many technicalities which can induce this feeling of motion sickness, such as "mismatched motion" [131]. Mismatched motion is caused by discrepancies between what the user sees in the HMD and what they expect [131]. For example, the user may turn their head while wearing the HMD, however the virtual environment may respond slower than the user moves, which creates a mismatch between what the users body expects and what actually happens. These discrepancies are often caused by low frame-rates which result in this kind of latency in a VR environment. The research as presented by Jeng-Weei Lin *et al.* suggests that manipulating and controlling this frame-rate, such as by using a static frame rate for background animations and models, can improve or reduce the symptoms and feelings of nausea/motion sickness [132]. Additionally, hardware acceleration is being actively researched to try and combat this for future iterations of VR peripherals [132]. GameCrew Creative Lab, a South Korean start-up company, have claimed that they have resolved the issue of nausea and eye fatigue with two new softwares (GREW AutoFocus and MOSKIT) which are currently in a beta testing phase. The softwares are designed to improve focus and depth perception, while simultaneously analysing the VR content to identify causes of motion sickness [133].

This study is limited due to the low number of participants and also the lack of comparison to other learning methods. However, the choice to exclude a control/comparative group is due to the study objective. This evaluation aims to identify if the Lung Experience can be of benefit to medical students on respiratory attachments as the tool offers a practical learning environment that can be used in their free-time to complement their practical attachments. The Lung Experience is not developed to replace any current learning medium. This study also aims to identify if this system is desirable to students. Similarly a comparison group was not included at this stage as it is a pilot study only. However futur testing would include a comparison study of the system against tradition learning techniques. Although only eight participants are recruited, it is found that there is an average increase of 35.5% in scores from the pre and post questionnaire; with an average score of 67%. Moreover, the desirability questions provide evidence that the majority of users are engaged by this tool and agree that it compliments

their learning. Overall, these results may indicate a pattern or trend towards the usefulness and desirability of a virtual reality learning environment for medical students.

4.10 Summary

In this chapter, the educational multimedia interventions found in Chapter 2 were reviewed with similar works found on MERLOT. It was observed that there is a paucity of interactive and visualisation elements and as such it is agreed with the CF Multidisciplinary team to create an exploratory environment of a healthy human lung and CF lung. This can be of benefit to novice bronchoscopists, medical students, and medical professionals. To develop such an environment a game engine was employed to accommodate for free roaming navigation and environment interaction. Subsequently, the system incorporates a gamified approach to certain features such as interest points, maps, user interaction, and user navigation. The framework was used to create three applications, The Lung Anatomy Quiz, Travel Through a CF Lung, and the Lung Experience. The first two applications were assessed via performance and usability with promising results. The Lung Experience is an adaptation of the Travel Through a CF Lung which incorporates the use of VR headset. This VR environment was then tested with medical students and demonstrates promising results towards knowledge gain and exemplifies the desirability of the tool.

The contribution of this chapter is the educational system for medical professionals. Although this tool cannot offer all the features and benefits to a large scale simulator (motor skills for controlling and navigating a bronchoscope), it does offer a lightweight simulator which can be freely explored (not possible to current lightweight simulators). Virtual reality and its capabilities in medicine are constantly being challenged and expanded. For example surgical simulators, Accident and Emergency Room simulators, and data visualisation. By developing this system for VR, the system can contend with modern multimedia research and also contribute to it. Most notably is the ability to visualise and explore an internal human organic structure. It also presents ways in which educational content can be presented in VR to medical students and professionals. However since the first iteration of this VR tool in 2015, many developments have been made in

the fields of user navigation, graphical capabilities, and data visualisation. Examples of this advances include, the ability to teleport around 3D environments using one button, and the graphical capabilities of the HTC Vive Pro. For the VR Lung Experience tool, it is noted from the study that one participant found reading information from slides difficult, and as such is an area which requires improvement. Other means in which to communicate this educational material, such as the use of audio and environment animations may further enhance the educational capabilities of the system. Likewise the system requires further evaluation with a comparative group to fully understand and realise its educational potential, which is acknowledged as a limitation.

This chapter touches on the idea of games to benefit medical students; however, it is yet to be seen if games can be of benefit to CF patients. This is further explored in Chapter 5.

Chapter 5

Biofeedback Game and Data Analysis System

This chapter will begin by outlining serious games and its current use in the medical sector before introducing a CF smartphone biofeedback game with custom SMS alerts. In Chapter 4, gamified experiences were investigated for student learning. However, from these findings it can be surmised that such an experience could be of similar benefit to CF patients. Chapter 4 grapples with the idea of games in medical education, whereas this chapter aims to further leverage the engaging nature of games for patients. Biofeedback is described as a method that allows a user to learn how to control body functions with the intention of improving health or physical condition. Biofeedback can encompass many body functions such as brainwave, breathing, heart rate, muscle, sweat glands, and temperature [134]. For the purpose of this research, the proposed and reviewed biofeedback games focus on breathing only. Biofeedback games for CF children have been developed and tested with great success. However, there is often technical and human limitations, such as accessibility of the platform in which the game is disseminated and the attention and commitment required to setup and replay the game. The significant contributions of this chapter are threefold. The first is that the presented biofeedback game is intended for CF adults which, to the authors knowledge, is the first of its kind. The second significant contribution is that this game is deployed for an Android smartphone for anticipated ease of accessibility and removing the need for specialised equipment. Thirdly, the data from this game is analysed via a web tool that can also be viewed by the CF multidisciplinary team. This web tool allows the team to customise the SMS

alert criteria for each patient to provide a more individualised approach to their care. This chapter also begins to explore the possibilities of mHealth applications for CF adults and thus influenced the implemented solution for Chapter 6; which focuses on patient education. The manuscripts published to support this research Chapter includes: "A Serious Mobile Game App For Adults With Cystic Fibrosis" [135], "Using a Mobile Game Application to Monitor Well-Being Data for Patients with Cystic Fibrosis" [136], and "A mHealth App with Game for Adult Cystic Fibrosis Patients" [137].

5.1 Serious Games

Serious games are an interactive media mechanism commonly utilised in many sectors such as healthcare, military, defense, corporate, marketing, education, training, and communication. In contrast with entertainment games, serious games are digital games with the objective of positively affecting a user in some way [138]. The authors of "Serious Games: Mechanisms and Effects" define serious games as advancing the players learning experience in some form that should not cause any detrimental effects to the player [139]. This definition explicitly states that learning experiences are one of the essential outcomes required of a serious game. However, this definition is not unyielding and often varies depending on the sector or discipline it is being harnessed within. For healthcare and medicine, serious games are incorporated to facilitate a positive change to the player in several areas including attitude or physical ability. This alteration in meaning for the healthcare sector can be verified by Simon McCallum [140]. McCallum describes serious games as those which are designed to achieve a change in the user such as knowledge, attitude, physical ability, cognitive ability, health, or mental well being [140]. For CF, serious games often tend to positively affect a patient by improving attitude, physical ability and health. This is described in the proceeding subsection.

5.1.1 Serious Games for CF

To manage their condition CF patients must adhere to a combination of therapies; such as exercise, diet, physiotherapy, and medication. Chest physiotherapy (also known as airway clearence) clears mucus from the patient's airways, which is vital to the managing of CF as it reduces possible infections and damage caused to the

lungs. However, adherence to physiotherapy is often low and for CF adults is often attributed to the difficulty with incorporating the routine into daily lifestyle [141]. Many non-digital games are available to engage and motivate CF children to perform the necessary extensive physiotherapy and airway clearence. Some such games include the blowing of bubbles, blowing cotton balls using a straw, and fogging mirrors [142]. However the entertaining aspects provided by games and their novel approach to engaging CF patients may be further leveraged through the use of digital games.

Of the final 12 papers reviewed in Chapter 2, three papers incorporate knowledge based games into the multimedia intervention for patients [21, 22, 25]. One other paper from the literature review conducted in Chapter 2 also investigated the use of games, but instead presents serious games as a means of improving the transition from pediatric to adult care for those adolescents with chronic diseases, such as CF [29]. Wilson *et al.* reviewed a biofeedback game created for CF pediatrics as an exemplar for game features which can be used to create a game for transitioning in care [29]. The biofeedback game was created by Bingham *et al.* [30] and harnessed a digital spirometer to capture blow data and subsequently control game movement. This digital spirometer acts as an input for the computer-based serious game. The aim of the game based application was to promote awareness of breathing techniques by visualising breath (biofeedback) [30]. The game was also adapted to coordinate with airway clearence objectives to improve self management. The design of this serious game is devised using simple sine-wave mechanisms which requires the user to control and navigate a green circle within the boundaries of an animating sine curve. The game was tested with ten CF patients between seven and 17 years old with a mean age of 12. Participants were given five 15 minute sessions with the game. The results found; 1) that the patients could use the visual representation to adjust breathing requirements to control sprite movements, 2) they did not experience any fatigue or exhaustion, 3) they showed an interest in the using the game, 4) they were engaged and responded to scores, and 5) evaluated their own breathing patterns to onlookers. It was found that the participants demonstrated a significant increase ($P = 0.026$) in game-breathing fidelity and coordination after the five sessions [30].

Following this rudimentary game, Bingham *et al.* further enhanced the game to a more visually rich environment by creating "Ludicross" and "Creep Frontier", two biofeedback games [143], which can be seen in Figure 5.1. Again, the authors

maintain their hypothesis that such serious games can motivate CF children to perform forced expiratory maneuvers. These Flash based games retain the original digital spirometer as means of an input and are again deployed for a Personal Computer (PC) platform. Ludicross is a racing game, and requires two blowing activities. The first consolidates forced exhalation to advance a car around a race track. The second activity uses forced exhalation, this time to wash the car. The second game, Creep Frontier, is an exploratory adventure game where a "Sludge" has taken over the world and requires the player to locate flora and fauna afflicted with sludge. Once located the user must remove the sludge by using forced exhalation [143]. Thirteen CF adolescents were recruited to evaluate the engaging qualities of these games and their effect on pulmonary function. The participants were given electronic spirometry devices and randomised into the game software intervention group and control software care. The control software comprises of standard digital spirometer coach software. The results found that both groups used the control software and game software for similar timeframes. However, there was a tendency for more time to be spent using the games. It was also found that the game group had some minor improvements in Forced Expiratory Volume (FEV1) lung function; however, the authors conclude that a clinical evaluation is required to determine to what effect the game had on this improvement [143].

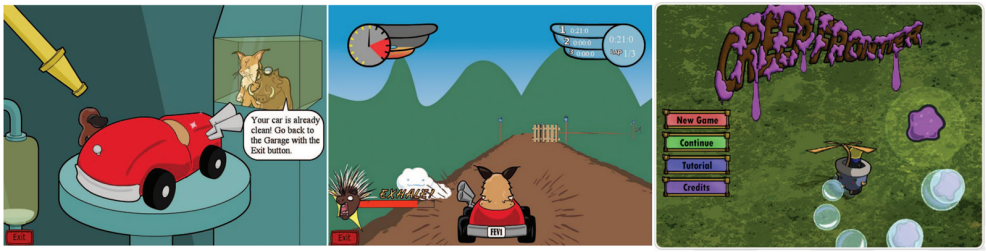


Figure 5.1: Ludicross Racing and Creep Frontier, Image taken from [143].

It is evident from the findings of Bingham *et al.* that the biofeedback game showed potential and improvement for the CF pediatric and adolescent population [30]. Following on from this work, Oikonomou *et al.* explored the use of a serious game to improve compliance to Positive Expiratory Pressure (PEP) for children with CF [144]. Akin to the previous CF biofeedback game, the authors created a custom input for the game by inserting a sensor into a PEP device. Oikonomou *et al.* developed three games to be used in conjunction with the custom PEP input

device, which can be seen in Figure 5.2. The design of these games differ from that of the Bingham *et al.* sine-wave game [30], as the visual content is engaging and appealing by incorporating avatars, colours, cartoon like representations, UI, and game theme.



Figure 5.2: Cave Flight, Flower, and Pirates. Image taken from [144].

The first game involves the navigation of a cartoon dragon through a cave by avoiding obstacles such as stalactites and stalagmites. The second game moves away from this controlled navigation and instead allows the user to blow colourful flower seeds across a garden within predefined boundaries. The last game developed by the authors is a pirate treasure collection game which requires the user to blow the sails of the boat to explore a map to locate the treasure, and to control the cannons when dealing with enemy pirates [144]. The suite of games was subjected to usability testing with one young CF patient and their family over a two week period.

It was found that the custom PEP device performed as expected, however, minor usability concerns were noted with the game design; such as the limited blowing time available in the dragon cave and flower game. It was reported that the game would often end at a point where the user was not ready to stop blowing, which caused frustration. For this reason the family suggest an "Unlimited" game play as opposed to timed. Adding to this, if the user did not continuously blow during the dragon cave session, the game would pause, limiting the playable time the participant had and increased frustration. It was suggested by the participants to remove this pause function and instead focus on blowing to elevate the dragon. It was also noted from the flower game, that the pattern in which the user must replicate with a limited number of blows was impossible for both the CF participant and his/her non-CF family members. Again, it was suggested to remove such restrictions. In contrast, the users did not report frustrating restrictions with the pirates game, but instead requested more features such as avoiding

sharks or chasing other pirate ships and perhaps control over the difficulty of this game [144]. Despite this feedback, the participant played the games an average of eight minutes per session and did not exemplify any resistance to the exercises. It was also noted that the participant did not wish to return back to the standard PEP routine and preferred to continuously use the PEP games. The authors conclude that the game suite in its current state showed promise but requires further modification and improvement before more rigorous and extensive testing [144].

Oikonomou *et al.* continued the research outlined in [144] through an extended study and published their findings two years later [145]. The new approach to CF serious games for children includes the games as discussed previously, which are now modified based on the feedback received in the previous study. Such changes include lengthening the game time and improved game mechanics. The games also included a new mechanism to record game statistics such as IP address (to distinguish between players), age of the player, title of the game, score and number of deaths, session start and end time, time spent in game, time spent in the game software including menus and games, max pressure and average pressure, number of breaths, max breath time, and average breath time [145].

This data was then exported to an online external server for analysis and observation by the authors. Oikonomou *et al.* recruited 14 CF children between the ages of two and 12 to test the system over 14 days. All users were subjected to an usability questionnaire in addition to the aforementioned data being collected. Oikonomou *et al.* found that the transference of PEP physiotherapy to a game format is desirable among CF children and their carers. The authors also suggest that the game can perform similarly to existing airway clearence physiotherapy techniques and can be used as an alternative to allow CF children to engage with their PEP physiotherapy. The authors also suggest that such a tool could be used to record the quantity and quality of airway clearence physiotherapy performed by an individual which is not currently possible by conventional means [145].

5.1.2 Critical Observations From Existing Work

One observation which can be made from the available literature is the small quantity of articles available that research digital serious games for CF. To note, there are other articles that investigate the effects of active console games, such as the Wii, on exercise for CF patients [146, 147]; however, the authors of these console games do not create or develop games specifically for the care of CF. In

addition to the lack of manuscripts and research available, the four papers can be divided amongst two research groups Bingham [30,143] and Oikonomou [144,145]. Furthermore, each group published two papers, the first can be described as initial findings [30, 144] and the second can be described as a continuation or extensive study [143, 145].

Both groups identified breathing exercises and airway clearence physiotherapy as an area in which serious games can be beneficial, such as breathing technique, forced expiratory, and PEP. In all cases, there were reported benefits of using these serious games; most notably, the engagement patients had with the games. Often patients wanted to spend more time playing the games and stated their preference for the games over traditional exercises. The engagement that comes with the games can result in a paradigm allowing for the collection of large quantities of data, which is traditionally captured via patient self reporting methods and may suffer from inaccuracies [145]. As such, Oikonomou *et al.* collected data pertaining to the game software as well as breathing data captured via the digital spirometer [145]. This data was used in the usability assessment of the tool and is anticipated to be used to further evaluate the quality of an individual's breathing technique. However, this system of collecting large quantities of data could be used for other exploratory care scenarios and analysis. Such as monitoring the performance of a player over time to predict possible deteriorations in health and to detect possible exacerbations. Moreover, the data collected by Oikonomou *et al.* in this way does not appear to be available to health care professionals and is instead viewed by the authors. Considering the exploratory nature of this data, health care professionals should become more actively involved in determining what data is recorded and analysed in the event of medical significance. In this way, CF serious games are no longer used for just patient engagement, but they may also be used as an indicator of health status. Health care professionals may also use such a game data collection system to record additional care data for patients inbetween clinic appointments which can complement self reported data. This system can be used for pediatrics, adolescents and adults patients.

Another observation from these serious games is that the games are developed for CF pediatrics only. CF for a time was considered to be a pediatric disease due to the low survival rates. This changed due to advances in research, therapies and care. The median survival age for CF patients rose from 14 years old in 1968 to 20 years old by the mid 1970 [148]. The Cystic Fibrosis Foundation annual

patient registry data report released in 2012 states that the median predicted age for survival will increase from 31 years old in 2002 to 41 years old in 2012 [149]. Furthermore, other research has also predicted that life expectancy for CF patients will increase to over 40 years old [150]. However none of the four reviewed manuscripts target their serious game towards CF adults and instead focus on CF pediatrics and adolescents. This may be attributed to the common idea that digital games are more effective and appealing to children and adolescents as opposed to adults.

Perhaps a limitation of these manuscripts that is preventing the transference of serious games to the adult population is the time required to play the game. Throughout the four papers, it was expected that each CF participant would spend approximately 15 minutes playing each game. For CF adults, this regular time requirement may be restrictive to their schedules. This becomes more encumbered with the added constraint of device and machine requirements. All the serious games reviewed in the previous section deploy their intervention for a PC [30, 143–145]. In one scenario, the game also connects to an external online server for data collection and analysis [145]. This was perhaps the most convenient platform for the development of such a tool at this time as the aforementioned papers were published between 2010 and 2014. Although other platforms were more readily available in 2014, the continuation of previous work limited the authors to utilising the PC platform. For CF children, the PC is an adequate platform for this intervention as there is no strain or pressure for the user to interact with such a game inbetween a busy schedule and they can instead play the game during their leisure time. The same cannot be said for CF adults. For CF adults, a serious game would need to be developed on a platform that would allow the user to play the game inbetween their busy schedules with work, families, college, *etc.* In this case, a PC would not be sufficient; however, a smartphone may pose as a solution to this issue due to its popularity and high adoption rates. In 2012, 39% of the Irish population owned a smartphone, this has since increased to 70% of the Irish population in 2015 [38]. Venturing outside of Ireland, it is predicted that there are 2.32 billion smartphone users worldwide, as of 2017 [151]. Furthermore, technical capabilities of the smartphone can allow for the capturing of biofeedback data without the use of external equipment.

Games for smartphone often use simple game mechanics and are designed for frequent play by using game techniques such as a score to entice the user through

their own competitive nature. In 2017, Google Play released their list of most played games [152]. This list includes, "Candy Crush" [153], "Color Switch" [154] and "Fruit Ninja" [155] all of which encompassing simple game mechanics and player interactions. Color Switch incorporates the concept of simple game mechanics for frequential play by requiring the user to tap the screen to control a small coloured circle through obstacles. It is regarded by the developers as the *"The #1 addictive game of the year!"* and has already received over 150,000,000 downloads worldwide [154]. In a report released in 2017 by the Entertainment Software Association (ESA), it was found that the average age for an individual who plays games amongst the American population is 35 years old [156], which has increased from 31 years old in their 2014 report [40]. Moreover, the report outlines that games for smartphone has reached the interest of a larger population without restriction on demographics or gender [40,156]. As such, it can be postulated that a serious game for smartphone can be of interest and benefit to CF adults. In addition to this, the smartphone platform would allow the user to play this game inbetween their demanding schedule, which can be regarded as more flexible and engaging than standard care.

Considering the above, it can be concluded that the available research in the field of serious games for CF has been led by two research groups, showing the paucity of research into this area. Despite this limitation, the four manuscripts highlight the benefits serious games can have on CF patients and the increase in motivation and engagement these patients have with their breathing and airway clearence exercises. However, the developed games have so far been limited to CF children and adolescents. This is perhaps due to the platform in which the games have been developed. However, it can also be hypothesised that CF adults may too experience benefits of a serious game for airway clearence and breathing exercises if they are created for a more accessible platform, such as the smartphone. These benefits could range from engagement and motivation to play the game and the possibility of increased therapy compliance. Moreover, the serious game would need to be designed in such a way that it does not require specialist equipment and all inputs and interactions should be handled by the smartphone. Additionally, the game model should be designed for frequential play to allow the user to return and play the game intermittently throughout the day for convenience.

Lastly, from the research presented by Oikonomou *et al.* it can be ascertained

that a data tracking system provides key insights into the usage of a serious game and its possible effects on patient health [145]. However, as mentioned previously, the data collected by these authors are limited as it does not analyse the data for possible changes. Likewise, the collected data is not viewable by members of the healthcare team. Therefore, the proposed serious game should also record and send data to a platform that is viewable by healthcare experts for analysis. As the proposed serious game is intended for smartphone and will collect medical data, it is considered as an mHealth app. The following subsections will describe the creation of such a system with reference to the mHealth Design Pipeline in Chapter 3.

5.2 mHealth Design Pipeline

The serious game and web based data analysis tool are discussed in this section with reference to the pipeline in Chapter 3. Similarly the design and implmentation of this system is discussed under Preparation, Back-End, Front-End, and Deployment, in accordance with the mHealth Design Pipeline. Members of the CF multidisciplinary team consulted and validated all aspects of the pipeline during the development and design stages.

5.2.1 Preparation

In this category, the purpose of the mHealth serious game, the app type, and ethics and regulations are outlined. As this proposed system also includes a web tool a new sub section, Data Visualisation and Analysis Tool have been added to outline the purpose of including such a tool.

Purpose

Before embarking on any medical ICT multimedia, key insights from healthcare professionals are required to identify features and data for the proposed biofeedback game system. To this end, members of the CF multidisciplinary team in the Cork University Hospital (see description 4.2.3), two computer science researchers, and a senior lecture from the Computer Science Department in the University College Cork discussed the game development over a series of three formal meetings. In addition, informal meetings with select members of the CF

multidisciplinary team and Computer Science researchers were made continuously throughout the production of the multimedia intervention. During the initial formal meeting, the proposed system and its anticipated functionality was outlined. The CF multidisciplinary team were asked what data and functionality could be of benefit to the CF patient and their interactions with the team. During this meeting, all proposed aspects of the system were noted during an initial brainstorming session before being discussed more in depth. For any feature or functionality to be implemented, it needed to be be agreed upon by consensus. The features and functionality agreed upon are outlined in accordance to each team member below.

CF Consultant Perspective: The CF Consultants noted that by recording patient data to be reviewed by any member of the CF multidisciplinary team, the game must extend its scope to record profile data such as CF number (unique identifier), Name, Age, Weight, Height, Ethnicity. In addition to this, it is agreed that breath biofeedback data on a smartphone is exploratory data and requires the use of additional reputable data to benchmark and correlate the meaning of the captured blow data. As such, it is suggested to include a baseline questionnaire to be completed by the CF participant once a day. It is agreed by all attendees that the questionnaire should be designed as a MCQ to allow for quick entry and submission by the user and also for data coding and analysis by the back end system. The eight multiple choice questions can be seen in Table 5.1.

CF Nurse Perspective: The CF Nurses noted that lung function differs between patients, and differs individually per day. As such a game that does not consider the individual's lung function capabilities could deter or frustrate the user. Therefore, it is agreed to include a game calibration feature to alter the difficulty of the game on a daily basis. Similarly, the nurses note that an analysis system for this exploratory data and baseline questionnaire will again differ for each individual CF patient. Therefore, it is suggested that a mechanism should be included to alter the analysis on a per patient basis by a member of the health care team.

Table 5.1: Multiple choice questions.

Question	Answer Choices
Do you feel that your baseline is:	• The same • Better • Worse
What is your current sputum volume	• The same • Increased • Decreased
When was your last course of antibiotics	• Months (calendar selection) • Years (calendar selection)
Have you done your airway clearance today	• Yes • No
What is your chest physio technique	• PEP • Acapella • Autogenic Drainage
Are you on inhaled therapy	• Yes • No
If so, have you taken it today	• Yes • No
Would you be interested in playing again	• Yes • No

CF Physiotherapist Perspective: The CF Physiotherapist notes that a game could not entirely replicate the complicated airway clearence physiotherapy techniques without additional devices. CF Physiotherapists actively encourage CF pediatrics to engage in breathing exercises; as the patient transitions to adult care the focus moves towards mucus clearing techniques such as PEP, Autogenic Drainage (AD), and Active Cycle of Breathing Technique (ACBT). Although a mucus clearing technique cannot be easily mapped into a game mechanic without the use of an external device, it is suggested that the game should encompass varying blowing durations and strengths.

CF Respiratory Technician Perspective: Similar to the CF Physiotherapist, the CF Respiratory Technician notes that lung function could not be calculated easily

using the smartphone without specialist equipment. However, it is agreed that the *initial blow* data recorded by the serious game app during game calibration could be of some relevance and interest.

Patient Attitudes Towards mHealth Survey: From the patient survey conducted in Chapter 3 Section 3.4, it can first be acknowledged that participants had dispersed opinions regarding playing a game as part of their healthcare. This may be attributed to the vagueness of the question. Games can come in many mediums such as physical, digital, and board, among others. As discussed previously in this chapter, CF patients may have more experience with physical games such as blowing bubbles or cotton buds when in paediatrics and may associate this form of game with the survey question. Furthermore, in a study conducted by Hillard *et al.* it was found that CF patients were hesitant with using games as part of their healthcare as they did not want to have their performance compared against other patients [157]. Patients felt that comparing scores or leadership boards may be too indicative of a players possible deteriorating health [157]. However when examining the statistical data regarding player demographics, and the gamified webtool for adults with RA in the literature review [50], it can be postulated that a digital smartphone game may be of interest to patients. As identified in the literature, this game should not include any leadership boards or score comparisons. Instead, further features and mechanics from the survey must be included. Firstly, this proposed serious game system is intended to target airway clearance physiotherapy, which is the second most highly rated interest area among participants (47.5%). Likewise, receiving notifications and alerts was one of the most favourable feature among patients (85%), therefore any meaningful or intuitive results from the data analysis will be notified to the patient via SMS.

From the insights of the CF multidisciplinary team, and the patient attitudes towards mHealth survey conducted in Chapter 3, it is decided that a smartphone biofeedback game will be developed for the purpose of improving patients engagement with their breathing exercises. The game will also record medical data to be analysed and visualised on a web tool. This is done to investigate whether this data can provide further insights to a patient's condition while outside of a hospital context. As the mHealth serious game presented in this chapter is a

prototype, the app is developed for Android only. This will allow for the app to be easily disseminated among study participants without using an app store.

Application Type

The proposed serious game mHealth app collects medical data, it is therefore considered as an In Vitro app. The data collected is used for the analysis of possible exacerbations which subsequently sends an SMS alert to the patient. In this way, the mHealth app type is similar to a medical Device. However, as the data recorded is exploratory, the mHealth app is not regarded as a Device. The app can also be considered as a Wellbeing/Lifestyle app as it may promote healthy behavioural changes in the user. Changes anticipated by this research include: increased therapy compliance and patient engagement. In addition to these app types, the mHealth app is also a serious game. As such, this section will also further describe the game theme chosen and rationale for this mHealth intervention.

Game Theme: When designing the game and choosing a theme several considerations were taken from the pre-existing serious games research for CF children, as discussed earlier. Namely, ensuring there is no restriction on breathing time, or the requirement for the user to continuously blow to avoid the game pausing. To make the game more desirable and interesting to the users, it was decided to replicate a well known popular game. For this, it was agreed to model the game after "Flappy Bird" which was created by Dong Nguyen and released freely on May 2013 on the iOS App Store and the Google Play Store. The game became popular in 2014 when it was featured as the most downloaded free game on the iOS App Store in January 2014 [158]. However, the game received criticism for its use of plagiarised graphics and was later removed in February 2014 by the creator as he believed that it was addictive and often overused [158]. Since this time, app stores and HTML5 games have seen the emergence of similar games such as "Flippy Bottle"; often featured on the Google Play Store as the most played game [159].

Flappy Bird is a right to left side scroller game that requires the user to tap the screen to control sprite movement through continuously approaching obstacle pairs, this can be seen in Figure 5.3. Each pair of obstacles comprises of a green pipe protruding down from the top of the screen and a second protruding up

from the bottom of the screen at the same x axis or horizontal position, resulting in a narrow clearance for the user to pass through. A similar game mechanic to Dragon Caves [144, 145]. The sprite or bird is applied with a "gravity" attribute resulting in the sprite continuously descending down the screen. When the user taps the screen, the bird jumps upwards, reversing the gravity effect for as long as the user is pressing down on the screen. The gravity attribute is then reinstated once the user releases. The bird will die if it collides with the top or bottom of the screen and with any part of the obstacles. In the case of any collision, the game is then terminated and the user is given a score screen. The score is incremented with each obstacle pair the user can successfully navigate through.

For the purposes of this application, which is intended for CF adults, the touch screen input was replaced with biofeedback data recorded by the user blowing into the microphone. However, this game theme and model are slightly altered to incorporate the features and functionality agreed upon by the CF multidisciplinary team. Firstly, the user must create a profile which includes data such as CF Number, Age, Weight, Height, and Ethnicity. The user creates this profile once only. Thereafter, all data stored through the app will be associated with the user's profile. On opening the app, the user is presented with the game calibration screen. The game will be calibrated once a day only. Similarly, the user will be presented with the eight part baseline questionnaire which will only appear once per day. Game mechanics used in this mHealth app which are new to the Flappy Bird model includes *lives.* By default the user is given three lives which allows the user to collide the bird with an obstacle or screen edge three times without the game terminating. Although the game will not terminate, the score is decremented per life. This is again to encourage the user to play the game often and limit any frustration which could be caused.

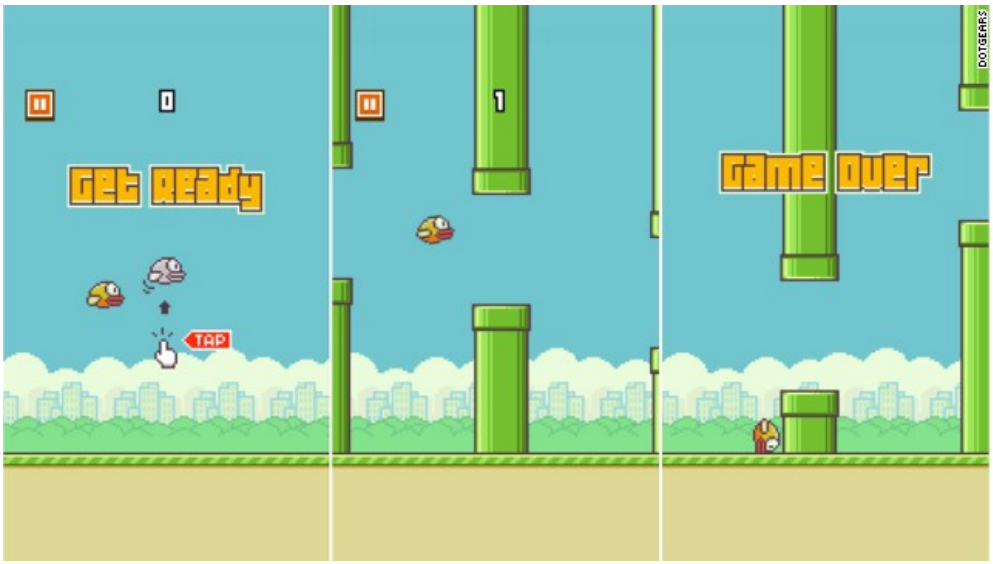


Figure 5.3: Flappy Bird [158].

Data Visualisation and Analysis Tool

A web tool was created in addition to the smartphone app as the data which is stored externally will be viewed by the healthcare team. The web tool also allows the healthcare team to customise the alert criteria for each patient, edit the alert message sent under these categories, view the frequency of each alert category sent to a patient, and also view information collected from the mobile application in a table and graphical representation. In this way, the web tool serves as a visual aid for pattern interpretation [136]. One of the benefits of incorporating the web platform is ease of distribution and access. The accessibility of this platform allows the healthcare team member with the correct login details to access the data from any machine with an internet connection. In this way, the healthcare team members can view the data while traveling abroad or between respiratory wards. Using web technologies also allows the aforementioned data to be sent and stored in a MySQL database. This also allows for web APIs and Javascript libraries to visualise the data graphically and send SMS alerts. The flow of the biofeedback game with web analysis system can be seen in Figure 5.4.

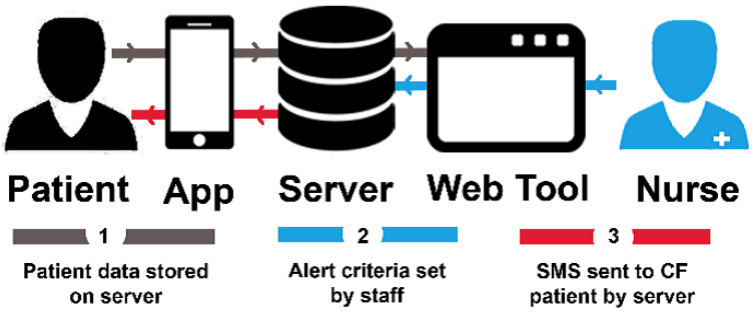


Figure 5.4: The delivery framework of the biofeedback game and web analysis tool [136].

Ethics and Regulations

An mHealth serious game was created so that multimedia interventions could be investigated for CF adults. As such, the app adheres to ethical regulations enforced by the University College Cork.

5.2.2 Back-End

In this section, the validation of content and dialogue is presented along with components which focus specifically on data collection and analysis. To note, as the proposed system records biofeedback data via a smartphone for analysis on a web tool, two new components are introduced to the Back-End category to provide further insight into their technical implementation.

Dialogue and Content Validation

As the app is a serious game among other types, there is little dialogue and content requiring validation. However, the questionnaire and instructions used to guide the user through the calibration screen and game is reviewed by CF nurse and physiotherapists. These CF team members are chosen to validate this dialogue content due to their extensive knowledge and experience with communicating physiotherapy and spirometry techniques to patients. All dialogue and instructions were modified and received validation from this group.

Data Information Requirements

As the mHealth app was made for a pilot study, the data collected and how this data is analysed was communicated to patients via a participant information sheet. The data collected via this system was analysed for possible exacerbations (further discussed in the proceeding section). The data will also be visualised in a graphical and tabular format via a web tool so that the data can be further interpreted by medical professionals. For this pilot study, the CF multidisciplinary team in the Cork University Hospital and select members of the Computer Science Department in the University College Cork are authorised to view this data. As the mHealth serious game is developed to inform the research of this chapter, users cannot opt-out of the data collection aspects of the system at this time. However, the user can request a copy of all data collected via the system. Instructions on how to request this data was made available via the participant information sheet.

Data To Be Recorded

Careful consideration is given to the data recorded through this system which is then agreed upon by consensus by the CF multidisciplinary team. Firstly, data specific to the user for identification and to provide further detail on the game data is required. Game performance data, game calibration data, respective timestamps, questionnaire data, and SMS alert frequency data will also be stored and analysed.

For the alert criteria, it is agreed by the CF consultants that an SMS alert should be sent to the patient in the event of potential exacerbation. As previously outlined, this data will differ on a per patient basis; however, each patient profile should be given default criteria before being revised by the CF healthcare team. In this case it is agreed that the default criterium are threefold: 1) the user reports five consecutive instances of increased sputum, or 2) five instances of worsening baseline through the questionnaire, or 3) if the user performs poorly in the game five times consecutively. Subsequently, the system collects both qualitative and quantitative data which are listed in Table 5.2. The CF profile data will be stored locally on the device as well as on an external server. All remaining data will be stored on an external server for viewing and analysis.

Table 5.2: Data to be Collected.

Category	Data to be collected
CF Profile Date:	• "CF Number" • "Age" • "Weight" • "Height" • "Ethnicity" • "Physiotherapy Technique"
Calibration Data:	• "Timestamp" • "Blow Intensity" • "Average Intensity" • "Variance"
Game Performance Data:	• "Average Intensity" • "Total Time in the App" • "Total Time Spent Blowing" • "Score"
Questionnaire Data:	• "Timestamp" • "Answers For Each of the Eight Questions"
Alerts Criteria:	• "Default Value of Five for Worsening Baseline" • "Default Value of Five for Increased Sputum" • "Default Value of Five for Poor Game Performance"
Alert History:	• "Timestamp" • "Reason for Alert" • "Alert Criteria Value"

Data and Data Analysis: Serious Game Technical Implementation

This section will elaborate on the most pivotal feature of the serious game app: the biofeedback input. The data generated by the user blowing is captured through the smartphone microphone without the need for external equipment. By doing so, this game can be more accommodating to a CF adults busy lifestyle. This input replaces the traditional touch events used for Flappy Bird with blowing into the microphone. Likewise, this input is also utilised for the calibrating of the game difficulty. Oikonomou *et al.* also incorporate a game calibration mechanism; however, this was done by the user manually inputting lung function values [145]. As this serious game instead requires the user to blow directly into the microphone, the game can be calibrated more accurately. A complete prototype of the

serious game can be seen in Figure 5.5.

Biofeedback Input: The Android platform allows for set durations of sound data collected via the device microphone to be stored and analysed. By storing this data, maximum absolute amplitude for that duration can be sampled. Subsequently, characteristics attributed to speech and blowing could be differentiated. When a user blows into the microphone, the captured data has a higher amplitude, with every proceeding amplitude being close to the mean. Based on these observations, a filter is created that takes several (five minimum) max amplitudes to form several sound recordings with the same duration. The filter can then detect a blowing event via the following two conditions [136]:

- *The variance of max amplitudes:* A characteristic identified is that amplitudes are close to the mean while a user is blowing. Therefore, the variance of max amplitudes should be small [136].
- *The total amount of max amplitudes:* Not every sound with a small variance is caused by blowing. To accommodate for these other sounds, the total amount of max amplitudes is considered as another important condition when filtering the sound data. Blowing sounds should contain a higher total amount of max amplitudes [136].

The data recorded is measured by amplitude and variance, which does not currently hold any medical meaning. However, it is postulated that this data (representing loudness) could be translated to represent blow strength or flow, similar to the work of Goel *et al.* [160]. Goel *et al.*, in their research "spiroCall" present a service which allows users to call a computer via a phone and blow into the device microphone in order to calculate FEV1 [160]. To note, the authors report that this calculation can be done using any phone's microphone; i.e smartphone, internet phone, and landline. The research by Goel *et al.* [160] holds significant potential for this biofeedback game as user game interaction may be able to calculate or represent flow, which can then be recorded and visualised on the web tool for medical professionals. Future works for this research would include investigating how the research by Goel *et al.* can be harnessed for this serious game system.

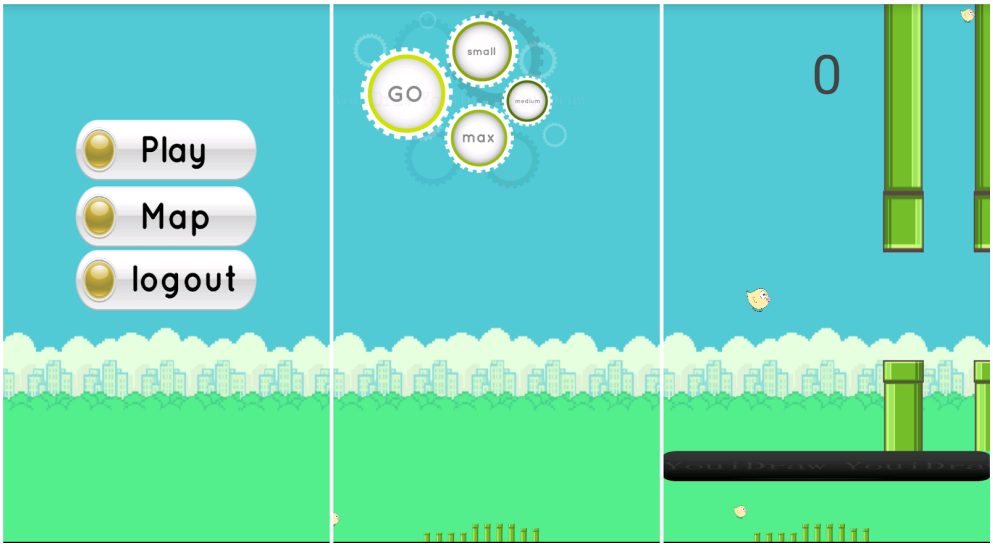


Figure 5.5: Game Main Menu, Custom Map Creator, and Game Screen [136].

Data and Data Analysis: Web Tool Technical Implementation

As the data recorded via the mHealth serious game is sent to an external server for analysis, this section will discuss how the data is managed and analysed. The framework used in the design of this tool is based on that of the big data analytics framework guideline described by Kuo *et. al.* [161]. As such, the web tool will be discussed with reference to data aggregation, data integration, and pattern interpretation, as represented in Figure 5.6. The technologies incorporated into this web tool includes: PHP, MySQL, JavaScript, HTML, CSS, AJAX, Text Magic API, and JSON. The overall web tool is created using PHP with inline HTML to accommodate for the web page structure and layout. CSS style elements from an open source Bootstrap library are then used to apply style to the web tool. Data from the smartphone app is sent as a string to a PHP script which handles the storing of this data in a MySQL database. Similarly, PHP queries this database to retrieve data in a JSON format for visualisation in tables, or in graphs generated by HighCharts.js; a JavaScript library. Due to the quantity of data, tables, and graphs, AJAX is used for asynchronous calls to an external PHP script to retrieve the data and thus reduce the need for page reloading and consequential page load time. The SMS alerts are sent via the Textmagic API. The data collected by the smartphone app is stored in a MySQL database, which is further described in the proceeding section.

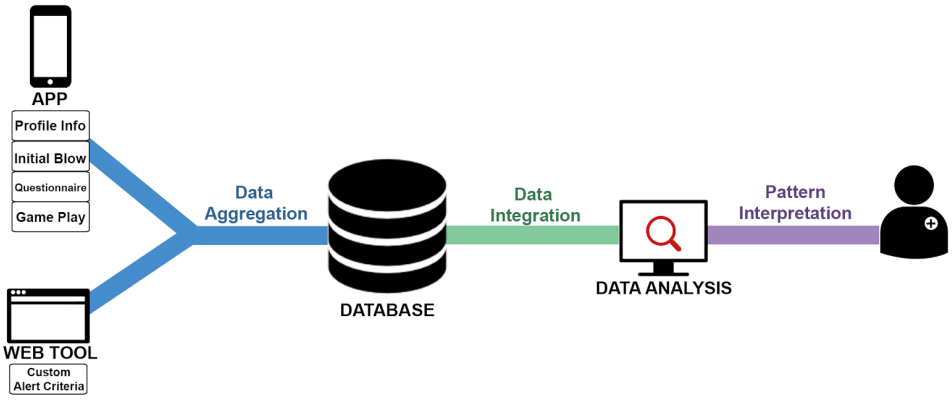


Figure 5.6: Structure of Biofeedback data analysis system.

Data Aggregation: *Data Size:* The data pertaining to each patient is generally stored on an external server, with a subset of data being maintained locally on the device. If the app is used without an internet connection, data that would be stored on the external server is maintained locally until an internet connection becomes available. The size and frequency of each type of data generated by the app and stored in the external server is shown in Table 5.3. The size of the data set gathered per-patient is small. Based on this data observation, if a single patient used the app twice a day, for a year, and received an SMS alert each month, the data generated would equal approximately 0.106MB. As a result of the small data volumes required, a standard database with 10GB of capacity could support approximately 1,850 CF patients using the app twice each day for 50 years, with one SMS alert per month. This data size is reflective of the CF population in Ireland which is approximately 1100-1200. To note, this example is a rough estimation on data volume observation only.

Table 5.3: Breakdown of data size.

Table Name	**Approx Entry Size**	**Number of Entries**
Profile	143 Bytes	Once
Initial Blow	64 Bytes	Once per day
Game Performance	45 Bytes	Every Game Play
Questionnaire Answers	140 Bytes	Once per day
Alert Criteria	45 Bytes	Once
Alert History	64 Bytes	Every sent SMS Alert
Total	501 Bytes	

Data Collection Methods: Data collected from the smartphone app are sent to

be recorded externally in a secured MySQL database. The custom alert criteria and edited alert script created for each patient through the web tool by the health care team are also stored in the database. All collected data, such as game performance and questionnaire results, are stored immediately after completion or submission. In the event the user's smartphone does not have an internet connection, the collected data is stored locally on the device until the device receives an internet signal through WiFi or a phone service provider. Once an internet connection has been made, the data is recorded in the external database.

The process of storing the data locally on the device until an internet connection is made may result in the data being stored with an incorrect timestamp or in the incorrect order, presenting a possible challenge. An example of this incorrect timestamp is the time in which the data is entered into the database as opposed to being generated by the user. As a solution to this, a timestamp is recorded for each data collection event. These data collection events include completing the questionnaire, gameplay, and game calibration. Once the data is received into the external MySQL database, the data collection event time stamp is stored into each database row respectively.

Data Maintenance: Once the smartphone application has received an internet connection, the data is posted via JSON to PHP for collection. PHP then inserts this data into the correct MySQL database table. Each MySQL table contains a column dedicated to the user's CF number. The CF number of each patient acts as a unique identifier and as such, can allow the web tool to later arrange and categorise the data under each patient respectively. As mentioned previously, the data collected from the smartphone app for each patient are minimal. Likewise, due to the small quantity of registered CF adult patients in each hospital, storage space requirements do not produce or cause any challenges or issues. However, the same cannot be said for the patient's smartphone device. Due to the variance of storage space, available space, and phone usage on each smartphone, it is unclear whether long term data collection could cause issues with device performance.

Subsequently, to avoid causing any potential inconvenience to the user, only Profile data is stored locally on the device only. Should the app be uninstalled from the device, this Profile data will also be erased. All other data collected by the system is only stored on the device temporarily, including: Game Performance, Game Calibration, and Questionnaire data. Once the data is handed

over to PHP for storage, the data are removed from the app. The app could potentially record data locally for varying lengths of time while awaiting an internet connection; however, as the data size is minimal, this should not cause any hindrance to the user or their device performance.

Data Integration: The system currently incorporates data via two entries. The first is data collected via the smartphone app. The second entry is sent via a POST method from the web tool to PHP, which again integrates the data in the database. Likewise, the data is then extracted, analysed, and prepared for visualisation by PHP. However, there are three main challenges with this structured data integration as identified by Kuo *et. al.* [162]. These challenges, along with paralleled solutions with regards to the presented system are discussed below.

Functional Integration: This challenge results from the various data types encompassed across different systems and languages. A common example of this is the "date" data type. This challenge manifested in the proposed system as the Android app describes time information as Unix Time; an opposing structure to MySQL, which records the information as a DATETIME. Further complicating this, the app date data is converted to a String type to be handled by the POST method harnessed by the app. Consequently, this string data cannot be integrated correctly into the database or later interpreted or understood for analysis or graphical representation. To overcome this challenge, once PHP has received the POST data, it performs a simple data conversion method so that the String containing the Unix Time data is now converted to a DATETIME and is ready for insertion into the MySQL table.

Similarly, numerical data recorded through the app is sent via a POST, converting the numerical data to a String. However in this instance, the received String data is inserted into the MySQL database as a VARCHAR. By doing this, proprietary app-specific formats (such as DATETIME) are eliminated, avoiding the siloing of data. This VARCHAR data is then extracted and converted by PHP and Javascript for analysis and visualisation.

Metadata Integration: is imposed by conflicting metadata tags that describe the data. For example: "Gender" and "Sex". This can also refer to column naming conventions within a database. An example of this may be the use of 'patient' as

a column name in one database and 'patient_name' in another database. As the data recorded through the proposed system is not currently extrapolating data from other databases this issue has been avoided. Additionally, column names across all tables within this database are kept consistent.

Instance variation: refers to conflicting medical terminology that can be found across multiple health disciplines and systems. For this system, no terminology was incorporated through patient reports. Instead, this system tailors the data in a common language for interpretation by the CF multidisciplinary team.

Data Analysis: As the data that is being recorded is both exploratory and nascent, it is agreed that the analysis performed on the data shall aim to identify possible exacerbations as discussed previously with the CF consultants in Section 5.2.2. In this instance, an exacerbation is defined with respect to the recorded app data as 1) a user reports five consecutive instances of increased sputum or 2) five consecutive reports of worsening baseline through the questionnaire, or 3) if the user performs poorly in the game five times consecutively. Should the recorded data of a user meet these requirements, an SMS alert is sent to the patient advising them to contact their healthcare team if their symptoms do not improve over the next 48 hours. This alert criteria is then modified by members of the CF health care team to provide a more targeted approach to the data analysis. Due to the simple nature of this analysis, PHP can perform this on the web platform without the need for analytics specific software such as Hadoop (an open-source framework used for storage and processing of big datasets).

Pattern Interpretation: The function which analyses the data for the three alert criterium is called each time new data is entered into the database table. If the user meets any of the three criteria, the system then interprets the data resulting in a SMS being sent to the user. Data pertaining to the alert, such as Time, Criteria Category, and Criteria Value, are then recorded into the Alert History Table in the MySQL database.

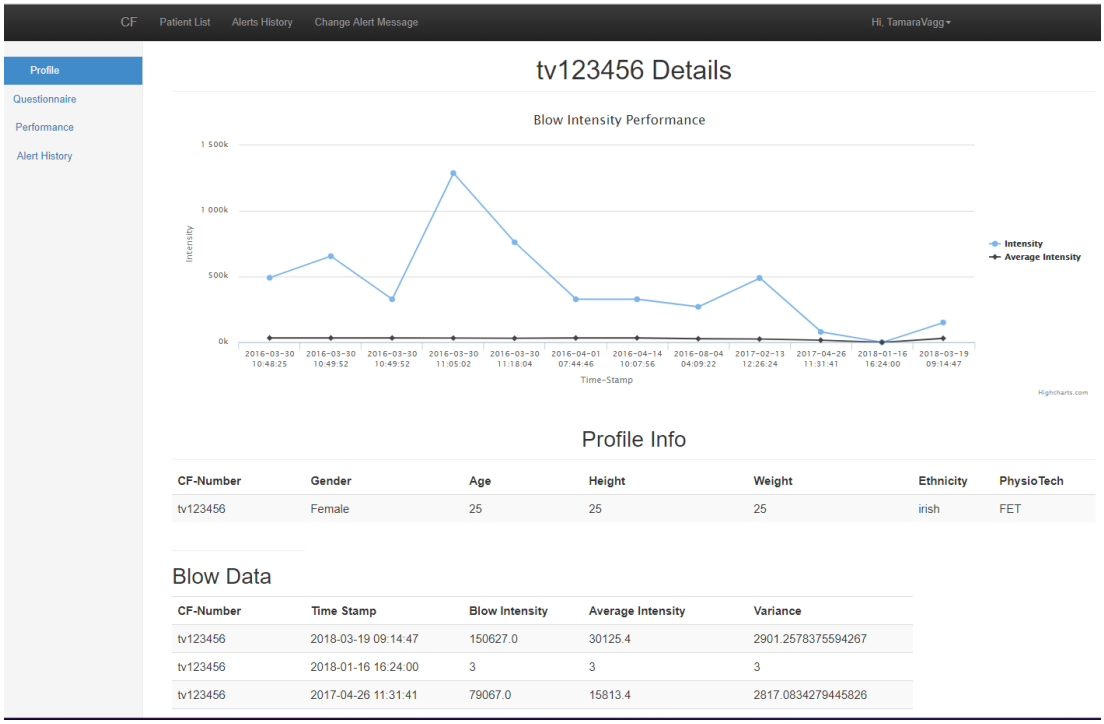


Figure 5.7: A screenshot of the web tool showing patient calibration data. Further screenshots in Appendix E.

The web tool acts as an interface for the CF health care team members to view the recorded data. On opening the tool, the team member is presented with the login screen. Once the CF health care team member logs into the web application, they have the ability to view data, edit alert criteria, view alerts sent for all patients, and alter the SMS alert script. The team member can view data for each registered CF adult patient by selecting their CF number from a list. The corresponding page gives an overview to all the data collected for the specific patient. The data is then filtered by navigating using a menu on the left-hand side, as seen in Figure 5.7. The side menu segregates the data under Profile (which also includes initial blow/calibration data), Questionnaire Data, Game Performance, and Alert History and Criteria. A table including all data available for that patient and a graphical representation created using Highcharts.js can be seen in Figure 5.7. By visualising the data graphically and in a table, the healthcare team member can interpret possible patterns or correlations in the data. An example of this could be the correlation between reported sputum levels and game performance, or self reported airway clearence adherence and game performance. Furthermore, historical data could facilitate

for the identification of other pre-emptive exacerbation criteria. For example, if a user self-reports not adhering to their airway clearence regime for a week and then begins to report an increase in sputum. The completed biofeedback game and data analysis system are represented in Figure 5.8.

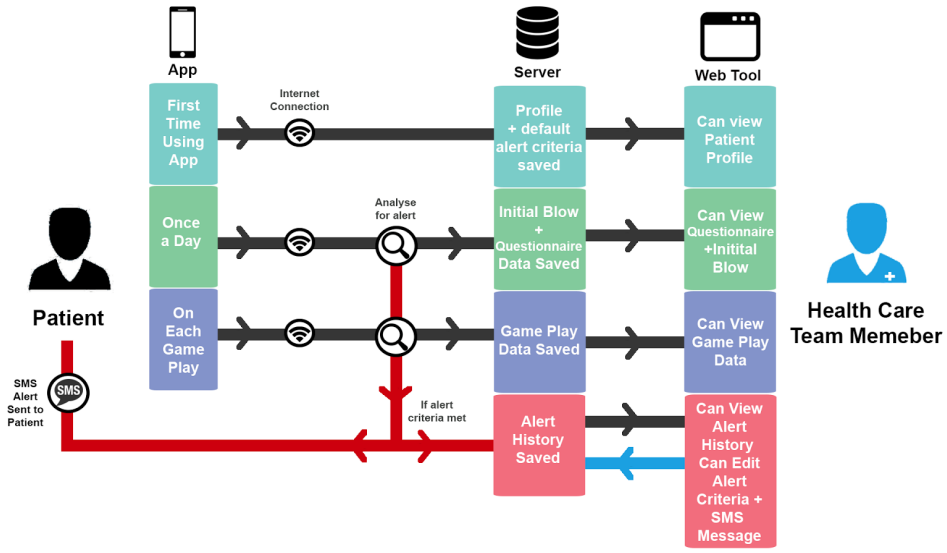


Figure 5.8: The relationship of biofeedback game and data analysis system [137].

Security Operations

The data from this system is recorded locally, and then transmitted to be stored in an external database. The data stored locally on the smartphone is stored in a secure SQLite table. The data is then securely transmitted to a PHP file which inserts the data into a password protected MySQL database. All data recorded and stored in the external database is viewable by the web tool. This web tool is again password protected and logins are provided only to the CF multidisciplinary team and two members of the Computer Science Department.

Testing

Throughout the development process, the mHealth smartphone app is continuously tested with ICT professionals and members of the CF Multidisciplinary team. The app also underwent a stress test which is discussed further in Section 5.2.4.

5.2.3 Front-End

This section will discuss the UI and UX considerations for the design and development of the mHealth app. As the app also includes a serious game, UI features pertaining to the game are also described.

UI

A meeting was held with the CF nurse specialists to discuss the need for an Adaptive UI. In this case as the mHealth app is a game, an Adaptive UI is not required. However, it is suggested by the medical professionals to design the UI elements so that they are reflective of the original game and the overall app design does not appear to be a medical or clinical application.

Subsequently, the app UI design is based on Flappy Bird. When the user opens the app they are prompted to first calibrate the game and complete the questionnaire, after this they are brought to the main menu. This menu includes two options which are "map customisation" and "play game". A random map will be generated should the user not choose to create a custom map; otherwise the user can create a map in any combination of small, medium and large obstacles. Respectively, the size of the obstacles requires the user to control blow strength and duration to successfully navigate through the obstacle clearance. This feature is included so that the user can create maps that they believe match their current capabilities. As the aim of this application is to motivate users to perform breathing exercises and to record the corresponding data, there is no restrictions on the strength at which the user must blow. A new feature added to the Flappy Bird theme of the app is the use of a visual blow strength indicator, which was also incorporated into the serious games as created by Oikonomou *et al.* [144, 145]. Once the user loses all their lives, they are given a score before being returned to the home menu.

UX

Earlier in this chapter, serious games which are currently available for CF children are reviewed. On analysing the found literature further it was found that these games could not be used for CF adults as the games cannot be played seamlessly with their lifestyle. Subsequently, this research has implemented many considerations so that the serious game can be played periodically and more conveniently

by CF adults. The first consideration is the developing of the serious game as an mHealth app. Following this, the game theme is designed for frequential play and is not restricted to a time limit. Furthermore, additional features such as the game calibration and wellbeing questionnaire are presented once a day only. The wellbeing questionnaire is also created as an MCQ so that it may be completed quickly. Lastly, the mHealth serious game is designed to reflect the popular game Flappy Bird without appearing to be medically orientated. This is done so that CF adults can play the game in public.

5.2.4 Deployment

This section reports on the initial stress testing conducted on the mHealth biofeedback game as well as results from the peer and patient review. As the data collected via the system is exploratory in nature, a detailed discussion is also presented in the patient review section.

Initial Stress Testing

The proposed system is initially tested with 10 healthy individuals who develop or who have studied serious games to some degree to evaluate the performance of such a system [136]. All users are given the app to download and are requested to play the game a minimum of once per day over a week. During this testing, any reported issues are communicated via email. These encountered issues are then remedied and an updated app is sent to the participants. The most reported issue was the game and calibration being too difficult; however, this was quickly resolved. All participants reported the app as being usable, easy-to-navigate and easy-to-use. Of the ten participants, eight reported that they would play the game again. However, two participants reported that they would not play the game again as the continuous level may soon become too repetitive and instead suggest implementing game levels or additional game modes [136].

Peer Review

Following this, the serious game app was presented to a CF nurse, CF consultant, CF physiotherapist, and respiratory technician. During this presentation, the members of the CF multidisciplinary team are encouraged to explore and use the app while reporting any feedback they may have out loud to the group for

discussion. The feedback from the group primarily focused on the blow data and CF information in the application. It is agreed that the biofeedback data may provide some insights to a user's condition at a minor level; however, this insight is reliant on the frequency of game play and also the quality of the self reported data through the questionnaire. The team also suggested that future developments could include a feature that would display CF facts throughout the game, the incorporation of a blowing apparatus as an input, and the recording of sudden blows. The reasoning to record sudden blows is to help differentiate between controlled blowing for navigation as opposed to sudden forced blows. This would allow the healthcare team to distinguish if the user is playing the game correctly, or possibly causing discomfort from harsh erratic blowing.

Patient Stress Testing and Review

Following on from the initial testing, the app was subjected to stress testing with three adult CF patients from the Cork University Hospital CF Adult Day Ward. These three patients were selected by the CF nurse specialists during a single day of CF outpatient clinical appointments. The goal of this selection was to achieve a mixed representative group of adult CF patients. Participation in this study was voluntary. If a participant consented to the study, they were provided with an Android smartphone pre-installed with the app and participant information sheet outlining the purpose of the app along with the data collected and all intentions for that data. Contact details, such as an email address, were also given to the participant to allow them to contact the development team with any feedback they may have pertaining to the serious game. To note, for the sake of testing, participants were provided with the same model smartphone (Google Nexus) which was acquired through the University College Cork Computer Science Department. During the time of testing only three models were available. Testing took place over a two month period, after which the users returned the Android devices at their next scheduled clinic appointment.

Participant Data and Analysis: For this stress test two male patients aged 26 and 32 and one female patient aged 22 were recruited. These patients are referred to as patient 1, 2 and 3 respectively. One other female patient was also recruited, but later retracted from the study as she was admitted to hospital. Alert criteria for the three participants was not altered and instead they are

analysed using the default criteria. The following two Tables 5.4 and 5.5 will discuss the data that is collected from these participants and the implications this has on the proposed system.

Table 5.4: Participants' Game Performances over 2 months.

Patient	**Max Score**	**Average Score**	**Max Blow Time**	**Average Blow Time**
1	1	0.26	7.82 s	4.7 s
2	4	2	12.57 s	4.5 s
3	2	0.17	14.04 s	3.62 s

For clarification in Table 5.4, max blow-time refers to the collective time a participant spent blowing into the microphone during each game play and excludes time of rest and inhalation. Additionally, the average blow time and average score is calculated for all database entries for each individual patient. Average blow time and average score refers to each individual's average. In Table 5.5, the values displayed in the second and third column quantify the percentage of "yes" answers submitted through the questionnaire. The fourth column title, "Average Intensity of Initial Blow", refers to the initial blow data used to calibrate the game. Lastly, the sixth column in Table 5.5 displays the average total time spent in the app, this includes the initial opening of the app until the user closes the app.

Table 5.5: Participants' reported compliance.

Patient	Airway Clearance Compliance	Inhaled Therapy Compliance	Average Intensity (initial blow)	Alerts Sent	Average total time spent in the app
1	0%	50%	30778	0	23.1 s
2	100%	100%	30452.6	0	24.1 s
3	82%	82%	30119.4	0	24.05 s

Furthermore, it can be seen that the average time spent blowing into the microphone is approximately less than 5 seconds. However users played the game multiple times during the day with between 2-7 daily game plays. The data collected for Average Blow Time and Average Intensity of Initial Blow for each patient is approximately the same. However, Patient 2 achieved the highest score and average score compared to Patient 1 and 3. This could perhaps be attributed to the questionnaire recorded compliance rates as seen in Table 5.5. Patient 2 reported 100% compliance for both Airway Clearance and Inhaled Therapy. Whereas Patient 3 reported 82% for both Airway Clearance and Inhaled Therapy

(Max score = 2, average score = 0.17). and Patient 1 reported 0% compliance for Airway Clearance and 50% compliance for Inhaled Therapies (Max score = 1, average score = 0.26). Thus demonstrating that therapy compliance can variate game performance at some level. In contrast to this, Patient 1 reported the lowest levels of compliance and received a higher average score to Patient 3 with high compliance. Likewise, Patient 3 recorded the lowest calibration blow data on average. This may be attributed to the patient's current condition or gender, as female CF patients are generally smaller anatomically to male CF patients which can affect lung function ability [163].

Although Patient 2 reported being fully compliant to therapies over the two month stress test period, Patient 2 also reported an increase in sputum and a worsening of baseline sporadically throughout the two months. This increase of sputum or worsening baseline is recorded no more than twice consecutively. During the days of recorded worsening baseline or increased sputum, game performance was directly affected. This is a similar finding for Patient 3, who on days of recorded worsening baseline and increased sputum, game performance and blow time is also affected. This can be seen in Table 5.6 across multiple days. To note, the last table entry with the longest blow time is after a period of the user recording two consecutive days of their baseline being better and the sputum levels either decreased or the same.

Table 5.6: Patient 3 Game Performance and Baseline Data.

Patient	Blow Time	Score	Baseline	Sputum Volume
3	2.57	0	Better	Decreased
3	1.23	0	Worse	Increased
3	5.68	1	The Same	The Same

During the time of recorded increase of sputum or worsening baseline, the maximum score achieved by Patient 2 was zero. Following on from this a conversation is held with Patient 2 to discuss if any alterations were made to therapies or medications. The participant reported that no changes were made to therapies or medications and confirmed that a SMS alert was not necessary. From Table 5.5 it can also be seen that the app in its current state does not intrude on the user's lifestyle as users spent less than 30 seconds on average per use. Furthermore, all participants recorded through the questionnaire that they would play the game again.

Participants also provided informal feedback regarding the performance of the

app. The participants reported that the calibration screen and the game could sometimes be difficult to view the screen and blow on some days when users felt tight-chested. This was rectified by the use of the microphone on the headphones that accompany the smartphone as opposed to the device microphone. The participants also reported that question three in the multiple choice questionnaire should include "unsure" or "can't remember", in the event the patient can't remember their last course of antibiotics. Overall, these patients also recorded that the app was non-intrusive or demanding to their lifestyle [136]. Patients also commented that they liked that the app icon and game style as it does not appear to be for their CF and as such each participant felt comfortable playing in front of friends or in public.

Future Developments

As noted in the previous section, baseline and sputum volume appears to affect game performance. Subsequently, future developments of this application could include the ability to visualise comparative data from the questionnaire and game performance. This may demonstrate a practical correlation between therapy adherence and patient baseline data. The web tool could also be expanded to serve as a communication portal for health care team members to communicate identified patterns to patients in between clinical appointments.

The data currently being collected by the system is specific to the serious game smartphone app. However, it can be scaled further to integrate additional CF patient data such as scans, FEV1, and Forced Vital Capacity (FVC) lung function data, and patient medications. The incorporation of this additional patient data could then be included in the analysis process for data interpretation. Thusly, the tool could include vast amounts of patient data to be analysed against game and questionnaire data in between clinical appointments. The results of which could have the potential of being incorporated into a system for viewing by medical professionals, such as an Electronic Medical Record (EMR), or similar.

5.3 Summary

To date, a serious game has not been developed for CF adults. This forms the premise of this chapter's research objective. This chapter describes a serious game that incorporates a new mechanism by which recorded data is analysed to

determine if a patient is experiencing a possible exacerbation. In the event of an exacerbation the user is then sent an SMS alert. The criteria for this and the overall design of the system was agreed upon by consensus by the CF multidisciplinary team. Thusly, a serious game app for a smartphone that harnesses biofeedback blowing data captured through the device microphone is presented. This game was also coupled with a web-based data analysis framework that provides health care team members the ability to view and interpret the data recorded. The web tool also allowed the team members the option to customise SMS alert criteria for a more individualised intervention.

The game theme chosen for this research was Flappy Bird, which had proven itself to be popular during the initial development stages of this research. Since then, Flappy Bird has been regarded as "The best dead game" as players still wished to play the game even though it is no longer supported on newer operating systems [164]. However, it is acknowledged that the game itself is repetitive, which can present challenges in the medical and health industry. Specifically to this research, patients are given various airway clearance techniques which can be repetitive and disengaging. Likewise, although games are an engaging medium which can encourage users to perform this exercise, it too can become repetitive. To combat this, serious games for health will need to offer a progressive game, or offer multiple games so that playing the game does not become monotonous and is still perceived as exciting. For this research, future works would include developing multiple games, similar to the games found for CF paediatrics, or developing a game where the user can feel a sense of progression, such as advancing through levels.

The benefits of serious games have often been debated by academics as some feel what serious games can offer to medicine and health is unclear. Similar to these debates, this research does not produce conclusive evidence of the effects of a serious game on a user's health. However it demonstrates a new application for serious games in the collection of medical data outside of the hospital. This research suggests that although it is unclear what effect the serious game had on the patients health, it is an engaging medium and can allow medicine to appear less medical. Another finding that this research contributes to serious games in medicine is the idea of "inclusiveness" and in contrast "individualisation". It was found throughout this research that patients often want to feel and be seen as "normal" as such the serious game should allow the user to feel normal

and comfortable playing in public settings. It is also important to note that a health condition affects individuals differently with ranging severities and as such game mechanics must adapt (calibrate) to suit the users capabilities and thus complement the engaging medium. These two concepts and considerations can have application for serious games in other chronic conditions.

The aim of this presented system is to motivate CF adults to perform breathing exercises and analyse the recorded data for possible exacerbations. From the testing, the system was found to be usable and appealing. The exploratory data recorded shows promise; however, it relies significantly on the user's commitment to playing the game as well as the accuracy of self-reported data. Due to this, further pattern interpretation is required with a much larger cohort. However, all participants agreed that they found the game engaging and reported that they would play the game again. An observation noted from this research is the use of a serious game in a mHealth application. This medium proved to be not only the most accessible platform but also minimally intrusive to a CF adult's lifestyle. It is also postulated that visualising recorded data to the patient may have some implication for the user's therapy compliance. These observations are taken into considerations for future patient education and engagement research in the proceeding chapter.

Chapter 6

Patient Education; e-Learning and CF Management

The previous chapter presents a serious game app that is deployed onto a smartphone for Adult CF patients. It can be seen from the presented results that a smartphone application proved itself to be an accessible and feasible platform for the delivery of a multimedia intervention. Mobile applications, which are developed for medical and health purposes, can be regarded as MHealth apps. Thus, the serious game presented previously can be considered as an mHealth application in addition to a serious game. Another conclusion reached in the previous chapter suggests that the serious game mHealth app can be expanded to further visualise game performance data and self reported compliance data, which is anticipated to serve as a practical example of physiotherapy adherence. This will simultaneously allow the user to become more aware of their health related data and to become a more active participant in their care. This chapter builds upon these results to research and develop patient education tools for CF adults. It begins by investigating the use of an e-learning based platform for a bedside tablet and personal computer before exploring the use of mHealth apps for patient education. The significant contribution of this chapter is a "CF Patient Passport" which allows CF adults to record their basic medical information so that they can receive care when travelling abroad and simultaneously become active participants in their care. The manuscripts published to support this research Chapter include "A mhealth patient passport for adult cystic fibrosis patients" [165] and "Patient E-Learning Tools for Adults with Cystic Fibrosis" [166].

6.1 Patient Education

Patient education is considered to be an integral part of care and can often improve quality of life [167]. Adult cystic fibrosis patients are often considered to be a well educated cohort; however, previous studies have identified knowledge gaps with this population [168,169]. Life expectancy of this cohort is predicted to rise, with some patients expected to live to retirement age. As such, further disease complications and medical procedures may arise [44, 150]. With these medical obstacles, CF patients will be given new information and educated respectively. From a study conducted by Kessels *et al.*, it was found that between 40% to 80% of the medical information provided to patients by practitioners was forgotten immediately [39]. Subsequently, there is need for education strategies and interventions which can be of benefit to the care of these patients and overcome education barriers. It is also imperative that such interventions will not impede on their daily lifestyles, as described in the previous chapter.

6.1.1 Patient Education Systems and Dissemination Strategy

From the literature review conducted in Chapter 2, eight manuscripts were found that focused on some educational aspects of CF [22–25, 27, 28, 31]. Interestingly, six manuscripts deploy their educational intervention as a website [23–25, 27, 28, 31]. By doing so, these interventions can be considered as e-learning or eLearning (electronic learning) tools. E-learning is described as instruction which is typically conducted via the internet or other electronic media or device to support learning [170]. All six e-learning sites found in the literature review are accessed by patients via their personal computers and laptops; however, other dissemination scenarios and settings may improve patient engagement with these web tools: such as, the deployment of these e-learning tools to tablet computers (tablets) for hospitalised patients. An example of this can be seen in the study conducted by Greysen *et al.,* who developed an interactive video on hospital safety which was made available over the internet and on tablet computers situated in the hospital [171]. The study found that 90% of participants were satisfied with using the tablets to engage with patient education materials [171].

Interventions from two of the eight manuscripts found in the literature review target adult CF patients [25, 28], whereas the remaining five focus on CF

pediatrics, adolescents and their families [23–25, 27, 31]. This finding is similar to that of the previous chapter regarding the availability of serious games for CF adults. For this reason and others (such as life expectancy, new complications and medication adherence) this chapter will investigate an e-learning intervention for CF adults. During the design stages of this research, a patient engagement initiative took place in the Cork University Hospital. As part of this initiative, bedside tablets were installed into a new CF ward in the hospital and maintained by Lincor Solutions [172]. As such, web based patient e-learning tools were developed so that they can be accessed by the patient in the hospital via the bedside tablets, or at home via other devices. As these e-learning tools will be accessible to patients in both settings, it is agreed to track website usage and button interactions. This is done with the intention of evaluating whether a bedside tablet is a feasible medium for the intervention and if the patients access the web tools from outside of a hospital setting. The tracking of button interactions will also provide insights into what multimedia content is preferred by CF adults; for example 2D animation, video, text, or images.

6.2 Web Tools

To determine what subjects the e-learning tools should target, a meeting with the CF multidisciplinary team in the Cork University Hospital was held (see description 4.2.3). During this meeting the team discussed common conditions or procedures that a CF adult may encounter. From these identified topics, the procedures or conditions that are currently without validated online resources for the Cork University Hospital were chosen. It was then agreed to create three educational web tools which focuses on Portacaths, Gastrostomy Tubes, and Bronchoscopies.

The tools are created in a Frequently Asked Questions (FAQ) format; *i.e* a series of commonly asked questions that are of interest to CF patients and the corresponding answer. These questions have been identified from the years of experience of the CF multidisciplinary team. An example of these questions include “What is a Portacath?”, “Why do I need one?” and “What will it look like?”. These questions can also be seen on the buttons in Figure 6.2, 6.3, and 6.4.

6.2.1 Web Tool Content

All the textual information was written and validated by respiratory consultants and members of the CF multidisciplinary team. Careful consideration was taken to the wording and language of this textual information so that it is understandable to patients with varying literacy levels. Similarly, the multimedia content such as 2D illustrations and animations were then created and validated by the team to complement the textual information. All the e-learning tools include 2D images, photos, text, 2D animations, and videos.

6.2.2 Web Tool Methodologies

Due to the limited hardware capabilities of these bedside tablets, the decision was made to alter and manipulate the content shown by using Asynchronous JavaScript And XML (AJAX). This will both lower the number of requests made while viewing the web page and also any possible latency in displaying content. The final applications utilised HTML and CSS to form the structure, design and layout of the web tools.

Patient Log

When the user first requests the web page via the bedside tablets, a JavaScript function checks to see if a numerical value which serves as a device ID for the web tool is stored in the browser's local storage. If this data is not found, it is then considered that this is the first instance of the browser accessing the patient education tools. Subsequently, JavaScript calls a PHP function that generates a unique ID which is then passed back to JavaScript and inserted into the browser's local storage. The advantage of using the browser's local storage in this way means that cookies are not required. This approach was chosen as the browsers on the bedside tablets do not support the storage of cookies. After this information is stored the PHP function then generates a EXtensible Markup Language (XML) file that is named with the timestamp (date and time) of creation and user ID. The syntax of this file name is as follows: log_yyyymmdd-time_ID.xml. The ID, time of creation, browser, and IP address are then stored in the file. IP addresses are unique numerical identifiers given to a device on a network. By recording the IP it is possible to ascertain which devices have been used multiple times. This is done so that each interaction with the patient education tools can be stored

respective to each bedside computer.

HTML buttons were created based on the content developed by the CF multidisciplinary team to adhere to the FAQ format as previously described. On each buttons "onclick" event, an AJAX request is sent to locate and insert HTML content stored in a text file to the e-learning tool. This AJAX call simultaneously sends information pertaining to the button name, time, and date of the "onclick" event to PHP, so that it can be stored into the aforementioned log file. This relationship and process is visualised in Figure 6.1. Lastly, once the user navigates away from the e-learning tool or closes the web browser, a final interaction event called "navigated away" and corresponding timestamp are then stored into the XML file.

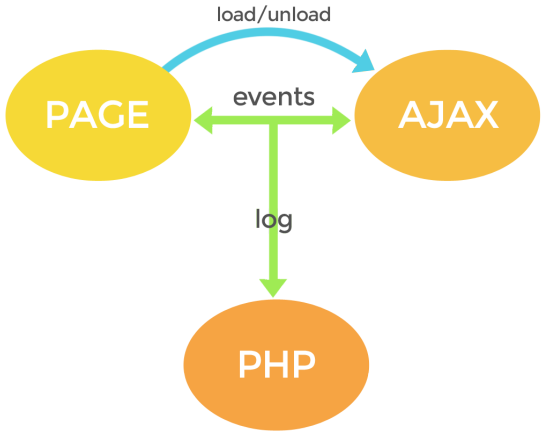


Figure 6.1: The relationship between AJAX, PHP, and the creation of the XML log files.

6.2.3 XML Log File Results

The e-learning applications are stored on an external server so that they can be accessed by patients at home, and also via a menu button which is made available on the Lincor bedside tablets in the Cork University Hospital. Interactions with the web tool are recorded in XML files over 12 months. From the XML files collected for the three web applications, it can be seen that the "Portacath" app is the most visited of the three applications, followed by "Bronchoscopy" and "Gastrostomy" respectively. These three web applications and their corresponding interactions will now be discussed separately in the proceeding paragraphs.

Before discussing this data however, it is worth noting one limitation of this

form of data recording. The manner in which the device IDs are recorded means that they are associated to a device such as the bedside tablet. In this way the unique IDs do not account for new patients who may be staying in the specific room in the ward and using a tablet that already has an assigned ID. Instead the recording system interprets this data as a revisit from the same device ID. As the XML files also record IP address, it was found that the local storage on the browser of the bedside tablets are being cleared intermittently which has aided in identifying new patient visits; however, this does not account for all new patients. Subsequently the data recorded and discussed below is analysed as visits only and does not investigate or interpret the number of patients and their revisits.

Portacath XML Data



Figure 6.2: Screenshots of the Portacath e-learning tools.

The Portacath tool was visited 72 times in total over twelve months by 36 unique device IDs. Of these 36 IDs, 22 were generated via the bedside tablets and the remaining 14 were generated by other devices. These devices can include personal computers, laptops, tablets, and smartphones. Ten of the 36 device IDs interacted with the website by viewing and navigating through content via button clicks. The remaining 26 IDs visited the e-learning tool, but did not click any buttons to view content. Of the ten interactive device recordings, three IDs were generated via bedside tablets and the remaining seven were generated by other devices. Each device ID, number of visits, average time spent during interactive visits, the longest interactive visit, most frequently viewed content, and longest

viewed content is displayed in Tables 6.1 - 6.6. To note, although a unique ID may have visited the e-learning tool a number of times, only a portion of these visits may have involved the user interacting and navigating through the content; therefore, for the purposes of the Tables below, IV will refer to an "Interactive Visit". Additionally, the unique IDs generated for the devices are not noted in the Tables 6.1 - 6.6; instead, they are assigned iterative numbers to simplify their visualisation in the aforementioned tables. In the event that the users did not view any specific content more frequently or for long periods of time, Not Applicable (NA) is used.

Table 6.1: Interactive visits for the Portacath tool generated by bedside tablets (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	2	1	16m 59s	16m 59s	Xray image and text of procedure	Photos of the port and text on how long the port must remain in situ
2	1	1	1m 39s	1m 39s	n/a	Textual information on port complications
3	1	1	1m 30s	1m 30s	Textual information on port complications	Textual information on port complications

Table 6.2: Interactive visits for the Portacath tool generated by other devices (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	15	3	53.34s	1m 40s	2D images and text on how a port can limit activities	Textual information on port complications
2	5	1	1m 42s	1m 42s	2D images and text on how a port can limit activities	Photos, 2D images and text explaining what a port is
3	1	1	1m 56s	1m 56s	Xray image and text of procedure	Photos, 2D images and text explaining what a port is
4	2	2	1m 55s	3m 14s	n/a	Photos of the port and text on how long the port must remain in situ
5	8	6	2m 11.16s	22m 33s	2D images, photos and text explaining what the port will look like	Photos of the port and text on how long the port must remain in situ
6	3	2	10m 32.5s	20m 19s	Photos of the port and text on how long the port must remain in situ	Xray image and text of procedure
7	2	1	24s	24s	n/a	Photos and text explaining why someone would need a port

From the data presented in Tables 6.1 and 6.2, it can be seen that the Portacath e-learning tool is accessed more frequently from other devices than from the bedside tablets. It can also be seen that both groups (bedside tablets and other devices) tended to use the Portacath e-learning tool for less than two minutes. However, one instance was noted for both groups where the device spent greater than ten minutes viewing the content. Among the interactive visits recorded with the bedside tablets, it can be seen that content surrounding potential complications was of the greatest interest to the users. However, the unique IDs generated from other devices focused on more general information, such as what a Portacath is, how long will the user need one, and will it limit their activities. The multimedia which was most frequently visited included 2D images, photos, and text.

Bronchoscopy XML Data

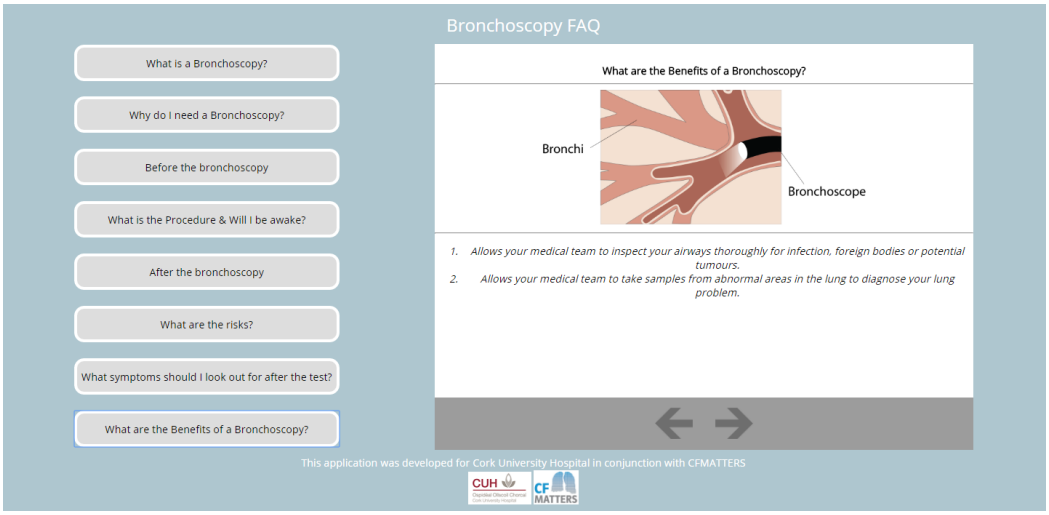


Figure 6.3: Screenshots of the Bronchoscopy e-learning tools.

The Bronchoscopy e-learning application generated log files for 21 unique device IDs which visited the application 31 times over 12 months. From these 21 unique IDs, ten were created for the bedside tablets, while 11 were generated by other devices. On inspecting this further, nine of these user IDs interacted with the web tool, whereas the remaining 12 visited the site but left shortly after without interacting with the web page. Of the nine device IDs, two were generated by bedside tablets and the remaining seven were generated by other devices.

Table 6.3: Interactive visits for the Bronchoscopy tool generated by bedside tablets (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	2	1	1m 56s	1m 56s	2D images and text describing the procedure	2D images and text describing the procedure
2	2	1	53s	53s	2D images and text describing the risks involved in a bronchoscopy	2D image and text describing what a bronchoscopy is

On examining the data pertaining to the other devices, one device was used to view one page of the web tool for over seven hours before leaving the website. Due to the excessive amount of time compared to the average time spent by other

IDs, this interaction is considered as accidental and an outlier, and is therefore omitted from Table 6.4.

Table 6.4: Interactive visits for the Bronchoscopy tool generated by other devices (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	1	1	15m 28s	15m 28s	2D images and text describing the procedure	2D images and text describing the procedure
2	2	2	43s	1m 2s	2D image and text describing why you would need a bronchoscopy	2D image and text describing why you would need a bronchoscopy
3	4	3	13m 59s	31m 34s	2D image and text describing what a bronchoscopy is	2D image and text describing why you would need a bronchoscopy
4	2	1	11s	11s	n/a	2D image and text describing why you would need a bronchoscopy
5	3	2	8m 1s	15m 43s	2D images and text describing the procedure	2D images and text describing the risks involved in a bronchoscopy
6	4	4	53s	1m 33s	2D images and text describing the risks involved in a bronchoscopy	2D images and text describing the risks involved in a bronchoscopy

Similar to the previous e-learning tool, it can be seen that this tool was also accessed more frequently from other devices. It can also be seen that the web tools were accessed for shorter periods of time via the bedside tablets (less than two minutes) compared to other devices which shows more instances of longer viewing times (over eight minutes). The content that was visited most and for the longest periods of time via the bedside tablets was information regarding the procedure, risks, and what a bronchoscopy is. This was almost directly mirrored in the other device group; however, there is also cases of users viewing information on why they would need a bronchoscopy. The multimedia content most frequently viewed on this web tool includes 2D images and text.

Gastrostomy XML Data

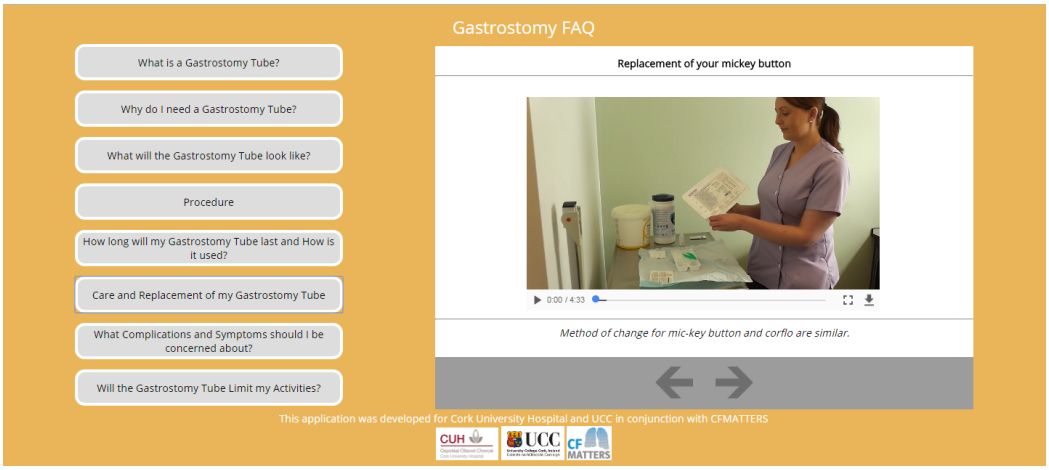


Figure 6.4: Screenshots of the Gastrostomy e-learning tools.

Similar to the Bronchoscopy tool, the Gastrostomy tool was visited a total of 34 times by 21 unique device IDs. These 21 device IDs were generated by seven bedside tablets and 14 other devices. From the 21 device IDs, seven interacted with the web page via button clicks, whereas the remaining 14 IDs only viewed the main landing page. Of these seven device IDs, three IDs were generated by bedside tablets and the remaining four were generated by other devices.

Table 6.5: Interactive visits for the Gastrostomy tool generated by bedside tablets (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	1	1	2m 29s	2m 29s	n/a	2D images and text describing complications and symptoms to monitor for
2	1	1	19s	19s	Video to show how to care, clean and replace gastro tube	Video to show how to care, clean and replace gastro tube
3	1	1	55s	55s	2D images, photos, text of what the gastro tube will look like + 2D image and text on how long the gastro tube must remain in situ	Video to show how to care, clean and replace gastro tube

Table 6.6: Interactive visits for the Gastrostomy tool generated by other tablets (IV = interactive visit).

Unique ID	No. of Visits	No of IV	Avg time spent IV	Longest IV	Most Frequently viewed content	Content viewed longest
1	9	5	2m 18.3s	9m 30s	2D images, photos, text of what the gastro tube will look like	2D images, photos, text of what the gastro tube will look like
2	2	2	3m 20s	4m 22s	2D image and text on how long the gastro tube must remain in situ + Video to show how to care, clean and replace gastro tube	2D images and text on what is a gastro tube
3	2	1	2m 2s	2m 2s	2D image and text describing the procedure	2D images and text on what is a gastro tube
4	1	1	24s	24s	n/a	2D images, photos, text of what the gastro tube will look like
5	3	3	1m 1.6s	2m 23s	2D image and text on how long the gastro tube must remain in situ	Video to show how to care, clean and replace gastro tube

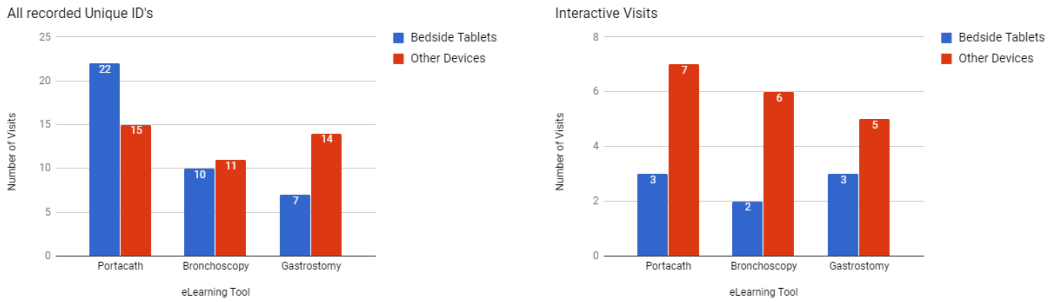
Similar to the previous e-learning tools, this web tool was viewed more frequently by other devices. Both the bedside tablets and the other devices recorded short viewing durations of less than four minutes. For the bedside tablets, the most frequently viewed content and longest viewed content included the care of a gastrostomy tube, what it will look like, complications, and how long the patient may need it. This is a very similar finding to the other devices, however there was also a tendency to view content explaining what a gastrostomy tube is and the procedure for installing it. The most visited multimedia content included 2D images, photos, text and videos.

6.2.4 XML Data Discussion

Overall, the number of interactive visits was low. This may be attributed to a number of factors. The first is that hospital bedside tablets were a new communication portal for both patients and medical professionals and as such medical professionals may not have harnessed their full capabilities by directing patients to its content in all cases. Similarly for patients, they may be unsure and lack

confidence with using the device. From a human perspective, it may be a case that patients who are currently admitted to the ward with the bedside tablets may not have energy or motivation to interact with the tool. However, from a multimedia perspective, the tools currently do not contain any audio which may have been more desirable to those admitted patients.

It can be seen from the data recorded for the Portacath e-learning tool that the majority of unique IDs were generated by bedside tablets. However, on further investigation, it can be seen that other devices accounted for a higher proportion of interactive visits across all three e-learning tools. This can be seen in Figure 6.5. It can be surmised from this that users who visited the e-learning tools via the bedside tablets had a higher tendency to leave the e-learning tool without interacting with the content via button clicks.



(a) All recorded visits.

(b) All interactive visits.

Figure 6.5: Graphs showing the number of visits and interactive visits for each tool on bedside tablets and other devices.

The average time spent viewing and interacting with content during interactive visits was short (less than three mins). For these short visits, the user tended to view specific pieces of content as opposed to browsing through all the content. This sort of browsing behavior is more commonly seen for those users who spent more time interacting with the web tool. In the Portacath and Bronchoscopy web tools there was a tendency for users to view information surrounding the procedure and its risks. Other information, such as "what it will look like" and "what is it", were viewed more often by those using other devices. This may indicate the type of content CF patients have a greater interest in while in a hospital setting compared to a non-hospital setting. However, for the Gastrostomy e-learning application, both bedside tablets and other devices tended to view care information, what it will look like, and how long they will need the Gastrostomy

Tube.

2D images, photos, and text were the most frequently viewed and revisited multimedia in the Portacath and Bronchoscopy tools. The 2D animations and videos for these web tools tended to be viewed only once. This contrasts with the Gastrostomy e-learning tool, as users tended to view the care videos more frequently, both on the bedside tablets and other devices. Overall, it can be considered that 2D images, photos, and text may perhaps be the preferred multimedia for patients, due to its speed of delivery and not requiring extended periods of time watching animations and videos. However, of the three web tools, the Gastrostomy tube was the only tool that required the user to care for the device at home which may attribute to the increased viewing of video material.

Overall, from the minimal interactions recorded for this intervention, the usage pattern may indicate that a bedside tablet is a feasible medium for patient education interventions. However, it is suggested that this content also be made available for users to access at home as there appears to be a change in motivation between a hospital and non hospital context. In addition to this, it would appear that 2D images, photos, and text are more desirable to patients when viewing general information on a topic; however, there is also a preference towards animated or video content for patients who may need to perform some actions outside of the hospital as part of their ongoing care. Extended analysis with a larger quantity of data generated from interactive visits is required before establishing any concrete conclusions.

6.3 Other Patient Education Considerations

The data collected in the previous section shows that the patient education web tools are used infrequently. It can also be seen that users visit these tools for short periods of time on average. These results can be attributed to a number of parameters. One such factor is the probability of one adult CF patient (from the registered 178 CF adults at the Cork University Hospital), being admitted and consequently requiring a Bronchoscopy, a Gastrostomy tube, or a Portacath for the first time. Although these web tools were used during the allotted time and showed promise, one limitation of this intervention was the low number of interactive visits. Simultaneously, although the besides tablets were used, other devices accounted for a higher proportion of interactive visits. From these

observations it can speculated that the platform and limited interactivity of these web tools may account for the low use rates, among others.

As such, it can be considered that a patient education intervention which provides more opportunities for users to interact with information that is of interest to them (or is more personalised to them) could prove more advantageous. Personalising educational content in this way is synonymous with patient management mechanisms and interventions, as the multimedia is educating the patient on their medical condition data or personal symptoms. Examples of patient management interventions include: audio tapes, booklets, patient credit card/patient passports, counselling, exercise sessions, individual plan/goal setting, manuals, videos, and lectures/talks [173].

Similarly, other platforms could potentially improve dissemination and patient engagement. On revisiting the six web based patient education tools from Chapter 2, three manuscripts incorporate a complimentary smartphone application in addition to the web tool [24,25,31]. Of note was the intervention as presented by Stark *et al.* [31]. The authors of this manuscript provided a smartphone application that allowed mothers of CF patients to record calorie intake [31]. As the app allowed the study participants to view, monitor, and record calorie intake, there was a significant increase in BMI [31]. Interestingly, as the participants became more active in the monitoring and recording of their data, there was a significant improvement in their health status. Due to this, and the potential advantages of smartphone applications as discussed in the previous chapter, a smartphone patient education intervention may demonstrate higher adoption rates and greater general use cases that could be considered more beneficial to the patient.

The patient mHealth survey in Chapter 3 suggests that CF patients are interested in an mHealth app that can aid in many aspects of their condition, such as medication, physiotherapy, and monitoring. This is further echoed when the patients provided their own opinions on the types of mHealth apps that would be of interest to them. Patients who expressed interest in recording their CF medical data suggested recording genotype, current medications and history of medications, current and historical lung function, and current and historical weight. By recording this information, the patient becomes a more active participant in their own healthcare, and are also equipped with the necessary medical data to receive care outside of their regular clinic. This also serves to improve the patient's experience and engagement with their healthcare. In the provision of such medical

data reporting and patient self-management, the concept of a patient passport has seen use among patient cohorts with long-term conditions. Patient passports, their definition, and their potential application and use for adult CF patients and healthcare professionals are discussed in the proceeding section.

6.4 Patient Passport

A patient passport is described by the National Quality Forum (NQF) and Health Service Executive (HSE) as a paper based system which provides immediate and important information regarding a patient's health or condition to medical professionals [174, 175]. This passport system is implemented for a number of reasons, such as improved patient experience, improving the speed that care is delivered, and as a solution for those patients with learning disabilities [174,175].

One such passport was developed by Newell *et al.* [176] for asthma management. This passport was paper based and could be folded so that it fit into a wallet. The agenda of this passport was to store the information needed for an asthmatic to receive care on arrival to an emergency unit. By storing the information in a passport it lessens the onus on the patient to repeat this information to various medical professionals and allows the care professionals more time with the patient rather than sourcing the information [176]. Similarly, a medication aid passport was developed by Barber *et al.* which allowed patients to record details of their medicines [177]. This study found that the passport had a positive effect on patients and that it can aid in the dialogue related to treatment and medications between patients and healthcare team members [177].

Patient passports have also been created for other long-term conditions, such as diabetes. Similar to other chronic conditions, diabetic patients must meet with various members of the multidisciplinary healthcare team. For diabetic patients, passports can be beneficial as they allow the patient to record medical data received from each member of the diabetes multidisciplinary team [178]. In this way, passports bridge a communication gap between patients and these various multidisciplinary members [178]. When researching "CF Patient Passports", only two bodies of work were found. The first was a book titled "The Cystic Fibrosis Passport" by Dominic A. Fitzgerald, which aims to aid family members in understanding the needs of children with cystic fibrosis, and to serve as a

practical guide to those who care for these children [179]. The second was a quality improvement initiative taken by the Stanford CF Center, which presented a paper-based system that used a passport-sized document containing instructions on how to care for a patient with CF [180]. The document could be presented by a CF patient to a hospital or clinic to ensure the correct measures are taken to avoid potential issues with infection and cross-contamination. Although both passports are important for the care of CF, and follow the definition of patient passports, they do not follow features common to long term condition passports as they do not facilitate self-reported medical data that is accessible to patients at all times.

In addition to paper-based CF passports, a search was performed for digital CF patient passports on both the Google Play and iOS mobile App Stores. From this search, only one app was found that allows CF patients to record their medical data, similar to a passport; "CF View" [181]. This app was also identified by patients in the mHealth survey conducted in Chapter 3. CFView is an app which was created by "CF Ireland", a CF charity in the Republic of Ireland. The app allows patients to view medical data that has been collected regarding their condition; however, it does not allow patients to enter or save data. In addition to this, CF patients can only use this app if they are part of a CF registry in Ireland, Denmark or Slovenia, and have been issued with an account by that registry. From the findings of the paper based and digital based search, it would appear that there is no freely or publicly available CF patient passport system that allows patients to record basic medical data. Considering the benefits of a patient passport, it can be stipulated that such a tool would be beneficial to adult CF patients. Before considering a CF patient passport, literature pertaining to existing passports for other conditions was first investigated. This investigation will discuss issues found with the previous passports and how these issues may be resolved.

6.4.1 Potential Pitfalls

Paper based patient passports have been developed for diabetics, asthmatics, and the older adult, with each study reporting a positive response from the patient. In a study conducted by Dijkstra *et al.* it was found from interviewing patients that, while these various patient passports have shown beneficial results, there continue to be issues which may result in the poor adoption of the passport or negative

effects for the patient [182]. Such issues include: 1) security, if the passport was to become lost or stolen there is potential for identity theft, 2) forgetting to bring the passport to appointments with various members of the health care team, 3) size and space, some patient passports can be the size of a small booklet and due to this can be unwieldy for patients to carry on their person, and 4) patients felt they had no time to enter information into their passport and did not want to waste valuable consultation time [182]. Dijkstra *et al.* [182] also found that while interviewing members of the diabetes healthcare team, there were issues that affected using a patient passport as a patient intervention. One such issue was the lack of clearly defined agendas for these passports. Without clearly stating this agenda it is unclear as to how the passport should be implemented into the patient's care and at which point of care it should be introduced [182]. Other shortcomings found in this study included: 1) if the passport is of any use to the health care team, 2) clearly stating who is responsible for filling out the passport, and 3) a sufficient introduction to the passport by the health care team so that the patient knows how to use the passport [182].

6.4.2 Solutions and App Implementation

The issues with patient passports, as listed in the previous section, pertain to diabetes passports only; however, these problems are transferable. As such, the above has been considered in the design of the adult cystic fibrosis passport. By deploying the CF passport as a mobile app, the passport can be password protected and all data encrypted to avoid security issues in the event the phone is lost or stolen. An image of the login screen can be seen in Figure 6.6 A. Physical size and space will no longer be an issue as no additional space will be used to carry the app. Subsequently, space in memory is now raised as a new consideration. However, the data recorded through this app will store basic information only, resulting in a minimal amount of memory being used on the smartphone device. Lastly, the issue of forgetting the passport is also reduced due to the popularity of smartphones, as mentioned in the previous chapter.

The remaining issues, as highlighted by members of the diabetes healthcare team, were discussed with cystic fibrosis nurse specialists at the Cork University Hospital, and the corresponding solutions were agreed upon by consensus. The app is intended to be introduced when CF pediatric patients transfer to the adult ward; however, it can also be implemented for existing adult CF patients. For

those patients who are interested in the app, they will be given a short workshop by the CF nurses. The workshop will detail the purpose of the app, what can be recorded, why this will be of benefit, where to record the data, and how this app can be implemented into their care. During this workshop, the nurses will also assist the patient in inserting data that needs only to be recorded once. It will be communicated to the patient that it is the responsibility of the patient to enter and record data, and that all data recorded is voluntary and will not be viewed by any other persons. A standard adult CF clinic appointment in Ireland can take up to 1 hour and 15 minutes. In this time, the patient will meet with the CF nurse, the physiotherapist, the dietician, and a CF registrar or consultant. The patient will be encouraged to fill in data with the CF nurses and time will be designated for this. However, if they would prefer not to enter data with the nurses, there is approximately 15 minutes of non-contact time in between meeting the multidisciplinary team members where the patient can record this information.

Considering the benefits of a patient passport and the patient insight provided by the survey in Chapter 4, it can be stipulated that such a tool would be beneficial to adult CF patients. Hence, this research will develop and evaluate a patient passport targeted at adults with cystic fibrosis. However, unlike the aforementioned passports, the proposed passport will be developed as a mobile application (app). The agenda for this app is to provide CF adults with their basic medical information and also to allow them to record their medications, along with medical data from clinical appointments. In doing this, adult CF patients may become more aware of their condition and symptoms. Additionally, three scenarios have been identified in which the proposed app may be of use to a CF adult. Firstly, it can allow a patient to receive immediate care when traveling abroad. Secondly, it will allow patients to receive care if travelling between adult CF centres. Lastly, it can be used to communicate between health care team members. These scenarios and the design of the passport app with reference to the mHealth pipeline in Chapter 3 will be discussed further in the following section.

6.5 mHealth Design Pipeline

As the CF passport was created for a smartphone and collects medical data, it is considered to be a mHealth application. Hence, this section will discuss the design and development of the app under the headings Preparation, Back-End, Front-End, and Deployment, in accordance to the mHealth Design Pipeline. To note, a series of informal scoping meetings was held with the CF nurse specialists from the Cork adult CF unit (>10). Post initial development a further formal meeting with the entire CF multidisciplinary team (see description 4.2.3) was held to sign off on the CF passport app.

6.5.1 Preparation

Before developing or designing the CF Patient Passport, the app's purpose, app type, ethics, and regulations had to be defined. These considerations are discussed and outlined in the proceeding sub-sections.

Purpose

This section will discuss the components necessary to create a written report before developing the app. Firstly, providing a tool for adult CF patients to record their basic medical information may prove beneficial; however, it is pertinent to highlight scenarios that may require the use of the passport, so that such a tool can be incorporated into the current care system. The scenarios in which this passport is considered to be of use are agreed upon by consensus with the CF Multidisciplinary team in Cork and outlined in the following paragraphs.

Travel between centres: There are currently five adult CF centres in Ireland. As such patients may transfer between hospitals to receive care, depending on medical/personal reasons. CF patient files are stored as hard copies only and it is not always possible to gain access to this file. As such scenarios where patients will move from one hospital to another or are transferred, involve a patient arriving to a unit with limited information. This is usually resolved by frequent phone calls or requests for missing medical data. However, with this proposed app, a patient can arrive with their basic care information such as genotype, medications, recent history of lung function results, allergies, and other medical conditions.

Travel outside of the country: Similarly, if a patient is to travel abroad and is then in need of care, the patient will have access to their most basic medical information necessary to receive care. The app also records contact details of their health care team members for further information.

Bridging Gaps for the health care team: It is essential that all antibiotics that are prescribed to a patient are recorded. Generally, it can be two months between standard clinical visits, and during this time it is possible for a patient to begin a new antibiotic as prescribed by a General Practitioner (GP). During the next clinical visit, CF nurses will ask patients if they have been on any new medications, this information can be stored in their patient file. The details of the new antibiotics can be either forgotten, or only partially remembered. Through the use of this app a patient can record any interaction with any member of their health care team as well as new prescriptions or changes to care to provide a broader view of their care.

It is anticipated that the app will be first offered to CF adolescents transferring to adult care. However, it can also be suggested to any CF adult. The app will be made available on both iOS app store and Google Play store, in addition to being made available on the Cork Hospital CF Centre web page. Patients will be given time during clinical appointments to enter the data with the CF nurse specialists, or they can enter the data during non-contact time.

All data collected through the app will be stored locally on the device. It shall not be transmitted or viewed by any other personnel. The data recorded will not be analysed; however, some data shall be visualised in two interactive graphs. The first graph will display *Weight* over time, and the second will display lung function as *FVC %* and *FEV1 %*. An example of this graph can be seen in Figure 6.6 E. The user can tap on the graph for more details on the data points, or hide/reveal values on the x and y axis. Lastly, the app also provides access to the default device calendar. By doing this the user can save reminders for clinical and other related medical appointments. The app will be developed so that it can be deployed onto both Android and iOS. Simultaneously, it is anticipated that the app will be submitted to both app stores and other medical app websites.

Application Type

The proposed CF Patient Passport can be considered as both an In Vitro app and a Wellbeing/Lifestyle app. The passport is intended to record a patient's basic medical information and simultaneously plot data on a graph; as such, it is considered an In Vitro app. It is not considered a Medical Device, as this data is not being used to perform a diagnostic or any immediate decision making for the patient. However, it can also be considered as a Wellbeing/Lifestyle app as it may improve health behaviours among this cohort as they become more aware of their own medical data/symptoms.

Ethics and Regulations

As the passport is currently being developed as part of a pilot study, the mHealth app will adhere to ethics and regulations as set by ethical committees in the University College Cork and Cork University Hospital. Following the results of this pilot study the app is anticipated to adhere to national and EU regulations.

6.5.2 Back-End

The app is developed using Cordova Phonegap [183] which utilises web technologies such as HTML, JavaScript and CSS. The web technologies are compiled by PhoneGap so that the app can be deployed to both Android and iOS. The app also utilises the Framework 7 [184] framework for app navigation, style, and layouts. The language and dialogue used in the app is simple, so that it can be understood by non-medical persons. All graphs are developed using the Highcharts.js framework [185]. This section will discuss the validation of content and dialogue within the application before discussing the data that can be recorded via the passport app.

Content and Dialogue Validation

As CF is a genetic disease, patients have grown up listening to and using medical terminology to aid in the management of their condition. Therefore, the medical data that can be recorded in the app is familiar to this cohort; however, the manner in which the data is requested may be new to these patients, and subsequently may require validation. A meeting was held with CF nurse specialists to discuss the instructions on how to enter data in the app. The CF Nurse specialists were

enlisted for this task due to their extensible knowledge in communicating with this cohort. There is no imagery used within the app, however, there are two proposed graphs. The graphs and app instruction were modified until validation from the nurse specialists was given.

Data Information Requirements

As the data are not being transferred and viewed by other personnel, an opt-out service and DPA policy was not required in the app. As the CF Patient Passport was developed as part of a pilot study, information pertaining to all intentions of what data was to be collected and how it was then stored was provided to patients in a participant information sheet. It was anticipated that once the app was made available via app stores and over the web, these intentions would also need to be listed.

Data and Data Analysis

A meeting was held with members of the CF multidisciplinary team to discuss which data are of importance to a patient in the scenarios outlined previously. It is agreed that this mHealth passport should follow the same structure as that of a patient file; see Appendix F. Patient files include data that are recorded only once, such as profile information, and other data that are recorded rarely and can be edited and amended, such as medical conditions and procedures. In addition, data will be recorded at each clinic appointment such as weight, height, FEV1, and FVC. To note, although the app follows the same structure as a patient file, it only stores the basic information required for treatment.

The passport app is then divided into three sections to reflect the structure above. These sections are named "My CF Information", "My Medical History", and "My Clinic Appointments", this can be seen in Figure 6.6 B. The data stored in these sections are discussed below:

My CF Information: Data in this section are recorded once and can be amended by the user if required. Information that can be recorded include: date of birth, date of diagnosis, sweat test, genotype, blood group, allergies, medications, medical team contact numbers, and physiotherapy techniques. This can be seen in Figure 6.6 C.

My Medical History: The data in this section will be filled out once initially and amended over time. This section is broken down into two sub sections. The first is "My Medical Procedures" which records data such as the insertion and removal of a Portacath. The second section, "My Medical Conditions" records other diseases and conditions which CF patients can develop such as Diabetes and Renal Disease.

My Clinic Appointments: This section is intended to record data for each meeting with a member of the health care team, which can occur every two to four months. The types of data that can be recorded here include Date, BMI, Weight, Health, Blood Pressure (BP), FVC Liters, FVC %, FEV1 Liters, FEV1 %, Bugs in Mucus, Treatment, and Comments. This section can also be used for annual assessments, phone calls to the health care team and GP visits. This can be seen in Figure 6.6 D.

Security Operations

As the data is being stored on the smartphone, security precautions are put in place for local storage. First, the mHealth app is password protected (as seen in Figure 6.6 A). In the event of a forgotten password, a randomly generated password is created within the app and emailed to the user. All data stored in the CF Patient Passport is optional. Any data that is recorded is encrypted using the Advanced Encryption Standard (AES) algorithm and stored in a local SQLite database. If the app is uninstalled from the device, the databases will also be deleted.

Testing

During the development stages, continuous testing took place to ensure the security of the data. Further stress testing was also conducted with a small number of ICT specialists, this is discussed under Deployment, in section 6.5.4.

6.5.3 Front-End

In keeping with the mHealth pipeline discussed in Chapter 3, the UI and UX of the app is discussed. The current prototype of the CF Patient Passport can be seen in Figure 6.6.

UI

A meeting was held with CF nurse specialists and physiotherapists to discuss the plausibility of an Adaptive UI. From this meeting it was determined that a UI model was not required. It was considered that perhaps an Adaptive Navigation model may be beneficial for the use cases as described in 6.5.1 under Preparation; however this was later dismissed as data recorded and shown in the app is at the patient's discretion.

Informal discussions between the CF nurse specialists and the CF adults attending clinic found that this cohort would prefer the UI to be designed so that it does not appear to be a mHealth app. As such, the icon that was to appear on the main screen of the user's smartphone does not contain any indications that the app is for CF; hence this icon is named "My Passport". Furthermore, the style and UI elements in the app were designed so that they do not appear to be "medical" or "clinical". Similarly all menus and buttons were created to reflect the data collected as outlined in Section 6.5.2.

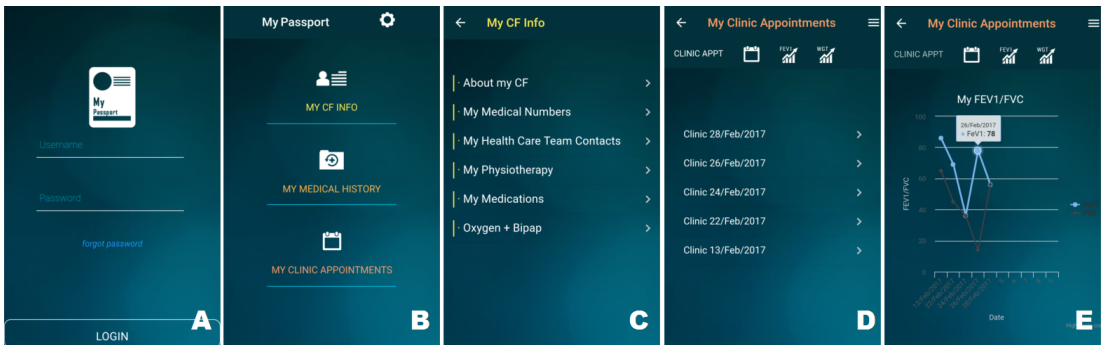


Figure 6.6: Images showing: A) Login Screen. B) Main Menu. C) My CF Info Screen. D) My Clinic Appointments Screen. E) and Graphs.

UX

On reviewing diabetic patient passports, a number of issues which could prevent the use of such of an intervention was found. Of interest to the UX aspects of this mHealth app is outlining how the app should be implemented into the current care system. A solution for this is discussed in Section 6.4.2. It is agreed by CF nurse specialists that the app will be offered to CF adolescents transferring to CF adult care and CF adults already registered in the hospital. If the patients are interested in using the app a workshop will be given by nurses on how to use the app and the data that can be recorded. The nurses will then assist the patient

in entering any historical and profile data. Time is then allocated during clinical visits for patients to enter this data with a CF nurse or during non-contact time.

6.5.4 Deployment

In this section, further testing and reviews conducted on the app are discussed. Following on from the results of the reviews and testing, future plans for the deployment of this mHealth app are outlined.

Stress Test

The purpose of this test was to evaluate the performance of this app and its design. Seven participants without CF were enlisted who all owned Android devices. The decision to recruit non-CF participants was intended to identify performance and design issues and to remedy them before clinical testing. The participants included three females and four males. The youngest participant was 19 years old and the oldest was 51. This age range is similar to that of the CF adults that the app is intended for. The participants varied in technical background *e.g.* some participants were actively working in the ICT industry and were familiar with stress testing devices, while others would be considered novices.

The participants were given the app for three months and asked to add, edit, and delete information to the "My CF Information" and "My Medical History" once a month. Similarly, they were asked to do the same for "My Clinic Appointments" once a week. At the end of every month the participants were asked to report on any performance or usability issues they encountered using the app via email. The participants from technical backgrounds were familiar with stress testing and were asked to focus on performance issues. The other users who would be considered novice were asked to focus on usability issues and features of the app that were easy or difficult.

Overall, the app was received positively by the participants. No user reported difficulty using the app or of any serious issues in the apps performance. From the study some minor cosmetic issues were identified with varying phone screen sizes and resolutions. For example the button outline would remain stationary on larger screens when the keyboard was visible, as opposed to moving with the button element. All users reported confusion with the format for the date entry

in each section. Another common issue reported by the users is that the "Go" button on the keyboard did not navigate the user through a form as expected. The solutions to these issues were implemented into the app in preparation for pilot testing with CF adult patients.

Peer Review

The CF Patient Passport was then presented to CF nurse specialists, CF physiotherapists and respiratory consultants for review. During this review, the app purpose, aesthetics, dialogue, content, and functionality was reviewed. Slight modifications are recommended by the reviewers to improve the quality of data entered and prevent errors. Examples of this feedback included the incorporation of a drop-down menu which contains all possible bugs that can be growing in mucus as opposed to the patient manually entering this data. Similarly, in places where patients must enter a date range (*e.g.* start date and end date) it should be possible for the user to enter just a month and year as opposed to date, month, and year. Overall it is agreed that the CF patient passport can be of benefit to CF adult patients as it will allow for this cohort to always have access to their basic medical data and become more aware of their own condition and symptoms.

Patient Review

Following on from the stress test and peer review, ethical approval was granted by the Clinical Research Ethics Committee in the University College Cork for pilot testing with CF adults from the Cork University Hospital. The inclusion criteria for this study was that patients must be 18 years old or older and own an Android smartphone. Participation in this study was voluntary, and was offered to patients during clinical appointments over two consecutive days. Five eligible patients were identified and recruited by the CF nurse specialists. All five patients agreed to partake in the study; one participant was female and the remaining four were male. Each participant was provided with an information sheet outlining the purpose of the app, the data collected, intentions for the data, and security measures. After the app was installed on their devices, the participants partook in a short workshop with the CF nurse specialists, who demonstrated how to use the app. The CF nurse specialists also assisted the participants in entering any of their historical or patient file data into the passport app. The patients were then asked to test the app over three months before

completing a feedback questionnaire, which was provided to them at their next closest clinical appointment (see Appendix G).

Results: During the three month study period, one male participant lost his smartphone and as such was unable to complete the feedback questionnaire. Of the remaining four participants, three reported their smartphone models: a Oneplus 5, Sony Xperia M5, and Samsung Galaxy. All four participants agreed that they were provided with sufficient information to use the app. The participants were then asked to rate the appearance of the app from 1-5 (1 being Dont Like It, 3 being Neutral, and 5 being Like It), with two participants rating the app a 3 and the remaining participants rating the appearence a 4.

During the study period all participants reported inserting data into the app. Two participants confirmed they used the app to share their medical information. When asked to explain this further, one participant reported using the app in a clinical appointment. When asked to rate the difficulty of the app from 1-5 (1 being Difficult, 3 being Moderate, and 5 being Easy), one participant rated the app a 5, two participants rated the app a 4, and the remaining participant rated the app a 3. When asked which parts of the app was difficult, the participant who rated the app a 3 reported difficulty in inputting "some information". One other participant also advised that the built in back button on their device caused the app to close instead of returning to the previous page and was therefore reliant on the built-in navigation bar. When asked which features the participant would like to remove from the app, three participants reported none. When asked what features the participant would like to add to the app, one participant advised they would like for their doctor to be able to access the data or input new data remotely.

The participants were next asked to rate the helpfulness of the app from 1-5 (1 being Not Helpful, 3 Indifferent, and 5 being Helpful). One participant reported a 5 for this question, two reported a 4, and one participant reported a 3. When asked to explain their answer, the participant who reported a 3 did not elaborate further. However, two other participants remarked that the app is helpful as it allows them access to their medical information:

"It's useful to have this information in an easily accessible place"
"It's handy for me to have my information so readily accessible"

This is further enforced in Question 10, where all participants agreed that it was beneficial to have access to their basic medical information through the app. When asked who the participants believe is responsible for inputting data into the app, three participants reported that the responsibility is theirs, while one participant believed it was the shared responsibility of the participant and their CF treatment team. The users were then asked to explain their answer. It was found from these answers that users believe it is their responsibility as entering data should be at their discretion. However, one participant welcomes guidance from their healthcare team.

"I put what I think is necessary"
"Personal info on a personal device should only be entered by the owner unless explicit permission is given. I think I am ultimately responsible for knowing about my condition and recording the information but I might not always know the most important information to be recorded which is why my nurses and doctors should also have input. "
"It's my app and on my phone, so it's my own responsibility to keep it updated"

One participant reported a barrier which prevented the editing of data. This participant found that some saved data in the My CF Info section of the app could not be edited, and instead needed to be deleted and inputted again, which they regarded as frustrating. The participants were then asked to rate the regularity of using the app from 1-5 (1 being Not Regularly, 3 being Sometimes, and 5 being Regularly). Two participants rated this question a 1, one participant reported a 3, and the remaining participant reported a 4. When asked to list scenarios in which they felt the app maybe useful, the participants reported the following scenarios:

"If I got sick on holidays could show what I'm on"
"Listing medication/medical details at clinics etc"
"Sharing information with my GP or if I'm traveling and need to share information with a doctor. Going abroad or another hospital/GP"

It can be seen from the above scenarios that participants felt that the app may

be of most benefit when travelling abroad or sharing information with medical and healthcare professionals. Lastly, the participants were asked to rate how adequate the security precautions within the app are from 1-5 (1 being not adequate and 5 being adequate), to which two participants rated a 5, and the remaining two rated a 4.

Initial Observations: It is acknowledged that some limitations of this study are the small number of participants and the disproportionate ratio of male to female participants, which could present a potential gender bias. There was a notable difference in the participants reported regularity of the apps use. Patients were asked about how often they would use the app. At face value, not regularly could be perceived as concerning; however, CF patients attend CF clinic appointments quarterly, and entering data is at the patient's discretion. In addition to this, minor issues in device functionality were reported by this cohort which will be addressed and resolved in future iterations of the app.

Interestingly, unlike the findings of the paper-based patient passport, participants of this study identified themselves as the sole or major inputter of data. This is perhaps a clear advantage to paper-based passports, which reported uncertainties in this responsibility, as discussed previously. This may be attributed to the passport being based on a patient's personal device, as opposed being provided to them in a hospital branded booklet.

Moreover, the app in its current form was received positively by the participants of this study. All participants agreed that having access to their basic medical information is of benefit to them. Furthermore, these patients envision practical scenarios in which this app may be of benefit to them in the future.

Future Works

Future developments for this app includes the implementation of feedback suggested by the CF patients. The app will also undergo a certification process before being made available on app stores and websites for free. Information pertaining to data intentions and storage will also be made available.

6.6 Summary

This chapter aimed to investigate the use of e-learning and mHealth apps as a patient education intervention for CF adults. From the literature review conducted in Chapter 2, it was found that web based interventions are effective and accessible to CF pediatrics and their families; however, as yet such interventions have not been developed for CF adults. As such, this chapter developed three web based education tools which can be accessed by patients via bedside tablets and personal computers outside of the hospital. These web tools tracked simple website interactions via button clicks; the results of which demonstrate that patients access these web tools more frequently from outside the hospital for short periods of time. Generally, patients had a preference for 2D multimedia and text content. Overall, adoption rates for this intervention were low and this may be attributed to a number of factors. The first is that the bedside tablets are nascent and perhaps was not advertised frequently to patients by medical staff. One finding is that there was a higher number of visits to the e-learning tools where the user did not interact with the content. It is unclear what may have caused this; it may be simply down to human nature where patients were asked to view the content by the medical staff but chose not too as they felt unwell. It is important to note that bedside tablets are provided to those admitted patients, and current health condition contributes largely to how the multimedia content should be communicated via the elearning tools. For this reason, it is advised that audio be used more frequently in patient education content via bedside tablets. Although the tools contained animations and videos, there was no audio to support this and instead the users must read text from this screen. This reading of text may have been too demanding on the user in their current condition, where as listening to audio may have been more passive. Likewise the use of audio can be of benefit to those with learning or sight difficulties. It is suggested that future patient elearning applications for bedside tablets harness audio for more effective results.

This research revisited interventions which may be more accessible to CF adults. It was found from research conducted in Chapter 5, and the literature from Chapter 2, that mHealth apps may provide a suitable solution. The results of the patient survey conducted in Chapter 3 found that this cohort showed interest in the recording and viewing of their medical data in a convenient and manageable way. To this end, it was found that the concept of a patient passport could prove to be a suitable solution. Patient passports have been proven to help patients with

self management as it facilitates the ability to closely monitor their own condition. Hence a passport application was developed so that CF adults could record their medications and basic CF information. It is also anticipated that this will allow these patients to receive care when travelling between centres and abroad. A pilot study with four participants demonstrates that CF adults perceive this passport app to be beneficial as it allows them access to their basic medical information. It was also found that through the pilot study, that participants would not use this mHealth app frequently. This is perhaps a similar finding to paper-based passports as patients only enter the data into the app during clinical appointments (quarterly) and share data is specific scenarios such as with a GP, or travelling abroad. As the app is password protected, the user must be able to enter in their correct credentials and navigate through the app to share data. However, in certain situations such as needing to attend the accident and emergency room, this may cause further frustration to the patient. Whereas a paper-based passport can be handed to medical professional who can locate all data needed in order to provide care. This perhaps one advantage of the paper-based system over the digital mHealth app. To contend with this, future iterations of the app may include a Generate PDF button on the main menu which will compile all the most pertinent medical data into an A4 PDF which can be shown to medical professionals via the device, or emailed to them directly. This suggestion can also be applied to mHealth patient passports for other conditions.

Chapter 7

Conclusion

"A wise man will make more opportunities than he finds"
– Sir Francis Bacon

This chapter will begin by outlining the aims and objectives of this research before describing the findings of the literature review. The chapter will describe how the findings of the literature review informed the multimedia interventions developed in each of the previous chapters. The contributions and limitations of this research will then be outlined before providing suggestions for future works and developments.

7.1 Research Objective

Cystic fibrosis is the most common life limiting genetic disease which affects Caucasians; however, as CF is an orphan lung disease, more common respiratory diseases take precedence for multimedia interventions. Ireland has the highest occurrence of this disease in the world and the highest prevelence of the most severe CF gene mutation. Life expectancy for these patients is predicted to rise and as such it is postulated that multimedia may aid these adults in the management of their disease. Moreover, multimedia may prove beneficial in CF education for medical professionals. This research aims 1) To develop an interactive 3D educational tool for medical professionals that can also be used on multiple platforms such as the web, standalone applications, and Virtual Reality headsets, 2) To propose a conceptual pipeline which consolidates regulations as

well as researcher considerations for the development of mHealth applications, 3) To develop a serious game for mobile using the mHealth pipeline with web based data analysis system; to engage CF patients with their physiotherapy and record medical data, and 4) To develop a multimedia intervention for CF patients' education and management of their condition. To identify which specific areas could benefit cystic fibrosis a scoping literature review was conducted in Chapter 2.

7.2 Literature Observations

The search conducted in Chapter 2 yielded 12 results, two of which focus on educating medical professionals, one which focuses on those who do not have CF, while the remaining manuscripts focus on CF patients. Three distinct observations emerged from this review.

The first observation was that there is a paucity in educational multimedia for medical professionals. Of the two manuscripts identified in the scoping search, only one focused on CF. The second manuscript used CF as an exemplar or case study for a much larger educational program of children with long term conditions. In both cases there was a lack of visual multimedia for education and interactive multimedia for practical learning.

The second observation was that games are commonly used as part of the found manuscripts' multimedia interventions. In some cases, games are harnessed as a distraction for patients during medications or against pain. In other scenarios, games are used to inform the patient on the management of their disease. One of the found manuscripts does not present a developed game intervention, but instead reviews serious games and their application for CF patients.

Lastly, of the final 12 manuscripts identified in the literature review, nine are focused on CF patients. None of these nine papers focus their intervention on CF adults only. Instead three papers develop multimedia content and applications for both CF adolescents and adults, thus demonstrating the lack of educational interventions for CF adults and the ageing CF adult. These three observations provide the foundation for each chapter and its subsequent multimedia intervention development and purpose.

7.3 Chapter Insights

Following the observations of the scoping literature review, three multimedia interventions were developed. Both Chapter 5 and 6 implemented mHealth apps as part of their proposed multimedia intervention. Hence, Chapter 3 first outlined a General mHealth Design pipeline to inform the development and design process as seen in Chapter 5 and 6. This pipeline was the first body of work which consolidated various research findings and policies. In keeping with this pipeline CF adult patient's attitudes towards mHealth apps were gathered via a questionnaire to provide insight into the research presented in Chapters 5 and 6.

Chapter 4 focused its research on the first observation identified by the literature review, which was the lack of CF educational content for medical professionals. This was investigated further through a student survey and discussion with the CF multidisciplinary team. From this, it was found that an interactive 3D system to visualise bronchial anatomy, as well as pathologies may serve as an appropriate multimedia intervention for medical professionals. Hence, an interactive 3D system was developed. From this system, three educational tools were created for medical students and professionals alike. These tools include the web based "Lung Anatomy Quiz", Windows based "Travel Through a CF Lung", and the Virtual Reality (VR) "Lung Experience". As the system was developed using a game engine, the three tools allowed for the exploration and free navigation around a 3D environment with a gamified approach to displaying educational content. The VR system was evaluated with eight medical students currently in fourth or fifth year, attending the University College Cork. Students were given a pre and post questionnaire developed by the CF multidisciplinary team regarding the CF content found within the tool. The results of this study found an average of 35% improvement in the knowledge based post questionnaire. In addition to this, seven of the eight students regarded the visualisation tool as beneficial to their learning and agreed they would use the tool again.

Chapter 5 began by drawing on the gamified approach from Chapter 4 and further investigating the games and gamified concepts found in the literature review of Chapter 2. It was found that the games from the literature review were targeted at CF pediatrics and adolescents only. The same could be said of the available literature pertaining to serious games. Hence, this chapter developed a serious game on smartphone for CF adults. The game was based on the popular smartphone game "Flappy Bird" and requires the user to blow into the device

microphone to navigate the bird character through oncoming obstacles. The game also collected game performance data, questionnaire data and calibration data which was then sent and stored in an external server. A web tool was then created for members of the healthcare team to view this collected data for interpretation. The system included the ability to send an SMS alert to a patient based on three criteria which may be indicative of an exacerbation. From the evaluation conducted with three CF adult patients, it was found that the game was played frequently and it was enjoyable and desirable for these patients.

Chapter 6 approached another gap identified in the literature review which was the lack of educational interventions for CF adults. The literature from Chapter 2 found that the majority of educational interventions were deployed over a web-based platform due to its accessibility and popularity. Subsequently, three web based e-learning tools were developed for CF adults. These tools were accessible via bedside tablets in the Cork University Hospital and via personal devices outside of the hospital. Website interactions, such as button clicks and time spent looking at the content, was recorded in XML files over a 12 month period. The results of this study found that the web tools were more frequently interacted with by users on their personal devices. It was also found that there was a pattern of interest towards specific content when interacting with the website in a hospital setting, such as complications or procedures. Although these web tools showed promise, the dissemination impact for such tools remained relatively low. Hence the research drew upon the concept of a smartphone application as seen in the previous chapter and the literature review of Chapter 2. The results from the patient attitudes survey in Chapter 3 found that this cohort were most interested in the tracking and recording of their basic medical information. Consequently a CF Patient Passport app for smartphone was developed and evaluated with five CF adults from the Cork University Hospital CF Day Ward. This pilot study reports that CF adults agreed that the CF Patient Passport is beneficial as it allows them access to their basic medical information and can be used when communicating with medical and healthcare professionals.

7.4 Research Contributions

Following the chronological order of the chapters, the contributions of this research are as follows. There is an evident gap of multimedia content for CF

patients and medical professionals. This research first proposes an mHealth design pipeline which consolidates research and government considerations into one body of work. Next this research contributes an interactive 3D tool for bronchial anatomy and pathologies. This is the first 3D bronchial tool that allows for self navigation on the web. Similarly this is the first virtual reality tool for CF. The serious game and data analysis system developed and tested in Chapter 5, is the first of its kind for CF adults. Lastly, the patient passport developed in Chapter 6 is the first digital passport of its kind made for CF patients. More importantly, this research contributes new multimedia to benefit CF adults in the management and education of their condition. All three multimedia contributions were evaluated with their target audience and were found to be both desirable and beneficial. In this way, this research contributes tools and concepts for both CF patients and medical professionals. Through the literature review and the comparison with other chronic conditions, it is acknowledged that medical professionals and adult patients are often not the target of medical multimedia. Overall this research contributes to the field of medical multimedia as it targets these groups and provides development considerations for such multimedia for other chronic conditions. In tandem with these contributions, there are also some limitations of the research. These limitations are discussed further in the next section.

7.5 Limitations

Although this research contributes new multimedia interventions for CF, there are limitations. The first limitation is that, although the 3D bronchial anatomy tool can be deployed onto the web, the way in which the software is compiled means that the website cannot be edited to be more visually pleasing. In addition, there are three redundant buttons (play, pause and stop) which are compulsory with the web tool composite. Moreover, both the web and VR tools required further evaluation with a larger student group. In addition to this, VR, although a nascent and booming industry, is still in its infancy, and as such there is a limitation for VR equipment and its cost. The headset used for the testing is currently priced at EUR 900 and requires a powerful machine to run the experience. Such machines can cost between EUR 1,000 and EUR 3,000.

For the work in Chapter 5, the nature of the data recorded via the game is exploratory and, although it presents opportunity for future endeavours, it also

limits the study. Due to the exploratory data recorded via the app, it is yet to be seen to what extent this data has medical merit or meaning. Moreover, the data recorded from the game is restricted to game performance. Further limitations can be seen in the device hardware. Although smartphones are becoming increasingly more powerful, hardware capabilities vary between device and brand. Consequently, there was an issue identified with distance when blowing into the device microphone. With some smartphones the user could blow into the microphone from a distance that would allow them to view the screen. However, other users had to be in close proximity to the microphone to interact with the game. A resolution to this was found in the microphone found on the smartphone headphones. Despite this resolution a more advanced solution will be needed to contend with this varying hardware.

A limitation of the final chapter can first of all be seen in the web based patient education tools. The web applications reported a common tendency for users to open the applications on bedside tablets and then navigate away before interacting with the web page; similarly the websites recorded a low number of valid interactions. This perhaps demonstrated their limited outreach or perhaps slow adoption rates. Another explanation for this could also be due to its restricted use cases, as the educational content is specifically created for CF adult's first encounter with a Portacath, Gastrostomy tube, or Bronchoscopy.

Lastly the passport shows two possible limitations. The first is that the data is self reported and can be erroneous. It is intended that this data will be inputted while in the company of medical professionals; however, there is still potential for incorrect or inaccurate data to be entered. Furthermore, the passport at this time does not account for users purchasing new smartphones. As such, the data cannot be transferred and would instead need to be inputted manually on the new device. In this way, the user may feel discouraged or deterred from re-entering their historical data and continuing to store future data. These limitations serve to inform future work and progress of this research which is discussed in the next section.

It is acknowledged that the user/patient insights gathered through the questionnaire in Chapter 3 are modest, and as such it ia acknowledged as a limitation. However it lends itself to future works, where this research suggests that more patient insights be gathered in the development of medical multimedia via interviews or by workshops.A perceived limitation through all pilot studies throughout

this research is the modest numbers of participants used during testing and the potential for gender bias. In addition to this, these pilot studies were conducted in a single CF centre. However due to the paucity of multimedia to support CF education and management, and the large scale potential of multimedia in CF, these pilot studies serve to provide insights and preliminary data to inform future developments.

7.6 Future Works

Throughout each chapters' summary section, recommendations for future works have been given which can contribute to the field further. This section will further discuss these future works and their rationale. For the web-based bronchial anatomy tool, suggestions for future work would include adapting the web tool with each new release of the UE4 game engine software. This would accommodate for removal of the redundant buttons. As for the VR application, this research would first suggest the use of the "Lung Experience" system to be developed further to encompass the visualisation of the effects of CF at a cellular level. From the perspective of hardware, future works can include the translation of the VR experience to a mobile VR headset. This would aid in higher dissemination and adoption rates. Particularly if developed to perform for such low cost headsets as the Google Cardboard which costs less than EUR 5.00 [186]. Similarly this research suggests further investigation into the application of the VR lung experience for CF patients. Again, for feasibility, this patient VR experience will need to be developed for a lightweight, non tethered, head mounted display such as the aforementioned Google Cardboard.

For the serious game, this research would first suggest the development of the game for iOS. Likewise the serious game can be developed further to include other popular smartphone game themes. This will provide a choice for the patients to which game they would like to play. More importantly, it allows users to engage with their physiotherapy without appearing as a medical app. As for the data recorded through the app, further research is required for the interpretation of the blow data from the game to meaningful medical data, such as lung function (FEV1). This may be achieved through the incorporation of a blow recording device such as a smartphone spirometer. The benefits of serious games have often been debated by academics as some feel what serious games can offer to

medicine and health is unclear. Similar to these debates, this research does not produce conclusive evidence of the effects of serious games on a user's health. However it demonstrates a new application for serious games in the collection of medical data outside of the hospital. This research suggests that although it is unclear what effect the serious game had on the patient's health, it is an engaging medium and can allow medicine to appear less medical. Another finding that this research contributes to serious games in medicine is the idea of "inclusiveness" and in contrast "individualisation". It was found throughout this research that patients often want to feel and be seen as "normal" and as such the serious game should allow the user to feel normal and comfortable playing in public settings. It is also important to note that a condition affects individuals differently with ranging severities and as such game mechanics must adapt (calibrate) to suit the users capabilities and thus complement the engaging medium. These two concepts and considerations can have applications for serious games in other chronic conditions. This research also suggests that, although it is unclear what effect the serious game had on the patients health, it is an engaging medium and can allow medicine to appear less medical. Likewise it is suggested that further evaluation and gathering of patient insight is needed to examine what effect serious games have on a patients health.

For the final chapter, future work would include expanding of the passport to include the patient feedback, such as the ability to rearrange/filter the clinical appointment data. Likewise, the passport should be expanded to allow users a means to transfer their data to a new device.

CFMATTERS is funded by an EU Framework 7 grant and operates across nine international sites. This research has been presented at general assemblies for CFMATTERS as part of the outreach programme. To date, the multimedia interventions and tools have been tested with modest numbers in a single site and it is intended that these multimedia systems can be made available to the other sites for future testing and validation.

This thesis identified through the literature review that there is a paucity in available multimedia for CF. This research began by creating multimedia interventions to bridge this gap; however, there are many areas of CF management, patient education, and medical professional education that could benefit from further multimedia development. For example, multimedia to communicate the effects of CF on other organs within the body. The fundamental suggestion for

future research in this field is to continue this development to not only aid medical professionals in their research but also benefit CF patients in the management of their condition.

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Appendices

Appendix A

Medical Students Attitudes to Multimedia Survey

Thank you for your interest and partaking in this study. This is an online questionnaire designed to gather information about students' attitude towards using Multimedia for education and learning. Should you wish to withdraw from this study please contact Tamara Vagg at tv3@cs.ucc.ie, or Dr Sabin Tabirca at tabirca@cs.ucc.ie with your student number. Consent: By ticking the below checkbox, I agree to participate in this research study. The purpose of this study has been explained to me in writing. I am participating voluntarily. I give permission for my data to be used for further analysis and research. I understand that my participation will not affect in anyway my grades/exam performance. I understand that anonymity will be ensured throughout the research process.

Student Number: _____

Todays Date: dd/mm/yy: _____

Attitudes To Multimedia for Education

1.	**Please specify the course you are enrolled in:**	
2.	**Please indicate which year of the course you are in:**	
3.	**What is your gender?**	
a	Male	○
b	Female	○
c	Other	○
4.	**What is your age?**	
5.	**What is your Country of origin?**	
6.	**What is your education qualification to date?**	
7.	**If you have already completed a degree/diploma, please specify:**	

Attitudes To Multimedia for Education

1.	**Please rank below (1 remember least, 5 remember the most)**	**I remember more from: 1 (remember least) to 5 (remember most)**
a	Things I hear	☐
b	Things I see/ watch	☐
c	Things I read	☐
d	Things I practise or do	☐
e	Things I write after reading	☐
2.	**Please rank below (1 remember least, 3 remember the most)**	**I remember more from:**
	Watching a tutorial/educational video with audio	☐
	Reading class/lecture notes and viewing images related to that topic	☐
	Reading class/lecture notes while listening to a lecture	☐

3. Please tick the most currently relevant to you: (You can select multiple items):

Device:	**Own or have owned:**	**Use Frequently i.e Daily/Weekly**	**Experience of these devices: (1= not pleasant, 3 neutral, 5 pleasant)**
Smartphone	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
Desktop Machine	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
Laptop	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
Notebook	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
Tablet/iPad	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
Game Console	☐	☐	1 ○ 2 ○ 3 ○ 4 ○ 5 ○

4.	**Please answer rate the following questions: (1 Strongly disagree,3 Neither agree nor disagree, 5 Strongly agree)**	**(1 Strongly disagree,3 Neither agree nor disagree, 5 Strongly agree)**
a	I have an interest in technology	1 2 3 4 5
b	I have an interest in technology but can find it intimidating	1 2 3 4 5
c	I do not get frustrated at technology easily	1 2 3 4 5
d	I stay current with the latest technology	1 2 3 4 5

Attitudes To Multimedia for Education

1. Please tick the most relevant to you: (You can select multiple items):

Multimedia:	Heard of/familiar with:	Used during any point of study	Enjoyed/Pleasent Experience	Want to see more of in Health/Medical Education
E-Learning	☐	☐	☐	☐
Interactive 3D	☐	☐	☐	☐
3D Animations	☐	☐	☐	☐
2D Animations	☐	☐	☐	☐
Simulators	☐	☐	☐	☐
Virtual Reality	☐	☐	☐	☐
Augmented Reality	☐	☐	☐	☐
Mobile Applications	☐	☐	☐	☐
Game Based Learning	☐	☐	☐	☐
3D Websites	☐	☐	☐	☐
None of these	☐	☐	☐	☐

2.	Please rate the following from 1-5 (1 Strongly disagree,3 Neither agree nor disagree, 5 Strongly agree)	(1 Strongly disagree,3 Neither agree nor disagree, 5 Strongly agree)
a	I am satisfied with the level of multimedia content in education	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
b	I would be interested in more multimedia in education	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
c	I find multimedia in education to be engaging	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
d	I prefer multimedia to text books	1 ○ 2 ○ 3 ○ 4 ○ 5 ○
e	I find multimedia to be as good as a class lecture	1 ○ 2 ○ 3 ○ 4 ○ 5 ○

f	I find multimedia helps me understand what we covered in a class or lecture	1 2 3 4 5
g	I find interactive multimedia to be a good source of practical learning	1 2 3 4 5
3.	**Please answer True or False for the below questions:**	
a	Have you ever watched an educational animation?	True: False:
b	Have you ever searched for a video/animation to explain a difficult topic you encountered during your learning?	True: False:
c	Have you ever used a 3D educational tool such as a website or software?	True: False:
d	Do you prefer a class/lecture to multimedia content?	True: False:
e	Do you own any educational games?	True: False:
f	Have you ever used an educational game?	True: False:
4.	**Please rate the following 1-5 (1 lowest possible, 3 neutral, 5 highest possible)**	**(1 lowest possible, 3 neutral, 5 highest possible)**
a	How confident are you at using a computer to view or search for educational material such as a video on youtube, online quiz or to research a topic?	1 2 3 4 5
b	How confident are you at using a computer to view or search for educational material such as a video on youtube, online quiz or to research a topic?	1 2 3 4 5
c	How comfortable are you maneuvering and rotating a 3D model on a smartphone app?	1 2 3 4 5
d	How comfortable are you at maneuvering/rotating a 3D image model on a laptop/computer?	1 2 3 4 5
e	How important do you think it is for multimedia to be interactive	1 2 3 4 5
5.	**Please answer Yes or No to the following questions:**	
a	Do you have any educational apps downloaded on your phone?	No Yes
i	If Yes: How often do you these?	Daily Weekly Monthly Only when needed
b	Have you ever taken part in or used a training simulator? Such as the iStan or Sim Man	Unsure No Yes

i	If Yes: Did you find it beneficial to your learning experience?	No ○ Yes ○
c	Have your ever used an virtual reality education device? Such as a head mounted display	Unsure ○ No ○ Yes ○
i	If Yes: Did you find it beneficial to your learning experience?	No ○ Yes ○
d	Have you ever used an augmented reality educational tool/app?	Unsure ○ No ○ Yes ○
i	If Yes: Did you find it beneficial to your learning experience?	No ○ Yes ○
e	Do you enjoy learning with games?	No ○ Yes ○ Unsure ○ Indifferent ○
f	Do you prefer to learn in 2D or 3D?	2D ○ 3D ○ Neither ○ Unsure ○
g	Do you prefer reading educational books and informational website to multimedia?	No ○ Yes ○ Unsure ○ The same ○
6.	**Please choose one of the following: I do not use multimedia for education because:**	
a	I like traditional learning with textbooks, diagrams and lecture notes	○
b	Advances in technology intimidate me	○
c	I cannot understand 3D or VR	○
d	I dont have the time for using technology while studying	○
e	There is no multimedia resources available to benefit my learning	○
f	I had a bad experience with multimedia learning	○

Please Choose One

Attitudes To Multimedia for Education

1.	**Please rate the below question (1 = disagree, 3 = neutral, 5= agree):**	
	The college/university/hospital I attend has sufficient multimedia educational elements:	1(disagree) 2 3(neither agree or disagree 4 5(agree)
2.	**Please answer true or false to the below:**	
a	When studying or revising I would look for additional videos/ animations/ images on the topic online (over the internet) or through smartphone apps.	True False
b	When studying or revising I would look for additional information / research papers / wikipedia online or through smartphone apps.	True False
c	Educational multimedia content is expensive	True False
d	Educational multimedia is not expensive	True False
e	Educational multimedia is difficult to locate/source	True False
f	Educational multimedia is easy to locate/source	True False

Thank you for taking the time to fill out this survey.
Your time is greatly appreciated

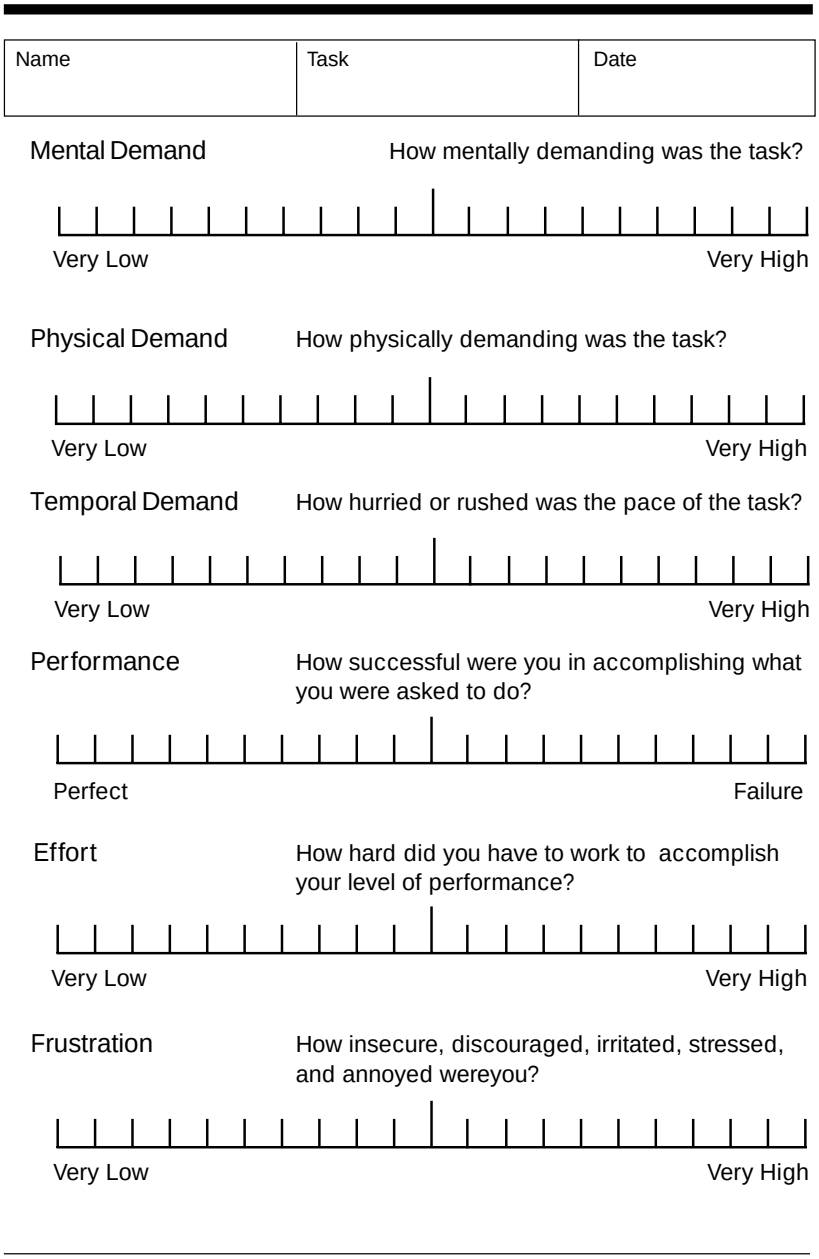
Appendix B

Nasa Task Load Index (NASA-TLX)

Figure 8.6

NASA Task Load Index

Hart and Staveland's NASA Task Load Index (TLX) method assesses work load on five 7-point scales. Increments of high, medium and low estimates for each point result in 21 gradations on the scales.



Appendix C

Lung Experience Pre and Post Questionnaire

Survey Number: _____

1. **Why do patients with Cystic Fibrosis have thick mucus in their lungs?**

2. **What can Cystic fibrosis patients do to help thin their mucus?**

3. **What techniques do cystic fibrosis patients use to clear their mucus?**

4. **List 5 organisms that are common to cystic fibrosis patients?**

5. **What are the three most common nebulised antibiotics used to treat the organisms?**

6. **Are there cross infection risks for patients with cystic fibrosis?**

7. **How many classes of CFTR modulation are there?**

8. **What are the two most common genetic mutations in the Irish CF population?**

9. **Name the CFTR modulator drugs available for these mutations?**

10. **Describe how they work?**

Survey Number: _____

1. **Why do patients with Cystic Fibrosis have thick mucus in their lungs?**

2. **What can Cystic fibrosis patients do to help thin their mucus?**

3. **What techniques do cystic fibrosis patients use to clear their mucus?**

4. **List 5 organisms that are common to cystic fibrosis patients?**

5. **What are the three most common nebulised antibiotics used to treat the organisms?**

6. **Are there cross infection risks for patients with cystic fibrosis?**

7. **How many classes of CFTR modulation are there?**

8. **What are the two most common genetic mutations in the Irish CF population?**

9. **Name the CFTR modulator drugs available for these mutations?**

10. **Describe how they work?**

11. How useful did you find the virtual Reality Experience?

Not Useful		Indifferent		Useful
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

12. How likely are you to use a virtual reality experience for your education in future?

Not Likely		Indifferent		Likely
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

13. Do you think a virtual reality experience would be useful during attachments?

Not Useful		Indifferent		Likely
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

Please Explain your answer:

14. Do you think VR compliments lecture based learning and clinical attachment learning?

☐ Yes ☐ No ☐ Unsure

Appendix D

CF Adult Patient Attitudes to mHealth Survey

Survey Number: _____

Survey VersionNo 001 – dated 04/12/2016

Study Outline: The aim of this study is to survey attitudes towards smartphone apps for Cystic Fibrosis. The survey is very short and should only take you a few minutes to complete. All data collected will be anonymous. Thank you for your interest in this study.

---

1. What kind of smartphone do you have?

☐ Windows ☐ Android ☐ iPhone

2. Do you have any medical or health apps downloaded onto your phone? Such as exercise trackers, dietary apps, or medical information apps

☐ Yes ☐ No ☐ Unsure

3. Would you download and use an app for your cystic fibrosis care?

☐ Yes ☐ No ☐ Unsure

4. Do you know of any apps available for your cystic fibrosis care?

☐ Yes ☐ No

If yes please specify the name or purpose of the app:

_____

5. Do you have any apps specific to CF on your phone? Such as disease information apps or care management apps.

☐ Yes ☐ No

If yes please specify the name or purpose of the app:

_____

If no please specify why

_____

6. What aspects of CF would you like targeted by an app? Please select as many or little as you like:

☐ Physiotherapy ☐ Medication ☐ Diet ☐ Education
☐ Monitoring ☐ Self-Psychological Help ☐ Management ☐ News
☐ CF Forum/ Social Networks for Patients with CF ☐ New Research Developments
☐ Other
If other please specify:_____
☐ None

7. Would you play a game in an app that is designed to support your CF care?

☐ Yes ☐ No ☐ Unsure

8. Would you like to receive notifications or reminders from a CF app e.g reminders to take medication or reminders for clinic appointments?

☐ Yes ☐ No ☐ Unsure

9. Would you find it helpful to have access to your CF medical data through an app? (e.g Lung Function Data)

☐ Yes ☐ No ☐ Unsure

10. Would you store your CF medical information, such as Lung Function and genotype, in an app on your phone?

☐ Yes ☐ Yes if it is secured by a password
☐ Yes if it was secured by a password and does not have access to the internet
☐ Not Sure ☐ No

Please briefly describe your answer: _____

11. What do you think a CF mobile app should focus on or be targeted towards:

☐ Please write answer here:_____
☐ Don't Know/Unsure
☐ I Don't think an app would be beneficial

12. Have you ever gone travelling outside of Ireland?

☐ Yes ☐ No

13. Have you ever been to the accident and emergency department due to your CF?

☐ Yes ☐ No

14. Is it easy or difficult to remember your CF medical information? Such as genotype, medical history, current/previous medications?

Difficult		Neither		Easy
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

15. Would you use a mobile app that recorded this information for you?

☐ Yes ☐ No ☐ Unsure

16. Would you find an app that recorded your CF medical information and clinical appointments useful?

Not Useful		Neither		Useful
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

17. If a virtual hospital was set up, *i.e* meeting and interfacing with your healthcare team through webcams and other technology.
Would you use an app in place of a clinical appointment?

☐ Yes ☐ No

If yes please specify why:

_____

If no please specify why:

_____

18. Have you ever participated in a clinical trial?

☐ Yes ☐ No

If yes, Do you think a mobile app would make it easier to participate in the trial?

_____

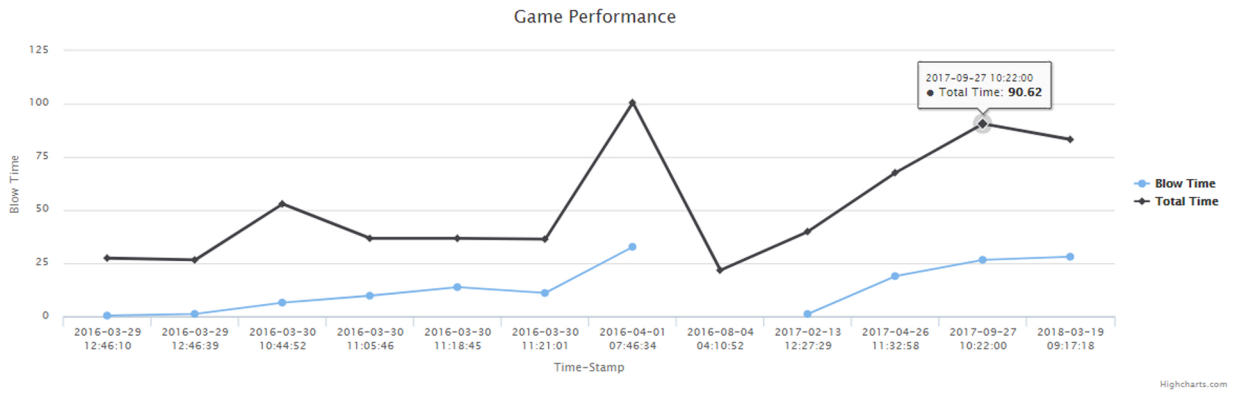
Appendix E

Screenshot of the Web Tool

CF Patient List Alerts History Change Alert Message Hi, TamaraVagg

Profile
Questionnaire
Performance
Alert History

tv123456 Details



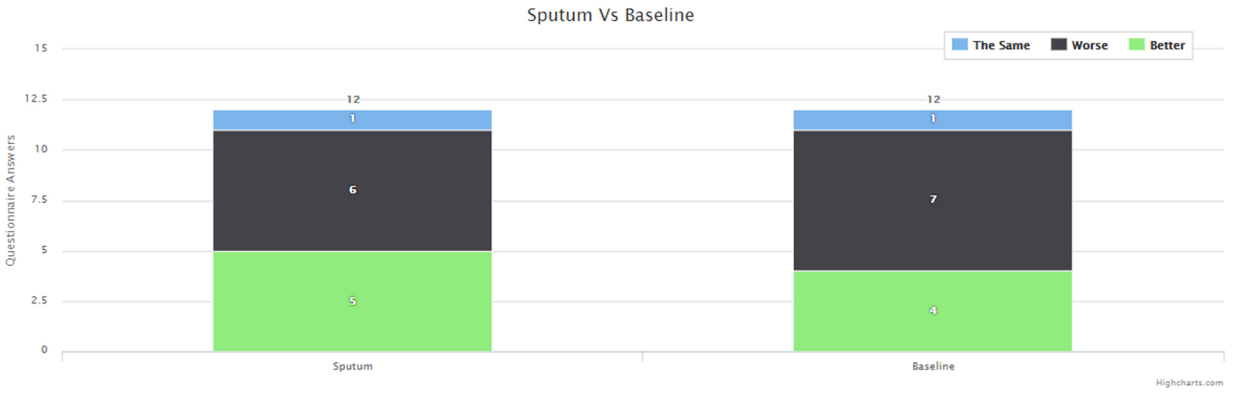
Game Performance Info

CF-Number	Intensity Average	Total Time	Blow Time	Max Level	Will play again
tv123456	2018-03-19 09:17:18	83.24	28.11	9	yes
tv123456	2017-09-27 10:22:00	90.62	26.64	8	yes
tv123456	2017-04-26 11:32:58	67.63	19.00	5	yes
tv123456	2017-02-13 12:27:29	39.94	1.17	0	yes
tv123456	2016-08-04 04:10:52	21.76	.00	0	yes
tv123456	2016-04-01 07:46:34	100.59	32.76	9	yes
tv123456	2016-03-30 11:21:01	36.38	11.06	0	yes
tv123456	2016-03-30 11:18:45	36.75	13.81	0	yes

CF Patient List Alerts History Change Alert Message Hi, TamaraVagg

Profile
Questionnaire
Performance
Alert History

tv123456 Details



Questionnaire Info

CF-Number	Time-stamp	Baseline	Sputum Volume	Done airway clearence today	Chest Physio	On Inhaled Therapy	Taken Inhaled Therapy Today	Last IV Antibiotic	Last Oral Antibiotic
tv123456	2017-09-27 10:19:33	Better	Increased	No	Autogenic drainage	No	No	Wed Sep 06 22:19:33 IST 2017	Wed Sep 06 22:19:33 IST 2017
tv123456	2017-04-26 11:31:26	Better	Decreased	No	Autogenic drainage	No	No	Wed Apr 19 11:31:26 IST 2017	Wed Mar 29 11:31:26 IST 2017
tv123456	2017-02-13 12:25:50	The same	The same	Yes	PEP	No	No	Mon Feb 13 12:25:50 GMT+00:00 2017	Mon Feb 13 12:25:50 GMT+00:00 20
tv123456	2016-08-08 11:09:30	Worse	Decreased	No	Acapella	No	No	Wed Aug 10 11:09:30 IST 2016	Fri Aug 26 11:09:30 IST 2016
tv123456	2016-08-04	Better	Decreased	No	Autogenic	No	No	Tue Aug 16 16:02:13 IST	Mon Aug 15 16:02:13

Appendix F

CF Patient File Example

Name: _

Date	R/V	Wgt	Hgt / BMI	BP	FVC Ltrs	FVC %	FEV1 Ltrs	FEV1 %	Urine	Resp	Others	Treatment	Nursing Comments	Adm
7/7/16	DN	—	—	—	—	—	—	—				Gastrografin x 2/7 · Constipated tt thereafter c/a August		
04/8/16	DN	55.4	156 / 22.7	124/82	2.44	75%	1.55	55%	NAD		Annual assessment + Post flush	Glucose 2hPP=11.4 macros bresto monitoring	• Referred to psychiatry ongoing anxiety	
16/08/16	DN											• Continue monitoring • 2/12 visit @ next	CBG's reviewed by diabetic CNS ↓ some ↑ 11.4 advised regds	
18/8/16	DN	55.0	156	—	2.43	74%	1.67	54%	—	—	Scan Mount Vrad	Amphotericin Po 625mg TDS		
12/9/16	DN	55.0	156	—	2.36	73%	1.56	56%		✓		Mincapsan 3g a Tobramycin 160mg BD		
21/9/16	DN	55.1	156	—	2.52	78%	1.49	53%			Tobi Levels			
17/10/16	DN	55.0	156		2.13	66%	1.47	52%		✓		Fortim 4g a Tobramycin 160mg	Brand caplan + ciprofloxacin 750mg	
27/10/16	HV	—	—		2.48	77%	1.57	56%				• Recurrent hypoglycaemic nurse will ring edel	Much improved from chest point of view as per Edel	
7/12/16	Phone-call							50%		✓		azithromycin ↑ 500mg od • ciprofloxacin 750mg bd	↑ chesty cough	
12/12/16	DN		156		2.34	72%	1.41	50%		✓		Mincapsan 4g a Tobramycin 160mg BD		
22/12/16	DN	—	—		2.36	73%	1.40	50%			Levels	not on productive		
24/1/17	DN	56.4	156		2.66	82%	1.60	57%			study			

Name: [redacted]

Address: [redacted]

Date of Birth: [redacted]

Tel No. [redacted]

Marital Status: Single

Employment Status: Private Organisation

NEXT OF KIN:

Name: [redacted]

Address: [redacted]

Marital Status: Married

Employment Status: Mother Housewife

Father Plumber

Tel No: [redacted]

Presentation: F.T

Date of Diagnosis: 5 months old

Sibling's Date of Birth:

Patrick

Gerald

Anthony

Sweat Test:

Genotype: AF508 / AF508

Allergies: None.

Relatives with Cystic Fibrosis:

A positive

Date	Medical Condition
	polyps removed 2004 U/S and normal.
13/6/2007	Bone Density - normal U/S Bone Density normal 2007
23/6/2014	Portacath

Appendix G

CF Passport App Feedback

Survey Number: _____

Phone Make and Model: _____

Survey VersionNo 001 – dated 04/02/2017

Study Outline: The purpose of this study is to evaluate if a digital passport made as a mobile application would be of benefit to Adult CF patients and in which scenarios it is used.

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1. Do you feel you were given enough information to use the app?

☐ Yes ☐ No

Please explain your answer:

_____

2. How do you feel about the appearance of the app?

Did not Like it		Neutral		Liked it
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

3. Did you insert information into the passport app?

☐ Yes ☐ No

If no, please explain why:

_____

4. Did you use the app to share any of your medical information at any time? For example: Sharing information at a clinical visit, with a GP, or with a family member or friend.

☐ Yes ☐ No

If yes please explain when you used the app:

_____

5. What possible scenarios do you think the app could be helpful for, if any?

6. Did you find the app difficult to use?

Difficult		Moderate		Easy
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

Which parts did you find difficult?

_____

7. What features would you remove from the app, if any?

8. What features would you like to add to the app if any?

9. Did you find the app helpful?

Not Helpful		Indifferent		Helpful
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

Please explain your answer?

_____

10. The app has the ability to store your basic medical information. Do you find this beneficial?

☐ Yes ☐ No ☐ Indifferent

11. Who do you think is responsible for inserting information into the app?

_____

Please explain your answer?

_____

12. Did you experience barriers that stopped you from saving your information in the app?

☐ Yes ☐ No

Please explain your answer?

_____

13. Would you use the app regularly?

Not Regularly		Sometimes		Regularly
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)

14. Do you think there is adequate security on this app?

Not Adequate				Adequate
☐ (1)	☐ (2)	☐ (3)	☐ (4)	☐ (5)