



***An exploration of information needs for
adolescents with epilepsy.***



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Dublin, in partial fulfilment of the requirements
for the degree of Master of Science in Health
Informatics

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Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

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Summary/Foreword

Epilepsy is the most common neurological disease affecting children and adolescents (Wheless & Kim 2002, Appleton & Neville 1999). Approximately 1 in 200 people under the age of 18 years in Ireland have epilepsy (EI, 2015a). It is a complex disease requiring ongoing care and various lifestyle adaptations. Education about treatment, lifestyle changes and seizure management are important particularly for adolescents and families so the disease is managed effectively.

Adolescence is the period in which children develop and begin transition to adulthood. Young people experience many changes and while they wish to become more independent, there is still much to learn in order to achieve the independence they so truly desire. The adolescent period becomes more challenging with the presence of a chronic health diseases (Suris et al, 2004), for example cystic fibrosis, diabetes and epilepsy. Teens do not wish to stand out from their peers but due to a disease such as epilepsy that causes unprovoked and unpredictable seizures, there may be times when a young person will be noticeably different. As adolescents with epilepsy begin their transition to adult services, they need to become more informed about their disease and be aware of the potential risks and triggers for their seizures (England et al, 2012).

Subsequently, information plays a vital role in the ongoing management of the disease. With the increasing presence of health information available on the internet coupled with the high volume of adolescents that have access to the internet on a daily basis, there is the opportunity for adolescents to learn more about their illnesses or diseases. The prevalence of Health Information technology (HIT) will have an expanding role to play for people with chronic illnesses (Healthy people.gov 2016, Himes & Weitzman, 2016).

This research study investigated through a literature review what a complete list of topics should contain and from the primary research whether adolescents believe that the information available to them is complete and useful. It also researched the sources they use to seek advice and information, whether they prefer information in digital or paper format.

The findings suggest that health informatics is becoming a major part of epilepsy care in Ireland and there are many projects currently underway and in the pipeline such as the lighthouse project and epilepsy EPR (eHealth Ireland, 2016). It is also evident that availability of complete and useful information is essential for adolescents with epilepsy regardless of format, once it is appropriate for their communication needs and level of health literacy. A complete list of topics was produced from the literature review and more primary research is needed to ensure all topics are approached by HCPs with adolescent that have epilepsy.

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Abbreviations

| | |
|----------------|---|
| AMNCH | Adelaide, Meath National Children’s Hospital |
| ANP | Advanced Nurse Practitioner |
| AFQuATs | Adolescent Friendly Quality Assessment Tools |
| CPS | Canadian Paediatric Society |
| CSO | Central Statistics Office |
| CUH | Children’s University Hospital |
| DOH | Department of Health |
| EEG | Electroencephalography |
| EI | Epilepsy Ireland |
| EPR | Electronic Patient Record |
| HCI | Human Computer Interaction |
| HCPs | Health Care Professionals |
| HIMSS | Healthcare information and Management Systems Society |
| HIT | Health Information Technology |
| HRB | Health and Research Board |
| HSE | Health Service Executive |
| ICT | Information Communication Technology |
| ILAE | International League Against Epilepsy |
| IT | Information Technology |
| JAE | Juvenile Absence Epilepsy |
| JME | Juvenile Myoclonic Epilepsy |
| NECP | The National Epilepsy Care Programme |
| NICE | National Institute for Health and Care Excellence |
| OLCHC | Our Lady’s Children’s Hospital, Crumlin |
| OPD | Outpatient’s Department |
| PIL | Patient Information Leaflets |
| PAC | Programme of Action for Children |
| QOL | Quality of Life |
| RCSI | Royal College of Surgeons, Ireland |
| SIGN | Scottish Intercollegiate Guidelines Network |
| SUDEP | Sudden Unexpected Death from Epilepsy |
| TCD | Trinity College Dublin |
| TLE | Temporal Lobe Epilepsy |
| TSCUH | Temple Street, Children’s University Hospital |
| UK | United Kingdom |
| WHO | World Health Organisation |

Chapter 1. Introduction

1.1 Aim of the research

The title of this dissertation is “An exploration of information needs for adolescents with epilepsy.”

This chapter describes the rationale for the chosen topic and study cohort under investigation and how the author came to construct the following research question:

“What does a complete and useful list of information topics for adolescents with epilepsy entail?”

The aim of this research is to explore whether adolescents either newly diagnosed or well established with epilepsy are provided with all the required information to meet their needs and manage their disease. The research also sought to discover whether they are more likely to access health information electronically or from their healthcare provider. From this exploratory study, the researcher investigated from the adolescents’ perspective if the information they receive in hospitals is sufficient, if they are satisfied with the method in which the information is delivered and whether they follow the advice given to them. By understanding the communication needs of this cohort, it is hoped that future health promotion strategies can be targeted to their unique needs and preferences.

A review of the literature was conducted not only to learn about the difficulties of epilepsy in adolescence, but also to ascertain what methods of delivery were used to provide health information to adolescents with chronic diseases in other countries. This was done to gain knowledge about current best practice. The literature review identified what is currently known about the communication and information seeking habits of teens with chronic illnesses, particularly epilepsy. From this review, relevant themes which emerged were: transition to adult services, information and communication in adolescence, health literacy and use of information communication technology (ICT) in epilepsy.

Following on from the literature review, it was decided that a qualitative research study would be conducted to explore if the current method of healthcare information delivery is adequate in comparison to what was recommended from the literature. The research would be carried out in the form of structured interviews and questionnaires involving adolescents with epilepsy in a children's hospital in Dublin. The methods, findings and results will be discussed later in this dissertation.

1.2 Motivation for choosing the topic

There are many factors, both professional and personal, that impacted the researcher's choice of topic for this dissertation which is the information needs in people with epilepsy. Throughout her nursing career as both a Registered Children's and General Nurse she has always been interested in the management of chronic diseases, particularly epilepsy. Her varied experience in adult and children's nursing in the following settings; hospital wards, outpatient clinics, respite facilities and clinical trials, has increased the interest. The choice to focus on epilepsy for this study arose from the researcher's experience from working with children and adolescents that have epilepsy.

The relevance of reviewing adolescents' and separating their information needs from that of younger children became apparent when undertaking a group assignment in which 300 children hospital websites were reviewed to determine whether teen usability was considered. From this systematic review, it became clear that adolescents' information needs are different to children's and adolescents' are quite particular about the type and format of the information they read. (Loranger & Neilson 2013) The information needs of adolescents with other chronic diseases such as diabetes and haemophilia have been widely researched however there seems to be a scarcity of research carried out on adolescents with epilepsy. Adolescents with epilepsy are an interesting group due to all the changes and developments that occur in adolescence and the researcher believes that more research is needed in Ireland to learn about their information needs, thus ensuring they receive the best possible care.

On a personal level, the author was recently diagnosed with Temporal Lobe Epilepsy (TLE). This contributed to an increased interest in the disease along with empathy with others due to first-hand experience as a person newly diagnosed with epilepsy. The diagnosis of a chronic illness such as epilepsy can be an overwhelming experience. Often the person feels overloaded with information and the uncertainty of where to best seek advice from (Patient 2016, England et al, 2012). Appendix 1 shows one of the mind maps created in the early stages of the research which conveys the original thoughts when trying to decide upon a topic.

The initial plan was to gain an insight into the information needs of all people with epilepsy; parents of babies, children, adolescents and adults that were either newly diagnosed or those with long term epilepsy. However, it became apparent early on in the research, particularly when speaking to

professionals working in the healthcare and informatics area of epilepsy, that this would be too vast a project in the short time frame. This eventually led to the decision to choose a single cohort to focus on. As the author has experience in working in the three children's hospitals in Dublin and is currently working in the outpatient's department of one of the hospitals, the clear choice was to look at the needs of younger people with epilepsy as opposed to adult's due ease of access to this cohort. Throughout the process of seeking ethical approval, the author realised that more knowledge about epilepsy was required to ensure that any participants would be given the necessary support and advice when participating in this study. Therefore, an Epilepsy module was undertaken in the Royal College of Surgeons, Ireland (RCSI) in order to achieve a level 9 certificate and upskill and obtain the knowledge to deal with any concerns that may arise in the interview process. This decision proved beneficial for carrying out all aspects of the research.

1.3 Background

As outlined earlier, this chapter aims to explain the rationale behind the research and it has also been identified that the information needs for adolescents with epilepsy in Ireland will be the main focus. Therefore, a brief paragraph explaining the period of adolescence will be given first. The author believes it is essential to have an understanding of this period in order to fully comprehend the significance of having epilepsy during the adolescent period and the importance of accessibility to information about the disease. These topics will then be discussed in detail in chapter 2.

1.3.1 Adolescence

Simply put, adolescence is the transition from childhood to adulthood (Lalor et al 2007). It is a major time of adaption in a child's/young person's life as there are many physical and psychological changes taking place (Mulye et al, 2009). Adolescence can be a critical period in which young people begin preparations to become more independent in all aspects of their life (Agarwal et al, 2014). Puberty is a major part of adolescence as it represents a time of rapid adaptations for a young person including physical, cognitive, psychological and social circumstances. These adaptations are explained below (Canadian Paediatric Society, 2008);

- Physical: Puberty causes many physical changes to occur such as rapid growth in height and enhanced development of sexual and reproductive organs.
- Cognitive: The thought processes of adolescents become more sophisticated during puberty, increasing the abilities of young people to make decisions and lean towards independence.

- Psychological: As adolescents become closer to adulthood, they learn to develop coping mechanisms enabling them to increase their level of maturity and this helps them to face the more advanced challenges they need to face in life such as higher education, employment and mature relationships.
- Social: Puberty also brings social changes in line with the psychological. Adolescents become more independent and as they go through higher education and work, they require less financial and emotional support from their parents.

These stages of adolescence convey that there are many things to consider during this time and highlight the importance of this period. Most adolescents progress to adulthood smoothly, but there may be interruptions to the above stages with the presence of a chronic illness. For example, social development can be delayed if there is a reduction in activities due to illness that would otherwise be a part of the adolescent's daily life for example sports, school and meeting with friends. Adolescents/teenagers both want and need to have a greater awareness about their bodies and all the changes that occur during puberty and there is a greater emphasis on their desire to learn if these changes are related to health issues or chronic illnesses especially if developmental progression is impacted by the illness (Holder & , Blaustein 2013, McNeely & Blanchard 2009, Suris et al 2004).

It is an interesting era in a young person's life with so many changes to consider, causing their lives to be somewhat erratic even without having any illnesses. Therefore, it is hoped that the explanation of adolescence will enhance the reader's knowledge of this period. The reason for the potential difficulties when there is a presence of a chronic health disease such as epilepsy will also be conveyed as this can make an adolescents' life even more unpredictable and complicated (Sundstorm, 2007). The impact of chronic illness in adolescence will be explored further in chapter 2.

1.4 Methodology

The methodology will be discussed in greater detail in chapter 3 but this section gives a brief outline of the research plan and objectives of the study:

- 1.4.1 Research objectives
 - To gain an understanding of how information is delivered to teens with epilepsy.
 - To determine if information delivery regarding in Ireland is similar to other countries.

- To carry out both a review of the literature and primary research to answer the question.
- To ascertain who epilepsy information is designed for.
- To explore what role health information plays and if Information Technology (IT) help.

1.4.2 Overview of the Research (Literature Review)

- Comprehensive review of the literature on information needs for adolescents with epilepsy.
- Learn what they need to know in addition to what they want from the information.
- Identify gaps or issues with current methods of information delivery.
- Ascertain what is meant by “complete and useful” information for adolescents with epilepsy.
- Review the best of breed guidelines in Ireland and Internationally.
- Review possible IT, ICT and informatics solutions (apps, online resources, etc.).
- Construct plan to carry out primary research with emerging themes from literature review.

1.4.3 Research plan for Primary Research

- Review methods of information delivery in a children’s hospital in Ireland.
- Create informed consent and assent forms for adolescents with epilepsy.
- Compile questionnaires guided by the literature, aimed at adolescents.
- Apply for ethical approval in the 3 children’s hospitals and in Trinity College.
- Recruit suitable participants once ethical approval granted.
- Collect and collate the data from the completed questionnaires.
- Compile a table of results and convey the findings.
- Evaluate findings and relate to the literature.
- Display common themes, if applicable.

1.5 Challenges

After the final topic was decided upon and the appropriate cohort was chosen, it became apparent that the main challenge of this research was the short time frame that remained to conduct the study. It was hoped that adolescents with epilepsy attending all three children’s hospitals in Dublin would be recruited to participate in interviews or complete questionnaires. This would then provide a general overview of the adolescents’ views of the information they receive in all three hospitals. However, along with the short timeline, ethical approval became one of the other biggest hurdles to overcome in this study. This was due to the complicated nature of the ethical application process in hospitals, especially when dealing with children and teenagers under the age of 18. These issues will all be discussed in more detail later.

1.6 Dissertation Layout

This dissertation consists of 6 chapters, followed then by a reference list and many appendices. A brief overview of the content of each of the chapters is listed below:

- Chapter 1: This chapter is titled “Introduction” and gives the reader an overview of the chosen topic and explains the reasons for choosing to focus on epilepsy
- Chapter 2: The “Literature Review” identifies the main themes of reviewing literature regarding adolescents, epilepsy and healthcare information. This chapter will hopefully give the reader an insight to why it is important to have an understanding of the information needs of adolescents with epilepsy.
- Chapter 3: This chapter explains the chosen methods used to answer the research question will be discussed in this chapter.
- Chapter 4: The “Ethics” chapter explains the researcher’s ethical journey throughout the study. As adolescent patients were the study participants, ethical approval proved to be challenging and this chapter will explain the difficulties encountered.
- Chapter 5: Findings: this chapter outlines how the research was implemented and conveys the findings from the questionnaires along with evaluation and analysis of the results
- Chapter 6: Conclusion and further work, this chapter provides the key findings of both the literature review and the primary research. The strengths and limitations that were met while conducting this research are highlighted. Recommendation for practice and future research will then be given with a discussion on what else could be learned from this study or could have been done to enhance the research carried out. Lastly, reflection and overall conclusions will be made

1.7 Conclusion

This chapter gave an overview of the aim and rationale for this research study. An explanation of the period of adolescence was provided to give the reader an understanding of why it is important to focus on this cohort in relation to information needs in epilepsy. The layout of this paper has also given an outline of the intended flow and structure of this dissertation.

Chapter 2. Literature Review

2.1 Introduction

The aim of this literature review is to follow the tasks outlined in 1.4.2 and provide a descriptive overview of the health information needs of adolescents who are diagnosed with epilepsy and the methods in which information and advice should be given to them throughout their ongoing care. This comprehensive review of the literature aims to ascertain what is meant by “complete and useful” information for adolescents with epilepsy by reviewing the best of breed in Ireland and Internationally with a particular focus on adolescents with epilepsy. In order to give a better comprehension of the relevance of carrying out such a literature review, a brief outline of the period the adolescent period has been given in chapter one along with the reasons for focusing on this particular age group when looking at information needs in epilepsy.

This literature review aims to explore the following:

- (i) Epilepsy, the prevalence of the disease in Ireland and its significance during adolescence.
- (ii) Caring for adolescents in hospitals and the period of transition to adult services.
- (iii) Health Information, literacy, information seeking and communication habits of adolescents.
- (iv) Availability of epilepsy information in healthcare, “best of breed” methods of health information delivery and current best practice, information needs for young people with epilepsy.
- (v) The potential role of ICT in education for families of children and teenagers with chronic health diseases, particularly epilepsy.

2.2 Search strategies

The researcher carried out many searches throughout this study which began quite broad before the topic was narrowed; the key words used included the following:

- Adolescence.
- Adolescents/teenagers with epilepsy.
- Adolescents/teenagers and technology.
- Adolescents/teenagers with chronic illnesses.
- Health information and adolescents/teenagers.
- Epilepsy.
- Epilepsy and adolescents/teenagers.

In all, 102 references have been used throughout from academic journals, websites, online publications and sources from governing bodies both in Ireland and internationally. The following database searches were used; CINAHL, PubMed, Sage, ScienceDirect and SpringerLink. Some of the search results are portrayed in the table below (Table 1). This table shows the number of articles that were retrieved before and after limitations were put in place. Further refinements were done by the researcher to limit the final number of references.

Table 1: Summary of literature search

| Database(s) | Keywords | Results | Refinements | Total Results |
|----------------------------------|---|---------|---|---------------|
| CINAHL | Transition in adolescence | 208,349 | Full text, Peer reviewed, UK & Ireland, Great Britain and England | 1916 |
| CINAHL, PubMed, Sage | Adolescents with epilepsy | 76,585 | Full text, Peer reviewed, UK & Ireland | 522 |
| CINAHL, ScienceDirect | Adolescents and technology | 397,747 | Full text, Peer reviewed, Ireland, Great Britain and England | 2995 |
| CINAHL, PubMed | Adolescents and chronic illness | 237068 | Full text, Peer reviewed, UK & Ireland, Great Britain and England | 1980 |
| CINAHL, Springerlink | health information and adolescents | 979025 | Full text, Peer reviewed, Europe | 6222 |
| CINAHL | epilepsy information and adolescents | 49220 | Full text, Peer reviewed, UK & Ireland, Great Britain and England | 642 |

The approach for each of the above searches was to review full text, peer reviewed articles written in English. The timeline was set from the year 2000 onwards to ensure the most up-to date articles were used with the majority of articles no older than 10 years. There are a few articles over 15 years old that were used and the oldest source is 23 years old. Relevant articles were also selected from

citations and references from reviewed literature or articles. In addition to these searches, relevant websites, books and information leaflets were reviewed by the researcher to ascertain appropriateness for use in this dissertation.

The next section of this literature review will focus on the disease pathology of epilepsy, its prevalence in Ireland and the significance of having the disease in adolescence.

2.3 Epilepsy

Epilepsy affects almost 60 million people worldwide (Sahoo et al, 2014). It is a chronic neurological disease that causes recurrent unprovoked seizures to occur and is the most common neurological disease in children (EI 2015a, Gurshaw et al 2014, Dunkley & Cross 2006). A seizure is merely a symptom of epilepsy and can be described as a sudden but temporary loss of consciousness, awareness, body posture or movement (EI, 2015b). Epilepsy can affect children and adults of all ages from various socioeconomic backgrounds. It is a complex disease that affects people at various stages of life and in various ways (England et al, 2012). Epilepsy is not a single disease entity, it is an umbrella term covering hundreds of diseases with many causes, prognoses and management (Panayiotopolulos, 1999). The International League against Epilepsy (ILAE) put together a task force to update the clinical definition for epilepsy for purposes of diagnosis in a clinical environment and the following is the definition they proposed (Fisher et al, 2014):

“Epilepsy is a disease of the brain defined by any of the following conditions

- 1. At least two unprovoked (or reflex) seizures occurring >24 h apart*
- 2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years*
- 3. Diagnosis of an epilepsy syndrome.*

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.”

The definition gives an indication of how complex the disease is and indicates that the management of epilepsy is not simple. In many cases, a diagnosis of epilepsy requires neuroimaging, electroencephalography (EEG) and detailed report from the patient or witness about the unprovoked seizure event(s) that have occurred (Sahoo et al, 2013).

2.3.1 The Prevalence of Epilepsy in Ireland

There are approximately 40,000 people in Ireland that have been diagnosed with epilepsy (EI, 2015a) and 1 in 200 children in Ireland have epilepsy (EI, 2015c). This figure is in line with the rest of Europe as there are approximately 0.9% children and adolescents that have active epilepsy across the continent (Varley et al, 2011). There are an estimated 2000 new cases every year with prevalence of 6-8 per 1,000 people. Epilepsy accounts for 2-3% of hospital admissions in Ireland and there are approximately 130 deaths caused by epilepsy each year (HSE, 2016 about epilepsy).

2.3.2 Epilepsy in Adolescence

The prevalence of epilepsy in adolescence is high (Shakirullah et al, 2014), however information and services are rarely aimed specifically for this age group (Besag, 2016). This is important because adolescents want to be more independent and learn for themselves but lack of information designed with their needs in mind makes this more difficult for them (Agarwal et al, 2014).

Adolescence can be a difficult time for young people even when they do not have a chronic disease. This becomes an even harder period for those with health issues. Adolescents just wish to be the same as everyone else, but having epilepsy can potentially make them feel like they stand out from their peers and the can cause concerns for them in their daily lives. Epilepsy can have a major impact on their quality of life (QOL) as the disease can affect self-esteem and social circumstances (Thomson et al 2013, Collins 2011). They worry about having seizures around their classmates and friends as this would highlight the fact that they are somewhat different (Sundstorm, 2007). This is an important factor to consider because the seizures caused by having epilepsy are unprovoked and unpredictable meaning there is uncertainty around the possibility of their recurrence. There are seizure inducing factors to be considered, knowledge of the type of epilepsy and possible risks and being aware of the triggers are essential for individuals with epilepsy in order to gain some control of the disease. This is why availability of information about all aspects of the disease is extremely important (Macleod & Appleton, 2007).

It is very important to understand that epilepsy is not the same for every individual affected and there are many types to be considered. The following is a list of some of the syndromes that may present in adolescence (Besag, 2016):

- Juvenile myoclonic epilepsy (JME).
- Juvenile absence epilepsy (JAE).
- Epilepsy with generalised tonic-clonic seizures on awakening.

- Benign partial seizures in adolescence.
- Photosensitive epilepsy.
- Reading epilepsy.
- Subacute sclerosing panencephalitis.
- Epilepsy from cortical brain tumours.

Depending on the epilepsy type or syndrome, some children may cease to have seizures as they grow older and no longer suffer from epilepsy. However, many will continue to have epilepsy into adulthood (Thomson et al 2013, Carbone et al 2013). This is why careful thought and consideration is needed when preparing young people to be more involved in their care and providing them with information in order to have them on the right path when transitioning to adult services. The next section looks caring for adolescents in paediatric hospitals and transitioning to adult services.

2.4 Caring for Adolescents in paediatric hospitals

It is important to appropriately plan health care geared specifically towards adolescents (Canadian Paediatric Society, 2008). In order to do this, Health Care Professionals (HCPs) need to have a good understanding of adolescent development and be aware of the issues and changes that occur during this period (as identified in Chapter 1), The age in which a child is deemed to be an adolescent can be anywhere from the age of 10-13 years up until 16-18 years depending on the source of the definition. The World Health Organization (WHO) and the Canadian Paediatric Society (CPS), define an adolescent as an individual aged between 10 and 19 years of age (CPS, 2003). In Ireland's paediatric hospitals, children are seen to be adolescents between the ages 12-18. In Ireland, new patients are only accepted if they are under 16 years of age. In many services, they begin transition to adult services at 16 years or even younger but cannot legally consent to medical treatment till the age of 18 (HSE, 2006). Comprehensive health care also requires a clear understanding of the legal and ethical issues that affect the adolescent population.

2.4.1 Tools for caring for Adolescents in Irish paediatric hospitals

There is an awareness of the need for adolescent friendly quality standards in hospitals and this is evident in the Adolescent Friendly Quality Assessment Tools (AFQuATs) that were developed by the Programme of Action for Children (PAC) and the Health Service Executive HSE (2006). The rationale for developing such a tool was to ensure quality services for adolescents and having the best possible

results. In order to achieve this, PAC in conjunction with the HSE began the process of creating the tool (AFQuATs). The following is a list of areas that are assessed:

- Accessibility of service
- Flexibility of service
- Staff training
- Quality information for young people
- Partnership approach
- Confidentiality and Privacy

One of the functions for this tool is to assess the quality of information provided by the service and a copy of the assessment tool can be seen in appendix 2.

2.4.2 Transition to adult services for adolescents with epilepsy

There are many transitions that occur throughout the normal development of children, from the baby stage right through to adulthood. Transition from childhood to adolescence appears quite challenging as there are many physical and psychological changes that occur. Upon reviewing the literature, it is quite clear that this process becomes even more challenging when the young person has a chronic health disease or illness (Simmons et al, 2014). Parents and health care professionals (HCPs) have an important role to play in ensuring that the children and adolescents in their care develop to become happy and healthy individuals who are increasingly independent with their own health and personal needs as they grow older (Sundstorm, 2007). Information about chronic diseases can be given to parents and children in various ways but it is important that the information given is suitable for the adolescent so they become more involved in their own care (Ancker & Kaufman 2007).

The process of transition from a children's hospital is a significant era for young people and can be overwhelming, especially when these young people have grown up with their disease and the paediatric health care team also. Many changes occur when adolescents become adults and this includes changes in the multidisciplinary team that cares for those with epilepsy (Maceleod & Appleton, 2007). Transition can also be dynamic with the main goal being to ensure the young person reaches their best potential in life and from their health. The approach should be very patient centred with careful and purposeful planning to minimise any fears and give more empowerment to the individual (Paediatrics, 2016).

2.4.3 Risks associated with lack of information

Children and teens with epilepsy need to be well educated about their disease management prior to transition from paediatric to adult services in order to alleviate any potential concerns and, maximise compliance and decrease potentially harmful self-management. Self-management is an essential component of transition and adherence to treatment plans can improve the level of self-care therefore limiting the potential risks. (Agarwal et al, 2014, Carbone et al, 2013, Snead et al, 2004).

One particular example of needing to be more knowledgeable includes the risks that can occur when there is a non-compliance with treatment, particularly medication (Kyngas, 2000). Medication compliance can be a problem for some adolescents with epilepsy due to the fact that they may not fully comprehend the consequences that can arise when they do not take their tablets or if they skip doses (Carbone et al, 2013, Kyngas, 2000, Jarvie et al, 1993). Good medication compliance means that the adolescent is fully aware of the reasons they need to take the medication and follows the recommended timing and dosage (Day et al, 1992).

The risk of seizure recurrence increases when there is non-compliance with medication which could lead to other complications for the adolescent such as; fear of being witnessed by one of their peers while having a seizure. Therefore, it is essential for adolescents to understand what the purpose of taking medication is in order to reduce the possibility of further complications arising before they become independent individuals that manage their own medication needs.

Transition for young people with a chronic disease such as epilepsy can be problematic if they were diagnosed early in life and there is evidence of gaps in communication between the individual with epilepsy and their HCP (Agarwal et al, 2014). Transition in health care is one particular occurrence that needs consideration for adolescents or young adults with chronic illnesses and special health care needs as they need to evolve from being dependent children to more independent adults (Winocour, 2014).

Good communication between adolescents and HCPs is essential prior to transition to adult services (Reiss & Gibson, 2002). In order to understand how HCPs can enhance their communication skills with adolescents, an exploration of how children and teens communicate and seek information is necessary. In Ireland, the process of transition from paediatric to adult services will soon become

standardised and a much smoother process due to the appointment of a Community Epilepsy Transition Nurse.

The role of this post will be shared across the three paediatric hospitals working in partnership with Epilepsy Ireland and is intended to improve the outcomes as well as engage this age group in their care and future healthcare needs and follow up (Epilepsy Ireland, 2016a). The following section addresses health information and communication in adolescence including how they prefer to access information according to the literature.

2.5 Health information

To empower individuals, it is important for anyone who suffers from a chronic illness to be well informed and knowledgeable about their disease. However, as health information is becoming more available and easier to access, there can be an overload of information particularly at the initial diagnosis of an illness (Tonberg et al 2015). The methods in which information is accessed and delivered are constantly evolving. This can make it easier to access multiple sources of information, however many of these sources can prove to be unreliable.

Information needs vary from person to person and also between different illnesses (Kivits, 2014). The position a patient is at in their disease trajectory can also be a factor that causes individuals information needs to differentiate. Patients suffering from acute health illnesses may not have the same information requirements as those with chronic illnesses (Kivits 2014, Celler et al, 2003). This is also true for people that are newly diagnosed with an illness compared with others that have been living with the same disease for many years.

2.6 Information and Communication in Adolescence

The strength of the relationship between HCPs and adolescents with epilepsy can be a factor that affects whether the adolescent with epilepsy listens to the advice and adhere to a treatment plan. HCPs can educate and teach skills to adolescents in numerous ways such as demonstrating, explaining, monitoring and giving feedback (Lewis et al, 2010). A greater understanding of how adolescents seek information and how they prefer it to be portrayed is needed in order to ensure that any resources provided for them will be appropriate to their specific needs and desires. Along with people of all ages, adolescents are becoming more technologically advanced and with easier

access to the internet, which could indicate that they are more likely to search online for answers to any questions they have. The methods in which adolescents seek information has been explored in the literature and findings will now be presented.

2.6.1 Health literacy and Information seeking habits of adolescents

The general consensus or belief is that adolescents are good at searching for information on the internet, this may be due to the fact that they access the internet as frequently as outlined in the statistics in the next section. However, the truth is that teens are not as good at finding information on what they are looking for as would be expected (Holmes, 2005). Teens are not as successful as adults when searching the web for answers and here are many factors causing their low success rate (Madden et al 2013, Loranger & Neilson 2013):

- Insufficient reading skills.
- Lack of experience using research strategies.
- Impatience when waiting for websites to load.
- They tend to get bored easily.

2.6.2 Internet access by adolescents

Globally, there is a high percentage of adolescents who have access to the internet and according to the PEW Research centre, approximately 24% of adolescents aged between 13-17 are online several times daily while 56% log in and out numerous times a day and 12% reported accessing the internet once daily. These significant numbers are aided by the number of adolescents that have internet access via smartphones, tablets and computers. (Lenhart, 2015). In Ireland, a high percentage of adolescents (86%) access the internet on a daily basis according to the Central Statistics Office (CSO) and approximately 62% go online via mobile phones while 88% use tablets or laptops (CSO, 2014). This is similar to the UK (89%) but lower than the number of teens in America where 93% have a computer or have access to internet at home and approximately 78% of adolescents now have a mobile phone (www.internetsociety.org 2016, Madden et al, 2013).

It is important to be aware of the internet usage statistics for adolescents here in Ireland compared to other countries to give an indication of how Irish teens fit in the global situation with regards to internet access. It is evident that Irish teens have good access to the internet (www.internetsociety.org 2016, Lenhart 2015), therefore, it would be valuable to learn about the

types of information that they seek online and gain an understanding of their abilities to find what they are looking for. It would also be important to know what adolescents want from online sources to ensure that recommended websites are appropriate for their needs and expectations. The following section looks at usability of websites for adolescents to give a better comprehension of what adolescents prefer when searching for information online.

2.6.3 Usability of online sources for adolescents

Human Computer Interaction (HCI) is an umbrella term regarding the interaction of people with technology and there are important factors to consider to ensure the interaction is positive (Carroll 2014, Dix 2004). One of the main focuses of HCI is Usability. Usability is a term used to describe how user friendly a computer system and user experience is the key concept (Chow et al 2014, Sharp et al 2007). Usability for adolescents differs from children and adults as they have different aspirations and needs when using computers, tablet devices or smart phones to search the internet.

Loranger and Neilson (2013) have researched how teenagers/adolescents search the internet and concluded that usability is crucial for teenagers and they generally have an end goal or specific reason for going online. The study found that adolescents dislike certain elements of websites and in their finding, they compiled a list of 111 important usability factors to consider when designing teen/adolescent specific websites. Francois-Beehan et al, (2015) conducted a review of children’s hospital websites by using some of Loranger and Neilson’s guidelines. Table 2 shows the 6 main points they used to review the websites and assess them for teen specific usability.

Table 2: Relevant guidelines for review of children’s hospital websites

| No | Relevant Loranger and Neilson Guidelines (Francois-Beehan et al, 2015) |
|----|---|
| 1 | Sites should be well written with short paragraphs with visual illustrations and no long paragraphs. Font should be clear. |
| 2 | Teens dislike boring sites and sites with too much unnecessary clutter. |
| 3 | Sites should load quickly. Teens do not have the patience to wait for a site to load. |
| 4 | Teens do not like to be categorized with kids. Teen sections should not be overly colourful or animated but should contain content from their peers such as real stories, images and examples from other teens. |
| 5 | The social aspects of the site should not be made public. Teens want to control what they share and who they share it with. |
| 6 | Sites must be usable on portable devices such as laptops, tablets and mobile devices without losing content. |

Their review of 297 children's hospital websites showed that just 32 had a teen section and they compared the usability of these websites using a checklist of 20 questions to ascertain the websites usability score for teens/adolescents. The top scoring websites had ease of access to teen section, real life stories and information regarding transition to adult services.

2.6.4 Adolescents and social media usage

Adolescents are increasingly using social media and there are many websites and apps that are easily accessed via smart phones, tablets and PCs. Research shows that approximately 71% of adolescents use more than one social media site. The main reason to use social media is to message peers and share information about themselves (Lenhart, 2015).

2.6.5 Communication habits of adolescents with chronic illnesses.

It is evident from the literature that while some differences exist between the various diseases, the information needs and communication needs of adolescents are mostly similar. Research carried out by Simmons et al (2014) on adolescents with haemophilia revealed that the scarcity of information can be distressing for teens. In order to help deal with the complex nature of haemophilia, teenagers want more information about the disease. This study also showed that adolescents liked searching online for answers and particularly enjoyed watching videos and hearing messages from others in their situation.

Similarly, research carried out by McDarby et al (2015) on adolescents with diabetes conveyed that the World Wide Web plays an important role in information seeking. The use of social media can be a powerful tool to group similar aged teens with the same condition together and link them with a HCP to answer any queries they have. This study used Facebook as a controlled online venue for teens to socialise and raise concerns about their diabetes amongst their peers and with the bonus of having access to a physician and psychologist as part of the Facebook group (McDarby et al, 2015).

It is essential for adolescents to have the skills to seek information and communicate with HCPs and others about their disease but it is also important to ensure that the information that is provided for them is correct suitable for their needs (Ha & Longnecker 2010, McCray 2005). The following section explores some of the available sources for epilepsy information in Ireland.

2.7 Methods of information delivery in Healthcare

The main method of information delivery in hospitals and healthcare centres is through clinicians on the wards or in clinic based settings. Education about the disease, treatment and self-management is discussed between the HCP and the patient. There are opportunities for questions to be asked and concerns to be raised. This HCP uses their own expertise and experiences of providing care for others with the same illness but can also be enhanced with other information sources such as:

1. Books.
2. Leaflets.
3. Internet sites.
4. Support groups.
5. Regional charities and events.

There are books/leaflets available for almost every condition, illness or disease and many of them have been compiled by the HCPs directly involved in patient care while some are produced by pharmaceutical companies or medical device manufacturers (see appendix 3 for examples of epilepsy information). The epilepsy Electronic Patient Record (EPR) that is currently used in a number of hospitals in Ireland is a great source for storing information about people with epilepsy and could prove to be a valuable source for extracting secondary data for research purposes. However, this is a fairly new service and is not available nationwide (eHealth Ireland, 2016, HRB 2016).

There is also limited information that can be downloaded from hospital websites regarding particular diseases. A variety of support groups and charities throughout Ireland provide funding, support and education about certain conditions and illnesses. The HCPs need to be aware of the best available sources before making recommendations to patients. For epilepsy information needs, there are well known sources that can be recommended to patients and these will be discussed in the following section in addition to the information needs of adolescents with epilepsy.

2.8 Information needs for adolescents with epilepsy

There is evidence from the literature to suggest that the information needs of young people with epilepsy are not being met and that they feel they are not being told enough which results in many of them feeling excluded (Sundstorm, 2007). This may explain why adolescents with epilepsy are more prone to having challenging behaviour and increased dependence on their parents/carers (Lua et al 2013, Freilinger et al 2006, Keene et al 2005). Adolescents are future adults and therefore need to be

more informed of their healthcare needs particularly those with epilepsy. According to Besag (2016), in addition to the occasional clinic visit or check-up there are many factors to be considered in the daily life of people with this neurological condition including the following:

- Seizures and safety (risk factors)
- Medicine side affects
- Effect of irregular sleep
- SUDEP (Sudden Unexpected Death from Epilepsy)
- Lifestyle choices
- Driving
- Alcohol
- Sport
- Environmental and Home Safety
- Pregnancy and contraception
- Work and disclosure

Many of the above have been considered by parents and caregivers on behalf of children with epilepsy but as they grow older and want to be more involved in their own care, they need to be educated on these topics. Literature suggests (Eseibge et al 2014, England et al 2012, Lewis et al 2010) that adolescents have limited knowledge of epilepsy and the importance of the vital information regarding these topics. Studies have shown that children and adolescents with epilepsy only have a slightly higher knowledge base or understanding of the disease than those of their peers without epilepsy (Lua et al 2013, McNeilus et al 1998).

This is alarming because adolescents need to become better informed in order to gain more control of their epilepsy so that they can live their adult lives as independently as possible. The level of independence that can be achieved varies from person to person depending on the severity of the epilepsy and seizures associated with each person. As stated, there are many types of epilepsy and each adolescent can be affected in different ways. The type of epilepsy can be a factor that limits the degree of independence that individuals can potentially have, therefore it is important to manage the adolescent's expectations for independence in accordance with their abilities and unique characteristics of the disease that they have (England et al, 2012).

It is important to realise that a person with epilepsy is reliant on others with regards maintaining a safe environment. Although the ultimate aim is to ensure that adolescents with epilepsy will become adults leading independent lives, there may always be a dependency on others, particularly in times of seizures that cause a loss of consciousness (Besag, 2016). The following section explores the “best of breed” in terms of guidelines for information delivery and topics to be covered when caring for adolescents with epilepsy which, if followed, will ensure that they are well equipped with knowledge prior to transitioning to adult services.

2.9 Complete and useful information for adolescents and their families

As the title of this dissertation is “An exploration of information needs for adolescents with epilepsy.”

It is important to explore:

- (i) What are the best standards for delivering information to adolescents with epilepsy?
- (ii) What topics need to be covered?
- (iii) When is the most suitable time to deliver the information?

Some of the topics that need to be covered have been mentioned in section 2.8 but it is essential to be aware of what is recommended by the experts in the field to ensure that the information is as complete and useful as possible. The researcher carried out a review of the organisations that suggest information topics about epilepsy in Ireland, Scotland and the UK (United Kingdom). The review in Ireland included the HSE (Health Service Executive), Epilepsy Ireland and Spunout as the three combined cover a more complete list of topics. In Scotland the chosen organisation to review is SIGN (Scottish Intercollegiate Guidelines Network), and in the UK a review of the NICE (National Institute for Health and Care Excellence) guidelines was carried out in relation to their policies for providing information in epilepsy care.

This was done to achieve a greater understanding of what topics should be discussed with children and adolescents who have epilepsy in order to give an overview of the most complete and useful information needed to provide the best possible care. It is important to realise that there are guidelines in other English speaking countries such in Europe, America, Canada but the reason for choosing the UK and Scotland to review was because of their proximity to Ireland and ease of access to the policies of these organisations. The afore mentioned organisations have created policies for providing information to young people with epilepsy and these policies will now be briefly discussed.

2.10 Availability of Epilepsy information in Ireland

The majority of the information that is available to adolescents with epilepsy in Ireland is provided by the following organisations:

1. HSE (Health Service executive).
2. Epilepsy Ireland.
3. Spunout.

2.10.1 Health Service Executive (HSE)

The Health Service Executive (HSE) is an organisation that runs all of the public health services in Ireland under the remit of the Department of Health (DOH). See appendix 4 for diagram of the organisational structure. In Irish hospitals, information leaflets are mainly provided by the HSE and also there is a website where information can be sought, downloaded and printed (www.hse.ie). The epilepsy section is informative and concise and there are multiple links to other sites for those seeking further information (HSE, 2016).

Presently, there is no specific national standard in place for the management of epilepsy for young people in Ireland; the HSE follows the NICE guidelines which will be discussed in UK section. However, even though there is no standard in place, the HSE has developed a National Clinical Programme in Epilepsy Care. The National Epilepsy Care Programme (NECP) created a draft document which determines the best way to deliver epilepsy care for all with epilepsy in Ireland and includes a section specifically for paediatrics. The NECP was established in 2010 and the document provides the vision of epilepsy care over a 10-year period. The overall aim of the programme is outlined below (HSE, 2016):

“To provide the best value, safe care for all people with epilepsy in the right place, at the right time, sharing the best available information.”

The aim is to be achieved by addressing three core objectives:

1. Improving access to expert care and information.
2. Improving the quality of care across the healthcare spectrum from prevention, through managed primary care to complex surgical care for difficult epilepsy
3. To improve value conscious care by shifting care where possible from expensive hospital based care to the community.

It is clear to see that there is a realisation that a standardized, evidence based, approach needs to be developed. It is also evident that the information needs of HCP's who care for people with epilepsy

and also the information needs of people of all ages and with all forms of epilepsy, is considered of the utmost importance in this document.

2.10.2 Epilepsy Ireland

Epilepsy Ireland is an association formed 50 years ago to educate the people of Ireland about epilepsy, provides all five sources of information mentioned in section 2.7. The following is a list of Epilepsy Ireland's objectives (Epilepsy.ie, 2016):

- To provide support, information and advice to people with epilepsy.
- To provide information and advice to health professionals in dealing with epilepsy.
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice) through awareness campaigns and education programmes.
- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition.
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them.
- To assist in support groups for people with epilepsy for training and employment.
- To provide information on issues related to driving: insurance, changing legislation.
- To provide practical aids to people with epilepsy (pillows, bracelets).
- To operate as a public forum and an advocate for the condition of epilepsy.
- To raise funds to support its work in an awareness-creating manner.

2.10.3 Spunout

Spunout is a website that provides information about education, employment and health, created for young people by young people. It is another example of a valuable source for adolescents with epilepsy. There is a section specifically for epilepsy and provides information about the factors which adolescents would be most concerned about (Spunout.ie, 2016). This website is aimed specifically towards young people and is a good resource for adolescents seeking health related information. (Spunout.ie, 2016).

The above three organisations show that there are many sources of health information for people affected by epilepsy including age specific websites. They are excellent sources of information in Ireland for adolescents with epilepsy and together cover an extensive list of topics. However, more information is needed to determine if these sources are accessed by the targeted audience and also if the information provided along with the education given by HCPs is sufficient.

2.11 Availability of Epilepsy information in Scotland

2.11.1 Scottish Intercollegiate Guidelines Network (SIGN)

In 2005 under the remit of the NHS (National Health Service), a guideline was developed in Scotland for the diagnosis and management of epilepsy in adolescents. Even though the guideline has not been updated since the initial publication, many of the topics are still relevant today. Within the guideline there are information checklists for specific age groups along with a general epilepsy information checklist. The recommended topics to be discussed with young people older than 12 years are (Sign.ac.uk. 2016):

- Explanation of epilepsy
- Probable cause
- Recurrence risk
- Explanation of investigative procedures
- Classification of seizures
- Syndromes
- Prognosis
- Epidemiology
- Genetics
- AEDs
- Lifestyle; safety, education
- First aid
- Sudden death in epilepsy (SUDEP)
- Driving
- Employment
- Relationships
- Alcohol and recreational drugs
- Seizure triggers
- Contraception & Preconception
- Pregnancy and breastfeeding
- Free prescriptions.

The above list given above was compiled from section 4.1.1 of the guideline and consolidates with the NICE guideline. The remit of the guideline is to ensure that people with epilepsy have access to clear and accurate information and that the quality of the information is as important as the way in

which it is delivered. The guideline recognises that information needs vary and advised providers of the information to compliment the receivers' needs.

2.12 Availability of Epilepsy information in the UK

2.12.1 National Institute for Health and Care Excellence (NICE)
NICE (2012) have compiled a standard which outlines the best clinical practice for caring for children and young people with epilepsy. The standard covers management and diagnosis of epilepsy for young people up to the age of 18 years. NICE guideline CG137 titled "Epilepsies: Diagnosis and management" has a section listing information topics that young people with epilepsy and their families should be aware of. The following is the list as suggested by the NICE guideline:

- Epilepsy in general
- Diagnosis and treatment options
- Medication and side effects
- Seizure type(s), triggers and seizure control
- Management and self-care
- Risk management
- First aid, safety and injury prevention at home and at school or work
- Psychological issues
- Social security benefits and social services
- Insurance issues
- Education and healthcare at school
- Employment and independent living for adults
- Importance of disclosing epilepsy at work, if relevant
- Road safety and driving
- Prognosis
- SUDEP
- Status epilepticus
- Lifestyle, leisure and social issues
- Family planning and pregnancy.
- Voluntary organisations.

Apart from this extensive list, the guidelines states that information should be given at the appropriate time and in suitable formats for each individual to ensure it is presented in a way that the young person understands with sufficient time given at consultation (NICE, 2012). There are many topics

included in the list which convey the many considerations to be taken into account for people with epilepsy throughout the care and management of the disease from medication to education, work, driving and family planning. The list covers every situation that an adolescent could potentially go through in life which suggests that the NICE guideline could be used as the gold standard by other organisations by providing a comprehensive list to adhere to.

2.12.2 Summary of the review

All three of the Countries have recognised the importance of having information aimed specifically at the needs of the individual recipient. However, each Country is at different levels in their provision of up to date information. In Ireland, while the HSE runs the health system, it is not the main source that provides information but there are links on the website to external sources for those seeking more information. The majority of leaflets given to adolescents with epilepsy in Ireland are funded and provided by Epilepsy Ireland and the website is a valuable online source with information on many topics available. Spunout is a great online source for teens and provides information on social and lifestyle but is not as detailed as the HSE website or Epilepsy Ireland. The HSE realise the need to update and improve the service for those with epilepsy in Ireland and this is evident with the NECP. There is also plenty of work being carried out to ensure people with epilepsy in Ireland not only receive the best and most up to date information but are also heavily involved in any improvements to be made including the introduction of the epilepsy EPR (HRB, 2016).

In the UK, the NICE guidelines are well established and appear to be updated regularly in line with emerging knowledge and evidence. There is a vast amount of information and the guidelines give HCPs clear indication of topics needed to be approached for adolescents with epilepsy. In Scotland, SIGN had created guidelines over a decade ago but have failed to update it since it was created which would suggest that it should be renewed as many developments have occurred in the past 10 years both in healthcare management and technology in healthcare.

There are similarities in the suggested topics to be discussed in the three countries, which help towards providing a picture of what can be defined as “complete and useful” information. Table 3 is a compilation of the topics recommended by each of the organisations mentioned.

Table 3 recommended topics by the different organisations

| UK | Scotland | Ireland | |
|---|--|---|---|
| NICE | SIGN | HSE | Epilepsy Ireland |
| <ul style="list-style-type: none"> - Epilepsy in general - Diagnosis and treatment - Medication side effects - Seizure type(s), triggers and seizure control - Management & self-care - Risk management - First aid, safety and injury prevention - Psychological issues - Social security benefits and social services - Insurance issues - Education and healthcare at school - Employment and independent living for adults - Importance of disclosing epilepsy at work, if - Road safety and driving - Prognosis - SUDEP - Status epilepticus - Lifestyle, leisure and social issues - Pregnancy - Voluntary organisations, | <ul style="list-style-type: none"> - Explanation of epilepsy - Probable cause - Recurrence risk - Explanation of investigative procedures - Classification of seizures - Syndromes - Prognosis - Epidemiology - Genetics - AEDs - Lifestyle education - First aid - SUDEP - Driving - Employment - Relationships - Alcohol and recreational drugs - Seizure triggers - Contraception & Preconception - Pregnancy and breastfeeding | <ul style="list-style-type: none"> - Epilepsy type - Epilepsy symptoms - Triggers - Diagnostic tests (EEG, CT, MRI) - Treatment (AEDs, Surgery, VNS, Ketogenic diet) - Self-care - Health and lifestyle - Driving - Education and employment - Women with epilepsy - Contraception - Pregnancy - Entitlements - Status epilepticus - SUDEP - Long Term Illness Scheme (LTI Scheme) - Links to useful organisations (www.ilae.org, www.epilepsy.ie) | <ul style="list-style-type: none"> - Epilepsy cause & type - Epilepsy Syndromes of Childhood & Adolescence - Seizure types - Seizure recording - Seizure triggers - Diagnosis (imaging, blood tests, EEG) - Treatment (AEDs, VNS, Surgery) - Lifestyle: (Sport, Leisure, Discos, TV, alcohol, travel) - Work - Safety in the Home - Parenting Young People with Epilepsy - Folic Acid - Contraception for Women - Republic of Ireland Pregnancy Register - Explaining Epilepsy to a Child - Epilepsy & Autism |

There are also many suggestions from the documents created by the organisations that were reviewed to suggest that information delivery could be improved or assisted by Information Communication Technology (ICT) and the next section discusses the methods of delivering information in healthcare and the potential role of ICT. The researcher grouped the topics under separate headings and these can be seen in table 4.

Table 4 topics grouped by subject matter

| Disease | Lifestyle issues: | Safety: | Information access |
|--|---|---|--|
| Epilepsy definitions Diagnostic procedures tests involved Disease and Seizure classification Syndromes Seizure triggers and control Treatment options Medication management Genetics Epidemiology Prognosis | Education Employment issues Social and cognitive issues Psychological issues Relationships Women and folic acid Family planning, Preconception Pregnancy Travel and commuting issues Insurance issues Entitlements | First aid Driving regulations and road safety Alcohol and drugs Disclosure of epilepsy to others SUDEP Status epilepticus Self-care and risk management Seizure triggers Sleep Stress | Leaflets Books Voluntary organisations Secure online sources Peer support groups EPRs Mobile Applications |

2.13 Potential role of ICT in healthcare information.

ICT advances happen continuously and the importance of investment in ICT has been identified by healthcare governing bodies worldwide. Organisations such as HIMSS (Healthcare information and Management Systems Society) ensure that healthcare delivery is improved through the use of ICT (HIMSS, 2014). This in addition to the overwhelming statistics of internet usage would suggest that use of ICT could benefit people with health needs, particularly young people (Lenhart, 2015). The world wide web has already got a huge part to play in ensuring information is available globally. It has been clearly shown that the ease of access to health information is important to people but more needs to be known about what people want from the information they seek and how they would like it to be portrayed.

2.14 Potential role of ICT in health information in Ireland

The HSE recognises the importance of ICT in healthcare and this is evident in the eHealth strategy for Ireland (HSE, 2013). The strategy aims to integrate information and knowledge sources involved in the delivery of healthcare via information technology-based systems. There are also many other projects that are underway that will improve the delivery of healthcare in Ireland and some are specifically focusing on epilepsy such as:

1. Epilepsy EPR, Beaumont
2. Lighthouse Project
3. Epilepsy Ireland app

2.14.1 Epilepsy EPR, Beaumont

An electronic patient record (EPR) developed at Beaumont Hospital is improving the care of patients with epilepsy. Compared to traditional paper-based records, the EPR means fewer delays for patients in receiving the clinical services they need, and it also helps to monitor, improve and streamline how the epilepsy service is provided (HRB, 2016).

2.14.2 Lighthouse Project

The Lighthouse project involves genomic sequencing of an individual patient; this would allow scientists to read genetic codes so they can make comparisons between normal versions of a gene and disease-causing versions of a gene thereby assisting in developing a treatment and care pathway. (eHealth Ireland, 2016).

2.14.3 Epilepsy Ireland application

Epilepsy Ireland have developed an application which enables users to track and record their seizures, as well as identify potential trigger factors and seizure patterns. Some of the features include the ability for parents or family members to quickly capture and link videos to a person's seizure record and it also has customisable emergency SMS ready to send with one touch e.g. during aura stage or following a seizure. The app is still in development and feedback is welcomed for suggested improvements (epilepsy Ireland.ie, 2016b).

2.15 Summary

This chapter aimed to give an overview of the ways in which young people seek information and outline the specific information needs for adolescents with epilepsy. Epilepsy as a chronic disease was discussed in detail. The impact that such an illness can have on an adolescent's life along with need for smooth transition to adult services was also discussed in accordance with the available literature. Adolescents are likely to search online for answers as access to the internet is at their fingertips, but more education about where to look for useful information is needed as adolescents are not as good at finding information as may be assumed. Availability of clear and accurate health information is essential for people of all ages living with chronic diseases. However, it is important for guidelines to be in place to ensure all the relevant topics are covered and discussed with HCPs. ICT does have a role to play in healthcare information delivery and there are many organisations and services that use ICT to promote and improve healthcare.

2.16 Conclusion

Completeness of information is essential for adolescents as they transition to adulthood. There are many topics that need to be discussed such as disease type, lifestyle issues and safety concerns to ensure that young people have more control of their lives from the physical, psychological, cognitive and social perspectives. The HSE are making great advances in epilepsy care with the NECP and it is hoped that they take into consideration the needs of people of all ages with epilepsy, particularly adolescents.

Although the majority of topics are recommended via the HSE website and Epilepsy Ireland, there is no defined list and the information is accessible from the one source. The HSE could follow the lead of the NICE guidelines with regards the level of information and topics that need to be discussed with young people as their list appears to be the most complete, covering all the essential issues for adolescents before, during and after transition to adulthood.

ICT is emerging as a significant factor of epilepsy care in Ireland with the development of the EPR, Lighthouse project and with the Epilepsy Ireland application (eHealth Ireland, 2016, HRB 2016). The following chapters outline the primary research that was carried out following the literature review. The methods used to recruit participants, capture data and analyse the results will be covered along with the ethical journey.

Chapter 3. Research Methods

3.1 Introduction

This chapter explains the formulation of the research design behind the study and outlines the methodology that was used in order to answer the research question. Firstly, an overview of research methodology and study design will be given, then explanations of how the study cohort was chosen and how the data was collected and analysed.

Although it may be considered an appropriate chapter to discuss the ethical aspects of the study, the researcher believed that ethics warranted a full chapter as it was a major part of the primary study and took a considerable amount of time and effort to ensure all requirements were met. Therefore, ethics will be mentioned in this chapter when discussing interview structure and design. There will be greater emphasis on the ethical application process in Chapter 4. This chapter will be concluded by discussing the data validity and the limitations of the study design.

3.2 The Research Process

The research process describes what happens in a study from the beginning right up to the end, it outlines the tasks that were carried out to answer the research questions. The process can be influenced by many factors including; the researcher's beliefs, ethical considerations, work practices, available support and resources (Parahoo, 1997). Formulating these questions and choosing the initial topic was the first step in the research process, the second step was to do a review of the literature that was relevant to the chosen topic and question as outlined in the first two chapters. This section aims to give an overview of the steps in the research process that were used in this study after finalising the topic or research question and carrying out the initial literature review. The aim is to outline the methods used to define the type of research to be used along with the reasons for the chosen study population and will be explained under the following headings:

- Selecting a research design.
- Narrowing the topic.
- Choosing the study cohort.
- Location and source of data.
- Methods of data collection.
- Method of data analysis.

3.2.1 Selecting a Research Design

After the topic was decided upon and the research questions were identified, the appropriate methodology was considered. The terms research design and research methodology can be used interchangeably but both terms are used to describe the process of collecting and analysing data in addition to explaining how participants were chosen or recruited (Creswell 2012, Parahoo 1997). Therefore, the researcher decided to use a mixed method approach combining both qualitative and quantitative methods to gather both primary and secondary data in order to answer the research questions as outlined in chapter 1.

A general definition of this type of research methodology was offered by Johnson et al (2007) after they analysed 19 definitions of mixed methods research by leaders in the Field:

“Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.” (pg. 123)

The above definition gives an explanation of the planned approaches for this study. Although this study may appear mainly qualitative due to the number of participants recruited in the primary research, it involves a mixture of two methods as there is also a quantitative element with the collated data from the questionnaires and the literature review.

3.2.2 Narrowing the topic

Epilepsy and the information needs for people with the disease was always the topic of choice for the researcher. Initially, the researcher hoped to gather data from as many people with epilepsy as possible regardless of age or variation of the disease. The original idea was to interview both HCPs and people of all ages with epilepsy to learn about the opinions of all involved about the information resources currently available in Ireland. It was hoped that by carrying out such a study, an overview of the current opinion regarding the information needs and expectations of the various age groups affected by the many stages of the disease would emerge. The aim initially was to give a general consensus of what is happening in current practice and also identify if any changes need to be made. This started to become an overwhelming task even in the early stages when searching for

information in the literature review and discussing the idea and plan with HCPs. Therefore, the choice to narrow the topic became an obvious but regrettable one.

Although the decision to limit the cohort was difficult at first, the researcher soon realised the potential difficulties and workload that could arise from having such a broad topic and cohort. The topic remained the same but the criteria for potential study participants were changed in order to identify information needs in a more focused group of people.

3.2.3 Choosing the study cohort

As a children’s nurse working in the Outpatient department (OPD) in one of Dublin’s Children’s hospitals, the choice to focus on children seemed appropriate. Having experience in obtaining consent and assent in a previous role as a clinical research nurse geared the decision to focus on older children/adolescents as there was an awareness of the potential difficulties that could arise when interviewing young children. Knowledge and experience working with adolescents also enhanced the decision to focus on 12-18 year olds as the belief was that this age group would be more accessible and able to answer questions due to their desire to be more independent and involved in their healthcare. Table 4 shows the inclusion/exclusion criteria for participants:

Table 5 Inclusion/exclusion criteria for participants

| Inclusion Criteria | Exclusion Criteria |
|--|---|
| Adolescents (both male and female) diagnosed with epilepsy aged between 12 and 18 years, | Children <12-years-old with epilepsy and their parents, |
| Parents/guardians of the 12-18 year olds with epilepsy, currently attending one of the three children’s hospitals in Dublin, | 12-18 year olds that do not have epilepsy or their parents and are not currently attending one of the three children’s hospitals in Dublin, |
| HCPs that care for children and adolescents with epilepsy | HCPs that do not care for children/adolescents with epilepsy, |
| Willing participants aged 12-18 that have signed consents/assent forms | Unwilling participants or absence of signed consent/assent forms |
| English speaking participants that are able to comprehend the questions and also answer them | 12-18 year olds that are unable to answer or comprehend the interview questions |

3.2.4 Location and source of data collection

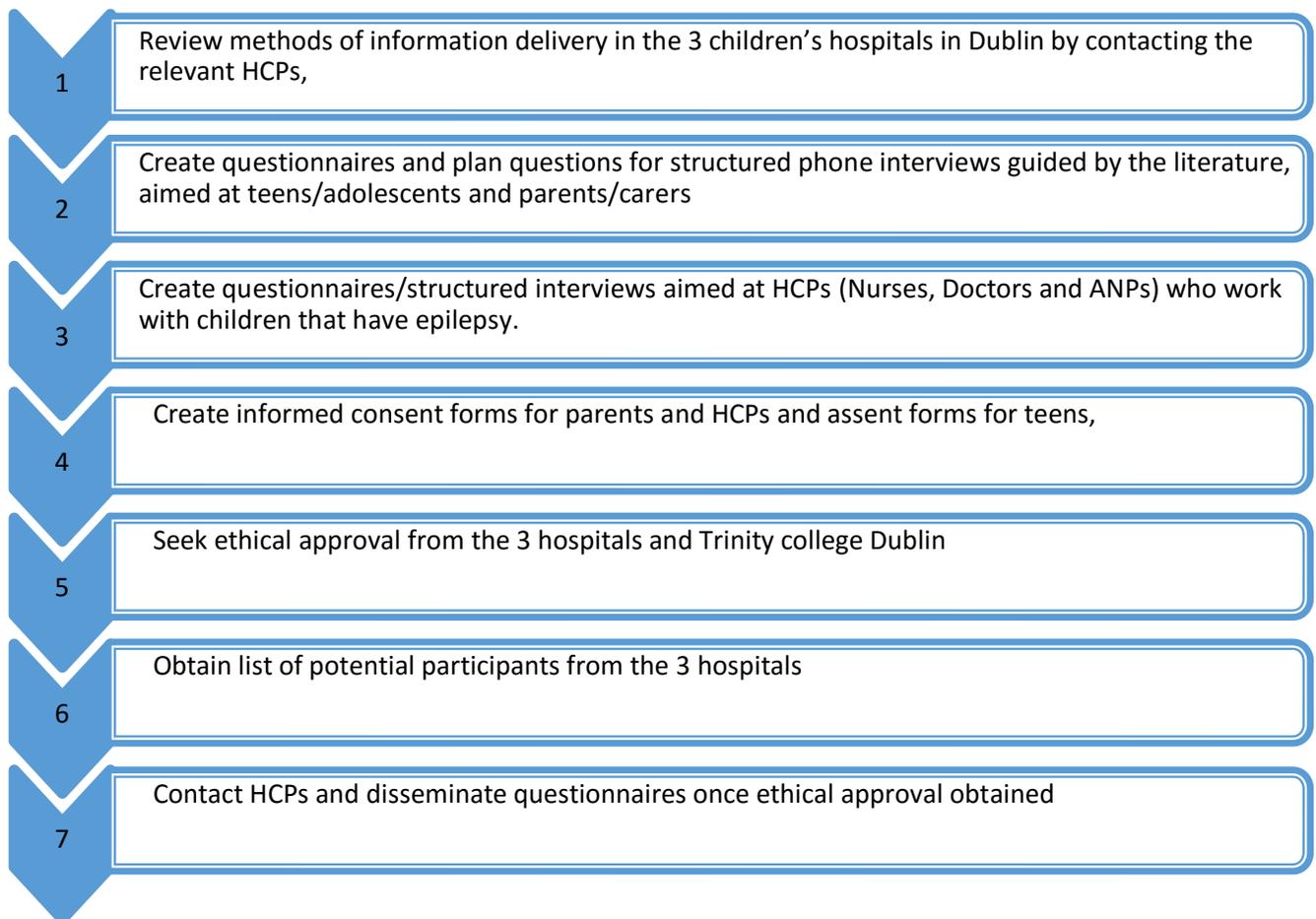
As the researcher has worked in all 3 of the children’s hospitals in Dublin in different contexts, the decision was made to recruit adolescents from each of these hospitals and gain an overall picture of the adolescents’ views of available information regarding their epilepsy. This in addition to the potential amalgamation of the three hospitals encouraged the researcher to seek ethical approval and recruit participants in the following hospitals:

1. AMNCH: The Adelaide and Meath incorporating the National Children’s Hospital, Tallaght
2. OLCHC: Our Lady’s Children’s Hospital Crumlin, Dublin
3. TSCUH: Temple Street Children’s University Hospital, Dublin.

3.2.5 Methods of data collection

The researcher planned to obtain a purposeful selection of suitable participants from each of the above mentioned hospitals either from database/registries of adolescents with epilepsy or from the HCPs working in Neurology who would be in a position to identify possible candidates. Potential candidates were identified, who the researcher felt could complete questionnaires or participate in structured interviews. The questions in both data collection methods were guided by the literature review and designed to answer the research questions. In order for this to take place, ethical approval needed to be obtained from each of the hospitals and the academic institute in which the researcher was attending. The ethical process will be discussed in detail in chapter 4. A brief overview of the planned steps involved in collecting the data is given in figure 1.

Figure 1: Overview of data collection methods



3.2.6 Method of data analysis

The plan was to compile a spreadsheet to collate all the data collected after all questionnaires were returned and interviews completed. More details of this analysis can be seen in chapters 5 & 6.

3.2.7 Summary

This chapter described the research process that was used in this study with an explanation of why the study location was chosen in addition to the reasons for the chosen study participants. The planned methods of data collection and analysis were explained. This chapter outlined the methodology employed to explore the research questions and the rationale for same was provided along with the motivation behind the research.

3.2.8 Conclusion

This research was an explorative one which used a mixed method approach to learn about the information needs of adolescents with epilepsy. This topic needs addressing but is also a sensitive subject to approach especially in young people that are unable to give consent for treatment or to provide answers to research questions, even if they would like to. The original plan changed for various reasons and the ethical processes caused many of these adaptations in the design and plan for primary research. The following chapter presents the ethical component of this study and the challenges faced when obtaining approval to interview adolescent patients.

Chapter 4. Ethics

4.1 Introduction

Ethical approval to carry out research in paediatric settings can be difficult to obtain due to the sensitive nature surrounding paediatric patients with health issues and chronic diseases. This study proved no exception therefore the ethical application presented challenges. However, many lessons were learned which is a positive reminder that the ethical needs of children and adolescents in our paediatric hospitals are being catered for and all measures are put in place to ensure their safety is always at the forefront. The researcher found it reassuring to learn that the needs of children and adolescents are being met in the three hospitals that ethical approval was sought from. This chapter explains the difficulties faced from the time the study cohort and potential sites were chosen until the applications were finally accepted and approval was granted. Although the journey was a difficult one the understanding and knowledge gained from the process was invaluable.

4.2 Importance of Ethics

As stated, ethical implications need to be considered at every stage of the research, even from the outset when deciding on a topic right through to the design selection and right up to the conclusion when conveying any findings in a paper or dissertation (Parahoo, 1997). This study relied heavily upon ethical approval which ensured all participants were not placed in any harm and were treated fairly.

4.2.1 Research and ethics in children/adolescents

The Department of Health and Children (DOH, 2000) and Department of Children and Youth Affairs (DCYA 2012, DCYA 2011), recognise that research and healthcare involving children is essential in order to protect, promote and support their health and well-being. There are specific issues arising from children's and young people's legal status, their knowledge and experience of the world, their differing levels of cognition and their relative lack of independence and autonomy, all of which require particular attention in order to ensure appropriate and ethical research practice.

4.3 Ethical application Plan for this Study

The researcher wished to pursue the three children's hospitals with the vision of generating a clear overview of the methods of information delivery used to educate adolescents about their epilepsy both at diagnosis and throughout their care. The aspiration was to recruit adolescents with epilepsy

from each of the hospitals to participate in a structured interview or complete a questionnaire in order to gain an overview and compare/contrast the methods of disseminating information from the perceptions of adolescents attending the three hospitals.

4.4 Preparation

4.4.1 Ethical application form completion

The Health Research Board state that a well written application is one of the key ingredients required when seeking ethical approval in addition to a good idea and sound methodology (HRB, 2016). The ethical application form used for submission to the three hospitals was version (V5.6) of the “Standard Application Form for the Ethical Review of Health-Related Research Studies, which are not clinical trials of medicinal products for human use as defined in SI190/2004” (see appendix 5). This is the form that is recommended by the Health and Research Board (HRB) and also deemed sufficient by the ethics committee board of each of the hospitals. This form is informative with detailed instructions of how to complete.

4.4.2 Information leaflets

Patient Information leaflets (PILs) are an essential component when recruiting people of any age to participate in research whether it is for academic purposes or for a clinical trial (Dawson & Spencer 2005). Participants need to be well aware of the following before informed consent can be given:

- Study background
- Rationale for the study (why it is being carried out)
- Aim of the study
- Why they have been asked to take part
- Procedures and potential risks
- Confidentiality measures
- They can leave the study or withdraw consent at any time

The information leaflets that were created for this study had adolescents in mind. The language used was easy to read without being childish. Adolescents can get bored easily and do not like to read long detailed paragraphs (Madden et al 2013, Loranger & Neilson 2013). The researcher ensured all information was included without overloading the potential participants with unnecessary information. Appendix 6 shows a copy of the information leaflet used in this study. The three children’s hospital logos are included in addition to the Trinity college logo as it was hoped that all three hospitals would be included.

4.4.3 Consent and assent forms

The process of obtaining informed consent is challenging for research but can become even more so when the research involves people under the age of 18 such as children and adolescents because of the issue of competence. Young people <18 years must be deemed competent to understand what the research aims and benefits and be aware of the implications of the research in order to give appropriate consent. (Dawson & Spencer 2005, Royal College of Paediatrics, 2000). The consent forms used for this study are attached to the PIL and questionnaire and includes room for the adolescent, his/her parent and the researcher to sign and date. A copy of the form is shown in appendix 7.

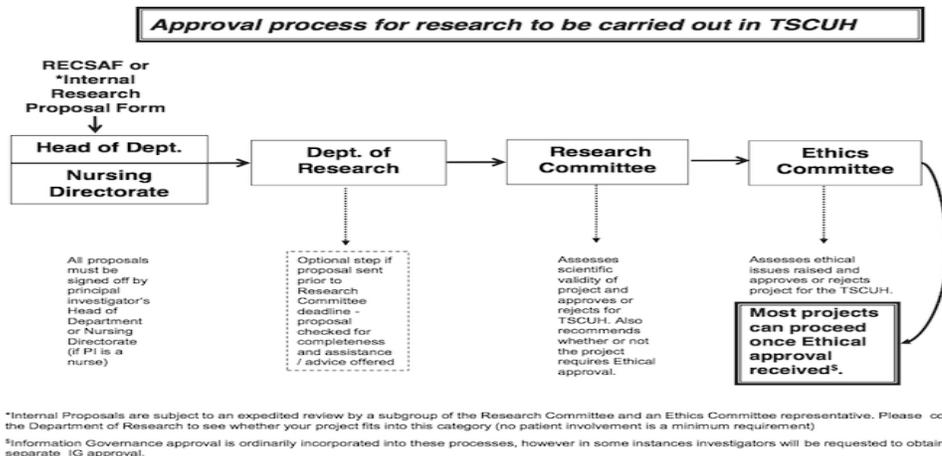
4.5 Application Process

4.5.1 Submission of application forms.

After the preparation of the documents as outlined above, the next step was to apply to each of the three hospitals. The initial submission was using the standard form mentioned in section 4.4.1 and the researcher completed the form stating that structured interviews was the method of data collection as opposed to questionnaires. This form and copies of patient information leaflets explaining the interview procedure to both parents and adolescents were submitted. The reason for introduction of questionnaires and changes made to the application forms will be explained in section 4.6 when discussing the procedures in each of the hospitals. Ethical approval was also sought from Trinity College Dublin and the process for this will also be discussed. Figure 2 below shows an example of the typical approval process in TSCUH which is similar to the procedure in most hospitals. This process conveys the complexity of the approval process.

Figure 2: Typical Ethical Approval Process Temple Street (CUH, 2016)

All research undertaken at Temple St Children's University Hospital must undergo a strict approvals process before it can begin.



The process in each of the hospitals differed in many ways. Therefore, each of these journeys will be explained separately to convey the researcher’s experience and ethical journey for this study.

4.5.2 Journey of ethical application process, TSCUH

After submitting the application by email to the ethics committee in Temple Street on 01/01/2016, a confirmation email was sent in return on 01/01/2016 to confirm application had been received. Then on the 03/01/2016, the researcher was invited to attend an Ethics Committee Board meeting to discuss the plans for the study and any concerns that the committee had.

4.5.2.1 Interview with ethical committee TSCUH

The interview took place on the 09/02/2016 with the researcher and approximately 13 members of the Ethics Committee Board. The researcher introduced herself and explained the aims and rationale for the study. Each member of the committee had the opportunity to raise any issues or concerns that they had. After the interview was completed, a letter was posted to the researcher outlining reasons for initial refusal in addition to some suggested changes. A copy of this letter can be seen in appendix 8.

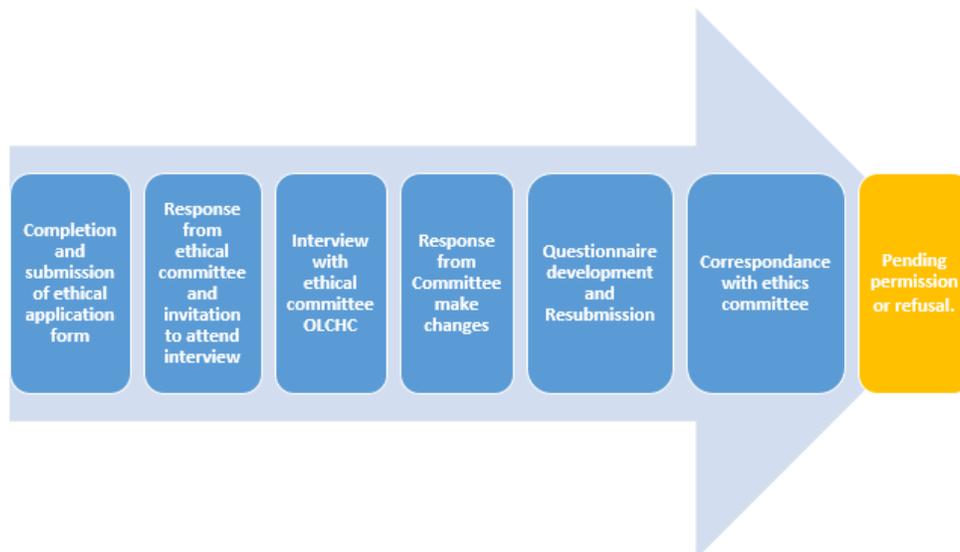
4.5.2.2 Resubmission

After receiving the letter from TSCUH Ethics Committee, the researcher made suggested changes including the development of the questionnaire. This process will be explained further in section 4.6. Once all changes were made, the amended application was submitted on 14/03/2016.

4.5.2.3 Correspondence

The researcher has been in contact with the committee and is awaiting word of confirmation for either acceptance or refusal. Figure 3 shows the steps in the journey for ethical approval in TSCUH:

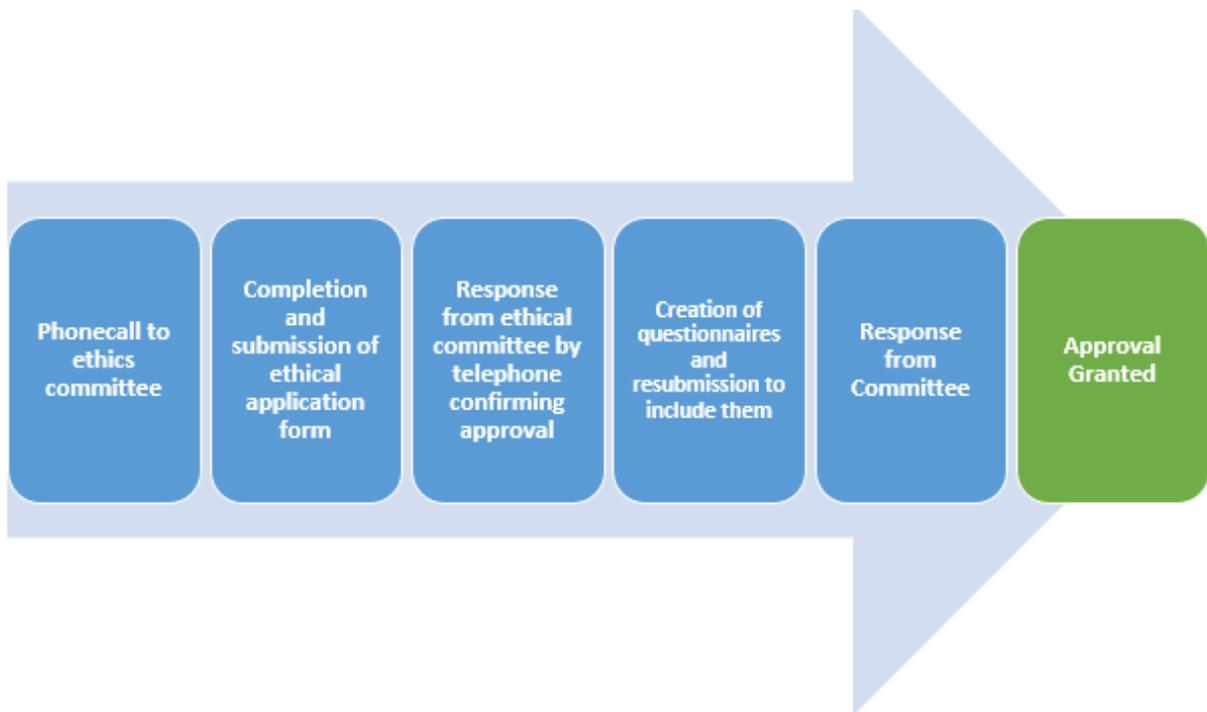
Figure 3: The researcher’s journey for ethical approval TSCUH



4.5.3 Journey of ethical application process, AMNCH

The application process in AMNCH proved to be less complex. The initial application was emailed on the 01/02/2016 after a discussion with a member of the ethics committee to ensure the correct measures were being taken. In the meantime, the meeting with TSCUH took place where the suggestion to incorporate questionnaires arose. The decision to create questionnaires meant either a resubmission to ethics board in AMNCH to include the questionnaires or to continue with original application and just do structured interviews. The researcher decided to resubmit and include the questionnaires as they had already been created. Figure 4 shows the steps in the journey:

Figure 4: The researcher's journey for ethical approval, AMNCH.



After ethical approval was granted, the researcher prepared questionnaire packs to be disseminated to suitable adolescents at clinics that met the inclusion criteria. The pack included the questionnaire and two copies of the consent forms and PILs (one copy to be returned to the researcher and the other to be kept by the participant). A copy of the ethical application including questionnaires disclosed as one of the proposed procedure is shown in appendix 9 and the approval letter is shown in appendix 10.

4.5.4 Journey of ethical application process, OLCHC

There were many difficulties encountered throughout this particular journey. The first step was to email the application; this was done on the 02/02/2016. Confirmation that the application was received via email and telephone with a request for multiple copies of the application form. These were posted as requested, then an invitation to attend a meeting with the committee was received.

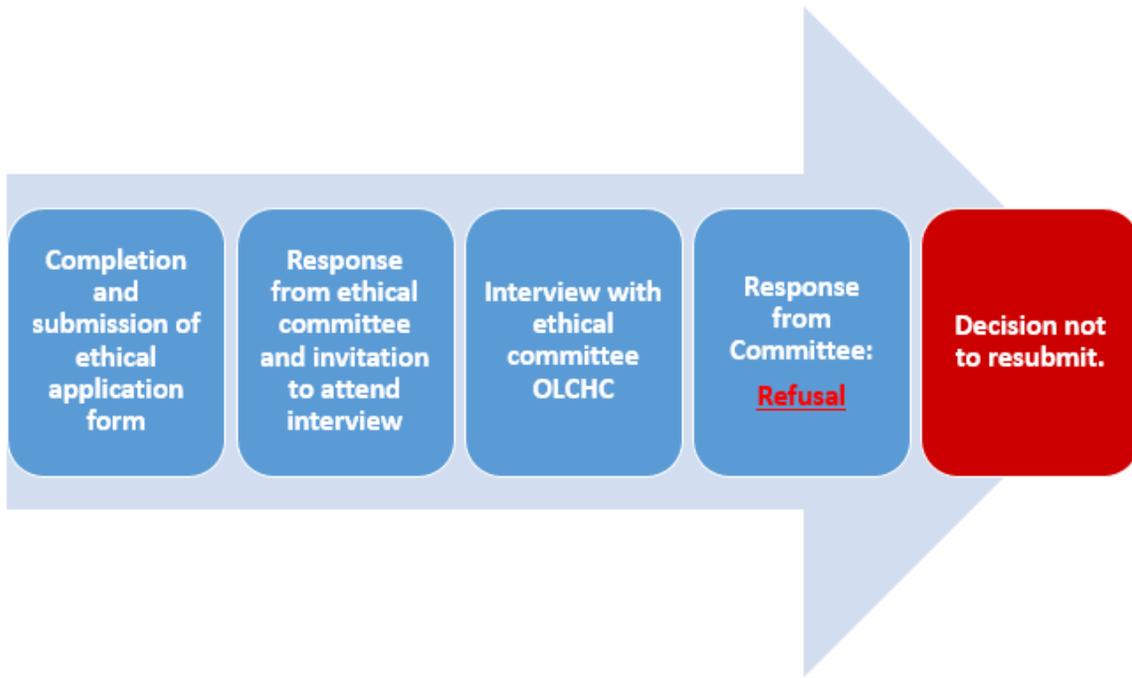
4.5.4.1 Interview with ethical committee OLCHC

The email inviting the researcher to attend the interview also had a request for copies of questionnaires to be used to be posted in advance of the meeting. The questionnaires were only shown to the committee at the meeting which took place on the 15/03/2016. There was a number of issues raised at the meeting and these were highlighted in a letter that was sent to the researcher. A copy of this letter can be seen in appendix 11.

4.5.4.2 Decision not to resubmit

The decision not to proceed further with the ethical application in OLCHC was not taken lightly as the vision was to incorporate data from the 3 children's hospitals especially as they will eventually become one with the planned development of the new children's hospital. However, some of the suggestions were too difficult to achieve given the restrictions of time and place. Figure 5 shows the steps in the ethical approval process in OLCHC which led to refusal and decision not to resubmit.

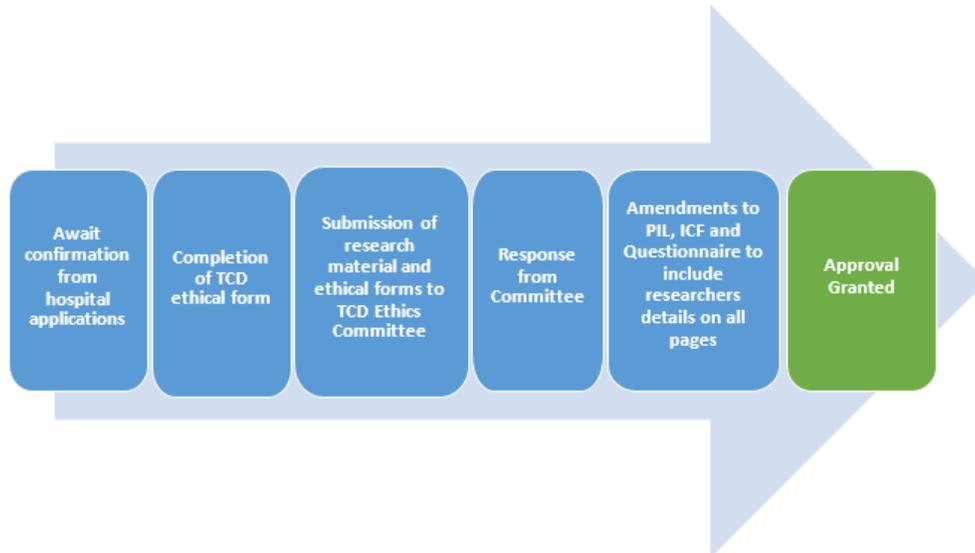
Figure 5: The researcher's journey for ethical approval OLCHC.



4.5.5 Journey of ethical application process, Trinity College, Dublin (TCD).

After finalising the ethical application for the three hospitals, an application was made to TCD. This process was done later than anticipated due to the complicated nature of ethical applications in the hospitals. The process appeared easier due to the fact that all groundwork had been done. The approval was granted on 11/05/2016 which enabled the researcher to begin recruitment of adolescents in AMNCH. (Appendix 12 shows a copy of the approval email).

Figure 6: The researcher's journey for ethical approval, TCD



4.6 Questionnaire development

The researcher had originally planned to carry out structured interviews only, however as already explained, the need for questionnaires was highlighted. The inspiration behind the design of the questionnaires arose from a group assignment that was carried out in year 1 of the MSc programme. The study conducted by Francois-Beehan, Connolly & Gaule (2015), identified that adolescents are particular about usability and design when searching the web and reading online. The same methods recommended for designing web pages for teen and adolescent usage were followed in the creation of the questionnaire to ensure appropriate usability for the potential participants. Some of the principles followed include:

- Short concise questions.
- Tick box answers (yes or no).
- Clear font with no childish graphics.
- Non cluttered design.
- Space to write own opinions or give feedback.

Advice was also sought from HCPs with experience developing adolescent questionnaires and further suggested changes were identified. The headings for the grouped topics outlined previously in sec-

tion 2.12.2, table 4, helped to guide the questions and the researcher tried to include some aspects of each heading throughout the questionnaire. The final questionnaire used is shown in appendix 13.

4.7 Summary

This chapter explained the processes involved in application for ethical approval to recruit adolescents in three of Ireland's children's Hospitals. Unfortunately, ethical approval proved too difficult to obtain in two of the hospitals and aside from this there were other difficulties in relation to recruiting participants off site. These included setting aside time to visit the hospitals to review charts or attend neurology clinics due to work commitments and limitations of having a single researcher. Therefore, the decision was made to focus on the hospital that the researcher works in. However, the process of applying to these hospitals still needed to be portrayed as there is a lot to be learned from being refused approval. The decision to formulate questionnaires was decided from the feedback that was received and perhaps for future researchers the lessons learned will be beneficial to others carrying out research in multi sites. The overall journey for ethical approval is portrayed in appendix 14.

4.8 Conclusion

Despite the difficult journey undertaken to obtain ethical approval for this study, there were many lessons learned along the way such as:

1. How beneficial it is to be aware of and be introduced to the local HCPs working in the area you wish to study, this ensures that you have support and backup should any issues arise.
2. Another valuable lesson was to always have an open mind, questionnaires were never intended to be used as part of this study but it became apparent that are truly beneficial for obtaining consistent information and make the application process easier. This is because there can be no surprises for the ethical committee, researcher or participants and a more defined plan is in place to seek the desired data.
3. The value of open-ended questions within questionnaires was another discovery made when conducting this research.
4. The last and probably most valuable lesson learned was the fact that it is never too early to apply and believe when people say that ethical applications are a timely process.

The following chapter discusses the implementation of the questionnaires with an explanation for each question. The results from the questionnaires will also be given.

Chapter 5. Findings

5.1 Introduction

The purpose of this primary research was to review ways in which information is being delivered to young people with epilepsy in a children's hospital in Ireland by following the plan outlined in section 1.4.3. Chapter 4 covered the ethical steps of the plan while this chapter focuses on the remainder of the list to gain an insight about type and platform of information given both at diagnosis and during ongoing management from the adolescent's perspective.

This chapter describes how data was captured and results were interpreted from the questionnaires. Firstly, an introduction to the study site will be done, then an explanation of how participants were identified and recruited will be given. Explanations of the reasons behind each section of the questionnaire used in this study will then be discussed to ensure the reader has an understanding of the significance of the questions used. Then, the results will be discussed with use of graphs and tables to display how they were obtained and to show that they are reliable.

This chapter also aims to evaluate the data from the completed questionnaires to portray the significance and convey the themes that emerged from the answers. Appendix 15 shows the steps that were taken from participant selection to presentation of findings with the intention of portraying an overview of how the data was collected and collated.

5.2 The study site

The study site was a children's hospital based in one of Dublin's teaching hospital, it is one of the two main teaching hospitals of Trinity College Dublin. The hospital is located in southwest Dublin and incorporates paediatric, psychiatric and general medical care in one building and there are 625 beds in total (AMNCH, 2016). The recruitment took place in the paediatric outpatient department which handles approximately 30,000 outpatient appointments each year across the various specialities including:

- Allergy
- Cystic fibrosis
- Diabetes and Endocrinology
- Dental
- Dermatology
- Developmental
- ENT
- Gastrology
- Medical

- Neurology & Neuromuscular
- Ophthalmology
- Orthopaedic
- Phlebotomy
- Respiratory
- Surgical & Urology

Many of these specialist clinics run alongside each other and patients may attend more than one of the clinics throughout their childhood. The neurology clinic was the focus for this research study and this takes place every Thursday morning. The consultant Neurologist is Dr. David Webb and advanced nurse practitioner (ANP) is Ann Connolly. Approximately 10 patients are seen each week with various neurological illnesses and diseases. An estimated 500 patients are seen on a yearly basis with 80% of these children and adolescents having epilepsy. The process of the clinic can be seen in appendix 16.

5.3 Identifying possible candidates

Various meetings with the ANP took place in order to review the clinic lists in advance to pre-empt the days in which there would be suitable adolescents attending the neurology clinic. The lists were scanned to ascertain if patients meeting the inclusion criteria for the study as outlined previously in section 3.2.3. Once ethical approval was granted both in AMNCH and TCD, the researcher planned to identify potential candidates and begin recruitment. A total of 8 participants agreed to complete the questionnaire. Ideally, more participants would have been recruited however, these participants gave a snapshot of the views of adolescents with epilepsy regarding the availability of information. 4 of these were captured at clinic and 4 returned questionnaires after the study was discussed over the telephone with parents and questionnaires were subsequently posted.

5.4 The questionnaire description, results and evaluation.

This section aims to justify the rationale for inclusion of each of the questions in the questionnaire. The explanation for inclusion of each question will be done followed by the findings for each question. Then analysis of the findings will be given. The various sections of the questionnaire will be discussed under the following headings:

1. All about you.
2. Your epilepsy.
3. Information at initial diagnosis.
4. Information used in ongoing care at hospital/clinic.
5. Self-education about epilepsy.

5.5 All about you

Firstly, there is a brief introduction to the questionnaire and a reminder that the information given is confidential and anonymous. This section aims to learn about the adolescent's demographic information. For example, to find out if they are male or female, what county they live in and what age they are on the date they fill out the questionnaire. The questions were designed with teen usability in mind. They are simply put and provide sufficient space for answers with explanation at Q2 to circle the correct answer. There is also a question asking if they own an electronic device including a list for them to tick yes or no to.

Figure 7: All about you section

Teen/adolescent Questionnaire on information needs in Epilepsy

This questionnaire aims to determine if and how you access information about epilepsy. Your answers will help us to understand the best ways to deliver information regarding epilepsy to others. **This questionnaire is confidential and anonymous.** We don't need your name in this section, but we would like to know a little bit about you. Thanks for taking time to answer these questions.

All about you!

1. Your age: _____
2. Your gender (circle one): Male Female
3. What is your home county? _____
4. Today's date: ____/____/____
5. Do you own any of the following (Tick either yes or no for each)?

| Item | Yes | No |
|--------------------|-----|----|
| Smart phone/mobile | | |
| iPad/Tablet | | |
| Laptop | | |
| Desktop computer | | |

In total, eight adolescents agreed to complete the questionnaires. The data from these questionnaires were entered and stored in an excel spreadsheet which helped to calculate results (see appendix 17). The results from this section of the questionnaire will now be discussed.

5.5.1 Results in "All about you" section.

All the adolescent participants met the inclusion criteria meaning they had epilepsy, attend the OPD neurology clinics at AMNCH and were aged between 12 and 18 years of both genders (1 boy and 7 girls). Of the eight participants, seven owned at least one electronic device. Table 5 demonstrates the participant's demographic breakdown and table 6 shows the results from the questions in relation to electronic device ownership and the mean age of the participants.

Table 6: Participant's demographic details

| Demographic information. | |
|------------------------------------|-----|
| Parent participant characteristics | |
| Participant | (N) |
| Total | 8 |
| Female participants | 7 |
| Male participants | 1 |

Table 7: Participant's demographic and epilepsy details

| Participants' epilepsy information. | |
|--|---------|
| Adolescent with epilepsy characteristics | |
| Adolescent age | (Years) |
| Mean | 14 |
| Electronic devices owned | (N) |
| Smartphone | 4 |
| iPad/tablet | 5 |
| Laptop | 3 |
| Desktop | 1 |

5.5.2 Evaluation and analysis of all about you section.

The majority of the participants were female and this was due to ease of access to female adolescents with epilepsy and the low availability of suitable male patients. This does not reflect the ratio of willingness to participate between male and female adolescents but is more a representation of the adolescents that were available to the researcher who met the inclusion criteria. Seven of the eight participants owned at least one electronic device but the number of participants that owned a smart phone was lower than expected as only 50% (4) stated that they did. However, 5 participants owned a tablet device and only one had no electronic device or access to the internet. This is in line with the statistics mentioned in 2.6.2 where it is stated that majority of adolescents in Ireland have daily access to the internet with over 80% using smart phones, tablets or laptops to access the web (CSO, 2014).

5.6 Your epilepsy

This section addressed the adolescents' epilepsy with 6 questions which was inspired by the "disease" heading in table 4. The aim is to identify how long the adolescent has been diagnosed with the disease and at what age. They are asked if they tell others about their epilepsy. it is important to know the level of understanding that the participants have of their disease and their openness about informing others as this can be a factor that affects adolescent's social circumstances (Thomson et al

2013, Collins 2011). The last question of this section aims to determine which hospital they attend as this questionnaire was developed with the potential to use in all three of the children’s hospitals. However, it is also possible for children or adolescents to attend more than one of the hospitals for access to various clinicians and services and this further emphasises that the participants met the inclusion criteria.

Figure 8: Your epilepsy section

Your Epilepsy

1. What age were you diagnosed with epilepsy? _____
2. What age were you when you knew you had epilepsy (enter details in box below)? _____
3. Who first told you about your epilepsy? _____
4. What type of epilepsy do you have? _____
5. Do you tell people about your epilepsy (circle yes or no)? Yes No

| People you tell (Tick either yes or no for each) | Yes | No |
|--|-----|----|
| Teachers | | |
| Classmates | | |
| Close friends | | |
| Relatives (other than parents, brothers and sisters) | | |

6. Which Children’s Hospital do you attend for your epilepsy care (Tick either yes or no for each):

| Hospital | Yes | No |
|---|-----|----|
| National Children’s Hospital, Tallaght | | |
| Children’s University Hospital, Temple Street | | |
| Our Lady’s Children’s Hospital, Crumlin | | |

5.6.1 Results from “Your Epilepsy” section.

Although all of the eight participants attended AMNCH, one also attended OLCHC. The mean age at diagnosis was 8.873, the youngest was 3 and the oldest was 16. Seven tell others about their epilepsy. Table 7 demonstrates the participant’s epilepsy information breakdown and the results from the questions in relation to electronic device ownership and who they tell about their epilepsy.

Table 8: Participant’s epilepsy details

| Participant’s Epilepsy Information | |
|------------------------------------|---------|
| Age at diagnosis | (Years) |
| Mean | 8.875 |
| Age they found out | (Years) |
| Mean | 9 |
| Who they tell | (N) |
| Teachers | 7 |
| Classmates | 6 |
| Close friends | 6 |
| Relatives | 7 |
| Hospital they Attend | (N) |
| AMNCH | 8 |
| TSCUH | 0 |
| OLCHC | 1 |

5.6.2 Free text questions

Although the majority of the questions were structured to give “yes” or “no” answers, there were many opportunities for the participants to write free text answers asking them to elaborate further if they answered “no” or “other” to specific questions or to give details of the time they were diagnosed with epilepsy. The answers from these questions gave important information that the researcher would have not been able to allow for if all the answers were pre-empted and participants had to tick “yes” or “no” if the answer applied to them. The first example of this can be seen in fig 9 below which shows questions 2-4 in the “Your Epilepsy” section:

Figure 9: Questions 2-4 in the “Your Epilepsy” section

2. What age were you when you knew you had epilepsy (enter details in box below)? _____

3. Who first told you about your epilepsy? _____

4. What type of epilepsy do you have? _____

This gave the opportunity for the participant to express their own thoughts on the details surrounding the period that they were given a diagnosis of epilepsy and who they remember hearing about having the disease from first. The box in question 2 proved useful for participants as it allowed them to give details about the initial diagnosis, in their own words and five of the participants chose to write additional information here.

5.6.3 Evaluation and analysis of “Your Epilepsy” section.

Seven reported that they disclose their epilepsy to others including teachers, classmates, family and close friends. This is crucial for their safety as awareness that the adolescent has epilepsy and knowing the first aid steps to take is important should a seizure take place (Besag 2016, Macleod & Appleton 2007). Five participants elaborated on question 2 in this section “what age were you when you knew you had epilepsy?” the answers given and a brief analysis can be seen in table 8:

Table 9: Answers to question 2 in “Your Epilepsy” section

| Participant | Answer to question 2 | Brief analysis |
|-------------|--|--|
| 1 | “1 st seizure- febrile convulsion- hospitalised. 2 nd seizure- no temperature- hospitalised. Diagnosed as family history of epilepsy.” | Detailed account of events that led to diagnosis of epilepsy |
| 3 | “I had epilepsy when I was 9” | Brief line stating age of diagnosis |
| 4 | “I used to zone out a lot in school and I knew there was something not right, but I didn’t get it checked till the year later.” | Details of when this participant knew there was something wrong even a year before diagnosis |
| 5 | “4 or 5” | Short answer showing uncertainty of exact age |
| 7 | “about 10 or 12” | Short answer showing uncertainty of exact age |

Question three also allowed the participant to express in their words who told them about their epilepsy with a short line provided to write the answer. The question asked “who first told you about your epilepsy?” Each participant provided an answer to this question and five of the participants were informed by their parents table 9 shows the answers given by each participant along with analysis of the answer:

Table 10: Answers to question 3 in “Your Epilepsy” section

| Participant | Answer to question 3 | Brief analysis |
|-------------|----------------------|--|
| 1 | “Mum” | One-word answer, participant informed by mother |
| 2 | “Hospital” | One-word answer, participant informed by someone at the hospital |
| 3 | “Mother” | One-word answer, participant informed by mother |
| 4 | “Dr Webb” | Short answer, participant informed by the Neurologist |
| 5 | “Mother” | One-word answer, participant informed by mother |
| 6 | “Dr David Webb” | Short answer, participant informed by the Neurologist |
| 7 | “Mum & Dad” | Short answer, participant informed by parents |
| 8 | “Parents” | One-word answer, participant informed by parents |

Question four gives the participant an opportunity to share what type of epilepsy they have and it is in the same format as the previous question. Six of the participants answered this question and table 10 shows their answers along with a brief analysis.

Table 11: Answers to question 4 in “Your Epilepsy” section

| Participant | Answer to question 4 | Brief analysis |
|-------------|-----------------------------|--|
| 1 | “Secondary generalised” | Short answer with broad terminology used to name seizures type but doesn’t specify exact type of location seizures begin |
| 2 | “Complex and absence” | Short answer outlining seizure types but not naming epilepsy type |
| 4 | “Juvenile absence epilepsy” | Short answer naming epilepsy type |
| 5 | “Tonic clonic” | Short answer outlining seizure type |
| 7 | “Nocturnal” | One-word answer using broad term which describes when seizures occur not what type or area of brain affected |
| 8 | “Petitmal” | Short answer outlining seizure type |

The fact that all the answers to questions 3 and 4 were short and concise conveys that adolescents not only prefer to read short paragraphs and pieced of text (Loranger and Neilson, 2013) but the above table proves they like giving short, to the point answers without elaboration if not encouraged to do so. It shows the level of knowledge these adolescents have about their disease and seizure type

5.7 Information at initial diagnosis

All the questions in this section, the aim is to find out about the time when the adolescent was diagnosed and the information they received. Question 1 asks about the type of information given:

Figure 10: Question 1 in initial diagnosis section

Information given at Initial diagnosis:

1. What type of information did you get when you were diagnosed? (Tick either yes or no for each)

| Information type | Yes | No |
|--------------------------|-----|----|
| Leaflets | | |
| Verbal advice | | |
| Books | | |
| Suggested online sources | | |
| Other? | | |

if other, please specify: _____

Question 2 asks who the information was aimed at and gives suggested people:

Figure 11: Question 2 in initial diagnosis section

2. Who was the information for? (Tick either yes or no for each)

| People | Yes | No |
|-------------------|-----|----|
| Children | | |
| Teens/adolescents | | |
| Parents/Carers | | |
| All the above | | |
| Other? | | |

if other, please specify: _____

Question 3 asks the adolescent who they received the information from:

Figure 12: Question 3 in initial diagnosis section

3. Who gave you with this information (Tick either yes or no for each)?

| People | Yes | No |
|-------------------------|-----|----|
| Nurse/ Nurse specialist | | |
| Consultant/Neurologist | | |
| All the above | | |
| Other? | | |
| I don't remember | | |

If other, please specify: _____

Question 4 is laid out differently, even though the question is aimed to provide a yes/no answer, the participant is asked to circle the answer as there is also the option of circling “can’t remember” there is also space for the participant to explain why the information wasn’t helpful if “no” was circled:

Figure 13: Question 4 in initial diagnosis section

4. Did the information help? (circle one)

Yes

No

Can't Remember

If answer is no, please explain what would you change and why?

2

There are 4 questions in this section spread out on one page, 3 of which have tick box answers and one asks participants to circle the answer. This was designed to ensure layout was clear and uncluttered and easy for the participant to answer.

5.7.1 Results from “Initial Diagnosis” section.

A small number (one participant) stated that they did not receive any of the outlined information types at initial diagnosis and ticked yes on other. Six were told that they had epilepsy at the time of diagnosis. Of the eight that participated, five reported that found information at initial diagnosis helpful. Table 11 shows the results to the questions asked in the initial diagnosis section.

Table 12: Participant's answers to initial diagnosis section

| Answers to Initial diagnosis questions. | |
|--|-----|
| Information given at initial diagnosis | (N) |
| leaflets | 7 |
| Verbal advice | 7 |
| Books | 4 |
| Suggested online sources | 2 |
| Other | 2 |
| Information aimed at | (N) |
| Children | 6 |
| Teens/adolescents | 4 |
| Parents/carers | 6 |
| All the above | 3 |
| Other | 0 |
| Who gave information | (N) |
| Nurse/Nurse specialist | 7 |
| Consultant/Neurologist | 4 |
| Parent | 2 |
| Don't remember | 2 |
| Other | 2 |
| Did the information help | (N) |
| Yes | 5 |
| No | 0 |
| Can't remember | 1 |
| Didn't answer | 2 |

5.7.2 Evaluation of results in "initial diagnosis" section

In the initial diagnosis section, for question 1 when asked to specify the response was "My mum" which would indicate that it was the mother who explained the diagnosis. This participant was diagnosed at 3 years of age which would explain the reasoning for this. The nurse specialist appears to be the main source for providing information at diagnosis with 7 stating that this is who they received information from. This shows that the nurse specialist plays an important role in the provision of information to adolescents with epilepsy and highlights how beneficial the Community Epilepsy Transition Nurse will be for adolescents transitioning to adult services (Epilepsy Ireland, 2016a).

The question that asks "Did the information help" was not answered by two participants and one ticked "can't remember". This may be due to the length of time since diagnosis or lack of awareness at the time. There is a box provided with question 4 to allow the participant to write free text if they answered "no" to the question "Did the information help?" Seven out of the eight participants

circled the answer “yes” to this question and one circled the answer “Can’t remember” as already seen in table above. This meant that none of the participants wrote anything in the box provided. One participant provided further information to question 3 when asked for if other specify? see table 12 below for the answer given and analysis:

Table 13: Answers to question 3 if ticked “other” in list provided, please specify:

| Participant | Question | Answer, if other or no: | Brief analysis |
|-------------|----------|-------------------------|---|
| 6 | 3 | “Epilepsy Association” | Short answer, indicates info received from voluntary organisation |

5.8 Information used in ongoing care at hospital/clinic

The fourth section is almost identical to section 3 but aims to address the ongoing care in clinical situations with regards information delivery. There is one additional question that was not in the previous section. This question lists certain topics and asks the participants if they receive information about them. These topics are included in the suggested list of information needs recommended by NICE, SIGN and Epilepsy Ireland outlined previously. The list is not extensive but covers some of the most important issues of the main headings already identified. There is also room for the participant to expand if they wish.

Figure 14: Question 4 in ongoing care section

4. Did you get information about these topics from hospital? (Tick either yes or no for each)

| Topic | Yes | No |
|----------------------------|-----|----|
| Medications | | |
| Seizure types and triggers | | |
| Lifestyle changes | | |
| Emergency procedures | | |
| Other? | | |

If other, please specify: _____

5.8.1 Results from “ongoing care” section.

A total of six participants reported that leaflets are given throughout their ongoing care and all eight reported that verbal advice is given throughout. Only two reported that books are given and similarly, just two reported that suggested online sources are given throughout their ongoing care. Five stated that information is aimed at teens/adolescents throughout their ongoing care. Five stated that the information is helpful while three didn’t answer that. Table 12 shows results to the questions asked in the ongoing care section.

Table 14: Participant's answers to ongoing care section

| Answers to Ongoing care questions. | |
|---|-----|
| Information given during ongoing care | (N) |
| leaflets | 6 |
| Verbal advice | 8 |
| Books | 2 |
| Suggested online sources | 2 |
| Other | 1 |
| Who Information aimed at in ongoing care | (N) |
| Children | 5 |
| Teens/adolescents | 5 |
| Parents/carers | 5 |
| Other | 2 |
| Topics they get info on during ongoing care | (N) |
| Medications | 7 |
| Seizure triggers and types | 8 |
| Lifestyle changes | 5 |
| Emergency procedures | 6 |
| Who gives information during ongoing care | (N) |
| Nurse/Nurse specialist | 7 |
| Consultant/Neurologist | 5 |
| Other | 1 |
| Does the information help | (N) |
| Yes | 5 |
| No | 0 |
| Didn't answer | 3 |

5.8.2 Evaluation of results in "ongoing care" section

Leaflets and verbal advice appear to be the main source of information for these adolescents with the Nurse specialist providing the majority of information throughout their care just like at diagnosis. The "Ongoing care" section had five questions and each had the option to write free text if participants wanted to specify. Two participants (no 1 and 7) provided further information to two of these questions see table 14 below for the answers:

Table 15: Answers to question if other or, please specify questions in "Ongoing care" section

| Participant | Q | Answer | Brief analysis |
|-------------|---|------------------------------|--|
| 1 | 2 | "Bystanders" | One-word answer, indicates info available freely |
| 1 | 5 | "Mum" | One-word answer, indicates mum gives info |
| 7 | 1 | "Consultation" | One-word answer, indicates info given at clinic |
| 7 | 3 | "No explanation of symptoms" | Short answer but descriptive |

These answers further convey that adolescents give short descriptive answers without elaboration. In these instances, an interview would have been more beneficial as the researcher could ask additional questions to draw more information from the participant.

5.9 Self-education about epilepsy

In section 5, the participants are asked if they search for further information and if so, where? There is a list of sources for the participant to choose from by ticking “yes” or “no” to each.

Figure 15: Questions 1-3 in self-education section

Self-education about epilepsy

1. Do you read the information given to you at hospital/clinic (circle)? Yes No
2. Have you ever looked for more information about your epilepsy (circle)? Yes No
3. If yes, where did/do you look for further information? (Tick either yes or no for each)?

| Information sources | Yes | No |
|---------------------------------|-----|----|
| Books | | |
| Articles | | |
| Google search | | |
| Apps | | |
| Social media | | |
| Forums / Blogs | | |
| Real life stories | | |
| From other people with epilepsy | | |
| Other? | | |

If other, please specify: _____

Then there is an opportunity for the participants to write down any topics they would like to learn more about, if any with sufficient space for multiple topics to be written:

Figure 16: Question 4 in self-education section

4. Is there any topic that you would like to learn more about (circle)? Yes No

If yes, please write down/list the topic(s)?

They are then asked if they have preference to paper or digital information and who they would share new information with:

Figure 17: Questions 5 and 6 of self-education section

5. Which type of information do you prefer (circle)? Paper Digital
 6. If you find new information, who will you discuss with (Tick either yes or no for each)?

| People | Yes | No |
|---------------------------|-----|----|
| Parents/guardians | | |
| Other teens with epilepsy | | |
| Doctors | | |
| Nurses | | |
| Other? | | |

If other, please specify: _____

The final part of the section and of the whole questionnaire contains two open ended questions allowing the participant an opportunity to suggest a new way of giving information to teens and also to add anything else if they would like.

5.9.1 Results from “self-education” section

Only half (4) of the participants have searched for more information about their epilepsy. Five reported that they read the leaflets given. Just one participant wants to learn about a new topic. Half of them prefer digital, three prefer paper and one participant did not answer this question. Table 14 shows the results of the answers in the self-education section. The last two questions allowed the adolescent to write freely and these answers cannot be quantified. The number of participants that chose to answer will be displayed in the table but the significance and meaning to the answers that were given will be discussed separately afterwards.

Table 16: Participant’s answers to self-education section

| Answers to self-education questions. | |
|---|-----|
| Looked for more info themselves | (N) |
| Yes | 4 |
| No | 3 |
| Didn’t answer | 1 |
| Read the info given to them | (N) |
| Yes | 5 |
| No | 1 |
| Didn’t answer | 2 |
| Information sources used themselves | (N) |
| Books | 2 |
| Articles | 2 |
| Google search | 3 |
| Apps | 1 |
| Social media | 0 |
| Real life stories | 2 |
| From others with epilepsy | 1 |

| Answers to self-education questions. (continued) | |
|---|-----|
| Topic they'd like to learn more about | (N) |
| Yes | 1 |
| No | 7 |
| Preferred info type | (N) |
| Paper | 4 |
| Digital | 3 |
| Who they would share new info with | (N) |
| Parents/guardians | 6 |
| Other teens with epilepsy | 4 |
| Doctors | 4 |
| Nurses | 5 |
| Answered designing new method question | (N) |
| Yes | 5 |
| No | 3 |
| Anything you would like to add | (N) |
| Yes | 2 |

5.9.2 Evaluation of results in "self-education" section

In the final section "self-education about epilepsy", just 50% of the participants prefer digital information which shows paper based information still has an important role to play for adolescents with epilepsy. Less than half (3) search google for information about epilepsy which may be due to a number of reasons that were highlighted in the literature review such as not wanting to learn more about epilepsy, that they are happy with the information that is provided or that they do not know how or where to seek information regarding epilepsy.

This section provides plenty of opportunity and space for participants to elaborate and express any additional thoughts or ideas. For example, question 4 asks "is there any topic that you would like to learn more about?" which if the participant circles "yes" to can elaborate and list the topic(s) if desired. Seven participants answered "no" and didn't add anything further. However, one participant (no 7) circled the answer "yes" and the following is the answer that was provided:

"Seizures and the causes and how to keep them to a minimum"

This would indicate that participant number 7 would like to know more about seizure control and this is a topic that most adolescents are concerned about as identified in the literature review that awareness of seizure type, cause and triggers are important for adolescents with epilepsy to be aware of (Sundstorm 2007, Macleod & Appleton, 2007).

Question 7 asks the participants what method of information delivery would they like to design for teens and why. Five participants provided an answer and table 16 displays these answers including an analysis:

Table 17: Answer to question 7 in “self-education about epilepsy” section

| Answer to question 7 | Brief analysis |
|---|--|
| “through school because the other kids need to know that it not fun to be bullied” | Indicates that this participant gets bullied and would like other kids to know about epilepsy so they stop |
| “I personally think that the way the hospital is delivering my information at the moment is very good as I have received and read every letter I have got from Tallaght hospital about my epilepsy” | Indicates this participant is happy, reads information given to them and wouldn’t change anything about their care |
| “try to educate people that don’t have epilepsy in there life to be more understanding” | Indicates this participant would like others to learn more and understand what having epilepsy is like |
| “Audio visual. Its easier faster and can be more fun and easier to understand” | Indicates this participant would like info delivered in a visual format that is quick and easy |
| “special websites for teenagers Text alerts with new information” | Indicates the need for a teenage specific website or info via mobile phones |

Question 7 provided a lot of useful information and from the above answers, the main emerging themes that appeared are:

- Education about epilepsy for other adolescents in schools
- Easy and quick information in visual format
- The need for adolescent specific website

These themes have been mentioned or touched upon in the literature review. The subject about educating others that don’t have epilepsy was discussed as was the fear of standing out from their peers for adolescents with epilepsy (Thomson et al 2013, Collins 2011, Sundstorm, 2007). The idea of having teen specific information with short paragraphs and illustrations to demonstrate information was also discussed with references to research that reviewed usability of online sources and hospital websites for teenagers (Francois-Beehan et al 2015, Loranger and Neilson 2013).

The final question on the questionnaire is completely open and gives the participant to suggest or add anything that they would like. Of the eight participants, just three wrote something in the box provided and table 17 shows the answers that were given with a brief analysis:

Table 18: Answer to question 8 in “self-education about epilepsy” section.

| Answer to question 8 in “Self-education about epilepsy” section details | Brief analysis |
|--|---|
| “no” | Short answer indicating this participant doesn’t want to add anything further |
| “Maybe a teen section on the epilepsy association website? New to epilepsy and don’t want to know anything about it but enjoy hearing and finding out about the good stuff that people with epilepsy can do” | Indicates this participant doesn’t want to learn too much information as only newly diagnosed but that a teen section would be beneficial to hear real life stories and see the success stories of adolescents with the disease |
| “help with family members to deal with episodes and aftermath” | Indicates that this participant would like family members to be more educated in the safety and management of seizures |

Question 8 proved to be quite beneficial even though just two participants gave detailed answers.

The emerging themes from these answers are:

- Education and training about first aid for families regarding seizure management
- The need for adolescent specific website with real life success stories

Again education for those that do not have epilepsy was mentioned. The need for teen specific website or section of a website was also discussed which further highlights that adolescents like to be separated from young children when looking online for answers and that they enjoy real life stories (Loranger and Neilson, 2013).

5.10 Summary

This chapter presented the results from the questionnaires that adolescent participants completed. The methods of implementing the study and recruiting participants at the chosen study site have been identified and each of the questions in the adolescent questionnaire have been explained. The overall results from structured questions were portrayed in table format and all open ended answers were explained with examples and direct quotes from the completed questionnaires. An evaluation of the answers has also been done to outline the proposed meanings with links to the findings from the literature review. The questions were mainly guided by the complete list of topics suggested from the literature review and table 19 shows the topics that were covered throughout the questionnaire

Table 19 Linkage of questions to useful topics

| Disease | Lifestyle issues: | Safety: | Information access |
|---|---|--|--|
| Epilepsy definitions Diagnostic procedures tests involved Disease and Seizure classification Syndromes Seizure triggers and control Treatment options Medication management Genetics Epidemiology Prognosis | Education Employment issues Social and cognitive issues Psychological issues Relationships Women and folic acid Family planning, Preconception Pregnancy Travel and commuting issues Insurance issues Entitlements | First aid Driving regulations and road safety Alcohol and drugs Disclosure of epilepsy to others SUDEP Status epilepticus Self-care and risk management Seizure triggers Sleep Stress | Leaflets Books Voluntary organisations Secure online sources Peer support groups EPRs Mobile Applications |
| Questions topics were covered in | | | |
| Q 4 in “Your epilepsy” section covered disease and seizure classification | Q 5 in “Your epilepsy” section covered social and relationship issues | Q 4 in “ongoing care” section addressed safety by asking if they get information about emergency procedures | Q 5 in “All about you” section addressed electronic device ownership and all other sections asked about information types and access to same |
| Q 4 in “ongoing care” section addressed medication, seizure types and triggers | Q 2 in both “initial diagnosis” and “ongoing care” section asks who the information is aimed at covering psychological, social and cognitive issues | Q 5 in “Your epilepsy” section asks who they tell which is important from a safety aspect | The final 2 questions allow freedom of speech to add additional topics or new methods to deliver info to teens with epilepsy |
| Q 4 in “self-education” section gives an opportunity to list topics participants want to learn more about | Q 4 in “ongoing care” section addressed lifestyle | The self-education section tries to ascertain if they seek information from other sources to get a picture of their reliance on HCPs | |

5.11 Conclusion

This was an explorative study using mixed method approach and the questionnaire used allowed for answers to be collated both in a quantitative and qualitative manner. Although this was a small sample, the results give a brief synopsis of the beliefs regarding information delivery at the proposed study site from the purposefully selected participants. The use of mixed question types to include both structured and non-structured answers, not only made it easy for the participant to complete

the questionnaire but also allowed them freedom of speech to express themselves if they desired to do so. This provided rich data that otherwise may not have been captured. It is hoped that by explaining the questions first that the reader will understand the reasons for each of them and hence realise the significance of the results which were also discussed. Table 19 shows the topics that were covered throughout the questionnaire as suggested in the literature.

The evaluation of the results from the questionnaires backed up the literature review in relation to information needs and wants for adolescents with epilepsy. However, if this study were to be repeated, the researcher recommends that structured interviews be carried out and also that a greater number of participants be recruited.

The following chapter will give an overall evaluation of the research that was carried out for this dissertation including the literature review and the primary research that took place. Recommendations for future work or research will also be discussed.

Chapter 6. Conclusion and future work

7.1 Introduction

Ease of access to health information is important for all living with chronic diseases including adolescents who are living with epilepsy. Information surrounding the disease itself in addition to management, lifestyle, family planning and safety are important to be aware of particularly before transition to adulthood and services (Tonberg et al 2015). This became apparent in the literature review which influenced the themes for the primary research and also formed the basis of the questionnaire. Chapter 5 presented the findings from this study by conveying the answers obtained from the questionnaires that were completed by adolescents with epilepsy at the study site (AMNCH). Exploration of those findings and evaluation were also done in relation to the work carried out and the emerging themes from the literature review. This chapter outlines the key findings, strengths and limitations of the study. An explanation of how the findings will be disseminated will be given and finally, this chapter will provide reflection and recommendations for future research.

7.2 Key findings

There were many findings that emerged from both the literature review and the primary research that was carried out. The main themes will now be discussed in terms of what was learned from both methods of collecting data (review of literature and questionnaires).

1) Epilepsy in adolescence:

- From the literature review, it was clear to see that adolescence is a challenging period in a young person's life and can be further complicated with the addition of a chronic disease such as epilepsy. It is essential to ensure that information is aimed specifically at them (Besag, 2016). Dissemination of information at the appropriate stage of the disease and people's ability to comprehend the available information appears to be an area that needs more consideration (Ancker & Kaufman 2007). It is vital for transition to adult services for adolescents with epilepsy to be planned in conjunction with the HCPs, the adolescent with epilepsy and their families in order to ensure smooth transition occurs (Agarwal et al, 2014, Carbone et al, 2013).
- From the data collected in the questionnaires, it was also evident that adolescence can be a difficult time for those with epilepsy, particularly if other adolescents don't know about the disease and bully teens with epilepsy if they stand out or appear different.

2) Availability of complete and useful health information

- The review of the literature showed that access to health information about any chronic disease is important and in epilepsy, adolescents are not fully independent or knowledgeable about their epilepsy as their parents/carers have been managing their care especially if they had epilepsy from early childhood (Lewis et al, 2010). HCPs need to ensure that information is given to them on all the important topics via leaflets, books, online or in a discussion (Besag, 2016). Guidelines for HCPs outlining a checklist of topics that adolescents need education on are vital resources ensuring that the adolescent is receiving complete and useful information. NICE (2012) have the most extensive list of topics in the guideline for managing adolescents with epilepsy, however there are some topics that are not included. A table containing the topics suggested here in Ireland (HSE and Epilepsy Ireland), UK (NICE) and Scotland (SIGN) provides a comprehensive range of topics and if followed, would provide adolescents with complete and useful information.
- The questionnaires highlighted how important HCPs are in delivering information with the nurse specialist being the main source. Most of the participants were happy with the type and level of information they received both at initial diagnosis and during their ongoing care. Their lack of motivation to search for more information online was evident and only one wanted to learn about other topics which showed the majority are happy with the level of information that they receive.

3) Information and communication needs in adolescence

- The literature review revealed that adolescents have easy access to the internet but are not great at finding the exact information regarding information they want as they are not as health literate as adults (Holmes, 2005). Adolescents have specific likes and dislikes, usability is a major factor when they access the internet and are likely to quit the search if they are unhappy or bored with the design or content of a website (Francois-Beehan et al 2015, Loranger and Neilson 2013). Social media could be a useful platform for adolescents wanting information from peers or HCPs but this needs to be controlled (McDarby et al, 2015)
- The questionnaires were designed with Loranger and Neilson's usability guidelines (2013) to ensure questions were short and concise with mainly tick box answers but also opportunities for participants to write free text if desired. Some of the answers provided in the open ended questions proved that adolescents like things short and simple as there were many one-word and very short responses for some of the questions. Some of the questions were not

completed which could prove the theory that adolescents avoid questions if they find it boring or dislike the question. The majority of the participants were happy with the information they receive in clinic from the HCPS and hence didn't look online for epilepsy information which further proves Loranger and Neilson's theory that teens have specific goals when they search the web.

4) Role of ICT in healthcare and epilepsy

- The literature showed that ICT is increasingly playing a part in healthcare (HIMSS, 2014). There are ICT developments that are taking place in Ireland such as development of the Epilepsy Ireland App, EPR and Lighthouse project (HRB, 2016, eHealth Ireland, 2016, epilepsy Ireland.ie, 2016b). These will prove beneficial for both HCPs and people of all ages with epilepsy and will also be beneficial for research. The development of teen/adolescent specific areas on hospital websites would be a welcome development for adolescents as they do not like to be associated with or referred to as children.
- The primary research identified that ICT could have a role to play in epilepsy care and information delivery as half the participants had a preference to digital information. The development of teen specific websites was mentioned by two participants and the use of audio or visual formats to deliver information was also suggested.

7.3 Strengths and Limitations of this study

The literature review is the backbone of this thesis and provides vast information on useful topics in relation to adolescents with epilepsy and their information needs. There were thousands of available articles on this topic and the researcher limited the number of articles used by location, age and availability of the full text article. The other formats used were websites, voluntary organisations and statutory bodies. The literature review gave a descriptive analysis of the emerging themes from the final list of references used. The researcher had to eliminate many articles and there were more available that may have been deemed relevant but were omitted due to the overwhelming number in the original searches as seen in table 1 earlier.

The biggest limitation for the primary research was ethics and the difficulties obtaining approval delayed the recruitment of participants and number of sites involved. However, this was understandable as the participants were adolescents with a chronic disease causing them to be a potentially vulnerable cohort.

The findings from the questionnaires provide a snapshot of the thoughts of adolescents with epilepsy in one centre regarding the information they receive. Unfortunately, only eight participants were recruited which limited the potential for quantifying the results. However, the open ended questions proved to be valuable and provided answers and themes which were relevant to the information gathered in the literature review.

7.4 Dissemination of Findings

The findings and evaluation of results from this research will be made available for all HCPs that were involved or assisted with any aspect of the study from choosing the topic, providing useful information, recruiting participants and even proof reading the draft documents. The format for disseminating the information include an overview in poster or leaflet format and also in a PDF version of the final dissertation.

7.5 Recommendations for Future Research

Research needs to be carried out in all children's hospitals in Dublin and nationwide in order to gain a greater perspective of the information needs of adolescents with epilepsy and other chronic illnesses, especially with the proposed development of Ireland's first National Paediatric Hospital in the pipeline. This hospital aims to be paperless, therefore ICT will be at the core and now is the time to plan how information will be delivered to and accessed by all the patients attending this facility. This development and the other ICT projects underway such as the epilepsy EPR, the Lighthouse project and the Epilepsy Ireland mobile application need to be researched to gain insight to the beliefs and apprehensions of the present and future end users to ensure their usability needs are being considered. It would be ideal if further studies to be carried out in on all the ICT systems used in epilepsy care in order to obtain feedback from users of the to comprehend their thoughts, apprehensions and further recommendations for the future to ensure that the best care is being provided for people in Ireland with epilepsy.

7.6 Reflections on the Study

The enormity of carrying out this research and the level of work required was overwhelming. At the beginning there was great enthusiasm and aspirations to obtain first-hand information from people of all ages with epilepsy to ascertain if information available to them is "complete and useful". It soon became apparent that this was too vast a task and when one cohort of participants was decided upon, there was still some enthusiasm and hopes that more than one study site could be included.

However as ethical approval proved difficult in two other hospitals the decision to focus on one hospital was disappointing at first as this limited the potential participants that could be recruited. The researcher averted the main focus to the literature review and the realisation that vast amounts could be learned from the literature improved the researcher's overall outlook to use the feedback from questionnaires to support the findings in the literature.

Although the researcher realised that the primary research would play a minor part in the overall study, the journey taken to obtain ethical approval and the work involved in gathering and collating the data from the questionnaires taught her so much and it was all worthwhile. However, if the opportunity arose to carry out similar research, ethical approval would be sought much earlier on in order to include multiple sites and use alternative methods for obtaining information including focus groups and structured interviews in addition to the questionnaires.

7.7 Conclusion

This dissertation outlined the researcher's area of study from the chosen topic, research plan, methods used to obtain the findings and analysis of same. There were two approaches used to answer the research question:

“What does a complete and useful list of information topics for adolescents with epilepsy entail?”

One approach was to find out what is known or recommended in the literature and the other was to obtain first-hand primary data from adolescents with epilepsy themselves. Both methods when combined together helped to answer the research question and achieved the intended goals and objectives outlined at the beginning in section 1.4. The findings convey that complete and useful information is essential for adolescents with epilepsy and there are guidelines in place (NICE 2012, SIGN 2005) recommending the complete and useful list of topics needed to ensure adolescents have all the information necessary to be as safe and independent as possible when they transition to adult services. ICT and informatics do have a role to play in the future for adolescents with epilepsy in Ireland but more education and knowledge is needed for HCPs, people with epilepsy and their families to ensure that standards are in place and guidelines are followed.

To conclude, it is important to remember that adolescents are future adults and their information needs in a healthcare environment must be met to ensure their ongoing understanding particularly if they have a chronic disease requiring long-term care, informatics has a role but standards need to be established for the ICT systems and the type and format of the information itself.

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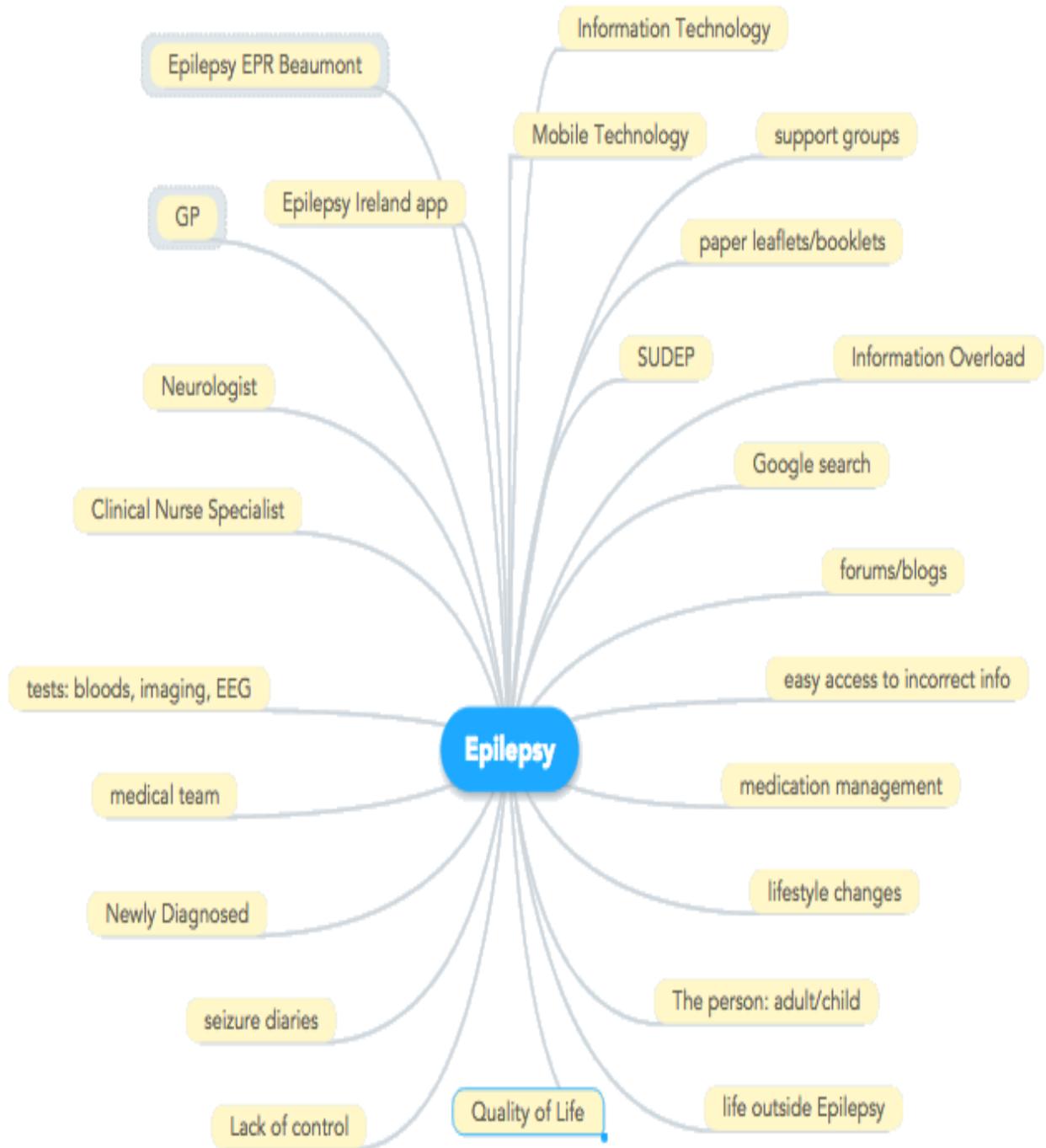
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Appendices

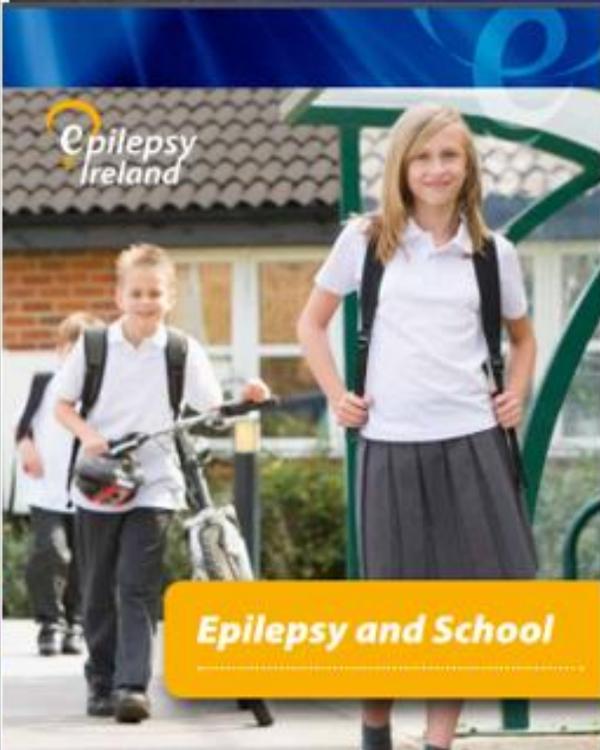
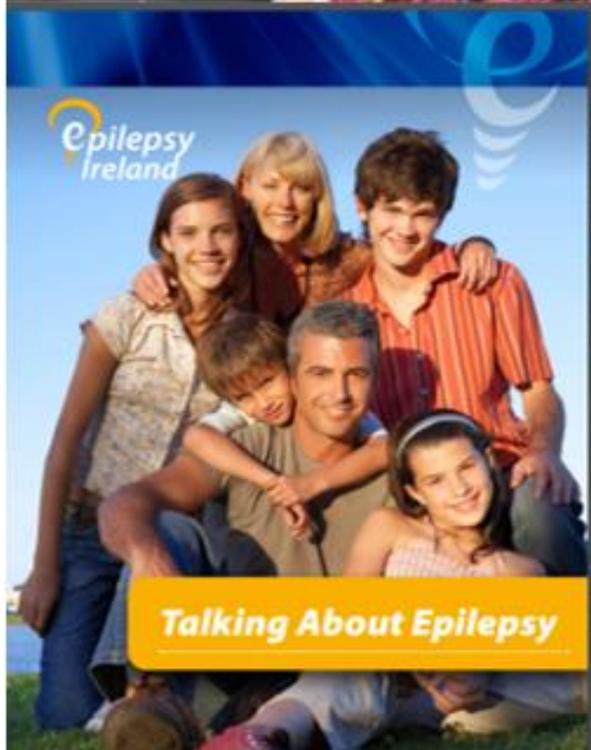
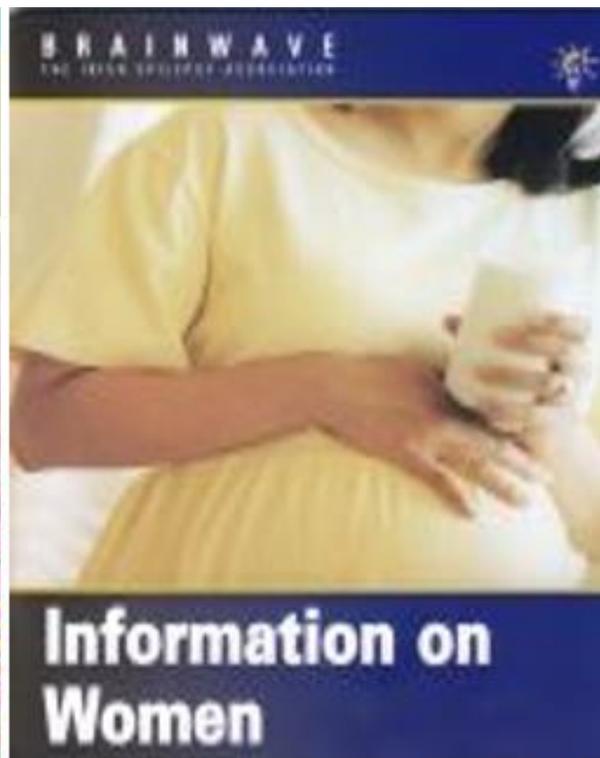
Appendix 1. Mind map



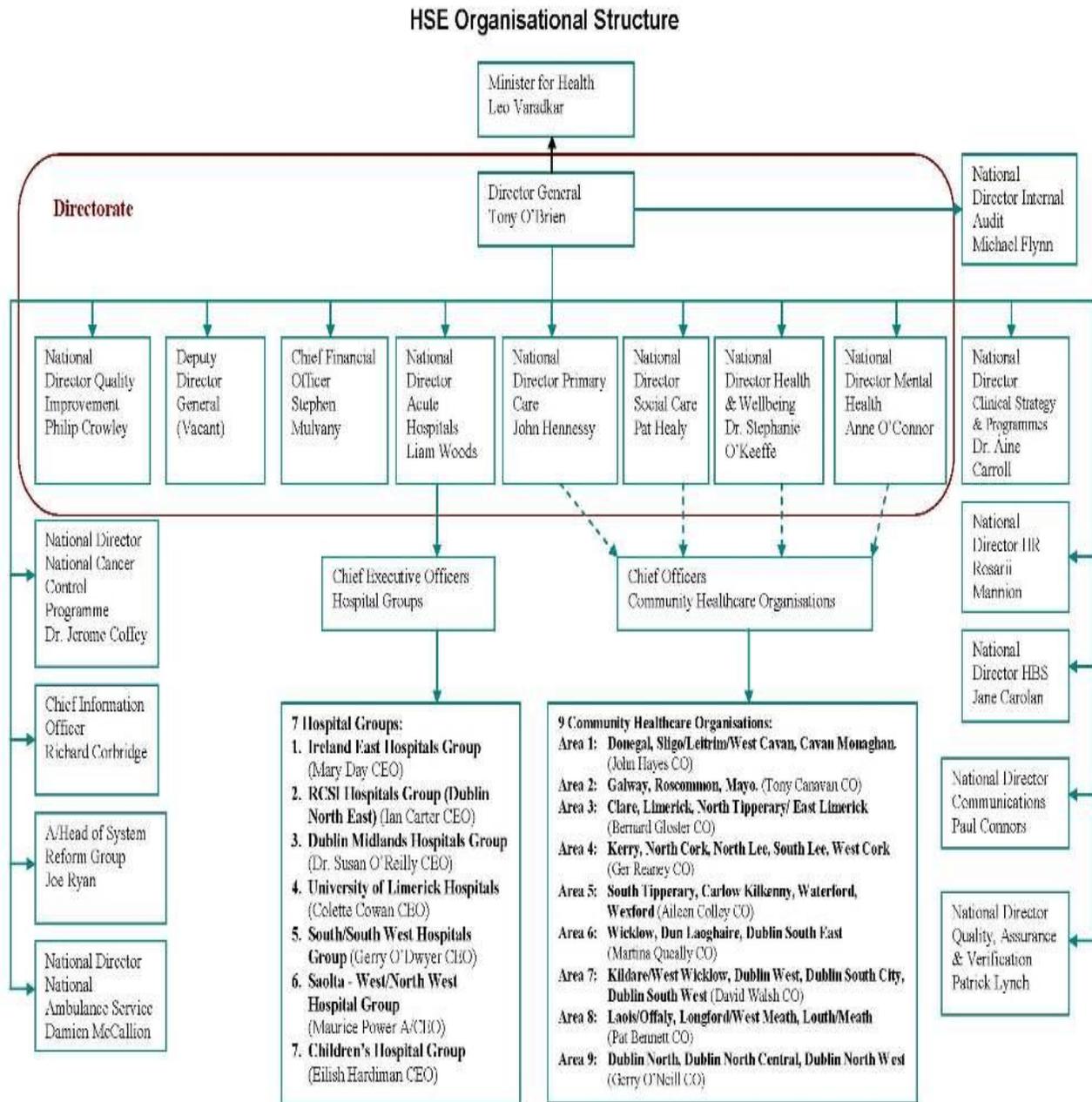
Appendix 2. Adolescent Friendly Quality Assessment Tool for quality information

| Quality Information | | | | |
|--|---|-----|----|-------------------------|
| | | Yes | No | Action for improvement? |
| Type of information provided | Have staff received adequate training in the information which is required by adolescents e.g.: <ul style="list-style-type: none"> - Available health and support? - Accessing appropriate services? - Options, rights & entitlements? - Backup services and after hours numbers? - General health issues? - Health promotion and adolescent health issues? - Process for making complaints (e.g. Ombudsman for Children)? | | | |
| | Does the service have a system where parents are briefed in relation to information and services offered for adolescents (e.g., information on the health issue, adolescents needs for confidential services, rights of parental consent)? | | | |
| How the information is provided | Does the service have an agreed format on the provision of information for young people (e.g., accurate, age appropriate, complete, eye-catching, language appropriate, relevant, tailored for special needs, through a variety of media, updated)? | | | |
| | Does the service provide open access to medical records? | | | |
| | Is the information complete and are all records present in the service? | | | |
| | Does the service provide information through attractive and appealing media (e.g. Interactive tools/computers/DVDs, telephone hotlines by trained counsellors, contemporary designed leaflets, through a variety of points of contact)? | | | |
| | Does the service provide a one-stop-shop approach to provision of information: <ul style="list-style-type: none"> • on the service provided? • on other relevant services? • on general health information for adolescents? | | | |

Appendix 3. Leaflets on epilepsy in hospitals including AMNCH



Appendix 4. Organisational structure of HSE



Appendix 5. Standard Application Form for the Ethical Review of Health-Related Research Studies

RECSAF V5.6

Sept 2014

STANDARD APPLICATION FORM

For the Ethical Review of Health-Related Research Studies, which are not Clinical Trials of Medicinal Products For Human Use as defined in S.I. 190/2004

DO NOT COMPLETE THIS APPLICATION FORM
IF YOUR STUDY IS A CLINICAL TRIAL OF A MEDICINAL PRODUCT

Title of Study: _____

Application Version No: _____

Application Date: _____

| |
|---|
| For Official Use Only – Date Stamp of Receipt by REC: |
| |
| |

Appendix 6. Adolescent information leaflet pg.1

What is this leaflet about?

This leaflet gives an explanation about a research study that I am doing about information needs for adolescents in Ireland with epilepsy.

Research Title:

"How complete and useful is the information that is given to children/adolescents with epilepsy and their families in Ireland?"

Introduction:

My name is Patricia Gaule, I work as a registered children's nurse in the National Children's Hospital Tallaght, Dublin. I am also studying in Trinity College Dublin with the hope of achieving a Master's Degree in Health Informatics. This research study will help me to complete the course. All information gathered will be portrayed in the final paper.

Background:

Adolescence is an important time in every young person's life, especially when living with a chronic condition such as epilepsy. As teenagers have good access to many Electronic and paper information, I am interested in learning how teens with epilepsy in Ireland access information about health and their epilepsy.

Aim:

I hope to learn more about the information needs and preferences for young people with epilepsy in Ireland and their families. I would like to speak with teens who attend the following three children's hospitals for the ongoing care of their epilepsy:

1. Children's University Hospital, Temple Street,
2. National Children's Hospital Tallaght,
3. Our Lady's Children's Hospital, Crumlin.

I would also like to speak to your parents/guardians and the health care professionals who care for you and your epilepsy in the above hospitals.

Why have you been asked to take part in this study?

You have been asked to take part because you fit the following criteria:

- You have epilepsy,
- You are aged between 12-18 years
- You attend one of the children's hospitals for care of your epilepsy

Appendix 6, Adolescent information leaflet pg.2



The National Children's
Hospital



Procedures:

1. As a participant you and your parent/guardian are asked to complete, sign and return the attached questionnaire,
2. Once you and your parent/guardian have signed the consent form then you can begin answering the questions and return all to the researcher in the SAE provided when signed and completed.
3. I will also be interviewing the healthcare professionals who care for you in an effort to learn about their thoughts too.
4. It is estimated that it should take approximately 20 minutes to complete the questionnaire.
5. You may also be invited to participate in a focus group or interview once all questionnaires have been returned.

Do you have to take part?

No! It is up to you.

If you agree to take part and sign the form, you are free to change your mind and stop taking part at any time without giving a reason.

If you decide not to take part, or stop taking part at any time during the course of the study, this will not affect the care you get in any way and no one will be upset with you.

Confidentiality:

Anonymity will be maintained for all participants who complete the questionnaire and for those who attend the focus groups, your identity will remain confidential. No names will be published or disclosed to anyone. The findings from this study may be used for further studies that the researcher or others may undertake.

Permission:

The study has gained Ethical approval from AMNCH hospitals and TCD

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Patricia Gaule who can be contacted at pgaule@tcd.ie or 0857875068

Appendix 7. Consent/assent form



The National Children's
Hospital



Consent/Assent Form

Title of research study: *How complete and useful is the information that is given to children/adolescents with epilepsy and their families in Ireland?*

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I agree that by means of completing this questionnaire that information obtained will be used to complete a research paper and also for reference for future studies. I am aware that if I wish to withdraw from the study at any time, it will not affect your ongoing care.

To be completed by the Adolescent

Name please complete in block letters: _____

Name please sign: _____

Date please complete _____

As the participant is a minor (under the age of 18), you the guardian must read the above statement to give consent for both the adolescent's and your own participation in this study.

To be completed by the Parent/Guardian

Name (*in block letters please*): _____

Signature: _____

Relationship to adolescent: _____

Date: ____/____/____

To be completed by the Researcher

Name please complete in block letters: _____

Name please sign: _____

Date please complete: _____

Appendix 8. Pg 1 of letter from TSCUH Ethics Committee Board



DEPARTMENT OF RESEARCH

Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: resmech@cuh.ie Web: www.cuh.ie

Ms Patricia Gaule
Post grad student
School of Computer Science and Statistics (SCSS)
Trinity College Dublin
College Green
Dublin 2

10th March 2016

Re: 16.012. How complete and useful is the information that is given to children/adolescents with epilepsy and their families in Ireland?

Dear Ms Gaule,

We thank you for attending the Ethics Research Committee meeting held on Tuesday 9th February. Further to the meeting the Committee would request a re-submission of a revised application with a number of amendments and clarifications. The committee recommends the following:

1. Please nominate a lead co-investigator at the TSCUH site. The committee suggests contacting Prof Mary King for further information.
2. Please provide consent and assent forms for the study.
3. Considering the sensitive subject matter involved and the fact newly diagnosed patients will be involved, please clarify how this will be dealt with. The Committee were specifically concerned as to how parents' questions or concerns about the management of their children's epilepsy might be follow up on if issues arise during the interviews.
4. Please elaborate how data will be collected and provide the data collection proforma.
5. Please elaborate the data management plan. How will the data be anonymised, who will have access to the data, when will the data be destroyed and how?

Considering the above suggests and the complex nature of the clinical condition under review, the committee suggests that this study be re-submitted with a different study design. It is recommended that parents be provided with information regarding the study, facilitated through TSCUH, and provided with contact details if they wished to further partake in a phone interview but contact should only be initiated by the parents.

Excellence in research – making a difference to the lives of children

Appendix 8. Pg 2 of Letter from TSCUH Ethics Committee Board

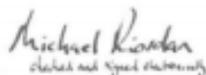


DEPARTMENT OF RESEARCH

Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Please contact Dr Aoife Carey, Research Manager for advice regarding resubmission and future submission deadlines.

Yours sincerely,


Michael Riordan
Medical Secretary Ethics Research Committee

Dr Michael Riordan
Medical Secretary Ethics Research Committee
MCRN: 281464

c.c. Department of Research

Appendix 9. Ethical application form pg.1

RECSAF V5.6

Sept 2014

STANDARD APPLICATION FORM

For the Ethical Review of
Health-Related Research Studies, which
are not Clinical Trials of Medicinal
Products for Human Use
as defined in S.I. 190/2004

DO NOT COMPLETE THIS APPLICATION FORM
IF YOUR STUDY IS A CLINICAL TRIAL OF A MEDICINAL PRODUCT

Title of Study: *How complete and useful is the information that is given to
children/adolescents with epilepsy and their families in Ireland?*

Application Version No: 1

Application Date: 15/02/2016

For Official Use Only – Date Stamp of Receipt by REC:

| |
|--|
| |
| |

Page 1

Appendix 9. Ethical application form pg.2

RECSAF V5.6

Sept 2014

| TABLE OF CONTENTS | MANDATORY /OPTIONAL |
|--|---------------------|
| SECTION A GENERAL INFORMATION | MANDATORY* |
| SECTION B STUDY DESCRIPTORS | MANDATORY* |
| SECTION C STUDY PARTICIPANTS | MANDATORY* |
| SECTION D RESEARCH PROCEDURES | MANDATORY* |
| SECTION E DATA PROTECTION | MANDATORY* |
| SECTION F HUMAN BIOLOGICAL MATERIAL | (OPTIONAL) |
| SECTION G RADIATION | (OPTIONAL) |
| SECTION H MEDICAL DEVICES | (OPTIONAL) |
| SECTION I MEDICINAL PRODUCTS / COSMETICS / FOOD AND FOODSTUFFS | (OPTIONAL) |
| SECTION J INDEMNITY AND INSURANCE | MANDATORY* |
| SECTION K COST AND RESOURCE IMPLICATIONS, FUNDING AND PAYMENTS | MANDATORY* |
| SECTION L ADDITIONAL ETHICAL ISSUES | (OPTIONAL) |

This Application Form is divided into Sections.

***Sections A, B, C, D, E, J and K Are Mandatory.**

(Sections F, G, H, I and L are optional. Please delete Sections F, G, H, I and L if these sections do not apply to the application being submitted for review.)

IMPORTANT NOTE: Please refer to **Section I** within the form before any attempt to complete the Standard Application Form. **Section I** is designed to assist applicants in ascertaining if their research study is in fact a clinical trial of a medicinal product.

IMPORTANT NOTE: This application form permits the applicant to delete individual questions within each section depending on their response to the preceding questions. Please respond to each question carefully and refer to the accompanying *Guidance Manual* for more in-depth advice prior to deleting any question.

**PLEASE ENSURE TO REFER TO THE ACCOMPANYING GUIDANCE MANUAL
WHEN COMPLETING THIS APPLICATION FORM.**

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Appendix 9. Ethical application form pg.3

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SECTION A GENERAL INFORMATION

SECTION A IS MANDATORY

A1 TITLE OF THE RESEARCH STUDY:

How complete and useful is the information that is given to adolescents with epilepsy and their families in Ireland?

A2 (a) Is this a multi-site study? Yes

IF YOU CHOSE 'YES' PLEASE DELETE QUESTIONS A2 (E) AND (F), IF YOU CHOSE 'NO' PLEASE DELETE QUESTIONS A2 (B) (C) AND (D)

A2 (b) If yes, please name the principal investigator with overall responsibility for the conduct of this multi-site study.

Title: Ms. **Name:** Patricia Gaule
Qualifications: RCN/RGN
Dent: Computer science and statistics TCD and Paediatrics Outpatients Department, NCH, Tallaght
Organisation: Trinity college Dublin
Address:
TEL: 0857875069 **E-MAIL:** pgaule@tcd.ie/patricia.gaule@amnch.ie

A2 (c) For multi-site studies, please name each site where this study is proposed to take place, state the lead co-investigator for each of these sites and state if you have got an outcome from the relevant research ethics committee(s).

| Site: | Lead Investigator for each site: | Co- | Research Ethics Committee Outcome |
|---|----------------------------------|-----|---|
| NATIONAL CHILDREN'S HOSPITAL TALLAGHT | PATRICIA GAULE | | AWAITING |
| CHILDREN'S UNIVERSITY HOSPITAL, TEMPLE STREET | PATRICIA GAULE | | AWAITING FEEDBACK FROM ETHICS COMMITTEE |
| OUR LADIES CHILDREN'S HOSPITAL, CRUMLIN | PATRICIA GAULE | | AWAITING FEEDBACK FROM ETHICS COMMITTEE |
| TRINITY COLLEGE DUBLIN | PATRICIA GAULE | | AWAITING |
| EPILEPSY IRELAND | PATRICIA GAULE | | AWAITING |

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A2 (D) FOR MULTI-SITE STUDIES, PLEASE PROVIDE DETAILS OF THE LEAD CO-INVESTIGATORS AT EACH SITE.

Title: Ms. **Name:** Patricia Gaule
Qualifications: RCN/RGN
Dept: Computer science and statistics TCD and Paediatrics Outpatients Department, NCH, Tallaght
Organisation: Trinity college Dublin
Address:
TEL: 0857875069 **E-MAIL:** pgaule@tcd.ie/patricia.gaule@amnch.ie

A4. Lead contact person who is to receive correspondence in relation to this application or be contacted with queries about this application.

Title: Ms. **Name:** Patricia Gaule
Qualifications: RCN/RGN
Dept: Post grad student of School of Computer Science and Statistics (SCSS) TCD and Registered Children's Nurse in Paediatrics Outpatients Department, NCH, Tallaght
Organisation: Trinity college Dublin
Address:
TEL: 0857875069 **E-MAIL:** pgaule@tcd.ie/patricia.gaule@amnch.ie

A5 (A) IS THIS STUDY BEING UNDERTAKEN AS PART OF AN ACADEMIC QUALIFICATION? Yes

If answer is No, please delete remaining questions in Section A

A5 (b) IF YES, please complete the following:

Student Name(s): Patricia Gaule
Academic Course: Masters Science Degree in Health Informatics
Academic Institution: Trinity College Dublin

A5 (c) Academic Supervisor(s):

Title: Prof. **Name:** Gaye Stephens
Qualifications:
Position: Professor/lecturer
Dept: School of Computer Science and Statistics (SCSS)
Organisation: Trinity college Dublin

SECTION B STUDY DESCRIPTORS

SECTION B IS MANDATORY

B1. What is the anticipated start date of this study?

Feb 2016

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Sept 2014

B2. What is the anticipated duration of this study?

5-6 months

B3. Please provide a brief lay (plain English) description of the study. Please ensure the language used in your answer is at a level suitable for use in a research participant information leaflet.

I plan to evaluate the methods of information delivery for families of children with epilepsy in Ireland, both from the patients' and Health Care Professionals' perspective. I am interested to learn what teenagers and parents feel about the information they received when they were initially affected by the diagnosis of epilepsy and throughout the continuing care of their epilepsy. I would like to obtain primary data regarding what families think about the way the information was presented and also did they try to access further information; if they think that the information was sufficient or did they seek further knowledge from alternative sources (internet, books, other families etc.) I aim to identify if staging of information depending on disease progression would be beneficial. I also aim to focus on the family as a unit. I also hope to assess what Healthcare professionals' opinions are and provide IT solutions for any issues that arise.

B4. Provide brief information on the study background.

Epilepsy is the commonest neurological condition affecting children and teens in Ireland. Approximately 1 in 200 children have epilepsy. It is a complex condition requiring ongoing care and various lifestyle adaptations to be considered. Education about treatment, lifestyle changes and seizure management are important, particularly for families of children with epilepsy. Adolescence is a difficult time for those with epilepsy as teens do not wish to stand out from their peers, but as they are beginning their transition to adult services they need to become more knowledgeable about their condition and the potential risks and triggers for their seizures. Information plays a vital role in the ongoing care of the condition and I am interested to learn if teens/adolescents and their families are satisfied with the information that is available to them and what sources do they seek advice from.

B5. List the study aims and objectives.

- To gain an understanding of the viewpoints of parents and teens regarding how information was delivered to them.
- To gain an insight into HCPs viewpoint on the information leaflets available for them to give to families,
- To determine if information delivery regarding epilepsy is standardised in Ireland
- To ascertain if current information is geared towards parents/children/teenagers
- Suggest a standardised approach throughout all health centres (if not already in place) in the form of a story board to be used for developing leaflets, apps etc.
- To find out what role information plays and if IT can be helpful

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B6. List the study endpoints / measurable outcomes (if applicable).

The following is a list of potential questions to be answered from this research

- Do teens/adolescents read information about their epilepsy?
- What sources do they obtain information from?
- Do they prefer paper or digital information?
- Do teens tell their peers about their epilepsy?
- Do parents research their child's condition further?
- Do parents disclose all the information to their child/teen?
- What format is the information currently given to families in the 3 hospitals?
- Are the information leaflets given the same in each hospital?
- Who is the current information aimed at? (parents or child themselves)
- Is there a comparison in information needs for children diagnosed at different ages and also disease type?
- Do parents/children read leaflets or search online for support?
- Is it easy to access information?
- What are the HCPs views on current practice and possible areas to improve?
- Are better informed parents/children easier to treat?
- Can patient education empower families?

B7. Provide information on the study design.

- Literature review on information needs for children with chronic illness including epilepsy and what families need/want from the info they receive
- Research what is already known about the needs of families and look for gaps/issues/problems with current methods of information delivery.
- Compare how information is given to families of children with other complex conditions (diabetes/respiratory etc.)
- Find out if there is a model for the other conditions that can be adapted to suit needs for families of children with epilepsy
- Review possible IT solutions (apps, online resources etc.)

B8. Provide information on the study methodology.

- Review methods of information delivery in the 3 children's hospitals in Dublin by contacting the relevant HCPs,
- Create informed consent forms for parents and HCPs and assent forms for teens,
- Compile questionnaires/structured phone interviews guided by the literature, aimed at teens/adolescents and parents/carers
- Also to compile questionnaires/structured interviews aimed at HCPs (Nurses, Doctors and ANPs) that work with children that have epilepsy.

B9. Provide information on the statistical approach to be used in the analysis of your results (if appropriate) / source of any statistical advice.

As this study is a Qualitative one, the interviews will be semi structured and while there are chosen topics to be discussed. Questionnaires may also be used to obtain information in the event that an interview is not possible, the results from the questionnaires will be more structured. However, a table of results will be compiled to show the results of the interviews and the potential varying opinions of the interviewees.

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Sept 2014

B10 (a) Please justify the proposed sample size and provide details of its calculation (including minimum clinically important difference).

We hope that about 3-4 teenagers will take part in this research study in each of the three Children's Hospitals, with a minimum of 1 teen and parent and if possible, more. Ideally one HCP from each hospital will participate if possible to recruit.

B10 (b) Where sample size calculation is impossible (e.g. it is a pilot study and previous studies cannot be used to provide the required estimates) then please explain why the sample size to be used has been chosen.

N/A

B11. How many research participants are to be recruited in total?

It is hoped that a total of 10-12 teenagers will take part between the three Children's Hospitals in Dublin and potentially more if possible.
All HCPs that care for teens with epilepsy will be invited to participate and do an interview.

B12 (a) How many research participants are to be recruited in each study group (where applicable)? Please complete the following table (where applicable).

| Name of Study Group: | Name of Study Group: | Name of Study Group: |
|---|---|---|
| Teens/Adolescents with epilepsy | Parents/Guardians | HCPs |
| Number of Participants in this Study Group: | Number of Participants in this Study Group: | Number of Participants in this Study Group: |
| 3-6 + | 3 + | 3 + |

B12 (b) Please provide details on the method of randomisation (where applicable).

n/a

B13. How many research participants are to be recruited at each study site (where applicable)? Please complete the following table.

| Site: | Number of Research Participants at this site: |
|--|---|
| NATIONAL CHILDREN'S HOSPITAL TALLAGHT | >1, <6 |
| CHILDREN'S UNIVERSITY HOSPITAL TEMPLE STREET | >1, <6 |
| OUR LADIES CHILDREN'S HOSPITAL, CRUMLIN | >1, <6 |

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Sept 2014

SECTION C STUDY PARTICIPANTS

SECTION C IS MANDATORY

C1 PARTICIPANTS – SELECTION AND RECRUITMENT

C1.1 HOW will the participants in the study be selected?

The researcher will obtain a list of suitable participants from each of the hospitals either from database/registry of adolescents with epilepsy or from speaking with the HCPs that work in Neurology to assist in identifying possible candidates.

C1.2 HOW will the participants in the study be recruited?

- Information leaflets and consent/assent forms will be posted to parents and teenagers or given in person if opportunity allows,
- If happy to participate, signed copies of the consent/assent forms by both the teenager and the parent should be posted to the researcher with the SAE that is provided including details of a suitable time and date for the phone call to occur.
- Once signed informed consent/assent forms are received by the researcher, the phone call will be made and the interview will take place,
- After interviewing a sufficient number of teens and parents, the researcher will correlate the data and compile results of the information obtained
- The final outcome will be portrayed in the researcher's dissertation which will be available once completed for all participants upon request.

C1.3 What are the inclusion criteria for research participants? (Please justify, where necessary)

Inclusion criteria:
Adolescents (both male and female) with epilepsy aged between 12 and 18 years,
Parents/guardians of the 12-18 year olds with epilepsy,
Currently attending one of the three children's hospitals in Dublin,
HCPs that care for children and adolescents with epilepsy
Willing participants that have signed consents/assent forms
Participants that are able to comprehend the questions and also answer them

C1.4 What are the exclusion criteria for research participants? (Please justify, where necessary)

Exclusion criteria:
Children <12-years-old with epilepsy and their parents,
12-18 year olds that do not have epilepsy or their parents,
HCPs that do not care for children/adolescents with epilepsy,
12-18 year olds that are unable to answer or comprehend the interview questions
No signed consent/assent forms

C1.5 Will any participants recruited to this research study be simultaneously involved in any other research project? Not to my knowledge

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C2 PARTICIPANTS – INFORMED CONSENT

C2.1 (a) Will informed consent and assent be obtained? Yes

C2.1 (b) If no, please justify. You must provide a full and detailed explanation as to why informed consent will not be obtained.

N/A

C2.1 (c) If yes, please outline the consent process in full. (How will consent be obtained, when, by whom and from whom etc.)

Assent will be obtained from each participant aged < 18 years and Parental informed consent will be obtained from their parent/carer. Informed consent will be obtained from parents that are recruited and also any health care professionals willing to participate

C2.2 (a) Will participants be informed of their right to refuse to participate and their right to withdraw from this research study? Yes

C2.2 (b) If no, please justify.

N/A

C2.3 (a) Will there be a time interval between giving information and seeking consent? Yes

C2.3 (b) If yes, please elaborate.

Consent and assent forms will be posted to families with SAE and once signed copies are returned, the phone calls will be placed.

C2.3 (c) If no, please justify and explain why an instantaneous decision is reasonable having regard to the rights of the prospective research participants and the risks of the study.

N/A

C3 ADULT PARTICIPANTS (AGED 18 OR OVER) - CAPACITY

C3.1 (a) Will all adult research participants have the capacity to give informed consent? YES

C4 PARTICIPANTS UNDER THE AGE OF 18

C4.1 (a) Will any research participants be under the age of 18 i.e. Children? Yes

If answer is No, please delete remaining questions in Section C4

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C4.1 (b) If yes, please specify:

Persons < 16 **Yes**

Persons aged 16 – 18 **Yes**

Children in care **Yes**

C4.1 (c) If yes to persons < 16, please specify:

Pre-term neonates **No**

Full-term neonates **No**

Infants and Toddlers 0 - 4 **No**

Children 5 - 8 **No**

Children 9 - 12 **Yes**

Adolescents 13 -15 **Yes**

C4.2 Is this research of such a nature that it can only be carried out on children? Please elaborate.

It is hoped that a greater understanding of information needs of adolescents with chronic conditions particularly epilepsy will be obtained from carrying out this research from their perspectives and their parents/guardians

C4.3 Is the purpose of the research to generate knowledge about the health or social care needs of children?

Yes, it is hoped that more knowledge of the information needs of adolescents with epilepsy will be identified

C4.4 Is the research expected to provide direct benefit to child participants, or if there is no prospect of direct benefit, are the risks no more than minimal? Please elaborate.

The research may not benefit the participants directly but hopefully will benefit children and adolescents with epilepsy in the future.

C4.5 Will each child receive information about the risks and benefits of the study according to his/her capacity to understand? Please elaborate and provide copies.

Information leaflets will be provided for all participants explaining the procedures for carrying out the study and storing any information that is captured. All information will be aimed towards the participants in the hope that it is portrayed in an appropriate manner.

C4.6 Will the explicit wish of the child who is capable of forming an opinion and assessing information to refuse to participate or to be withdrawn from the study be considered by the investigators? Please elaborate, outlining the assent process in full. (How will assent be obtained, when and by whom etc.)

All participants have the right to withdraw at any stage and there is no pressure for any child or parent/guardian to participate

C4.7 Please comment on the involvement of parents / legal guardians of the child in the consent process.

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Parents/guardians will sign informed consent allowing the adolescents to participate. They will also be asked to participate themselves.

C4.8 Please explain your approach to reviewing assent where research subjects reach the age of 18 during the course of the study.

Assent forms will be designed to suit participants' capabilities for understanding the information.

C4.9 Please comment on what will occur if the researcher discovers that a child is at risk during the course of this study?

If a child is considered at risk, they will be withdrawn from the study and offered support. It is hoped that there is no potential for any harm to be caused to participants during the course of the study.

C5 PARTICIPANTS - CHECKLIST

C5.1 Please confirm if persons from any of the following groups will participate in this study. This is a quick checklist to assist research ethics committee members and to identify whether study participants include persons from vulnerable groups and to establish what special arrangements, if any, have been made to deal with issues of consent. It is recognised that not all groups in this listing will automatically be vulnerable or lacking in capacity. Please refer to the HSE's National Consent Policy, particularly Part 3, Section 5.

Committees are particularly interested to know if persons in any of these groups are being targeted for inclusion, as per the inclusion criteria.

(a) Healthy Volunteers **Yes**

(b) Patients **Yes**

- Unconscious patients **No**
- Current psychiatric in-patients **No**
- Patients in an emergency medical setting **No**

(c) Relatives / Carers of patients **Yes**

(d) Persons in dependent or unequal relationships **Yes**

- Students **No**
- Employees / staff members **Yes**
- Persons in residential care **No**
- Persons highly dependent on medical care **No**

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(e) Intellectually impaired persons Yes (if able to comprehend and answer questions relating to their epilepsy)

(f) Persons with a life-limiting condition No
(Please refer to guidance manual for definition)

(g) Persons with an acquired brain injury Yes

C5.2 If yes to any of the above, please comment on the vulnerability of the research participants, and outline the special arrangements in recognition of this vulnerability (if any).

The adolescent participants will all have epilepsy; some may be newly diagnosed while others have had the condition for years. Great care will be taken to ensure that all participants will be treated with dignity and respect and not asked any questions they might find difficult to answer.

C5.3 Please comment on whether women of child-bearing potential, breastfeeding mothers, or pregnant women will be included or excluded in this research study.

Both female and male adolescents will be asked to participate, therefore there is a chance that women of childbearing age will be included. This will not affect the study.

SECTION D RESEARCH PROCEDURES

SECTION D IS MANDATORY

D1 (A) What activities, procedures or interventions (if any) are research participants asked to undergo or engage in for the purposes of this research study?

Participants will be asked to answer some questions in interviews or via a questionnaire regarding a number of topics in relation to their epilepsy. These semi structured interviews will be done by telephone or in person if possible. The questionnaires will be posted to families that meet the inclusion/exclusion criteria complete with SAE to return them to the researcher when completed.

D1 (B) WHAT OTHER ACTIVITIES (IF ANY) ARE TAKING PLACE FOR THE PURPOSES OF THIS RESEARCH STUDY E.G. CHART REVIEW, SAMPLE ANALYSIS ETC?

Time permitting, there will also be focus groups taking place to evaluate the information obtained from the interviews. All participants will be invited to attend. Chart reviews may take place initially when trying to find potential participants and once interviews are completed, an analysis of the findings will be carried out and portrayed in a dissertation.

D2. Please provide details below of any potential harm that may result from any of the activities, procedures, interventions or other activities listed above.

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D2. Please provide details below of any potential harm that may result from any of the activities, procedures, interventions or other activities listed above.

It is hoped that there is little or no potential for physical harm to occur. Breach of confidentiality is a risk but strict measures will be put in place when recording and storing any information that is gathered. All participants will remain anonymous and given pseudo names in the event that they will be discussed in the dissertation

D3. What is the potential benefit that may occur as a result of this study?

The potential benefits that could occur is that there will be a greater understanding of adolescents' information needs regarding their epilepsy, enabling them to be partners in their health care. This will be good for the adolescents, their guardians and the health care professionals that provide care for them.

D4 (A) WILL THE STUDY INVOLVE THE WITHHOLDING OF TREATMENT?

NO

D4 (B) WILL THERE BE ANY HARMS THAT COULD RESULT FROM WITHHOLDING TREATMENT? NO

D4 (C) IF YES, PLEASE ELABORATE.

N/A

D5 (A) HOW WILL THE HEALTH OF PARTICIPANTS BE MONITORED DURING THE STUDY, AND WHO WILL BE RESPONSIBLE FOR THIS?

N/A

D5 (B) HOW WILL THE HEALTH OF PARTICIPANTS BE MONITORED AFTER THE STUDY, AND WHO WILL BE RESPONSIBLE FOR THIS?

N/A

D6 (A) WILL THE INTERVENTIONS PROVIDED DURING THE STUDY BE AVAILABLE IF NEEDED AFTER THE TERMINATION OF THE STUDY? NON-APPLICABLE

D6 (B) IF YES, PLEASE STATE THE INTERVENTION YOU ARE REFERRING TO AND STATE WHO WILL BEAR THE COST OF PROVISION OF THIS INTERVENTION?

N/A

D7. PLEASE COMMENT ON HOW INDIVIDUAL RESULTS WILL BE MANAGED.

Every effort will be made to make all participant's information confidential. The researcher will store all research records securely. The researchers will not put any names on any research data. Instead, each participant will be given a study number. The master list that links a person's name to their study number will be stored securely. If results of this research are published, we would not use information that identifies any participant.

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D8. PLEASE COMMENT ON HOW AGGREGATED STUDY RESULTS WILL BE MADE AVAILABLE.

The study results will be available to all participants upon request once the dissertation has been submitted and corrected. The completed thesis will be available through Trinity's library for further students undertaking the MSc in Health Informatics course.

D9. WILL THE RESEARCH PARTICIPANT'S GENERAL PRACTITIONER BE INFORMED THAT THE RESEARCH PARTICIPANT IS TAKING PART IN THE STUDY (IF APPROPRIATE)? NON-APPLICABLE

D10. WILL THE RESEARCH PARTICIPANT'S HOSPITAL CONSULTANT BE INFORMED THAT THE RESEARCH PARTICIPANT IS TAKING PART IN THE STUDY (IF APPROPRIATE)? NON-APPLICABLE

SECTION E DATA PROTECTION

SECTION E IS MANDATORY

E1 DATA PROCESSING - CONSENT

E1.1 (A) WILL CONSENT BE SOUGHT FOR THE PROCESSING OF DATA? YES

E2 DATA PROCESSING - GENERAL

E2.1 WHO WILL HAVE ACCESS TO THE DATA WHICH IS COLLECTED?

The researcher, supervisor and exam board will have access to the completed data

E2.2 WHAT MEDIA OF DATA WILL BE COLLECTED?

The researcher will carry out interviews in person or over the telephone and will record the answers either by manually writing them or recording the conversations. Time permitting, focus groups will be held and participants will be invited, this will involve either video or audio recording.

E2.3 (A) WOULD YOU CLASS THE DATA COLLECTED IN THIS STUDY AS anonymous, irrevocably ~~anonymised, pseudonymised,~~ coded or identifiable data?

The data regarding teens and parents will be ~~pseudonymised~~ and the data regarding HCPs will be anonymised upon their request.

E2.3 (B) IF 'CODED', PLEASE CONFIRM WHO WILL RETAIN THE 'KEY' TO RE-IDENTIFY THE DATA?

The researcher (Patricia ~~Stow~~ Gaule)

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E2.4 WHERE WILL DATA WHICH IS COLLECTED BE STORED?

All data will be stored either in locked cabinets or secure computer files

E2.5 PLEASE COMMENT ON SECURITY MEASURES WHICH HAVE BEEN PUT IN PLACE TO ENSURE THE SECURITY OF COLLECTED DATA.

All computer files will be password protected and paper files will be in a locked cabinet

E2.6 (A) WILL DATA COLLECTED BE AT ANY STAGE LEAVING THE SITE(S) OF ORIGIN?

YES

E2.6 (B) IF YES, PLEASE ELABORATE.

The researcher may bring the data to various places to carry out the analysis (e.g. library or home)

E2.7 WHERE WILL DATA ANALYSIS TAKE PLACE AND WHO WILL PERFORM DATA ANALYSIS (IF KNOWN)?

The data analysis will be carried out by the researcher at work, in the college library or at home

E2.8 (A) AFTER DATA ANALYSIS HAS TAKEN PLACE, WILL DATA BE DESTROYED OR RETAINED?

The paper data will be converted to digital data and retained till the dissertation has been submitted and marked and also for as long as necessary afterwards.

E2.8 (B) PLEASE ELABORATE.

The data may need to be reviewed by examiners or referred to in the future by the researcher

E2.8 (C) IF DESTROYED, HOW, WHEN AND BY WHOM WILL IT BE DESTROYED?

Paper files will be shredded and computer files will be securely deleted.

E2.8 (D) IF RETAINED, FOR HOW LONG, FOR WHAT PURPOSE, AND WHERE WILL IT BE RETAINED?

The data may need to be reviewed by examiners or referred to in the future by the researcher

E2.9 PLEASE COMMENT ON THE CONFIDENTIALITY OF COLLECTED DATA.

Every precaution necessary will be made to ensure that all participants' privacy and confidentiality is not breached and to make sure that this does not happen as the researcher aims to maintain anonymity of participants at all times.

E2.10 (A) WILL ANY OF THE INTERVIEW DATA COLLECTED CONSIST OF AUDIO RECORDINGS / VIDEO RECORDINGS? YES

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E2.10 (B) IF YES, WILL PARTICIPANTS BE GIVEN THE OPPORTUNITY TO REVIEW AND AMEND TRANSCRIPTS OF THE TAPES?

Yes, if they request same

E2.11 (A) WILL ANY OF THE STUDY DATA COLLECTED CONSIST OF PHOTOGRAPHS/ VIDEO RECORDINGS? NO

E2.11 (B) IF YES, PLEASE ELABORATE.

N/A

E3 ACCESS TO HEALTHCARE RECORDS

E3.1 (A) DOES THE STUDY INVOLVE ACCESS TO HEALTHCARE RECORDS (HARD COPY / ELECTRONIC)? YES

If answer is No, please delete remaining questions in Section E3

E3.1 (B) IF YES, PLEASE ELABORATE.

A review of the patient charts will be done if necessary to ensure that the children/teens fit the inclusion criteria for the study. The researcher will also gain access to patients' demographic data to make initial contact regarding the study

E3.1 (C) WHO WILL ACCESS THESE HEALTHCARE RECORDS?

The researcher

E3.1 (D) WILL CONSENT BE SOUGHT FROM PATIENTS FOR RESEARCH TEAM MEMBERS TO ACCESS THEIR HEALTHCARE RECORDS? NO

If answer is Yes, please delete remaining questions in Section E3

E3.2 (A) WHO OR WHAT LEGAL ENTITY IS THE DATA CONTROLLER IN RESPECT OF THE HEALTHCARE RECORDS?

HSE

E3.2 (B) WHAT MEASURES HAVE BEEN PUT IN PLACE BY THE DATA CONTROLLER WHICH MAY MAKE ACCESS TO HEALTHCARE RECORDS PERMISSIBLE WITHOUT CONSENT?

N/A

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SECTION F HUMAN BIOLOGICAL MATERIAL

F1 BODILY TISSUE / BODILY FLUID SAMPLES - GENERAL

F1.1 (a) Does this study involve human biological material? NO

SECTION G RADIATION

G1 RADIATION – GENERAL

G1.1 (a) Does this study/trial involve exposure to radiation? NO

SECTION H MEDICAL DEVICES

H1 (A) IS THE FOCUS OF THIS STUDY/TRIAL TO INVESTIGATE/EVALUATE A MEDICAL DEVICE? NO

SECTION I MEDICINAL PRODUCTS / COSMETICS / FOOD AND FOODSTUFFS

I.1 NON-INTERVENTIONAL TRIALS OF MEDICINAL PRODUCTS

I1.1 (a) Does this study involve a medicinal product? No

I.2 COSMETICS

I2.1 (a) Does this study involve a cosmetic? No

I.3 FOOD AND FOOD SUPPLEMENTS

I3.1 (a) Does this study involve food or food supplements? No

SECTION J INDEMNITY AND INSURANCE

SECTION J IS MANDATORY

J1 PLEASE CONFIRM AND PROVIDE EVIDENCE THAT APPROPRIATE INSURANCE/INDEMNITY IS IN PLACE FOR THIS RESEARCH STUDY AT EACH SITE.

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I am working in the AMNCH as a paediatric nurse so am covered by insurance/indemnity of this hospital and the HSE

J2 PLEASE CONFIRM AND PROVIDE EVIDENCE THAT APPROPRIATE INSURANCE/INDEMNITY IS IN PLACE FOR THIS RESEARCH STUDY FOR EACH INVESTIGATOR.

I am working in the AMNCH as a paediatric nurse so am covered by insurance/indemnity of this hospital and the HSE also.

J3.1 Please give the name and address of the organisation / or individual legally responsible for this research study?

AMNCH, HSE

J3.2 Where an organisation is legally responsible, please specify if this organisation is: N/A

A pharmaceutical company NO

A medical device company NO

A university YES

A registered charity NO

Other YES If yes, please specify: Hospital (HSE)

J3.3 PLEASE CONFIRM AND PROVIDE EVIDENCE OF ANY SPECIFIC ADDITIONAL INSURANCE / INDEMNITY ARRANGEMENTS WHICH HAVE BEEN PUT IN PLACE, IF ANY, BY THIS ORGANISATION / OR INDIVIDUAL FOR THIS RESEARCH STUDY?

N/A

SECTION K COST AND RESOURCE IMPLICATIONS, FUNDING AND PAYMENTS

SECTION K IS MANDATORY

K1 COST AND RESOURCE IMPLICATIONS

K1.1 PLEASE PROVIDE DETAILS OF ALL COST / RESOURCE IMPLICATIONS RELATED TO THIS STUDY (E.G. STAFF TIME, OFFICE USE, TELEPHONE / PRINTING COSTS ETC.)

The researcher does not anticipate any potential cost implications.

K2 FUNDING

K2.1 (a) Is funding in place to conduct this study?

NO

K2.1 (b) If no, has funding been sought to conduct this study? From where? Please elaborate. N/A

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K2.1 (c) If yes, please state the source of funding (industry, grant or other), the name of the funder, the amount of funding and duration of funding. N/A

K2.1(d) Please provide additional details in relation to management of funds.

N/A

K2.1(e) Is the study funded by a 'for profit' organisation? NO

K2.2 (a) Do any conflicts of interest exist in relation to funding or potential funding? NO

K2.2 (b) If yes, please elaborate.

N/A

K3 PAYMENTS TO INVESTIGATORS

K3.1 (a) Will any payments (monetary or otherwise) be made to investigators? NO

K3.1 (b) If yes, please provide details of payments (including amount).

N/A

K4 PAYMENTS TO PARTICIPANTS

K4.1 (a) Will any payments / reimbursements (monetary or otherwise) be made to participants? NO

K4.1 (b) If yes, please provide details of payments / reimbursements (including amount).

N/A

SECTION L ADDITIONAL ETHICAL ISSUES

L1 (a) Does this project raise any additional ethical issues? NO

PLEASE ENSURE THIS APPLICATION FORM IS FULLY COMPLETED AS INCOMPLETE SUBMISSIONS WILL NOT BE REVIEWED.

Appendix 10. Copy of Ethical approval AMNCH

THIS NOTE/PAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

Ms. Patricia Gaule
Computer science and statistics TCD
& Paediatrics OPD, NCH
Tallaght Hospital
Tallaght
Dublin 24.

25th February 2016

Re: How complete and useful is the information that is given to children/adolescents with epilepsy and their families in Ireland?

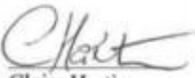
REC Reference: 2016 - 02 Chairman's action (15)
(Please quote reference on all correspondence)

Dear Ms Gaule,

Thank you for your recent application to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above referenced study.

The Chairman, on behalf of the Research Ethics Committee, has reviewed this application and grants ethical approval for it to proceed.

Yours sincerely,


Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee



**THE ADELAIDE & MEATH
HOSPITAL, DUBLIN**
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND
TELEPHONE +353 1 4142000

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

Appendix 11. Copy of refusal letter from OLCHC pg 1

Not for prescription purposes



Ospidéal
Mhuire na Leanaí,
Cromghlinn

Our Lady's
Children's Hospital,
Crumlin

**ETHICS (MEDICAL RESEARCH)
COMMITTEE OFFICE**

Tel: +353 (0)1 409 6307/6243

Ms Patricia Gaule - RCN/RGN
Paediatric Outpatients Department
National Children's Hospital
Tallaght
Dublin 24

22nd March 2016

REC Reference: GEN/488/16

**How complete and useful is the information that is given to children/
adolescents with epilepsy and their families in Ireland?**
Principal Investigator: Ms. Patricia Gaule

Dear Ms Gaule

The Ethics (Medical Research) Committee at this hospital reviewed the above Study at a meeting which took place on, 15th March 2016.

The Committee noted that the aims and objectives of this Study are as follows:

- to gain an understanding of the viewpoints of parents and teens regarding how information was delivered to them;
- to gain an insight into Health Care Professionals' viewpoint on the information leaflets available for them to give to families;
- to determine if information delivery regarding epilepsy is standardised in Ireland;
- to ascertain if current information is geared towards parents/children/teenagers;
- to suggest a standardised approach throughout all health centres (if not already in place) in the form of a story board to be used for developing leaflets, software applications etc.;

Cont'd/

Ospidéal Mhuire na Leanaí, Cromghlinn, Baile Átha Cliath 12, Éire
Our Lady's Children's Hospital, Crumlin, Dublin 12, Ireland
Tel: +353 (0)1 409 6100 | Fax: +353 (0)1 455 8873 | Website: www.olchc.ie

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Mr. John Healy, Ms. Geraldine Hickey, Ms. Mary Kelly, Ms. Rachel Keenan, Sr. Anna Kennedy, Council for Brian Mc Ginley, Council for Ray Mc Hugh, Mr. Martin O'Rourke,
Mr. Turbough O'Sullivan, Dr. Maurice Smyth, Dr. Sean Walsh, Ms. Paul White, Company Secretary, Ms P McDonald

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Appendix 11. Copy of refusal letter from OLCHC pg 2

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- to find out what role information plays and if I.T. can be helpful.

The Committee requested that documentation be amended appropriately to reflect the fact that all data collected will be anonymised – not anonymised on request, as stated, and that statements such as “...every effort will be made to keep information confidential...” are not acceptable.

With regard to Question B6 “*List the Study endpoints/measurable outcomes (if applicable)*” the answer given is very broad and should be refined.

With regard to Question C4.9 “*Please comment on what will occur if the Researcher discovers that a child is at risk during the course of this Study*” on the Ethics Committee Standard Application Form, the Committee requested that the answer should read “*that practice procedures which are already in place in this hospital must be adhered to*”.

The Committee noted that you advised that Maria Keegan, Clinical Nurse Specialist, Neurology, Our Lady’s Children’s Hospital, Crumlin, has been approached for a list of potential candidates.

The Committee advised that you would require an Investigator who is based at Our Lady’s Children’s Hospital, Crumlin and that, as you are not an employee of this hospital, the Information Leaflets and Questionnaires in relation to this Study should only be sent to Parents/Children by this Investigator.

The Committee requested copies of the Assent/Consent Forms and the Questionnaires.

The Committee suggested that, as this is a big project with a short timeframe, you should consider conducting this study as a pilot study in the Adelaide, Meath and National Children’s Hospital, Tallaght.

This study was **not** approved.

Yours sincerely



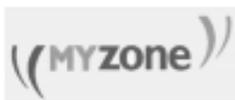
Claire Rice
Secretary
Ethics (Medical Research) Committee

CC: Ms. Maria Keegan, Clinical Nurse Specialist, Neurology, OLCHC.

Appendix 12. Copy of approval email TCD

6/12/2016

Trinity College Dublin Mail - RE: [Research-ethics] ethical application for Msc in HI thesis I.D. No. 84/16



Trisha Gaule <pgaule@tcd.ie>

RE: [Research-ethics] ethical application for Msc in HI thesis I.D. No. 84/16

6 messages

Una O'Malley <Una.OMalley@scss.tcd.ie>

6 May 2016 at 14:45

To: Trisha Gaule <pgaule@tcd.ie>

Cc: research-ethics@scss.tcd.ie, Gaye Stephens <gaye.stephens@tcd.ie>

Dear Patricia,

Thank you for your application for ethics approval which we received on 3rd April 2016. The Research Ethics Committee will consider each application and will normally provide a response within four to six weeks. Your application number is 84/16.

Regards,

Una

Una O'Malley
Senior Executive Officer – Research Unit
School of Computer Science & Statistics
Trinity College Dublin, the University of Dublin
Dublin 2, Ireland.

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Una.OMalley@scss.tcd.ie
www.tcd.ie

Trinity College Dublin, the University of Dublin is ranked 1st in Ireland and in the top 100 world universities by the QS World University Rankings.

From: Research-ethics [mailto:research-ethics@scss.tcd.ie] **On Behalf Of** Trisha Gaule

Sent: 02 May 2016 22:17

To: research-ethics@scss.tcd.ie; gaye.stephens@tcd.ie

Subject: [Research-ethics] ethical application for Msc in HI thesis

Dear research ethics committee,

Please find enclosed my ethical application to conduct research in the three children's hospitals in Dublin. to date approval has been granted in the National Children's Hospital Tallaght. However, I am still pending approval from OLCHC and TSCUH. I have submitted to both, received feedback and resubmitted to TSCUH but still need to make amendments for OLCHC.

I have attached copies of consent/assent forms for both questionnaires and structured interviews and the questionnaire to be used also. the ethical application from that was accepted in AMNCH and submitted to the other 2hosps have also been attached.

Appendix 13. Adolescent questionnaire pg.1



The National Children's Hospital



Teen/adolescent Questionnaire on information needs in Epilepsy

This questionnaire aims to determine if and how you (teens with epilepsy in Ireland) access information about epilepsy. Your responses will help us to understand the best ways to deliver information regarding epilepsy to children and teens. **This questionnaire is confidential and anonymous.** Your name is needed on the consent form but will not be used in the findings. We would like to know a little bit about you. Thanks for taking time to answer these questions.

All about you!

- Your age: _____
- Your gender (circle one): Male Female
- What is your home county? _____
- Today's date: ____/____/____
- Do you own any of the following (Tick either yes or no for each)?

| Item | Yes | No |
|--------------------|-----|----|
| Smart phone/mobile | | |
| iPad/Tablet | | |
| Laptop | | |
| Desktop computer | | |

Your Epilepsy

- What age were you diagnosed with epilepsy? _____
- What age were you when you knew you had epilepsy (enter details in box below)? _____

- Who first told you about your epilepsy? _____
- What type of epilepsy do you have? _____
- Do you tell people about your epilepsy (Tick either yes or no for each)?

| People | Yes | No |
|--|-----|----|
| Teachers | | |
| Classmates | | |
| Close friends | | |
| Relatives (other than parents, brothers and sisters) | | |

- Which Children's Hospital do you attend for your epilepsy care (Tick either yes or no for each):

| Hospital | Yes | No |
|---|-----|----|
| National Children's Hospital, Tallaght | | |
| Children's University Hospital, Temple Street | | |
| Our Lady's Children's Hospital, Crumlin | | |

Appendix 13. Adolescent questionnaire pg.2



The National Children's Hospital



Information at **Initial diagnosis:**

1. What type of information did you get when you were diagnosed? (Tick either yes or no for each)

| Information type | Yes | No |
|--------------------------|-----|----|
| Leaflets | | |
| Verbal advice | | |
| Books | | |
| Suggested online sources | | |
| Other? | | |

If other, please specify: _____

2. Who was the information for? (Tick either yes or no for each)

| People | Yes | No |
|-------------------|-----|----|
| Children | | |
| Teens/adolescents | | |
| Parents/Carers | | |
| All the above | | |
| Other? | | |

If other, please specify: _____

3. Who gave you with this information (Tick either yes or no for each)?

| People | Yes | No |
|-----------------------------|-----|----|
| Nurse/ Nurse specialist | | |
| Advanced Nurse Practitioner | | |
| Consultant/Doctor | | |
| Neurologist | | |
| All the above | | |
| Other? | | |
| I don't remember | | |

If other, please specify: _____

4. Did the information help? (circle one)

Yes No Can't Remember

If answer is no, please explain what would you change and why?

Appendix 13. Adolescent questionnaire pg.3



The National Children's Hospital



Information used in **ongoing care** at hospital/clinic setting:

1. What type of information is currently given in hospital setting? (Tick either yes or no for each)

| Information type | Yes | No |
|--------------------------|-----|----|
| Leaflets | | |
| Verbal advice | | |
| Books | | |
| Suggested online sources | | |
| Other? | | |

If other, please specify: _____

2. Who is the information aimed at (Tick either yes or no for each)?

| People | Yes | No |
|-------------------|-----|----|
| Children | | |
| Teens/adolescents | | |
| Parents/carers | | |
| Other? | | |

If other, please specify: _____

3. Are you satisfied with the type of information you receive? (circle correct answer)?

Yes No

If the answer is no, please explain: _____

4. Did you get information about any of these topics from hospital (Tick either yes or no for each)?

| Topic | Yes | No |
|----------------------------|-----|----|
| Medications | | |
| Seizure types and triggers | | |
| Lifestyle changes | | |
| Emergency procedures | | |
| Other? | | |

If other, please specify: _____

5. Who gives you with this information (Tick either yes or no for each)?

| People | Yes | No |
|-----------------------------|-----|----|
| Nurse/ Nurse specialist | | |
| Advanced Nurse Practitioner | | |
| Consultant/Doctor | | |
| Neurologist | | |
| All the above | | |
| Other? | | |
| I don't remember | | |

If other, please specify: _____

Appendix 13. Adolescent questionnaire pg.4



The National Children's Hospital



Self-education about epilepsy

1. Have you ever looked for more information about your epilepsy (circle)? Yes No
2. Do you read the information given to you at hospital/clinic (circle)? Yes No
3. If yes, where did/do you look for further information? (Tick either yes or no for each)?

| Information sources | Yes | No |
|---------------------------------|-----|----|
| Books | | |
| Articles | | |
| Google search | | |
| Apps | | |
| Social media | | |
| Forums / Blogs | | |
| Real life stories | | |
| From other people with epilepsy | | |
| Other? | | |

4. Is there any topic that you would like to learn more about (circle)? Yes No

If yes, please write down/list the topic(s)?

5. Which type of information do you prefer (circle)? Paper Digital
6. If you do find new information, who will/would you discuss with (Tick either yes or no for each)?

| People | Yes | No |
|---------------------------|-----|----|
| Parents/guardians | | |
| Other teens with epilepsy | | |
| Doctors | | |
| Nurses | | |
| Other? | | |

If other, please specify: _____

Appendix 13. Adolescent questionnaire pg.5



The National Children's Hospital

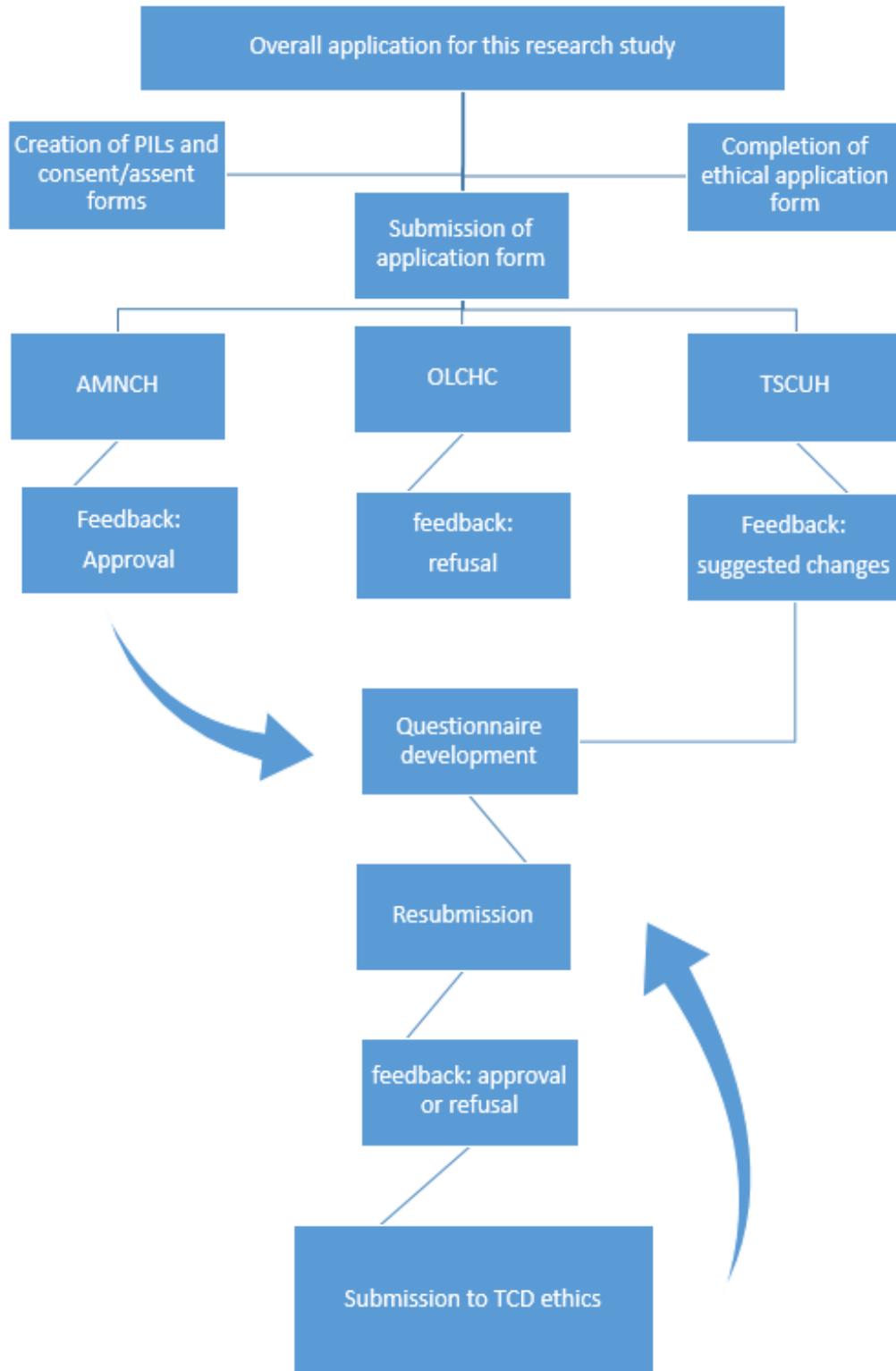


7. If you had to design a new method of delivering information to teens about epilepsy, how would you do it and why? (add pages if needed)

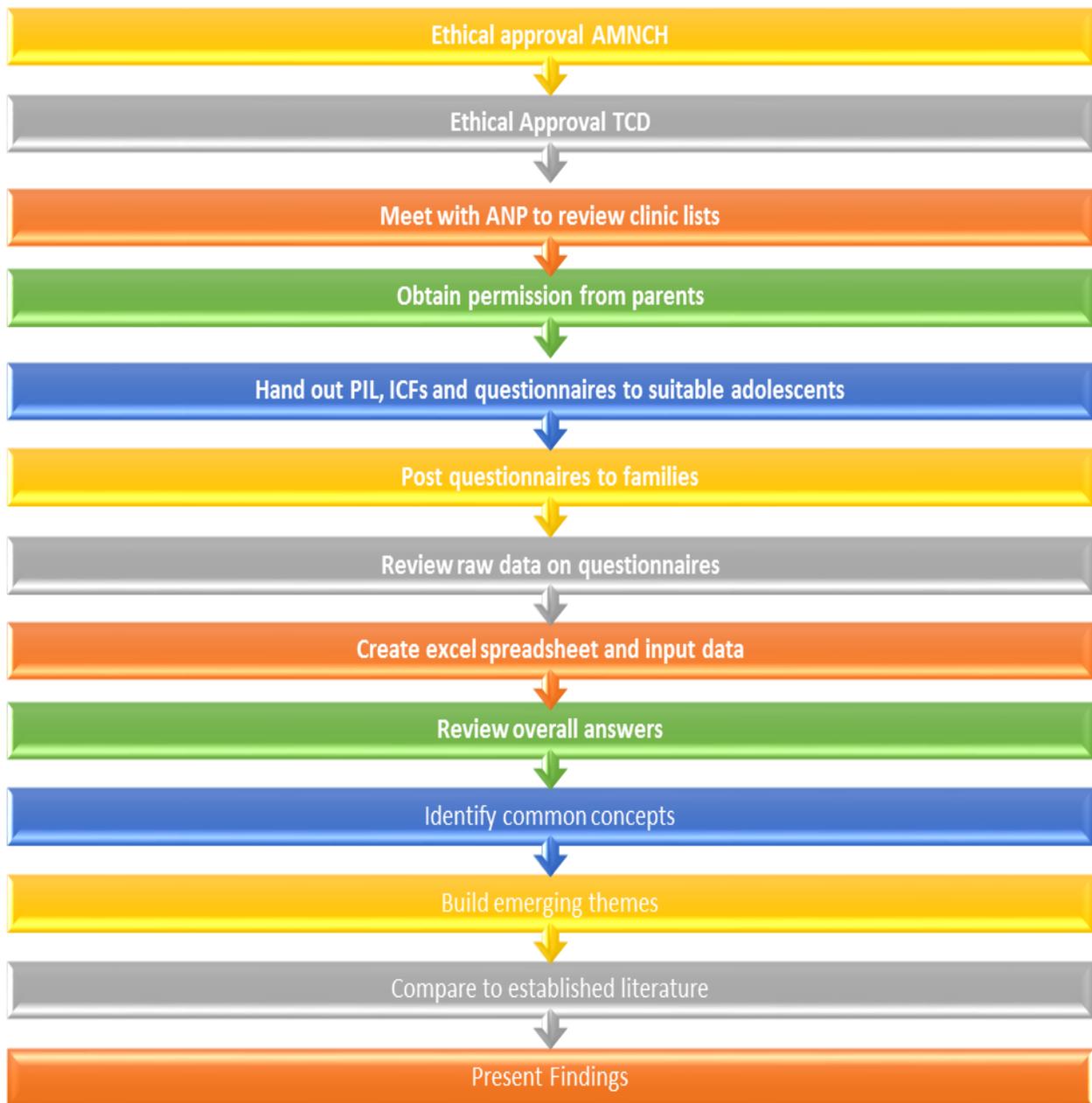


8. Is there anything you would like to suggest or add?

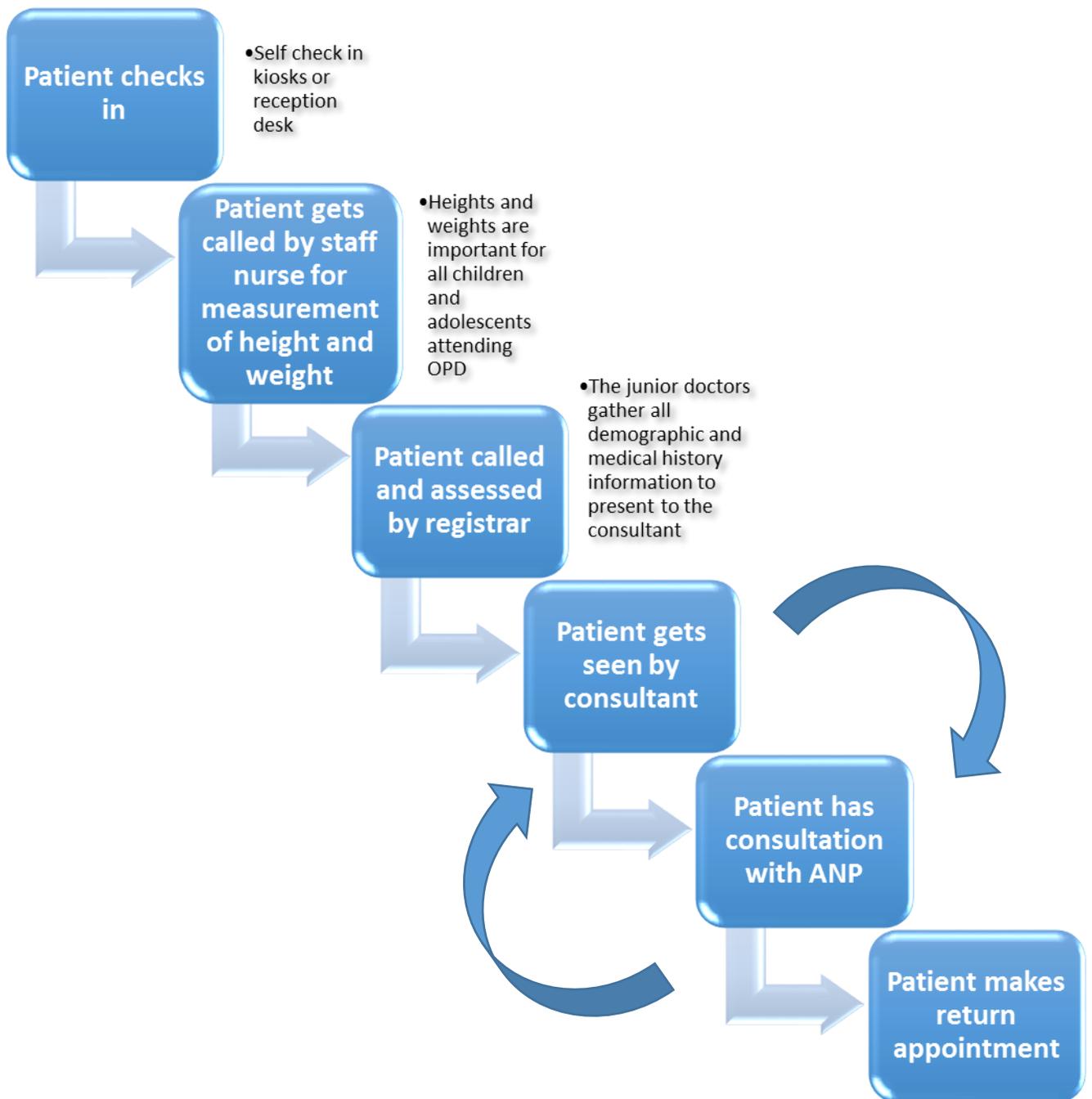
Appendix 14. Journey of ethical application process



Appendix 15. Journey through participant selection and presentation of findings



Appendix 16. Neurology OPD Clinic process



Appendix 17. Snapshot of excel spreadsheet containing anonymised data

| | A | B | C | D | E | F | G |
|----|--------------------------|-----------------------|---------------------|---------------|---------------------------|---------------|----------------------|
| | Question: | Participant 1 | Participant 2 | Participant 3 | Participant 4 | Participant 5 | Participant 6 |
| 1 | Age | 12 | 14 | 15 | 16 | 12 | 12 |
| 2 | Gender | female | female | female | male | female | female |
| 3 | County | Dublin | Wicklow | | Dublin | Wicklow | Dublin |
| 4 | Date of consent | 12/05/2016 | 12/05/2016 | 12/05/2016 | 26/05/2016 | 02/06/2016 | 30/05/2016 |
| 5 | electronics owned | | | | | | |
| 6 | smart phone/mobile | no | yes | no | yes | no | no |
| 7 | iPad/tablet | no | no | no | yes | yes | yes |
| 8 | Laptop | yes | yes | no | no | no | yes |
| 9 | desktop | no | no | no | yes | no | no |
| 10 | Age diagnosed | 3 | 11 | 9 | 14 | 3 | 10 |
| 11 | Age aware | 3 | 11 | 9 | 12 | 4 | 10 |
| 12 | who told them | mother | Hospital | mother | Dr Webb | mother | Dr Webb |
| 13 | epilepsy type | secondary generalised | complex and absence | not answered | juvenile absence epilepsy | tonic clonic | |
| 14 | Do they tell | | | | | | |
| 15 | Teachers | yes | yes | yes | yes | no | yes |
| 16 | classmates | yes | yes | yes | yes | no | yes |
| 17 | close friends | yes | yes | yes | yes | no | yes |
| 18 | relatives | yes | yes | yes | yes | no | yes |
| 19 | Hospital attended | | | | | | |
| 20 | NCH | yes | yes | yes | yes | yes | yes |
| 21 | TSCUH | no | no | no | no | no | no |
| 22 | OLCHC | yes | no | no | no | no | no |
| 23 | info type at diagnosis | | | | | | |
| 24 | leaflets | no | yes | yes | yes | yes | yes |
| 25 | verbal advice | no | yes | yes | yes | yes | yes |
| 26 | books | no | yes | yes | no | yes | yes |
| 27 | suggested online sources | no | yes | yes | no | no | no |
| 28 | other? | yes | n/a | no | no | no | no |
| 29 | If Other, specify? | mother | | | | | |
| 30 | who was info for? | | | | | | |
| 31 | children | yes | yes | yes | no | yes | yes |
| 32 | teens/adolescents | n/a | yes | yes | yes | yes | no |
| 33 | parents/carers | yes | yes | yes | no | yes | yes |
| 34 | all the above | n/a | yes | yes | no | yes | no |
| 35 | other? | no | n/a | no | no | no | no |
| 36 | if other, please specify | | | | | | |
| 37 | who gave info? | | | | | | |
| 38 | Nurse/nurse specialist | yes | yes | yes | no | yes | yes |
| 39 | Consultant/Neurologist | yes | yes | yes | yes | no | no |
| 40 | Parent | yes | n/a | yes | no | no | no |
| 41 | I don't remember | yes | n/a | n/a | no | no | no |
| 42 | Other | yes | n/a | n/a | no | no | yes |
| 43 | If Other, specify? | mother | | | | | Epilepsy association |
| 44 | Did info help? | yes | yes | yes | yes | | yes |
| 45 | if not, why? | | | | | | |
| 46 | | | | | | | |