Rare Diseases Web-Information

For

Families in Ireland (RD-WIFI)

An exploratory study to identify the web information sources used by parents of children with rare conditions towards the development of an Irish website specifically designed to meet the needs of these parents.

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Executive Summary

This descriptive exploratory study was undertaken to identify for the first time in Ireland the web information sources used by parents of children with rare conditions for the purposes of identifying the design and content of an Irish website specifically designed to meet the web-based information needs of these parents.

A number of major factors underpinned the need for this study. The use of the web by parents of children with rare conditions for information, advice and support is increasing. However searching the web can be an overwhelming, frustrating and disappointing experience as literally thousands of links may be returned to web pages that contain irrelevant and incomprehensible material. In Ireland no dedicated website exists to assist these parents.

The aim of this study was to identify appropriate information sources for use by parents of children with rare conditions in Ireland. It focused on the identification of content to meet the needs of parents who seek health information, support and advice on the Internet. The purpose was to develop an Irish website specifically designed to meet the web-based information needs of these parents.

The objectives were to:

(i) identify parents web-based information needs

(ii) make recommendations from the information collected to help provide data that can be used to devise a web information resource for parents who are involved in the care of children with rare conditions

The study was conducted in two parts. In Part (1) a focus group interview and Part (2) a questionnaire for completion either online or by post.

Part (1) the focus group interview; eight (n=8) parents participated. Data collected from the interview informed the development and refinement of the questionnaire. The interview data were analysed and five themes were identified. These related to needing accurate information at the point of diagnosis, the need for peer support and reassurance from other parents, difficulties managing conflicting information, accessing support groups and the 'ideal' web site. These findings informed the development and refinement of the questionnaire.

In Part (2) one hundred and twenty-eight (n=128) respondents completed the questionnaire. All respondents completed the online version and none chose the postal option. The majority of respondents who completed the questionnaire were mothers followed by fathers and one legal guardian. They represented persons across all educational levels. They were aged between 35-49 years followed by those aged between 18-34 years and no parent over 65 years took part. The vast majority of respondents were resident in the Republic of Ireland and most lived in towns while the remaining respondents lived in rural, city and village locations. For the vast majority their primary occupational role is that of carer followed by those in part-time employment, full-time employment and homemakers.

A total of (n=117) children were reported on in this study. The vast majority of respondents have one child with a rare condition, some have two children and two have three, and two have four or more children with a rare condition. More than half the children are male. Children's ages range from less than twelve months to thirty-nine years with the majority being between 4-7 years, followed by those aged between 8-12 years, 1-3 years, 13-19 years and 20-29 years. Five children were aged less then twelve months and three were aged 30-39 years.

While the majority of children reported on have a diagnosis twelve do not. The majority of children's conditions were diagnosed when they were less twelve months to three years

old, followed by those when between 1-3 years, 4-7 years and 8-12 years. Four children were diagnosed 13-19 years while one was diagnosed between 20 to 29 years. The vast majority of children have a disability associated with their condition. The greatest number have a physical and intellectual disability; almost a quarter have a physical disability and less than ten percent have solely an intellectual disability. Most children need assistive equipment with some having multiple needs for this.

The Internet is used regularly by the majority of respondents when searching for information on their child's rare condition. The study also revealed that most are comfortable using the Internet and most often searched between 7pm to midnight and most commonly from home. The majority search sites are recommended by other parents of children with rare conditions and by a doctor or other healthcare professional. The person most likely to seek information on their child's condition is the mother. A variety of online accounts are used in networking when seeking information, advice and support. All parents use email and almost all use Facebook with half using Skype and more than a third use Twitter.

The majority of parents use the Internet to gain information to improve their understanding of their child's condition and more than half felt the knowledge gained improved their ability to care for their child and his/her condition. It also enabled them to explain their child's condition to others. The impact on parents of Internet information includes improving their understanding and management of their child's condition and influencing their interaction with healthcare professionals. For more than half the parents it has some influence on decisions made about their child's condition, for a fifth it has a major influence. However for one tenth it has no influence at all. Parents also use the Internet and other media in networking and seeking support on the impact and management of their child's condition.

When seeking information parents search a variety of sites including those specific to their child's condition and general sites for rare conditions. Their searching habits differ when their child is first diagnosed or when they suspect something is wrong to when diagnosis is confirmed and or to that of now. The types of information parents searched for at the point of diagnosis include the child's condition and symptoms, management of the child's condition, support groups and genetic information (See Table 3.7). However overall only less than a fifth reported that the information sourced decreased their anxiety.

In relation to developing a dedicated Irish website for children with rare conditions parents suggest the website be easily accessible, be credible and be disability friendly. It should provide links to other credible sites and be interactive in terms of information and support. The study's findings inform its recommendations for the development and design of this Irish website for parents of children with rare conditions. They indicate that:
The website be:

- Live, up-to-date, interactive
- Credible
- Disability friendly
- In English and Irish
- Plain understandable language
- Balanced in its presentations
- Available on different media for example online, Facebook

The website content should provide:

- Reliable and credible information
    - on rare conditions, care of the child, state services, healthcare services, educational services and financial services
- Information, advice and support to parents
- Parent to parent support
- Details of support groups and support organisations

- Not ‘ just the science but also real life stories’
- Links to national and international organisations
- Up-to-date research information

Healthcare professionals involved in the website should facilitate:

- Specialist expert knowledge
- Multidisciplinary team involvement
- Interactivity with parents using the site
- Psychological contact and support between parents

Further research is required into:

- Parents searching habits at the time of their child’s diagnosis or when they first suspect some is wrong compared to later
- Healthcare professionals interaction with parents when parents inform healthcare professionals of information they have sourced on the Internet
- Rare conditions website designs impact on parents, families and carers
- Parent to parent support
- Parents use of social media for information

Abstract

The aim of this study was to identify for the first time in Ireland information sources used by parents of children with rare conditions. It focused on the identification of content to meet the needs of parents who seek health information, support and advice on the Internet for the purposes developing an Irish website specifically designed to meet the web-based information needs of these parents.

The study was conducted in two parts:

- Part (1) a focus group interview; eight parents (n=8) participated. Data collected from the interview informed the development and refinement of the questionnaire.
- Part (2) the questionnaire administered either online or by post. One hundred and twenty-eight (n=128) initially responded. All completed online questionnaires with no requests for postal copies.

The study's results identified that the majority of parents who took part use the Internet regularly. Parents search the Internet for information on their child's rare condition and use the Internet and other media in networking and seeking support on the impact and management of this. The majority of parents search sites recommended by other parents of children with rare conditions and by a doctor or other healthcare professional. Parents use a variety of online accounts in networking when seeking information, advice and support. All parents use email and almost all use Facebook with half using Skype and more than a third using Twitter.

In relation to developing a dedicated Irish website for children with rare conditions parents suggest the website should be easily accessible, credible and disability friendly. It should provide links to other credible sites and be interactive in terms of information and

support. The study's findings inform its recommendations for the development and design of this Irish website for parents of children with rare conditions include that:

The website be:

- Live, up-to-date, interactive
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Contents

List of Figures

List of Tables

Glossary of Terms

For the purpose of this report terms used are defined as:

(1) **Rare conditions** – findings from the study's focus group indicated that all parents preference is for the term "rare condition" when referring to their children's rare condition, disorder or disease. In acknowledging this preference in this report rare condition refers to and includes rare conditions, rare diseases and rare disorders.

(2) **Parent** refers to and includes mothers, fathers, legal guardians and/or caregivers.

(3) **Participants** refer to and includes all parents who took part in the study.

(4) **A respondent refers to and includes** all parents who responded to the questionnaire.

(5) **Children** refer to and include all children aged between less than twelve months to thirty-nine years.

(6) **Child** refers to the child or children of the respondents. His or her infers no bias but his is used for ease of reading as appropriate.

Chapter One: Background

The use of the web by parents of children with rare conditions for information, advice and support is increasing. However searching the web can be an overwhelming, frustrating and disappointing experience as literally thousands of links may be returned to web pages that contain irrelevant and incomprehensible material. In Ireland no dedicated website exists to assist these parents.

1.1 Introduction

This collaborative study is the first Irish study to identify web-based resources required by parents of children with rare conditions.

1.2 The purpose of the study

The purpose of this study was to identify the web-based sources used by parents of children with rare conditions, to contribute towards the design and content of a specifically designed website and the development of information sources to parents of children with rare conditions and to provide a baseline for further investigation.

1.3 The aim of the study

The aim of this study was to identify information sources for use by parents of children with rare conditions in Ireland. It focused on the identification of content to meet the needs of parents who seek health information, support and advice on the Internet.

The objectives were to:

(i) identify parents web-based information needs

(ii) make recommendations from the information collected to help provide data that can be used to devise a web information resource for parents who are involved in the care of children with rare conditions.

1.4 The Literature

A brief synopsis of the literature on parents of children with rare conditions use of web bases resources is provided.

1.4.1 Background

The Internet is a significant source of health information for all parents (Allen 2002, Scharer 2005, Plantin and Daneback 2009). The Internet is changing the way health information is exchanged. This is particularly true when searching for information about a rare condition (Dragusin *et al.* 2013) which is defined by The European Commission as a condition that has a prevalence of less than 5 per 10,000 (European Commission 2009). The number of conditions that fit this definition is large so the number of individuals and families affected by rare conditions may be numerous (Patton 2003, Schieppati *et al.* 2008). However, there may be small numbers of individuals with specific conditions identified in any country. Consequently some families may feel isolated and lack information on the condition that affects their child.

Parents of children with rare conditions are now believed to be better informed and empowered as a result of having more information (Ayme *et al.* 2008). This means that parent-professional relationships are changing with parents of children with rare conditions viewed as experts in the care of their children particularly in how the condition is expressed in their child (Nicholl *et al.* 2014). Wed based information also means that parents can share information and provide support services regardless of geographical location (Hesse *et al.* 2005) or condition. Parents of children with the same conditions can communicate across

the world and share information which strengthens their knowledge of diagnosis, treatments and supports. However the extent and the purpose to which Irish parents of children with rare conditions use the Internet is unknown.

1.4.2 Internet Use

Parents search for both information and social support on the Internet. This varies by gender, age and socio economic status (Allen 2002, Plantin and Daneback 2009). Prevalent users are described as mothers, under 35's, middle class, white or other races [Asian], socially isolated and those with a higher level of income and education (Cotten and Gupta 2004, Hesse *et al.* 2005, Hummelink and Pollock 2006, Madge and O' Connor 2006, Porter and Edirippilige 2007, Plantin and Daneback 2009, Powell *et al.* 2011). People with lower incomes, unemployed, living in rented accommodation and with lower levels of education are less likely to use the Internet but are also those that are less likely to have access to it (Blackburn and Read 2005, Plantin and Daneback 2009, Roche and Skinner 2009). In addition to these factors others may not have the confidence to search, may not have a diagnostic term or do not believe that a search would find relevant medical or genetic information (Roche and Skinner 2009).

1.4.3 Diagnosis

Traditionally, parents of children with rare conditions have difficulties with diagnosis as each is rare and diverse in symptoms (Dragusin *et al.* 2013) and obtaining a diagnosis for their child takes time. Parents use the Internet while their child is being investigated as well as after receiving a diagnosis (Powell *et al.* 2003). The Internet is then used by parents to confirm the diagnosis and to interpret the information they have been given (Christian *et al.* 2001, van den Bree *et al.* 2013). When searching parents look for information in common terms that they understand (Taylor *et al.* 2001).

Information helps parents cope with an uncertain future regarding the condition itself (Hummelink and Pollock 2006), prognosis and management (Roche and Skinner 2009). It enables parents to become experts in their child's rare condition and care (Skinner and Schaffer 2006, Roche and Skinner 2009, Nicholl and Begley 2012), while assisting them to educate others about their child's condition including healthcare professionals (Roche and

Skinner 2009, Nicholl *et al.* 2014). However evidence exists that without additional resources, parents are left to interpret, understand and cope with the diagnosis on their own (Pain 1999, van den Bree *et al.* 2013). The majority find that information on the Internet is difficult to understand (Graber *et al.* 1999, Taylor *et al.* 2001) and multiple sites are accessed to overcome this.

1.4.4 Information Gathering

Searching generic databases means information is not filtered and can be found to be misleading and inaccurate (Eysenbach *et al.* 2002). Given the vast amount of information available on the Internet there is a significant risk that some of it may be inaccurate and unreliable (Plantin and Daneback 2009). However in the quest for information parents may not be overly concerned about the accuracy of information found on the Internet (Leonard *et al.* 2004) which may lead to misinterpretation. Those that are concerned about accuracy may be unaware of how to interpret or use the information they find (Roche and Skinner 2009) and so the accuracy of information is evaluated by inspecting a number of sites to verify any information found (Plantin and Daneback 2009). This too can lead to time wasting and add to their responsibilities.

1.4.5 Social Support

The Internet also provides a valuable role of assisting parents of children with rare conditions find social support. Birch (1998) describes four types of social support as emotional, informational, material and appraisal. Internet support groups can give parents emotional, informational and appraisal support. Parental support groups are considered useful as it is widely recognised that parents of children with similar conditions are suitable help to each other (Kerr and McIntosh 2000). Support groups that facilitate shared information and have dialogue opportunities have led to less social exclusion and increased empowerment of parents (Ayme *et al.* 2008). Online social support is considered to be peer to peer support, where people share common interests and experiences, ask questions or provide emotional support and self-help with the Internet allowing for virtual communities to develop. This support can be in the form of mailing lists, newsletters, discussion forums and chat rooms (Eysenbach *et al.* 2004).

Leonard *et al.* (2004) also identified parents not working, those living in rural areas, those requiring emotional support and those looking to make friends and share feelings spent more time accessing Internet support groups. It was found to be of most benefit for younger parents who joined to make friends and get emotional support. This is supported by Dunham *et al.* (1998) who identify that young isolated mothers use more electronic support. However, there is a risk that online relationships, while valuable, may detract from personal social contact. Despite this, online peer support means parents interact with parents whose children have the same condition and can connect with those who would otherwise be isolated. It also means that they can access peer support from their home which does not impact on their ability to care for their child (Leonard *et al.* 2004) or require travelling.

1.4.6 Difficulties with Internet Use

It may be the case that information parents find on the Internet particularly after diagnosis may cause anxiety. Initial searches and first time encounters with support groups can be stressful as parents encounter others with progressed conditions or more severe presentations of the conditions (Patton 2003). This may be related to the sites accessed as the majority of parents use generic Internet searches to find the information they require (Fox 2006). Accessing the Internet is also a problem for patients without a diagnosis as most websites/ support groups/ web-based education are designed to help those with specific conditions (Ayme *et al.* 2008, Patton 2003). The advantages, however, may outweigh these disadvantages for many parents as the Internet provides 24/7 availability, anonymity, no geographical barriers and parents have time to read and compose messages. It does however not impact on non-verbal communication and therefore interpretation in the messages can vary.

1.5 Conclusion

Patients with rare conditions and their support organisations are viewed as some of the most empowered groups in the health sector, mainly as a result of their own fight for recognition and improved care (Ayme *et al.* 2008). Parents need to access information in order to advocate for their child and continue to fight. This advocacy is necessary as rare

conditions are usually chronic, complex and so rare that care may not fit within current health regimes and can be largely overlooked by the research and policy makers (Ayme *et al.* 2008). The Internet has dramatically changed parents' access to information which may increase expectations and affect relationships with healthcare professionals (Roche and Skinner 2009). The potential uses, benefits and disadvantages of the Internet have been outlined but there is limited research in the past 5 years particularly about parents of children with rare conditions. This is important as the use of Internet telephony (Skype), social media such as Facebook and Twitter and the increased use of Smartphones have expanded Internet use significantly during that time (Tozzi *et al.* 2013).

Chapter Two: Methodology

2.1 Introduction

This chapter outlines the research design of this descriptive exploratory study where both qualitative and quantitative designs were used to determine parents' views of their web-based information needs in caring for their child with a rare condition. It outlines the aim and objectives, recruitment of the sample, inclusion and exclusion criteria, methods of data collection and ethical approval.

2.2 The aim and objectives of the study

The aim of this study was to identify appropriate information sources used by parents of children with rare conditions in Ireland. It focused on the identification of content to meet the needs of parents who seek health information, support and advice on the Internet for the purposes developing an Irish web site specifically designed to meet the web-based information needs of these parents.

The objectives were to:

(i) identify parents web-based information needs

(ii) make recommendations from the information collected to help provide data that can be used to devise a web information resource for parents who are involved in the care of children with rare conditions.

2.3 Recruitment of the sample

Parents of children with rare conditions were recruited by The Saoirse Foundation who acted as a gatekeeper for this study. The gatekeeper recruited potential participants by advertising the study (i) via their databases (families of children with rare conditions, various voluntary organisations) and (ii) using the gatekeeper's website and social media links (Twitter, Facebook, blogs). Potential participants were also provided with a brief synopsis of

the study by the gatekeeper. Parents who wished to participate in Part (1) the focus group interviews were provided with further information and a consent form. Parents who wished to participate in Part (2) the questionnaire online (Appendix 2) were provided with the hyperlink to access further information (the participation information leaflet) and the questionnaire. Completion of the questionnaire was taken as consent to taking part in the study.

2.4 Inclusion and Exclusion Criteria

2.4.1 Inclusion Criteria

Parents:

- with a child with a rare condition
- who use the Internet to source information about their child's condition.

2.4.2 Exclusion Criteria

Parents who:

- having received the study information, declined participation
- completed the questionnaire initially in Part (2) but who indicated they did not use the Internet to obtain information were exited at question 3.

2.5 Data Collection

Data were collected in two parts. Part (1) involved a focus group interview and Part (2) involved the completion of a questionnaire.

2.5.1 Part (1): focus group interview

A purposive sample of parents were recruited via the gatekeeper (Nicholl *et al.* 2013), (n=8) took part in the interview. Data from the focus group were used to generate questions, modify and refine the questionnaire (Nassar-McMillan and Borders 2002). Thematic analysis was used to analyse qualitative data.

2.5.2 Part (2): questionnaire

A structured questionnaire was developed and adapted from (i) the focus group findings and (ii) the literature (Porter and Edirippulige 2007, Tozzi *et al.* 2013). It consisted of four main sections: information about the respondent, information about the child/children, sources of information and the use of the Internet to find information about the child's condition (Appendix 2). The questionnaire comprised of sixty-six (66) questions, which were all in the multiple choice format apart from two open questions (Appendix 2 Q17 and Q66). The questionnaire was available online on SurveyMonkey at: https://www.surveymonkey.com/s/RD-WIFI and paper copies were also available from the study's gatekeeper, though all respondents chose to complete the online version.

The resultant data from the questionnaire was analysed using simple descriptive statistics on SurveyMonkey and MS Excel. All graphs represent the percentage of respondents who chose a particular option and for many questions respondents could chose more than one option.

2.6 Ethical Approval

Ethical approval was obtained from the Faculty of Health Sciences Ethics Committee, Trinity College Dublin. The study adhered to the principles of good ethical practice in research as identified by the International Council of Nurses (2006). Confidentiality was assured so that any identifiers from the focus group interview would not appear in any report, publication or presentation. There were no identifiers in the anonymous online questionnaire. All information and data is stored in either a locked cabinet or a password protected folder and can only be accessed by the research team. Respondents volunteered to participate in this study and were free to withdraw at any time without penalty.

Chapter Three: The Findings

3.1 Introduction

This descriptive exploratory study was conducted in two parts, Part (1) a focus group interview and Part (2) a questionnaire online. A total of one hundred and thirty-six (n=136) parents took part in the study, eight (n=8) in the focus group interview and one hundred and twenty-eight (n=128) responded to the questionnaire. This chapter focuses mainly on Part (2) findings as Part (1) findings were essentially for use to inform and develop Part (2).

3.2 Part (1) Focus Group Interview

Eight (n=8) parents took part in the focus group interview (Appendix 1). The purpose of Part (1) was to serve the development and refinement of Part (2) the questionnaire.

3.2.1 Results

Biographical data are presented (Appendix 1). Qualitative data analysis identified five themes; needing accurate information at the point of diagnosis, the need for peer support and reassurance from other parents, difficulties managing conflicting information, accessing support groups and the 'ideal' web site. This data informed the development and refinement of the questionnaire.

3.3 Part (2) Questionnaire

The questionnaire was divided into four main sections; Section 1: sources of information about your child's condition; Section 2: information about your use of the Internet, Section 3: information about your child or children and Section 4: information about yourself (Appendix 2).

3.3.1 Questionnaire Analysis

Simple descriptive analysis was undertaken using frequencies for categorical variables using SurveyMonkey. Simple thematic analysis was used to analyse qualitative data.

One hundred and twenty–eight (n=128) parents initially responded to the questionnaire and a summary of the number who completed the questionnaire in full is detailed in Appendix 3.

Section 1, respondents (n=128) commenced the questionnaire; of these (n=121) were eligible to participate as they use the Internet to find information about the child's condition. The remaining (n=7) were not eligible to participate because they did not use the Internet and as such were exited.

Section 2, commenced with (n=121) respondents but (n= 25) of these exited along the way or at the end of the section leaving (n=96).

Section 3, started with (n=96) respondents however (n=3) exited along the way or at the end of the section resulting in (n=93) remaining.

Section 4, started with (n=93) respondents but (n=2) exited along the way leaving (n= 91). Resulting in (n= 91) completing the questionnaire up to question 66. Question 66, the final open question was completed by (n= 82) respondents (Table3.1) (Appendix 3).

Table 3.1: Questionnaire sections

Questionnaire	Start %	Start (n)	Exit %	Exit (n)	Completed %	Completed (n=)
Section 1	100%	n=128	5.5%	n=7	94.6%	n=121
Section 2	94.5%	n=121	19.5%	n=25	75%	n=96
Section 3	75%	n=96	2.0%	n=3	72.6%	n=93
Section 4	72.6%	n=93	8.6%	n=11	64%	n=91 *

* Of the 91 people who completed the questionnaire, 82 completed the last open question which was optional (Appendix 3).

In addition in each section there are variations in the number of actual replies to each question because for many questions, more than one option was available. As a result the actual number of replies to each question is provided.

3.3.2 Biographical Data

Biographical data is presented for respondents (n=121) who took part in the questionnaire and for their children (n=117).

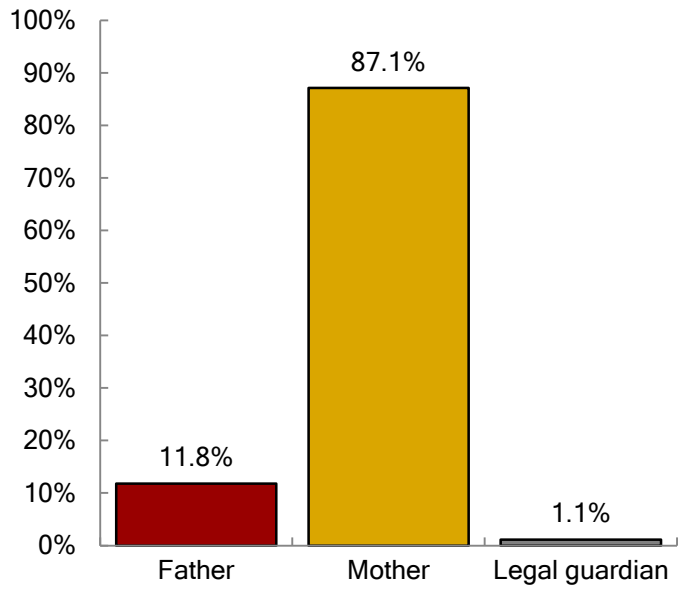
3.3.2.1 Respondents

Of the (n=93) who completed this question (n=12) were male and 87.1% (n=81) were female (Appendix 4 Q57).

3.3.2.1.1 Relationship to Child

Relationship to child, (n= 93) replied. The largest proportion were mothers (n= 81), fathers (n=11) and legal guardian (n=1) (Figure 3.1).

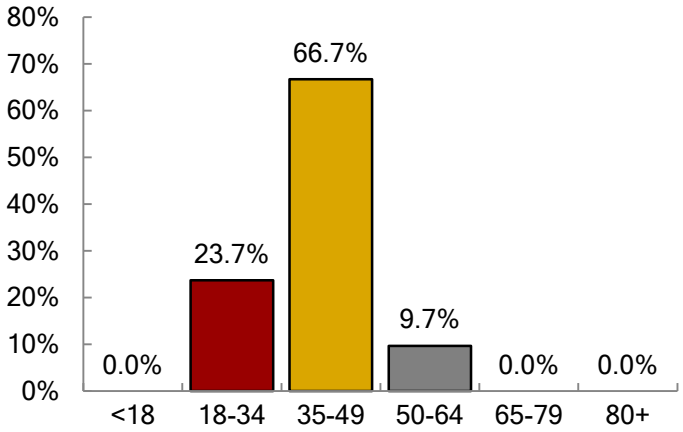
Figure 3.1 Relationship of respondent to child



3.3.2.1.2 Respondents Age Profile

Ninety-three (n=93) respondents completed this, (n= 62) of whom were in the age range "35-49" years, (n=22) were aged "18-34" years with (n=9) aged "50-64" years. No respondent was under 18 or over 64 years of age (Figure 3.2).

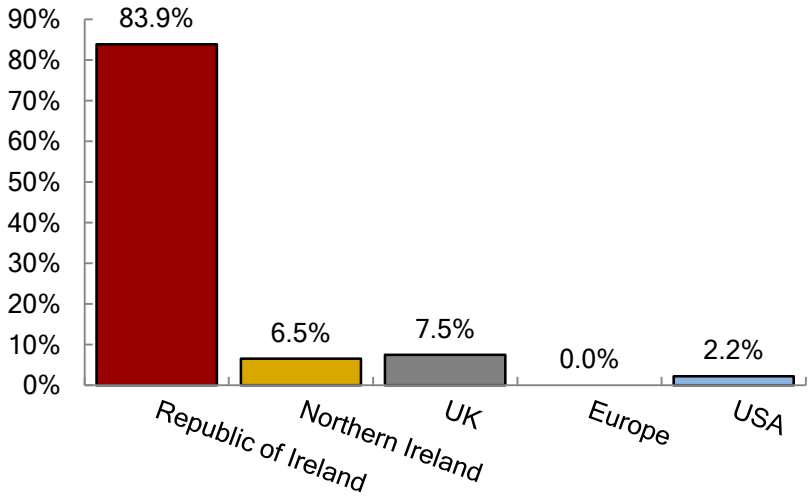
Figure 3.2 Age of respondent



3.3.2.1.3 Country of Residence

Asked where do you live, (n=93) replied. The vast majority (n=78) live in the "Republic of Ireland", followed by (n=7) in "UK", (n=6) in "Northern Ireland" and (n=2) in "USA." No one from "Europe" completed the question (Figure 3.3).

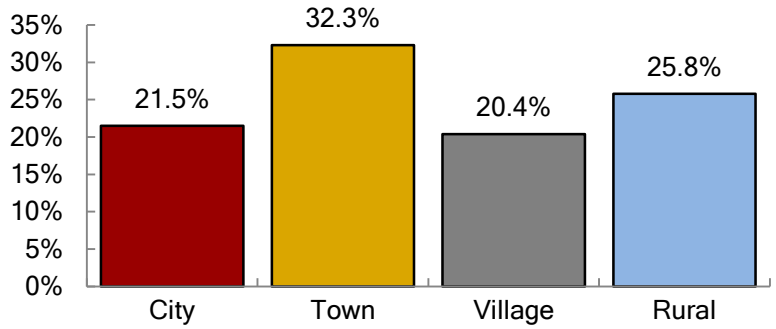
Figure 3.3 Respondents country of residence



3.3.2.1.4 Respondents Domicile

Asked what location best describes where you live, (n=93) replied. The majority (n=30) chose "town" followed by (n=24), "rural" and an almost equal spread across "city" (n=20) and "village" (n=19) (Figure 3.4).

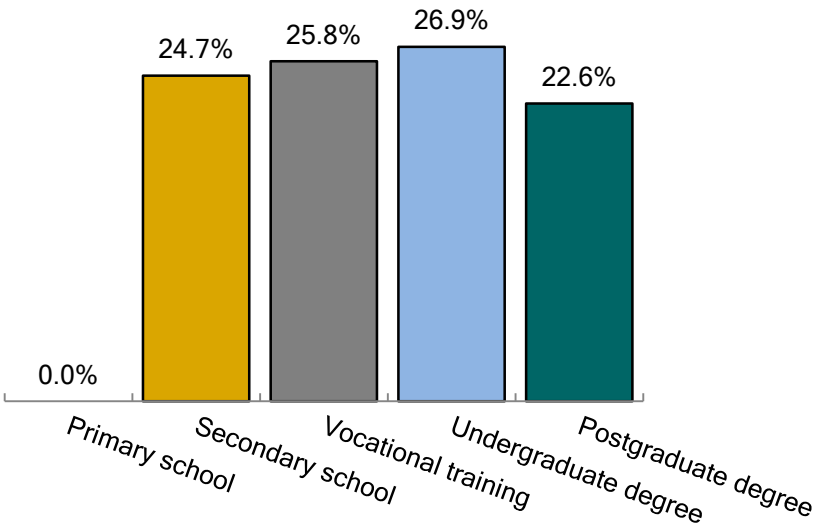
Figure 3.4 Respondents domicile



3.3.2.1.5 Level of Education

Asked what is your highest level of education, (n=93) replied. There was almost an equal spread across four levels, with (n=25) "undergraduate degree", (n=24) "vocational training", (n=23) "secondary school" and (n=21) having a "postgraduate degree". None replied "primary school" (Figure 3.5). Asked how comfortable are you speaking and writing English, (n=91) replied. All (n=91) indicated "very comfortable" (Appendix 4 Q64, 65).

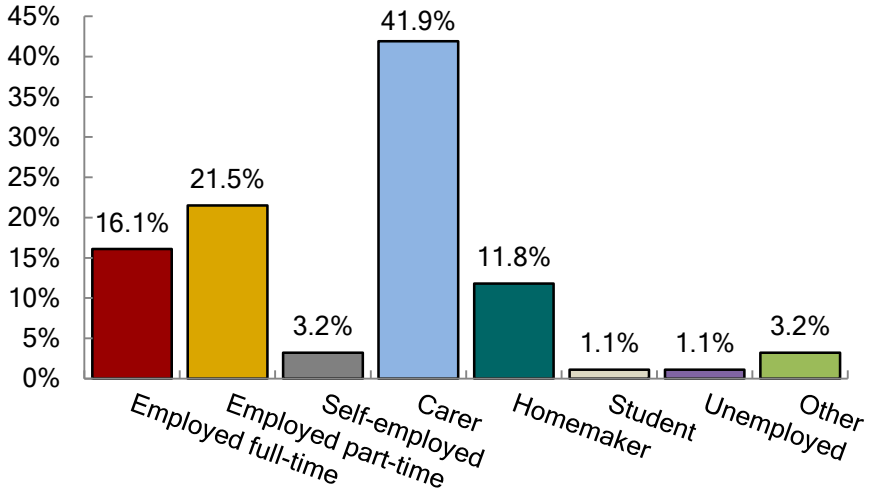
Figure 3.5 Respondents level of education



3.3.2.1.6 Primary Occupational Role

Asked about primary occupational role, (n=93) replied. The majority (n=39) selected "carer", followed by (n=20) "employed part-time", (n=15) "employed full-time", (n=11) "homemaker". Three (n=3) selected "self-employed" while (n=1) was an equal spread across "student" and "unemployed" respectively. While (n=3) chose "other" they did not specify the role (Figure 3.6).

Figure 3.6 Respondents primary occupational role



Respondents (n=78) not in "employed full-time" were invited to reply to "if not employed full-time did you leave your full-time job to care for your child". Fifty-one (n=51) of the (n=78) selected "yes", (n=20) selected "no". The remaining (n=7) selected "not applicable" but did not elaborate (Appendix 4 Q63).

3.3.3 Children Reported on in Questionnaire

A total of (n=117) children with rare conditions are reported on by their parents. Respondents were asked how many of their children have a rare condition, (n=96) replied. Seventy-eight (n=78) of the (n=96) respondents have one child, (n=14) have two children and (n=2) equally have three and four or more children with a rare condition (Appendix 4 Q27).

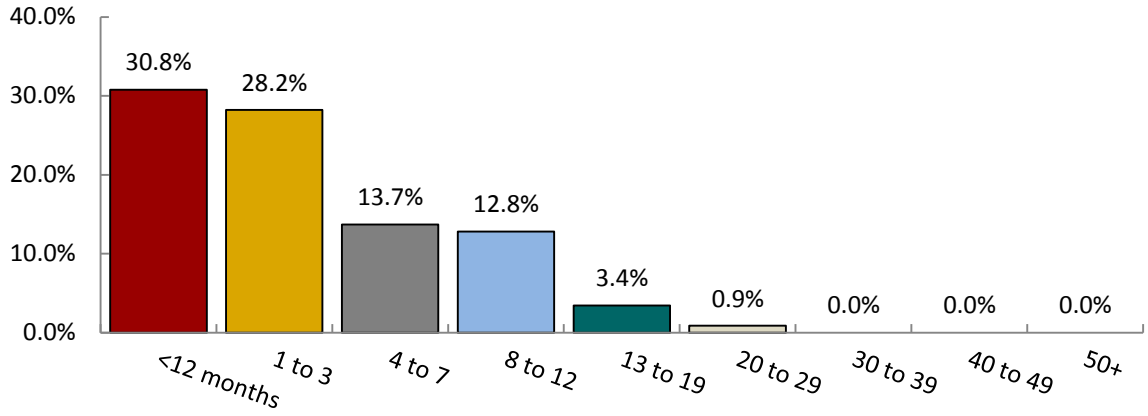
3.3.3.1 Children's Profile

Of the children (n=117) reported on (n=64) are male and (n=53) are female (Appendix 4 Q29, 36, 43, 50). Their age range is from less than twelve months to thirty-nine years. The majority (n=33) of children are in the age range "4 to 7" years, followed by (n=28) aged "8-12" years, (n=24) aged "1 to 3" years, (n=15) aged "13 to 19" years , (n=9) aged "20-29" years, (n=5) aged less than twelve months and (n=3) aged "30 to 39" years. No children were in the higher age ranges (Appendix 4 Q28, 35, 42, 49). The majority (n=71) of children were reported as needing assistive equipment while (n=46) do not need assistive equipment. Findings indicate children may have needs which require multiples of assistive equipment for their multiple needs. The majority (n=48) of children have an overall need for equipment to assist with "moving", (n=23) with "eating", (n=13) with "breathing" and (n=10) with "speech". Equipment is also needed for activities such as sitting, hearing, bathing, sleeping and seeing (Appendix 4 Q34, 41, 48, 55).

3.3.3.2 Diagnosed Conditions

Asked does your child condition have a diagnosis (n=117) children were reported on. One hundred (n=105) children have a diagnosis for their condition while (n=12) have no diagnosis (Appendix 2 Q30). Of the children (n=105) with a diagnosis, the majority (n=69) were diagnosed when they were under twelve months to three years, that is (n=36) were diagnosed before the age of 1 year and (n=33) between the ages "1 to 3" years. Followed by (n=16) between ages "4 to 7" years and (n=15) between ages "8 to 12" years. Four (n=4) were diagnosed in years "13 to 19", while 0 .9% (n=1) was in the age range "20 to 29" years. No age of diagnosis was reported in the higher age ranges (Figure 3.7).

Figure 3.7 Child's age when diagnosed

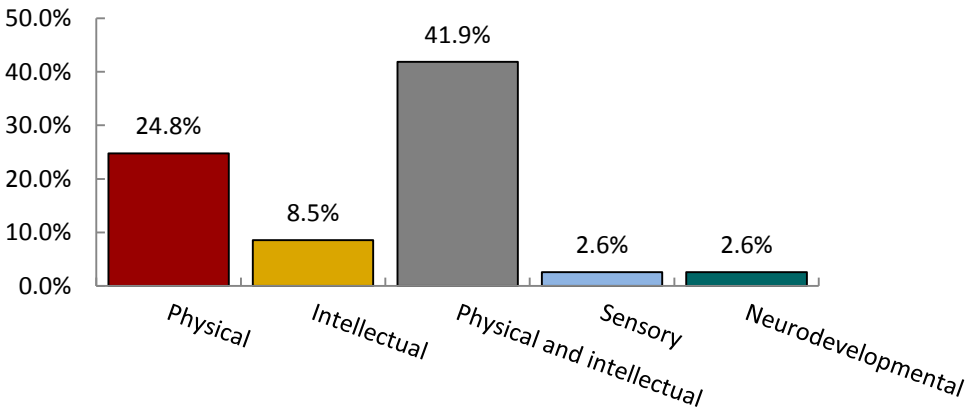


3.3.3.3 Conditions and Disability

Asked does the child's condition include a disability children (n=116) were reported on. The vast majority (n=92) of rare conditions include a disability while (n=24) do not (Appendix 4 Q32, 39, 46, 53).

Respondents who reported children's conditions as including a disability where invited to complete a follow up question in which they were asked to specify the type of disability. Ninety-four (n=94) replied of these, the majority (n=49) indicated a "physical and intellectual" disability, (n=29) a "physical" disability and (n=10) an "intellectual" disability. There was an equal spread of (n=3) across sensory and neurodevelopmental disabilities respectively (Figure 3.8).

Figure 3.8 Nature of child's disability



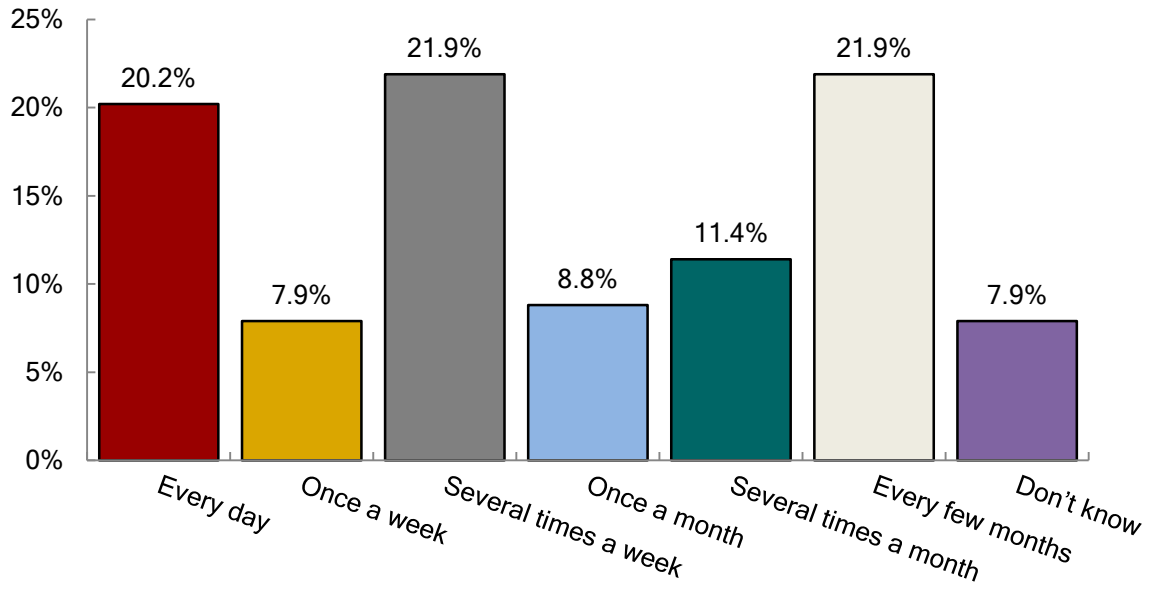
3.3.4 Internet Use to find Information about Child's Condition

3.3.4.1 Internet Use Profile

The Internet or websites to source information about their child's condition is used by all respondents (n=121) who completed the questionnaire (Appendix 4 Q2). Respondents (n=121) were asked how comfortable are you using the Internet, (n=114) replied. The majority (n=83) indicated "very comfortable", (n=16) "somewhat comfortable", (n=12) "comfortable", (n=2) "somewhat uncomfortable" and (n=1) "uncomfortable" (Appendix 4 Q4). Asked the location where the Internet is most often accessed (n=114) replied. The vast majority searched from "home" (n=106), (n=7) from "work" and (n=1) indicated "other" and specified a Smartphone. None use the "public library" (Appendix 4 Q5).

Asked the frequency and times the Internet is used, (n=114) replied. There is an equal spread across "several times a week" and "every few months" (n=25) respectively. Followed by "every day" (n=23), "several times a month" (n=13), "once a month" (n=10) with again equal distribution across "once a week" and "don't know" (n=9) respectively (Figure 3.9).

Figure 3.9 Frequency the Internet is searched to find information about child's condition



In relation to time of day, the majority (n=49) access the Internet between "7pm and midnight", (n=46) have "no pattern", (n=10) access between "1pm to 6pm" while (n=7) access between "7am and midday" and (n=2) from "midnight to 6am" (Appendix 4 Q6).

3.3.4.2 Websites

Asked how many websites usually visited or browsed when looking for information about your child's condition, (n=112) replied. The majority (n=45) access "2-3", (n=34) access "4-5", (n=12) "don't know", (n=9) access "6-9", (n=7) access "10-20" and (n=3) access more "than 20" websites (Appendix 4 Q9).

3.3.4.2.1 Finding Websites

Asked how do you find websites about your child's condition, "*choose all that apply",* (n=102) replied. Because as many as applied could be selected, sources are ranked not by the number of replies to the question but by the number of times sources were selected (Table: 3.2) (Appendix 4 Q15).

Table 3.2: Finding websites about the child's condition

Rank	Sources	Response 100%	Responses (n=102)
1	• Search Engines -Google, Yahoo, Bing, Ask Jeeves, Aol, Baidu etc.	93.1%	95
2	• Specialised website	28.4%	29
3	• Orphanet • Social media	6.9%	7
4	• Recommended by others	2.9%	3
5	• Other (uncategorised)	1.0%	1

3.3.4.2.2 Recommended Websites

Asked do you visit websites on recommendations, "*choose all that apply"*, (n= 102) replied**.** Because as many as applied could be selected, websites are ranked not by the number of replies to the question but by the number of times sources were selected (Table 3.3) (Appendix 4 Q16).

Table 3.3: Websites visited on recommendations

Rank	Recommended By	Response 100%	Responses (n=102)
1	• Parents of children with rare conditions	63.7%	65
2	• A doctor or healthcare professional	46.1%	47
3	• Not applicable	23.5%	24
4	• A friend or family member	21.6%	22
5	• Support groups/organisations	2.0%%	2
6	• Child with condition	1.0%%	1

3.3.4.2.3 Frequently Visited Websites

Asked in an open question to specify the websites most frequently visited, (n=131) entries were made. Specified websites are ranked not by the number of replies to the question but by the number of times websites were specified. In total (n=80) websites were named and across (n=131) specifications (Table 3.4) (Appendix 4 Q17).

Table 3.4: Websites frequently visited

Rank	Websites (n=80)		Specified (n=131)
1	• Facebook (including support groups and organisations)		22
2	• Unique The Rare Chromosome Disorder Support Group • Google		7
3	• The Brittle Bone Society		6
4	• Osteogenesis Imperfecta Foundation		5
5	• The United Mitochondrial Disease Foundation		4
6	• National Fragile X Foundation • MitoAction • Epilepsy Ireland		3
7	• 22Q Foundation • 22Q11 Charity Ireland • LGS Foundation Lennox-Gastaut Syndrome • Marfan Syndrome Support Group Ireland • National Marfan Foundation		2
8	• Aaron's Ohtahara • Aicardi Syndrome • Allergy Ireland • Anaphylaxis Ireland • Autoinflammatory Alliance • Boston University Medical Campus, Boston University • British Medical Journal	• Liam's Lodge • Kids With Food Allergies • Max Appeal! • Mayo Clinic • Metachromatic Leukodystrophy Foundation • Monarch Initiative • Mumsnet • National Center for Learning Disabilities	1

	• CDKL5 UK • Child Growth Foundation • Child Lung Foundation: ChILD • Children's Craniofacial Association • Chromosome 18 • Cohen Syndrome • DBA UK • Disability is Natural • Epilepsy.com • EURORDIS • Foundation for Mitochondrial Medicine • Fragile X Ireland • Genetic and Rare Disorders Organisation (GRDO) • Genetic.Org • Great Ormond Street Hospital Children's Charity • Histiocytic Disorders • Hunter Syndrome Foundation • Hypermobility Syndromes Association • Inclusion Ireland • International Children's Palliative Care Network • International Foundation for CDKL5 Research • International Patient Organisation for C1 Inhibitor Deficiencies • Irish Autism Action	• National Organization for Rare Disorders • Neurofibromatosis Association of Ireland • Newcastle Hospitals – Children's Services • NINDS Alpers' Disease Information Page • NINDS Lissencephaly Information Page • Orphanet • Pachygyria - Right Diagnosis • Rollercoaster • Rubinstein-Taybi Syndrome • Special Needs Parents Association • Spina Bifida Hydrocephalus Ireland • Stanford Medicine • SWAN UK • Teeter's Page on Apert's syndrome • The Histiocytosis Research Trust • The MAGIC Foundation • The Society for Mucopolysaccharide Diseases • The US Hereditary Angioedema Association • Tuberous Sclerosis Alliance • Tuberous Sclerosis Alliance • VCFS Educational Foundation • WebMD • XLH Network (X-Linked Hypophosphatemia)	

3.3.5 Networking

Asked are you registered in social network groups dedicated to the child's condition (n=112) replied, of these (n=90) are registered, (n=22) are not (Appendix 4 Q13). Of the (n=90) registered, (n=77) share information, while (n=13) do not (Appendix 4 Q14).

Asked about online accounts subscribed to *"choose all that apply",* (n=112) replied.

Because as many as applied could be selected, online accounts are ranked not by the number of replies to the question but by the number of times online accounts were selected. All (n=112) have "email", (n=106) have "Facebook", (n=57) "Skype", (n=48) have "twitter", (n=31) have "LinkedIn", (n-23) have "MSN/Messenger", (n=12) "blog" and (n=9) have "health-related apps" (Table 3.5) (Appendix 4 Q12).

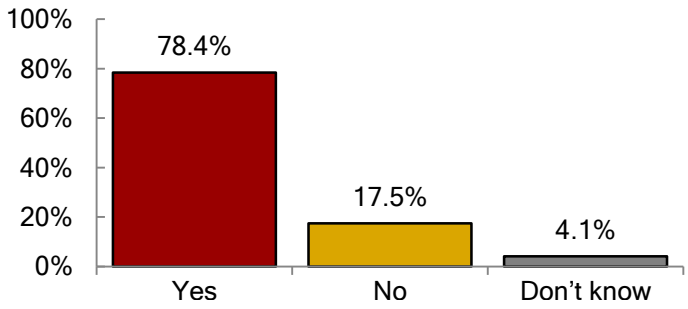
Table 3.5: Online accounts subscribed to

Rank	Recommended By	Response 100%	Response (n=112)
1	• Email	100%	112
2	• Facebook	94.6%	106
3	• Skype	50.9%	57
4	• Twitter	42.9%	48
5	• LinkedIn	27.7%	31
6	• MSN/Messenger	20.5%	23
7	• Blog	10.7%	12
8	• Health-related apps	8.0%	9

3.3.5.1 Healthcare Professionals

Asked have you told a doctor or healthcare professional about the information found on the Internet about the child's condition, (n=97) replied. The vast majority of which (n=76) had told a healthcare professional, while (n=17) indicated "no" and while (n=4) indicated they "didn't know" (Figure 3.10).

Figure 3.10 Doctor or healthcare professional told about information found on Internet about child's condition



Seventy-six (n=76) indicated they had told a healthcare professional. When asked how did you tell your doctor or healthcare professional about the information found on the Internet, (n=84) replied. Of these (n=84), the vast majority (n=74) indicated they "spoke to him/her directly", (n=9) "used email" and (n=1) selected "other". "Facebook", "telemedicine" and "other social networks" were not selected (Appendix 4 Q23).

Asked how interested where your doctor of healthcare professional when you told him/her about the information found on the Internet, (n=75) replied. The majority (n=38) indicated the professional was "somewhat interested", (n=17) indicated "very interested", (n=12) indicated "not too interested", (n=7) found they were "not at all interested" and (n=1) "didn't know" (Appendix 4 Q24).

3.3.6 Information

3.3.6.1 Impact

Asked about of the impact on them as parents of information found on the Internet about their child's condition, "*choose all that apply",* (n=86) replied. Because as many as applied could be selected, impact selections are ranked not by the number of replies but by the number of times selected (Table 3.6) (Appendix 4 Q21).

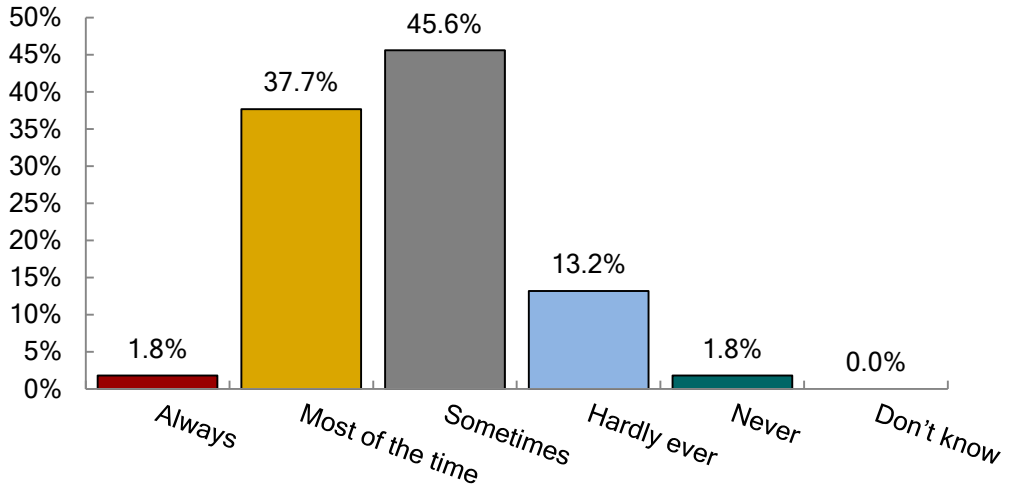
Table 3.6: Internet information impact on parents

Rank	Impact	Response 100%	Response (n=86)
1	• Improved my understanding of my child's condition	72.1%	62
2	• Enabled me to explain my child's condition	58.1%	50
3	• Improved my ability to manage and care for my child's condition	57.0%	49
4	• Increased my anxiety	32.6%	28
5	• Was useful for diagnosing my child's condition	23.3%	20
6	• Decreased my anxiety • Was useful for accessing medicines or alternative treatments / therapies online	16.3%	14
7	• Made me change my medical / healthcare professional	9.3%	8
8	• Made me change my child's food habits	7.0%	6
9	• Made me change my child's physical activity	5.8%	5
10	• Was not useful • Not sure	4.7%	4
11	• Empowered me • Other (please specify)	2.3%	2
12	• Helped me educate my healthcare professional • Useful for making new contacts	1.2%	1

3.3.6.2 Relevant Information

Asked how often is relevant information found online, (n=114) replied. The majority (n=52) indicated "sometimes" while (n=43) indicated "most of the time", (n=15) found "hardly ever" and equal number (n=2) indicated "always" and "never" respectively (Figure 3.11).

Figure 3.11 How often relevant online information is found



3.3.6.3 Topics of Information

Asked when your child was first diagnosed or when you first had a concern that something was wrong, what topics of information did you look for on the Internet, (n=101) replied. Because respondents could choose as many as applied topics are ranked not by the number of replies to question but in the order of number of times topics of information were selected. While when asked the next question currently what information do they look for now just (n=98) replied. Again, because respondents could choose as many as applied topics are ranked not by the number of replies to question but in the order of number of times topics of information were selected (Appendix 4 Q18, 19). While "my child's condition or symptoms" is ranked first in both time frames there is a change in both timeframes across most all other topics (Table 3.7).

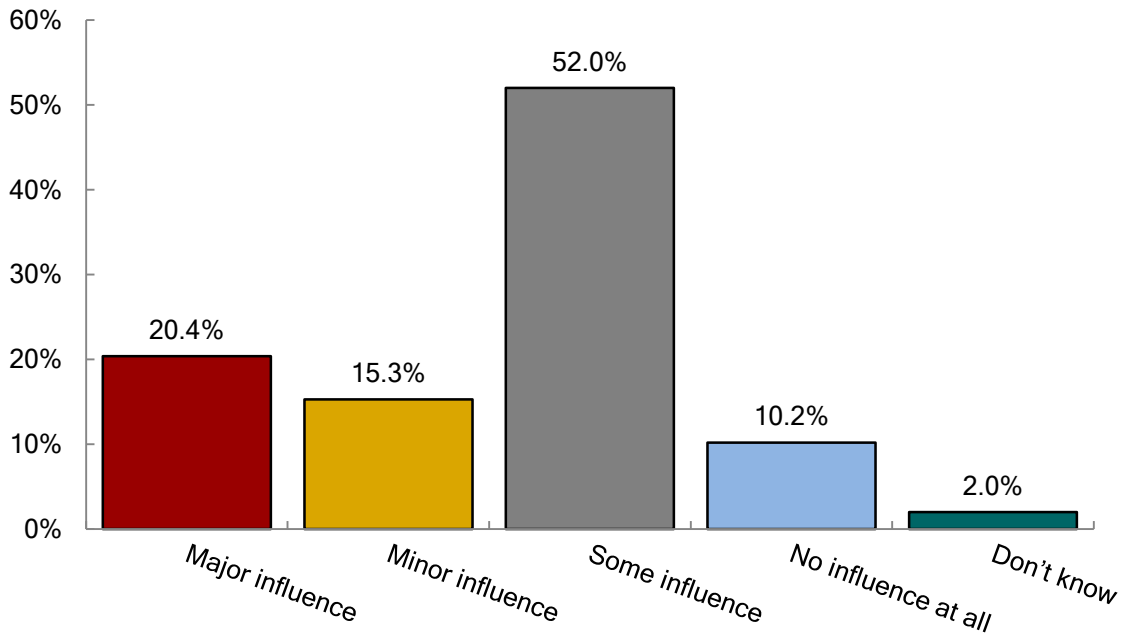
Table 3.7: Information topics

Rank	First Diagnosed	Rank	Current
1	• my child's condition or symptoms	1	• my child's condition or symptoms
2	• my child's diagnosis	2	• the management of my child's condition
3	• the management of my child's condition	3	• the care of my child's condition • treatments
4	• treatments • support groups	4	• my child's diagnosis
5	• genetics	5	• support groups
6	• the care of my child's condition • child development	6	• child development
7	• organisations and/or societies	7	• research and innovation
8	• medical / healthcare professionals	8	• genetics
9	• research and innovation	9	• educational options • organisations and/or societies
10	• early intervention options	10	• medical / healthcare professionals
11	• physical activities	11	• preventing complications • upcoming events or workshops
12	• hospitals, hospices, medical centres	12	• physical activities
13	• alternative treatments / therapies • nutrition	13	• nutrition
14	• preventing complications	14	• accessing medicines or alternative treatments / therapies • financial assistance
15	• future pregnancies	15	• hospitals, hospices, medical centres • state services
16	• educational options	16	• managing family dynamics
17	• state services • financial assistance	17	• early intervention options • future pregnancies
18	• where to get a second opinion	18	• accessing medicines or alternative treatments / therapies online
19	• upcoming events or workshops	19	• vaccinations
20	• managing family dynamics	20	• other (please specify)
21	• accessing medicines or alternative treatments / therapies online	21	• where to get a second opinion
22	• vaccinations		
23	• other (please specify)		

3.3.6.4 Influence on Decisions

Asked would you say information found on the Internet influences decisions you make about your child's condition, (n=98) replied. For the vast majority (n=51) information sourced on the Internet has "some influence", for (n=20) it has "major influence, for (n=15) it has "minor influence" while for (n=10) it has "no influence at all" and (n=2) "don't know" (Figure 3.12) (Appendix 4 Q20).

Figure 3.12 Influence information sourced on the Internet has on decisions made about child's condition



3.3.7 Designing a Website for Parents of Children with Rare Conditions

3.3.7.1 Choosing a Website

Asked which factors do you take into account when choosing a website, "*choose all that apply",* (n=112) replied. Because as many as applied could be chosen topics are ranked not by the number of replies to the question but in the order of number of factors selected. Ranked first are "relevant and accurate", second "trustworthiness", third "up-to-date", fourth "recommended by others" and fifth "easy to understand". Factors such as "has other website links within it" and "nice layout" have minimum appeal (Table 3.9) (Appendix 4 Q10).

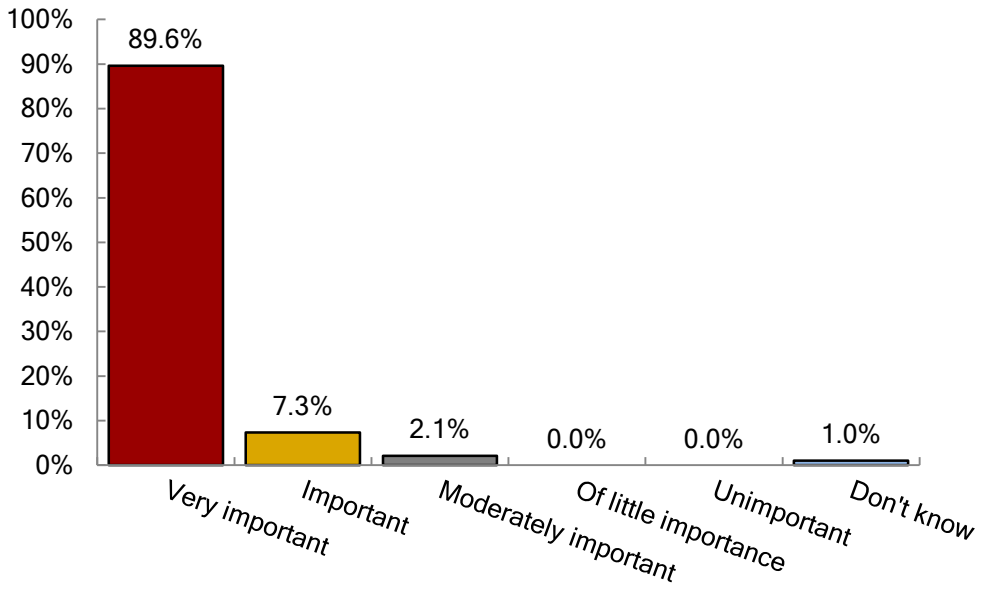
Table 3.8: Factors when choosing a website

Rank	Factors	Response 100%	Responses (n=112)
1	• relevant and accurate	65.2%	73
2	• trustworthiness	62.5%	70
3	• up-to-date	60.7%	68
4	• recommended by others	46.4%	52
5	• easy to understand	37.5%	42
6	• has other website links within it	8.0%	9
7	• nice layout	5.4%	6
8	• other (uncategorised)	2.7%	3

3.3.7.2 Accessibility

Asked the importance of making the website accessible to persons with a disability, (n=96) replied. Of these, the vast majority (n=86) indicated "very important", (n=7) indicated "important", (n=2) indicated "moderately important" while (n=1) indicated "don't know (Figure 3.13). Asked should this website be available in the Irish language (n=96) replied of which (n=32) indicated "yes", (n=18) indicated "no" while (n=46) indicated "don't know (Appendix 4 Q26).

Figure 3.13 Importance of making a website for parents of children with a rare condition accessible to anyone with a disability



3.3.7.3 Design

Asked to name what is the ONE thing if you were creating a website for parents of children with rare conditions you would like to see, respondents had to write in their "One thing". Eighty-two (n=82) wrote in their preferences. The data gathered in this question were analysed using simple thematic analysis. Data analysis identified four master themes, website design (n=32), content (n=39), healthcare professionals (n=8) and credibility (n=3) (Appendix 4 Q66).

3.3.7.3.1. Website Design

In this theme design and presentation were the two issues identified. In relation to design respondents suggest that the newly designed website should be an excellent platform, navigation friendly, interactive and have links and "*all content should be in PLAIN ENGLISH, that every parent could understand"* (N24). One respondent wrote:

> *"Personally I find a 'live', up-to-date and changing website is key. Also that it is easy to navigate and is obviously useful and of benefit. Epilepsy Ireland have a very good website and the best feature I've come across as a parent is an on-line forum they run regularly with a nurse. While I haven't used this facility I feel it is an excellent platform for parents/carers as quite often it is hard to leave the house and knowing that is there to link in with is a great help. I get reminders by email the day of the forum a couple of hours in*

> *advance. The main reason I haven't used it is because I feel my children's needs are greater than most and it would not be of direct benefit to me at present. I also find on-line discussion with other parents on Facebook really helpful as it's so easy to hear of other's experience's in accessing services, using equipment etc. and it is all up to date information. The problem with so many websites is that they are not kept up to minute"* (N78).

It would contain real life stories not just the science bits:

> *"Parents stories...good and bad"* (N12).

3.3.7.3.2 Content

In this theme information and support were the two issues identified.

Respondents suggested the website provide practical and factual information such as:

> *"Information on the care of the child such as on feeding the child, on toilet training, HELP WITH COMMUNICATION..., tips on dealing with hypersensitivity to noise or to touch, information on likely complications such as contractures and on what steps to take to avoid them..., information on other co morbidity commonly associated with the condition and for which the child should be screened, information on the help that is available from voluntary organisations... (if only we had known of them those first years - we could have got an occasional night's sleep and that would really have helped)."* (N1).

> *"Clear information as to what child is entitled to by way of educational input, therapy input, medical input and financial input. Information is hit and miss currently"* (N48).

Respondents would like to see the website provide support with details of support groups and support organisations:

> *"Advice on where to turn, how to get medical support, support group information and a guide on how to make medical personnel listen to and accept the possibilities of a rare disease. Possibly register of specialists within the area of specified rare diseases"* (N5).

> *"What you need to do at the start...if you suspect something is wrong...once you have received a working diagnosis...steps to take with GP, support groups and early intervention as nothing appears to be coordinated"* (N43).

3.3.7.3.3 Healthcare Professionals

Where healthcare professionals be involved in the website respondents suggest that proof be given of the professionals' specialist knowledge. The website should be interactive and give access to a centre of excellence for "rare disorders" with Irish experts and multidisciplinary team members (N59) and:

> *"for Ireland other options for seeking second opinions and having the proper specialists in this country and to have their names and emails displayed clearly on the site"* (N73).

3.3.7.3.4 Credibility

In relation to credibility respondents indicated the trustworthiness of the website in that it would provide accurate information and have links to reputable research papers as one wrote:

> *"Concise, accurate, reassuring information with a high degree of confident certainly about the information contained within..."* (N20).

Chapter Four: Discussion, Conclusions, Limitations and Recommendations

4.1 Introduction

The study serves for the first time in Ireland to explore and identify the needs of parents in their Internet searches for information relating to their children with rare conditions. This was for the purposes of providing information for the development of a specific purpose web site for parents of children with rare conditions.

The study is timely in that the Irish Government has recently published the first National Rare Diseases Plan for Ireland in which a key is the recognition is *"difficulties in accessing appropriate information, was a concern for patients, carers, specialists and Family Doctors"* and proposing "*an evidence-based and trustworthy online source of information about the condition"* would be helpful (Department of Health 2014:58).

4.2 Discussion

The purpose of an Irish dedicated website for rare conditions arises because of parental needs for accessible, clear, reliable information, access to expert genetic and medical advice and clear information relating to diagnostic tests and investigations (Department of Health 2014). This may assist the development of parental information and empowerment (Ayme *et al.* 2008) and give recognition to parental expertise in the management and care of their child's condition (Skinner and Schaffer 2006, Roche and Skinner 2009, Nicholl and Begley 2012). It may also enable the parents to share information with health service providers involved in the planning of care delivery for their child (Ayme et 2008, Roche and Skinner 2009, Nicholl *et al.* 2014).

In developing the first Irish website for parents of children with rare conditions this study's findings indicate two major considerations: firstly parents current Internet use and secondly their suggestions for an "ideal" website.

4.2.1 Current Internet Use

The Internet is a significant source of information about rare conditions (Pain 1999, Christian *et al.* 2001, Taylor *et al.* 2001, Allen 2002, Powell *et al.* 2003, Scharer 2005, Plantin and Daneback 2009, Dragusin *et al.* 2013, van den Bree *et al.* 2013, Department of Health 2014) and as the findings demonstrate the Internet is used regularly by the majority of parents when searching for information on their child's condition. The findings revealed that the majority of parents are comfortable using the Internet. A variety of online accounts are used in networking when seeking information, advice and support. When seeking information the majority search up to five sites, generally search sites recommended by other parents of children with rare conditions and/or recommended by a doctor or healthcare professional. The most frequently used sites were largely related to the child's condition. Facebook was the most frequently used site. All use email with half using Skype, more than a third using Twitter, a fifth use MSN/Messenger, a little more than a tenth use Blogs and some use Health–related apps. When accessing information, most use general search engines (Google, Yahoo, Bing, AOL and Baidu) with more than a third use selected specialised sites and some use Orphanet and social media. The majority were registered with social network groups dedicated to their child's condition. The majority access between 2-5 sites and most commonly search between 7pm to midnight and home was the most common location. Contrary to findings by Leonard *et al.* 2004 that those who use the internet live in rural settings, are unemployed and have lower educational attainments, about 40% of the respondents in this study were employed and the majority live in urban settings and had a higher level of education. Similar to others (Powell *et al.* 2011) the majority of respondents were female and mothers.

The majority use it to gain information about their child's condition and for more than half felt the information gained improved their ability to care for their child and their condition. The information gained has, for some parents, influenced decisions made about their child's condition and for a fifth it has major influence. However for one tenth it has no influence at all. The types of information searched for included the child's condition, presenting symptoms, available treatments and therapy, genetic information, support groups, early intervention options the prevention of complications, state and educational services available and the issues related to future pregnancies. The majority of parents had discussed the information they had obtained from the Internet with a doctor or health care professional while less than a fifth had not. Some indicated the information retrieved was relevant most of the time, while less than half indicated it was relevant sometimes. This supports the work of Roche and Skinner (2009) who indicated the potential inaccuracy of information and the difficulty of interpretation. Despite parents providing this information to others the findings indicate that majority of doctors or health care professionals were somewhat interested and fewer were 'very interested' with parent provided information. Of the respondents 10% approximately indicate that they felt doctors to be 'not at all interested'. This is a new finding not reported in the literature. Healthcare professionals' interest in patient reported information and enacting on this information needs further attention.

The need for sharing experiences and learning from other parents emerged from this study as being very important and this helped to lessen the feeling of isolation frequently experienced by them (Ayme *et al.* 2008). This requirement for on-going support for parents reflects the changing needs for both the child and parents over time. While support systems involve families, friends, healthcare providers, community services and educational services the support of other experienced parents was valued by parents in this study.

Parents use the Internet and other media in networking and seeking support on the impact and management of their child's condition; a finding supported by Leonard *et al.* (2004), Skinner and Schaffer (2006) and Roche and Skinner (2009). The online use of Facebook, Email, Skype, Twitter, LinkedIn, MSN /Messenger, Health related apps and Blogs indicates a change (Tozzi *et al.* 2013) which underlines the importance of networking and building social support systems. However the impact of Internet use on parental anxiety needs consideration as 28 respondents in this study identified increased anxiety and for 14, Internet use decreased their anxiety.

4.2.2 Irish Website

In terms of current online use cognisance needs to be taken of afore discussed current Internet use by parents in terms of media, sites, search habits used and the types of information and support sought.

In terms of an "ideal" and "monitored" website, parents indicated the following as important requirements; it should *be* reliable and accurate, trustworthy, up to date and recommended by others. Features should include ease of understanding, the embedding of credible links, a clear attractive layout and be disability friendly that it is accessible to all with disabilities. In addition the site should be *friendly.* Important for these parents, and supporting Hesse's *et al.* (2005) views, is that the site should be interactive, interactive with other parents, support groups and *expert credible* healthcare professionals. In terms of language some indicated it should be delivered in English and Irish. However the need for *plain English was* stressed so as information could be clearly understood by all.

In relation to content parents identified the following as being important the inclusion of scientific and practical information, and real life experiences including life stories. Parents also suggested linkage to reputable research articles and the provision of detailed information including information on relevant healthcare professionals including their qualifications with linkage to centres of excellence relating to their child's condition. The

website should also provide information on support groups and organisations research also indicates that parents provide each other with support (Keer and McIntosh 2000, Ayme *et al.* 2008). The sharing of information and experiences facilitates parents in helping other parents who may have the same or similar challenges (Skinner and Schaffer 2006, Roche and Skinner 2009). Birch (1998) described four strands of social support which may be gained from Internet usage. They include the following: emotional, informational, material and appraisal. The use of such supports may also lessen the experience of social exclusion and isolation (Ayme *et al.* 2008) but its impact on levels of anxiety may need to be considered and examined. Use of the Internet for support allows parents to communicate and build networks within and outside Ireland. Its convenience and accessibility enables communication at anytime, anywhere in the world and does not require instant responses which allow time for thought and reflection. It is important that information on services and social welfare allowances and clear identification of support groups and services which parents may use at this difficult time and throughout their child's life is provided.

In addition, developers in constructing the site, need to be mindful of the significant source the Internet is for parents (Pain 1999, Christian *et al.* 2001, Taylor *et al.* 2001, Allen 2002, Powell *et al.* 2003 Scharer 2005, Plantin and Daneback 2009, Dragusin *et al.* 2013, van den Bree *et al.* 2013, Department of Health 2014) and that satisfactory parental usage of the site and access to the information it contains may be hampered by the search terms used (Taylor *et al.* 2001). They also need to be cognisant that research indicates when parents do not have a diagnosis for their child's condition, or find that the condition is rare, have further problems in the accessing of information and in locating an expert practitioner who may give them up to date evidence based information (Patton 2003, Ayme *et al.* 2008). In addition the needs of parents may vary over this time and may be complicated by the nature of the suspected condition, the diversity of the possible range of symptoms and the possible or probable prognosis (Department of Health 2014). In addition, as each infant and child's condition is rare and unique parents may find the

information available does not always match their infants/child's capabilities and abilities (Dragusin *et al.* 2013). Indeed some information available may relate only to "the worst case scenario" and not be reflective of the wide range of variations within some conditions. Parents may find it difficult to understand information so the provision of short online leaflets may be a starting point on their journey to assist them in understanding and managing their child's condition and in explaining it to family and healthcare professionals. In addition Roche and Skinner (2009) indicate that searches for information change over time, for example, as a child makes the transition from childhood into adulthood, a finding confirmed in this study which indicated parents' searches for information changed from time of diagnosis to the present.

Consideration also needs to be given to the fact that that not all parents have computer access in their homes and may find it difficult or inconvenient to access a computer at the times they need it most. However this study's findings, and others Tozzi *et al.* (2013), indicate a developing trend in that all parents have online accounts using a variety of media. Parents who themselves have disabilities, may also find accessing information to be a challenge and when English is not the parents' first language. Translation will be required for both soft and hard information sources.

For the website managers, evaluation of information may present challenges as, at first sight, it may be difficult to establish the validity and reliability of the information provided. Parents need reliable and evidence based information in order to make informed decisions. The National Rare Disease Plan for Ireland stated *"Rare Diseases registries were considered a critical tool to support many types of rare disease research" and* also recommended that guidelines on the coding of rare conditions be developed, and that all existing databases be mobilised with a view to establishing an all Ireland Network of Rare Diseases Registries (Department of Health 2014, p14-16).

4.3 Conclusion

This study adds to the body of research which is emerging and gives, for the first time in Ireland, an insight into the web-based needs and practices of parents caring for their children with rare conditions. Findings from this study indicate that the creation of an evidence based credible Irish website for parents of children with rare conditions would provide reliable evidence based information with linkages to credible web sites, to support groups and services to assist parents in the care and management of their children. It would also provide a valuable resource to families, carers and healthcare professionals caring for children with rare conditions.

4.4 Limitations

4.4.1 The Sample

The sample for this study comprised of parents of children with rare conditions.

4.4.2 Data Collection

The sample is limited to parents of children with rare conditions who were recruited by The Saoirse Foundation who acted as gatekeeper. The gatekeeper recruited potential participants by advertising the study (i) via their databases (families of children with rare conditions, various voluntary organisations) and (ii) using the gatekeeper's website and social media links (Twitter, Facebook, blogs) which also limits the findings. SurveyMonkey is recognised as having its own limitations for data collection.

4.4.3 Part (2) The Questionnaire

The questionnaire was designed specifically for this study and while it was reviewed for content and face validity its reliability and validity warrants further testing. The questionnaire only captured information on up to four children in any family.

4.4.4 The Findings

The study's findings reflect the views of those who took part in the study and are only representative of these respondents.

4.5 Recommendations

The study's recommendations are directed to:

4.5.1 Web Site Developers

- Develop and design a dedicated Irish website for parents of children with rare conditions

4.5.1.1 The website be:

- Live, up-to-date, interactive
- Credible
- Disability friendly
- In English and Irish
- Plain understandable language
- Balanced in its presentations
- Available on different media for example online, Facebook

4.5.1.2 The website content should provide:

- Reliable and credible information
    - on rare conditions, care of the child, state services, healthcare services, educational services and financial services
- Information, advice and support to parents
- Parent to parent support
- Details of support groups and support organisations
- Not ' just the science but also real life stories'

- Links to national and international organisations
- Up-to-date research information

4.5.1.3 Healthcare professionals involved in the website should facilitate:

- Specialist expert knowledge
- Multidisciplinary team involvement
- Interactivity with parents using the site
- Psychological support between parents

4.5.2 Research

Further research is required into:

- Parents searching habits at the time of their child's diagnosis or when they first suspect some is wrong compared to later
- Healthcare professionals interaction with parents when parents inform healthcare professionals of information they have sourced on the Internet
- Rare conditions website designs impact on parents, families and carers
- Parent to parent support
- Parents use of social media for information

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Appendices

Appendix 1

Part (1) Focus Group Interview Biographical Results

Participants (n=8)

Relationship to child	(n)	Age in Years	(n)	Place of Residence	(n)	Residence Location	(n)
Father	2	Under 18		Rep Ireland	8	City	4
Mother	6	18-34	2	Northern Ireland		Town	
Guardian		35-49	4	UK		Village	1
Sibling		50-64	1	Europe		Rural	3
Grandparent		65-79		Other			
Other relative		80 or older					
Total	**8**		**8**		**8**		**8**

Level of education	(n)	Occupation	(n)	Gave up full-time employment to care for child	(n)
Primary school		Employed full-time	4	Yes	5
Secondary school	3	Employed part-time	2	No	1
Vocational training	2	Self employed		Not applicable	1
Undergraduate degree	2	Homemaker	1	Not answered	1
Postgraduate degree	1	Carer	1		
		Student			
		Unemployed			
Total	**8**		**8**		**8**

Level Speaking English	(n)	Level Reading English	(n)
Very comfortable	8	Very comfortable	8
Somewhat comfortable		Somewhat comfortable	
Comfortable		Comfortable	
Somewhat uncomfortable		Somewhat uncomfortable	
Very uncomfortable		Very uncomfortable	
Total	**8**	**Total**	**8**

Level Speaking Irish	(n)	Level Reading Irish	(n)
Very comfortable		Very comfortable	
Somewhat comfortable		Somewhat comfortable	
Comfortable		Comfortable	2
Somewhat uncomfortable	3	Somewhat uncomfortable	1
Very uncomfortable	5	Very uncomfortable	5
Total	**8**	**Total**	**8**

Participants' Children (n=8)

Child with rare condition	(n)	Sex of child	(n)	Disability associated with condition	(n)
1	*8	Male	3	Yes	8
2		Female	5	No	
Total	**8**		**8**		**8**

** All 8 participants indicated 1 child with a rare condition*

Conditions with Disability	(n)	Assistive equipment Required	(n)
Physical	2	Yes	5
Intellectual	1	No	3
Physical and intellectual	5		
Total	**8**		**8**

Assistive equipment Required	(n)	Comment
Moving	4	
Eating	2	
Breathing	2	Suction machine cpap (FG 6)
Other		Sitting splints (abducted thumbs), standing splints (legs assist in standing) (FG4) Bathing and buggy (FG5)
In Q8 indicated "No"		In Q9 wrote needs protective equip –administration of chem. orally in the home (FG11)

Age	(n)	Age at Diagnosis	(n)	Comment
		Antenatal	1	At 28 weeks
Under 12 mths	2	Under 12 mths	3	
1 to 3 years	1	1 to 3 years	1	
4 to 7 years	3	4 to 7 years	2	*FG7 “re-diagnosed”
8 to 12 years	1	8 to 12 years		
13 to 19 years		13 to 19 years	1	
20 to 29 years		20 to 29 years		
30 to 39 years	1	30 to 39 years		
Total	**8**		**8**	

Childrens’ Diagnoses (n=8)
Linked hydrocephalus LCAM1, severe global developmental delay and seizures (FG4)
Coffin Siris syndrome ARID 1B mutation (FG5)
Cri du chat and translation of Down’s syndrome (FG6)
IQ43 (FG7)
Osteogensis imperfect type 4 (FG8)
JxG Juvenile xantogranulomatous disease (FG11)
22q11.2 deletion syndrome (FG13)
Box left blank (FG12)

Appendix 2

Part (2) Questionnaire Online

SOURCES OF INFORMATION ABOUT YOUR CHILD'S CONDITION

1. Who is the person in your family MOST likely to seek information about your child's condition?

☐ Myself
☐ Spouse or partner
☐ Other (please specify)

2. Where do you get information about your child's condition?
Please choose all that apply.

☐ Internet or websites
☐ Health care provider
☐ Early intervention service
☐ Books or literature
☐ Family and friends
☐ Word of mouth
☐ Media e.g. television and newspapers
☐ Other (please specify)

3. Do you use the Internet to get information about your child's condition?

☐ Yes *(Please go to Q4)*
☐ No *(Many thanks for the information that you have provided above. You do not need to proceed any further).*

INFORMATION ABOUT YOUR USE OF THE INTERNET TO FIND INFORMATION ABOUT YOUR CHILD'S CONDITION

4. How comfortable are you using the Internet?

- ☐ Very comfortable
- ☐ Somewhat comfortable
- ☐ Comfortable
- ☐ Somewhat uncomfortable
- ☐ Very uncomfortable

5. From where do you most often access the Internet?

- ☐ Home
- ☐ Work
- ☐ Public library
- ☐ Don't know
- ☐ Other (please specify)

6. What time of the day do you MOST OFTEN use the Internet?

- ☐ Midnight to 6am
- ☐ 7am to midday
- ☐ 1pm to 6pm
- ☐ 7pm to midnight
- ☐ No pattern

7. How often do you use the Internet to find information about your child's condition?

- ☐ Every day
- ☐ Once a week
- ☐ Several times a week
- ☐ Once a month
- ☐ Several times a month
- ☐ Every few months
- ☐ Don't know

8. When you go online to look for information about your child's condition, how often are you able to find the information you are looking for?

- ☐ Always
- ☐ Most of the time
- ☐ Sometimes
- ☐ Hardly ever
- ☐ Never
- ☐ Don't know

9. How many websites do you usually visit or browse when looking for information about your child's condition?

- ☐ 1
- ☐ 2 to 3
- ☐ 4 to 5
- ☐ 6 to 9
- ☐ 10 to 20
- ☐ More than 20
- ☐ Don't know

10. Which of the following factors do you take into account when choosing a website? *Please choose all that apply.*

- ☐ Trustworthiness e.g. author, qualifications, IP address
- ☐ Up-to-date
- ☐ Relevant and accurate
- ☐ Nice layout
- ☐ Easy to understand
- ☐ Recommended to me by a medical/healthcare professional
- ☐ Has other website links within it
- ☐ Other (please specify)

11. What device do you use MOST OFTEN to access the Internet?

- ☐ PC or Mac
- ☐ Smartphone
- ☐ Tablet (iPad or similar)
- ☐ Other (please specify)

12. Which of the following applies to you?
Please choose all that apply.

- ☐ I have an email address
- ☐ I have a Facebook account
- ☐ I have a Twitter account
- ☐ I have a Skype account
- ☐ I have a LinkedIn account
- ☐ I have an MSN/Messenger account
- ☐ I write or contribute to a blog
- ☐ I use health-related apps for my smartphone/tablet (please specify)

13. Are you registered in a forum or social network group dedicated to your child's condition?

- ☐ Yes *(Please go to Q14)*
- ☐ No *(Please go to Q15)*

14. Do you share information about your child's condition with these communities?

- ☐ Yes
- ☐ No

15. How do you find websites about your child's condition?
Please choose all that apply.

- ☐ By visiting search engines such as Google, Yahoo, Bing, Ask Jeeves, Aol, Baidu etc.
- ☐ By visiting Orphanet
- ☐ By visiting a website that specialises in rare conditions (please specify)
- ☐ Other (please specify)

16. Do you visit websites recommended by:
Please choose all that apply.

- ☐ A doctor or healthcare professional
- ☐ A friend or family member
- ☐ Parents of children with rare conditions
- ☐ Not applicable
- ☐ Other (please specify)

17. The website(s) I **MOST FREQUENTLY** visit is(are):

18. When your child was **FIRST** diagnosed or when you **FIRST** had a concern that something was wrong, what topics of information did you look for on the Internet? *Please choose all that apply.*

- ☐ my child's diagnosis
- ☐ my child's condition or symptoms
- ☐ the care of my child's condition
- ☐ the management of my child's condition
- ☐ child development
- ☐ managing family dynamics
- ☐ medical / healthcare professionals
- ☐ where to get a second opinion
- ☐ early intervention options
- ☐ educational options
- ☐ treatments
- ☐ alternative treatments / therapies
- ☐ preventing complications
- ☐ nutrition
- ☐ physical activities
- ☐ vaccinations
- ☐ hospitals, hospices, medical centres
- ☐ genetics
- ☐ future pregnancies
- ☐ support groups
- ☐ organisations and/or societies
- ☐ upcoming events or workshops
- ☐ state services
- ☐ financial assistance
- ☐ research and innovation
- ☐ accessing medicines or alternative treatments / therapies online
- ☐ other topics (please specify)

19. I **CURRENTLY** use the Internet to look for information about:
Please choose all that apply.

- ☐ my child's diagnosis
- ☐ my child's condition or symptoms
- ☐ the care of my child's condition
- ☐ the management of my child's condition
- ☐ child development
- ☐ managing family dynamics
- ☐ medical / healthcare professionals
- ☐ where to get a second opinion
- ☐ early intervention options
- ☐ educational options
- ☐ treatments
- ☐ alternative treatments / therapies
- ☐ preventing complications
- ☐ nutrition
- ☐ physical activities
- ☐ vaccinations
- ☐ hospitals, hospices, medical centres
- ☐ genetics
- ☐ future pregnancies
- ☐ support groups
- ☐ organisations and/or societies
- ☐ upcoming events or workshops
- ☐ state services
- ☐ financial assistance
- ☐ research and innovation
- ☐ accessing medicines or alternative treatments / therapies online
- ☐ other topics (please specify)

20. Would you say that the information you find on the Internet influences the decisions you make about your child's condition?

- ☐ Major influence *(Please go to Q21)*
- ☐ Minor influence *(Please go to Q21)*
- ☐ Some influence *(Please go to Q21)*
- ☐ No influence at all *(Please go to Q22)*
- ☐ Don't know *(Please go to Q22)*

21. The information I found on the Internet:
Please choose all that apply.

- ☐ Was not useful
- ☐ Was useful for diagnosing my child's condition
- ☐ Improved my understanding of my child's condition
- ☐ Improved my ability to manage and care for my child's condition
- ☐ Enabled me to explain my child's condition
- ☐ Increased my anxiety
- ☐ Decreased my anxiety
- ☐ Made me change my medical / healthcare professional
- ☐ Made me change my child's food habits
- ☐ Made me change my child's physical activity
- ☐ Was useful for accessing medicines or alternative treatments / therapies online
- ☐ Not sure
- ☐ Other (please specify)

22. Have you told your doctor or healthcare professional about the information you found on the Internet regarding your child's condition?

- ☐ Yes *(Please go to Q23)*
- ☐ No *(Please go to Q25)*
- ☐ Don't know *(Please go to Q25)*

23. How did you tell your doctor or healthcare professional about the information you found on the Internet?
Please choose all that apply.

- ☐ I spoke to him/her directly
- ☐ I used email
- ☐ I used Facebook
- ☐ I used other social networks
- ☐ I used telemedicine services
- ☐ Other (please specify)

24. When you told your doctor or healthcare professional about the information you found on the Internet, how interested where they?

- ☐ Very interested
- ☐ Somewhat interested
- ☐ Not too interested
- ☐ Not at all interested
- ☐ Don't know

25. How important is it that a website for parents of children with rare conditions is accessible to anyone with a disability?

- ☐ Very important
- ☐ Important
- ☐ Moderately important
- ☐ Of little importance
- ☐ Unimportant
- ☐ Don't know

26. Should a website for parents of children with rare conditions be available in the Irish language?

- ☐ Yes
- ☐ No
- ☐ Don't know

INFORMATION ABOUT YOUR CHILD OR CHILDREN

27. How many of your children have a rare condition?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4+

CHILD 1

28. Child's age

- ☐ Under 12 months
- ☐ 1 to 3
- ☐ 4 to 7
- ☐ 8 to 12
- ☐ 13 to 19
- ☐ 20 to 29
- ☐ 30 to 39
- ☐ 40 to 49
- ☐ 50+

29. Child's sex

- ☐ Male
- ☐ Female

30. Does your child have a diagnosis?
- ☐ Yes *(Please go to Q31)*
- ☐ No *(Please go to Q32)*

31. Child's age when diagnosed
- ☐ Under 12 months
- ☐ 1 to 3
- ☐ 4 to 7
- ☐ 8 to 12
- ☐ 13 to 19
- ☐ 20 to 29
- ☐ 30 to 39
- ☐ 40 to 49
- ☐ 50+

32. Does your child's condition include a disability?
- ☐ Yes *(Please go to Q33)*
- ☐ No *(Please go to Q34)*

33. If you answered Yes to question 32, please specify the type or types of disability:
- ☐ Physical
- ☐ Intellectual
- ☐ Physical and intellectual
- ☐ Other (please specify)

34. Does your child use equipment for:
Please choose all that apply.
- ☐ Moving
- ☐ Eating
- ☐ Breathing
- ☐ Hearing
- ☐ Speech
- ☐ None
- ☐ Other (please specify)

If you have additional children with a rare condition please complete the following pages for each child. Otherwise please go to "Information About Yourself".

CHILD 2

35. Child's age
36. Child's sex
37. Does your child have a diagnosis?
38. Child's age when diagnosed
39. Does your child's condition include a disability?
40. If you answered Yes to question 39, please specify the type or types of disability:
41. Does your child use equipment for:

CHILD 3

42. Child's age
43. Child's sex
44. Does your child have a diagnosis?
45. Child's age when diagnosed
46. Does your child's condition include a disability?
47. If you answered Yes to question 46, please specify the type or types of disability:
48. Does your child use equipment for:

CHILD 4

49. Child's age
50. Child's sex
51. Does your child have a diagnosis?
52. Child's age when diagnosed
53. Does your child's condition include a disability?
54. If you answered Yes to question 53, please specify the type or types of disability:
55. Does your child use equipment for:

INFORMATION ABOUT YOURSELF

56. Are you the child or children's:

- ☐ Father
- ☐ Mother
- ☐ Legal guardian
- ☐ None of the above

57. Are you?

- ☐ Male

- ☐ Female

58. What is your age?

- ☐ Under 18
- ☐ 18 to 34
- ☐ 35 to 49
- ☐ 50 to 64
- ☐ 65 to 79
- ☐ 80 or older

59. Do you live in?

- ☐ The Republic of Ireland
- ☐ Northern Ireland
- ☐ The United Kingdom
- ☐ Europe
- ☐ Other (please specify)

60. What location BEST describes where you live?

- ☐ City
- ☐ Town
- ☐ Village
- ☐ Rural

61. What is your HIGHEST level of education?

- ☐ Primary school
- ☐ Secondary school
- ☐ Vocational training
- ☐ Undergraduate degree
- ☐ Postgraduate degree

62. Are you:

- ☐ Employed full-time *(Please go to Q64)*
- ☐ Employed part-time *(Please go to Q63)*
- ☐ Self-employed *(Please go to Q63)*
- ☐ Your child/children's main carer *(Please go to Q63)*
- ☐ A homemaker *(Please go to Q63)*
- ☐ A student *(Please go to Q63)*
- ☐ Unemployed *(Please go to Q63)*
- ☐ Other (please specify) *(Please go to Q63)*

63. If not employed full-time, did you leave your full-time job to care for your child/children?

- ☐ Yes
- ☐ No
- ☐ Not applicable

64. How comfortable are you SPEAKING English?

- ☐ Very comfortable
- ☐ Somewhat comfortable
- ☐ Comfortable
- ☐ Somewhat uncomfortable
- ☐ Very uncomfortable

65. How comfortable are you READING English?

- ☐ Very comfortable
- ☐ Somewhat comfortable
- ☐ Comfortable
- ☐ Somewhat uncomfortable
- ☐ Very uncomfortable

66. Finally, if you were creating a website for parents of children with rare conditions, what is the **ONE** thing you would like to see on that website?

Thank you for your time, input to and support of this study.
The results of this study will be available on The Saoirse Foundation website:
www.saoirsefoundation.com

References: Porter & Edirippulige (2007), Roberts (2010) and Tozzi *et al.* (2013).

Appendix 3

Part (2) Questionnaire Section Results

The following is an overview of the number of respondents who completed the entire questionnaire.
The final download of all data occurred on 14th July 2014, so all numbers are based on those on that date.

In brief:

Number of respondents	**(n=128)**
7 disqualified after the 3rd question *(i.e. they did not use the internet to get information about their child's condition)*	128 minus 7 = 121
30 people exited out of the questionnaire at various stages along the way	121 minus 30 = 91
Therefore the number who completed the questionnaire in full	91

In more detail:
The questionnaire was divided into 4 main sections and the number of respondents who answered each section is detailed next.

- **Section 1:** Sources of information about your child's condition (3 questions; Q1-3)
  - *128 respondents started this section; 7 disqualified so 121 continued to Section 2.*

- **Section 2:** Information about your use of the Internet (23 questions; Q4-Q26)
  - *121 respondents started this section; 25 exited along the way or at the end of the section so 96 continued to section 3.*

- **Section 3:** Information about your child or children (7 questions per child; from Q27 onwards)
  - *96 respondents started this section; 3 exited along the way **or** at the end of the section so 93 continued to section 4.*
  - Distribution of respondents in this section
    - 78 people had 1 child & 78 completed this sub-section
    - 14 people had 2 children & 14 completed this sub-section
    - 2 people had 3 children & only 1 completed this sub-*section i.e. even though 2 people selected in Q27 that they had 3 children with a rare condition, only 1 person filled in the answers*
    - 2 people had 4 children & 2 completed this sub-section
    - 2 more people exited after the last question in this section.

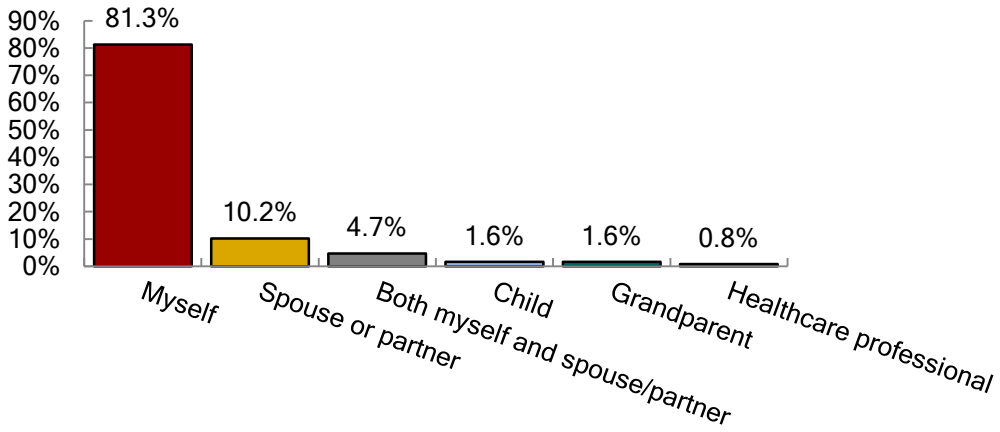
- **Section 4:** Information about yourself (11 questions; Q56-Q65; Appendix 2)
  - *93 respondents started this section but 2 exited along the way so 91 answered the last mandatory question (this was the second last question; Q65; Appendix 2).*
  - *The final question (*Q66; Appendix 2*) was an optional open question and was answered by 82 people.*

In summary, 93 completed section 3 regarding their 117 children but only 91 of them gave us information about themselves (section 4).

Appendix 4

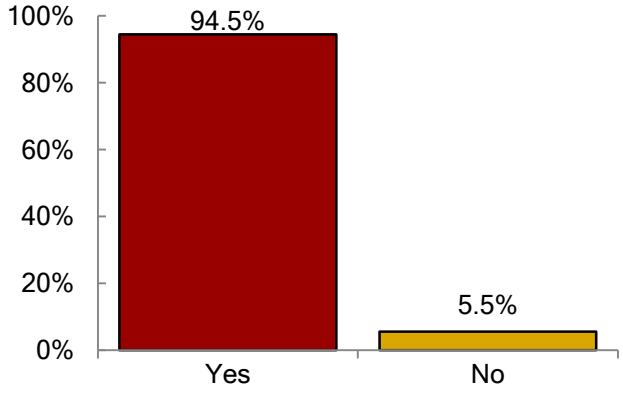
Part (2) Questionnaire Results

Q1The person in your family most likely to seek information about your child's condition



Answer Options	Response %	Response (n)
Myself	81.3%	104
Spouse or partner	10.2%	13
Both myself and spouse/partner	4.7%	6
Child	1.6%	2
Grandparent	1.6%	2
Healthcare professional	0.8%	1

Q3 The Internet used to get information about the child's condition



Answer Options	Response %	Response (n)
Yes	94.5%	121
No	5.5%	7

Q4 How comfortable the respondent is using the Internet

Answer Options	Response %	Response (n)
Very comfortable	72.8%	83
Somewhat comfortable	14.0%	16
Comfortable	10.5%	12
Somewhat uncomfortable	1.8%	2
Very uncomfortable	0.9%	1
Other (Smartphone)	0.9%	1

Q5 Location where the Internet is most often accessed

Answer Options	Response %	Response (n)
Home	93.0%	106
Work	6.1%	7
Public library	0.0%	0
Don't know	0.0%	0
Other (Smartphone)	0.9%	1

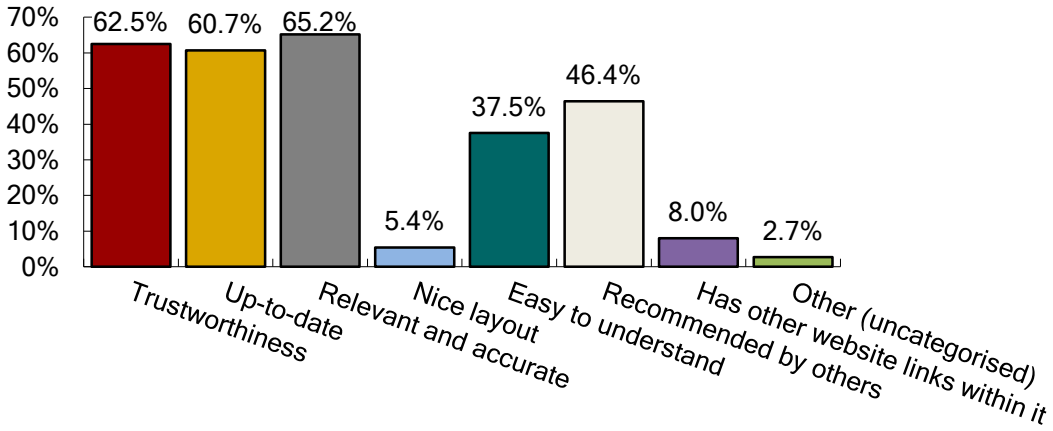
Q6 Time of day when the Internet is most often accessed

Answer Options	Response %	Response (n)
Midnight-6am	1.8%	2
7am-midday	6.1%	7
1pm-6pm	8.8%	10
7pm-midnight	43.0%	49
No pattern	40.4%	46

Q9 The number of websites usually accessed when looking for information about the child's condition

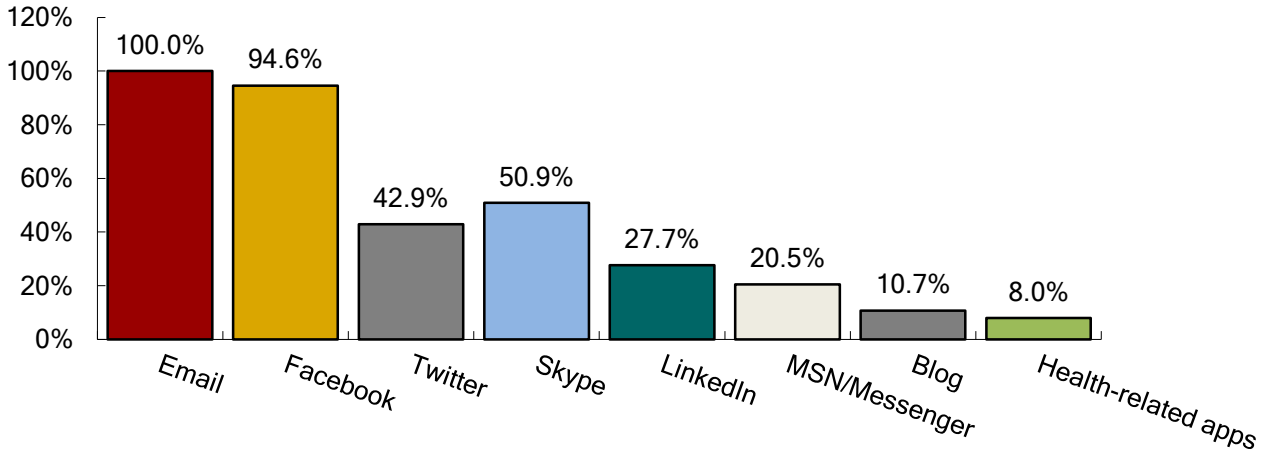
Answer Options	Response %	Response (n)
1	1.8%	2
2-3	40.2%	45
4-5	30.4%	34
6-9	8.0%	9
10-20	6.3%	7
20+	2.7%	3
Don't know	10.7%	12

Q10 The factors taken into account when choosing a website



Answer Options	Response %	Response (n)
Trustworthiness	62.5%	70
Up-to-date	60.7%	68
Relevant and accurate	65.2%	73
Nice layout	5.4%	6
Easy to understand	37.5%	42
Recommended by others	46.4%	52
Has other website links within it	8.0%	9
Other (uncategorised)	2.7%	3

Q12 The range of online accounts subscribed to by the respondents



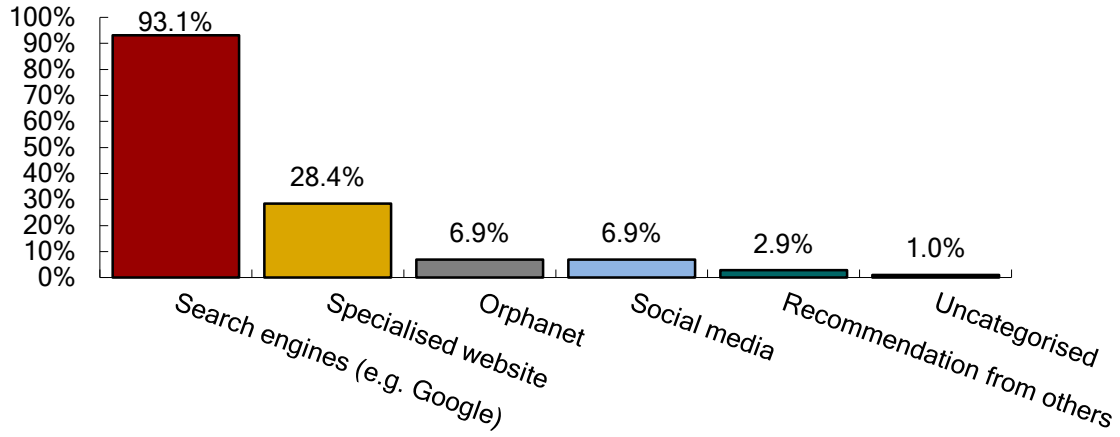
Q13 Are you registered in social network groups dedicated to the child's condition

Answer Options	Response %	Response (n)
Yes	80.4%	90
No	19.6%	22

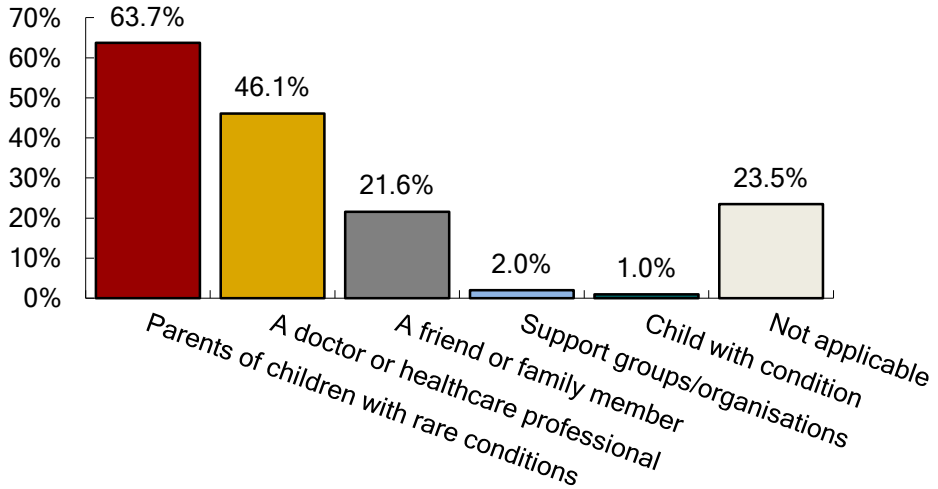
Q14 Do you share information about the child's condition with online communities

Answer Options	Response %	Response (n)
Yes	85.6%	77
No	14.4%	13

Q15 Locating websites about the child's condition?



Q16 Recommendations about relevant websites are made by a range of sources?



Q17 Websites Frequently Visited

Website Name	Website Address	(n)
22Q Foundation	www.22q.org	2
22Q11 Charity Ireland	www.22q11ireland.org	2
Aaron's Ohtahara	www.ohtahara.org	1
Aicardi Syndrome	www.aicardisyndrome.org	1
Allergy Ireland	www.allergy-ireland.ie	1
Anaphylaxis Ireland	www.irishanaphylaxis.org	1
Autoinflammatory Alliance	www.nomidalliance.org	1
Boston University Medical Campus, Boston University	www.bumc.bu.edu	1
British Medical Journal	www.bmj.com	1
CDKL5 UK	www.cdkl5uk.org	1
Child Growth Foundation	www.childgrowthfoundation.org	1
Child Lung Foundation: ChILD	www.childlungfoundation.org	1
Children's Craniofacial Association	www.ccakids.com	1
Chromosome 18	www.chromosome18.org	1
Cohen Syndrome	www.cohen-syndrome.org	1
DBA UK	www.diamondblackfan.org.uk	1
Disability is Natural	www.disabilityisnatural.com	1
Epilepsy Ireland	www.epilepsy.ie	3
Epilepsy.com	www.epilepsy.com	1
EURORDIS	www.eurordis.org	1
Facebook (including support groups and organisations)	www.Facebook.com	22
Foundation for Mitochondrial Medicine	www.mitochondrialdiseases.org	1
Fragile X Ireland	www.fragilexireland.org	1
Genetic and Rare Disorders Organisation (GRDO)	www.grdo.ie	1
Genetic.Org	www.genetic.org	1
Google	www.google.com	7
Great Ormond Street Hospital Children's Charity	www.gosh.org	1
Histiocytic Disorders	www.histio.org	1
Hunter Syndrome Foundation	www.huntersyndromefoundation.org	1
Hypermobility Syndromes Association	www.hypermobility.org	1
Inclusion Ireland	www.inclusionireland.ie	1
International Children's	www.icpcn.org	1

Palliative Care Network		
International Foundation for CDKL5 Research	www.Cdkl5.com	1
International Patient Organisation for C1 Inhibitor Deficiencies	www.haei.org	1
Irish Autism Action	www.autismireland.ie	1
Kids With Food Allergies	www.kidswithfoodallergies.org	1
Klinefelter's Syndrome UK	www.ksa-uk.co.uk	1
LGS Foundation: Lennox-Gastaut Syndrome	www.lgsfoundation.org	2
Liam's Lodge	www.liamslodge.com	1
Marfan Syndrome Support Group Ireland	www.marfan.ie	2
Max Appeal!	www.maxappeal.org.uk	1
Mayo Clinic	www.mayoclinic.org	1
Metachromatic Leukodystrophy Foundation	www.MLDfoundation.org	1
MitoAction	www.mitoaction.org	3
Monarch Initiative	www.monarchinitiative.org	1
Mumsnet	www.mumsnet.com	1
National Center for Learning Disabilities	www.ncld.org	1
National Marfan Foundation	www.marfan.org	2
National Organization for Rare Disorders	www.rarediseases.org	1
Neurofibromatosis Association of Ireland	www.nfaireland.ie	1
Newcastle Hospitals - Childrens Services	www.newcastle-hospitals.org.uk	1
NINDS Alpers' Disease Information Page	www.ninds.nih.gov/disorders/alpersdisease/alpersdisease.htm	1
NINDS Lissencephaly Information Page	www.ninds.nih.gov/disorders/lissemcephaly/lissencephaly.htm.	
Osteogenesis Imperfecta Foundation	www.oif.org	5
Pachygyria - Right Diagnosis	www.rightdiagnosis.com/p/pachygyria/intro.htm	1
Rollercoaster	www.Rollercoaster.ie	1
Rubinstein-Taybi Syndrome	www.rubinstein-taybi.com	1
Special Needs Parents Association	www.specialneedsparents.ie	1
Spina Bifida Hydrocephalus	www.sbhi.ie	1

Ireland		
Stanford Medicine	www.med.stanford.edu	1
SWAN UK	www.undiagnosed.org.uk	1
Teeter's Page on Apert's syndrome	www.apert.org	1
The Brittle Bone Society	www.brittlebone.org	6
The Histiocytosis Research Trust	www.hrtrust.org	1
The MAGIC Foundation	www.magicfoundation.org	1
The Society for Mucopolysaccharide Diseases	www.mpssociety.co.uk	1
The United Mitochondrial Disease Foundation	www.umdf.org	4
The US Hereditary Angioedema Association	www.haea.org	1
Tuberous Sclerosis Alliance	www.tsalliance.org	1
Unique The Rare Chromosome Disorder Support Group	www.rarechromo.org	7
VCFS Educational Foundation	www.vcfsef.org	1
WebMD	www.webmd.com	1
XLH Network (X-Linked Hypophoshpatemia)	www.xlhnetwork.org	1

Qs 18, 19 Information Topics

Topics	1st Diagnosed (n=101)	Current Use (n=98)	Difference
my child's condition or symptoms	86.1%	72.4%	-13.7%
my child's diagnosis	76.2%	48.0%	-28.2%
the management of my child's condition	68.3%	71.4%	3.1%
treatments	65.3%	52.0%	-13.3%
support groups	65.3%	43.9%	-21.4%
genetics	63.4%	35.7%	-27.7%
the care of my child's condition	56.4%	52.0%	-4.4%
child development	56.4%	42.9%	-13.5%
organisations and/or societies	45.5%	33.7%	-11.8%
medical / healthcare professionals	39.6%	30.6%	-9.0%
research and innovation	32.7%	36.7%	4.0%
early intervention options	30.7%	12.2%	-18.5%
physical activities	29.7%	28.6%	-1.1%
hospitals, hospices, medical centres	28.7%	21.4%	-7.3%
alternative treatments / therapies	27.7%	22.4%	-5.3%
nutrition	27.7%	27.6%	-0.1%
preventing complications	26.7%	29.6%	2.9%

future pregnancies	25.7%	12.2%	-13.5%
educational options	24.8%	33.7%	8.9%
state services	23.8%	21.4%	-2.4%
financial assistance	23.8%	22.4%	-1.4%
where to get a second opinion	15.8%	6.1%	-9.7%
upcoming events or workshops	14.9%	29.6%	14.7%
managing family dynamics	11.9%	17.3%	5.4%
accessing medicines or alternative treatments / therapies online	10.9%	11.2%	0.3%
vaccinations	9.9%	8.2%	-1.7%
Other	5.0%	7.1%	2.1%

Table 2. The topics of information sought by respondents when the child was first diagnosed, and now.

Q18 Information Topics When FIRST Diagnosed

Rank	Use of Internet	Total Response 100%	Total Response (n=101)
1	• my child's condition or symptoms	86.1%	87
2	• my child's diagnosis	76.2%	77
3	• the management of my child's condition	68.3%	69
4	• Treatments • support groups	65.3%	66
5	• genetics	63.4%	64
6	• the care of my child's condition • child development	56.4%	57
7	• organisations and/or societies	45.5%	46
8	• medical / healthcare professionals	39.6%	40
9	• research and innovation	32.7%	33
10	• early intervention options	30.7%	31
11	• physical activities	29.7%	30
12	• hospitals, hospices, medical centres	28.7%	29
13	• alternative treatments / therapies • nutrition	27.7%	28
14	• preventing complications	26.7%	27
15	• future pregnancies	25.7%	26
16	• educational options	24.8%	25
17	• state services • financial assistance	23.8%	24
18	• where to get a second opinion	15.8%	16
19	• upcoming events or workshops	14.9%	15

20	• managing family dynamics	11.9%	12
21	• accessing medicines or alternative treatments / therapies online	10.9%	11
22	• vaccinations	9.9%	10
23	• Other (please specify)	5.0%	5

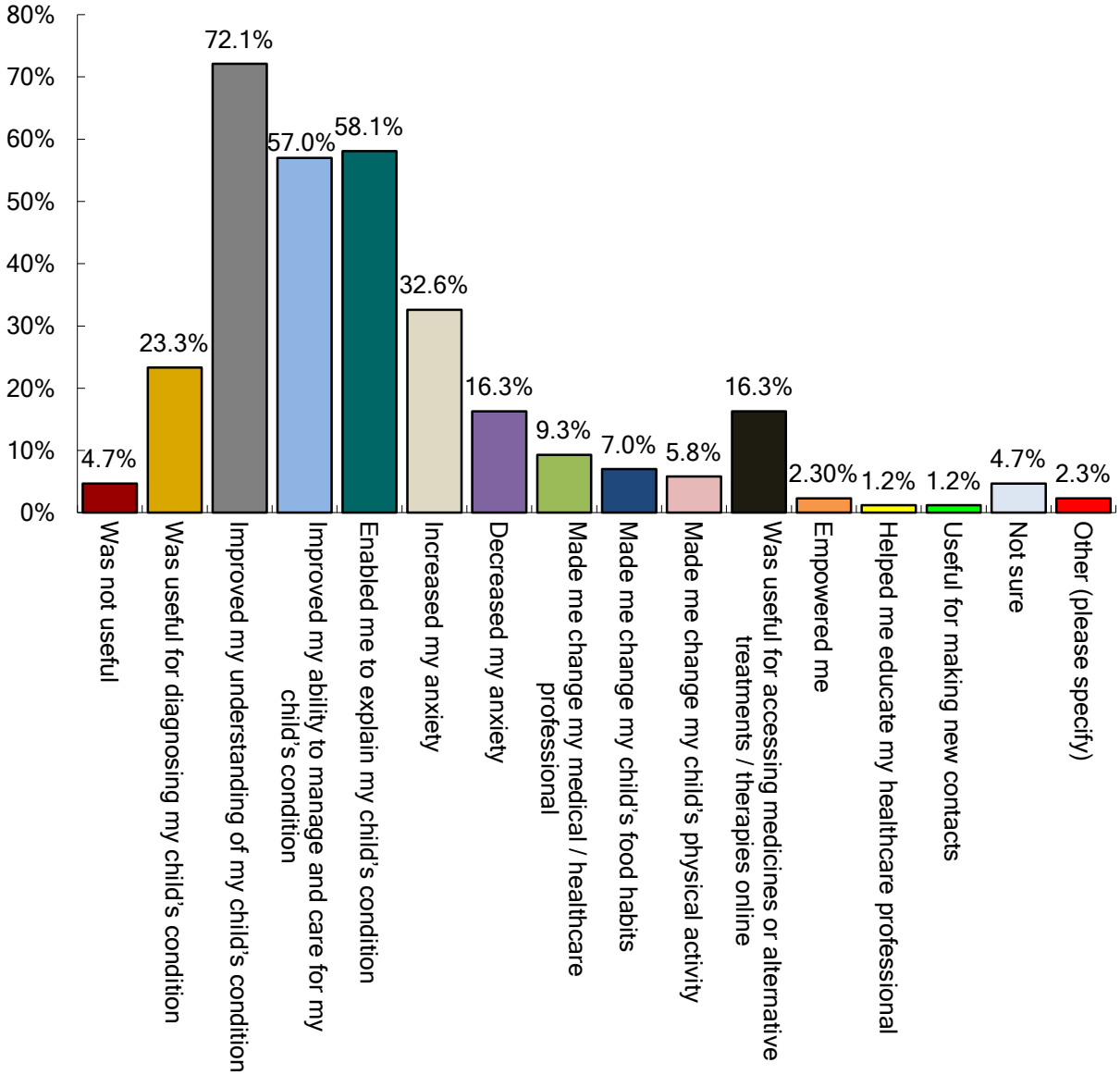
Q19 CURRENT Information Topics

Rank	Use of Internet	Total Response 100%	Total Response (n=101)
1	• my child's condition or symptoms	72.4%	71
2	• the management of my child's condition	71.4%	70
3	• the care of my child's condition • Treatments	52.0%	51
4	• my child's diagnosis	48.0%	47
5	• support groups	43.9%	43
6	• child development	42.9%	42
7	• research and innovation	36.7%	36
8	• Genetics	35.7%	35
9	• educational options • organisations and/or societies	33.7%	33
10	• medical / healthcare professionals	30.6%	30
11	• preventing complications • upcoming events or workshops	29.6%	29
12	• physical activities	28.6%	28
13	• nutrition	27.6%	27
14	• accessing medicines or alternative treatments / therapies • financial assistance	22.4%	22
15	• hospitals, hospices, medical centres • state services	21.4%	21
16	• managing family dynamics	17.3%	17
17	• early intervention options • future pregnancies	12.2%	12
18	• accessing medicines or alternative treatments / therapies online	11.2%	11
19	• vaccinations	8.2%	8
20	• Other (please specify)	7.1%	7
21	• where to get a second opinion	6.1%	6

Q20 The influence that information sourced on the Internet has on decisions made about the child's condition?

Answer Options	Response %	Response (n)
Major influence	20.4%	20
Minor influence	15.3%	15
Some influence	52.0%	51
No influence at all	10.2%	10
Don't know	2.0%	2

Q21 The impact on respondents of information found on the Internet about the child's condition?



Q22 Was a doctor or healthcare professional told about the information found on the Internet about the child's condition?

Answer Options	Response %	Response (n)
Yes	78.4%	76
No	17.5%	17
Don't know	4.1%	4

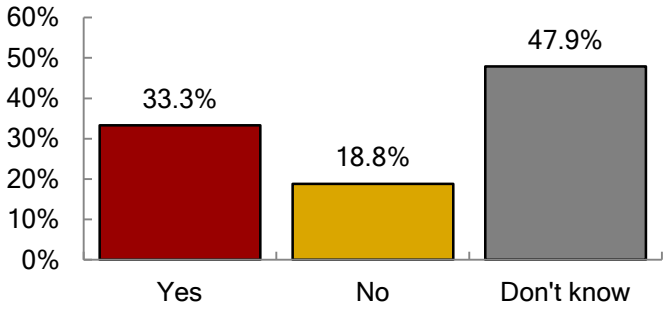
Q23 How did you tell your doctor or healthcare professional about the information you found on the Internet?

Answer Options	Response %	Response (n)
I spoke to him/her directly	98.7%	74
I used email	12.0%	9
I used Facebook	0.0%	0
I used other social networks	0.0%	0
I used telemedicine services	0.0%	0
Other (please specify)	1.33%	1

Q24 Doctor or healthcare professional's levels of interest when told about the information found on Internet?

Answer Options	Response %	Response (n)
Very interested	22.7%	17
Somewhat interested	50.7%	38
Not too interested	16.0%	12
Not at all interested	9.3%	7
Don't know	1.3%	1

Q26 Should a website for parents of children with rare conditions be available in the Irish language?



Answer Options	Response %	Response (n)
Yes	33.3%	32
No	18.8%	18
Don't know	47.9%	46

Q27 The number of children with a rare condition

Answer Options	Response %	Response (n)
1 Child	81.3%	78
2 Children	14.6%	14
3 Children	2.1%	2
4+ Children	2.1%	2

Qs 28, 35, 42, 49 Child's age

Child's Age	Response %	Response (n)
<12 months	4.3%	5
1 to 3	20.5%	24
4 to 7	28.2%	33
8 to 12	23.9%	28
13 to 19	12.8%	15
20 to 29	7.7%	9
30 to 39	2.6%	3
40 to 49	0.0%	0
50+	0.0%	0

Qs 29, 36, 43, 50 Child's sex

Answer Options	Response %	Response (n)
Male	54.7%	64
Female	45.3%	53

Qs 30, 37, 44, 51 Does the child have a diagnosis

Answer Options	Response %	Response (n)
Yes	89.7%	105
No	10.3%	12

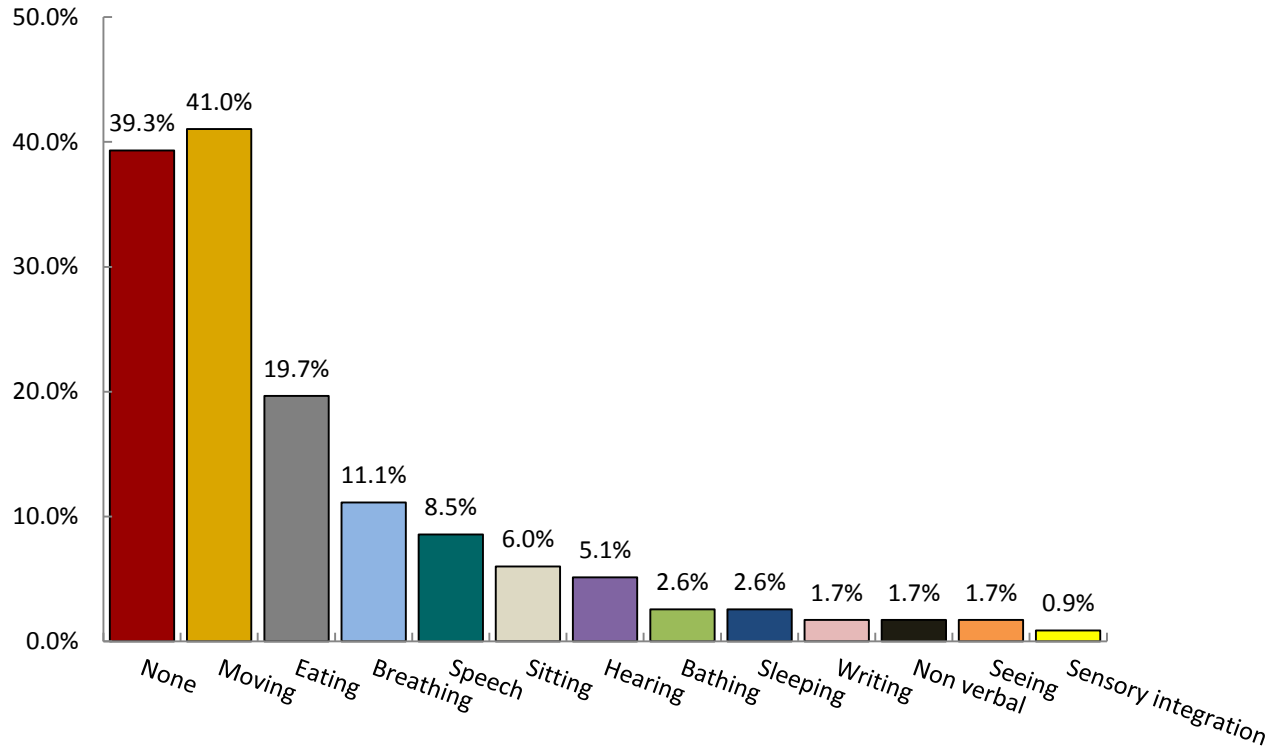
Qs 32, 39, 46, 53 Does the child's condition include a disability

Answer Options	Response %	Response (n)
Yes	78.6%	92
No	20.5%	24

Qs 33, 40, 47, 54 Nature of the child's disability

Answer Options	Response %	Response (n)
Physical	24.8%	29
Intellectual	8.5%	10
Physical and intellectual	41.9%	49
Sensory	2.6%	3
Neurodevelopmental	2.6%	3

Qs Q34, Q41, Q48, Q55 Equipment needed by the child



Answer Options	Response %	Response (n)
None	39.3%	46
Moving	41.0%	48
Eating	19.7%	23
Breathing	11.1%	13
Speech	8.5%	10
Sitting	6.0%	7
Hearing	5.1%	6
Bathing	2.6%	3
Sleeping	2.6%	3
Writing	1.7%	2
Non verbal	1.7%	2
Seeing	1.7%	2
Sensory integration	0.9%	1

Q57 Sex of respondents

Answer Options	Response %	Response (n)
Male	12.9%	12
Female	87.1%	81

Q63 If not employed full-time, did you leave full-time employment to care for your child/children

Answer Options	Response %	Response (n)
Yes	65.4%	51
No	25.6%	20
Not applicable	9.0%	7

Q64 How comfortable the respondent is at speaking English

Answer Options	Response %	Response (n)
Very comfortable	100%	91
Somewhat comfortable	0.0%	0
Comfortable	0.0%	0
Somewhat uncomfortable	0.0%	0
Very uncomfortable	0.0%	0

Q65 How comfortable the respondent is at reading English

Answer Options	Response %	Response (n)
Very comfortable	100.0%	91
Somewhat comfortable	0.0%	0
Comfortable	0.0%	0
Somewhat uncomfortable	0.0%	0
Very uncomfortable	0.0%	0

Q66: If you were creating a website for parents of children with rare conditions, what is the 1 thing you would like to see on that website (N=82)

Master Theme	**WEBSITE DESIGN (n=32)**
Sub Themes	**Design**
Navigation Friendly	Easy navigation(Number 51) Road map for helping child (Number 66) Diagrams (Number 22)
Excellent Platform	"Personally I find a 'live', up-to-date and changing website is key. Also that it is easy to navigate and is obviously useful and of benefit. Epilepsy Ireland have a very good website and the best feature I've come across as a parent is an on-line forum they run regularly with a nurse. While I haven't used this facility I feel it is an excellent platform for parents/carers as quiet often it is hard to leave the house and knowing that is there to link in with is a great help. I get reminders by email the day of the forum a couple of hours in advance. The main reason I haven't used it is because I feel my children's needs are greater than most and it would not be of direct benefit to me at present. I also find on-line discussion with other parents on Facebook really helpful as its so easy to hear of other's experience's in accessing services, using equipment etc. and it is all up to date information. The problem with so many websites is that they are not kept up to minute" (Number 78) Frequent updates! At least once per month!! Preferably linking to research (Number 30) "I would love to see photos of visual symptoms of disease. The two websites i currently use are very good and always up to date, however no photos. I made a video on youtube to explain & spread awareness of my sons disease in 2012 (it has over 5000 views, hoping it educates people about the disease):www.youtube.com/watch?v=fPpjRMiQ1AA"(Number 7)
Interactive	A parents forum for discussion (Number 4) A forum for parents to chat to other parents and hopefully find other families that have been through a similar diagnosis/position (Number 21) A discussion forum (Number 28) Forums for discussions (Number 35) ... a chat forum (Number 33) Forum to find other parent of children with similar condition (Number 45) a place to share fears and advice (Number 58) Parent groups for each condition (Number 50) A chat room to speak with other parents (Number 49) Chat room for parents to share information. Midwifes must have info about this site to help parents entering this parallel universe we live in (Number 54) a forum for parents to chat to other parents of children with the same illness (Number 55) An option to meet parents with children with the same condition (Number

	63) it's hard to say, perhaps a forum where parents can chat and gain support from each other if need be. Thank you (Number 80) Support from other families who are going through it or have gone through it (Number 68)
Blogs	Blogs (Number 19)
Links	Links to financial help (Number 62) ...and links to specific support groups for various conditions (Number 39) Links to support groups (Number 36) Links to parents' forums (Number 69) Link to specialist consultants/treatments centres (Number 67)
Sub Theme	**Presentation**
Plain English Parents Understand	All content should be in PLAIN ENGLISH, that every parent could understand (Number 24) Diagrams. Every day English (Number 22) Accurate, comprehensive, actionable information ... in layman's terms (Number 3) Input from medical professionals using language parents can understand (Number 77)
Perspective	Positivity!! (Number 34) Hope (Number 60)
Master Theme	**CONTENT (n=39)**
Sub Theme	**Information**
Practical	Information on the care of the child such as on feeding the child, on toilet training, HELP WITH COMMUNICATION (this is still not available), tips on dealing with hypersensitivity to noise or to touch, information on likely complications such as contractures and on what steps to take to avoid them (I have never got this information or advice), information on other co morbidity commonly associated with the condition and for which the child should be screened, information on the help that is available from voluntary organisations such as the Jack and Jill Foundation (if only we had known of them those first years - we could have got an occasional night's sleep and that would really have helped), what help is available from statutory services; what allowances / grant aid / tax reliefs might help with the additional cost involved in caring for someone with a disability (Number 1) "help and info about who to talk tohave found a lot of parents who don't know about simple thing that they should have for instance blue badges and toll passes for there cars" (Number 13) Support - advice for financial, medical, emotional. Advice on what to do when questioning medical advice given etc, or professionals you are dealing with as some do not have empathy when dealing with parents. Where to research trials, research. fundraising ideas given rarity of diseases and so little to no money for research. How to manage the system in terms of govt entitlements, tax breaks etc, (Number 32) Support information..i.e. Financial, emotional and state support , where how and what's available to USA, what medical support either here or in

	Europe is available (Number 39) Advice and resources (Number 41) Clear information as to what child is entitled to by way of educational input, therapy input, medical input and financial input. Information is hit and miss currently (Number 48) Information on available state benefits, allowances and supports for families (Number 81) Where to look for services (Number 16) All applicable entitlements through HSE (Number 25) Information regarding locally available help + support would be useful. (Number 44) Services directory...easy listings of grants, tax reliefs, services available to parents/carers and the young person with the disability...all too scattered at the moment (Number 64) Local information (Number 75) advice on where to turn, how to get medical support, support group information and a guide on how to make medical personnel listen to and accept the possibilities of a rare disease. Possibly register of specialists within the area of specified rare diseases (Number 5) What you need to do at the start...if you suspect something is wrong...once you have received a working diagnosis...steps to take with GP, support groups and early intervention as nothing appears to be coordinated (Number 43).
On Condition	Proven fact not opinion (Number 6) True Facts (Number 15) more about tuberous sclerosis in Ireland (Number 52) Information about what to expect and how best to deal with the issues that are likely to arise (Number 42) List of conditions (Number 82) Information for others about the condition (Number 71)
Sub Theme	**Support**
Requests	Other families (Number 23) Support (Number 46) Support & information (Number 26) Supports (Number 31) Support! !!!!! (Number 65) Support groups (Number 72) Local groups and more resources for health care professionals(Number 8) Support on syndrome (Number 10)
Contact Details	info on Irish support group (Number 11) Contact people and numbers (Number 14) Contact details for support groups (Number 18) Other peoples experiences (Number 37) Support group info (Number 38) support group locations (Number 47) List of conditions with links to support groups (Number 53) Support groups in lots of areas (Number 56) List if parents available to give 1.1 support in the particular condition.

	Hands on experience (Number 70)
Sub Theme	**Family Stories**
Parents Stories	Pictures and real life stories not just the science bits(Number 40) "Parents stories...good and bad (Number 12)
Master Theme	**Healthcare Professionals (n=8)**
Credibility	Proof of a medical professional giving the information that knows what the are talking about (Number 9)
Interactive	An opportunity to submit question to a doctor / (Number 27) Forum for health professional to interact with parents (Number 57) Professional feedback to concerns I my have (Number 74) Access to a Centre of Excellence for rare disorders with a list of Irish experts and multidisciplinary teams. (Number 59)
Contact Details	The name of a doctor who is compassionate and willing to listen to ideas other than their own (Number 29) Details of specialists professionals for different conditions (Number 2) for ireland other options for seeking second opinions and having the proper specialists in this country and to have their names and emails displayed clearly on the site (Number 73)
Master Theme	**CREDIBILITY (n=3)**
Trustworthy	Concise, accurate, reassuring information with a high degree of confident certainly about the information contained within. Minimum amount of jargon. Plain English with factual and direct information. Too many websites are purposely non-committal on their advice and sometimes extremely vague (Number 20) a page with links to reputable research papers and other sites that might provide parents with further information (Number 61) Accurate info re available help in Ireland (Number 17)