Involving Children in the Design of Healthcare Technology

by

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The candidate confirms that the work submitted is his/her own, except where work which has formed part of jointly-authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

Publications

Four publications have been produced from research that was undertaken as part of this thesis. Each publication is listed below with a full reference, a brief outline of content, and details of its location within this thesis. In the case of all publications listed, the candidate was solely responsible for the production of the content, with named authors providing support through review and modification only.

Allsop M, Holt R, Levesley M, Bhakta B (2010). The engagement of children with disabilities in health-related technology design processes: identifying methodology. Disability and Rehabilitation: Assistive Technology, 5 (1): 1 – 13.

This literature review discusses methods that are suitable for involving children with disabilities in the design of healthcare technology. The topics discussed within this paper also form a large portion of **Chapter 2** within this thesis.

Allsop M, Holt R, Levesley M, Bhakta B (2009). Involving children in the design of healthcare equipment: an investigation into methodology. Proceedings of INCLUDE 2009. London: UK.

This paper discusses a comparison of four interview methods used to involve children in the design of healthcare technology. The work within this paper was drawn from the experimental research that is discussed during **Chapter 3**, **Chapter 4** and **Chapter 5**.

Allsop M, Gallagher J, Holt R, Bhakta B, Wilkie R (2010). Involving children in the development of medical devices. Journal of Disability and Rehabilitation: Assistive Technology (under review).

This paper describes the development of an internet application to involve children in the evaluation of healthcare technology designs; this contributes to **Chapter 6**.

Allsop M, Holt R, Gallagher J, Levesley M, Bhakta B (2010). The Involvement of Primary Schools in the Design of Healthcare Technology for Children. In P Langdon, J Clarkson, P Robinson (Eds.), Designing Inclusive Interactions. Springer-Verlag: London.

This paper presents guidelines for the involvement of primary schools in healthcare technology development research. The guidelines are listed in full throughout **Chapter 7**.

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Abstract

Although children are potential end users of healthcare technology, very little research has investigated their role in its design. Subsequently, very little guidance and few research methods are available for designers of healthcare technology to use in practice. Given that research involving funding from public sector sources in the United Kingdom calls for the compulsory addition of user involvement, there is a need to explore the most suitable methods to ensure the involvement of child populations in the design of healthcare technology.

The first stage of the research explored the use of four interview methods for involving children in healthcare technology design. Personal and environmental factors influencing child involvement were examined, alongside the cost and value of child participation. A framework for examining the use of methods for designing with children was also developed and applied. The experience gathered from involving children in the first stage was used to inform the development of an internet application and practice guidelines in the second stage of the research. The internet application was provided as a means of overcoming a range of barriers to child involvement, including disability. The internet application also provided the opportunity to explore the involvement of children in the evaluation of healthcare technology. The experience gathered throughout all of the research was synthesised to produce guidelines for future research in the area.

Although interview methods were used to involve children in the design of healthcare technology, future research should focus on examining a wider range of methods. It is recommended that strategies for validating information gathered from children should also be developed. Such future endeavours could be assisted by the insight provided in the guidelines and experiences formed throughout this research.

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Abbreviations

A number of abbreviations and acronyms are used throughout this thesis. Although these are explained alongside their first instance in the text, they are listed here for ease of reference:

AAC	Alternative and Augmentative Communication
AT	Assistive Technology
FDA	United States Food and Drug Administration
DLI	Design-Led Interview
FEC	Full Economic Costing
FSM	Free School Meals
HCI	Human-Computer Interaction
ICF	International Classification of Functioning
ICT	Information and Communication Technology
NC	National Curriculum
PD	Participatory Design
RCT	Randomised Controlled Trial
RT	Rehabilitation Technology
UCD	User-Centered Design
UTM	Usability Testing Method

Chapter 1

Introduction

This thesis explores the involvement of children in the design of healthcare technologies. Although children and particularly children with disabilities are potential end users of a variety of healthcare technologies, very little research has investigated their role in its design. Subsequently, very little guidance and few research methods are available for use to enable children's views to be incorporated into technology design. Given that research involving funding from public sector sources in the United Kingdom (UK) calls for the compulsory addition of user involvement (Department of Health, 2001, 2005a, 2005b), there is a need to explore how best to involve child populations in the design of healthcare technology and investigate the most suitable methods with which this can be achieved.

Arnstein wrote that "…citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic process, to be included in the future." (Arnstein, 1969, p. 216). Arnstein's "Ladder of Citizen Participation" has shaped thinking on user involvement within healthcare, leading to the inclusion of patients and the public in decision-making processes surrounding the development, improvement and evaluation of services (Tritter and McCallum, 2006). Arnstein's model frames citizen participation as an overt struggle for power between government officials and community activists. With such a perspective at the heart of the model, policy makers and activists have been provided with a strong foundation on which to drive their decision-making. However, Tritter and McCallum (2006) note that Arnstein's original theory of participation is in need of a restructure if it is to be applied to healthcare today. Although Arnstein discusses and promotes user empowerment, there is conflation of the means and the ends of achieving it, with little consideration of any methods that might be used to accomplish it. Although varieties of methods exist to involve users in decision-making within healthcare, often there is a need to apply a range of methods to capture the diversity being displayed within a user population (Jordan et al. 1998). In order to develop a proficient and effective means of maintaining user involvement, research methods are required that account for diversity within a population (Tritter and McCallum, 2006).

This thesis begins to address means of establishing and supporting the involvement of children in the design of healthcare technology through an exploratory examination of methods and their application. This chapter provides a map of the thesis beginning with an outline of the research context. **Section 1.1** discusses the current involvement of users within healthcare technology research. **Section 1.2** addresses methods that are currently used to support user involvement within healthcare research, with attention drawn to the implications of involving children with disabilities. **Section 1.3** considers the implications of using design methods taken from other disciplines, such as human-computer interaction research, for application within healthcare technology development, alongside considering the theoretical implications of such practice. **Section 1.4** then delineates the scope of the research, the structure of the thesis and contents of each chapter, alongside outlining how the research questions are addressed. To begin, this chapter first enables the context of the thesis to be established by discussing user involvement within healthcare.

1.1 User Involvement in Healthcare Technology Research

Within the National Health Service (NHS) and the wider healthcare community within the UK, there has been an increasing emphasis on the development of user involvement as a means of reforming relationships between the public, patients, and healthcare practitioners and professionals. This drive to involve users extends into the design of technology that is intended for healthcare. Healthcare technology has an increasing range of applications and it is becoming an integral component to the optimisation of medical care (Spekowius and Wendler, 2007). One major application of healthcare technology has been the support of people with disabilities through the development of assistive technology (AT) and rehabilitation technology (RT). AT is defined as alternative and augmentative equipment, and more generally "…systems and devices that help alleviate the effects of a disability and, thus, improve function" (Desch et al. 2009, pg. 1271). Huang (2009) further extends this definition of AT to include the ability to reduce the effects of environmental barriers, ranging from simple devices (e.g., pencil grips) through to more advanced, high-tech equipment (e.g., powered wheelchairs) (Scherer, 2000). RT refers to the systematic application of technologies, engineering methodologies and scientific principles to meet the needs of, and address the barriers confronted by individuals with disabilities (Rehabilitation Act, 1973). Although the mention of disability is not as overt within the former definition of AT as can be found for RT, both types of device have disabled people as their largest category of user.

A large proportion of technology that is available has been developed for the mainstream; these are products that are designed or intended for general use rather than for use entirely or primarily by people with disabilities (Field and Jette, 2007). However, while changes in mainstream technologies have presented new opportunities for many individuals, they have not always resulted in improved access for individuals with disabilities (Stephanidis and Emiliani, 1999). Given the presence of disabilities amidst users of AT and

RT, there is a need to consider means of involving people with disabilities in the development of healthcare technology. In 2000, statistics from the Office of National Statistics reported that 19% of males and 17% of females aged less than 20 years of age reported having at least a mild disability. Rates of severe disabilities existed in 11 per 10,000 males and 5 per 10,000 females aged 17 years of age or younger. Therefore, the involvement of children in the design and development of healthcare technology stands to benefit a large number of people.

The difficulties that can be incurred when trying to involve people with disabilities in research have been documented (e.g., Barnes and Mercer, 1997). Research specifically involving children with disabilities has been criticised solely based on a failure to provide voices to such populations (National Disability Authority, 2006). However, the National Disability Association reports an increase in research that emphasises the need for the involvement of children with disabilities in equal partnerships with non-disabled researchers. Healthcare technology development with children provides the opportunity to explore methods of providing a voice for children with disabilities in research, alongside examining the viability of their involvement in such proposed equal partnerships.

Research indicates that user involvement in healthcare technology design typically encompasses people who have learning difficulties and disabilities, mental health service users and elderly people (Beresford et al. 2006). Such a definition can be extended to include clinicians and carers as users, dependent on the nature of the technology being developed. Recent research shows strong approval for wide involvement, stating that without involving users and the perspectives that can be gathered from their experiences, one runs the risk of obtaining a research picture that is incomplete (Hanley, 2003). Such research explains why user engagement is required under medical device regulations (Powers and Greenberg, 1999) alongside policies employed by the NHS and government in the UK for public sector funding of devices and services (Department of Health, 2001, 2005a, 2005b).

Promoting user involvement throughout product development increases the likelihood of a product being usable and clinically effective (Ram et al. 2007). In analysing the benefits and barriers to user involvement, it has been highlighted that there is a need to explore methodologies that reduce the costs and time associated with involving users in the development and evaluation of medical device development, as this can often cause reluctance to involve users (Shah and Robinson, 2007). The consideration of cost is of particular importance within healthcare technology as new medical technology has been highlighted as a dominant driver behind increases in healthcare costs (Goyen and Debatin, 2009). Current research needs to consider the measurement of the cost and value involved in the process of healthcare technology development. Ram et al. (2007) further emphasise the importance of maintaining user involvement that is driven by user needs rather than technological or commercial pressure. Despite support for the involvement of users throughout medical device development, active participation tends to occur primarily in the later stages of testing and trial phases. Such post marketing surveillance does not require end users to be involved in the earlier stages of design (Ram et al. 2007). However, it is the earlier stages when changes are easiest to implement and user views are less difficult to accommodate.

Objections to the ethos of user involvement in research exist. Within the medical domain, it has been noted that the lay participants included in user involvement are often not typical users and may be biased or partial (Entwistle, 1998). The extent to which end users can be fully involved in design and research has been questioned, given the complexity that often surrounds health-related devices (Mulholland et al., 2000). Additionally, the concept of user involvement has been criticised when applied to users of mental health services (Heyes, 1993), although research is available that reports positive user involvement with adults with mental health disorders (Lamey and Bristow, 2007). Due to the increasing necessity to involve users, such objections are the cause of 'significant tension' (Beresford et al. 2007). It has been reported that despite previous attempts to investigate and promote user engagement initiatives, participants often remain passive in research (Ram et al. 2007). As well as cost and time pressures in industry, other noted barriers to achieving effective user involvement include the perceived complexity of research governance procedures and the multiplicity of user groups and stakeholders (Martin et al. 2006). Given that the innovations and developments that stem from medical engineering are difficult to predict, it seems that it is important to establish ways to keep lay people informed and involved in research to promote an active, not passive involvement of the end user (Combs, 2006).

The ethos of user involvement has been well established within domains outside of healthcare. For example, user-centered design (UCD) principles governing design processes are outlined by the International Organisation for Standardisation (ISO 13407) (1999) as comprising four different basic principles; an appropriate allocation of function between user and system, active involvement of users, iterations of design solutions, and multidisciplinary teams. The active involvement of users as a central tenet in UCD design is synonymous with concepts of user involvement within healthcare. The amalgamation of these concepts can be seen within inclusive design theory and practice, where the central philosophy emphasises the importance of involving users with a range of physical and cognitive capabilities in developing everyday products. The intention here is to minimise design exclusion as much as possible. This approach emphasises users' capabilities rather than their disabilities. It also highlights the need for designers to involve a diverse array of users in the product development process (Keates and Clarkson, 2003). Factors of interest within this process extend beyond the mere usability of a product or device, and expand to cover its usefulness and social and practical acceptability to end users. By incorporating such factors into the development of healthcare technology, the design process can be extended from functionality to begin to consider the context of use.

Given the support for, and highlighted benefits of, user involvement, attention now needs to focus on how best to involve users in the development and evaluation of healthcare technology. Although the application of user involvement is becoming more widespread, there are still populations who have received little attention, particularly in relation to methods with which to achieve involvement. Children are one group that still tend to be excluded from the design process of healthcare technology, although the appropriateness of certain methods for involving children in healthcare research has started to be investigated (e.g., Morgan et al., 2002).

Developing methods that accommodate the unique characteristics of children is not a straightforward process, and applications of approaches that are typically used in adult populations are not satisfactory. As Morrow and Richards (2002) discuss, children are often positioned as vulnerable, incompetent and seemingly powerless elements within society. The difficulty arises in trying to form and develop research methods that are fair and respectful to child populations, without restricting a method to one that views the child as a competent participant in a shared, but adult-centred world. One proposed approach to overcome this is the ‘social child’ (James, 1995). This approach perceives children as research subjects that are comparable with adults, but identifies that the capabilities of children are different. Children are often encouraged to be skilled via a range of communication techniques (e.g., drawings, written work, stories); therefore, promoting the use of these skills in research may improve their involvement.

This research focuses on involving children in the design and development of healthcare technology. Although a full literature review is provided in **Chapter 2**, the remaining sections of this chapter provide a context for the work carried out in this thesis by broadly outlining issues that are related to the thesis. **Section 1.2** begins by outlining the involvement of children with disabilities in healthcare research. This provides a brief outline of current perspectives in the development of RT and AT and outlines theories to understand the participation of children with disabilities in research. **Section 1.3** then outlines design theory and its underlying philosophical structure, to ensure that the transfer of any design methods for use in the design of healthcare technology is informed. **Section 1.4** concludes the chapter by providing a research definition, outlining the research questions, and delineating the structure of the remaining chapters within the thesis.

1.2 Involving Children with Disabilities in Healthcare Research

The medical model views disability as a problem that requires medical intervention by practitioners. The social model has been perceived as an antithesis of the medical model (Silvers, 2010). The social model calls for changes to attitudes towards disability and a reformation of practice, viewing disability as a political problem. The increased adoption of this perspective has led to disability being reported from a societal perspective of what it entails to have a limitation in one or a number of levels of normally developed functioning (Scherer, 2002). Running alongside the two competing perspectives is a model of disability that draws together the interaction between what were previously two separate branches of investigation, the individual (personal) and the situation (environment). This model of disability was established by the World Health Organisation and was used to form the International Classification of Functioning (ICF) (WHO, 2001) that was designed for use in social policy, research, education, and clinical practice and draws attention to factors surrounding activities involving children with disabilities. The ICF highlights personal and environmental factors as having a major impact upon the participation of children with disabilities. The ICF is ideally situated to inform the development of technology such as rehabilitation or assistive devices as it considers the practicalities and function of a device but also accounts for the social and cultural standpoints on disability.

In order to gather social and cultural views that are relevant to the development of healthcare technology for children, the views of the end user population are required. However, in research involving children with disabilities, often the elicitation of views from children is displaced by reports from parents, carers and teachers (Huang et al., 2009). Research involving adults with disabilities is more established than children with disabilities, where the insight provided from research involving the former should act to drive the involvement of the latter. For example, Low (1996) noted that the adoption of AT is interrelated with an adult users' self-identity, and that this makes considerations regarding the technology very emotion-laden. Barber (1996) also identifies that for adults, the stereotype of disability is often fused into AT due to their specific design for disability. Given the link between self-identity, stereotypes and AT, there is a need to begin closer examination of their influence on children. The emergence of the self and identity are some of the most fundamental developmental tasks faced by children (Bennett and Sani, 2004) and it is important to understand how they are influenced by the need to use AT or RT. By beginning to consider and explore self and identity in technology design for children, the likelihood of creating healthcare technology that actively supports child users beyond the level of the function of a device will be increased.

Children with disabilities are often the focus of unitary identities that are "…degendered, asexual, culturally unspecific and classless" (Priestley, 1998, p. 220). The tendency to group children with disabilities into a unified group further serves to reduce the potential control a child user of AT may have over the identity that they could choose to reflect. However, identity is not the only area of existing research that explores the relationship between a child and healthcare technology. For example, children are more willing to use AT in environments outside of the home as they attribute the device as providing access to the social world around them (Huang et al. 2009). The lack of use in the home environment is attributed to the lower requirements for socialisation amongst carers and families members, with the device serving only to support physical function. Despite this, the social environment in which such technology is likely to be used has received little research investigating the preferences of users concerning the aesthetics of the devices for children. As highlighted by Huang et al. 2009, "…The views [of AT] held by children may be different from those of adult users due to their different developmental stages, experiences and roles acted out in the environment" (pg. 104). Moreover, these differences need to be further explored in order to understand how AT can be improved to suit the user and address its relationship to use and acceptance.

Research is required to investigate the involvement of children in the design of healthcare technology to establish how such participation can benefit the design of such technology. Due to the lack of research in this domain, there are few methods available to involve child users; therefore, there is a need to explore alternative sources of methods, or develop new methods to involve children in the design of healthcare technology. Sourcing alternative methods is the approach taken during the first stage of the research, with the development of a new method being outlined in the second stage of this thesis. Therefore, the focus of the next section involves identifying methods that may be able to support the involvement of children in the design of healthcare technology.

The next section focuses on human-computer interaction (HCI), which is a discipline that has explored technology design with children perhaps more extensively than any other. Although this has not involved healthcare technology design and development, methods exist that have been used to involve children in the design process. Children have been involved in the design of information technology via a range of design and usability studies (Nesset and Large, 2004). The scope to apply the experiences of the researchers, and the methods used, to the design and evaluation of healthcare technology has yet to be seen. **Section 1.3** briefly outlines how HCI could contribute design methods to facilitate child involvement in this thesis, followed by a detailed overview of design theory and the implications of using methods from such a discipline within healthcare research.

1.3 Design Theory and Methods

Although methods exist for involving children in healthcare research, their suitability for use in the design of healthcare technology is not known (Allsop et al., 2010). Existing methods have been used to gather children's evaluations of healthcare services during treatment (e.g., Noyes, 2001; Carroll, 2001), or through consultation and decision making processes (e.g., Coyne et al., 2009). However, the impact and comparative usefulness of these approaches to the design and development of healthcare technology has yet to be investigated. One rare example of involving children in healthcare technology design and evaluation consisted of the implementation of questionnaire and interview sessions to gather information from children (Weightman et al., 2008). Alongside the use of standard interview methods, the research also used a software evaluation method from HCI that examined the difficulty experienced by children in using a system. This involved children having to learn how to use a device and then provide instructions to a peer to teach them how to use the device. The gaps in information, that occurred by children during this process, or topics that caused confusion, may indicate areas of a device that needs refining for use by children. Such a method, called 'peer tutoring' (Höysniemi et al., 2003), provides insight into the alternative methods that may be useful in designing healthcare technology with children. HCI is used to search for methods for healthcare technology design because firstly, it reduces the scope of the research to one domain rather than examining a range of domains that have performed UCD research with children, and secondly, provides a discipline where the design and development of technology with children is central.

A lot of insight and research into user-centred technology development comes from HCI, particularly for UCD approaches to children. Over recent years the development of a subset examining child-computer interaction has emerged (Read et al., 2008), incorporating disciplines such as child psychology, learning and play into its research. Child-computer interaction has provided a foundation of technology design approaches with children, with a particular emphasis on methodology for involving children. Although this research area has not begun to consider technology that is used within the healthcare context with children, there is a wide range of methods that have been used to involve children in HCI technology design processes. Therefore, HCI research provides insight into potential approaches to involving children in healthcare technology design.

One difficulty with using HCI methods in healthcare technology design and development is the lack of research that has been focused on children with disabilities in the domain. Amidst healthcare technology users, there is a high incidence of children with disabilities as end users of healthcare technology. HCI research lacks any thorough consideration surrounding the involvement of children with disabilities in its existing literature, although this has started to receive attention in recent research (Guha et al., 2008). Guha et al. propose an inclusionary model that briefly outlines a proposed approach that should be taken by designers wanting to work with children with special needs. The model contains three stages; consideration of the level of expected involvement from a child with special needs, reflection on the nature and severity of the child's disability, and evaluating the level and intensity of available support. Despite its basic form, the model is of importance to this research as it serves to highlight the development of research in HCI that is beginning to consider how to involve children with disabilities. Although the paper by Guha et al. (2008) discusses their use of cooperative inquiry with children with disabilities, there is still a need to compare the use of a range of methods with such populations to begin comparisons and begin to gauge the suitability of their use.

Several methods are available from HCI that could be used for involving children in healthcare technology development, but it is not known how suitable they will for application to AT and RT, nor whether they will involve children with disabilities. An examination of methods within the context of healthcare technology that explores the involvement of children with disabilities is ideal to provide insight to the domain of HCI, but also support healthcare in developing means of involving end users in healthcare technology design and development. In order to complete such an examination, it is important to examine the implications of using design methods from HCI in the healthcare domain, and the consequences of using such an approach on healthcare practice. In order to consider the wider picture of transferring methods across domains, the underlying structure of HCI is discussed below, alongside the literature relating to design theory. This ensures that any research that takes place within the thesis is informed about the implications of applying methods identified in HCI, within healthcare.

The domain of HCI has emerged as a design-orientated field of research. However, the philosophical, theoretical and methodological aspects of design theory do not appear to be understood or applied within HCI research (Fallman, 2003). Design theory comprises of "…general theories which seek to describe the whole activity of designing and its relationship to the objects involved" (Love, 2000, pg. 306). However, Love (2005) performed a review of design literature and noted that the research was subject to two contradicting incompatible approaches. *Approach A* is the scientific approach that assumes that design can be completely understood. *Approach B* involves interpretative approaches that regard design as an 'intuitive' activity, dependent on creativity that is scientifically inaccessible. Where Love outlines the strengths and weaknesses of the contrasting approaches within design theory, the differences are further amplified. Where the scientific approach endeavours to pursue reliability, verifiability and testability, the interpretative approach lacks scientific rigour and instead applies human considerations. Love outlines the foundations for a unified theory to address such a dichotomy, suggesting the adoption of an ethological approach in research. Ethology is the study of animal behaviour, and by using an ethological meta-perspective humans are studied as animals rather than from a human-centric perspective. Love states that the implementation of such an approach offers the potential to gather insight without the biases that accompany human-centric perspectives (Fernandez-Armesto, 2004). Such an approach can be explored through the identification of causal physiological processes in research for example, which will provide understanding into that which *Approach B* often neglects, which will allow for the critique of subjective aspects of creativity.

In drawing comparisons with disciplines such as psychology, Love (2005) highlights that fields of study at the boundaries of the humanities and social sciences are often comparatively slow to firstly critique their own foundation literature, and further allow emerging physiological information about human functioning to inform their practice. This is beginning to change in areas of design such as affective engineering. Affective engineering evaluates the physical aspects of products with their affective influences on people, with subsequent applications in a range of contexts ranging from packaging (e.g., Henson et al., 2006) to “patient waiting areas” in primary healthcare centres (Ayas et al., 2008). Such practice supports the notion of product development that is “market-in”, with consumer-orientated product development rather than a “product-out” approach where decisions surrounding product specifications and development are made by the manufacturer (Nagamachi, 2008). Such practice is exemplified by product development methods such as Kansei engineering. The drive to ensure that product development is “market-in” is synonymous with calls for research in the development of medical devices to achieve product development that is led by user needs not commercial pressures (Ram et al. 2007).

A pragmatic issue to consider before approaching design research for methods is the problems that have arisen because of its neglected and disjointed development (Love, 2000). This has “…led to terms, concepts and theories being used in a variety of different and inconsistent ways” (pg. 1). As a result of this, Love (2000) highlights that i) there exists a substantial amount of confusion with respect to the underlying basis of many theories, concepts and methods ii) in developing and validating theoretical aspects of the study of design, many writers are unjustifiably conflating concepts drawn from a range of sources iii) there exists an unnecessary multiplicity of design theories and concepts and iv) the terminology of design research has become unnecessary and unhelpfully confused and imprecise by spoil of the aforementioned points.

Love (2000) cites Hamlyn's (1990) work on the theory of the black box regarding the philosophy of cognition, when outlining that the epistemological (concern with the origin, nature, methods and limits of human knowledge) and ontological (the essence of the nature of being) foundations of design theory need to be thickened to permit concepts, terminology, and theory used within the area to be reduced to the extent that they have singular meanings. In order to address this, Love proposes a meta-theoretical framework in which concepts and terminology that are often subject to conflation and consequent confusion are outlined and placed within a meta-theoretical hierarchy. Additionally, the framework outlines the underlying components of any design theory in a structured manner that allows for placement and questioning of once wandering theories, concepts and metaphors in design. This research begins to examine methods that can be used to involve children in the design of healthcare technology by identifying and trialling a range of available methods. To acknowledge Love's concerns surrounding existing design literature, the research considers the foundation literature upon which it is based, and it is from here that methods for involving children are drawn. The research also places an emphasis on evaluating current practice within design research with children before trying to apply findings to the domain of healthcare.

The need to consider concerns raised by Love (2000; 2005) is integral in this research because design research and any related methods could be a means of supporting the involvement of children in the design and development of technology. Love (2000) highlights the dichotomous nature of approaches adopted within design research. Although this research does not use causal physiological processes to gather an understanding of the role of children, it does investigate the preferences of children in relation to aesthetics and texture. Although this does not apply physiological measures, it begins to investigate how children can report on preferences of healthcare technology and how this information can be applied to a design. It is important to establish the value of involving children within the design before exploring the use of more objective measures. The subjective aspects of the design research will not remain inaccessible to assessment. Although this research does not critique the subjectivity of creativity and adopts a qualitative methodology, it begins to identify frameworks upon which methods can be assessed.

Although many methods have originated from design research, attempts to evaluate design methods in an empirical way have led to unsatisfactory outcomes (Mazzone, 2007). Causes for such poor outcomes have often been a result of concerns over too much variety and too many variables in a method. It is important to establish a means of identifying appropriate techniques and methods for use in future research within healthcare. In **Chapter 2**, a structured literature review is presented that outlines existing literature across HCI and healthcare and begins to consider areas of similarity and difference. The structured literature review was used to guide decisions about directions of research in this thesis.

1.4 Research Definition

Although this chapter has discussed literature regarding child involvement in research, less is known about child involvement specifically in healthcare technology development. Healthcare literature requires methods to involve child in technology design, and HCI could potentially supply them. However, there is a need to consider the practicalities and wider theoretical issues of transferring such methods across disciplines. Therefore, this thesis focuses on the critical appraisal and evaluation of design methods in healthcare. Given the multiplicity of theory and terminology that causes confusion within design research (Love, 2000) it is important to approach research in the area by clearly positioning any research in terms of its purpose and underlying assumptions (Holt, 2005). The inclusion of this section addresses this requirement by initially providing an outline of the focus of the research and the approach adopted. Following this there is a summary of the scope of the research and the presentation of the research questions that this thesis seeks to answer.

1.4.1 Research Focus

In order to clearly position research in terms of its purpose and underlying assumptions, this section begins with a consideration of the differences in the approaches adopted within healthcare research and design research. Where healthcare uses scientific research to inform the treatment and management of illness, design has no established research practice. Where scientific research is explanatory (generating explanations for the phenomena observed around us) and predictive (using these explanations to predict phenomena), design research is prescriptive (integrating explanatory and predictive elements with normative, i.e. gathering facts but also informing how an object of study can be improved). The theories also differ in their handling of purposeful behaviour, or goals; where goals are meaningless to the natural sciences (although the social sciences may incorporate goals in the objects of study), the purpose of a design theory is to support the achievement of goals (Walls et al., 1992). Goal orientation is the key element required in design theory that is missing from theories that can explain the natural and social sciences.

The prescriptive nature of design research means that its purpose is to improve the quality of designed artefacts by improving the design process, with the assumption that the physical artefact designed is affected by the process used to design it (Holt, 2005). There would be no practical application of design methodology if this were not true. Design research draws its conclusions by amalgamating the underlying structures of the physical and social sciences, which explain the range of disparate approaches being adopted in practice. It is not known as to whether the cause of the differing approaches is directly related to the multiplicity of scientific principles underlying design. However, methodology that is utilised within design theory reveals a range of methods that are in use. The suitability of these methods for use in healthcare is questionable. Healthcare has a reliance on outcome measures that are calibrated accurately with the current explanatory and predictive approaches expressed by research within their domain. Outcomes have been understood as '…the results of health care processes' (Baumberg, 1995), and, consequently, the use of methods taken from design require assessment before their appropriateness within this environment can be assessed.

Although there are differences in the underlying theoretical structures between healthcare and HCI, the two are closely connected through methods; HCI currently designs technology with children and healthcare requires methods to design technology with children. Healthcare currently uses a range of methods to elicit responses from children. For example, projective techniques such as storytelling have been used since the 1940s to elicit information from children that might otherwise be difficult to obtain via standard interviews (Poster, 1989). Although interviews are used within healthcare, less directive methods such as storytelling, or drawing for example, are often preferred due to their non-threatening properties, despite the most concrete information being obtained from structured interviews (Carney et al., 2003). Having a selection of methods is necessary to tailor their use to a situation, providing children with effective and safe opportunities to explore anxiety-inducing situations when required (e.g., Hudson et al., 1987). These methods are typically used in relation to treatment or services, and have not been evaluated when applied to healthcare technology design.

In HCI, a range of methods evolved during the 1980s to assist commercial software companies to identify the requirements and needs of users in relation to software use (Nesset and Large, 2004). These methods have been applied to the users of software and hardware, and more recently with an increasing sophistication of children’s preferences and expectations of technology, a range of child-orientated methods have arisen (Markopoulos et al., 2008). A range of approaches has been adapted to involve children in technology design, with varying levels of participation expected from children. However, a range of child-specific limitations has also been identified in existing methods. These include difficulties experienced by children when expressing ideas (e.g., Large et al., 2003), questions over the extent to which they can participate in the design process (e.g., Scaife and Rogers, 1999), and the need to separate them into similar age groups (e.g., Hanna et al., 1999). Despite these difficulties, HCI has a broad literature base of designing technology with children, and without concern for theoretical assumptions, HCI methodology could be used to complement methods available for such design in healthcare. However, before such methods are implemented within healthcare, there is a need to identify factors of importance in the design of related technology for children and assess the suitability of existing methods in both healthcare and HCI to accommodate these. As outlined previously, healthcare predominantly adopts less direct methods to investigate topics that may evoke anxiety or a range of unpleasant emotions within children. Before decisions regarding the appropriateness of methodology in the design of healthcare technology can be made, further focus on the surrounding factors relating to healthcare technology needs to occur. HCI typically develops child methods that are used in the design of interactive technology products that are for entertainment, education or enablement (Markopoulos et al., 2008a). It is not known whether these methods capture appropriate information to feed into the design of healthcare technology. If HCI develops technology that is characteristic of the mainstream, then there a need to establish what changes will be required to methods when applied in the context of healthcare and with a population of users containing a high incidence of disabled users.

To investigate available methods for use in the design of healthcare technology, research enquiries were classified as exploratory. The purpose of exploratory research enquiry is to i) find out what is occurring in an area with little understanding ii) seek new insights iii) ask questions iv) assess phenomena in a new light v) generate ideas and hypotheses for new research (Robson, 2002). The aims of exploratory research are satisfied with the research process, and the content that is gathered by this thesis. Methods for designing healthcare technology have received little attention in the literature, and there is a need to establish new methods and investigations for use with children. This thesis builds on existing user-centred approaches from HCI and healthcare and develops new avenues for future research.

Due to the novelty of this research, a structured approach was applied to the investigations. A structured literature review was used to identify practice across HCI and healthcare domains, and methods that were identified for possible use in healthcare technology development with children were examined according to an existing framework (i.e., a modified version of the Markopoulos and Bekker (2003) framework for assessing usability methods with children). This ensures that the research, despite its novelty, is directed and subsequently interpreted within existing literature. Although the findings of the research are for application to engineering design, the observations from this systematic approach could be used more widely. For example, although the content of this thesis is focused on improving children’s engagement in healthcare technology development, the ongoing development of design research with children can be further supported by its findings. This research utilises theory already identified within healthcare and medical paediatric research, technology design research, and psychology, to examine existing design methods to investigate child involvement in the design of healthcare technology.

1.4.2 Relevance, Scope and Research Question

This thesis examines the involvement of children in the design of healthcare technology alongside exploring factors relating to their participation in such research. In order to focus the goals of the research it is necessary to place limits on the scope of the project. The limits that have been placed on the thesis are as follows:

1. A range of factors may influence the involvement of children within healthcare technology design and development. However, this research focuses on personal and environmental factors relating to the end users of healthcare technology (i.e., AT or RT in this thesis). Personal and environmental factors have previously been highlighted as major causes to the exclusion of children with disabilities regarding decisions and consultations that directly relate to them (Rabiee et al., 2005). Although occupational factors are mentioned by Rabiee et al. (2005), they are not directly relevant to this research. These issues are further elaborated upon in **Chapter 2**.

2. Cost has been highlighted as a factor that limits user involvement generally (Shah and Robinson, 2007). It is, therefore, necessary to explore the cost of involving children and consider this against the value of their involvement. These measures will also begin to consider the cost of design methods within healthcare, where cost is essential to many strategies, such as those linked to expenditure and rationing (Ubel, 2000).

3. Ranges of methods are available from HCI and other domains to involve children in the design of healthcare technology. However, it is only possible due to the scope of this research to involve a small number of methods within comparisons and assessments of suitability. To narrow the scope of the research, only interview methods are used to involve children in the design of healthcare technology, where any design methods are only drawn from HCI practice.

4. The most appropriate location to hold large group tasks with children is the primary school setting, as mainstream schools provide access to children with and without disabilities. In addition to this, any accessibility equipment required by children with disabilities is often supplied in this environment due to a requirement outlined in the Disability Rights Commission (2005). All testing within this thesis takes place within the school environment.

Having outlined the focus of the research and the limitations placed on the scope, the aim of this thesis is to:

Explore the involvement of children in methods for use in the design of healthcare technology

Primarily, this research examines the involvement of children in the design of healthcare technology whilst considering the suitability of existing methods when used with children. The identification of barriers is central to such an examination, with factors that affect the ability of children to provide information being explored. Robson (2002) highlights factors to consider that will promote the likelihood of successful research, including the importance of theory, convergence, and real world value. Research questions should be clear, specific, answerable, interconnected, and substantively relevant (Punch, 1998). In applying this research, four specific research questions can be identified:

1. *Can current interview methods be used for gathering requirements from children for healthcare technology?*
2. *How do personal and environmental characteristics influence methods when gathering requirements from children?*
3. *What is the cost and value to involving children in the design of healthcare technology?*
4. *How should schools be involved in research relating to healthcare technology design?*

These questions indicate the topics that are focused on mainly within the first phase of the research, but they are extended throughout the thesis. Overall, an interest in examining the involvement of children remains central, but the priorities of the above questions vary through this research. The first three questions are explored in detail during the first stage of the research, with the findings from this being used to inform the later stages of the research, and the examination of the fourth question. The fourth question is addressed in the second stage of the research by synthesising the insight and experience obtained during the first stage to explore how schools should be involved in related research. The research questions were used to develop objectives of the research and guide the experimental structure of the thesis, with particular focus on the first stages.

1.4.3 Thesis Structure

The thesis is formed around the research questions and the objectives are used to guide the overall structure of the research, and consequently the thesis. The objectives of the research in accordance with the research questions are as follows:

1. Review literature to identify current research into methods for engaging children in technology design and healthcare research;
2. Complete a structured literature review for classifying methods identified in the literature review in order to position the research in relation to other work and avoid the problems identified by Love (2000; 2005);
3. Evaluate a number of methods identified in the structured literature review to:
    a. Evaluate their suitability for engaging children in the design of healthcare technology;
    b. Identify how personal and environmental characteristics influence methods used for engaging children in the design of healthcare technology;
    c. Identify the cost and relative value of using each selected method to engage children in the design of healthcare technology.
4. Apply the experience and insight gathered when answering the first three questions in order to:
    a. Develop a novel method for involving children in healthcare technology development research;
    b. Propose guidelines for researchers working with children in healthcare technology design based on an action research approach.

The first three objectives are addressed during **Chapters 3 – 5**, with examination of the fourth objective arising in the second half of the thesis. The later chapters were formed on the experiences gained during investigations outlined in **Chapters 3 – 5**. Firstly, the development of an internet application in **Chapter 6** used the insight gathered from involving children in a range of interview methods to create a more inclusive method. Secondly, the development of guidelines in **Chapter 7** provides direct insight into the approaches taken to design and run research visits that took place in primary schools. Within such objectives, engagement and involvement are central terms. In this research project, engagement and involvement are used as terms to describe the inclusion of children within research activities and practice. Therefore, a focus on engagement and involvement ensures the analysis of features that facilitate and prevent child involvement in the research.

The objectives that have been outlined were used to guide the formation of the chapters within the thesis. **Figure 1** outlines at which stage of the design cycle each of the chapters of the thesis can be used to inform the involvement of children in the design of healthcare technology. This is followed by a summary of the content of each chapter.

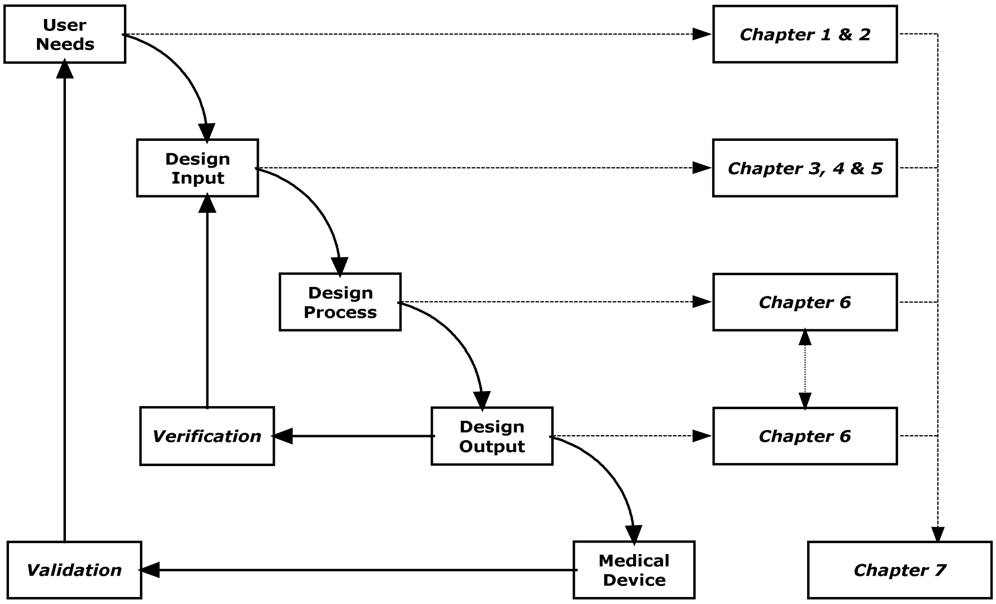


Figure 1 An outline of the structure of the chapters in the thesis indicating how they inform different stages of the design process; outlined as a simplified version of the Waterfall Model, from the United States Food and Drug Administration (FDA) (1997)

The Waterfall Method places an emphasis on the evaluation of emerging products or systems, whether mainstream or assistive. The model accounts for the review, *verification* ("Are we building the thing correctly?") and *validation* ("Have we built the correct thing?") of products during design (Keates and Clarkson, 2003). The use of the waterfall method to depict the design cycle was chosen due to its emphasis on the later stages of the design process. This research, although examining means of gathering requirements from children also begins to examine methods that can be used to involve children in the later, evaluative stages of the design process. All stages of the design cycle are investigated, with the exception of the medical device stage, as this would involve the testing of an actual product with end users. Although this thesis used devices from ongoing projects within the research team, no final medical device was created. Instead, the research explores different stages of the design cycle with a range of devices, and focuses on methods for involving populations of children at the different stages of the cycle. In **Figure 1**, the boxes that flow from the top left *user needs* box, diagonally down to *medical device* box are the main five components of the waterfall method. These five boxes are central to the waterfall process, with the *verification* and *validation* boxes serving to emphasise the considerations of Keates and Clarkson (2003), and the boxes to the left indicating which chapters explore the different stages of the design cycle within this thesis.

Chapter 2 outlines the background and context of research in the literature review, establishing the *user needs* in the design process. The literature addresses user needs by exploring existing literature regarding the involvement of children in the design of healthcare technology. Alongside detailing the sources of methods to apply in such a process, a structured literature review and taxonomy was used to identify trends in the literature. The taxonomy guided the choice of methods for use in the research visits with children in **Chapters 3 - 5**.

Chapter 3, alongside the following two chapters, considers the *design input* in the design cycle. The chapter begins to address the details of the protocol that outlines the initial exploratory research into design methods for use in the healthcare context. This chapter discusses the methodology used to gather data, alongside outlining the means of collecting and analysing the data from children for use in the design of healthcare technology. This section also guides the presentation of the findings in **Chapter 4** and **Chapter 5**.

Chapter 4 outlines the results from the analysis performed on data obtained from the methodology delineated in **Chapter 3**, for discussion relating to the personal and environmental factors of child involvement in healthcare technology design. The chapter also reports on a comparison of existing methods that can be used to involve children in healthcare technology design.

Chapter 5 outlines further results from the analysis performed on data that was obtained from the methodology delineated in **Chapter 3**. The focus in this chapter is the cost and value of the involvement of children in the design of healthcare technology. The number and quality of responses are considered, alongside evaluating the value of the research for the children who participated.

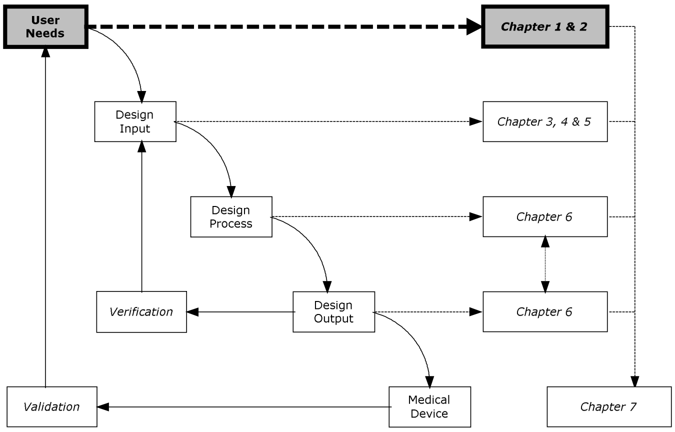
Chapter 6 outlines two stages of the design process; the *design process* and *design output*. The *design process* is explored when involving undergraduate students in the application of information gathered from the children in **Chapters 3 – 5** into design of healthcare technology. These designs were then fed into a novel internet-based application for evaluation by a range of child populations. This evaluative aspect of the research ensures that the *design output* stage of the design process is investigated. This stage is typically used for *verification*, which ensures that the information initially gathered from users is being applied correctly to a device.

Chapter 7 accumulates the experience gained by the research teams on the school visits that are presented in **Chapters 3 – 6**. This chapter outlines guidelines for researchers who wish to perform design research in the school environment. These guidelines were derived from action research. Alongside discussing access to the primary schools and the lessons learned from practical work within this thesis, experience is outlined that promotes the adoption of practice that is in line with that of the primary school.

Chapter 8 reflects on results obtained throughout the research visits, and discusses the contribution to knowledge made by the thesis, alongside outlining possible future research directions.

Chapter 2

Literature Review



This chapter provides an overview of the literature surrounding the involvement of children within the design of healthcare technology. The literature of user involvement in healthcare technology development is outlined and discussed to provide a context for the research, in particular the experimental work that is performed in **Chapters 3 – 5**. To begin, **Section 2.1** outlines the drive for involving users within healthcare research. This section begins with an overview of the research concerning user involvement generally, with the latter end focussing on the involvement of children. **Section 2.2** extends the focus of the literature to cover the involvement of children with disabilities in healthcare research. The identification of available methods for involving children in healthcare research is addressed in **Section 2.3**. **Section 2.4** then outlines available methods from HCI literature for involving children in healthcare research, and addresses the difficulties of transferring methods across domains with the use of a structured literature review. **Section 2.5** concludes the chapter by reviewing the case that has been put forward from the literature and explaining how this guided the chosen methodology within this thesis.

2.1 User Involvement in Healthcare Research

This section discusses the literature on user involvement in healthcare research. Firstly, the drive behind user involvement in healthcare research is discussed to contextualise research involving children. The discussion of child involvement in healthcare explores the existing literature and outlines issues that have been highlighted in previous work in the area.

2.1.1 The Drive Behind User Involvement in Healthcare Research

The drive for user involvement within the NHS and wider healthcare communities expands to cover healthcare technology design (Shah and Robinson, 2006). User involvement and patient-centred care can be seen in policy dating back to 1974 within the

NHS in the UK, and it can be seen as a component of many healthcare systems internationally (Tritter and McCallum, 2006). The integration of user engagement is not universal across all healthcare organisations, with only those in UK and the Netherlands incorporating systematic approaches to engaging users, patients and policymakers. Within the NHS in the UK, user involvement relies on the encouragement of patients to exercise greater control over their own healthcare and to become more involved in the development of health services (Department of Health, 2005). Now an established term within healthcare, there is an underlying assumption that through the transfer of power to patients there is an increased chance of improvements to the quality of services (Tritter and McCallum, 2006). However, such an approach fails to take account of the importance of evaluation and development of quality measures to identify whether user involvement leads to quality improvement. It has been highlighted that there is a shortage of good measures of dimensions of care that are directly relevant to service users (Pringle et al., 2002); therefore, future research needs to begin to consider the development of these measures.

Within healthcare, meta-analyses and systematic reviews have risen alongside evidence-based policy where the particular tendency of this convention to exclude non-experimental forms of evidence (e.g., qualitative research) has been noted (Dixon-Woods et al., 2007). Medical research and healthcare often subscribe to the Cochrane movement, which as Dixon-Woods et al. point out has led to a ‘rationalist’ perspective. Randomised controlled trials (RCT) are situated at the centre of this means of measuring effectiveness within research (e.g., Kirkevold, 1997; Evans and Pearson, 2001). Where RCT use is advocated as the leading process in healthcare, almost all other study designs, including qualitative and quantitative research, have been excluded. Developments that are more recent include the Campbell Collaboration, similar to the Cochrane movement, identifying a further increase in ‘evidence-based’ practice. This ethos is becoming embedded in discourses around healthcare (Harrison, 1996), with such ideology gradually transferring across many areas of practice and policy.

Although user involvement is applied within the development of a range of medical devices, its use to improve the understanding of both the user and their capabilities is shared with the UCD approach to technology design (Mao et al., 2005). Mao et al. (2005) gathered responses from 103 UCD practitioners with high levels of expertise, spread across a range of organisations within the USA and Europe, regarding their perception and use of methods in product development. In total, 72% of the practitioners who participated in the research reported that UCD methods had made a significant impact on product development within their own organisations. Some of the most commonly used methods included field studies, usability evaluation, focus groups, and user interviews. However, one major problem that was highlighted with the adoption of UCD methods was the lack of consensus on measures of effectiveness. Given the emphasis of ‘evidence-based’ practice within healthcare, the ability to develop approaches to ascertaining the effectiveness of applying UCD, or user involvement strategies to medical device development might be required.

UCD approaches and user involvement are similar in a range of their core beliefs, with further crossover being identified in the choice of methods used to involve users. Where Mao et al. (2005) highlight a range of methods commonly used by UCD practitioners, a literature review performed by Shah and Robinson (2006) identify the most commonly used methods to achieve user involvement in medical device development. The most common methods used to capture users’ perspectives included usability tests, interviews (mostly semi-structured and face-to-face interviews) and questionnaire surveys. Other methods included discussions and simulations, alongside design sessions, focus groups and observations. However, this review did not take into account literature from engineering, medical and nursing fields. A similar review of methods of capturing user requirements that included engineering and ergonomics literature concluded that the three most common methods were ethnographic (exploratory, open-ended research processes), contextual enquiry (observing and interviewing users as they complete a task), and focus groups. Both reviews highlighted user involvement as an essential component of medical device development, occurring most commonly at the design stage of a device, although each stage of the design process was highlighted as being important (Shah and Robinson, 2006). Similar to Mao et al. (2005), the potential benefits of involving users are identified in practice by a range practitioners, with Martin et al. (2006) outlining a range of the benefits of user involvement in medical device development. Martin et al. (2006) outline user involvement as providing a basis on which manufacturers can i) improve device safety ii) improve device usability iii) reduce device recalls iv) limit the need for ad hoc modifications v) improve user efficiency vi) improve patient outcomes and satisfaction, and vii) assist with obtaining development grants. There is, therefore, crossover between established UCD approaches that exist in product development within a range of organisations, and the approaches currently being utilised in medical device development. However, the identified reviews draw their findings from literature that analyses data collection techniques and practice in research that predominantly involves adult users and does not focus on the involvement of chidlren.

Currently very little research involves child users in the development of medical devices for children. There is scope to document the elicitation of information from children in the design of medical devices and gauge the extent to which the benefits that have been previously identified with adult populations can translate to those of children. The next section identifies current user involvement of children in healthcare research to discuss existing issues, followed by **Section 2.1.3** that looks specifically at issues relating to involving children with disabilities.

2.1.2 User Involvement of Children in Healthcare Research

Where once research involving children tended to be research *on* children, there are now growing reports of research *with* children (Kortesluoma et al., 2003) and even research *by* children (Alderson, 2001). If the benefits of user involvement in healthcare technology development and evaluation are going to be seen across all groups of people then methods that successfully involve children need to be investigated. This should encompass children with disabilities as they are often the end users of such technology and attribute importance to being treated sensitively and on an equal platform to all children. This includes having their perspectives and experiences valued and attributed the same worth as children without disabilities (Lewis et al., 2006). If the benefits of user involvement are to be realised across all populations, then methods that successfully involve children in healthcare technology development and evaluation need to be investigated.

When performing healthcare research with children, failing to acknowledge childhood as a distinct phase in the life cycle has been deemed irresponsible (Balen et al., 2006). Although the role of childhood may be a social construction, its members possess differential competencies, responsibilities and vulnerabilities within their role. The theory of development by Piaget (1970) identifies four stages of cognitive development that occur for a typically developing child from birth to 12 years onward. Given the well-established nature of this theory, suggestions of the irresponsibility of ignoring such unique characteristics seem founded. Since the late 1980s there has been a growing interest in children's experience of childhood which has been largely based on theories of interactionism and social constructionism and catalysed by the development of children's rights that reformulated the social status of children (James, 2001). Such newly emerged perspectives of children have permeated into research, where childhood is seen as socially constructed, emphasising the roles of the social, cultural and historical variability of childhood (James and Prout, 1997). Research has diversified from perceiving the child as passive, to seeing the child as an independent, social actor, actively contributing and reacting to the formation of his or her own social world (James and Prout, 1997; Christensen and James, 2008; Kirk, 2007). This change of perception has been accompanied by an increase in the appreciation that it is unsuitable to use adults to gather proxy information in place of children, and children themselves should be sought for information relating to their own views and experiences of their world (Dixon-Woods et al., 1999). Such underlying notions of children as a separate group has led to the formation of theories that use defined stages of cognitive, social, emotion, moral and language development to inform and improve areas of understanding in topics such as marketing to children (Acuff and Reiher, 1997).

Research regarding children in healthcare currently covers a variety of topics, from guidelines on their involvement in decision making (McCabe, 1994; Lightfoot and Sloper, 2001), research practice (Kirk, 2007; Morison et al., 2000), and explanation of treatments (Wu, 1965), through to descriptions of children's experiences of the care and treatment that they receive in hospital (Noyes, 2001; Carroll, 2001). Although general practice guidelines for methodology with children exist (e.g., Kortesluoma et al., 2003; Morison et al., 2000) Dixon-Woods et al. (1999) suggest that research based on partnerships with children in healthcare is limited in its success as children are not given a complete voice, nor are used very often in planning and decision making. Franklin and Sloper (2005) question whether things have changed in recent years. Although children are being involved more in research, the trend is not straightforward. Sinclair (2004) identifies that an increase in the number of young people and children being asked for their opinions runs parallel with a lack of data on how the information is being utilised. Of particular interest is how to provide feedback to children, as failure to do so appropriately can have negative implications. For example, a child or young person could perceive their participation in research as being for the purposes of tokenism. Tokenism in this context involves young people being seen to provide a voice in research that in reality is not applied and has no noticeable value (Franklin and Madge, 2000). Such beliefs can lead to a resultant disillusionment regarding potential benefits of being involved in research. Healthcare technology development and evaluation with children provides an opportunity to inform their involvement in healthcare more generally by providing further means of involvement. However, any resultant methods should look to address the highlighted issues of child involvement and ensure that they facilitate and increase the articulation of children's opinions and beliefs to ensure that disillusionment is not incurred.

2.2 Involvement of Children with Disabilities in Healthcare Research

Although there is a case for involving children in research, it is typically groups with disabilities that are associated with the term user involvement in healthcare research (Beresford et al., 2007). Rabiee et al. (2005) report that in this area, children with disabilities are mostly excluded from decisions and consultations that directly relate to them. Such exclusion includes higher levels of restriction in participation than their peers without disabilities, due to a variety of personal, environmental and occupational factors. Such restriction is furthered in instances where the child has cerebral palsy (CP) or another neurological impairment (Imms, 2008). These factors are central to investigations of methods in the first phase of investigations outlined in **Chapter 3**.

A literature review by the National Disability Authority (NDA) (2006) explains that although negative attitudes regarding disability still exist, improvements in attitudes have occurred worldwide since 2001. The effect of this gradual improvement on research has yet to be seen; such attitudes continue to prevent the complete perspectives of people with disabilities being revealed. One contributing factor is ‘disability spread’ (Wright, 1983), which is the tendency to have perceptions of a physical disability extending to a person’s social, emotional, and mental characteristics. To counter this, the Department of Health (2001) highlight that children with disabilities should not be linked to a lack of competence, and that there is a need to present information appropriately and supportively. Cavet and Sloper (2004) outline strong support for such involvement within healthcare, particularly when it comes to decision making. They cite several examples of people with disabilities expressing their views on matters directly related to them, and point out that more appropriate services result from the participation of children with disabilities. However, they stress that there is still a need to gather and reflect on information regarding the costs, ethnicity group coverage, and the consideration of individuals’ perspectives in methods currently being used to involve people with disabilities and young people in research. These problems occur in other areas of healthcare research with children in, for example, the delivery of strategic processes involving the Children’s Fund initiative (Spicer and Evans, 2005), where it is highlighted that ‘…despite widespread commitment to the principle, in practice achieving effective participation in the design, delivery and evaluation of programmes and services is challenging’ (pg. 178).

Through delivering guidance, Cavet and Sloper (2004) begin to address some of the challenges that occur when trying to achieve effective participation. Such guidance highlights that the way in which children with disabilities participate in research should be flexible, alongside the need to consider practical support, e.g., providing communication aids at all times for children who require them. However, it can be difficult to stimulate discussion about disability, even among families including a person with a disability. Parents often report high levels of anxiety towards the thought of providing explanations of disability to their children (Connors and Stalker, 2007). This further extends to reports of parents that have explained impairment to their other children despite not discussing the topic with their own child with a disability (Kelly, 2005). If explaining the presence of a disability to a child can cause a parent distress then the extent to which this hinders research needs to be investigated. An implication of this is discussed by Connors and Stalker (2007) who identified that a child having a distinct lack of contact with adults with disabilities will incur a consequential lack of language to articulate their experiences of disability. This could manifest itself in an inability to express perceived differences when comparing their experiences of impairment and disability to children without disabilities (Kelly, 2005).

Despite difficulties incurred by researchers making sense of, and conceptualising, the involvement of children with disabilities in research, there have still been continued efforts for their participation. Roberts (2006) uses think aloud protocols in software usability studies with individuals who are deaf by using gestures instead of spoken word when highlighting usability problems. In this research, participants were used only as task participants who performed the necessary usability tests, reporting their thoughts via sign language gestures. In contrast, the approach adopted by Sartain et al. (2004) to capturing the voices of chronically ill children involved participants expressing their opinions through the use of semi-structured interviews and drawings. Other approaches differ drastically with, for example, the use virtual reality to access populations of children with physical and intellectual disabilities (Lotan et al., 2008). Such a diverse array of methods pays tribute to the unique challenges that are present when developing healthcare technology with end users with disabilities.

Lewis and Porter (2004) identify that there is a growing expectation that methods used to involve children with disabilities in research will become increasingly inclusive and participatory in nature. For children with combined learning difficulties and disabilities they highlight that such involvement will be further complicated due to the cognitive and linguistic demands required when participating. However, they highlight that views and perspectives should still be obtained where possible. Franklin and Sloper (2004) note that recent policies calling for the increased involvement of children with disabilities in research have led to such populations being consulted more frequently, often using formal methods, yet the development of such methods remains rudimentary. The use of formal methods could be problematic when involving children with specific healthcare needs. For example, Carlsson et al. (2007) consider the methodological difficulties that can occur when dealing with a population of people with communication impairments. In their research, areas of complex difficulty include sampling, where it can be difficult to identify suitable participants without causing upset by obtaining a measure of cognitive capacity, and the difficulties in using proxy information as this may neglect perspectives from the specific population of interest.

The consideration of a wide variety of populations with disabilities is important when reflecting on the involvement of end users of technology for healthcare, such as rehabilitation equipment and alternative and augmentative communication (AAC) devices as it needs to account for a large heterogeneous group. Guidelines for interviewing children with learning difficulties do exist, such as those provided by Lewis and Porter (2004).

Firstly, they follow the guidance of Aitken and Millar (2002) in establishing a relationship between researcher and participant as the first step in collaboration. They then consider the most appropriate medium for gathering and exchanging ideas (e.g., establish the best medium through which communication takes place, deliver information in a way that is meaningful to the recipient, and consider whether to use a question-answer or statement expression in questioning). Like Carlsson et al. (2007), Lewis and Porter (2004) argue that researchers should question the methods that are currently in use. When trying to find alternative methods to approach groups of children posing particular barriers, both Carlsson et al. and Lewis and Porter anticipate technology-based interventions (e.g. internet forums) as a method by which marginalised populations will be accessed and participate in research. Such methods promote less obtrusion, including the removal of potential distress that may be caused by traditional interviewing.

With increased involvement, consideration must be given to how methods allow for the opinions of children with disabilities to be expressed. One of the primary roles of health professionals in paediatric practice is to work alongside a child and their families to understand the goals and priorities of their involvement in healthcare. Dunn et al. (2009) investigated the understanding of individual capabilities held by children with CP and compared this to the perspectives of their parents. When, for example, investigating ratings of capability and physical functioning, parents and the children provided different ratings to one another. This has implications for the healthcare that they could potentially receive. If a therapist, for example, is interested in improving a child's physical functioning, Dunn et al. point out that it is important to seek an understanding of how the child themselves feel about their condition and capabilities in order to provide an effective and informed intervention or treatment. The need to consult children directly carries into areas of healthcare technology, with for example, the prescription of AT. It is important to gauge a child's understanding of their own capabilities by working with a child alongside parents, guardians, teachers, therapists, and other physicians to ensure that they receive appropriate therapy services (Michaud, 2004). Despite contrary findings regarding their use, parents, guardians, and carers are still frequently consulted to gather proxy information in research involving children, with this trend occurring in different areas of healthcare (Sprangers and Aaronson, 1992). Parents and guardians are also consulted to provide information that complements information provided by their child (Ronen et al., 2003) despite research highlighting that populations of children are capable of providing reliable and valid self-reports of their own health (Johnson and Wang, 2008; Riley, 2004; Theunissen et al., 1998). Although instances of fatigue or severe illness in children may necessitate the use of a parent or adult to gather information, for the most part as Beresford et al. (2007) point out, children and adults experience situations differently, and the needs and opinions of both parties differ.

The reliance on the parent to accurately reflect a child's needs and feelings declines as a child becomes older and more independent (Hart and Chesson, 1998). Approaching peers has been applied as a means around this problem (Light et al., 2007). However, the extent to which information obtained from children without disabilities can inform the design of equipment for children with disabilities has yet to be investigated. Research can be found that involves both children with and without disabilities in the design of rehabilitation devices for children with CP (Holt et al., 2006), but the worth of gathering design information from peers of children with disabilities remains unclear. The use of children without disabilities may be useful when gathering information on topics such as aesthetics, but their use in the evaluation of the ergonomics of a device is more questionable. Therefore, the use of proxy information in the design of healthcare technology must be approached with caution, and further research should be completed into its usefulness in the design of healthcare technology.

In addition to the use of proxy information, informed consent is an issue in research involving children with disabilities. Demonstrating willingness to participate from children can be made difficult by the presence of limits in a participant's communication abilities. Carlsson et al. (2007) advise that researchers should have a thorough understanding of any participants' communication difficulties and should use this knowledge to consider the approach that they adopt. This draws the researcher away from ignoring difficult populations, and instead emphasises a more reflective inclusion. In order to obtain consent from a child in healthcare research, the use of 'assent' is increasing; this is not informed consent understood in law, but an agreement by a person that something be done to her or him, even where she or he does not understand the purpose behind the act (Montgomery, 1997). The need for a minor's assent is critical, even in the presence of parental consent, as it creates a situation in which children's rights and involvement in decision-making is taken seriously (Taylor, 1998; Balen et al., 2006). It is important to ensure that considerations for obtaining assent from children with disabilities are made, and that strategies for obtaining this information are put in place during research. The need to consider the individual differences in research with children with disabilities plays a role in this thesis. The first stage of experimental research within this thesis involves children with and without disabilities, but reviews the involvement of children with severe communication impairments separately. This occurs to allow insight to be detailed regarding the unique characteristics of such a population, allowing considerations of their involvement to be made clearer. In doing so, it will encourage the inclusion of a wider population of children to attack against an outcome in healthcare research where children remain '…talked about rather than talked to' (Watson et al., 2006).

2.3 Methods for Involving Children in Healthcare Technology Design and Development

As outlined in **Chapter 1**, HCI provides a range of methods that could be used to support calls for user involvement in healthcare technology design and development. HCI advocates user involvement in both software and hardware development with the use of approaches such as UCD in practice, with such an ethos extending to research focusing on children. Within this section, the literature surrounding both methods and approaches to child involvement from HCI are discussed. This is accompanied by research from healthcare when relevant, as for example, when discussing theories of child participation in research.

HCI began as a discipline over 40 years ago, incorporating philosophy, physiology, medicine, psychology, and ergonomics (Shackel, 1997). The choice to approach HCI and surrounding research areas for methods to use with children is linked to the vast amount of literature on the design of technology with people. In addition to this, HCI pays particular attention to the design of technology with children and considers many of the factors that influence their involvement. Methodology within this discipline was established to fulfil the criteria of "…design, evaluation, and implementation of interactive computing systems for human use and with the study of the major phenomenon surrounding them" (Hewett, 1996). In trying to attain such goals the HCI community has been divided into the evaluation community (concerned with usability), and the design community (where the focus is on the design of artefacts that require evaluation later). Wania et al. (2006) states that one cannot occur without the other and a major issue to contend with is that neither design nor evaluation has received a unified definition. An array of methods have been developed for the purposes of investigating the areas of design and evaluation within HCI nonetheless, although still to date there is no guidance regarding the suitability of methods for particular purposes and that "…there may not be one best method or technique for any given situation" (Wania et al., 2006, pg. 91).

Despite the segregation in the areas of investigation, child involvement in research has occurred in both factions. Manufacturers and service providers are both keen to involve an ever-growing segment of the market populated by children, but there is a demand for knowledge surrounding methods that can be used to achieve this (Markopoulos et al., 2008a). Researchers performing work with children echo a picture of HCI at large, where disparate methods of enquiry make it difficult to compare studies and gather an understanding of progress in the field. Therefore, there is a need to consider how methods are firstly used within HCI, and secondly establish a means with which to evaluate the effectiveness of the methods. Such an approach would bring order to the existence of methods so that researchers within and beyond the discipline might have better access to them. The rest of this section discusses a range of methods that are currently available in HCI research with children, before moving on to consider how these can be better understood with the use of a taxonomy in **Section 2.4**.

As a means of identifying methods that are suitable for involving children in the design of healthcare technology, existing design methods from HCI are first outlined. Methods for designing with children are widely available in HCI literature, although their suitability for use with children with disabilities has not been considered. HCI is an advocate of user involvement to improve the usability and appeal of both software and hardware. Given the growing contact that children have with computers and technology generally, there has been growing interest in the suitability of methods for use with children in the design and evaluation stages of technology development. A distinct domain of child-computer interaction research has started to emerge, offering a range of methods for eliciting information from children regarding their use of technology and its design (Markopoulos et al., 2008). This provides a rich source of methods that may be suitable for involving children in the design of healthcare technology. However, healthcare technology is separate from technology that is inserted into mainstream markets where HCI might typically operate. One such major difference is the necessity of technology use for children requiring healthcare equipment, alongside concern over negative associations that may be attached to such equipment (Clarke et al., 2001). Methods for use specifically in healthcare technology development with children do not currently exist. However, the existence of methods from HCI and other disciplines might be adequate for such a purpose. In order to examine the appropriateness of existing methods, healthcare literature already contains theory through which it is possible to identify expected levels of involvement and participation. It is with the use of such established theory that evaluations about the capability of existing methods for involving children in healthcare technology design can be based.

The participation of children within healthcare research ideally aims to represent children from differing ages, socioeconomic, and ethnic backgrounds, where each child is empowered and has an influence on resultant decisions or practice (Spicer and Evans, 2005; Alderson, 1990). This is difficult to achieve, with a variety of views offered by researchers on how to conceptualise and classify differing levels of participation from children (e.g., Arnstein, 1969; Hart, 1992; Shier, 2001). Often these classification systems are hierarchical, with the underlying assumption that the highest level is the most desirable. The highest level typically involves a child as a main deciding body within the research, with adults removed from the process (Franklin and Sloper, 2005). In contrast, research shows that children recognise the limits of their autonomy and desire adult input and support (Morrow, 1998).

The classification systems provide a critical stance with which to compare existing levels of participation. Alderson and Montgomery (1996) argue that four levels of participation exist; these are *being informed*, *expressing a view*, *influencing a decision*, and *being the main dealer*. As Franklin and Sloper (2004) point out, this framework can be applied to research involving children with disabilities. These children are capable of attaining any such level of participation affected only by the degree to which an existing disability may impede involvement.

Similar to Alderson and Montgomery (1996), a framework of child participation is used within HCI literature involving children. Druin (2002) outlines the four roles that children can adopt during the design process; child as *user*, *tester*, *informant*, and *design partner*. *Design partner*, the highest level of participation, is implied to be the desired goal, with Druin and her research team trying to develop methods to attain this level. **Figure 2** highlights the similarities between concepts of participation for children within research across healthcare and HCI.

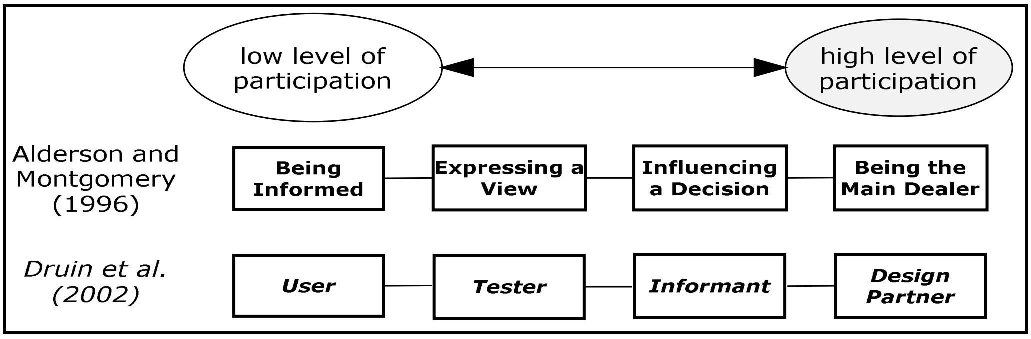


Figure 2 The four levels of participation as discussed in HCI and healthcare

The concepts presented by different theorists in **Figure 2** are more aligned in descriptions of the higher levels of participation, although similarities in the two theories can be identified throughout. A "User" as defined by Druin, would have no voice in the design process and only be informed of the design. A "Tester" would be able to express a view, which may or may not influence a decision, but is typically too late to influence the substantial decisions. An "Informant" can influence decisions throughout the process, and a "Design Partner" actually participates in decisions, although they may not be the main dealer. The focus on participation can bridge theories within HCI and those that can be used to describe participation by children with disabilities. Although the participation of children with disabilities has begun to be documented in healthcare research, HCI has become a rich source of debate regarding the extent to which children without disabilities can be involved in a design process. The lack of consideration for disability in HCI research needs to be addressed if methods from the domain are to be used or considered for use in healthcare.

However, the debates can potentially inform research involving children without disabilities in healthcare technology development.

It has been noted that a child can contribute to the design process but the nature of the relationship that they can attain with designers is less clear (Scaife et al., 1997; Rogers et al., 2002). Both Scaife and Rogers question whether traditional power relations between adults and children can be alleviated in a research process where children participate as full design partners. The highest level of participation may not always be the most desirable, or even obtainable. Alderson and Montgomery (1996) suggest that instead of trying to achieve the highest level, a researcher should gauge the extent to which a child with a disability is participating and then use this to guide and augment the extent of their participation. This approach is reflective, rather than evaluative. This has been applied in recent research by Guha et al. (2008) when investigating designing with and for children with special needs. The framework provides a vague method of envisaging the extent to which children with special needs might be involved in a design process. Beginning with a decision about the level of involvement a team wishes to achieve in a design process, the extent to which a child with a disability can be involved is decided firstly by evaluating the severity of disability followed by the identification of the availability and intensity of support. By considering these two aspects that form subsections of personal and environmental characteristics of a child with a disability, it is hoped that the research will develop an idea of the extent of participation that might be achieved.

Research involving children in the HCI domain generally favours participatory approaches that involve children working collaboratively with researchers to create low-tech prototypes (Rogers et al., 2002). Gallacher and Gallagher (2005) point out that the effectiveness of this approach is questionable. It could potentially limit and prescribe what children can do, not by the method itself, but in the way that it is applied. Additionally, several underlying assumptions are not addressed when the method is applied in practice. Such problems go some way to eradicating the proposed benefit of using this method over alternative interview methods. Although flexibility might be required in research involving children, the user of participatory approaches must realise that they are not foolproof methods and consider the framework in which they are located (Gallacher and Gallagher, 2005). Read et al. (2002) propose a continuum that describes the levels of involvement that can occur within the participatory design (PD) approach; this is the IBF (Informant, Balanced, and Facilitated) Participatory Continuum Model. The three modes of this framework include Informant, Balanced, and Facilitated. Although PD may naturally assume a facilitated approach should be adopted, Read et al. identified that this is not always the case, with variables such as participants' knowledge and skills controlling the extent to which a participant can be involved.

There are means of measuring and assessing children's participation in healthcare technology research, as indicated by existing frameworks being applied to other domains. However, in order to increase the participation of children with and without disabilities in the design of healthcare technology there is a need to begin to identify actual methods to involve children with and without disabilities in the process. Although PD is a popular method with HCI, new methods are continually developing to address specific design issues for use with children. Such practice of method adaptation to necessity is an appealing selling point of HCI given the need for methods in healthcare technology design that may need to overcome a range of barriers (i.e., disability, discussion of sensitive topics such as stigma of technology, experiences of healthcare). Recent developments of methods have covered research for requirements gathering (Antle, 2008), idea generation (Iversen and Brodersen, 2008), evaluating opinions of technology (Read, 2008; Zaman, 2008), usability identification (Höysniemi et al., 2003) and other evaluation methods (e.g., Barendregt et al., 2008). The only drawback to such enthusiastic means of involving children is the lack of citations that outline comparisons or similarities between the methods (e.g., Bekker et al., 2008; Baauw and Markopoulos, 2004; Als et al., 2005). The disordered distribution of methods across HCI research involving children makes it difficult to identify the most appropriate method to use for a given project. Although many reports of method use have included positive outcomes, there is a lack of consideration of means with which to validate or compare the range of available methods (Mazzone, 2007).

In a literature review of research involving children in the design process of technology, Nesset and Large (2004) identify the main approaches that are typically used. These include UCD, contextual design, PD, cooperative inquiry, and usability research. The principles of UCD and contextual design are applied to children in the same was as they would be used with adults. For example, UCD is typically applied after the design of technology where users, whether adults or children, have no control in the process. A range of methods are used to achieve this, such as observations and qualitative or quantitative surveys. Independent of the range of methods used, the purpose is for the researcher to gather information about the impact of the technology on its users and identify how this information can be used to improve the product.

PD and cooperative inquiry approaches differ from UCD and contextual design; however, as they take information from users and try to work this into the design of technology. With PD, professional communities have shown disinclination to involve children throughout the whole of a design process, although the basis of such attitudes are often the same as those related to adults; an unwillingness to allow untrained users to inform the design process (Nesset and Large, 2004). For cooperative inquiry, Druin et al. (1999) has adapted the basic principles of the PD design process to incorporate child populations with methods that aim to promote child involvement throughout the whole design process. This includes detailing the development of collaborative teams of children and researchers in the development of low-tech prototypes, with considerations surrounding intergenerational design teams. By documenting this, and outlining methods such as ‘technology immersion’, Druin et al. (1999) have developed a design theory that is regarded as perhaps the most suitable for involving children in the design process (Nesset and Large, 2004).

Usability research with children involves the child as a tester, as described in the four roles of children in the design process (Druin, 2002). Bruckleitner (1999) reported that the most common methods used for evaluating children’s software involved expert reviews from developers, not children. However, a range of usability methods that are not based on synonymous practice with adults have been developed, creating a diverse selection that is now available (e.g., Read, 2008; Zaman, 2008; Höysniemi et al., 2003). Although detailed guidelines (Hanna et al., 1997) and general practice suggestions (Druin, 2002) are available, decisions regarding the selection and appropriateness of methods is still not clear. Markopoulos and Bekker (2003) highlight that currently there is no report of a systematic comparison of usability testing methods (UTM’s) focusing on child users, nor does a systematic effort exist to specify the method and instrumentation of usability testing when test participants are children. In order to address this Markopoulos and Bekker (2003) propose a framework for the assessment of usability methodology for children which is noted as stemming from the ongoing debates in the field of HCI surrounding the comparison of usability evaluation methods for adult users.

The Markopoulos and Bekker (2003) framework comprises three dimensions on which to compare usability methods; a universal criteria for assessing methods, specific method characteristic criteria relating to information required by researchers to apply the methods (i.e., how many participants are required, how many users are required in a session etc.), and characteristics of children. The purpose of the framework is not to develop a classification or meta-analysis of research, as too few studies have taken place in the area. It aims to organise the research area so that links and lessons from different studies can be amalgamated for easier reference. The application of the framework to the relatively new and emerging area was an opportunity to make sense of what is and is not already known. This could further contribute to the synthesis of existing knowledge and minimise disorder and confusion in explorations within the area. It is from the standpoint of consolidated previous literature that methods used in research can be assessed for their suitability for application in areas such as healthcare technology. By applying a formal and structured approach in the development of methodology for use in healthcare technology, there could be a reduction in the issues of concept and theory being applied in different and inconsistent ways within design research (Love, 2000). Of the three dimensions in the Markopoulos and Bekker (2003) framework, two are generic to method testing, with the third dimension being linked to specific characteristics of the types of methods being compared. Whether the third dimension would have to be modified or omitted can be investigated in its application.

Although many methods developed in HCI for children could be applied to the development and evaluation of healthcare technology without consideration of a framework, they must be used with caution. As well as a lack of comparisons between methods, few studies have validated their findings. Mazzone (2007) points out that attempts to evaluate the value and quality of design methods in an empirical way have been made, but the results are often far from satisfactory. Authors often adopt a more holistic approach, reflecting on how a method contributes to an isolated design activity. This makes meta-evaluations of methods more difficult and leads to disparate trails of research, with ad hoc methods being created for use solely on one research project (Bekker et al., 2002; Dindler et al., 2005).

Davis (1998) argues that the key objective for researchers is to find tools that allow children to have the maximum opportunity to voice their opinions and experiences whilst being active participants. As Kirk (2007) points out, when trying to achieve participation for children, often researchers show an enthusiasm for developing fun, child-friendly methods (Punch, 2002). Structured activities are taking the place of interviews, with perceptions that they are more appropriate for research with children. Punch highlights that these methods and novel techniques have not been scrutinised enough, nor have they received sufficient critical reflection. The newly developed child-specific methods imply that children are not capable of the same type of conversations as adults, and weaken the argument that children should be treated as independent social actors (Kirk, 2007; Punch, 2002; Hill, 1997). Punch also highlights the paradoxical nature of childhood research where novel methods are being developed by those who promote the capabilities of children, asking why such methods are necessary if children are socially competent. The limited applications of methods that have been used in healthcare technology development with children to date have seen a range of approaches. For example, Light et al. (2007) involved children without disabilities in the design of AT for children with communication impairments. The researchers asked children without disabilities to create low-tech pencil and paper drawings that reflected their preferences, and used these to source information about children’s preferences. Rigby et al. (2006) on the other hand, requested children with a range of disabilities to provide their opinions and preferences to inform the design of an adaptive paediatric seating device. The methods applied during the research involved a unique protocol to establish the preferences of children with physical disabilities. Although both research papers attempt to investigate their participant’s opinions with methods that are child-friendly, methods that are more traditional have still not been fully investigated in healthcare technology development.

Away from the design of technology with children, Smith and Connolly (2008) examined factors that affect the continued or discontinued use of AAC technology. Of particular importance to users of such equipment is the meaning that they attribute to a device because this affects the role that the equipment plays in their life (Pape et al., 2002). This research involved an adult population, and similar investigations into such factors with children provide valuable insight for designers. For example, Clarke et al. (2001) investigated a population of children who were using AAC technology where most children described their devices as uncool and boring, although the children identified the systems as useful. The effect that the AAC technology has on a child’s image and identity is important, despite the necessity for the technology, and further understanding about this is required to inform designers. Through the involvement of children, and particularly child end users in the design of AAC technology, amelioration of users’ negative perspectives and associations with the technology can be addressed. When discussing the technology available for use by children with complex disabilities, Cowan and Khan (2005) state that “…Assistive technology appropriately assessed, prescribed, provided and supported can improve the quality of life for both carers and users” (pg. 211). If this technology can be developed further in terms of aesthetics and desirability, then the outcomes could be beneficial for all involved.

When involving children in the design of healthcare technology there is a need to consider the importance of acquiring certain types of information. Due to the lack of research surrounding the development of methods for this purpose, there is a similar lack of information exploring what information is firstly of importance to children in such a process, and secondly can be gathered from children via involvement in a method. When investigating the types of information that are of importance in the design of healthcare technology, Hocking (1999) describes two approaches; these are the functional and the psychosocial. The functional is a consideration of the improvement in the performance of an individual that comes about as the result of using a device. The psychosocial extends beyond improvement in function to begin to consider factors that affect the perception of a device by its user. For healthcare technology such as AT, often devices are intimate to the users’ appearance or personal functions and are likely to be seen as an extension of the users’ body, not a separate device (Brooks, 1991). Therefore, in considering which research topics are of interest to children during the design of related technology, psychosocial elements should be included, such as consideration of the aesthetic of a device. The aesthetic of a device may be of importance to many users, and the positive contributions of aesthetics to healthcare have already begun to be documented (e.g., Ulrich, 2001; Caspari, 2006). In addition to its effect on healthcare, the effect of aesthetic on children generally has received research attention. A child’s aesthetic sense is identified as coming long before the ability to interact with even the simplest media, with a large part of an infant's experiences having an aesthetic component (e.g., a soft satin-edged blanket, studying a bright mobile, or selecting a colourful toy) (Feeney and Moravcik, 1987). If a factor such as aesthetic can have such an influence on the life of a child, then healthcare technology that could potentially be used on a daily basis by a child should begin to consider how this information could be fed into its design.

Having identified aesthetic as an example of a category of importance in the design of healthcare technology for children, there is the need to consider the extent to which methods can retrieve information about this, and other categories. Light et al. (2007) investigated the design of AAC technology by involving six children without disabilities in the creation of low-tech prototypes as a means of exploring preferences. The research highlighted that the current generation of AAC technologies has few features that appeal to children (Light et al., 2007), such as bright lights and varied colours. Children might be more motivated to use AAC technologies if they were sufficiently appealing to capture their interest initially and maintain their engagement over time (Light and Drager, 2002). However, in order to design technology with such features it would seem necessary to gather this information when involving end users. Although Light et al. (2007) began to gather invaluable information, such as preferred aesthetic properties, they did not include children with disabilities, who are the most common users of such technology. In considering the extent to which methods can retrieve information from children, it is important to consider whether they will allow the inclusion of all potential users, including users that have one or more disabilities.

This section has outlined a range of methods that are currently applied within HCI that might be suitable for involving children in healthcare technology design. In addition to this, a means of understanding differences between measures of participation between HCI and healthcare have been considered, and there was discussion of current practice within HCI with children. The discussion above provides preliminary support for using HCI methods with healthcare design research, but there is a need to gather further insight into the literature of the two domains. Therefore, a structured literature review was performed to gather an overview of the publications and research within the two domains, and to ensure that there was scope to explore links between them.

2.4 Structured Literature Review regarding the Use of HCI Methods in Healthcare Research

As described by the literature above, HCI has involved children in a range of methods during the design of technology. Many of these methods have not been fully investigated or validated and require further consideration before they are used within healthcare research. However, healthcare literature highlights the need to involve children in research, but currently has few methods for this purpose. This section outlines the justification for completing a structured literature review on HCI and healthcare literature involving technology design with children. This ensured that the underlying theoretical assumptions of the two areas were considered alongside identifying any patterns that might exist within previously completed literature.

The aim of the review was to create a framework and tool with which to understand methods currently being used in the development of technology with children. The full details of the list of publications used can be found in **Appendix 1**, as compiled in April, 2007. The results of this review are presented in the form of a taxonomy. A taxonomy is a study of arrangements that can include the communication (Jeffrey, 1982), clarification (Derr, 1973), and organisation (Gershenson and Stauffer, 1999) of large amounts of information. In this instance, the development of the taxonomy was completed to aid the identification and organisation of methods to involve children from across separate domains of enquiry (i.e., HCI and healthcare). It was also used to identify and illustrate relationships between the two domains. By attempting to understand relationships between these, evaluations regarding the plausibility of using methods from HCI in healthcare were investigated. This section firstly outlines the background to the structured literature review, followed by an outline of the key findings and their influence on decisions within future research.

2.4.1 Background to the Structured Literature Review

The decision to create a structured literature review and taxonomy arose from criticisms of the design research literature that have been identified by Love (2000; 2005). Love (2000) highlights that a substantial amount of confusion regarding the underlying basis of existing theories, concepts and methods exist within design theory. In addition to this, many concepts are conflated by writers, with a multiplicity of design theories and concepts. In order to address this, Love (2000) applies the use of a meta-theoretical perspective to reduce the extent of confusion and conflation in the concepts, theories and terminology in design research. This provides a means of looking across the different theories and concepts and allows insight into the relationships between the separate parts. The use of a taxonomy assists in this process by developing a means of clearly identifying and expressing trends in research practice. Although this does not directly address confusion and conflation within research writing, it consolidates the sporadic development of methods in such areas as HCI for children (i.e., child-computer interaction). Further to this, if HCI and healthcare are to share methods, it is important to establish how they currently involve children in technology design, allowing for an assessment of differences in the use of methods across the domains. This will provide foresight into the potential use of HCI methods in healthcare, and will produce a bridge between the two domains to support any future amalgamation. A systematic literature review was used due to its potential to outline similarities and differences between existing methods for involving children in technology design that exist within HCI and healthcare.

The inclusion of children in research within HCI is a relatively new venture and it is advisable to consider the organisation of the literature from the early stages to reduce confusion and a lack of coherency that can be found within other design research literature (Love, 2000). This would be an opportunity to argue not only for rigour within research practice, but also in the writing of research, allowing a structured literature base to emerge. This is difficult as the nature of the new and emerging research with children has consisted of researchers writing non-experimental articles, often consisting only of a description of personal experiences in dealing with a topic (e.g., Druin, 1996; Hanna et al., 1997; Williamson, 2003). The challenge now lies in synthesising this early work into a form that can be used across disciplines. The test of a theory is in its validation and coherency alongside other well supported and established theories, drawn from relevant theoretical constructs across all disciplines (Love, 2000). In comparing HCI with healthcare, there is an opportunity to assess how well it currently holds up against more established theory. This exploration begins with a structured review of the literature where the scope has been limited to consider research involving children in the design of technology within HCI and healthcare.

HCI has begun to be applied in healthcare practice as highlighted in previous research (e.g., Fruhling and Wilson, 2007), although such literature has often involved a focus on the development of software or IT infrastructure. For example, Liu et al. (2009) report the design of an electronic assistive device for supporting the navigation of people with cognitive impairment. Although the paper highlights the need for the technology, it highlights that methods are required for dealing with limited study participation and accommodating individual abilities and disabilities. Therefore, although HCI has an established base in research relating to hardware and software development, the need to address its application to healthcare technology research requires consideration of problems that may be posed. A means of identifying such issues is through the examination of existing relationships and differences between the domains.

Before comparing the methods used within the two domains, it is important to consider any existing relationships between the two domains, as insight into their unique standpoints can inform the findings of the review. Both HCI and healthcare actively involve users within research, although the repercussions of outcomes vary. For healthcare, the need to consider means of attaining outcomes has ethical implications. The ability to ascertain causal associations between the changes made and any subsequent adjustments to the health of a population is crucial to inform the progress of a health service (Russell, 1999). Because healthcare cannot tailor for all who would benefit, choices are necessary, and these are led by the assumptions that are drawn from the outcomes of ongoing research. The recruitment of participants in qualitative research within healthcare for example, can be led by evidence-based guidelines on saturation (the point at which no new information or themes are observed in the data recruitment of patients) (e.g., Guest et al., 2006). Such an efficiency-based approach to recruitment is also common practice in usability research in HCI, with five users having been noted as adequate for the identification of around 80% of usability issues with a product (Nielsen, 1993; Virzi, 1992). However, this latter approach to usability research has been questioned (e.g., Faulkner, 2003). HCI and healthcare both consider outcomes in this sense to inform cost, but healthcare places a greater emphasis on this metric as the accountability of findings within healthcare is of importance.

In practice, there are clear differences between healthcare and HCI. Healthcare practice is largely founded upon a range of clinical practice guidelines, where good examples have attributes including validity, reliability, reproducibility, clinical applicability and flexibility, clarity, development through multidisciplinary processes, scheduled reviews, and documentation (Field et al., 1990). Research has demonstrated that with rigorous development and implementation, clinical practice guidelines can improve both the quality and outcomes of care (Grimshaw et al., 2004). Research in HCI does not rely on guidelines to manage practice, and most research is often generalised in terms of theories, models, methodologies and occasionally guidelines that are articulated in a manner neutral to users (Markopoulos and Bekker, 2003a). When considering research on children within HCI for example, there is only limited methodological advice currently available for usability research (e.g., Hanna et al., 1997) or survey techniques to measures children’s attitudes and preferences (Hanna et al., 1999; Read et al., 2002). Such a limited existence of guidelines adds difficulty to the role of the practitioner or researcher in HCI. Although a range of theories and methods exist within HCI research, practical guidelines on how to apply them in practice is limited and needs to be addressed in future research.

When assessing research, measures of outcomes in healthcare rely on identifying changes to physiology or well-researched constructs, such as quality of life (e.g., Varni et al., 2005). Having a clear demand for outcomes and measures of effectiveness within healthcare provides a means of developing accountability in an evidence-based environment, but such an easily perceptible process does not always equate to success amongst researchers (Robson, 2002). For example, Pawson and Tilley (1997) criticise the use of the randomised control trials (RCT) within healthcare research, as they believe they are embedded in the positive view of science, to which they question findings and the concentration on outcomes. The difficulty, as Robson (2002) points out, is that governments and decision-making bodies are moving towards research findings for guidance. This could be problematic if HCI methods were used in healthcare as measurements in HCI do not always use clear objectives or outcomes. In usability research for example, the term usability is largely determined by how it is measured (Hornbæk, 2006). This can be seen to extend to textbooks, where the name ‘usability’ is often understood in terms of aspects of the use of a computer system that can be measured (e.g., Nielsen, 1993). Such practice might involve the formation of an outcome with reference to a specific system or product (e.g., a product that is easy to manufacture or easier to assemble). How this outcome is assessed is generally appropriate only for the particular device and offers no means of applicability across a range of products. Further to this, in practice researchers attribute varying levels of importance to existing outcomes dependent on the situation. Dillon (2001) argues that users, designers and owners of a system may present variability in attributing importance to time. In addition to this, Hassenzahl et al. (2000) points out that many commonly applied usability measures do not account for the hedonic quality; a dimension relating to a quality that is unrelated to a task, but linked to factors such as originality, innovativeness or beauty that a user wants to accomplish with a system. Despite the lack of clear objectives and outcomes within HCI research, certain sub-disciplines have begun to attempt to increase their means of assessing outcomes. For example, within software engineering, there are calls for an increase in rigour, with appeals for the inclusion of statistical power (Dyba et al., 2006) and effect size reporting (Kampenes et al., 2007) in articles intended for publication. However, the lack of a shared sense of the need for objectives may be due to the increasing variation and constant development of new theory and practice. As pointed out by Barnard et al. (2000), “HCI is now effectively a boundless domain” (pg. 221). Although such a constant injection of research into the areas by multidisciplinary theorists provides promise for the future of the area, such rapid growth also brings an increased haziness to research directions, structure and coherence within the discipline (Rogers, 2005).

HCI and healthcare differ in their means of attaining outcomes, and both apply a mix of qualitative and quantitative methods to explore their own domains. HCI has no current means of identifying a standard for determining quality in its work, and is an area founded on multidisciplinary research. As pointed out by Grudin (2004), there is a noticeable divide between the use of lab study and qualitative exploration of the fundamentals of human behaviour in the area. Despite the ecological validity caveats within the former, the influence of psychologists within the multidisciplinary formation of HCI have dictated a norm of asserting a scientific advance when the probability of a type one error is less than 5% (“p < .05”). The real world plays its part too when identifying phenomena in such settings though the application of observatory methods for example. Although these two strands of research co-exist without opposition or conflict, difficulty can be incurred when trying to ascertain validity across the discipline. The use of a range of methods of enquiry could be insightful to a multidisciplinary domain if there was open discourse about the differences. However, co-existence in this context involves two independent modes of analysis. As pointed out by Thimbleby (2007), how can theorists agree to differ where differing is appropriate? Other researchers further this assertion, by questioning whether the notion of validity exists within HCI at all (Lindgaard, 2004).

Concerns regarding validity carry over into explorations within healthcare, although the disputes within this domain are considered more developed and stark, with descriptions of the ‘scandal’ of epidemiological research (Von Elm and Egger, 2004). Given the comparatively established debate surrounding validity in healthcare research, standards such as the Consolidated Standards for Reporting Visits (CONSORT) and the Standards for the Reporting of Observational Studies (STROBE) have been developed. The development of these organisations highlights a desire to maintain and communicate the validity of research across the studies applying the same methodology. Although the adoption of such standards within research in HCI have been suggested (e.g., Thimbleby (2007), in relation to validity and cross-validity in HCI publications), the feasibility of creating such comparisons within the domain has yet to be investigated. Given that this thesis suggests the possibility of applying HCI methods within healthcare, it may be beneficial for any measure development to incorporate metrics of interest to healthcare (e.g., validity of obtained information, quality and quantity of information obtained, enjoyment of children, and cost of materials for method) that can be used to assess HCI methods. This would support their implementation in healthcare practice. Due to the lack of literature suggesting metrics with which to compare literature across HCI and healthcare, the structured literature review did not incorporate an outcome measure, or measure of quality. Instead, the review gathered an understanding of the patterns of research relating to children in technology design from HCI and healthcare, and looked at the content of papers alongside their place of publication. This provides a foundation on which to guide future investigations into methods to involve children in healthcare technology design by mapping out the current state of the research area.

2.4.2 Description of the Structured Literature Review

The section describes the construction of the structured literature review alongside a brief outline of the taxonomies that were formed to present the findings. The main aim of completing a structured literature review was to identify current trends in research involving children in technology design within the two disciplines. The aim of the review was to identify popular areas of investigation in technology design with children and the quantity of research taking place within the separate domains. In addition to this, the review examined similarities between the research performed in HCI and healthcare, and looked at any crossovers in their practice. This section begins with an overview of the method used to construct the review and subsequent taxonomy diagrams that are based on the table of publications presented in **Appendix 1**. This is followed by an overview of the quantitative elements of the review (e.g., number of papers included, research topics of interest in each domain) and an outline of the main patterns that were identified between healthcare and HCI.

Method

A range of research articles were collated via a systematic search that was undertaken in both HCI and healthcare literature. This process involved gathering research related to technology design with children. Once the exclusion and inclusion criteria (outlined in **Appendix 1**) had been applied to the articles that were gathered, they were organised by categories of interest. The categories included domain (the discipline from where the research derives), the artefact tested (the central purpose of the research) and the place of publication (e.g., journal, conference proceedings). Although metrics used in the paper, and details of the methods were noted, they were not used to identify wider patterns between the two areas. The healthcare and HCI literature were analysed together, although the findings from the two domains were fed into two separate taxonomy diagrams for ease of interpretation (**Figure 3** and **Figure 4**).

Results

Once the inclusion and exclusion criteria had been applied to the extracted articles, a total of forty-three studies remained from HCI (*N*= 32) and healthcare (*N* = 11). A larger number of articles were drawn from HCI literature, although only four artefacts were identified within each of the different domains, although they shared methods research and specific research practice as similar artefacts (see **Table 1**).

An examination of the artefact being tested was performed to gather insight into the central purpose of the relevant literature. Within both HCI and healthcare, there seems to be a strong focus on methods research, with this accounting for the largest proportion of artefact across both domains. There is also synonymy in the second highest category for both domains; this involves investigations into specific research practice. Papers that were grouped under this term included outlines of guidelines for use in research, or descriptions of research groups that are active in the area. Despite the literature being drawn from two separate domains, there appears to be crossover in their focus on methodology and specific research practice in research relating to children in technology design.

Table 1 The artefacts investigated in the papers used from the literature in HCI and healthcare research

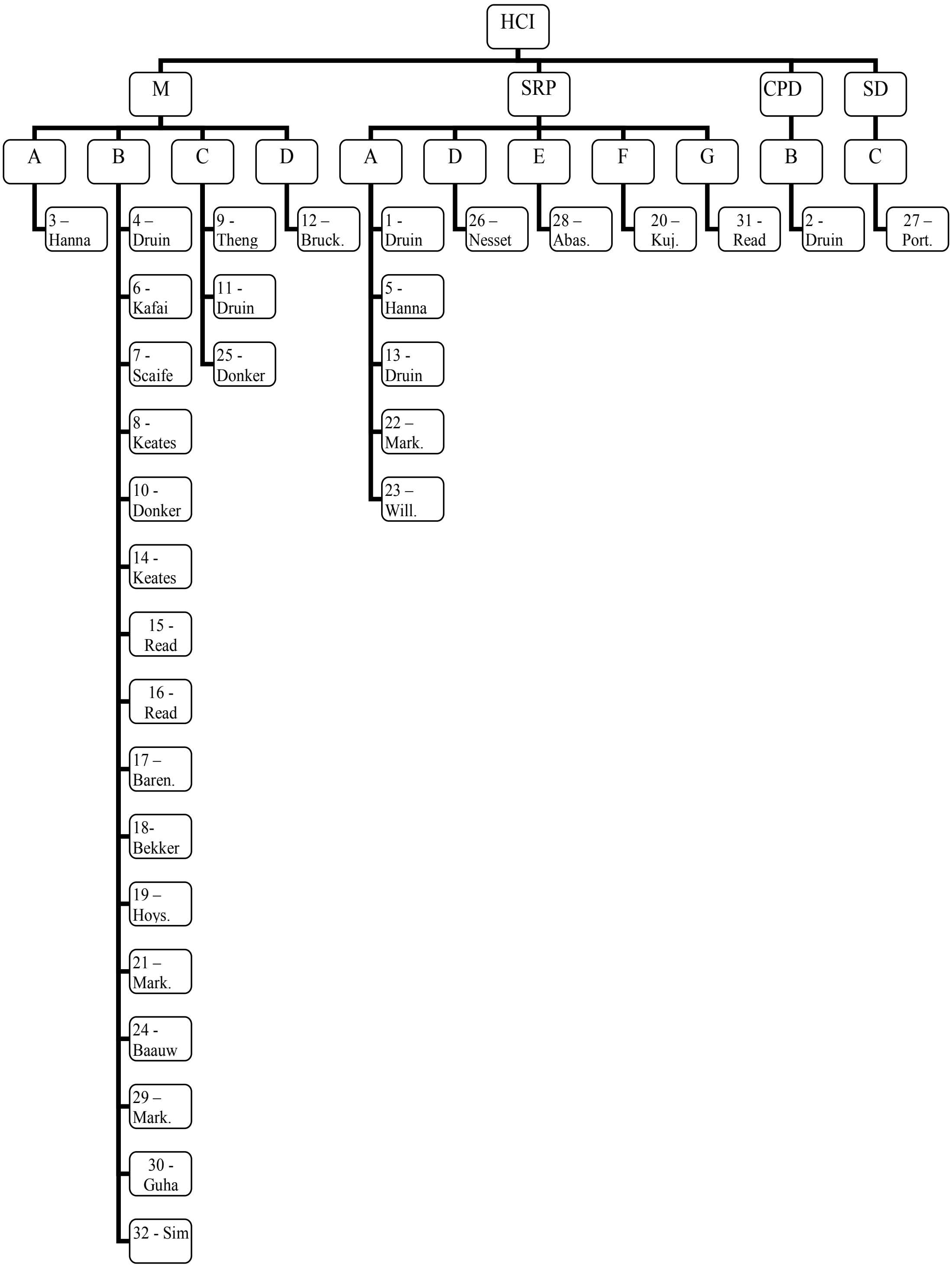
Domain	Artefact	Proportion of papers (%)
HCI	Methods Research	66
	Specific Research Practice	28
	Computer Product Design	3
	Software Development	3
Healthcare	Methods Research	64
	Specific Research Practice	18
	Multidisciplinary	9
	Rehabilitation Research	9

Table 2 outlines the types of publications that have arisen from the domains to disseminate findings. This provides insight into differences between the two domains, to guide the output of this thesis. Although this research is looking to HCI for potential methods to use to involve children, it is still based within healthcare research and looks to develop healthcare technology. Therefore, as shown in **Table 2**, journal publications are the most common means of publishing related literature in the healthcare domain by a clear margin, which can be used to guide the placement of any research papers from this thesis.

Table 2 The distribution of publication types across the studies used in the taxonomy from both HCI and healthcare literature

HCI		**Healthcare**	
Publication	**Proportion (%)**	**Publication**	**Proportion (%)**
Journal	44	Journal	80
Conference Proceedings	40	Conference Proceedings	10
Book	13	Book	0
Other (e.g., Internet Site)	3	Other (e.g., Internet Site)	10

Two separate taxonomy charts were created, where one outlines the literature from HCI and one from healthcare. The taxonomy charts were designed as a way of expressing the different areas of research taking place within the two domains. Both HCI and healthcare revealed similar patterns in biases towards investigating methods for use when researching children and technology design. As shown in **Figure 3** and **Figure 4**, the individual nodes represent research papers that have been published in the area. In **Figure 3**, the long extension of nodes down the left side represents the research in HCI that has investigated methods. In **Figure 4** there is similarly an extension of nodes representing method research that has taken place in healthcare research. Aside from this bias, the taxonomy did not indicate that any other area within HCI or healthcare that had undergone any extensive investigation into technology design with children. The HCI taxonomy does show a cluster of papers that can be seen towards the centre of the branches that represent research papers investigating research practice with children in technology design (e.g., practice guidelines for designing with children).



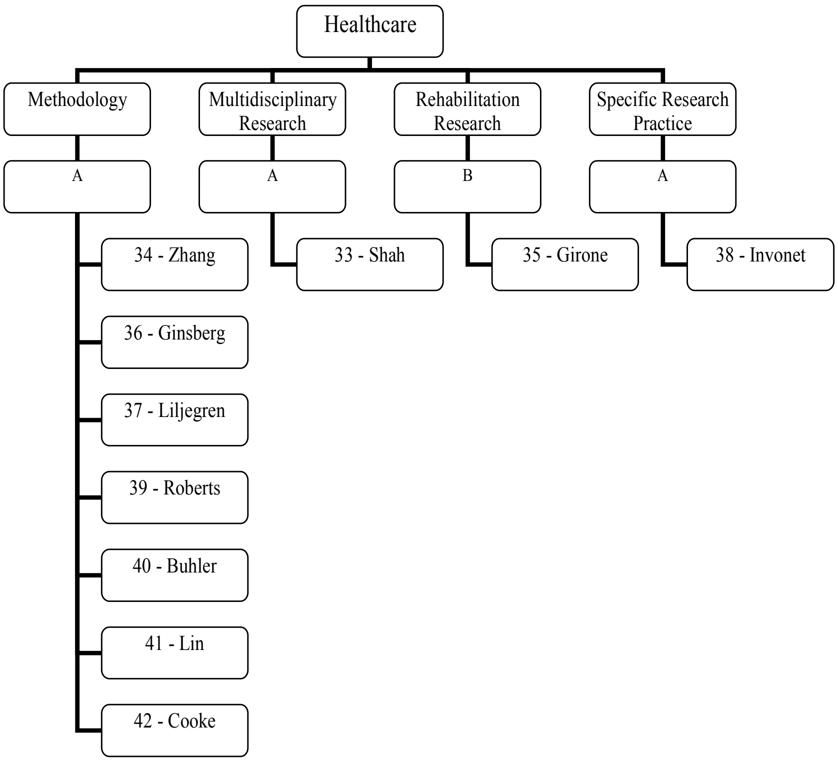
KEY: *Domain*: M = Methodology, SRP = Specific Research Practice, CPD = Computer Product Design, SD = Software Development; *Artefact Tested*: A = Research Practice, B = Methodology, C = Software, D = Literature, E = Theory, F = Opinions / beliefs, G = N / A; *Place of publication*: 1 = Journal articles, 2 = Conference proceedings, 3 = Book chapter, 4 = Internet paper

Figure 3 Taxonomy diagram for the research relating to HCI

The taxonomy suggests that from the research that was identified, HCI has produced a larger number of methods for involving children in technology design and development, although a few methods are already available and recommended for use within healthcare. The methods identified in the HCI taxonomy included a mix of established and novel methods for use in research. Firstly, a range of established design methods were noted (e.g., brainstorming on paper, participatory design and low-tech prototyping (Druin et al., 1997); high-tech prototyping (Scaife and Rogers, 1999); problem solving exercises (Druin and Fast, 2001); interviews (Bekker et al., 2003); group discussions (Guha et al., 2006)), alongside a range of less established design methods (e.g., card-sorting tasks (Hanna et al., 1999)). In addition to this, there were a range of observational methods used (e.g., contextual inquiry and technology immersion (Druin et al., 1999); behavioural observation (Donker and Reitsma, 2004); diary keeping (Markpoulos et al., 2005)) alongside a range of technology evaluation methods (e.g., talk-aloud (Barendregt et al., 2003); peer-tutoring (Höysniemi et al., 2003)).

The range of methods identified within the healthcare literature was less diverse than HCI literature, although there was a smaller sample of papers from the healthcare domain. Of the papers identified in healthcare, three papers involved children in the design of healthcare equipment (Roberts and Fels, 2006; Bühler, 2001; Cooke, 2004). Within these three papers, methods were identified for designing a children's hospital (i.e., questionnaires and focus groups (Cooke, 2004)), alongside technology evaluation methods for people with disabilities (i.e., usability testing and think-aloud protocol method (Roberts and Fels, 2006)). The remaining papers discussed practice in healthcare technology research and development, with one paper discussing a range of novel and established methods that can be applied at different stages of medical device development (i.e., Bühler (2001), who discusses novel methods such as the 'Wizard of Oz' method and more established methods such as interviews and focus groups).

Both domains are developing new methods for involving children, alongside using a range of existing methods (e.g., interviews and focus groups), but no comparative frameworks are currently being applied in either area. Within both healthcare and HCI, there was a strong research emphasis on method development and testing. However, very little research compared newly established methods beyond a single use.



KEY: *Artefact Tested*: A = Methodology, B = Hardware

Figure 4 Taxonomy diagram for the research relating to healthcare

Discussion of Taxonomy

The power of the taxonomy to examine differences between research practice in HCI and healthcare would have been improved with a metric of research quality. The current lack of a means of gauging quality within research in HCI limits the possibility of merging measures that exists in healthcare research. The difficulty in trying to establish a measure of quality would be in trying to account for the qualitative and descriptive methodology that is seen in HCI research with children and empirically-based research from healthcare; these patterns are seen in the structured literature review. Although methods used to improve metrics such as rigour are improving for qualitative research (e.g., Pope et al., 2000; Greenhalgh and Taylor, 1997) there is still concern that taking stringent measures from quantitative research and applying them to qualitative research may damage the values of the latter research philosophy. Research indicates that measures of qualitative research are increasing, with over 100 sets of proposals regarding quality in qualitative research having been identified (e.g., Dixon-Woods et al., 2007). Such research continues to investigate ways of synthesising both qualitative and quantitative research. The problem remains that several non-reconcilable issues remain in the amalgamation of qualitative and quantitative research.

Methods for involving children in technology design are present in both HCI and healthcare research, and were highlighted in the taxonomy diagrams. Methods were mostly identified and discussed within papers in the HCI literature amidst descriptions of novel methods for designing and evaluating technology with children, alongside being detailed in papers discussing the role of children in the design process. Only three papers discussed methods for designing healthcare equipment in the healthcare literature (i.e., Roberts and Fels, 2006; Bühler, 2001; Cooke, 2004). The remaining papers from the healthcare literature discuss the involvement of users in healthcare research more generally, alongside considering user involvement in healthcare research. This reveals that both areas share an interest to involve users, but apply separate approaches to achieving it. Although there are inherent differences and similarities between the two areas, it is important to consider what methods should be used that will be most appropriate for involving users of healthcare technology in its design and development.

Of the papers that were identified across both disciplines, very few involved children with disabilities. The papers that did involve children with disabilities were all drawn from healthcare research, and no papers provided methods or guidance for involving children in healthcare technology design and development. Given that the majority of end users of healthcare technology (particularly rehabilitation and assistive devices) have disabilities, it is crucial to consider ways in which to involve children with disabilities. This serves to indicate the youth of the research area and it is essential to establish means to carry out investigations from an early stage. It is vital that research in HCI and design literature begin to consider how to structure their literature base, so that application to other disciplines can occur more easily. Healthcare began using systematic reviews of evidence to overcome the deficiencies of subjectivity, selectivity and timeliness at a time when accuracy, transparency and digestible summaries to communicate information were in demand (Cullinan, 2005). HCI and design literature, although inherently multidisciplinary in nature, might benefit from the construction of a system that allows easier comparison across the discipline. Such an approach would also support accurate accounts of the state of HCI and design research, and begin to consider how to address the observed divides in approaches and methodology (e.g., Grudin, 2004).

2.5 Conclusions

This chapter has outlined the drive behind user involvement in healthcare for populations of children with and without disabilities. Further to this, it has outlined how methods from HCI could be used to supply methods currently required to involve children in healthcare technology design. Following a structured literature review, it was noted that more research is required to determine how to evaluate methods that might be suitable for involving children in this process. The literature has highlighted a need to involve users within the design process and existing research has failed to produce methods for designing with children that have undergone adequate validation. Given the uncertainty over the use of methods from HCI, and the difficulties in merging this discipline with healthcare, methodology used to investigate methods for involving children in healthcare technology design should occur with careful consideration and planning. When applying and comparing the methods it is important to take note of existing issues that can arise in healthcare research that have already been discussed earlier in the chapter. For example, the effect of personal and environmental factors has been highlighted as influencing the participation of children with disabilities in research (e.g., Rabiee et al., 2005). Given that the majority of end users of AT and RT have disabilities, such factors should be worked into investigations of methods for use in their design. In addition to this, research in the context of healthcare technology has established topics of interest, including the cost and time associated with involvement (e.g., Shah and Robinson, 2007; as outlined in **Chapter 1**). Therefore, these topics should be accommodated in any evaluation of methods for use in the area.

Grudin (2004) suggests that research within HCI currently contains two contrasting approaches; these are experimental work and observatory fieldwork. Although a framework that could potentially be expanded to compare and evaluate both types of research could be applied to methods exists (i.e., Markopoulos and Bekker, 2003), the framework has not been fully assessed or implemented. The use of this, or a newly developed framework to create order in the literature on methods might create a more straightforward means of assessing their use in healthcare. Markopoulos and Bekker (2003) highlight that the formation of their framework stemmed from a trend in HCI work to generate scientific and methodological knowledge about how to design interactive systems for children. However, since their paper, only a small number of theorists (e.g., Baauw and Markopoulos, 2004; Donker and Markopoulos, 2001) have begun to consider ways of comparing or analysing existing research methods, and there is currently a lack of validation in many of the existing methods (Mazzone, 2007). This has left the selection of methods for involving children in technology design in a state of disorder. Although there is no shortage of methods for child involvement in technology design research, there is a lack of accompanying philosophical and theoretical grounding. This is in part due to the creation of many methods for use in one-off projects with no further development (Mazzone, 2007). Consideration of the use or comparison of any methods from within this domain would benefit from the organisation that can be obtained through a structured assessment of the literature. Independent of whether or not this research begins to uncover factors of relevance to the use of methods in healthcare technology, an analysis of the literature within HCI is currently overdue. The disparity of novel method development and the existence of a range of competing approaches to child involvement could potentially fuel confusion and conflation in theory within the discipline. By beginning a structured approach to method comparisons that can be replicated in future research, there is an opportunity to begin to evaluate methods with which to assess new and emerging methods, as well as considering ways to evaluate those that already exist.

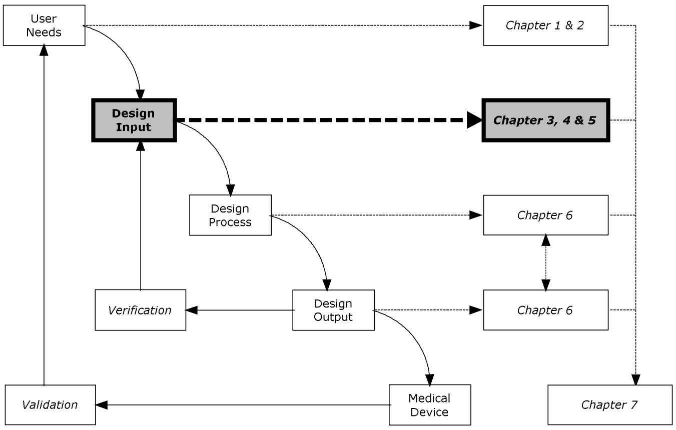
This research requires consideration of the involvement of children in the process of design within healthcare. Fallman (2003) highlights that the natural or social sciences do not typically hold an accurate or intricate understanding of design, nor do they provide insight into the role of design in research. This research has to consider the use of design within healthcare, typically built upon the natural sciences, although such practice is not directly related to user involvement. Therefore, the research is based upon a stance that sits between the robust, scientific approach to design, and one that focuses on creativity and individuality over methodology and control. The '*conservative*' approach (e.g., Alexander, 1964), where methodology and terminology are borrowed from the natural sciences have a philosophical base in rationalism. The focus on creativity is more in line with the '*romantic*' account where art is deemed a better role model for design than science (Coyne, 1999). This research adopts a '*pragmatic*' approach to design, that assists in the development of a framework method that accounts for both existing design research within HCI and allows for insight from healthcare. By approaching design research in this way it is hoped that future consideration of methods for involving children will be assisted by a framework that extends to account for variables within both domains. Given that HCI can be seen to be divided in distinct and contrasting approaches to research (Grudin, 2004), alongside the increasing adoption of qualitative research within healthcare (e.g., Pope and Mays, 2006), a pragmatic philosophy is deemed to provide the more secure foundation of future investigation in the area. In the adoption of a pragmatic approach, the research does not utilise stringent and rigorous experimental designs, nor does it opt for entirely qualitative research designs. With a high number of studies involving children and designing in HCI applying a flexible, case study approach, an entirely stringent and rigorous comparison would not be able to account for the more subtle observations drawn in such research. A structured approach is desirable to organise the literature discussed previously, but the use of more 'conservative' approaches currently appeals only to applications of HCI in areas of scientific or engineering endeavours (Fallman, 2003).

The largest focus of this investigation rests with the methods that are used to involve children in the design process. This research focuses on the involvement of children in healthcare technology design, alongside looking at means with which the different methods can be compared within the context of healthcare research. There is a need to consider how to compare methods that might be used with children in this process whilst accounting for the differences between the disciplines of HCI and healthcare. The research area of healthcare technology design with children is not mature, and in such areas an exploratory research approach is suggested (Morse and Field, 1995). This is suitable for exploring and reporting the factors that affect the ability of children to be involved in research (e.g., personal and environmental factors). For assessing the differences between the specific processes of the methods, a comparative design would be suitable. This would involve gathering an understanding of the relationship between two or more variables by documenting any observed similarities and differences between two or more groups. In comparative research the terms exploratory and outcome variables are often used instead of independent and dependent variables (Robson, 2002).

Checkland (1999) explicates the need to clarify differences between method and methodology and this is useful for research where the two terms may be conflated or confused. This helps to clarify the decisions to adopt a particular methodology. If a user is competent then it should be possible to relate the approach adopted, the specific method used, and the general framework that is the methodology. If these principles underlying the methodology are well thought out and clearly expressed, then it is thought that a repertoire of regularly used methods that are found to work will emerge over time as experience is gained. The methodology of this research is a comparison of existing design methods for use in healthcare technology design and development, whilst evaluating child involvement. The method applied in order to achieve this methodology involves a detailed analysis of methods within a comparative framework. Due to the literature that has been reviewed, and consideration of the implications of method comparisons, the choice to apply this method has been identified as being the most appropriate for this particular situation. In order to ensure that children are involved as users in the design of healthcare technology there is a need to establish the most appropriate ways of facilitating participation. If a means of comparing methods can be established, then the opportunity to assess the ability of a method to retrieve information following improvements can be achieved. **Chapter 3** outlines the methodology used to compare existing methods for use with children in healthcare technology development, whilst examining the involvement of children in the design of healthcare technology. As discussed in **Chapter 1**, the scope of the research is limited to exploring interview methods within the school context, which guides the development of the methodology in the next chapter.

Chapter 3

Methodology for Investigating the Involvement of Children in the Design of Healthcare Technology



The previous chapter outlined the relevant literature relating to the design of healthcare technology with children. The insight gathered from the literature was used to form the structured literature review and taxonomy diagrams. These were used to guide the choice of research topics and methods for use during this first phase of the research. This chapter firstly summarises the areas of investigation as established in **Chapter 2** and outlines the elements of each of these topics in **Section 3.1**. **Section 3.2** outlines the implications of adopting an exploratory research approach during this investigation. The protocol for the first phase of testing within this thesis, including an overview of the research visit procedure is outlined in **Section 3.3**, followed by **Section 3.4** that details how the data was collected and analysed at different stages of the research visits.

3.1 Topics of Interest in the Exploratory Investigation

The overall structure of the thesis contains two stages of investigation: an initial first stage to explore and observe the barriers to involvement of children in the design of healthcare technology, followed by a second stage that applies the experience and insight gathered from the first stage. The first stage, for which the methodology is described in this chapter, was focused on the identified gaps in the literature. **Chapter 1** and **Chapter 2** highlighted that research is required to i) investigate the involvement of children in the healthcare technology design process, ii) identify a means of comparing methods when involving children in the healthcare technology design process, and iii) evaluate the cost and value of the involvement of children within healthcare technology research. The second phase of the research, discussed in **Chapter 6** and **Chapter 7** adopted an applied research approach by considering the practicalities of involving children within the first exploratory phase.

The first stage of this research adopted an exploratory approach to investigate child involvement in healthcare technology design. This involved research visits to schools, where four interview methods were used to gather information from children. The methodology that was applied during the research visits was designed to gather information to inform the three gaps in the literature that are highlighted above. Three topics of interest were established that map onto the identified gaps, ensuring that each was investigated in detail. The three topics of interest included i) an examination of the personal and environmental factors that can influence child involvement in healthcare technology design, (discussed in **Section 3.1.1**), ii) the development of a framework to compare methods for involving children (discussed in **Section 3.1.2**), and iii) reporting the cost and value of child involvement (discussed in **Section 3.1.1**).

Figure 5 demonstrates how each of the research questions feed into the topics of interest within this first stage of research. The first, second and third research questions are outlined in this chapter, with the presentation of the results comprising **Chapter 4** and **Chapter 5**. The fourth research question, relating to how schools should be involved in research, is addressed in **Chapter 7** with the presentation of guidelines.

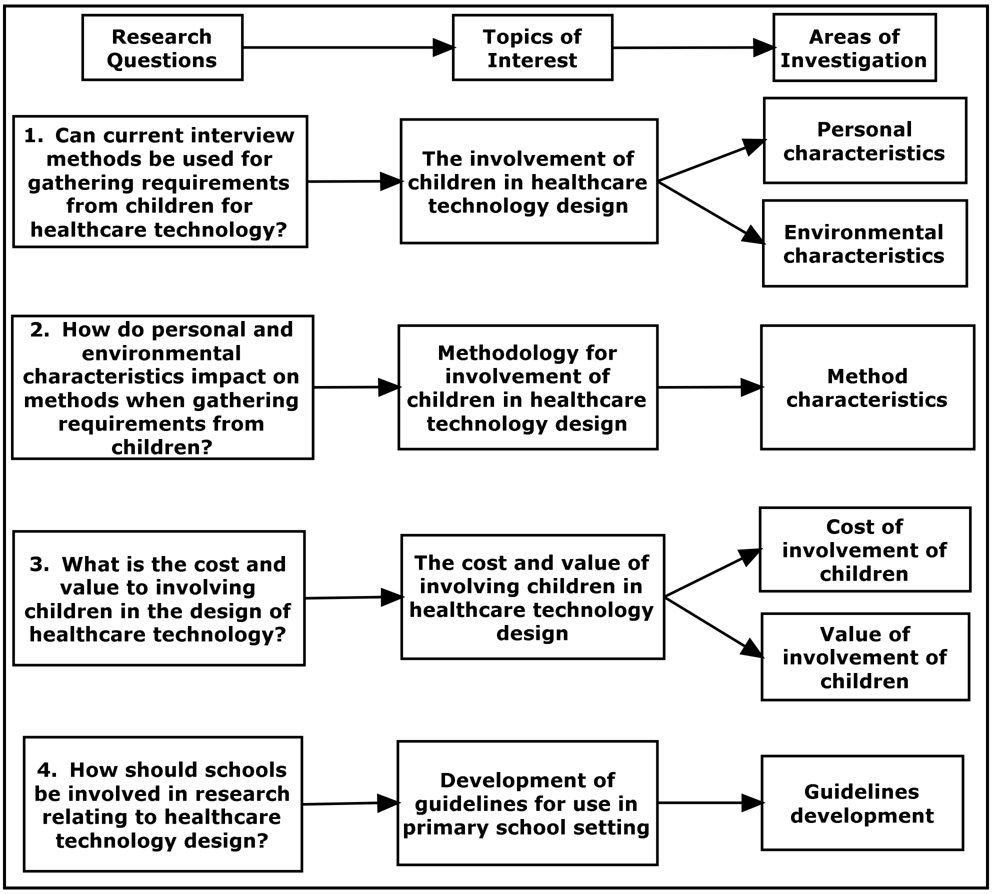


Figure 5 Topics of interest divided into areas of investigation

In outlining a research design, Burns and Grove (2005) highlight that a researcher should specify which research approaches are adopted in a project and how the researcher implemented controls to enhance the interpretability of the results. Therefore, for the first stage of the research, this chapter outlines the justification for adopting an exploratory research approach, followed by a detailed description of the measures and analysis that were applied. Before this, the topics of interest in the research are discussed. Such practice supports the assertion by Burns and Grove (2005) that a researcher’s work should be built on other people's, with the inclusion of a literature review ensuring that a researcher has critically analysed available literature on the topic.

3.1.1 Investigation into the Effects of Personal and Environmental Factors

Although the participation of children in healthcare research contains several areas in need of further research (Franklin and Sloper, 2005), this thesis limits its focus to topics previously identified in the literature. Alongside drawing on individual research papers of relevance, this research used the ICF (WHO, 2001) (see **Figure 6**) to guide the topics that are appropriate to investigate the involvement of children within the design of healthcare technology. The ICF was designed for use in social policy, research, education, and clinical practice and draws attention to factors surrounding activities that involve children with disabilities. Personal and environmental factors are highlighted in the ICF as having a major impact upon the participation of children with disabilities. Personal factors relate to individual characteristics of a person with a disability. These could include consideration of gender, age, coping styles, social background, education, and profession, for example. Environmental factors concentrate on the wider context, considering such factors as social attitudes, and legal and social structures. This research uses the two topics to focus the scope of the research. Although several personal and environmental factors might be identified that can influence the participation of children in the design of healthcare technology, only a small number are considered and examined in this research.

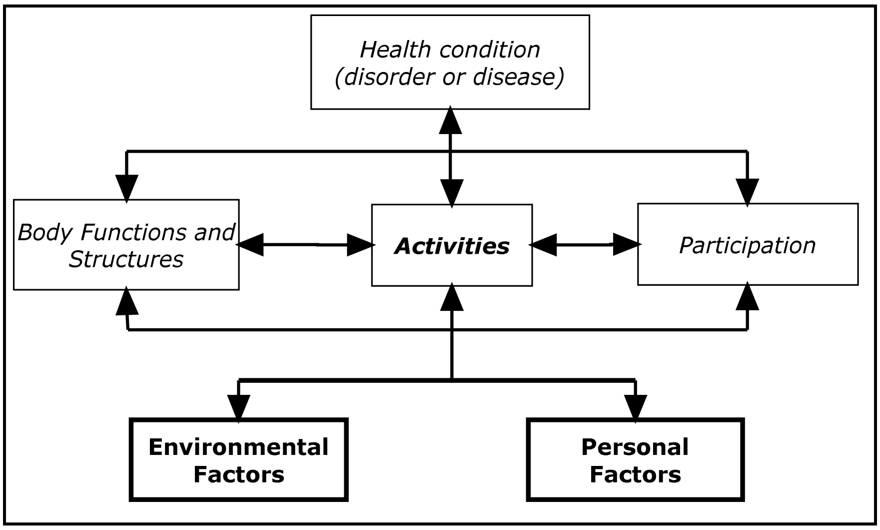


Figure 6 The International Classification of Functioning (ICF) (WHO, 2001)

The contextual factors of personal and environmental factors are sufficient to cover a preliminary investigation into an area that consists of children taking part in the design of healthcare technology. Factors that were used to examine the personal factors that may influence child involvement included age, gender and the experience of disability. In addition to this, verbal competency was included due to the reliance on language to involve children in the design process. The environmental factors that were examined included a focus on the school environment, the socio-economic status of a school, the role of carers within the school environment, and the role of teachers. Socio-economic status was included because of previous findings that highlight lower linguistic knowledge in children in low socioeconomic areas (Purcell-Gates et al., 1995) where an analysis of this factor could reveal differences between interview methods. The remaining components of the ICF were not examined to limit the scope of the investigation, although similar research in the future may consider incorporating more components from the framework.

Children with disabilities make up a large proportion of users of healthcare technology for children. However, as outlined in **Chapter 1**, there is little information available that describes child involvement in healthcare technology design research. This is particularly the case for the involvement of children with disabilities. Therefore, this research begins to explore child involvement in this process where disability is considered as a factor of importance. Although **Chapter 2** has begun to explicate the rationale to begin to look at child involvement during interview methods when informing healthcare technology design, there is a need to consider the topics of interest during such a process. Such considerations include how children with and without disabilities differ during participation, particularly in terms of the information that is gathered. Looking at the involvement of children in the design process was of interest in this research because of its capability to provide insight into the involvement of these populations when developing healthcare technology. The involvement of children without disabilities in this process has occurred briefly with AT (e.g., Light et al., 2007), but the involvement of children with disabilities has yet to be reported. By examining the effect of personal and environmental factors, the research question asking *how do personal and environmental characteristics influence methods when gathering requirements from children?* was addressed. When answering this question, the exploration of personal factors encompasses an examination of disability to begin to report on its influence on the participation of children in the design process.

3.1.2 Methodology for Involving Children in the Design Process

Chapter 2 indicated that interview methods would be used as a means of involving children in the research. Interview methods were used to narrow the scope of the methods that are to be investigated within the research. Their selection was based on existing research examples of their use in both HCI (e.g., Vermeeren et al., 2007) and healthcare (e.g., Kortesluoma et al., 2003), alongside the presence of guidelines for their use (e.g., Lewis and Porter, 2004). The interview method was also outlined as one of the most commonly used methods to involve adults in medical device development (Shah and Robinson, 2006), providing the opportunity to explore whether this could also be the case for children. A range of alternative methods exist that can be explored in future research, such as observations, task activities, questionnaires, brainstorming and prototyping (Nesset and Large, 2004). A range of these alternative methods are used within this research, although they are only used to gather additional data (e.g., questionnaires are used to gather post-task information from children after taking part in an interview method), and do not feature in the comparison of the interview methods.

In order to compare the four interview methods used within the research the Markopoulos and Bekker (2003) framework was used (**Figure 7**). This particular framework established a means with which to assess UTM's for children in the development of technology. The assessment criteria outlined in the framework presents a generic list of measures to use in a comparison of methods. This includes a focus on robustness, reliability, validity, thoroughness and efficiency. However, the use of the framework can be used to extend beyond the comparison of usability methods. For example, a number of the child characteristics were examined in the previous section when discussing the topics of interest covering personal and environmental characteristics. These included age, gender, and verbalisation. Although most of the UTM criteria were not applied to examine the interview methods, many of the characteristics were explored as a matter of good practice. For example, the role of the participants and evaluator are examined throughout. In addition to this, the procedure, tasks and methods for data capture are all explicated below.

Consideration is given to the inclusion of these factors in **Chapter 4** when a modified version of the framework is presented to account for research involving children in the design of healthcare technology in the primary school environment.

Figure 7 highlights the components of the framework that have been used during **Chapters 3 – 5**. The only category from the original framework to be used fully is the *assessment criteria*, and they are the components that guide the examination in this section. The component of *enjoyment* has been added to this criteria list, to explore how to measure such a construct with children in this research. By investigating methods for involving children, the research question that is addressed is, *how effective are current interview methods for gathering requirements from children?* One major concern is the lack of guidance on the most suitable methods to involve children in the design of healthcare technology. Several methods have been developed in HCI specifically for involving children in the design of technology that could potentially inform practice in healthcare, but such links have not currently been drawn together. An analysis of available methods is required to draw concrete conclusions about the use of particular methods in healthcare design processes with children. Markopoulos and Bekker (2003) note that the criteria highlighted in their framework can be applied to comparisons between methods generally, offering the opportunity to apply it within healthcare research. Although they highlight in their paper that the criteria list is not extensive, it is pointed out that it is satisfactory to form the basis of a comparison. Therefore, the framework provides a foundation for comparison, but equally allows for the tailoring of criteria and inclusion of specific topics for this investigation.

In order to clarify how the assessment criteria can be used within this research, the items listed in the framework are outlined, alongside discussing their relevance. These include:

Robustness

The robustness of a method refers to the feasibility of it being applied across different contexts, products, or domains. When focusing on child participants, robustness can refer to the effect of different ages, skills or capabilities and whether these make a method unsuitable for use with children. Robustness within the context of interview methods in this research can be measured by compiling observations regarding any age-specific issues that arise. This is accompanied by the identification of any participant traits that influence the ability of a method to gather data.

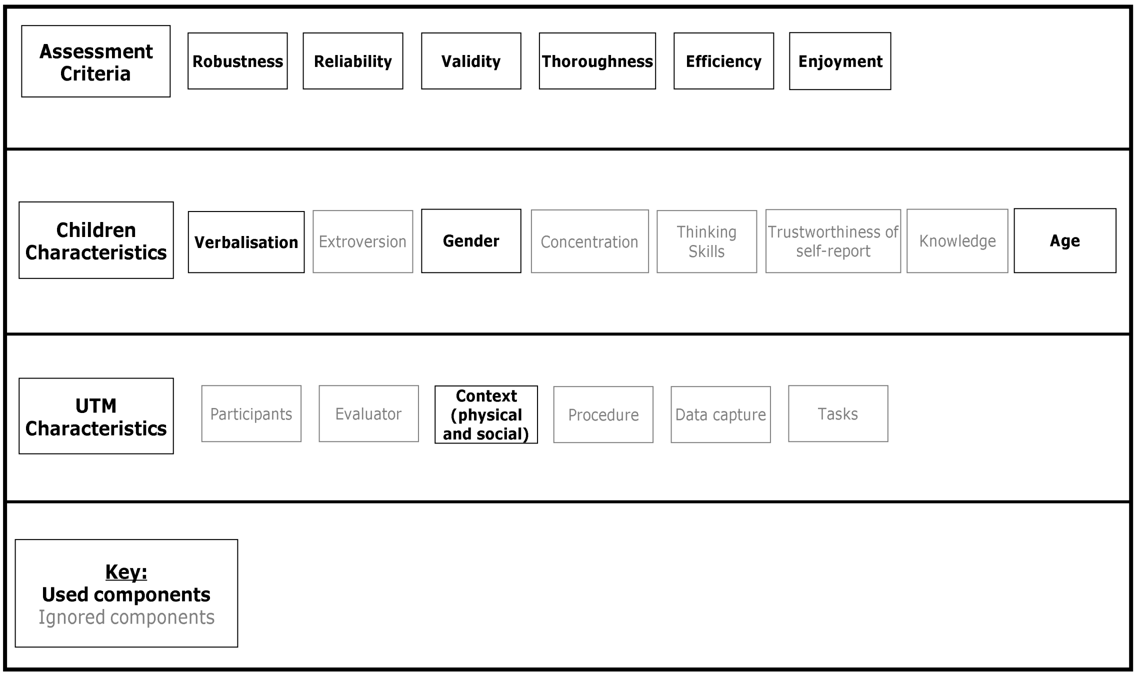


Figure 7 Framework for usability testing method assessment (Markopoulos and Bekker, 2003)

Reliability

This involves the examination of whether a method can extrapolate the same information from children in different conditions e.g., different settings, schools, and populations when the product remains the same. This may be affected by elements such as the participants or facilitators.

Validity

This involves the responses obtained through the interview methods that can be used in the design of healthcare technology. Validity refers to the ability of the methods to gather information that can be used by designers in the development of healthcare technology. This involves determining the type of information that methods can gather, alongside assessing the appropriateness of the information. The validity of obtained data can only be determined in the design process when it has been applied or evaluated with a product.

In this research, the information cannot be validated during the first phase of testing as this stage involves gathering information, not applying it. Therefore, to gather a preliminary understanding of the validity of the data, the information gathered during the first stage of the research was applied to develop rehabilitation joystick prototypes. The joystick prototypes were then evaluated by children who had not seen the joysticks before with the use of an internet application (described in **Chapter 7**) in the second phase of the research, which presented the prototypes as virtual prototypes.

The internet application also involved children who had participated in the first stage of the research during interviews. This involved using the internet application to present the same questions to children that they had responded to during the interviews. This examined the changes in children's responses over time, alongside considering the use of a different method to elicit responses.

Thoroughness

This involves an examination of the extent to which a method can obtain information about all aspects of a device being designed. The thoroughness of a method is largely determined by the questions that are posed, and given that the methods used within this phase used a mix of open- and closed-questions, the thoroughness can only be examined by looking at how well the methods allow children to respond to the questions. Although the questions posed by methods such as questionnaires can be more closed, the choice of interview methods to incorporate closed questions was to gather specific information from children.

Efficiency

The framework discusses the measure of efficiency as the number of resources used in relation to the outcome, an example being the number of responses gathered from a question per child participant by the cost to run the method. This research includes an analysis of the number of responses obtained per method, and the identification of the extent of response saturation for a range of questions as reported in **Chapter 5**.

Enjoyment

Enjoyment was not included in the original Markopoulos and Bekker (2003) framework, but it has been included in this analysis to investigate measures for gauging its presence in research where children complete design activities. Previous research that has involved designing with children has tried to establish a means of gauging children's enjoyment in research (e.g. Read et al., 2002), with enjoyment having been linked to engagement (Csikszentmihalyi, 1990). Although engagement has been highlighted as a difficult construct to measure (Airey et al., 2002), it is an important construct within design research with children (Macfarlane et al., 2005). Punch (2002) highlights that there are a number of reasons why adults develop child-friendly methods (e.g., adults assume children have shorter attention span, the nature of childhood means that children have less experience of being treated as equals by adults, children may be more competent at fun methods) but points out that it must not be assumed that all children are the same. The use of enjoyment has not been considered as a topic of interest within comparisons of research methods and it may be an important aspect of ensuring that children maintain concentration and contribute to an activity.

3.1.3 Cost and Value of Involvement

Investigating the cost and value of involvement fits into the research question, *what is the cost and value to involving children in the design of healthcare technology?* To date there has been no comprehensive reporting of the cost and value of involving children in the design of healthcare technology. Within **Chapter 2,** it was highlighted that the cost to involve children is one of the major causes of exclusion from user involvement in healthcare (Shah and Robinson, 2006). In addition to this, the practical issues of resources and dedicated funding reduces the participation of children (McNeish and Newman, 2002). Shah and Robinson (2006) highlight that there is a need to reduce the cost and time associated with user involvement with children. In order to modify or improve this process it is necessary to first identify the costs. The cost of materials and resources for use when involving children, alongside the amount of information that is obtained from the methods is reported.

The cost of involving children in research is necessary to deliver a concise description of involvement. This information is of particular value to researchers and practitioners in healthcare and industry. Healthcare often applies cost-effectiveness or cost-benefit analyses to gauge the effectiveness of interventions. Efficiency in healthcare relates to making choices to "…derive the maximum total benefit from the limited resources available" (Brown, 2005, pg. 314). This research explicates the costs of using the methods in the research visits, alongside commenting on the efficiency in terms of the Markopoulos and Bekker (2003) framework to assist with such decisions in the future.

The value of children's responses within this research involves the analysis of the content obtained from children, noting specifically how useful the information is to designers. In addition to this, enjoyment ratings from children and the benefits provided to the participating schools is highlighted.

3.1.4 Development of Primary School Guidelines

This topic of interest within the research addresses the research question, *How should schools be involved in research relating to healthcare technology design?* Although not directly measured, this section comprises an accumulation of the experience that was gathered during the research visits to the schools. During the process of approaching schools and running methods within them, observations and notes were taken about the successful ways to involve schools, and approaches that caused problems. All such findings, including those taken from the experimental work that is reported in **Chapters 3 – 5** are outlined in **Chapter 7** in the guidelines chapter.

3.2 Exploratory Research Approach

Two types of qualitative research have been distinguished by Kidder and Fine (1987); ‘big Q’, which involves open-ended, inductive research methodologies, and ‘little q’, referring to non-numerical data collection that is applied to a hypothetico-deductive research design. Although this research has based topics of interest on the literature, this research has not formed hypotheses, nor is it subscribing to a hypothetico-deductive methodology. Rather, this research uses a deductive research approach within the context of qualitative research. Although typically quantitative research works within the framework of deductive reasoning, with qualitative research employing inductive reasoning, it has been pointed out that a balance of both approaches to research is required (Parke, 1993). By subscribing to only inductive reasoning, research could limit access to theories and concepts that are relevant to the involvement of children in healthcare technology design (e.g., the need to build a literature base may inhibit the desire for researchers to try out more radical approaches to child involvement that may ultimately be insightful to practice). Similarly, in following only deductive reasoning, the development of new theory could be hampered (e.g., in not supporting the development of literature, guidelines and lessons are not developed and refined over time).

By introducing deductive reasoning into qualitative research, this thesis moves away from typical qualitative research that is applied in child technology development in HCI, where findings may remain untested, and establishes a more structured means to assure qualitative findings in healthcare technology design. The novel application of research to child involvement in healthcare technology development also calls for a definition of its focus, particularly given the time and resource constraints. As pointed out by Yin (1994), who discusses case study methodology, enquiries should begin with understanding of the proposition of the research, which should be tested by the findings of the research. In following this approach, the researcher is provided with the opportunity to enhance confidence in validity where propositions are confirmed by gathered data. Should propositions be disconfirmed, the opportunity exists to refine the theory. Adopting a structured approach to the investigation is also in response to the lack of validation that occurs in the development of methods in HCI (Mazzone, 2007). The need to structure investigations within design literature has been noted (i.e., Love, 2000; 2005), and the need to uphold transparent, rigorous methodology is important if the findings of this research are to hold up under scrutiny. Such scrutiny could arise from either researchers currently performing less controlled research, such as the examples of child technology development within HCI, or alternatively from healthcare researchers who demand higher levels of control and rigour in research.

This research, in following a deductive, qualitative approach, provides the opportunity to examine areas that have been highlighted as of interest from the literature. The examination of the factors is completed with four interview methods that are systematically compared through qualitative analyses. This research is provided with the opportunity to conclude findings from the initial, first phase of testing. The gathered data is then used to inform the second phase of the research. Any experience and data gathered relating to the causes of barriers to child involvement when investigating the methods can be used either to inform future practice or to guide modifications to the use of the methods in the future.

Although this research adopts a deductive approach to the preparation and planning of research visits, an exploratory stance is still maintained throughout the investigation. The aims of exploratory research include investigating little-understood situations, seeking new insights, asking questions and generating ideas and hypotheses for future research (Robson, 2002). This research has used previous literature to inform its current topics of interest, and aims to explore the involvement of children, with and without disabilities, in healthcare technology development and outline any barriers that currently exist. By describing this situation, the experiences gathered can be used to inform practitioners working in the area in the future, alongside guiding areas that require further investigation.

In exploratory research, variables outside the topics of interest might have an influence over the research and this could threaten the validity of the research. Random allocation of participants to groups is not possible in field research as is the case in this research, despite being comparative research. The threat of differential selection may influence findings if effects are caused by extraneous variables. In order to control against this threat, it is possible to match on variables that might be relevant (i.e. consider the impact of potential variables prior to the research) to ensure that they are monitored throughout and are actively observed. Within such comparative research, measures often consist of background variables such as ethnicity, which help to inform any differences that are revealed between the groups (Robson, 2002). Due to the lack of research into healthcare technology design the influence of topics of interest are not known, and the framework sweeps across a range of topics. By taking a structured approach to the examination of the topics of interest and their analysis, it is easier to outline how these topics impact on the involvement of children. Although initial exploratory research in the area might benefit from creating a research picture that is based on descriptive and exploratory methodology, the research would be lacking internal validity, particularly in relation to understanding any causal direction between topics of interest. Alternatively, a research project that is rigorously controlled may prevent a more in-depth exploration of the area. Given the need to gather insight into the use of methods with children in the design of healthcare technology, it is important to ensure that research maintains external validity whilst accounting for any measurements applied. Therefore, this preliminary research in the area ensured that it covered a range of related populations and settings.

Whilst considerations of validity are of importance to the value and trustworthiness that can be attributed to a fixed design, the importance of objectivity and credibility carry through into research applying a flexible design similar to this thesis. Objectivity must be instilled within the research methodology to ensure that values, interests and prejudices of the researcher do not interfere with the findings of the research. Therefore, the involvement of a range of researchers and their opinions can reduce such threats. The credibility of the research too, when considering its trustworthiness, requires attention. In order to increase credibility, researchers need to outline sufficient information about any methods used and the justification for their use. Therefore, **Section 3.3** and **Section 3.4** contain a detailed outline of the procedures and measures used during this stage of the research.

The approaches adopted within this research focus on gathering an understanding of methods available to assist with the participation of children in design research within healthcare. Such involvement of children in healthcare technology development is a novel exploration, and as such, although the overarching methodology of the research relies on exploratory values, the investigations at a lower level are detailed and structured. By applying structure in the analysis of methods, it will improve the reliability of findings for future researchers. Currently methods that have evolved from design research with technology in HCI have lacked formal validation (Mazzone et al., 2007); therefore, this approach aims to adopt a new means of exploring validation. Even methods that have been established within healthcare and used alongside children must be approached with caution, as their applicability in the context of healthcare technology design has not been examined. Although the research that has been discussed, such as contextual inquiry methods by Druin et al. (1999) and PD by Read et al. (2002) have been used with children previously, adequate consideration of measures that can be used to compare these methods has not taken place. Typically, research within HCI fails to include measures for comparative purposes; attempts to validate findings also occur infrequently (Mazzone, 2007). This research has chosen to adopt a structured approach to provide a clear and detailed description of the rationale behind using methods for technology design in healthcare technology, alongside providing examples of measures for HCI to utilise in future comparisons.

This section has outlined wider theoretical considerations that have informed the design of the data gathering with children during the design of healthcare technology. **Section 3.3** outlines the details of the procedure used to gather information from the children during the research process. Data was gathered to address the three topics of interest during research visits at primary schools, alongside trialling the use of four interview methods. This is followed by an outline of how data was retrieved and analysed from the visits described in **Section 3.4**.

3.3 Data Gathering Methods

Research concerning the involvement of children in the healthcare technology design process has not taken place previously; therefore, no guidelines exist on the suitability of environmental contexts in which to perform research. The school environment was chosen in this thesis because it provides access to a diverse sample of children in large groups. The school environment is a context that fosters learning, and is an ideal opportunity to explore the supply as well as retrieval of information (e.g., Hämeen-Anttila et al., 2006). In addition to this, the school environment accommodates any children with disabilities by supplying any required accessibility equipment listed on a child's statement of special educational needs (Disability Rights Commission, 2005). This ensures that children with and without disabilities can participate in the interview methods. Finally, by performing research in the school, and not in a laboratory setting, the children are accessed within an environment in which they are more familiar.

Read and Markopoulos (2008) highlight that HCI research with children has developed to explore a range of settings, including the home and school environments. Read and Markopoulos (2008) provide very brief details of research practice that should be undertaken when researching in the school although they offer no citations or examples of research carried out in the environment. The paper by Read and Markopoulos (2008) is included in Markopoulos et al. (2008a), where there is an increased emphasis on the value that can be attached to involving the teacher in the research if they are available. Typically, HCI research in the primary school setting is not well reported although examples do exist. Utilising the school environment characteristics has been noted in previous research in HCI when developing the Drawing Intervention method (Xu, 2007). The Drawing Intervention method involves children completing user testing tasks followed by a whole class drawing task. It is during the drawing task that children are approached for further questioning, as Xu (2007) observes that the children are more relaxed during such an activity. This may be because drawing activities can feature regularly in school activities for younger children. The difficulty is that this situation may be seen as exploitation of authority to gather responses; therefore, issues of power balances are discussed and considered at the end of this section.

Primary schools in the UK typically contain children from the ages of 5 – 11 years of age. Previous research by Druin et al. (1996) highlighted the influence of characteristics observed within certain age groups and how these might affect research involving usability tasks. Children of ‘preschool’ age (2 – 5 years old) are reported as having difficulty in expressing their likes and dislikes and often have difficulty following structured tasks. Their suitability for this research was deemed inappropriate. Children outlined as elementary school (6 – 10 years old) are highlighted as a more appropriate age group. The experience of these children within the school context ensures that the majority are capable of sitting down and completing a task from directions provided by an adult. In addition to this, Hanna et al. (1997) highlight how most children of this age are happy to be observed whilst completing tasks. Children’s ability to express themselves increases throughout the age groups and the latter end of the age spectrum will be likely to have a good understanding of technology. The shift from a reliance on peer approval and an increased independence from adults also occurs as a child increases in age (Markopoulos and Bekker, 2003). Although these guidelines referring to the ability of children to participate in research are linked to usability testing, the guidelines have been used to guide research in design (e.g., Large et al., 2003).

This research focuses on children aged 7 - 10 years of age, to promote the involvement of children that are capable of independence during testing, alongside increasing the likelihood that children will have been exposed to technology and have the ability to discuss surrounding issues relating to its use and context. Rather than controlling for age differences, the research gathers a preliminary insight into a specific age range. Once an initial understanding has been compiled regarding children aged 7 – 10 years of age, the involvement of the upper and lower age limits of primary school children can then be further investigated with a foundation of knowledge.

In terms of selecting the number of participants that should be involved in the research, the methodology of probabilitistic sampling theory can be used within most research, although its use in field research is perceived as being very difficult to achieve (e.g., Trotter and Schensul, 1998). This is further complicated when involving hard-to-reach or hidden populations. Although a large amount of qualitative research in healthcare relies on purposive sampling based on theoretical saturation guidelines (Guest et al., 2006), such recommendations are not available for this area of research. When attending the schools, it was known before the visits that children with disabilities would attend. Therefore, a variety of activities were included in the research visits to increase the likelihood of involving all children who were encountered in the research visits to schools.

As outlined in **Chapter 1**, the school environment is the chosen setting for this research. Participants were convenience sampled at mainstream primary schools from education authorities in Yorkshire, UK. Although convenience sampling can be criticised because its application is not random or typically representative, there are ways to improve its application. Gravetter and Forzano (2009) suggest that this can be improved by i) ensuring that a range of key features of the population are considered and are represented in the sample ii) providing a clear description of the participants and their selection iii) ensuring quota sampling is applied to the allocation of children to groups. In terms of recruiting children for this research, the age of year groups requested to be involved in schools was considered alongside the number of children at the school and the socio-economic status of the pupils being reported. When testing methods within the visits, allocation to groups was based on quota sampling to strengthen the recruitment of schools to ensure that the eventual comparisons contained a representative number of both boys and girls in the completion of the methods.

Christensen (2004) highlights issues for consideration when completing research with children that have a direct bearing on the methods that are applied within this research. The role of power is central to discussions about interactions with children. The role of 'adult' can be used to engage children through the use of authority, particularly within the school setting. This can have a direct impact upon the validity of the responses that children provide to the researchers. Christensen (2004) points out that the vulnerability of research lies in the people who take part. It is the notion of trust placed on an individual that might directly affect the responses and insight provided by children. To minimise the effect of power on the responses gathered from the children, the facilitators were always researchers who had experience and knowledge of research with children. Although they had a list of questions outlined, there was freedom for the researcher to act in a manner deemed appropriate to ensure that children were relaxed and aware that they were not answering to a direct figure of authority.

Open-ended questions are more suited to interviews within this research because they are flexible and encourage co-operation and rapport (Robson, 2002). This assisted with building trust and allowed the researcher to address issues with power as outlined above. Robson (2002) warns that a danger of using open-ended questions is the possibility that the interviewer might not maintain control within the interview, and the analysis will be more time consuming when compared to alternatives of closed-questions or scale items. Although open-ended questions are used, the question list was fixed so that children can participate and respond as they desire, but the directions of the questioning remains focused.

The research activities that were completed at each school during the first phase of the research followed a standardised structure. As shown in **Figure 8**, the procedure in the schools began with a group presentation and discussion by the teachers and researchers that involved talking about topics related to healthcare technology, such as disability and rehabilitation (**Section 3.3.1**). Following this, there was a group activity (**Section 3.2.2**) that involved the creation of designs of rehabilitation equipment by the child participants. This activity provided a means with which to incorporate the research into the framework of teaching and learning for the schools, outlined in the National Curriculum (NC), by aligning group activities into the existing Design and Technology curriculum. The main components of the NC covered in the group task were i) developing, planning and communicating ideas, and ii) knowledge and understanding of materials and components. This allowed the children to begin to explore their own preferences for healthcare technology before participating in an interview method where the children would be expected to provide preferences and opinions on healthcare technology. The group task was used as a means of acquiring further information from the children whilst simultaneously acting as a priming activity for involvement in the interview methods. Once the group task had begun, children were taken from the classroom to an assigned quieter area to take part in interview methods individually or in groups (**Section 3.2.3**). Following participation within an interview method, children were asked to complete a post-task questionnaire (**Section 3.2.4**). The children then returned to the classroom to continue their involvement in the group task.

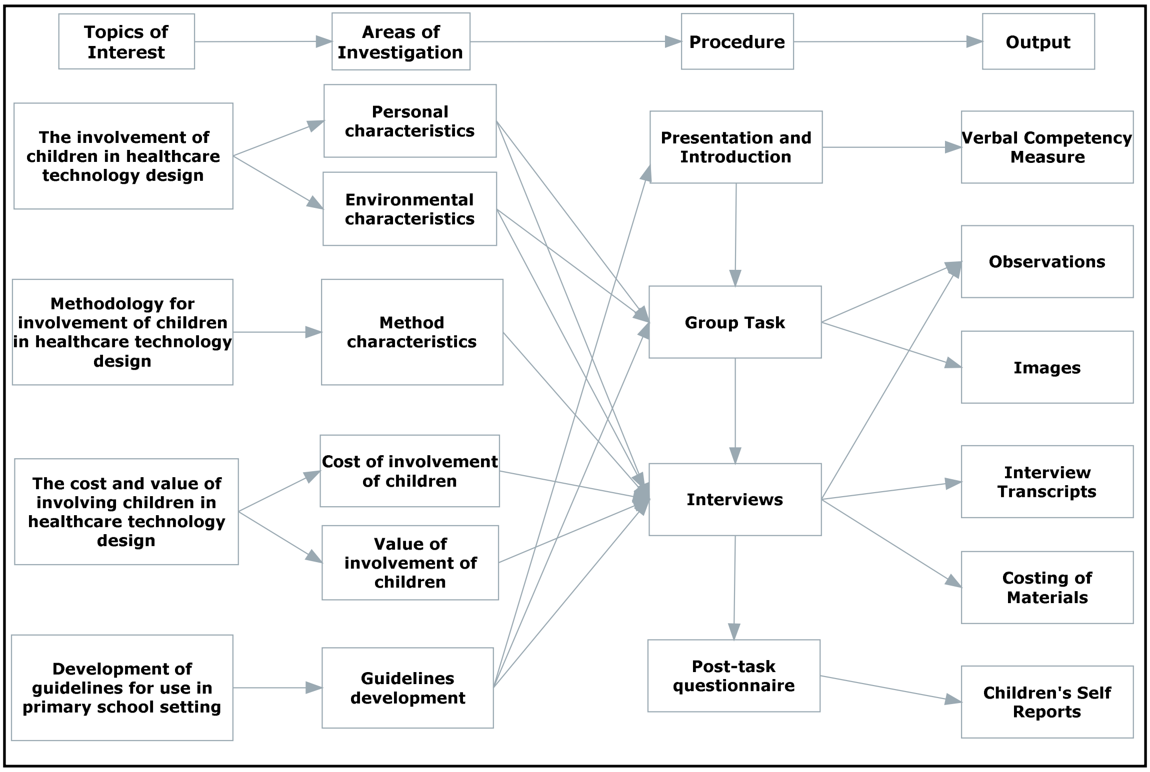


Figure 8 Overview of activities in research visits within the primary school and the output from the difference stages

3.3.1 Group Presentation and Discussion

The tasks that were completed by the children during the research visits contained discussions and reflection on disability, rehabilitation and healthcare technology. Therefore, the research team visited the schools prior to any activities taking place. Meetings with teachers were held to discuss the pupils in attendance, and to arrange tasks with their class about disability and rehabilitation before the day assigned to research activities. Teachers were asked to include the following two components into the introduction; i) provide a background to healthcare technology and describe how this can assist people with disabilities who require rehabilitation, and ii) hold interactive question and answer sessions with children about disability. By outlining the preferred content of the talks, it was ensured that all children received similar information before the visits that were delivered in a manner deemed most suitable by the class teacher.

The group presentation and discussion was an integral aspect of the research. This provided an opportunity to set the scene for the children about the research activities. An outline of the research visit was provided, ensuring that the children were informed about the content and purpose of the activities. When conducting research with children, any effects of infantilising or perceiving and treating them as immature serves to reinforce ideas of children as incompetent (Alderson, 2008). Alderson et al. (2006) point out that when views are collected from young children about topics such as long-term illness or disability, particularly for those who have a lot of experience with the conditions, they are seen to contain a greater moral understanding and responsibility that is typically thought possible at a young age. However, there has to be a balance regarding the amount of information that is relayed to the children, as being overcomplicated with topics such as disability and rehabilitation, and not explaining the concepts clearly can result in an outcome that is misleading and portrays children as ignorant or incapable (O'Kane, 2008). This outcome can arise because of the inability of the researcher to gauge the appropriateness of information that is presented, not the abilities of the children. Therefore, the group presentation and discussion provided the ideal opportunity to discuss concepts with the children, and answer any questions that they might have to ensure that they are ready for questioning within the interview methods and ensure that they were informed about the purpose of the research.

3.3.2 Group Task

The group task took place directly after the presentation and discussion. A class was shown one of two rehabilitation devices; a rehabilitation joystick or a handwriting device (see **Appendix 2** for detailed descriptions of the devices). These devices were used due to availability and were part of ongoing research projects at the University of Leeds. Both devices had accompanying software so that device could be attached to a computer and their operation could be demonstrated. Such a demonstration was provided to each class, followed by the opportunity for all class members to have a close look at the materials and design used to make the device. All children were encouraged to watch the device in operation, and if they wanted to, had the opportunity to touch and move the device once the demonstration had been completed. The demonstration was provided to the children to ensure that they were all aware of what a joystick or handwriting device is, and particularly how it can be used in rehabilitation.

The group task was based on the device shown to the children. The children, having gathered insight into the current use and properties of a rehabilitation device, were asked to create their own design by incorporating their preferred colours, shapes, materials and features into an image. During this activity, observations were made regarding the completion of the task by children. Props were provided in order to help children develop their ideas during the group task. The props included a range of stimuli, including colour charts and texture samples. The texture samples were 3″ x 3″ patches of aluminium, brass, plastic, cotton, rubber, sponge and sandpaper. Cremeens et al. (2006) has shown that props are not frequently used as a means of presenting information when gathering self-report information from children in healthcare research. However, their use can improve the reliability of responses provided by children and can be useful for improving their understanding of an item, alongside maintaining engagement. The props also ensure that all children are aware of the look and feel of each material rather than relying on recall of previous experiences.

The aim of the group activity was to provide children with an introduction into RT and to begin thinking about their preferences for technology. Whilst the children were taking part in the group task, the classroom teacher completed a subjective rating form that indicated each child's verbal competence level. The criterion for the verbal competency measure contained categories that are used in the verbal comprehension subset section of the Wechsler Intelligence Scale for Children (WISC, 4th edition) (Wechsler, 2003) (see **Appendix 3**). These measures of verbal competence were important when working with groups of children as it provided a basis on which to build groups for the interview methods. The verbal competence ratings also indicated children within the class that might require additional support when participating in the interviews.

3.3.3 Participation in Interviews Methods

Once the children had received a demonstration of the rehabilitation equipment, and the group task was underway, children were taken from their class group to participate in interview methods that involved either individual participation, or groups of four children. The interview methods that were used to examine methods for involving children in healthcare technology design included two traditional interview methods, a PD approach, and a novel method. The two traditional interview methods consisted of a one-to-one interview and a focus group. The PD method used the creation of a low-tech prototype to focus questioning and was called a design-led interview (DLI). The novel method was initially used to involve service users within a healthcare environment and was a board game method. Given the variation in methods constantly being developed within HCI, the choice to include the interview and focus group in this research was to ensure that well-established methods were capable of being analysed with the Markopoulos and Bekker (2003) framework to strengthen findings relating to less conventional methods. Additionally, both interviews and focus groups have been highlighted as commonly used methods to gather information from users within medical device development (e.g., Shah and Robinson, 2006). The methods have been highlighted as valuable tools for eliciting children's views and experiences (Detmar et al., 2006). Therefore, their inclusion in the comparison is with a means to assess and verify their use in healthcare technology design.

The board game method (Lamey and Bristow, 2007) was a novel design method used with adult users of a mental healthcare low secure unit. The inclusion of this method assessed its use in obtaining information from a child population, alongside examining the ability of the framework to assess novel methods. In addition to this, a new method was used to consider HCI-based approaches, such as PD. The DLI, in focusing the attention of the child participant on the development of a low-tech prototype increases the focus of the child participant in the interview. Most importantly, the inclusion of this method assesses the capability of the framework to assess methods that contain design tasks and are similar to methods used in HCI design research.

The focus group and board game method both required the participation of four children alongside a facilitator, whereas the interview and the DLI were conducted with an individual child and a facilitator. A detailed outline of the process required for each of these methods can be found in **Appendix 4**. These four methods satisfied the inclusion of interview methods as outlined in **Chapter 1** to reduce the scope of the research.

To begin the group task, children were taken out of their class in groups of four or individually to participate in one of the four methods. Each method used the same set of open-ended questions, and the list and information about their construction can be found in **Appendix 5**. The topics of interest for the questions included social and practical acceptability, materials, disability and healthcare equipment use. When reviewing the content from the questions the aim is to establish which aspects of this information can be retrieved from children during interview methods.

Each method ran for twenty minutes, or until all of the questions had been asked, and the groups comprised only same-sex children. In addition to this, researchers tried to use similar environments for interviewing across schools. Ethical consent from parents was obtained prior to the school visits (see **Appendix 6**) and children signed assent forms at the beginning of visits before taking part (see **Appendix 7**). A standardised set of instructions was read aloud to the children before questioning started (see **Appendix 8**) and it was further reinforced to the children that they were not obliged to answer any question unless they were willing. Each method that was performed with the children was facilitated by an adult researcher and audio recorded for later transcription.

To ensure the inclusion of the majority of children within the research, a separate method was available for children presenting severe physical or communicative impairments. In the examination of child involvement in healthcare technology design, it is essential to gather an understanding of methods that can be used with children displaying impairment. Although children's involvement in the development of AT has been considered in previous research (Light et al., 2007), the involvement of children with severe physical or communicative disabilities has been reported far less regarding the design of healthcare technology. For example, Light et al. (2007) asked children without disabilities to design devices for children with communication impairments. However, the methods used in this research involved asking questions to children with communication impairments and presented examples of communication devices to the children to get their feedback on the designs. Although typically the methods would adapt to the children being questioned, attempts were made to have a range of equipment available to make the interviews accessible. A face scale (further described in **Section 3.3.4**) was available during these methods but numbers were incorporated beneath the faces to make responses easier for the children who communicated via speech generating devices (see **Figure 9**). Instead of pointing to the relevant image, the children could indicate their choice by referring to the number beneath the image.

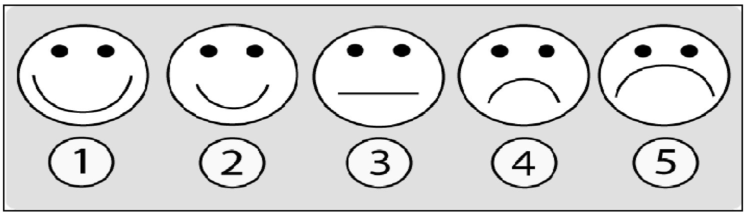


Figure 9 The face scale used in the interviews for children with communicative or physical disabilities

The focus of the questioning was not the joystick or handwriting device as these devices were not appropriate for the children. The joystick was designed to assist children with CP perform upper limb exercises, and the handwriting device was for use by children with co-ordination and handwriting impairments. Therefore, a communication fixture device for child electronic wheelchair users with moderate to severe communication impairments was used (see **Appendix 2** for a more detailed description). For these visits, reduced numbers of measures were taken with the children (e.g., verbal competency ratings were omitted). Only observations about the involvement of these children were taken by the researcher and are described in **Section 4.3.4** to add further insight into the involvement of children with disabilities in interview methods, but are not incorporated into the analysis for the remainder of the participants.

3.3.4 Post-task Questionnaire

After each child had completed their participation in one of the four interview methods they were asked to complete a post-task questionnaire (see **Appendix 9** for a copy of the post-task questionnaire). A researcher separate to that of the method facilitator was on hand to go through the questionnaire with a child if they required assistance. The post-task questionnaire addressed i) demographic information about children (including age and gender), ii) children's self-report rating of enjoyment during the visits, iii) any difficulties experienced during the visits, iv) children's understanding of rehabilitation after the research, and v) the extent of each child's experience of disability. These topics were presented as open-ended questions with space for the children to respond in the questionnaire.

A child's self-report of their enjoyment within the design tasks and the interview sessions was gauged using a face scale based on the Likert scale (see **Figure 10**). The use of a face scale to measure children's enjoyment in design activities has been performed in forms such as the 'Smileyometer' in technology design research with children by Read et al. (2002). The face scale used in this research is an adaptation from of a scale initially developed to measure pain in children (Wong and Baker, 1988).

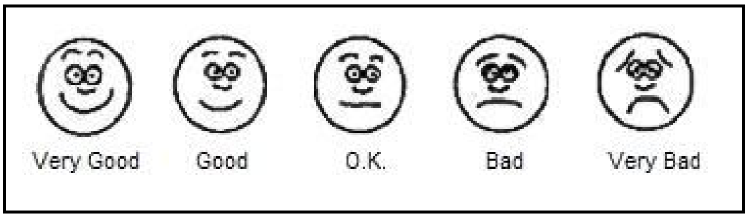


Figure 10 The face scale used as a self-report measure of enjoyment in children

It was ensured that the scale comprised a balanced series of faces and did not contain emotive words. Previous research using the smileyometer (Read et al., 2002) highlighted a bias towards children selecting the highest possible rating, but such findings may have been linked to the balancing of the faces (**see Figure 11**). The smileyometer inverts the smile used on the face of the 'awful' item (the lowest rating) for the 'really good' item (not the top rating), with the inclusion of the 'brilliant' rating biasing the scale towards more positive ratings. The smileyometer remains in this form despite literature highlighting positive response biases in research with younger children (Fritzley and Lee, 2003), and early investigations of the use of the smileyometer revealing a tendency for children to select the 'brilliant' item (Read and Macfarlane, 2008). The use of words such as 'awful' for ratings also creates an emotive element to the scale. The smileyometer has not been validated; although this would be difficult to achieve in practice, particularly given that the concept being measured has not been clearly defined. Although the face scale used in this research was originally used to measure pain, the images of faces used in the scale are balanced in terms of the shapes of the mouths, with the central image 'o.k.' having a neutral face. It is not known how well these faces map on to children's experiences of enjoyment. The development of face scales for use with children in design research is an area requiring future investigation by researchers requiring ratings of enjoyment.

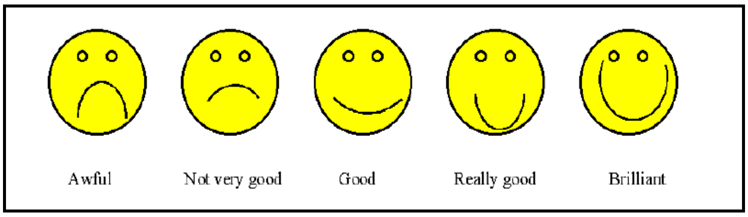


Figure 11 The 'Smileyometer' as devised by Read et al. (2002)

Following the completion of the research visits, teachers were asked to participate in semi-structured interviews that enquired about their experience in the process. An email equivalent of the interview was available for teachers who preferred to answer the questions at a different time. The questions enquired about information relating to teacher's perspectives of the involvement of children in the research, suggestions for improvements that can be made to the visits in the future, and recommendations relating to best practice for involving teachers in research.

The next section outlines how information that was obtained from the visits relates to the research questions, and how the data was both collected and analysed. **Chapter 4** and **Chapter 5** then present the results from the analysis and the findings from the gathered data.

3.4 Methods for Data Analysis

This section outlines the methods used to collect the data during the research visits in the schools. This section also documents the methods that were used to analyse the gathered data. **Figure 12** shows the output that was generated at each stage of the visits, and how this output was fed into an analysis. Each of the subsections within this section outline how the output from the methods was transformed to feed into the analysis as presented in **Chapter 4** and **Chapter 5**.

3.4.1 Verbal Competency Measure

The verbal competency ratings were gathered from categories used in the verbal comprehension subset section of the Wechsler Intelligence Scale for Children (WISC, 4th edition) (Wechsler, 2003). The measure was used to ensure that children of all language capabilities were spread amongst the interview groups, and to identify any children that may need additional support during the interviews. The data was tabulated and correlations with a range of variables were examined to contribute to the exploration of personal characteristics.

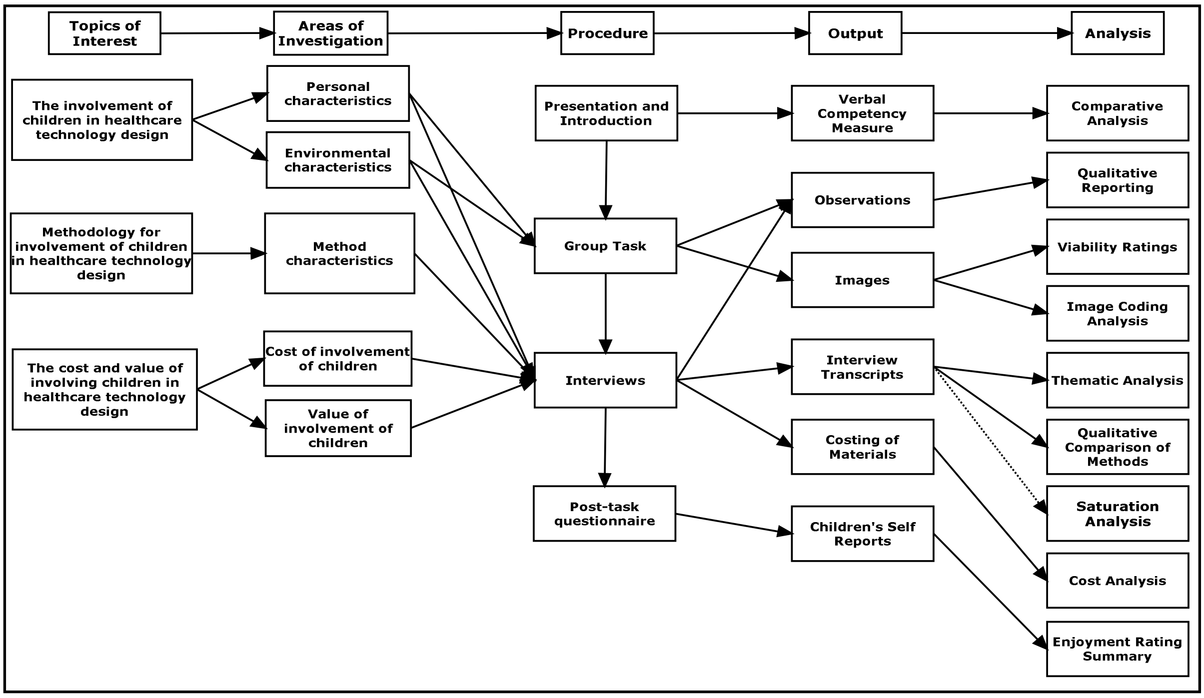


Figure 12 Outline of the output from the research visits and how the information will be analysed

3.4.2 Qualitative Reporting on the Markopoulos and Bekker Framework

Qualitative reporting of the Markopoulos and Bekker (2003) framework occurred by documenting the qualitative observations in line with the aspects of the framework discussed in **Section 3.1.2**. Observations were gathered from the reports of the researchers who attended the visits. The researchers were briefed on the topics of interest to observe, but any other observations were welcomed. For thoroughness, detailing the amount of information that can be gathered by a method involved looking at the saturation levels of responses from questions, although this is discussed in the examination of cost. Reliability was identified by comparing the types of responses gathered for the same question across different methods. The efficiency of responses was examined by noting the number of responses across questions dependent on the number of children taking part. The thoroughness of methods was based on previous coding regarding the ability of the methods to gather responses independent of the context and device being used. The validity of methods is discussed with reference to observations about the research setup, but this is further explored in **Chapter 6** when the internet site is outlined that feeds back information to children.

3.4.3 Images

The images that were obtained from the group tasks were predominantly pen and pencil drawings. These were collected from each class upon completion of the group task.

All images were then used to feed into an assessment completed by engineers regarding the viability of using the information from the diagrams in the design process of healthcare technology, and to code and identify any trends in features used by the children in the creation of their designs. Both forms of analysis are detailed in more depth below.

Viability Ratings

Scaife and Rogers (1999) point out that the goal of involving children in design tasks such as the DLI is not to recover final designs for the marketplace, as many ideas generated by children are reported to be unworkable. To investigate this point, the viability of the designs was examined through evaluations performed by two engineers. One engineer was a professional rehabilitation engineer and the second was an experienced engineer working at the University of Leeds. Each image of a design created by the children was rated on i) the plausibility of a child's design for use in rehabilitation, and ii) the clarity of the information as presented in the design. The ratings for the viability of a diagram were outlined on a scale of 1 (not viable) through to 5 (very viable) and the clarity of information was rated from 1 (very unclear) through to 5 (very clear).

Expert opinion in this sense gives an understanding of the content of obtained information that expresses functional consideration by the children. Confines exist at the earlier stages of the design process when applying low-tech prototypes such as pencil drawings. Children's ability to draw, conceptualise and express themselves is a clear determinant of the information that can be obtained via such methods.

Coding Analysis

The coding analysis involved the development of a coding structure to identify themes that emerged in the drawings provided by children in the group task. The main structure to guide the analysis was developed by deciding on the main features that were observed with a varied selection of the images. Having developed the main structure of topics, the subsections emerged. For example, when the use of colour was identified as a topic of interest, the subsections would list the colours used by the children and how frequently these occurred. Once all of the features of the images had been collated, this would make the differences in the use of particular features in the design of RT more apparent. This also adds structure to the analysis of a range of diverse and different images.

3.4.4 Interview Transcripts

There was a need to adopt a systematic approach to the analysis of data due to the large amount of information that was available following the transcription of audio data from the interviews. The transcripts were coded in a similar manner to the images, by identifying themes and responses from the children. A large amount of this information was placed into tables to display the summaries of coded information. This information was used in **Chapter 6** by designers in the production of virtual prototypes for the internet site.

For a more detailed analysis of the information gathered from the interviews, a robust systematic approach was required to deal with the large amount of information. Guidelines described by Bryman and Burgess (1994) on the analysis of qualitative data were used to structure the analysis. The early thematic structure of themes was led by the questions that were structured and fixed throughout questioning. As the analysis took place, themes emerged from the responses gathered from the different topics, along with sub-themes. Once a thematic structure had emerged, these were cross-referenced with other transcripts to ensure that the framework was grounded within the data. To ensure that the framework was sound, it was trialled against a small number of transcripts, before being used as a guide to the analysis of the remaining transcripts. The results are reported by firstly outlining the framework that was identified, and then supplementing the discussion of the themes and sub-themes with supporting quotations from the transcripts.

3.4.5 Observations: Qualitative Reporting

Observations were performed throughout all research visits. In addition to observations made by the primary author, further observations were gathered from the research team. This information was shared in research meetings that occurred directly after the visits to schools. Observations were documented regarding the effect of disability on a child's ability to participate, components from the Markopoulos and Bekker (2003) framework when the methods were taking place (discussed in **Section 3.4.2**), the involvement of carers for children with disabilities, how the physical environment and the teacher affected participation, and the identification of points at which children required support. These observations are reported qualitatively within the relevant sections in **Chapter 4** and **Chapter 5**.

A metric for socio-economic status was not gathered during the research visits. These were established for each school by acquiring information about the number of children in attendance at each school that were registered as eligible to receive free school meals (FSM). Although this is a general metric, it provides a proxy measure with which to evaluate the socio-economic status of the schools. The metric is frequently used throughout government research, although its use has been questioned recently (Hobbs and Vignoles, 2009). The measure is used as an exploratory measure and patterns that emerge in analysis are only used to examine any differences within the findings of this thesis. The information for the FSM statistics was acquired by contacting the education department within the local government and requesting the information under the Freedom of Information Act (2000).

3.4.6 Costing of Materials and Resources

The cost of resources was calculated for the materials used within each of the interview methods. This was calculated based on costs incurred within this research project. In addition to this, information regarding the time taken to complete the methods was examined. Although each method had a twenty-minute time limit, it was noted whether all questions on the list were covered within the method in this time. In addition to this, the number of responses gathered by each method was considered. The saturation of responses was also examined. Saturation in this context refers to the number of times a question needs to be asked to acquire all responses that are likely to be gathered from a population. Using such an approach to estimate the number of participants required within the research feeds into approaches currently adopted to guide sampling within healthcare (Guest et al., 2006) and usability research in HCI (e.g., Nielsen, 1993; Faulkner, 2003).

3.4.7 Post-task Questionnaire Analysis

The post-task questionnaire allowed for evaluation of the value of the methods. Of particular interest in this research was the value of the methods to both the children and their education. The post-task questionnaire identified the value of the methods to the children by gauging their enjoyment levels. The educational value was assessed by evaluating the understanding of disability reported by the children at the end of visits, and identifying aspects of the visits that the children enjoyed and disliked overall.

3.4.8 Summary of Analyses

Although there was a range of data gathered, there were three main topics of interest; the analysis of child involvement within healthcare technology design (containing an analysis of the personal and environmental characteristics of children), a comparison of methodology, and an analysis of the cost and value to the involvement of children. These topics begin to identify the process involved in designing healthcare equipment with children. Any further areas of investigation that are highlighted as necessary from the results presented in **Chapter 4** and **Chapter 5** are recommended, or further explored in the later chapters of this thesis.

3.5 Summary

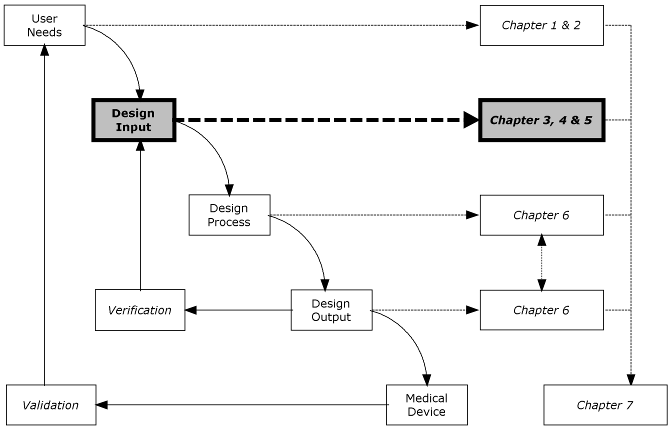
This chapter outlines the methodology that was used in the first stage of research during an investigation into the involvement of children in the design of healthcare technology. This first stage involves an exploration of factors affecting the involvement of children. This information can inform later research within the thesis that adopts an applied approach by considering the practicalities of the experience gained, and applying this to improve the situation. In this research, the second phase will continue the development of methods for involving children in healthcare technology design.

This first stage of the research applies an exploratory, deductive approach. Deductive reasoning is not typical in qualitative research, but research has occurred around the base of much of the literature used to inform this research. By involving children in healthcare technology development, literature on child research, HCI, healthcare and research methods must be accounted for. A deductive, qualitative approach provides a structured means to assure qualitative findings in healthcare technology design. This approach also provides researchers with the opportunity to enhance confidence in findings where propositions are confirmed by gathered data. Where findings are not clear, or have been disconfirmed, the opportunity exists to refine the theory in the later phases of the research, or in future investigations beyond the scope of this thesis.

Chapter 3 has outlined the procedure used to involve children in the first stage of exploratory research, and has outlined how the acquired data was gathered and analysed. Following this, **Chapter 4** and **Chapter 5** report the results of the analysis from the visits described above and begin to outline the involvement of children in the design of healthcare technology. The division of the reporting of the results across the two chapters was performed according to the topics of investigation within the research. The topics relating to the process of the research are outlined within **Chapter 4**. This includes the effects of personal and environmental factors, alongside considerations of disability, and the results that were generated for the method comparison using the Markopoulos and Bekker (2003) framework. **Chapter 5** reports on the cost and value of child involvement, and the content gathered during the research visits. This includes an analysis of both the images and transcripts from the research visits.

Chapter 4

Barriers to Involving Children: Process



This chapter presents the first half of the findings from the research visits to primary schools. **Section 4.1** begins the chapter by providing an overview of those who participated in the research visits; this includes the child participants, researchers, and teachers. Following this, **Section 4.2** outlines the results of the analyses performed on data relating to the influence of personal and environmental factors on the participation of the children during the methods. **Section 4.3** outlines the comparison of the methods that were involved in the visits and discusses the observations relating to the Markopoulos and Bekker (2003) framework.

4.1 Overview of Participation

Figure 13 outlines the process that was followed to gather and analyse information from the research visits. The diagram outlines how information was extracted from different stages within the research visits and was linked into the exploration of the areas of investigation within this research. The reporting of the analyses in the next two chapters is grouped into these areas of investigation and discussion of each of these factors follows the order shown in **Figure 13**.

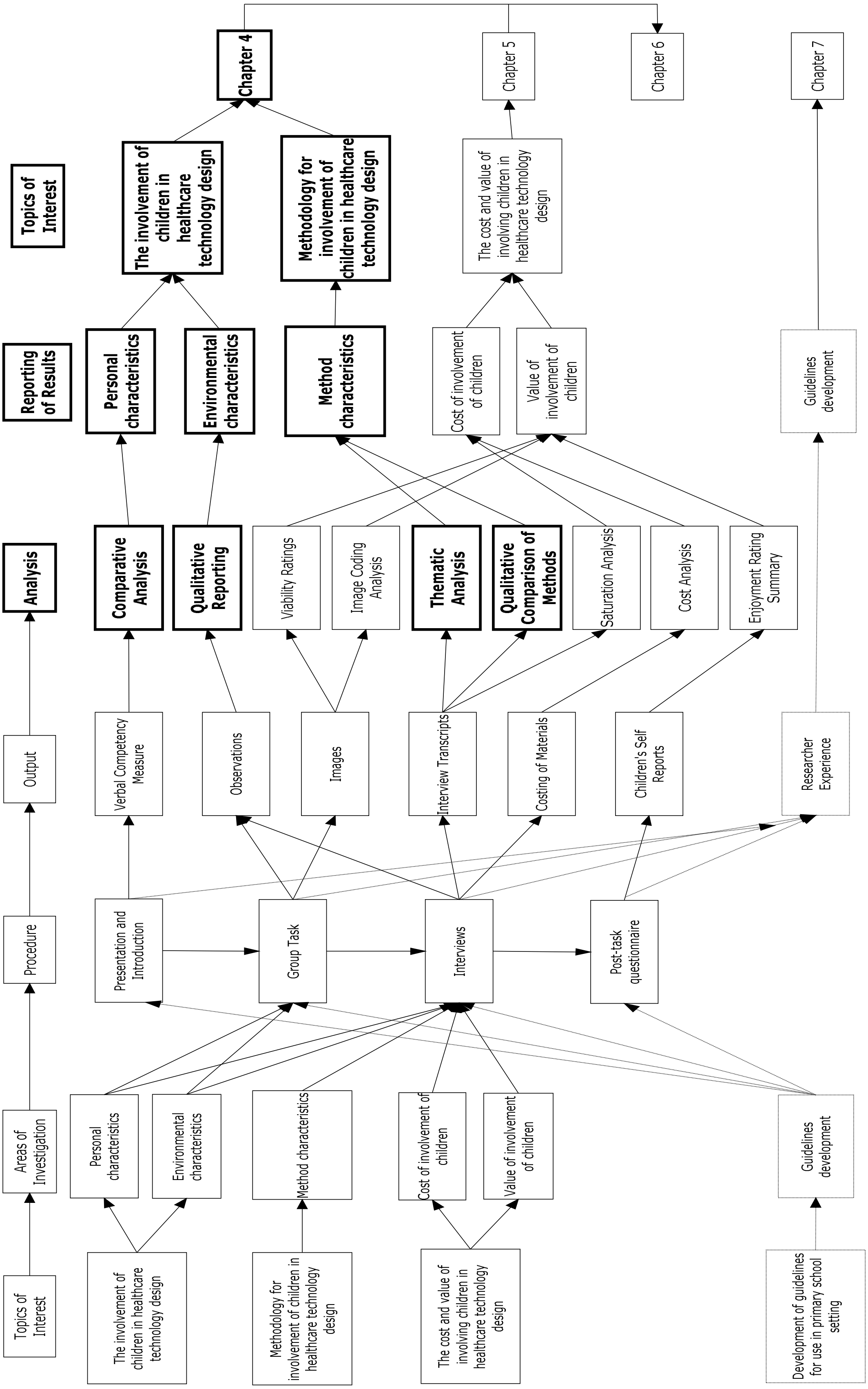


Figure 13 Graph to show the topics of investigation that are discussed within **Chapter 4**

4.1.1 Participants

Participants were recruited from mainstream primary schools in education authorities within Yorkshire, UK. In total, five primary schools were involved. Three of the schools had been involved in research collaborations with the research team previously. In total, 107 children aged 7 – 10 (*M* = 9.10 years old, *SD* = 0.864), including both males (*N* = 56) and females (*N* = 51), took part in the main visits outlined in **Chapter 3**. This involved children without disabilities (*N* = 102), and children with disabilities (*N* = 5). All children with disabilities had cerebral palsy. Almost all of these children had no prior knowledge or experience of the rehabilitation devices that were presented in the group tasks. Only one child with CP from a school had former exposure to the rehabilitation joystick when they had been involved in the usability testing of the device in an earlier project. Although the child had seen the device before, their involvement in this research was to examine the personal, environmental and methodology factors relating to gathering information from children, and prior exposure to the device did not affect these topics of interest.

As shown in **Table 3**, although attempts were made to evenly distribute the children across the four methods this was not always possible due to practicalities that arose. For example, the focus group was often used when there were a large number of children and time was limited, and the one-to-one interview was used when minimal resources were available due to other focus groups taking place.

Table 3 The distribution of participants across the four interview methods and the total number of times methods were performed in the research visits

Method	Focus Group	Board Game	DLI	One-to-one Interview
Male	30	16	5	5
Female	33	8	5	5
Total number of times a method was used	15	6	10	10

In addition to the standard visits, children who presented severe communication impairments also participated in the research, although they participated in alternative methods (*N* = 3). Due to the need to adopt alternative strategies to achieve involvement, their participation and the resultant obtained information is not documented amidst the analysis throughout this chapter and is instead discussed separately in **Section 4.3.4**.

4.1.2 Researchers

In total six researchers were involved in the collection of data on research visits. **Table 4** indicates the involvement of each researcher and the number of those who attended at each school. There were always a minimum of two researchers for each school visit. Those attending the visits alternated between facilitating interview methods, providing support during the group task and assisting children with the completion of post-task questionnaires when required.

Table 4 Summary of researcher involvement in the visits

	School				
Researcher	1	2	3	4	5
1: Primary researcher	X	X	X	X	X
2: Psychology undergraduate	X	X	X	X	X
3: PGCE student	X	X	X		
4: Mechanical engineer					X
5: Mechanical engineer					X
6: Mechanical engineer					X

Observations relating to the environmental factors discussed in **Section 4.2.2** and the qualitative reporting of the Markopoulos and Bekker (2003) framework in **Section 4.3** were acquired from the above researchers. The observations were gathered in research meetings that took place immediately after the visits. Although not formally documented, all researchers reported positive experiences about their involvement in the research process. There is scope to consider incorporating the experiences of the researches into the overall description of methods in future research. This could include outlining experiences of facilitating the methods with the children, and running the design tasks.

4.1.3 The Role of the Teacher

When visiting schools, if a whole year group was available, all of the children would be offered the opportunity to participate. When whole year groups took part, two classes of children would be involved. Although the classes would combine for the initial presentation about rehabilitation, the classes would revert to their usual groupings prior to being divided into interview groups. This occurred at four of the five schools, with only one school having a single class of children from a year group participate. The teachers always assisted with the general introduction to the class and introduced the researchers. Often the researchers would take lead of the class for the rest of the visit following the presentation. All teachers seemed happy to allow this to happen and would often assist with the general running of the activities. Teachers maintained a background authority in many of the classes, and some completed separate activities whilst the research activities took place. When the whole group activity began, the teachers completed the verbal competency ratings for each child in their class. All teachers completed the form without difficulty, although one teacher inverted the scoring on the 7-point scale. This was easily amended prior to analysis of the scores.

The following sections outline the findings in relation to the research activities and methods used in the schools. The reporting of statistics within this section is limited due to the exploratory nature of the research. This exploratory research analysis is intended to generate directions for future research to explore in more detail.

4.2 The Involvement of Children in the Design of Healthcare Technology: Personal and Environmental Factors

This section focuses on the personal and environmental factors that were investigated during the involvement of children in the group task and four interview methods. The section begins with a consideration of the personal factors, including an overview of the effect of age on the participation of children in the research. In addition to this, the influence of gender, verbal competency, and types of disability are discussed. This is followed by consideration of the environmental characteristics that may have influenced children's involvement in the interview methods; this includes an outline of qualitative observations relating to the school environment, the socio-economic status of the schools, and teacher involvement interviews.

4.2.1 Personal Characteristics

This section describes how age, gender, verbal ability and disability may have affected a child's involvement within the interview methods that were used to involve children in the design of healthcare technology.

Age

The age of a child participant did not influence their ability to participate in the research visits. All children indicated that they understood the instructions of both the group task and the interview method. All children without disabilities (i.e., CP) provided drawings and designs throughout the group task, and both children with and without disabilities gave responses to questions in the interview methods. The delivery of instructions for both tasks was verbal, which may have encouraged comprehension of the instructions. However, the effect of disability on the ability of children to participate in the design methods is discussed at the end of this chapter. Age is shown to account for differences when evaluating the measure of verbal competency and in the analysis of features in the images acquired during the group task; however, age alone did not account for any barriers to the involvement of children.

Gender

All methods were completed with same-sex groupings. Although no barriers arose that could be attributed directly to gender, gender differences are used to explain a range of findings within this chapter. These include gender differences in the consideration of verbal competency, behavioural observations regarding the male participants in the board game method, and the discussion of the robustness of methods in **Section 4.3.1**.

Verbal Competency

The verbal competency measure was taken to check the spread of verbal abilities across methods. The verbal competency rating was on a scale of 1 – 7 (where 1 = excellent verbal competency, to 7 = poor verbal competency). Although the subjective ratings were performed by different teachers, reviewing the distribution of ratings across age groups and methods was performed to verify that a range of children with differing levels of verbal ability (as rated by their classroom teacher) were involved in the research.

Figure 14 indicates that there was a range of scores that were awarded to the child participants during the research visits, although the most common rating was 3 (X = 2.66, SD = 1.50). The higher ratings of 5 – 7 (indicating low verbal competency) were not used very frequently by the teachers. Of the children who participated in the research (N = 107), five children were rated 7 on the verbal competency measure, of which four of these children had severe communication impairments. The fifth child had only recently immigrated to the UK and possessed very limited English language comprehension. This suggests that the lower ratings in the scale were assigned to children with good to moderate language skills, leaving the higher ratings reserved only for children with mild to severe communication impairments or difficulties.

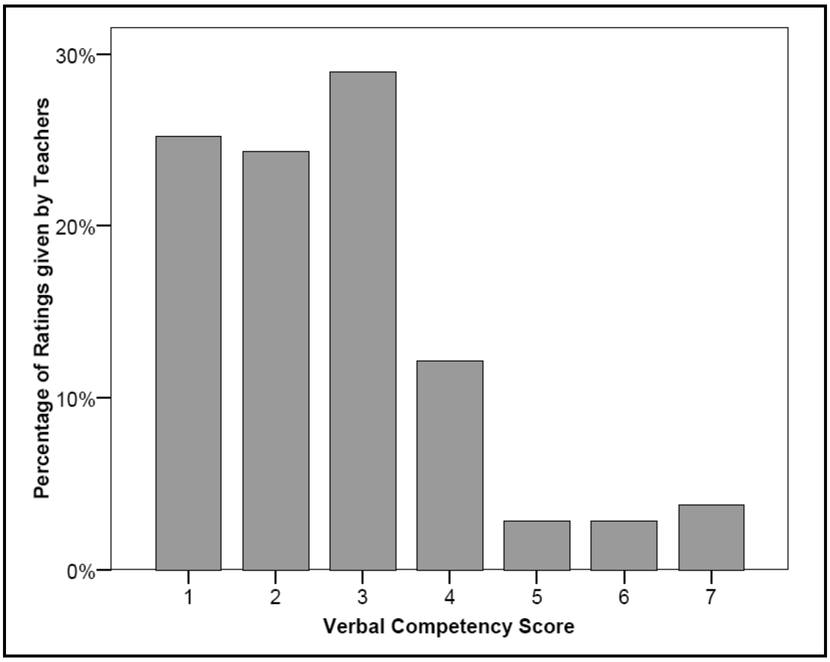


Figure 14 Average verbal competency ratings in the participants

When examining the distribution of the scores over the age groups, the 7-year old age group were excluded from **Figure 15** because the age group only contained four participants, with each participant receiving a different rating (1, 3, 4 and 6). The distribution of scores for the remaining age groups of 8-, 9-, and 10-year olds was similar to the overall distribution of verbal competency, with either a rating of 3, or 2 being the most selected by teachers. For all age groups, the ratings for 5 and 6 were the least used, with the use of 7 revealing a slight increase. The full spectrum of the scale was not used equally, and there seems to be a systematic response bias across age groups where the verbal competency categories are divided between those with average capability (rated as 1 – 4) with those of poor ratings (often rated as 7). If this scale is developed in future research, exploration into the use of a reduced number of items may improve such a bias.

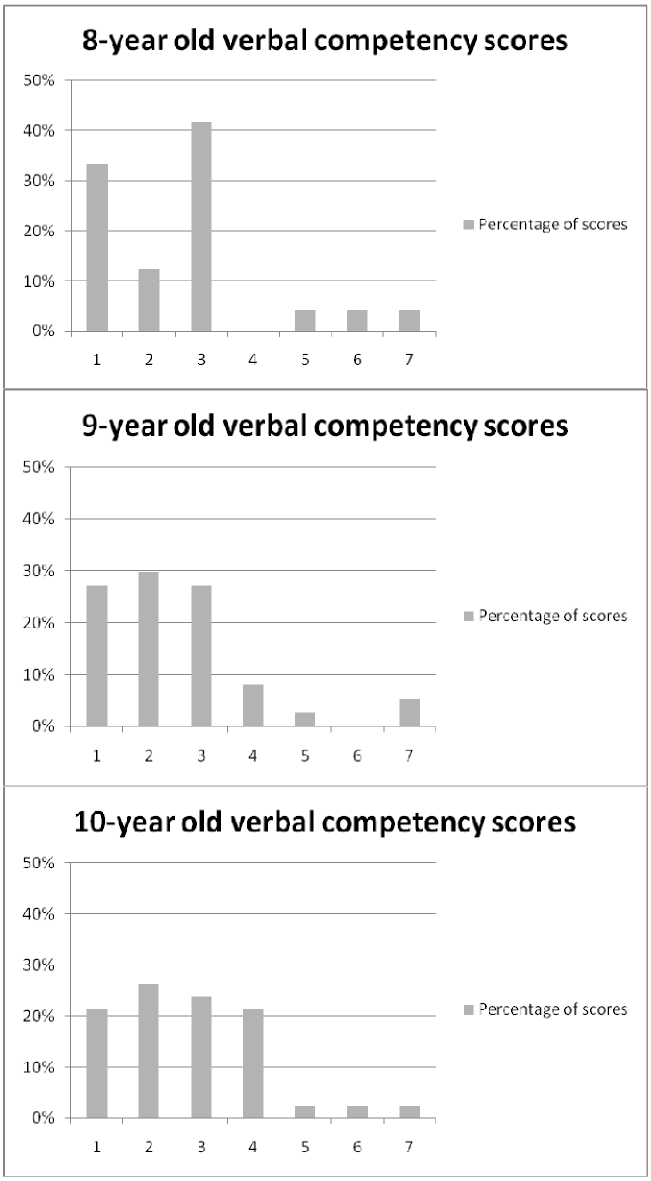


Figure 15 Distribution of scores on the verbal competency rating scale for the age groups of 8-, 9-, and 10-year old children. The scores indicate children's verbal competency level from '1' ('excellent') to '7' ('poor').

The differences in ratings of verbal competency given across age and gender can be seen in **Figure 16**. Although the male age group shows an initial decrease in verbal competency scores (indicating an increase in competence) from the 8-year old children ($X = 3$) to 9-year old children ($X = 2.81$), the verbal competency scores of the 10-year old group of males showed a slight increase ($X = 2.88$). Although the changes in the scores from the 8-year old to 9-year old group of males is in line with expected developmental stages, as children's language capabilities typically increase with age (Singleton and Ryan, 2004), the change from 9-year old to 10-year old goes against this trend. The female group attained higher scores that the males, which is similar to wider findings relating to literacy-related tasks (e.g., Swiatek et al., 2000). A gradual increase in scores was not found with the female group however, and instead the 8-year old group (*X* = 2.17) to the 9-year old group (*X* = 2.29) and 10-year old group (*X* = 2.56) showed a gradual worsening of scores on the verbal competency scores. The increase in the verbal competency rating when considering age may be explained by different teachers providing ratings for each class, alongside the increased use of the rating of 4 in the 10-year old group, weighing the overall mean verbal competency score towards a higher value. To explore the trend, a Kolmogorov-Smirnov test was performed to test the distribution of the data for verbal competency ratings across age group to inform the choice of correlation statistics. The verbal competency scores for the 8-year old group (*D*(24) = .273, p < .05), 9-year old group (*D*(37) = .211, p < .05) and 10-year old group (*D*(42) = .175, p < .05) were all significantly non-normal. Highly matched findings were also reported on the Shapiro-Wilk test. To investigate the relationship between age and verbal competency, a Kendall's tau statistic was used, as it is non-parametric, and more suitable for evaluating correlations in small data sets with large numbers of tied ranks. There was a positive relationship between a participants age and verbal competency score ($\tau = 0.75$, $p = .373$) although this was non-significant.

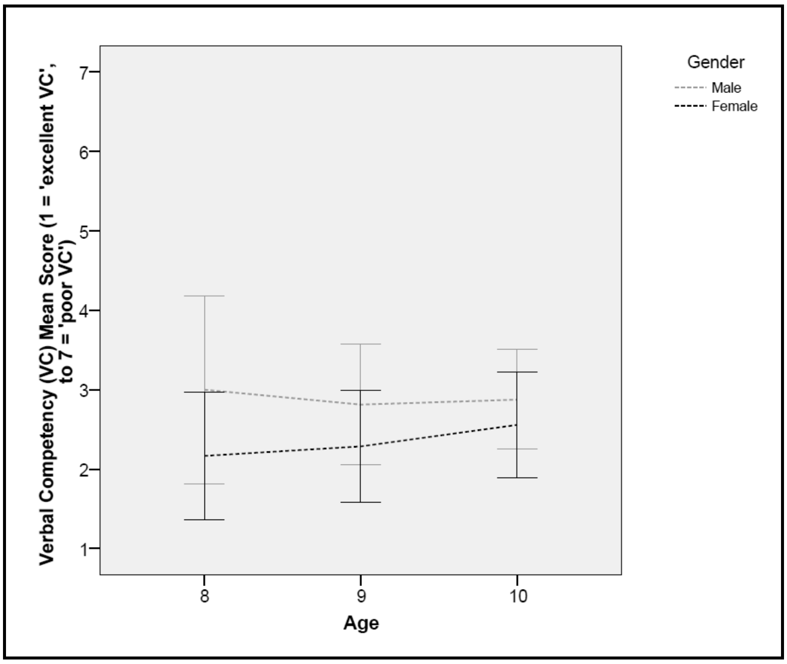


Figure 16 Average verbal competency ratings given across age and gender

Aside from ensuring a distribution of abilities across methods, the use of the rating scale was also used to identify children who had poor vocabulary and difficulties with communication. The children with communication impairments always attained scores of '7' on the scale, indicating their use to exemplify the lowest level of verbal competency. However, the only child within this category that struggled to answer any of the questions within the interviews was the child who had recently moved to the UK. The attribution of such scores of verbal competency to children with severe communication impairments requires consideration regarding the use of verbal competency measures. Given the skewness that was caused in the distribution due to the inclusion of their responses, omission of their scores or adaptation of measures is required in future research.

Individual teachers completed verbal competency measures, and no construct validation occurred on the verbal competency measure. However, the measure did provide a useful basis on which to organise groups to ensure that there was an even spread of verbal language capability throughout the different school visits. If such a measure is to be used in future research in the school settings to be compared to other co-existing factors, more consideration must be given to its development. Ratings from teachers can be subjective and reflect teachers' individual opinions (Mashburn et al., 2006), and an objective measure or one that can be completed by one researcher across visits may be necessary.

Type of Disability

This section outlines that effect of disability in the standard visits that took place. The discussion regarding the effect of disability of the children participating in the alternative method are outlined at the end. The involvement of children with severe communication impairment posed separate challenges to children with physical disabilities. In a similar way to the overall analysis, the process and content analysis of the visits are divided over **Chapter 4** and **Chapter 5**. The process of the methods that took place is outlined in this section, alongside discussions within the method comparison in **Section 4.3**. The content that was gathered from the standard visits, and those containing children with severe communication disorders are discussed in **Chapter 5**.

An initial problem identified when involving children with CP in the research visits was the need to consider alternative methods to obtain assent, as difficulties with handwriting were often present. The assent forms required a signature, and although most children could do this, it was often problematic for children with disabilities. Although the type of disability affected their ability to provide assent, it further dictated their ability to freely express themselves during the interviews. The children who participated with mild disabilities, such as a child with CP with a mildly affected upper limb not requiring assistance, participated in the method without any disability-dependent difficulties. The effect of disability only became apparent if a disability mildly limited the physical or communicative abilities of a child.

All schools provided the necessary accessibility equipment for children with disabilities. However, children with disabilities only participated in board games and focus groups. Their exclusion from DLI's was as a result of the teachers of the class groups not deeming the activity suitable. The manipulation of physical materials to create a prototype could have potentially caused difficulties for children presenting physical impairments.

Where children had severe communication impairments, AAC systems and mobility equipment were available so that they could access the rooms for the research activities and take part without difficulty. However, this was often reliant on the availability of a support assistant. All participating schools had support assistants in place for the three children with physical and communicative disabilities requiring high levels of assistance. The roles of support assistants included assisting in the production of the group task diagrams guided by the child, and providing mobility support for the child to attend the interview methods. One child with CP had spastic diplegia although their ability to talk was only marginally affected. This child only required mobility assistance and received no other support during the visits. Another child with CP and combined severe communication impairments had a support assistant who would often try to communicate for the child. This often occurred on questions unrelated to the questioning in the method to do with setting up for example, such as whether the child was ready to begin. Often the support assistant would try to identify an implicit movement that was regularly used to communicate between them. However, for the questions within the trials, the support assistant was more passive and the child answered the questions. The support assistant continued to maintain encouragement during this process.

Although the support assistant was required for the participation of some of the children with disabilities, it was not examined how their presence may have affected the behaviour of the children. This problem is discussed further in relation to the validity of the methods in the discussion of validity in **Section 4.3.3**. Any difficulties that arose as a result of the presence of disability within specific methods are discussed in **Section 4.3.1** when the robustness of methods is discussed.

Type of Disability: Children with Severe Communication Impairments

As discussed in **Chapter 3**, the involvement of three children with severe communication impairments did not follow the same procedure as the main trials. This method was used to ensure that all children who were involved in the research could participate in interview methods to inform the design of healthcare technology. This section describes the observations from a visit that took place at one school that involved three children with severe communication impairments. Separate activities took place because the children were not deemed capable of participating in one of the four available research methods due to the demands it would place on the individuals communicative capabilities. The methods aimed to retrieve similar information from the children as achieved in the standard method, but with a reduced list of questions (taken from the list used in the standard method; see **Appendix 5**). This section provides insight into the process of involving children who are heavily dependent on AT to communicate and the design of equipment for use by them is integral to the aims of this research. For this visit, the design of a communication fixture was used as it was appropriate to the daily activities of the children and presented a relevant device to the children (see **Appendix 2**).

Three researchers were involved in this observation of the use of alternative methods to acquire data from children with severe communication impairments. This allowed for the assignment of one researcher for each child. Following this pattern, each of the three researchers was assigned their own topic on which to question the children. The three children were rotated around the room ensuring that they saw each of the researchers. Variability in the times taken for the children to complete questions occurred for the different researchers. On occasions, a child had to wait to move to the next researcher because either they had completed their own questions earlier than expected, or because the child with the next researcher was taking longer than anticipated. One factor that may have affected this is the prescription of a new talker device to a child on the day of the visit. The display was novel to the child as they had moved from a small grid on the screen (around fifty-four visible cells at one time) to a larger (eighty-four cell) screen. The talkers used by the participants were vital to the clarity of information that could be delivered. It was observed that a few answers provided by this child were ambiguous. For the other two children, who had used their talking machines for several months, responses were often much faster. For all children, when questions were open-ended, the production of a response would take a minimum of ten seconds due to typical delays in the generation of responses on the talker. Despite such delays, one participant repeatedly asked the name of one of the interviewers. The participant appeared to attribute value in knowing the names of the researchers and this was confirmed by the carer. Throughout the questioning, the originally proposed means of gathering information from the children was developed, involving dynamic thinking to modify the procedure accordingly. An example of this was the choice to shorten the possible responses that the children could provide from open-ended to dichotomous yes or no responses. This was only used on occasions when a child was struggling with questioning and reshaping the question for them allowed for an accurate and fast response. The use of yes or no responses was often indicated by a child's head movement alone, which bypassed the talker device. However, the face scale and opened ended questions were means of gathering richer responses.

Dynamics from the group were still evident despite the three children completing separate tasks. One child was prone to distraction and often tried to distract the other two children. This occurred because the children were sat within audible range of one another whilst completing separate tasks and were turning to see the activities in which the other participants were involved. Unexpected behaviour was also incurred to which the researchers had to adjust. One child had spastic diplegia predominantly affecting their lower limbs. When a researcher displayed a face scale with numbered faces, instead of providing a response via the talker, the child reached out and pointed to the item on the face scale. This seemed to imply the desire of the child to use existing function rather than using the relatively inappropriate numbering system requiring a response from their talker.

Summary of Personal Characteristics

The evaluation of the effects of age and gender differences discussed on the participation of children within the methods revealed few findings alone. Their combination with a range of analyses within this chapter reveals interactions that are more elaborate. For example, when combined with verbal competency in this section, patterns in both age and gender were identified. Although average verbal competency ratings were not evenly distributed across the different methods, females consistently attained lower ratings from their teachers. The fluctuation of ratings across age revealed an abnormal pattern; females aged 8-years old attained the highest rating across all ages, gender and methods, but this was probably due to the uneven distribution of participants across the age groups.

The presence of disabilities was the only personal factor that limited participation in a method. The largest barriers included the need for mobility and communicative assistance by some of the children with disabilities. Although support assistants facilitated children with disabilities during participation in the methods, their input was limited. This was particularly the case for children with communicative impairment as the reliance of talker machines meant that their time taken to respond to questions was not only much longer but their responses were much less detailed, often comprising one-word responses. There is certainly scope to investigate such general barriers to the involvement of children with severe impairments in interview methods. The specific barriers posed by interview methods used within this research can be found in **Section 4.3.1** in the discussion of the robustness of the different interview methods.

4.2.2 Environmental Characteristics

The environmental characteristics section involves summarising qualitative observations that were gathered regarding the school environment. In addition to this, the influence of socio-economic status of the school (as measured by the number of children who are eligible for FSM) and teacher involvement are considered. The socio-economic status of the schools is reported to explore any relationship with measures of verbal competency, as the previous research has indicated links with linguistic knowledge (e.g., Purcell-Gates et al., 1995). In addition to this, interviews held with teachers provided insight into the involvement of children, and the findings are outlined at the end of the section.

Qualitative Observations regarding the School Environment

The different school environments revealed varied time schedules and provided a range of spaces in which to conduct the research visits. Children have a range of breaks during the day, and these occurred more frequently for the younger children. All teachers allowed the researchers to continue research activities throughout the break times, although this involved children missing their free time. Where possible, this situation was avoided; however, children often indicated that they were happy to continue throughout this time and maintained concentration.

Although all group tasks took place within the classroom, the interview methods were conducted in a range of environments. The areas available for use by the researchers within the schools varied considerably. Often the schools would try to provide a quiet area to perform the activities, but this was not always possible and communal areas and cloakrooms occasionally had to be used. This did not affect the ability of the method to take place, but it did mean that distractions were occasionally present.

As discussed in the section outlining the presence of disability when considering personal factors, support assistants were available in a range of schools that were attended. General classroom assistants attended within some of the classes where group activities were taking place. Their participation consisted of working to support the children complete the activities and ensure that they were staying on task. This eased the demand on the researchers, allowing them to focus solely on gathering information via the interview methods, but classroom assistants were not available at every school.

Effect of Socio-economic Status of a School

By gathering information on the socio-economic status of the schools, it was possible to ascertain whether schools from a range of areas were involved. This ensures that a more representative sample was included in the research. The figures for the number of children who attended a school and the proportion of children who were eligible for FSM was acquired from the local councils, governed by the Freedom of Information Act (2000). **Table 5** outlines the number of children who were eligible for FSM as a percentage of the whole school population.

Schools involving a range of children with different eligibility for FSM's were involved in the research, although the use of FSM as a reliable indicator of deprivation has been called into question in recent research (Kounali et al., 2008). The difficulty lies in trying to establish a single, catch-all measurement from routinely collected administrative data such as the FSM statistics. However, as a means of a coarse guide to the socio-economic status of participating schools, the measure is adequate. Currently no other measurement is available to identify individual economic disadvantage, with the exception of the Index of Multiple Deprivation (Noble et al., 2004) which Kounali et al. (2008) highlight is becoming popular for use in research.

Table 5 The proportion of children who are FSM eligible within the five participating schools

School	Proportion of school eligible for FSM
1	29.5%
2	1.32%
3	26.63%
4	7.78%
5	10%

Figure 17 demonstrates the large variation in the FSM proportions between the different schools that participated in the research. The graph included a y-axis reference line to indicate the average FSM statistics for primary schools within England (DfES, 2007), highlighting that there was a spread of scores from above and below the average.

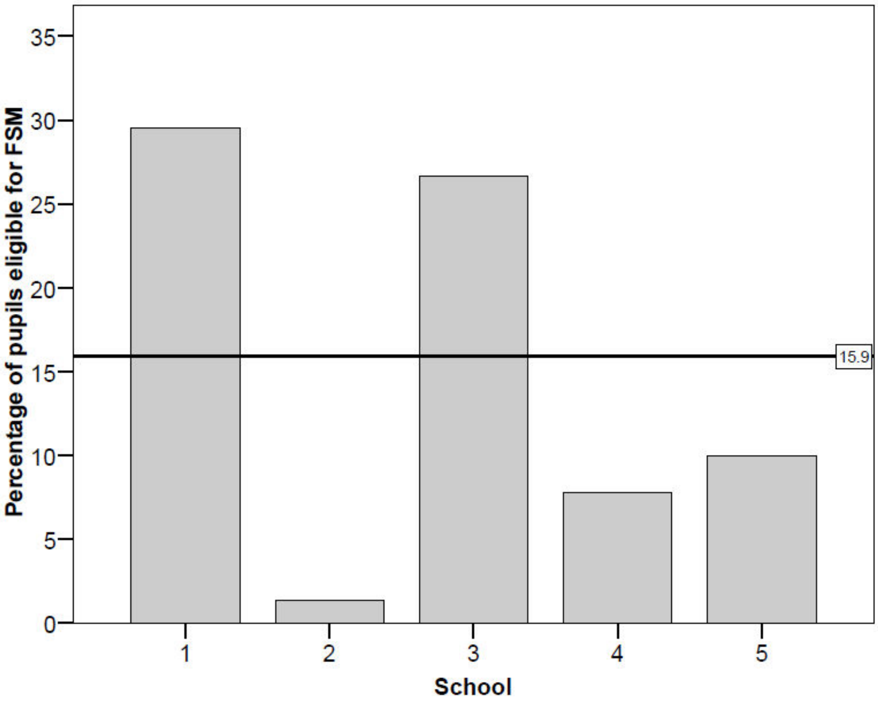


Figure 17 Graph to show the proportion of children who were eligible for free school meals with the inclusion of a y-axis reference line indicating the national average of the 15.9% (DfES, 2007)

Teacher Involvement Interviews

This section firstly outlines the information that was gathered from one teacher who completed questions regarding research involvement via an email version of the questionnaire. Following this, the semi-structured interviews that took place with four teachers is outlined, before a summary of all of the obtained information is presented. To conclude the discussions of teacher involvement, there is a summary of the information obtained from the teachers. In total, five teachers from three schools were involved in interviews, including both males (N = 3) and females (N = 2). Two teachers were interviewed from a school completing the standard method, two teachers were interviewed from the school where the children with communication impairments attended, and one teacher from another school completing the standard research trial requested to complete the email questionnaire. A copy of the email questionnaire and the questions used in the semi-structured interview can be found in **Appendix 10**.

Teacher Involvement Interviews: Questionnaire

Overall, the questionnaire revealed support for this research and methods used to involve the schools and engage the pupils in research activities (e.g., *"...our experience has been entirely positive... visits have been conducted in a friendly and professional manner... the children have been more than happy to work with the team and have been positive about their experiences"*). The visit was also highlighted as being useful to the children because it raised awareness of the process behind developing healthcare technology and discussed the issues faced by users. This was indicated as being particularly helpful because *"...children of this age are often not aware of the different fields of work taking place in the big wide world!"* The teacher also reported that they had received enough involvement in the decision-making and activity planning throughout the whole process.

The activities that were performed during the visit *"...were able to fit into the structure, space and routine of the school with minimal disruption"*. Concern was raised by the teacher regarding space allocation in different schools, as there was a large requirement on space for design activities and additional rooms for interviews. However, prior knowledge of the school environment in question ensured that the research design was suited to the setting.

The teacher reported that topics relating to rehabilitation and disability were dealt with sensitively and that this benefited and informed the participating children. Discussions of disability were highlighted by the teachers as potentially sensitive, but important for the children to discuss and the teachers fully supported such discussions in the research. In addition to this, it was reported that *"...the children do react positively when working with* *outside agencies and it raises their awareness of activities and agencies working in the wider world".*

Teacher Involvement Interviews: Semi-structured Interview

Semi-structured interviews with teachers at the schools revealed overall support for the involvement of the research team and that *"...the kids have been engaged through the whole morning which is fantastic"*. Teachers indicated satisfaction with the extent to which they had been involved with visit planning and decision-making. For some teachers, their involvement in the research was novel, although all staff had been involved in activities with external agents in the classroom setting previously. Both groups of teachers indicated that being involved in the research was not an additional pressure and that in some instances it can release time for a teacher.

Teachers were happy with the planning of the visits and the preparation that occurred prior to the research visit. An additional aspect associated with the engagement of children was the presence of children with disabilities in each of the classes that were involved. The teacher reported that *"...having children with disabilities in the class means they've got a really good point of reference and they can relate to what they know"*. For the group of children involved in the alternative communication fixture method, teachers highlighted that often children with communication impairments do not get the opportunity to be involved in such activities, and the relevance of the technology to their daily functioning provoked further support for their involvement.

Teachers were happy to provide suggestions for further improvements to the design of the research. For example, one teacher pointed out that a few of the questions asked to the children during the interviews were *"...a bit difficult"*, and that the children *"maybe needed a bit more time to think about it"*. In addition to this, during the alternative communication fixture method, teachers reported that often it would support research activities to get to know the child participants beforehand, as this would improve both the rapport with them, and an awareness of their capabilities.

Teacher Involvement Interviews: Summary of Findings

Overall teachers who were involved in interviews supported the research team carrying out activities in the school environment. However, given that the teachers had allowed access to the school and children for the research, a selection bias is evident in the reporting of their feedback in this section of the research. The teachers were happy to participate in the activities and were happy to provide critical feedback when required. The feedback regarding the teams' involvement was positive and teachers were happy with the extent to which they had been involved in the planning and decision-making for visits.

Performing activities that discuss disability and rehabilitation were also highlighted as being beneficial to children. This was particularly engaging for school classes where one or more children were present with a disability. Teachers were also happy to provide feedback on areas of concern for future research activities and considerations that should be applied to future visits.

The teacher interviews emphasised the importance of teacher involvement in research, in that important information can be gathered, even from a range of short semi-structured interviews or email questionnaires. Due to time constraints on the research visits, interviews were not possible at all of the participating schools discussed within this thesis. However, the information obtained provides support that the research activities carried out within this thesis were mostly suitable for their environment. Alongside providing guidance on possible modifications and considerations for future research, the teachers also provided support for ongoing projects that surrounded the research. This feedback has been used to develop guidelines for school involvement in research related to healthcare technology design, and these are presented in **Chapter 7**.

One point raised from the interviews was the need to consider space and the population. Although these were not concerns in the research visits that took place, teachers were keen to emphasise the need for forward thinking. Such an ethos links in to the approach adopted by educational researchers, highlighting the need to build up rapport with teachers and students, alongside understanding the layout and constraints of the environment to promote more profitable research experiences (e.g. Rathgen, 2006).

Involving teachers in the research process aids any pursuit of quality improvement in the research process within a school environment. However, practitioners have been criticised for failing to alter practice on the basis of research findings (Lather, 2004). If researchers use the information acquired, teachers and school can benefit from involvement. For example, research has revealed that exposing teachers to professional learning experiences, such as involvement in research, makes a difference to the quality of their students' learning (e.g. Hattie, 2003). The involvement of teachers can also assist in developing practice in a relatively recent area of investigation. The design and development of healthcare technology in the school environment stands to benefit from active teacher involvement, although it must be ensured that practitioners apply research findings.

Summary of Environmental Characteristics

The research involved schools with a range of socio-economic statuses (as defined within this research). The school environment was a suitable location to perform a range of interview methods with children. Although the environment did not lend itself to structured experimental designs, data collection was possible and no major problems occurred. An additional benefit of the school environment was the inclusion of support assistants for children with disabilities. This facilitated the process and ensured that children were encouraged and supported during participation.

The involvement of teachers within considerations of the environment was crucial to verify their experiences of involvement alongside identifying areas of possible improvement. Generally, the reports from the teachers were positive in relation to their involvement in decision-making and activity planning. The teachers were also happy to provide guidance relating to considerations of space and the child population being involved, alongside stressing the need for forward planning when knowingly working with children with communication impairments or other disabilities.

4.3 Methodology for Involving Children in the Design Process: Methodology Comparison

The main analysis that took place on the methods involved gathering observations from the visits about the method characteristics outlined by Markopoulos and Bekker (2003). The observations documented within this section were gathered throughout the entire series of interview activities. This section summarises the qualitative observations that were made by the researchers and uses these to draw comparisons between the methods. The methods are evaluated below when discussing robustness, reliability and validity, with the information summarised at the end to conclude the comparison. Consideration of thoroughness, referring to the examination of the ability of a method to gather information about all aspects of a device, is not covered in this section. This is presented in **Chapter 5** during the content analysis of the interviews. Additionally, the efficiency of the methods is not discussed during this chapter as it is similarly discussed in **Chapter 5**. Consideration of efficiency covers the number of responses obtained by the methods, the saturation of responses from the children, and the time taken to complete the methods.

4.3.1 Robustness

Robustness describes the feasibility of the method to be compared across different contexts and different products. In this instance, the observations compiled were regarding the ability of the methods to capture information independent of the participating population (i.e. children). Observing the robustness of a method also involved identifying any traits of the participants that may have influenced the ability of the method to gather data.

Design-Led Interview

All children without disabilities were able to participate in the DLI method without any reported or observed difficulty. No children with disabilities participated in this method because the manipulation of the materials required to create the prototypes was deemed unsuitable by the researchers and teachers present on the research visits. Independent of whether the joystick or handwriting device was the focus of the questioning, children were able to take part in the method with the exception of the children with physical disabilities. The presence of a communication impairment for children with one or more disabilities only served to further exclude a child.

The materials that were used during the DLI only consisted of classroom materials. It is presumed from their performance in other methods that children with disabilities will be able to answer any questions posed within the DLI. However, there is a clear need to identify alternative means to involve children with physical disabilities in the design element of this activity. The underlying ethos of incorporating design tasks into collaboration with users is to enhance communication and understanding, alongside establishing a means of explicating and incorporating new and emergent ideas (Muller, 2007). Participatory work, through the DLI in this instance, involves much more user contribution and user initiative than the more conventional use of techniques such as paper prototyping. If children with disabilities are to be involved in research using such design tasks then it must be ensured that researchers strive to maintain these principles. Firstly, there is a need to explore how children with disabilities can be involved in design tasks, but once completed, the process must be refined to fully explore their involvement in participatory, or design-led methods.

Focus Group

The focus group accommodated children with and without disabilities. Children with severe communication impairments and physical disabilities participated in the method alongside children without disabilities. The focus groups never involved more than one child with a disability at any one time. Children with disabilities often took longer to respond to questions, where this was particularly the case for children with a communication impairment. There was never an established equal platform on which children with and without disabilities could discuss topics with one another. Children without disabilities were very patient when a child with a disability took a long time to respond, and often treated any disabled children as the authority voice on any questioning related to disability or hospitals. In some instances, children without disabilities expressed compassion for children with disabilities, often when children with disabilities were not present. However, in one focus group children attempted to support a child with a severe communication impairment by constantly repeating questions for the child and trying to answer questions for them. In one instance, a question about equipment that disabled people use did not even feature the child in the group with CP:

Facilitator: What sort of equipment do you think disabled people normally use?

Child 1: Like buttons

Child 2: Standing frame

Child 3: Like buttons. This girl in year 6 has buttons on the back of her chair, and when she presses it, it does virtually anything, and she has an electric wheelchair

Supportive and patient behaviour was seen more in groups of females than males. Males would be more likely to become quieter when questions were asked regarding disability, allowing a child with a disability to respond first. In one male focus group with a child with CP, the child with CP was the first to answer most questions, and when a question was asked about equipment that disabled people use, the focus was on the child with CP:

Facilitator: What sort of equipment do you think disabled people use?

Child with CP: Power chair, wheel chair, playstation…

Child 1: Computers for writing and researching

Child 2: Joysticks

Child with CP: Keyboards

The focus group was successful in gathering responses across all age groups, although disruption occurred occasionally. The participants displayed a range of behaviours, varying from children who were frequently digressing in their responses, to children who were much more succinct. Digression did not last for a long time, as the facilitator would often bring responses back to the questions. For example:

Facilitator – What should a joystick for your bedroom not be made from?

Child 1: Wool

Child 2: Cheddar

Child 3: Ham

Facilitator: Sensible now...

Child 2: I wouldn’t like it to be made out of metal because it’ll shine onto it and my room will be really hot and set a fire or something…

Child 1: Or you might bang your head…

Child 3: I'd want a plastic one…

The majority of groups fitted somewhere between the two types of behaviour sets, with generally no disruption that stopped the flow of questions, and children appeared to occasionally have fun with their responses. The focus group was applied in every school without difficulty, as the method only required space to gather four or five children. Due to unforeseen circumstances in one school, there was hardly any space available to perform the research activities. In this instance, focus groups were performed in a cloakroom area. In most schools, the method was performed in quiet areas such as a library or a spare room. The location of where the method was performed did not seem to affect its ability to gather information from interview methods.

One-to-one Interview

There were no behavioural difficulties associated with this method. However, children often listed a series of responses to questions that required only one-word responses. This particularly occurred for questions relating to colour. It seemed as though the children were keen to provide as much information as possible for the researchers and tried to be as extensive as possible in any responses that were given. For example:

Facilitator: What different types of colours do you like?

Child: I prefer pastel colours, I like some bold colours, and I quite like orange and yellow

No children with disabilities participated in the one-to-one interview methods because it was deemed more appropriate to involve them in group methods instead. Research consisting of interviews involving children with disabilities is already available (e.g., Nathanson and Crank, 2004; Sandt, 1999), but there is very little research available regarding the interactions of children with and without disabilities in group tasks with a focus on healthcare. It was the intention of the researchers to involve children with disabilities in every method, but there was a limited number of children with disabilities. Instead, it was decided that the children with disabilities should be placed in methods that accounted for their impairment whilst trying to maintain enjoyment. The interactions of children in groups when there was a child with a disability was of particular interest for planning research activities in the future.

There were no differences observed across age or school when completing one-to-one interviews with the children. However, the involvement of children with disabilities in this method is an area of research that needs addressing.

Board Game

Only one child with a disability participated in the board game. The child had CP with a mildly affected upper limb and used their unaffected arm to roll the dice and move counters within the game. All children without disabilities had no difficulty participating in the method. However, some children required further explanations from the facilitator regarding the instructions for the game.

There were instances of disruptive behaviour from some participants, with such behaviour occurring across gender and school. For example, when completing a board game, a female group appeared to become restless and continued to digress with discussion between questions:

Facilitator: Would you use a joystick if it moved on its own

Child 1: No…

Child 2: No, I wouldn't

Child 1: Because you don't do any exercises and it's gonna be boring

Child 2: No, because I think there's a ghost in this school or something

(Discussion of ghosts in the schools…)

Facilitator: How would you make a joystick just for children and not for grown-ups?

Child 1: We would make it little so that the adults couldn't use it

Child 2: Make it tiny… I'd make it like cupboard height and width

(Discussion of school activities; namely, a boiled egg painting…)

This led to other participants becoming despondent, until the facilitator resumed the game by asking all of the children whether they would like to continue. Such instances only occurred for the 9 – 10 year old group, not the younger age groups.

The method was performed in schools without any difficulties beyond occasional instances of disruptive behaviour, although it did require a large space to set out the board. In one school, the board game had to be played in the cloakroom and was successfully placed on the floor and used by the children in the location.

4.3.2 Reliability

The reliability of the methods was linked to assessing their ability to extrapolate the same information from children in different conditions (e.g., different settings, schools, and populations). All of the methods were capable of being applied in different settings, and were also successful at gathering information in every school that was visited. However, the questions list that was used only allowed for confined responses from children. The extent to which information was obtained from participants did vary dependent on the methods in which they were participating. This is discussed further in **Section 4.4** when considering the cost of child involvement.

When looking at DLI's, where the resultant outcome of the method included a prototype alongside responses to questions from the children, there were observable differences. Not all children completed their prototype in the time allocated, and every child who participated in the DLI used a different method of creating a prototype. A variety of materials were available for the children to use, with the children opting for differing combinations of materials. Of the four children aged 9 – 10 who took part in the DLI methods, two opted for plasticine models, with the two remaining participants using paper and drawing materials. The prototype served an equal function across groups, where it was integrated into responses from the children, and allowed for the researcher to ask more in-depth questions through reference to the prototype.

Facilitator: So what materials would you use?

Child: Like metal… covered in something soft, like on the fingers, here… you put your hands on it, and the way you use it… the way you use your hands on it could be different… (the child demonstrates on the device at the same time)

With the board game, the levels of behaviour of the children provided varied outcomes in the way that the methods progressed and the final level of information obtained from the children. Dependent on the group of children taking part in the board game, responses varied in terms of the worth of responses. Instances arose where the children began to laugh and joke to the extent that the questions were not particularly considered before providing a response.

Facilitator: What do machines that are not from hospital look like?

Child1: Ok... squary pants

Child 2: Like cookies and that..

Child 3: 17 minutes it's been…

Child 2: They look like those modern robots and that…

Child 1: Who is green?

Child 3: If it looks ugly… with a cherry…

4.3.3 Validity

During the methods, children were required to respond to questions based on the recall of information. Although it has been shown that this does not affect the recall or recognition of colour information (e.g., Patel et al., 1999; Ling and Blades, 2002), the effect that this may have on the memory of textural preferences is not known. The external validity of responses will be examined later in **Chapter 6** with the internet site, where the information obtained from these research visits is applied to prototypes by designers, which are then evaluated by children.

During the interviews with the children, a valid response was an accurate response to questions surrounding healthcare technology. Responses to these questions were difficult to verify as children will often not have prior knowledge of the appearance of different colours or materials on healthcare technology, particularly the novel devices used during these visits. In the examination of children's responses in the design of novel healthcare technology, future research in the area may need to develop a means of improving the validity of responses provided by children. A potential method for achieving this could be through using computer-based graphics software during an interview. This would allow the researcher to generate instant changes to a design that could be directly discussed with a child. Feedback regarding aesthetic preferences would then be based on virtual prototypes rather than memory. This would be an alternative to the method applied during these research visits, gathering children's preferences more generally, and aim to use these to inform future designs.

As outlined previously when discussing reliability, during the DLI, when children had a prototype present, talk was directed towards this object, and the children frequently used it as a point of reference. In responses gathered in the other methods, children were reporting experiences of preferences and items from memory (e.g., the texture and feel of their favourite toys and games). In methods without a prop, the conceptual nature of some of the questions may have fed into a child's tendency to respond to questions, but not provided them with a platform that was concrete enough to achieve accurate recall. Although the object in the DLI was never an accurate depiction of the design that they were trying to create, it focused the attention of the children and provided a means through which to explore material and colour preferences whilst providing responses.

The mere presence of a facilitator within each of the methods may have affected reports provided by children. This is particularly the case when asking questions regarding topics that enquired about the children's opinions on disability and people with disabilities. Such questions were removed from the majority of methods involving a child with a disability for fear that it may draw direct attention to a child with a disability. Concerning the facilitator, the one-to-one interviews were still maintaining traditional adult-child relationships (where the child answers questions posed by the adult). This may have affected the responses obtained by children and may have inhibited their answers. In addition to this, future research might consider examining the influence of carers or support assistants (accompanying children with disabilities) on children's responses during group activities when they are present.

The researcher who facilitated during the interview methods alternated between the research team due to time constraints, allowing multiple sessions to run simultaneously. This is not accounted for in any analysis of content or responses obtained from the children. In addition to this, the dictaphone may have influenced behaviour. At points children directed comments at the dictaphone; therefore, its use may have influenced the responses of children. Despite these threats to validity, the research visits were completed in a school environment, which can be used by other researchers, and findings regarding children's behaviour in this context are of importance.

4.3.4 Summary of Methodology Characteristics

Children without disabilities completed all of the methods without any difficulty. Children with disabilities were excluded from the DLI because they were unable to create a prototype. There is a need to consider ways to involve children with disabilities in methods that incorporate design tasks. This was also the case for the whole class group activity, where children who were unable to manipulate objects to create designs were excluded. Attempts to address this have begun, with for instance, Wu et al. (2003) developing an assistive drawing device for children with CP. The device, which is hand-held, supports arm function and was shown to improve the drawing range and movement of the child participants. Such devices require further development so that these issues can be overcome in future research, allowing children with disabilities to participate in design activities and provide a wider range of information in healthcare technology research.

All methods were completed independent of the environment where they took place. Focus groups were the most inclusive method for involving all children who participated. This method involved the majority of children with disabilities as it was deemed the most suitable. Given the success of this method, future investigation should begin to identify how the method can be utilised fully alongside children with disabilities. However, it might be insightful for future investigations to involve children with disabilities in the interview methods that were deemed unsuitable.

When one-to-one interviews were used with children without disabilities, responses were obtained at a faster speed than other methods and all of the questions were completed.

This is mentioned further in discussions about the efficiency of the methods when considered in the next chapter. The board game involved a child with mild CP, and their participation in the method was without problems. However, similar to all of the other methods, there is need to consider how to make the methods more accessible when children present more severe disabilities affecting both the physical and communicative capabilities of the child. In these instances, there was often the need for a support assistant. Considerations regarding the necessity for a support assistant during research visits, and the effect that this might have on the validity of responses provided by children requires further investigation. Although literature relating to designing with children has begun to consider how to model the involvement of children with 'special needs' (Guha et al., 2008), there is a need to extend this out to report on the practicalities of this process and develop guidelines to support other researchers. This is the focus of **Chapter 7** within this thesis.

4.4 Summary

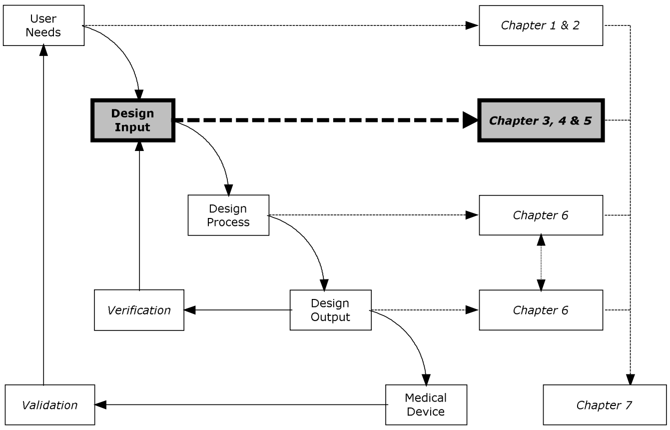
The chapter has outlined the effect of personal characteristics on child involvement in healthcare technology design. A child's age was not seen to act as a direct barrier to involvement within the interview methods that were used to involve children in the research. In addition to this, nor was gender, although gender was found to influence the verbal competency ratings of children. Disability was shown to have an influence on the ability of methods to involve children in the interview methods and the research activities. For the methods involving children with severe communication impairments, there was a need for dynamic thinking from the researchers throughout. A range of techniques were successfully implemented to assist the children in providing responses to questions, such as framing questions to suit dichotomous responses. This provided a relatively straightforward means of gathering preferences from the children, although alternative methods offering more engaging modes of questioning may be required. The children with communication impairments appeared to be tired by the end of questioning, which may have been a result of the requirement to provide several yes or no responses to a list of questions. **Chapter 6** presents an internet application that is designed for use by children with and without disabilities, offering a potential alternative means of questioning children with communication impairments.

The investigation of environmental characteristics gathered information on the participants' eligibility to claim FSM. This provided a basis for comparisons between FSM eligibility and verbal competency ratings, in which an indirectly proportional relationship was found. Whilst considering environmental factors, feedback from teachers regarding their involvement was also documented. Alongside gathering positive comment from the teachers regarding the involvement of the schools and children by the research team, the importance of involving teachers in such research was emphasised.

The comparison of four interview methods provided the opportunity to examine means with which to compare methods for involving children in future design research. Based on qualitative observations, the comparison of the methods provided information relating to the robustness, reliability and validity of the methods. Although the personal and environmental factors, alongside method characteristics, have been reported in the chapter, practice seen in the development of many products attributes significance to cost, alongside quality and functionality (Cooper, 1995), with a similar approach being used in healthcare service development. For example, cost-effectiveness and efficiency are key decision-making criteria in the NHS for the services that it provides (Appleby et al., 2009). Such practice carries through to consideration of cost and time pressures within medical device development (e.g., Shah and Robinson, 2007). The next chapter outlines the cost and value of child involvement, including consideration of the quality and quantity of the information that was obtained. Following this, there are conclusions outlining the findings from each topic of interest, before a discussion identifying areas of investigation for the next stage of the research.

Chapter 5

Cost and Value of Child Participation



This chapter presents the second half of the findings from the research visits to the primary schools. The chapter outlines the cost and value of child involvement in healthcare technology design and development. **Chapter 4** outlined the results for the topics of interest covering personal and environmental factors, and the method comparison.

This chapter begins with **Section 5.1,** which focuses on the cost of involving children in the design activities. Cost is used in this chapter to discuss an exploratory cost-benefit analysis of child involvement. This consists of not only gauging the actual cost of involving children, but also looks at factors such as the number of responses that can be obtained from their participation within interview methods. **Section 5.2** considers the value of child involvement, by outlining the analysis that was performed on the transcripts from the interview methods with the children to consider the content of the information that was obtained. **Section 5.3** begins by synthesising and presenting the content information gathered from the interview methods during the research visits.

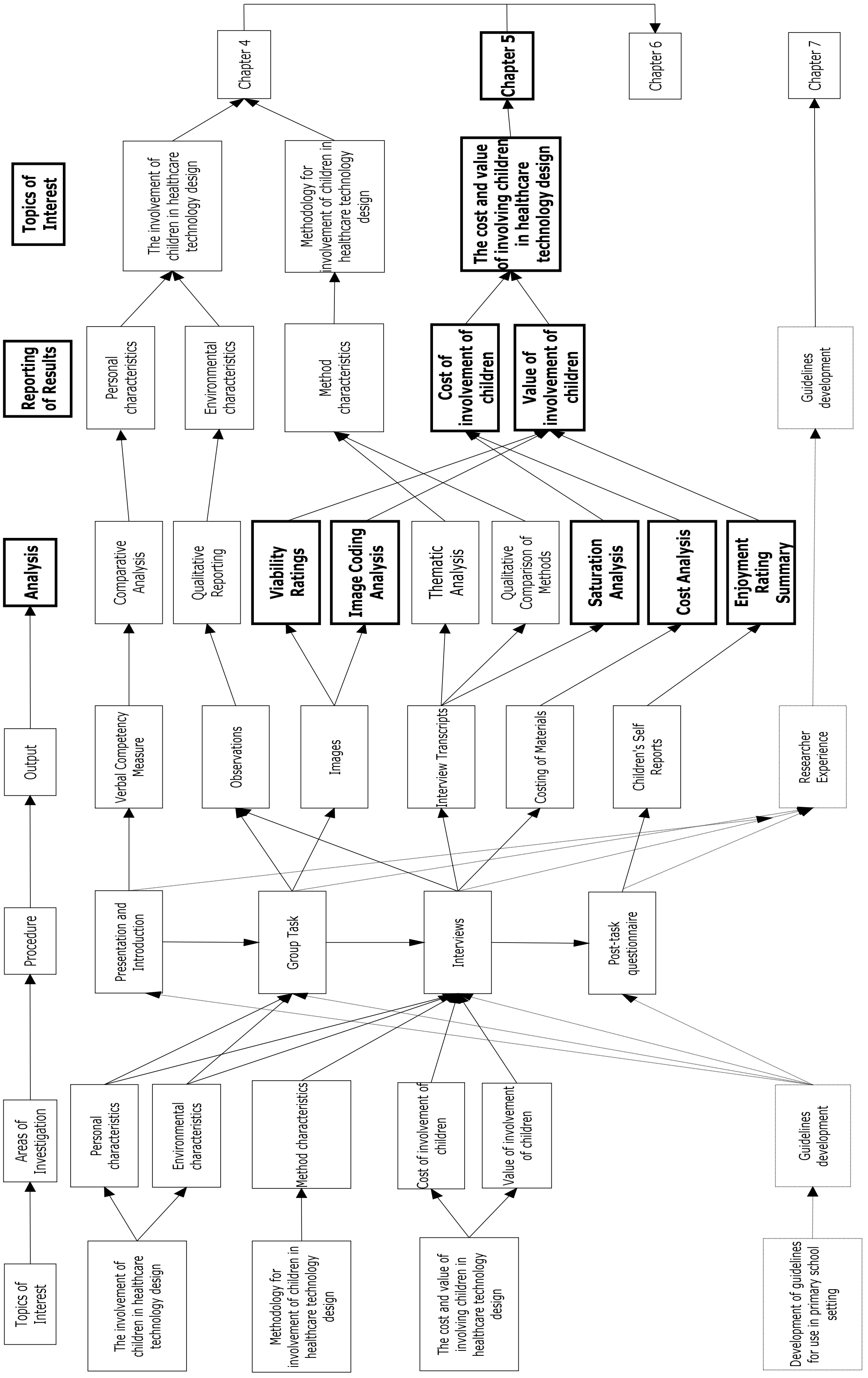


Figure 18 Graph to show the topics of investigation that are discussed within **Chapter 5**

5.1 Cost of Child Involvement

Within this section, a focus on cost is an exploratory means of evaluating the cost-benefit aspects of child involvement. The section is broken down into subsections of i) the time taken to set up and complete the methods, ii) the quantity of information gathered during the research visits, and iii) the physical costs of materials. Therefore, the focus of this chapter extends beyond actual cost, to consider aspects of efficiency and time. This section begins in **Section 5.1.1** with an overview of efficiency, examining the time and efforts required to setup and perform the four interview methods that were used during this research. This is followed by further examination of time in **Section 5.1.2** when looking at the ability of children to respond to all questions within the methods, alongside reviewing time taken by children to complete the different methods. **Section 5.1.3** identifies the number of responses that were gathered from the child participants whilst participating in the different methods. **Section 5.1.4** then considers the physical cost of materials, outlining the costing that took place within the process of performing the four interview methods in this research. The section concludes with recommendations of data analyses that can be used to inform healthcare technology research practice currently taking place with techniques such as purposive sampling.

5.1.1 Efficiency

The analysis of efficiency was taken from the Markopoulos and Bekker (2003) framework, as previously outlined in **Chapter 3**. It is discussed away from the main method comparison in **Chapter 4** because it relates more closely to considerations of cost, as presented in this chapter. The analysis of the efficiency of methods is outlined for each of the four methods, based on qualitative observations from the researchers.

Design-Led Interview

The DLI required a researcher to set up a room specifically for the method to be carried out. Further to this, the method required a number of material resources, including both drawing utensils and other materials for creating models (see **Section 5.1.4** for costing). The inclusion of so many materials meant that this method took the longest time to set up, with the need to arrange desks and tables to create enough space to run the methods. The resultant prototypes were often vague and lacking detail due to the lack of time, or often left incomplete. **Figure 19** shows examples of low-tech prototypes that were produced during the DLI's. The image on the left shows a child's design of a joystick, with the image on the right showing an unfinished design where a child wanted to create a machine that could be used by children to strengthen their wrists.

Figure 19 Examples of a low-tech prototype that was developed with a child during a DLI

Although the primary objective was to gather responses from the participants, in order for the prototype to provide additional information more time will be needed in future research visits. However, the prototype was still functional for providing a focus during discussions, so the need for completion of the prototype is not definite.

Board Game

The board game required the use of a prefabricated board game and question cards for the method (see **Section 5.1.4** for costing). The question cards and counters for the game all had to be created and obtained prior to the research visits. The board game requires at least three minutes to position all of the pieces and parts ready for use on a visit. During the board game method, the researcher has very little control over the game play itself, with the children guiding the activity; therefore, the time taken to complete the method is dependent on the approach adopted by the participating children.

Focus group and One-to-one Interview

Both the focus group and the one-to-one interview required low levels of resources. Only allocated space was required for these two methods, alongside the question list, although the focus group would take slightly longer than the interview to prepare. This was due to the need to set up the room with more chairs and space for completing a focus group. The clear point of differentiation between the two is the level of information obtained from the children in relation to the number of children taking part. Given that the focus group was one of two groups to contain multiple participants, it would be expected to generate more responses. This is discussed further in **Section 5.1.3**.

5.1.2 Completion Rates of Each Method

The completion of all of the questions in the set list was used to define whether a method was complete after the twenty-minute period assigned to each trial of a method. **Figure 20** indicates the proportion of complete and incomplete question lists for each of the four interview methods that were used**.**

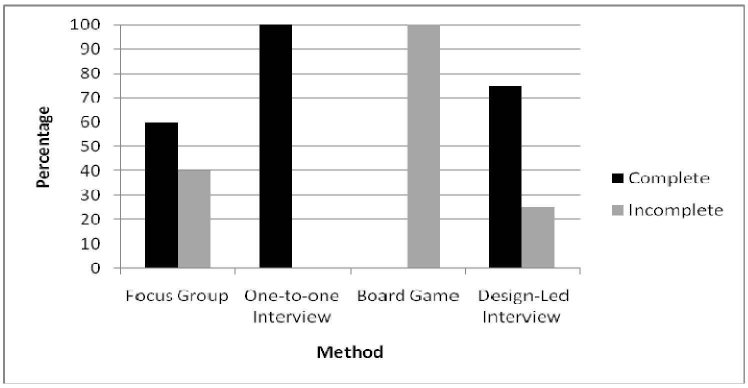


Figure 20 Graph to show the percentage of question lists that were either complete or incomplete at the end of the twenty-minute time allocation for each method

Children who participated in the one-to-one interview always completed all of the questions in the twenty-minute time limit set for each trial. The DLI and the focus group were similar in the proportions of visits that completed the questions in the given time. The board game did not complete all questions in the set list in any of the visits where the method was used. In order to explain these differences, the transcripts were examined for any interruptions or deviations that arose when children were participating. The one-to-one interview method did not receive any interruptions from the children in any of the visits, and the conversations between the researcher and child remained focused. The DLI received a small number of interruptions to questioning, although these were often questions from the children regarding the low-tech prototypes being developed, or similar questions. This may provide insight into the higher completion times for both the one-to-one interview and the DLI.

As outlined in **Section 4.3.1**, the board game and the focus group received a range of unrelated questions and disruptive behaviour from the children. The focus group presented a number of instances where children were laughing and joking, which often led to responses and discussions that were unrelated to the question. Similarly, for the board game, instances of interruptions were linked to arguments regarding the order of the game, or discussions about the way that the game was being played. As in the focus group, responses to the questions deviated away from the questions initially posed. Such behaviour provides insight into why the methods may have had lower completion rates in the set twenty-minute period.

Figure 21 shows the average time taken to complete the different methods. The board game took the longest average time for children to participate (*X* = 20.00 minutes, *SD* = 0.00), where the participants always took longer than the maximum time of twenty minutes to complete the question list. This further verifies the findings displayed in **Figure 20** where the board game method was not completed by any groups in the assigned time limit. The focus group took the second longest time to be completed (*X* = 18.44 minutes, *SD* = 2.17), followed by DLI (*X* =15.97 minutes, *SD* = 3.27) and the one-on-one interview (*X* =11.89 minutes, *SD* = 2.59). With the methods containing four participants, the presence of an activity in the board game method (i.e., moving pieces around the board, rolling the dice) may have contributed to the extra time required when compared to the focus group. Similarly, for the methods containing only one child participant, the DLI design of a low-tech prototype may have caused extensions to time that were not present during the one-to-one interview.

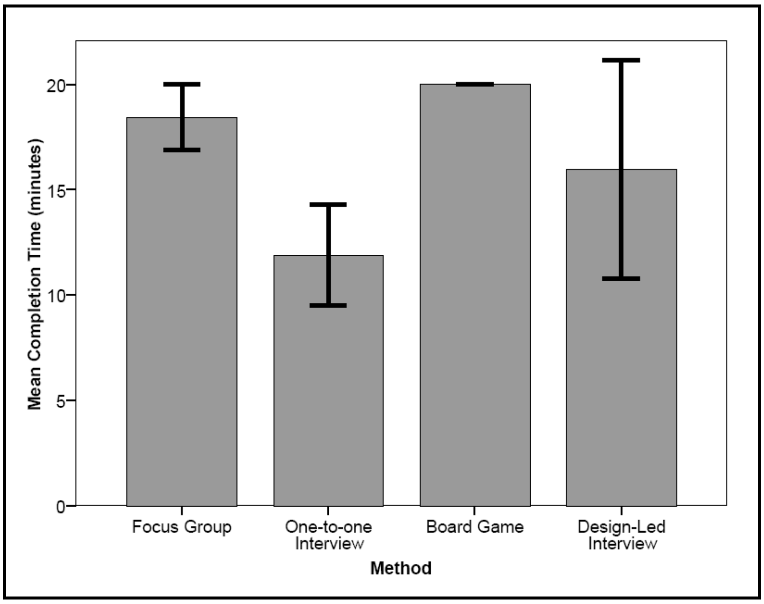


Figure 21 Graph to show the average time taken to answer all questions within a method across all participants. The error bars represent 95% confidence intervals.

The two methods taking the shortest time to complete all of the questions both involved only one participant. **Figure 21** shows overlapping error bars between the two groups so it is unlikely that the difference between the groups was significant. A Mann Whitney-U test was performed to examine the difference between the two shortest times, where it was found that the differences in times taken to answer all questions within these were non-significant (*U* = 4.00, *ns*, *r* = -.57).

5.1.3 Number of Obtained Responses

This section briefly considers the number of responses that were gathered to a question when it was posed within the different interview methods. The time and cost of materials required for involving children has already been considered, but this section outlines the quantity of information that was gathered from the different methods.

In order to represent the average number of responses gathered per participant, the number of responses gathered by the focus group and board game methods was divided by the number of participants in the method. Following this adjustment, the focus group was shown to gather the largest proportion of responses per participant ($X = 2.27$), but the difference when compared to the board game ($X = 2.24$) is very small. Both of these methods contained four, and occasionally five, participants. The two methods involving only one participant are represented as gathering fewer responses than the four-participant methods. Although the DLI ($X = 1.29$) gathered the least number of responses per question, the difference when compared to the one-to-one interview ($X = 1.36$) was only small.

In order to investigate the number of responses gathered during the methods, the distribution of gathered responses were examined by method. **Figure 22** outlines the distribution of the number of responses gathered to questions during each method. The number of responses gathered from a question was recorded as a single figure and plotted. Where a question may have gathered four responses on average, it was not accounted for in the preceding categories. As shown in **Figure 22** the methods involving one participant (i.e., the one-to-one interview and the DLI) often provided only one or two responses to a question. For example, 77% of the responses given to questions for the DLI involved one response from a participant. The distribution of the responses indicates that the methods with four participants provided more responses to questions. Within both the focus group and board game methods there were instances of participants providing up to six responses per participant (although this only accounts for 2% of the overall responses, with the majority of questions receiving fewer responses). The focus group gathered the largest number of responses with a selection of participants (i.e., 1%) providing up to seven responses per participant for a small number of questions.

Overall, the spread of scores shown in **Figure 22** shows a much wider distribution of responses per method for the focus group and the board game, with many responses for the one-to-one interview and DLI being grouped into the categories representing fewer responses.

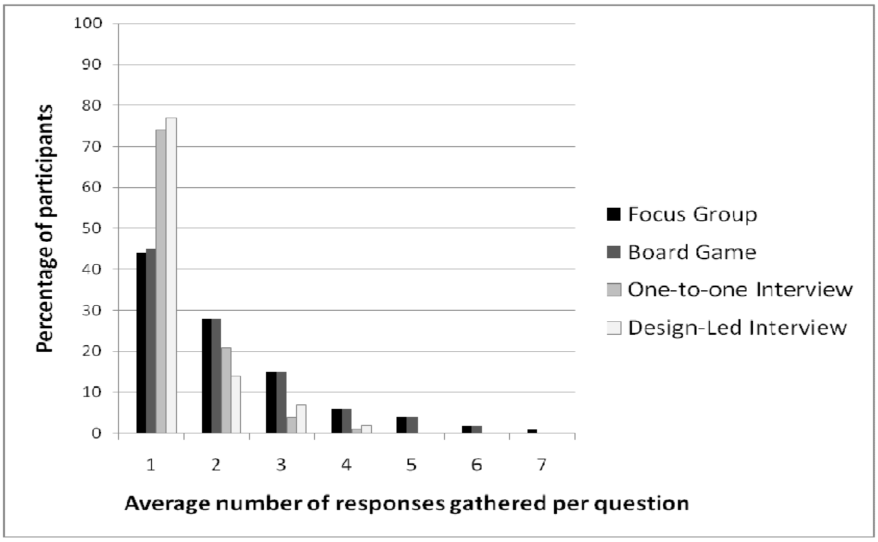


Figure 22 Number of responses to questions for each method

5.1.4 Costing of Interview Methods

This section considers the cost of conducting healthcare technology design research within the school environment. The researchers who participated and supported the primary author in the research trials did so at no cost, and volunteered to participate. However, in order to provide a more realistic representation of costs that can be involved in similar future research, a more comprehensive listing of potential expenditure is discussed. This contains a discussion about the wages that would have been required had the researchers been formally employed on the project instead of only volunteering. Further to this, there is consideration of resources such as materials used during the interview methods. Through calculating such figures, it is possible to gather an estimated average cost per child in relation to the participants involved in the research.

In order to develop costing for the hours spent working on the interview method visits by researchers in this stage of the thesis, calculations were made that reflected wage costs that would have been incurred had all researchers been in employment at the University of Leeds during the current 2009 / 2010 academic year. The information used to calculate this information was provided by the Faculty of Engineering Research Office at the University of Leeds; therefore, similar costs across different universities might differ. Wages were calculated for each researcher based on each researcher holding one full-time equivalent contract (i.e., 1 FTE) at the university, where this would require a staff member to work 37.5 hours per week for 44 weeks of the year, approximately. Before an hourly rate was calculated from these figures, it was ensured that full economic costing (FEC) was completed for each of the researchers. Since around 2000, higher education institutions have begun to develop a more transparent approach to the costing of their main activities (e.g., research and teaching), and FEC is an integral part of this process. FEC ensures that, alongside supporting wages and equipment costs in university activities, additional funding is provided by the government that considers the full costs of activities, such as the maintenance of laboratory space. FEC figures are not based on salary cost, and are instead determined by the percentage of one FTE contract that is worked by a researcher. Therefore, for the FEC figures represented in **Table 6** (i.e., indirect costs, estates, and infrastructure), the costing for each of the post-doctoral researchers are all equivalent to one another. Although a PGCE student and a psychology undergraduate student participated as researchers, their costing has been calculated in line with a PhD student, as this is the closest match that can be included in a research bid; therefore, the PGCE student and psychology undergraduate share the same hourly rate and FEC figures as the PhD student.

Table 6 Costing of hourly rates for the researchers who participated on the trials

Post-doctoral Research Assistant	**Cost**
Salary	£27,319.00
Pension	£4,371.00
National Insurance	£2,013.00
Indirect Costs	£38,464.00
Estates	£14,828.00
Infrastructure	£842.00
Total Cost (for 1 FTE contract) per annum	*£87,837.00*
Hourly Rate (inc. FEC, as calculated for 37.5 hours a week for 44 weeks)	**£53.23**
PhD Student	
Maintenance	£17,875
Fees	£3,633
Indirect Costs	£7,693
Estates	£11,862
Infrastructure	£842
Total Cost (for 1 FTE contract) per annum	*£41,905*
Hourly Rate (inc. FEC, as calculated for 37.5 hours a week for 44 weeks)	**£25.40**

The costs calculated within **Table 6** were used to develop **Table 7**, where the number of hours spent on the trials is multiplied by the hourly rate outlined above. This provides an overall cost of involving the researchers in the trials held at each of the schools. There is a link here between the methods that take longer to complete (information relating to this was reported in **Section 5.1.2** when evaluating the completion rates of the methods) with the cost of staff. Where a method takes longer to complete, there can be an expected rise in costs associated with staff running the trials. In addition to this, although PhD researchers and post-doctoral researchers were used in these trials, higher costs could again be anticipated should the research require the involvement of a member of staff typically on a higher grade of pay (e.g., professor).

Table 7 The wages associated with involving the researchers in the interview method trials

Staff details	Number of trials	Number of hours worked	Hourly rate	Total
PhD Reseacher	15	5.00	£25.40	£126.99
PhD Researcher	10	3.33	£25.40	£84.66
PhD Researcher	5	1.67	£25.40	£42.33
Post-doctoral Researcher	4	1.33	£53.23	£70.97
Post-doctoral Researcher	4	1.33	£53.23	£70.97
Post-doctoral Researcher	3	1.00	£53.23	£53.22
			Total Cost	**£449.13**

The cost of resources was another component to be considered in costing the research. Only the material resources are considered in this section, as costs of travel were not included. Travel costs may be required in future costing; although no claims were made for travel in this research, as the mileage was not thought to be high enough. In addition to this, this section does not account for transport for children and parents, as the research was field research within the school environment, although this may need to be considered in any similar work that is completed in a different environment. The cost of materials can be added to any existing costs relating to wages, to provide a general overall cost that would have been incurred by this research project if it had been formally presented as a research bid.

The outlined costs include all materials required to perform the interview methods with a child in the school environment. The costs reported in **Table 8** (the breakdown of the figures are available in **Appendix 11**) accurately reflect those incurred during this research. The table also uses information that was presented earlier in **Table 3** to provide details regarding the number of times each of the methods were used.

Table 8 Average cost of materials for the methods

Method	Cost per trial	Number of trials	Total cost for method
Focus Group	10p	15	£1.50
Interview	10p	10	£1.00
Board Game	£3.25	6	£19.50
DLI	£15.24	10	£152.40
		Total cost of resources for all methods:	**£174.40**

Table 8 indicates that the resources required to perform a focus group or one-to-one interview were the least expensive. A board game is more expensive than the focus group or one-to-one interview, although the DLI is shown to be the most expensive method to perform, by a large margin. These are indicative of the cost of resources to perform the methods within this research. The costs outlined within **Table 8** are representative of a DLI that immerses participants in a range of materials with which to create a low-tech prototype. Not all materials that were provided were used, so the cost will vary dependent on the number of materials that are chosen for use in an individual research project. The cost was calculated based on outgoings required to obtain resources to run each method within one visit. If the DLI was performed in a series of visits, then the materials could be reused without any additional expense.

Based on the figures outlined in this section, the cost per child for participants who were taking part in the interview methods can be calculated. In total, the staff wage costs and the resources used for running the interview methods totalled £623.53. When considering the total number of children who participated in this first stage of the research (N = 107), the cost per child on average for involvement in the interview methods was £5.83. In developing this cost, the staff wages were noted as being far higher than the resources required to run the trials.

5.1.5 Summary of Cost of Child Involvement

The review of cost was broken down to cover the time taken to perform the methods, the quantity of information obtained, and the material costs required to perform the methods. This section summarises the main findings from this exploration of the data, alongside discussing how the gathered data can be fed into ongoing practice within healthcare.

Calculating the efficiency of particular elements of a method is important to inform practitioners and researchers in their choice of methods in future research. In this research, the efficiency of a method was determined by reports relating to the time and effort required to set up the method to perform with children. The DLI was the most time-consuming to set up, requiring space to be created for the materials needed to develop low-tech prototypes. Similarly, it was necessary to create space for the board game method, although this took less time. The focus group and the interview were perhaps the most straightforward and least time-consuming methods to set up, and eventually run, with minimal demand on space and time, and only the need for a question list.

A consideration of time led to the exploration of the completion rates of the different methods. The board game failed to complete any trials that completed all questions on the set list within the twenty minutes assigned to each method. Conversely, the interview method completed all questions for every visit of the method within the assigned time limit. The two remaining methods had a mix of outcomes with completion rates of 70% for the focus group and 75% for the DLI. The average times taken to complete the interview methods followed a similar pattern to the completion rates, with the order of methods from the shortest to longest time being as follows: one-to-one interview, DLI, focus group, and board game.

Through an exploration of the number of responses, it was shown that the focus group and the board game both gathered the largest number of responses on average from participants during the interview methods. The methods that gathered the most responses both contained four participants or more during their use in schools, with the methods requiring one participant gathering fewer responses on average. This same trend carried through into the examination of the average number of responses that each participant provided to a question. The methods involving more participants showed higher levels of responses per participant, with the highest number of responses gathered per participant being up to seven responses by a small range of participants during the focus group. However, within this research there was no metric used to gauge the quality of responses as they occurred. This causes difficulty when accounting for the disruption that occurred during the focus group and board game methods, which can be used to explain the lower completion rates of the question lists found for these methods. Although the children may have produced more responses in methods involving four children, the relevance of the responses is questionable in a range of instances, particularly when compared to the focused responses that were reported in the methods involving only one child.

The analysis of the costing of the staff wages and material resources was presented for running the interview methods used during the trials described in this first stage of the research. It was calculated that on average, the cost per child during the interview methods in this phase of the research was £5.83. Considerations that will need to be made in future research include the addition of any travel costs should parents or children be required to travel beyond the school environment, or if the research team have to travel long distances. Additionally, the cost of any spaces that may be used beyond the school or university setting may need to be accounted for, as the FEC figures provided in **Section 5.1.4** only account for space used for research within university buildings.

When exploring the costs of the individual interview methods, the DLI was the most expensive method, although this was based on the cost of performing one visit. In practice, the materials used for the DLI method (e.g., plasticine, pencils, and card) could be reused if the method was repeated. The choice of materials was important during this method, as the children should have the freedom to create diverse low-tech prototypes, so the initial costs would be hard to avoid. The board game was the second most expensive method, although it was considerably cheaper than the DLI. The cost outlined for the board game was the initial expense to set up the materials needed, including the board on which to play the game, although once the initial cost had been expended, the board game would be available for continual use without any further cost. The focus group and the one-to-one interview were the methods with the lowest material costs, requiring only the cost of the question lists.

Cost and time were outlined as major barriers to user involvement in medical device development due to the reluctance that this can cause manufacturers to involve users (Shah and Robinson, 2007). The research outlined in this section begins to explicate figures relating to both the cost and time associated with child user involvement in healthcare technology. The findings in this research are limited to the cost of the four interview methods used in the school environment. Continued reporting of similar findings that extend to other methods and environments would begin to provide a basis on which practitioners working with children in healthcare technology development can make informed decisions relating to the suitability of methods in the context of their own research. Future research would also benefit from extending the outlined research on the number of responses gathered by participants. Such information can feed into work to inform practitioners of cost (input) and expected amount of acquired information (output).

The next section focuses on the analysis of the saturation of responses. This topic is not directly related to the time, quantity and material costs discussed above, although it is associated closely with ongoing practice in healthcare.

5.1.6 Analysis of Saturation of Responses

Within healthcare, a large amount of qualitative research relies on purposive sampling based on theoretical saturation guidelines (Guest et al., 2006). Purposive sampling is the non-random selection of participants to achieve a certain goal. Saturation in this sense relates to the point at which no new information or themes are observed in the collection of data for a question or topic (Guest et al., 2006). Therefore, the analysis of saturation within this section looks at how the responses gathered to particular questions can be used to inform the number of participants that might be required to uncover a similar level of content in other research. Currently guidelines do not exist that outline any saturation patterns in the information gathered from children in healthcare technology design. Therefore, this section of the research summarises the responses gathered from children to a range of questions, looking at the point at which the peak of newly obtained information occurs. This will help to inform research on saturation levels in healthcare technology development with children and will create a foundation on which to form decisions relating to purposive sampling practice in the area.

The descriptions of saturation that were performed during this section of the research were supported by saturation graphs that were designed specifically for the purposes of this analysis. These graphs were used to display the responses that were gathered for three questions during the interview methods. Only three questions were used due to space constraints within the thesis. The questions were used because they link directly to the engagement of children with healthcare technology, and can be used as examples from three specific topics of enquiry in the research; i) appearance (what does hospital equipment look like?), ii) function (what would make a rehabilitation device look like it's just for children?), and iii) texture (what would you like a rehabilitation device to feel like?). For each of these questions the responses were not analysed separately according to method, as the number of participants who took part was too small to identify saturation levels. Therefore, the saturation analysis took place by involving the responses from all of the children to the three questions above and plotting them in graphs. Although the findings of the saturation are limited to the multi-method approach performed during this research, the graphs can be used in future research on specific methods, should participant numbers be high enough to identify saturation levels.

Throughout the analysis of the saturation of results, a response was defined as an answer given by a child participant during an interview method that was relevant and in direct response to the question posed. The analysis within this section does not limit the number of responses to one per participant; therefore, a method such as the focus group may have reported multiple responses from participants when responding to questions. In addition to this, the facilitators did not prompt the children for a response if the children were unsure of an answer. In such instances, the responses were coded as 'don't know'.

Figure 23 shows the saturation of responses for the question, 'What does hospital equipment look like?' The graph can be interpreted by viewing each plotted item as a response from a participant. As the items move from left to right it reveals the cumulative responses that were gathered over the instances in which the question relating to the appearance of hospital equipment appeared in the interviews. A linear trend of plots can be seen moving from left to right in **Figure 23**. This indicates the gradual introduction of new items from responses obtained as the question appears during the interviews. Following the 32nd response gathered to the question, no new items were recorded, and participants only reported previously mentioned items. The graph indicates the point at which no new information emerged from questioning, and hence identifies the saturation point. To indicate this, the marker used to denote the final new item is in bold font, shown in **Figure 23** to be obtained during the board game method, with the marker being further identified with a line marking the item on the x-axis.

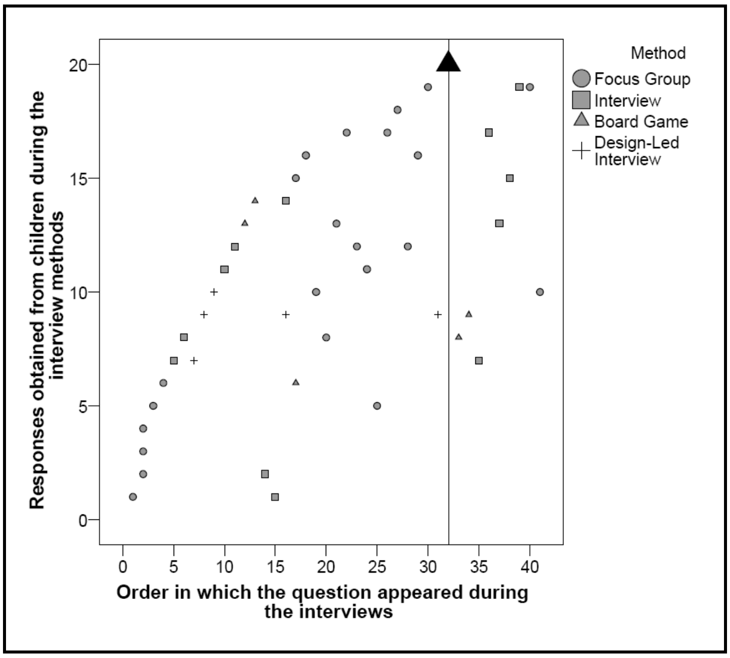


Figure 23 Graph to show the saturation of responses to the question, "what does hospital equipment look like?" The large black triangle indicates the point at which the saturation of information occurred.

As can be seen from **Figure 24**, when children were asked 'What would make a rehabilitation device look like it is just for children?' no new information was gathered for the question following the 15th response that was obtained to the question. This occurred during the one-to-one interview method.

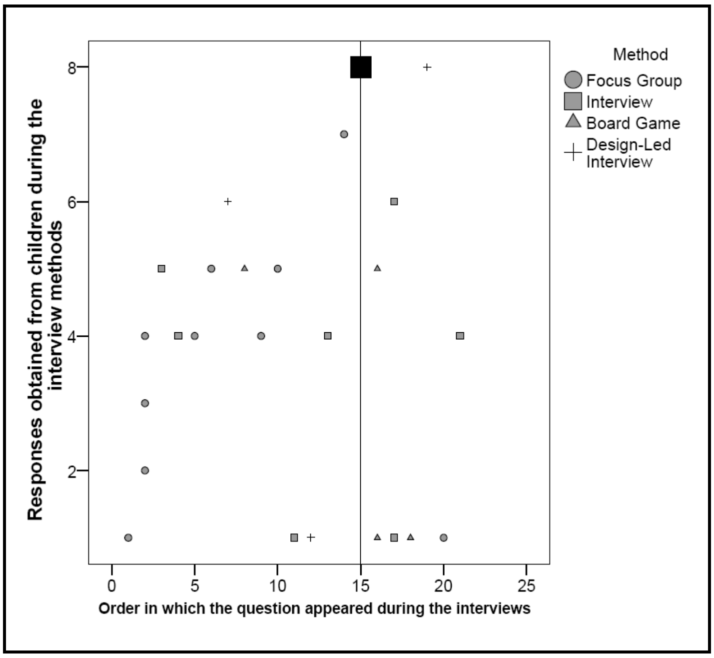


Figure 24 Graph to show the saturation of responses to the question, “what would make a rehabilitation device look like it is just for children?” The large black square indicates the point at which the saturation of information occurred.

The final saturation graph to be examined in this research is shown in **Figure 25**. The last new piece of information gathered to the question, ‘What would you like a rehabilitation device to feel like?’ occurred on the 15th instance of a response being obtained. This response was gathered from a focus group method.

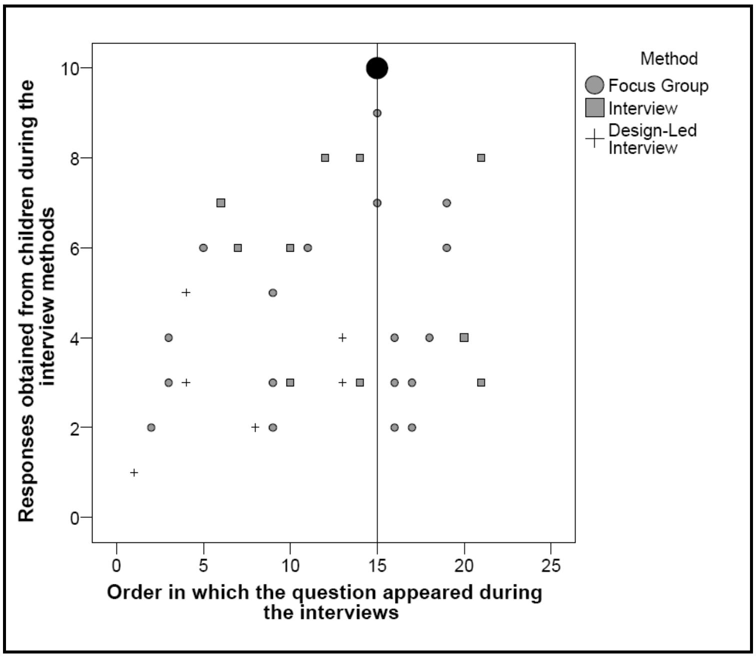


Figure 25 Graph to show the saturation of responses to the question, “what would you like a rehabilitation device to feel like?” The large black circle indicates the point at which the saturation of information occurred.

This analysis of saturation can inform typical patterns of retrieval when using an array of interview methods; however, it cannot report on the saturation that can be seen during individual methods because the population size was not large enough. In this sense, it was useful to approach the analysis of saturation with the perspective of having used a multi-method approach, where the results from all of the interviews were combined. Identifying levels of saturation was only possible by applying this approach, and further research into the process of displaying saturation levels is required before more solid conclusions can be drawn. To continue this research, future investigations will be required to involve larger groups of children within each interview method. Given that trends could be found for saturation when grouping together the scores of all participants (N = 107), it is advisable that further investigations begin with this number of participants or above for each method.

Although saturation has only been briefly explored within this section it has provided insight into the possible number of children that are required to gather information on three topics; appearance, function and texture. Although this process requires further investigation, saturation levels as addressed in this section could inform purposive sampling techniques currently used in healthcare by delivering information on theoretical saturation guidelines relating to healthcare technology design with children.

5.2 Value of Child Involvement

To accompany the costs associated with the involvement of children within this research this section evaluates the value of their participation. The value of child involvement within this research refers to the quality of information that can be obtained using the four interview methods, alongside investigating the topics for which children can provide responses. Value also involves understanding the experience of the children during the research visits, and involves their reported levels of enjoyment and any feedback they provide regarding improvements to the process.

This section begins with an overview of the images that were obtained in the group tasks in **Section 5.2.1**. **Section 5.2.2** outlines a more detailed analysis of the images when the information provided within them was assessed by engineers in terms of the clarity of information and the viability of the designs. **Section 5.2.3** outlines an analysis of the content that was acquired during the interviews with the children. Similar to the saturation analysis, the approach adopted during the content analysis considers all information obtained during the interview methods as a multi-method approach, and does not distinguish between the sources of information. The content acquired from the children who participated in methods designed for children with severe communication disorders is then discussed in **Section 5.2.4**. The content of the information obtained in the more commonly used visits alongside the visits designed for children with severe communication impairments is summarised in **Section 5.2.5**. **Section 5.2.6** provides an overview of the information that was obtained from the children with the use of the post-task questionnaires. This section discusses ratings of enjoyment and recommended areas of improvement provided by the children. The section concludes with a summary of the information relating to the value of child involvement in **Section 5.2.7**.

5.2.1 Image Content Analysis

The image content analysis involved coding the features that were created in the images by the children in the group task activity. Having initially evaluated a small number of the diagrams, the themes listed in **Figure 26** were used to categorise the information portrayed in the images.

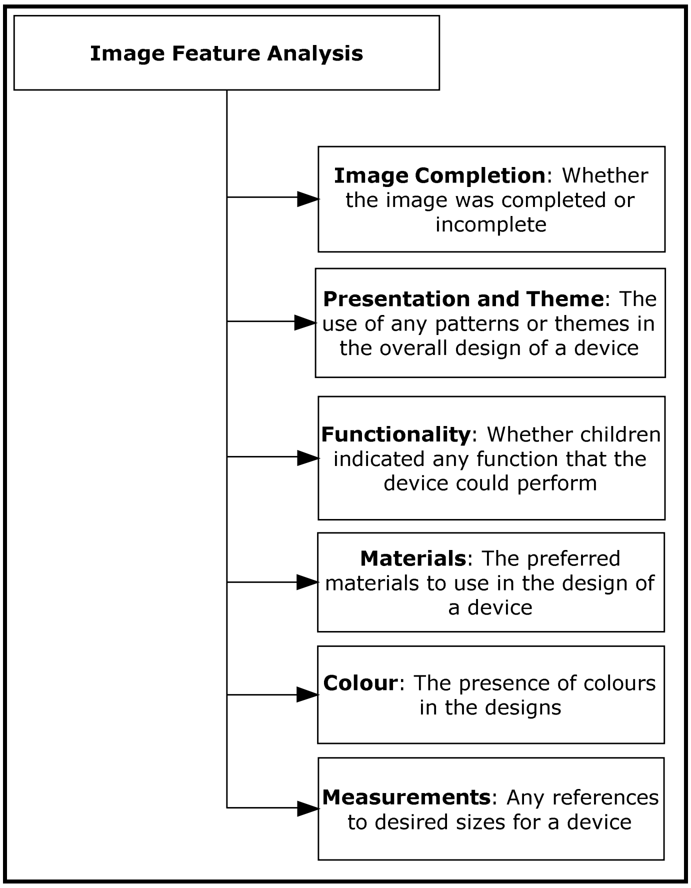


Figure 26 Themes identified from the image feature analysis

After the initial identification of a theme list, no further themes emerged that had to be added to the initial framework to code the images. The use of two devices presented during the group task has played no role in the analysis until considering the content. The descriptions of content, when making distinctions between the groups, involve three groups of differing age. Each group was presented with either the joystick or the handwriting device and the same device was then used as the focus of the group task and questions posed during the interview methods. The groups included 7 – 8 year olds who focused on the handwriting device, 7 – 8 year olds who concentrated on the joystick, and a 9 – 10 year old group that also focused on the joystick. The following sections provide a brief description of the main content that was identified within the outlined features.

Image Completion

All of the discussed images derived from the group task design. Of the images that were entered into the analysis, the majority (*N* = 84) came from the 9-10 year old group. There were fewer participants in the 7 – 8 year old group and subsequently there were fewer images that were generated (*N* = 29). Although a large number of images were generated from the group task (*N* = 147), several images were left incomplete (*N* = 34) and were not entered into the image feature analysis.

Presentation and Style

The number of styles that were identified in the designs by children was proportional to the number of children in the different age groups. The 9 – 10 year old group used the largest number of styles, although there was crossover in a range of categories between all groups. The most commonly used styles included the use of assorted shapes and stripes as shown in **Figure 27**.

Figure 27 Example of the most popular theme used when completing the designs during the group task

However, a large proportion of children used no design and simply coloured the separate portions of the design in one colour.

Functionality

Identifying whether children included any indication of intended functionality into the design of a device was an attempt to consider factors beyond the aesthetics of a device. Several children within the 9 - 10 year old group imitated the original design, with only two designs attempting to incorporate independent ideas of rehabilitative function by the children, with one example shown in **Figure 28**.

Figure 28 shows a device that is designed to support the wrists of its users, where the user applies force against the device to complete exercises and muscle building for the wrists. The device was designed by a child in the group task and discussed in more detail during the DLI.

No designs in the 7 – 8 year old groups included any rehabilitative or functional information; although no children imitated the original design of the device either. The majority of the images designed by this younger age group contained designs that were novel and not linked to the original device that they were shown during the initial discussion.

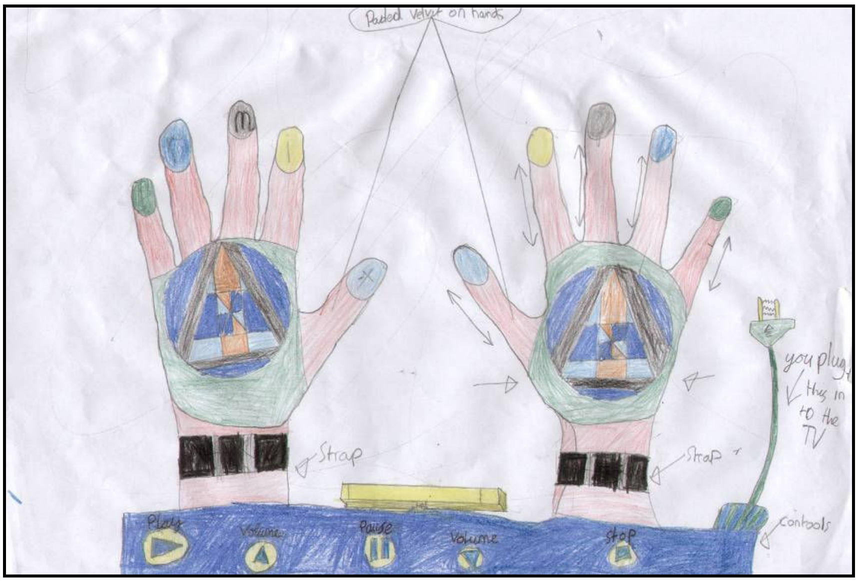


Figure 28 Image showing a design by a child from the 9 - 10 year old group that tried to incorporate rehabilitative function into their design

Materials

Metal, rubber and plastic were the materials most favoured for use in the image designs by the children across both age groups, where metal was the most widely used. Similar to the identification of themes within the images, several material suggestions were indicated.

Colour

Unlike other themes, the number of items generated by colour was limited. All children received the same design materials at each school and this may explain the use of similar colours across the images. The most commonly used colours across the groups included ‘red’, ‘yellow’ and ‘blue’. Many colour types were mentioned by the children, although ‘white’ was the least chosen category across all age groups.

Measurements

In a small number of cases, children in the 9 – 10 year old group indicated a range of desired measurements in their designs. The worth of the information included by the children is questionable since very few children seemed to reflect an understanding of the use of measurement units (e.g., a metre). Some children incorporated measurements within the images, but arbitrary metrics were used. A small proportion of children incorporated consistent measurements into their design, as seen in **Figure 29**. The presentation of consistent measurement information may improve the viability and clarity of a design if such information was to be interpreted by designers. Such issues are considered in the image analysis in **Section 5.2.2**.

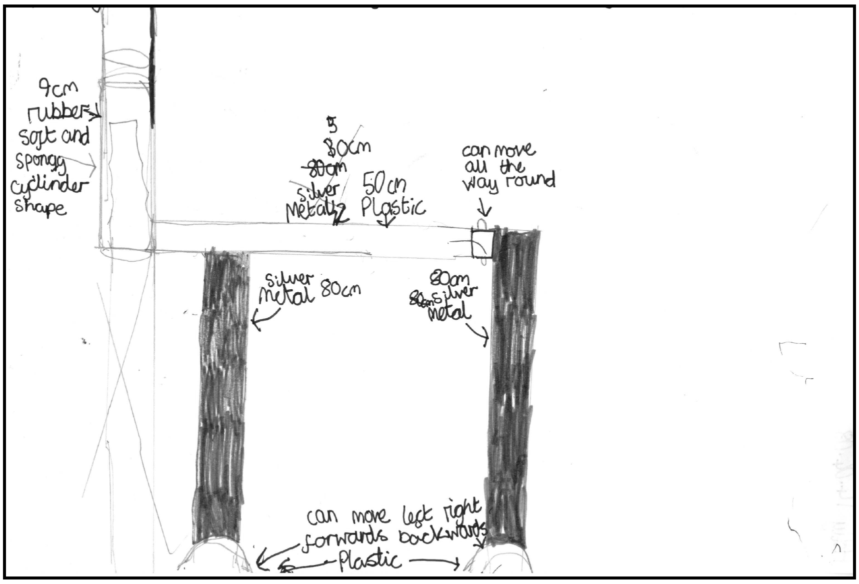


Figure 29 Image to show the use of measurement details within designs created during the group task

Children in the 7 – 8 year old group who focused on the handwriting device made occasional references to the height of a device, and four children referred to expected costs of the device. In a similar manner to the 9 – 10 year old group, many of the references to size and cost appeared to be arbitrary. Such findings support existing literature that highlights that children have difficulty understanding measurement (Kamii and Housman, 2000). One explanation for such difficulty has been the methods used to teach measurement to children, which often involve empirical procedures in using tools such as rulers, where little focus is placed on the child's ability to reason about measurement problems (Clements and Bright, 2003). Castle and Needham (2007) highlight that there is a need to encourage and consider alternative points of view when trying to gauge children's understanding of measurements. Castle and Needham (2007) recommend interviewing children about their ways of understanding measurement and encouraging children to keep books or journals that can be read by a teacher or researcher to gain a better understanding of a child's understanding of measurement. Although proposals by Castle and Needham (2007) may be practical for use by a teacher in the classroom, future research in technology design with children should consider the development of methods that gauge how a child understands measurement. Further to this, such information should be suitable for presentation to designers to express the ideas of children. Within this research, the strategies used to gather size and cost preferences from the children were not effective as very few children provided this information, and in most cases where this information was present, it was unclear.

Summary of Image Content Analysis

The information that was coded in the analysis of the images allowed the breakdown of features that emerged. The main themes used in children's drawings included assorted shapes and stripes. Only two children from the 9 – 10 year old group attempted to incorporate rehabilitative function into their group task designs. The most commonly used materials included metal, rubber and plastic, and the most popular colours were red, yellow and blue. Finally, some children incorporated size and cost information into their drawings but the reliability of this information is questionable.

Although it is possible to document the preferences that are outlined in the images, it is difficult to ascertain whether incorporating such properties into the design of a rehabilitation device would improve a child's engagement with a device.

5.2.2 Image Analysis

Following an overview of the content of the images obtained during the group task in **Section 5.2.1**, this section examines the viability and clarity of the information portrayed in the diagrams. All of the images were evaluated and rated on 5-point scales by two engineers from the University of Leeds. The rating scales asked the engineers to report their opinions on the viability (from 1 = 'not viable', to 5 = 'very viable') and the clarity of information (from 1 = 'very unclear', to 5 = 'very clear'). One of the engineers had previous experience in the development and realisation of a RT prototype, with the second engineer having practiced within a range of industrial settings. Both participants were working full-time at the University of Leeds.

Figure 30 shows the percentage of ratings that were placed in each item on the 5-point rating scale for the viability ratings of the images. The rating of ‘2’ was the most popular rating used by the engineers, accounting for 35.3% of ratings, although the rating of ‘3’ accounts for 32.6%. Overall the average rating of viability of the images was ‘3’ (*X* = 2.81, *SD* = .971). The standard deviation, relative to the mean viability image, suggests that the spread of scores was quite wide.

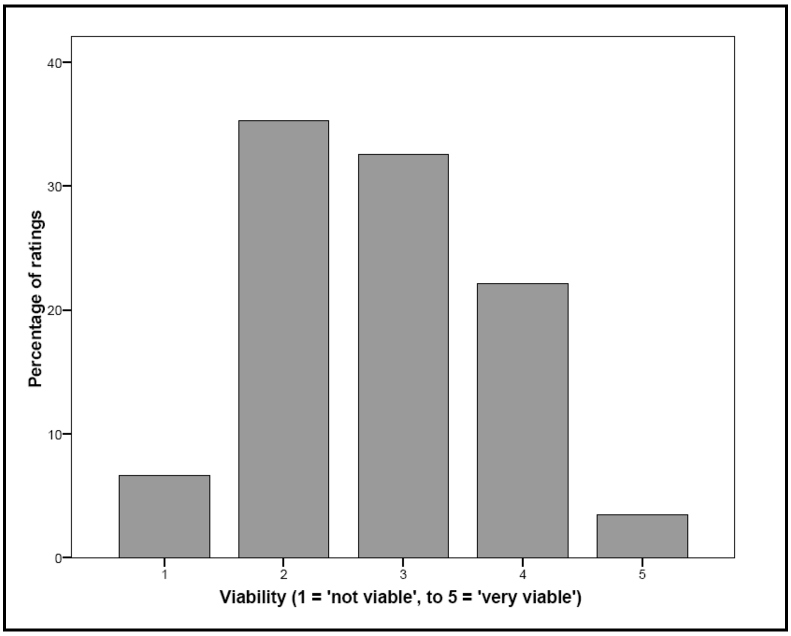


Figure 30 Graph to show the mean viability ratings provided from the two engineers

Figure 31 shows the percentage of ratings that were placed in each item on the 5-point rating scale for the clarity ratings of the images. The rating of ‘2’ was the most popular rating used by the engineers, similar to the viability ratings, accounting for 36.4% of the ratings. The difference between the distribution of ratings of ‘3’ and ‘2’ is greater for clarity ratings than viability, with ratings of ‘2’ accounting for 29.8% of the ratings. The average rating, like viability, was also ‘3’ (*X* = 2.82, *SD* = 1.07). Similarly, there is a large standard deviation when compared to the mean for clarity ratings; therefore, this is explored further when reviewing the ratings of the engineers separately below.

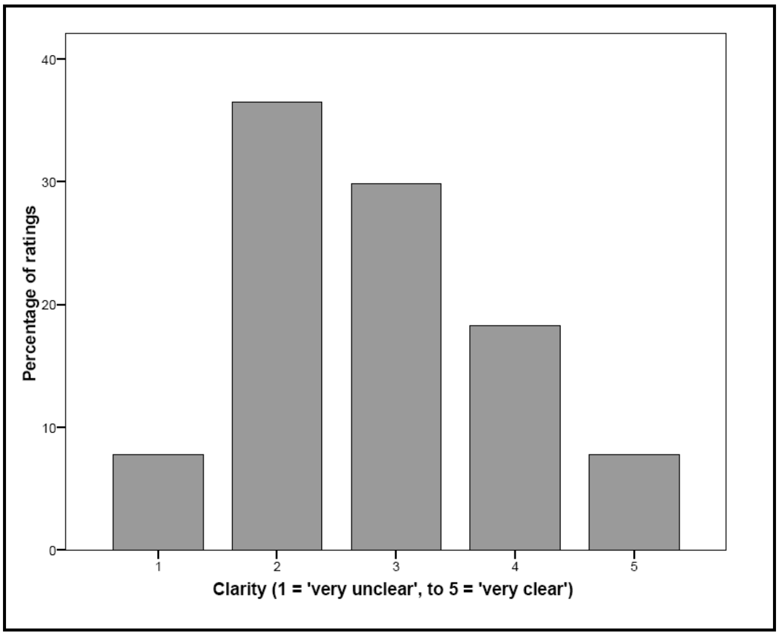


Figure 31 Graph to show the average clarity of information ratings given to images

To provide insight into the analysis that was completed, examples of the images that reflect the ratings by the engineers are provided. **Figure 32** provides an example of a diagram that was given a rating of '5' ('very viable') by both designers. The design shown in the figure shows the shape of a rehabilitation joystick that was very similar to the rehabilitation joystick device shown to the children before the group task activity. The children have taken the design of the original device and modified it to incorporate the colours of a football team of their choice, and have modified the design of the exterior of the joystick to incorporate relevant ideas into this theme.

Figure 32 Example of image rated as 'very viable' by both raters

For images relating to a rating of ‘5’ (very clear) for clarity, rater 2 did not list any images in this category. Instead, **Figure 33** demonstrates an image that was given a rating of ‘5’ by rater 1 and a ‘4’ by rater 2. The image uses a theme consistently throughout the design of the device and outlines how the joystick device design would be used with other peripheral devices.

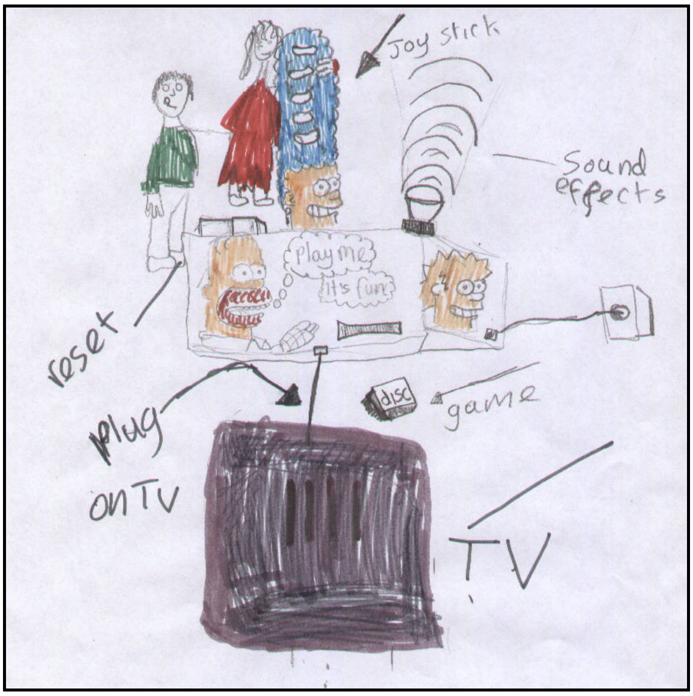


Figure 33 Example of image that received high clarity ratings from the two engineers

Although images can be provided that demonstrate agreement between the researchers on ratings, these instances were not very common within the data. As shown in **Figure 30** and **Figure 31**, overall the mean viability and clarity ratings from the two engineers show that the majority of ratings of images fell between scores of ‘2’ to ‘4’, with a smaller proportion of images being placed in the extreme positive or negative ratings. Although this may suggest a central tendency bias in the raters, when examining individual ratings by the engineers, differences can be observed in the overall trends in the ratings provided for both viability and clarity.

The distribution of scores differed according to the individual raters for viability, where the distribution of ratings for rater 1 ($X = 3.40$, $SD = .776$) was more biased towards higher ratings than rater 2 ($X = 2.21$, $SD = .789$). To investigate this relationship between the two sets of ratings (as shown in **Figure 34**), a Kendall’s tau statistic was used. Kendall’s tau is a non-parametric test that is suitable for evaluating correlations in small data sets with large numbers of tied ranks. A significant negative relationship was found between rater 1 scores and rater 2 scores for viability ratings of the images ($\tau = -.60(258)$, $p < 0.005$). With the continuous ratings provided by two engineers, the Kendall’s tau statistic suggests that the rater's scores correlate, but this does not indicate whether they are in agreement with the ratings of the viability of the images. In order to examine beyond the ordering of the ratings and look at the magnitude of the agreement between the raters, there is a need to examine the single measure intraclass correlation. This index of the reliability of the ratings for a typical, single judge can be used to estimate inter-rater reliability where at least two or more raters have been involved. Due to delays in obtaining information from other raters, only the data for two raters could be used and the intraclass correlations could not be calculated.

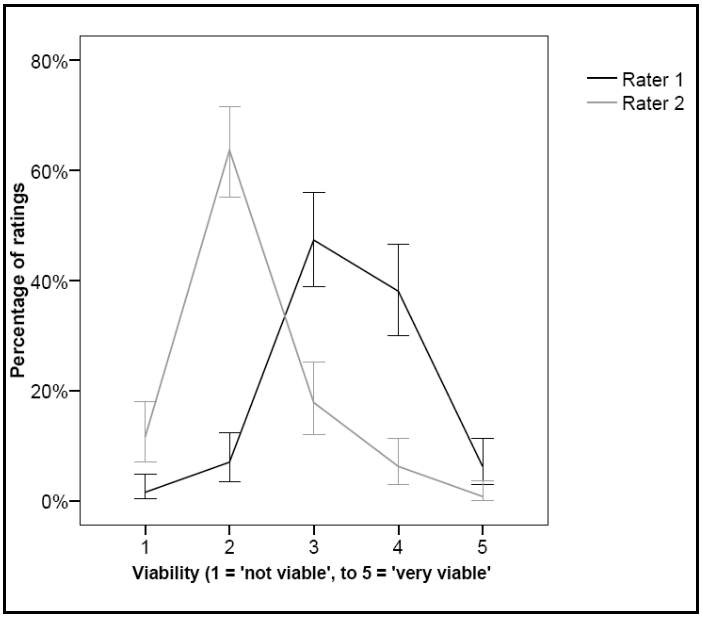


Figure 34 Graph to show the distribution of ratings for the viability of images by the individual engineers

As shown in **Figure 35**, the ratings provided for clarity by rater 1 (X = 3.33, *SD* = 1.07) are more biased towards higher ratings than rater 2 (X = 2.31, *SD* = .789). This trend is similar to that seen for viability. To investigate the relationship between the two raters further, a Kendall's tau statistic was used. A significant negative relationship was found between rater 1 scores and rater 2 scores for clarity ratings for the images (τ = -.438(258), *p* < .005). Similarly, the Kendall's tau statistic suggests that the ratings are related, but the magnitude cannot be calculated with intraclass correlations due to only using two raters.

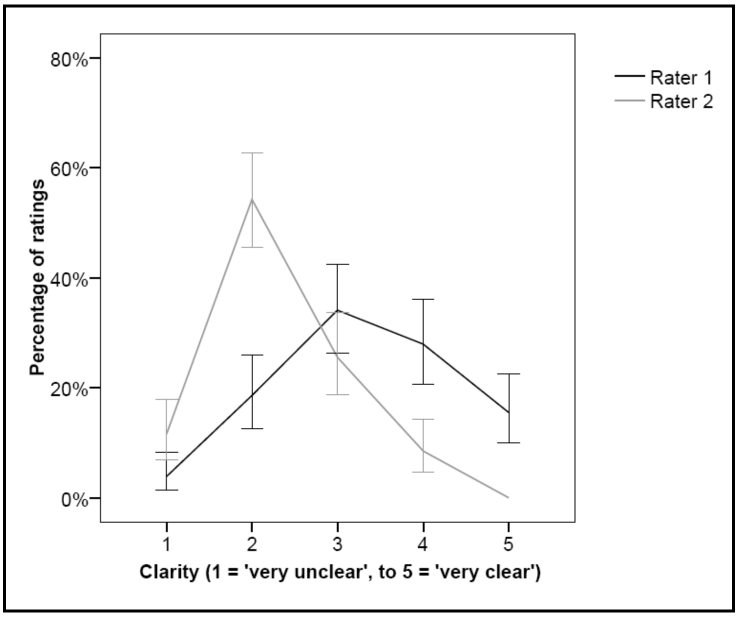


Figure 35 Graph to show the distribution of ratings for the clarity of images by the individual engineers

This analysis of the viability and clarity of images was capable of gathering ratings from two engineers regarding designs. The average mean ratings from both engineers initially reflected a central tendency bias in scoring, but analysing the ratings on an individual level revealed larger differences between the two raters. Consideration of factors relating to the assignment of ratings would have benefited from more raters participating in the activity; future research could look to involving larger numbers of raters in assessing images by children to explore what information designers can incorporate into the design of healthcare technology. The value of children's involvement in this sense is constructed by understanding the quality of the information gathered from children in relation to its practical use by designers. Although average ratings for both viability and clarity were around '3', there is a need to further explore the relationship between the information required by the designer, and the ability of the child to provide it.

5.2.3 Content Analysis

This section contains a summary of the content analysis from the visits that took place with the majority of the children in the research visits. The full version of the analysis is available in **Appendix 12**. This section derives from the thematic analysis that was used to explore the transcripts from the interviews to identify themes that emerged during questioning. The analysis contained the transcripts from both the joystick device and the handwriting device. A framework of themes was first devised and then trialled against seven transcripts to ensure that it was an adequate template. Following this, the remaining transcripts were examined and the template used to explore the information gathered from the interviews as presented in this section as developed. The resultant themes were closely linked to the topics that were present in the question list from the interviews, where the use of a range of closed questions may have limited the expanse of themes and ideas that could have emerged during the interview methods.

In total, two main themes were identified; preferences for technology design, and discussions relating to individuals and their own experiences of healthcare equipment. Each main theme contained sub-themes (as shown in **Figure 36**). This section discusses the content gathered during the interview methods following the structure outlined by the sub-themes. Given the large amount of information that was gathered during the interview methods, the use of sub-themes provides structure and direction to the following discussion of the content.

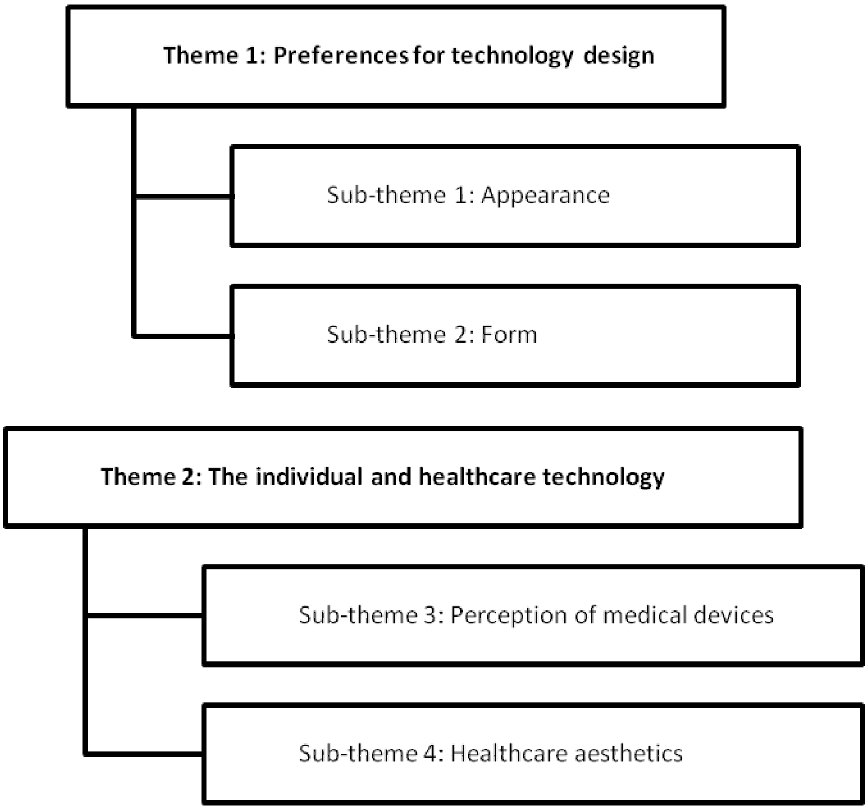


Figure 36 Main themes from interviews with the children

Preferences for Technology Design: Appearance

Discussions that surrounded appearance preferences in technology design included a range of topics. These contained the general preferences for colour, the use of colour dependent upon emotion and the context of a device, and suggestions of ways to improve the appearance of a device.

Children could provide their general preferences for colour without any difficulty, although asking children to disclose their favourite colour often led to children simply listing an array of colours. Although it was not noted in the younger age group, the older 9 – 10 year old group occasionally listed higher categories of colours, using such terms as *"...pastel colours"*. All of the children were capable of providing information on colours that made them happy or sad, such as *"...purple, orange... anything... except from brown and black"*, with a range of children providing justification for their responses to the question, e.g., *"...Red, black, green and yellow... because my dad... he says that red is a warm colour and blue is cold, so it feels like emotions"*. In addition to associating colour with emotion, children also provided justification for decisions to use colours in certain contexts such as the school environment e.g., *"...black, because school is boring"*, or *"...red, like our uniforms..."* Personalisation formed an important aspect of answering questions on colour and appearance, and this was a major factor in responses from children when discussing what would increase the likelihood of them using a rehabilitation device. One child reported that it is important that a rehabilitation device *"...looks good and moves your arms and your muscles more"*.

Preferences for Technology Design: Form

Discussions surrounding form covered the feeling of a device and preferences of materials to use in its design. Questions also related to the use of specific shapes and sizes of the devices. Material preferences often included devices that would be *"...smooth and easy to grip"*, or *"...easy to move"*, although the most popular material choices included metal, plastic and rubber. When listing material preferences, there was very often no accompanying explanation, where it seemed in many instances children were listing materials without being aware of their properties. Similarly, questions relating to shape often involved the arbitrary listing of shapes, indicating a preference for rounded shapes e.g. *"...well if it's pointed you might hurt yourself"*. This type of justification for the use of a particular shape was not very common and often children would just list shapes.

When children provided information about the size dimensions of a device the terms used were often confusing or imitative of an existing metric (e.g., "*...about the size of a table"*) or one introduced by the facilitator. Alternatively, children would demonstrate the size of the device e.g., *"...I don't know, about that big... (child outstretches arms to indicate the preferred size of a device)"*. Children did not appear to have an awareness of the correct use of measurements and sizes in order to describe their preferences for a device, and when children did use measures, terms seemed confused e.g., *"...like medium size"*. Such findings resonate with the literature discussed previously in relation to measurement information that was portrayed in the group task diagrams. The difficulty experienced by the children is in line with similar reports of children having difficulty in understanding measurement by Kamii and Housman (2000).

The Individual and Healthcare Technology: Perception of Medical Devices

Discussions surrounding healthcare equipment use involved topics that enquired about how a user looks when operating a device, alongside their perceptions of disability. There was awareness of the perception of others when discussing topics relating to medical device use by children without disabilities. These children were unwilling to use such machinery in view of other people because it would make them *"...look silly obviously"*. However, most children were willing to use such equipment at home. When discussing child users who have to use healthcare technology for rehabilitation for example, children without disabilities often portrayed feelings of pity or sadness towards them. One major reason for the sadness was the inability of children to be able to perform the same actions as other people e.g., *"...I feel sorry for them because they're not able to do as much stuff as you are"*.

Questions were also asked regarding the use of equipment that is associated with people with disabilities. When discussing equipment used by children with disabilities, AT items were listed, whether children were in groups or individually e.g., *"...electric wheelchairs (child 1)...stair lifts (child 2)...upright stand (child 3)...walker (child 4)"*. The mention of items often stemmed from the school environment of the children, where a child with a disability within their school would be used as a focal point with which to remember related technology. Children also indicated reluctance towards using such equipment irrespective of whether it provided force feedback, as both devices did in the group tasks, or if the devices moved on their own.

The Individual and Healthcare Technology: Healthcare Aesthetics

Discussion surrounding healthcare aesthetics covered perceptions of hospital equipment and how children could be encouraged to use such technology more frequently. Children often struggled to remember equipment from hospitals and often found it difficult to discuss. The children tended to describe large, white machines, or equipment such as the electrocardiograph (ECG). Most responses consisted of descriptions of devices that the children saw as *"...bland; loads of like straight lines and boxes"*. Children were capable of suggesting a range of ideas about improving the appeal of such equipment. The most popular method was the opportunity to personalise the appearance of the device, with children suggesting methods such as placing stickers on the equipment.

5.2.4 Content Analysis for Information Gathered from Children with Severe Communication Impairments

This section presents the information that was gathered from the research activities involving children with severe communication impairments. Due to the limited communicative capability of the children, only small amounts of information were generated by the children, so no content analysis took place on this data. The questioning used also differed, alongside the device (see **Appendix 2**) and the content gathered is presented separately. This section summarises the ability of the alternative methods to extract information relating to the three topics of interest that were used in the interviews with children with severe communication impairments; usability, user preferences, and future and potential designs.

Usability

The first of the three elements for which content was gathered concerned the usability of the proposed communication fixture device. A demonstration of the device used to focus questioning was provided to the children by holding the device next to a child's wheelchair to give a valid representation of where the device would be located. All of the participants reported that despite having a clear view of their feet they would not be able to navigate their electric wheelchair whilst the communication aid was attached in a horizontal position (a position chosen intentionally to assist children with navigation). Although it was necessary for the current design to rotate the talker device, it was indicated that moving the device through 90 degrees was not a desired resting position for the device. In addition to this, two of the three participants expressed dislike to the prospect of using an additional switch to operate the device.

User Preferences

When investigating the second content topic of interest, user preferences, it was observed by the researchers that a number of children added a degree of personalisation to their own wheelchairs, and that this was commonplace among many child wheelchair users. Two of the three child participants in this research had customised their own wheelchairs with stickers. The participants responded very positively when asked if they would like the option to personalise the device being developed with their favourite colour; the most popular choice of colour was blue.

When choosing materials to use on the exterior of the device, the participants preferred materials with a gloss finish (i.e., glossy polymer and painted aluminium, as chosen from images). Texture samples were provided to give children an understanding of the different materials that could be incorporated into the device and to gather children's touch preferences. All participants had contact with the different texture samples and unanimously preferred the feel of a matt polymer sample.

When gathering feedback from children regarding their preferred shape for use in designs, each participant provided different selections. The selections included a circle, triangle and rectangle.

Future and Potential Designs

The children were asked about future designs that could be used when creating communication fixtures for the children's communication aids (i.e., talker machines). The redesign of a communication aid was highlighted as a possible direction for future research by the children, which may have been a result of the continual functional problems that occurred with the use of the communication aids during the interviews (e.g., the screen freezing, slow menus when trying to navigate for specific words). However, when children were provided with options to improve visibility on the talker display, enhance the accessibility of icons, words, and pictures, and reduce the size of their current talker machine, the children expressed no desire to make changes to their existing talkers. The children reported finding their current communication devices easy to use and did not wish to cause any problems when trying to communicate and see their friends. Such augmentative and alternative communication (AAC) technology as the talkers used by the children in this research is designed largely on the basis of conceptual models developed by adults without disabilities (Light and Lindsay, 1991). Due to the layout and construction of such devices, there is a large amount of learning required by a child before they can become competent users (Drager et al., 2003). Therefore, the children may have shown reluctance to change their talker devices in anticipation of learning demands that would have been imposed on them should they have wanted to change the current design. Therefore, the lack of interest in changing the design of the talkers may not have been a lack of desire to do so, but more reluctant based on the necessity for learning that would be required to regain their current communication ability.

Overview of the Content from Children with Communication Impairments

When evaluating usability, demonstrating the function of the prototype fixture manually proved to be a successful means of representing how the device would work in practice. For user preference information, the child participants provided information on their favourite colour, material and textural preferences for use in the design of the communication fixture. The findings from this visit suggest that children presenting communication impairments can inform the design of healthcare technology. However, the information that the children can provide can be limited by the means with which it is sought. In this research, many of the questions were posed in a way that allowed the children to respond with dichotomous 'yes' and 'no' responses. Future research looking at the alternative means of gathering richer data from children with communications can be examined. The role of the carer in providing proxy information for a child with communication impairments can also be explored. Although, where possible, this research spoke directly to children for information relating to them, details regarding topics such as the daily activities of the children, alongside the use of the communication fixture from the perspective of the carer would have been beneficial to inform further design and development of the device.

Talkers are high-tech devices in terms of available AT and due to their components may be accompanied by software and practical issues that derive from the nature of the technology. For example, the use of electronic talker systems may be used for communication by a child in an outdoor environment. Without a means to charge the device, the battery can quickly drain, which leads to the removal of the user's capability to communicate. However, despite the errors that occur with the communication aids, they have the ability to promote language acquisition and cognitive development, alongside offering the opportunity to people who are nonverbal (because of a disability) to participate and provide their opinions within research (Desch and Gaebler-Spira, 2008). The reluctance of children to change the layout and design of their device was perhaps due to this capability to communicate effectively, and may explain why children are unwilling to alter a system that currently works for them.

The methodology used with the children with severe communication impairments involved rotating the children around three researchers who questioned the children on three different topics. This method was chosen to ensure that the children remained engaged and that time spent with the children was not wasted. However, two participants were noticeably fatigued by the end of the questions. In future research there is a need to consider the extent that a population of children having to use such means of communication can be expected to maintain engagement levels.

5.2.5 Summary of the Content Obtained from the Interview Methods

The social acceptability of a device refers to the aesthetic characters of a system, and the practical acceptability refers to the usefulness (usability and utility) of a device (Keates and Clarkson, 2003). During the research visits to schools, children participating in the standard interview methods were capable of outlining a range of preferences relating to the aesthetic characteristics of RT (e.g., preferences of colour and shape). The children were also capable of providing information relating to the practical acceptability of a device (e.g., environments in which a device could be used, how to make a joystick fun to use), although topics relating to the size and measurements of a device appeared to cause difficultly for most children. Another topic of interest within the research was a consideration of texture, where children outlined a range of material preferences. Children without disabilities were also capable of providing feedback on their opinions of people with disabilities, often expressing feelings of sadness or pity towards them.

Children with severe communication impairments also participated within interview methods that were designed to accommodate their participation. The main modification to the standard interview methods involved the construction of questions that promoted dichotomous responses. Although the talker machines used by the children with communication impairments occasionally obstructed the process, the children were capable of reporting on a variety of topics, including usability and colour and material preferences.

5.2.6 Post-task Questionnaire

The post-task questionnaire was an opportunity to reflect on the value of participation to the children. Alongside reviewing their levels of enjoyment, the post-task questionnaire also sought to establish areas of improvement in both the research process and the interview methods. This section first outlines the ratings obtained from the use of a face scale to measure children's enjoyment.

The post-task questionnaire was completed by most children who participated, with the exception of a small group of children (*N* = 13) from one school due to time constraints on the research visits. When using a face scale to gauge children's rating of enjoyment during participation, most children across all ages selected 'very good'; the highest rating on the scale. Ratings of 'O.K.' were the second most popular category, although these were only used by children in the 9 - 10 year old group. The majority of children in the 7 – 8 year old group selected 'Very Good', with the exception of a small number of children (*N* = 3) who selected 'Good'. Of the children with CP who participated in the standard interview methods, most children (*N* = 3) rated the interview methods as 'Very Good' (participating in the focus group (*N* = 2) and board game (*N* = 1)) and 'Good' (*N* = 1) (participating in the focus group). The remaining child did not complete a post-task questionnaire. No children selected the ratings of 'bad' or 'very bad'.

The results from the face scale can be used to differentiate between enjoyment ratings that were given for the different methods. **Table 9** outlines the distribution of ratings from children following their participation in the four interview methods. The board game and the DLI obtained the highest proportion of 'very good' ratings from the children who took part in the methods. The focus group and the one-to-one interview received a less positive distribution of ratings from the children, and up to 11% of children provided ratings of 'O.K.' for the one-to-one interview.

The ratings of 'bad' and 'very bad' were omitted from **Table 9**. In order to examine whether there is an association between the method and the enjoyment ratings provided by the children, a Pearson's chi-square test was performed. The association between the method and enjoyment ratings was non-significant ($\chi^2(6) = 5.66, p > .05$).

Table 9 Percentage of enjoyment ratings during the methods

	Board Game	**Focus Group**	**DLI**	**One-to-One Interview**
Very Good	83	69	89	67
Good	8	27	11	22
O.K.	8	4	0	11

The lack of negative rating use is in line with findings of a positive response bias in research with younger children (Fritzley and Lee, 2003). The use of a modified face scale in this research still revealed a tendency for children to select the most positive category on the scale, as was found with the use of the 'smileyometer' (Read and Macfarlane, 2008). The use of face scale to gauge enjoyment in research needs to be considered for two reasons: i) the use of a face scale unifies any understanding of enjoyment into happiness and sadness, over-simplifying the construct of enjoyment ii) children's involvement in a research activity is different to everyday activities in the school, and is often designed to ensure that children are engaged. Any measure of enjoyment in an activity may need to take account of baseline measures. There is a need to further define and understand how to measure constructs such as enjoyment or fun in research with children (Read et al., 2002) alongside considering the use of appropriate rating scales for this purpose.

For the question, '*Did you enjoy taking part?*' almost all of the children who participated in the visits answered '*yes*'. This was with the exception of one child who reported not enjoying participation in the board game because people were '*behaving badly*' and that consequently the pace of the game was too slow. When answering the question, '*What do you think the word 'rehabilitation' means?*' less than five percent of the participants provided an explanation of rehabilitation that was similar to descriptions provided by researchers at the beginning of the visit. Most responses were confused and incorrect. From the responses provided by those that were inline with the researcher's descriptions, answers included *"…when someone is disabled and you have to help them get better"* and *"…where people have done something to their arms or legs and have to use a rehabilitation machine to help people stretch and strengthen muscles"*.

The final part of the post-task questionnaire involved enquiring about the experiences that children have with disability. Despite the low proportion of children that could provide an explanation of the term 'rehabilitation', 36% of children reported having no experience of disability. When mentioning people who were known in the children's lives that had a disability, often children would mention peers in their school who have disabilities. This supports the ideas discussed during the teacher involvement interviews in **Section 4.2.2** that children with disabilities can act as a reference point for children without disabilities. Although children with disabilities provide insight into a disability, in many cases they were the only person with a disability that the children listed.

Children who participated in the alterative visits were also capable of providing post-task information. All children provided positive reports regarding their experience when asked after the visit had finished. For example, when asked their opinion on taking part, one child responded *"...this is fantastic"*. However, this information was documented informally as the children were not asked to complete formal evaluations of their participation.

5.2.7 Summary of Value of Child Involvement

The value of child involvement sought to examine the value to both the information that was gathered, and the experience that was acquired by the participating children. Overall, a large amount of information was obtained from the children. The analysis of images created by the children provides insight into many of the features and attributes of a design that children would choose to include. However, the worth of such information to designers requires further investigation. It would be helpful to establish a means of assessing the user satisfaction that might be achieved from a child should the features they request be integrated into the design of a device.

There were a large number of preferences obtained during the interview methods, although this varied between methods (outlined in the analysis of cost in **Section 5.1.2**). When gathering responses from children, one difficulty that arose was the tendency for children to list responses for topics such as colour and material preference. With the latter category there was also doubt raised about children's understanding of the items that were listed. Although the information obtained requires validation, there was immediate concern over preferences provided by children relating to the size and shapes of devices. Often children provided inconsistent references to metrics and did not seem to understand their use when referring to preferred size dimensions of RT.

Children may have benefited from the use of props when questions were posed that enquired about hospital equipment. Although some children could describe their perceptions of hospital equipment, many children struggled. A trend that occurred throughout a lot of the questioning was a reliance on recall. The use of props would also allow children to provide information about equipment and materials that they can see and manipulate, and this would inform their knowledge of materials or equipment that they have not seen or used before.

The post-task questionnaire reported positive experiences from children, although the use of measures to indicate children's enjoyment or fun during an activity still requires further refinement. From the post-task questionnaire, it was indicated that most of the children who participated in the group tasks and interview methods could not provide a definition of rehabilitation. Although the term is complex, the question served to indicate understanding of the terms for which they had just been provided with information. All children who participated in the research received a presentation about disability and rehabilitation at the beginning of the visit, alongside being given the opportunity to use a rehabilitation device. A failure to provide an understanding of rehabilitation following this process identifies the need to explore alternative means to inform children of the definitions and factors surrounding disability.

Since the introduction of a face scale, comparisons between different rating scales for use with children have been completed. For example, Van Laerhoven et al. (2004) compared the use of a standard face scale without words or numbers, with a numeric face scale and standard Likert scales with children. Children's order of preference for the different scales highlighted a standard Likert scale as being the most preferred and easiest to complete, followed by a numerical face scale, and with a simple face scale (without words or numbers) being the least preferred. Although van Laerhoven et al. (2004) suggest using a Likert scale in questionnaires with children, they acknowledge that research into larger and more diverse samples than their sample of paediatric outpatients is required. The current practice of using face scale in HCI research involving children (e.g., Read et al., 2002) goes against the findings of Laerhoven et al. (2004). However, the face scale may be more useful than the standard Likert scale in the context of technology design. Future research may wish to compare the alternative scales outlined above within the context of HCI research with children.

Doerr et al. (2008) states that in product improvement or invention it is important to establish which features will improve the end product. Preferences for such features can be obtained through user involvement, although this can result in designers having more features to select from than is practical to implement. In order to apply the information obtained from children in healthcare technology design, it is necessary to determine which outcomes are of importance to the child users of the technology, alongside identifying the uniqueness of this information when compared to preferences of everyday products. Social acceptability, for example, has been identified as an important construct in the development of AT (Keates and Clarkson, 2003) and was shown to be of importance in the interviews where children were reluctant to use a device that made them look silly when in the presence of others. However, identifying further aspects of importance in the development of such technology can guide information gathering for topics with a direct impact on the user satisfaction of a healthcare technology device. By comparing AT and RT with everyday products, it will begin to address their unique characteristics. For example, the concept of hedonic quality, which is a consideration of non-task-oriented quality aspects such as innovativeness and originality (Hassenzahl et al., 2000) within a device, may be apt for healthcare technology. Where everyday products may be expected to incorporate features into the device that exceed its capability to meet the pragmatic fulfilment of its function, the function of a rehabilitation device is central to its existence. Healthcare technology, encompassing RT and AT within this research, is brought about first and foremost through rehabilitation engineering; the application of science and technology to ameliorate the handicaps of individuals with disabilities (Reswick, 1982). The function of the device is central to this process but does not guarantee its successful use by children. In starting to consider the unique features of healthcare technology of importance to children, researchers can begin to understand the context of implementation. Although children may require the use of healthcare technology, there is a need to measure the preferences and expectations of the child to ensure that use is encouraged and maintained, so that the functional properties can execute their intended purpose.

5.3 Overview of the Results from the First Stage of Research

This first stage of testing has involved children with and without disabilities in the design of healthcare technology. The ongoing projects at the university involving a rehabilitation joystick and handwriting device (see **Appendix 2**) provided a focus for presentations, group tasks and interview methods to be used to gather information from children to feed into the ongoing projects. In addition to this, a project that involved the development of a communication aid fixture for wheelchair users provided a backing for separate research trials involving children with communication impairments. This first phase in the research has begun to address the research topics outlined within **Chapter 2**, and has provided a basis on which to suggest a wide range of future research topics.

This section firstly begins with an overview of the key findings of this chapter in **Section 5.3.1**, followed by a summary of the cost and value analyses of the interview methods in **Section 5.3.2**. This chapter ends with an overview of the modified Markopoulos and Bekker (2003) framework for potential application in future research in **Section 5.3.3**, alongside an outline of how the findings from the first stage of the research are used to inform the second phase in **Section 5.3.4**.

5.3.1 Summary of Key Findings

The summary of the keys findings of this chapter are divided into the research questions that they initially sought to answer. This is followed by an outline of areas of research that require further investigation.

How do personal and environmental characteristics influence methods when gathering requirements from children?

The effect of children's personal characteristics had varying levels of impact upon the ability of methods to gather information from children with and without disabilities in the development of healthcare technology. Factors relating to the age and gender of children were not identified as having a direct influence on their ability to participate in the research. However, when age and gender were evaluated alongside verbal competence, differences were seen between the scores obtained by the groups of males and females. Research has recently identified that language capabilities explained by language differences do not exist (Wallentin, 2009). However, it is reported that small differences can be seen in early development, where girls are favoured, but this trend disappears with age. The verbal competency ratings were completed by separate teachers and the subtle fluctuations in results across gender may only reveal differences in the completion of the ratings by separate individuals. Alternatively, differences may also be explained by the perception of pupils held by teachers or staff at a school. Given the exploratory nature of the research and the use of the verbal competency measure only to ensure an even balance of language ability within the interview groups, any identified relationships are being viewed cautiously. Despite the differences identified in the measure, no link was made between the verbal competency rating of the children with the output in the methods, as the distribution of responses from methods was spread across both males and females.

Disability was the largest personal factor to receive attention, as this alone was the largest determinant of whether children could participate in a method. Although the specific difficulties associated with the methods are discussed in the summary of the method comparison, the five children with CP who participated in this research were mostly limited to participation within the focus group or one child who participated in the board game. The role of the carers is still not fully understood, nor is the effect of their presence on other children participating in a method.

The largest factors that defined disability within this research involved physical and communicative impairment. Physical impairments in mobility could be overcome with aid from a support assistant, but a physical impairment associated with movement limited the capability of the children to contribute to most activities that involved the manipulation of materials (i.e., group task, DLI, board game) and raised concerns over the ability to obtain assent. Communicative impairments on the other hand caused an extension in the time taken to respond to questions during the interview methods. Using such information about the effect of the disabilities to explore methods that aim to overcome these difficulties should be explored, and attempts should be made to create methods that are more inclusive of disability. This is particularly the case for design methods such as the DLI. The one-to-one interview was not used to involve children with disabilities in this research, so an exploration of its use in similar research would be beneficial to creating a more complete research picture.

The environmental characteristics investigated within this research have less impact on the methods' capability to acquire information than the personal factors. One limit to the investigation of the environmental factors was the use of only a school environment to obtain information. This was intended as a limit for the scope of the research, but actually facilitated the process in terms of gathering information. The presence of accessibility equipment and support assistants to support children with disabilities ensured that for the children that chose to, participation in the methods was ensured as much as possible. In addition to this, the support of the teachers and classrooms assistants only served to improve the ease with which visits were carried out. The involvement of children within the school environment is worthy of further investigation for future research because it provides a dynamic and flexible environment in which to perform research. Therefore, guidelines to assist other researchers in accessing children to provide information about the development of healthcare technology will be valuable to ensuring such research continues. However, the school environment also creates a research setup that cannot rely on structured experimental designs, and this barrier to research must be accounted for before further exploring the environment.

How effective are current interview methods for gathering requirements from children?

All of the four methods that were involved in the comparison gathered information from children without disabilities. However, difficulties arose when trying to involve children with disabilities. Having witnessed the use of the DLI by children without disabilities, it was deemed unsuitable for any children with disabilities that were involved in this research. Future research needs to consider ways in which to involve children with disabilities or modify existing methods to make them more inclusive.

Although there were fluctuations in the volume of information extracted from children via the different methods, they all succeeded in gathering preferences and opinions from children about healthcare technology. There were also differences in the behaviour of children within the methods. Although the presence of a child with a disability and a support assistant often caused a group of children to be relatively more quiet and focused, there was variability in methods when only children without disabilities and a facilitator were present. There is a need to explore factors that influence the behaviour of the children within the different methods in future research. In addition to this, the board game method was originally designed for use with adults and it may be in need of further adaptation before it is used with children.

Focus must now be given predominantly to identifying means with which to involve children with disabilities in design tasks, and secondly methods to validate any retrieved information.

What is the cost and value to involving children in the design of healthcare technology?

The monetary value of the methods indicated that the one-to-one interview and focus group were the most efficient methods. In terms of efficiency, the one-to-one method continually completed all of items on the question list within the limited period of time and returned a higher average number of responses per participant than the focus group. The one-to-one interview was not used with children with disabilities, so its use to involve them in the design of healthcare technology is certainly worthy of exploration in future research. Although there are several factors involved in identifying the cost of involvement, those of importance vary between research projects. This research highlights that it is possible to begin gathering this information for children in the design of healthcare technology, and that it is a useful means with which to inform the choice of a method in practice.

The value of involving children in the design of healthcare technology proved to be high for both the researcher and the child. A vast array of information was gathered from the children regarding preferences and opinions; however, a measure of validation is required to allow conclusions to be drawn regarding the use of the information in practice. Firstly, there is a need to establish a wider base of information from a larger population of children, and particularly those with disabilities. Only five children with disabilities participated in the main activities of this phase of the research, but a larger number of children would allow comparisons to start being made against, for example, previous research that started to address the differences in textural preferences of children with and without disabilities (Curry and Exner, 1988). It is important to further examine the similarities in preferences between children with and without disabilities, to consider whether any children can provide information to inform the design of equipment such as AT and RT. If the end users, often being people with disabilities, indicate unique preferences, then the involvement of users without disabilities can be treated as superfluous.

Research by Light et al. (2007) sought preferences provided by children without disabilities in the design of AAC equipment for children with severe communication impairments. The research gathers its perspectives about preferences of six children without disability from a qualitative study into the development of low-tech prototypes of inventions for use in supporting the communication of another child who had impairments of both speech and motor skills. When analysing the colour preferences of the children, Light et al. (2007) found that children advise on the use of bright colours to decorate symbols and the body of their designs. This was also replicated within the findings of this research. In addition to this, Light et al. found that children emphasise the use of personalisation of colour for devices, and that the importance of the personalisation of devices was central to ensure improved use and appeal. Unlike Light et al. (2007), this research focused in more detail on the amount and content of information that can be gathered, alongside ways in which to validate the information before it is applied to a device.

The value of participation to the children was also assessed in the post-task questionnaire. Given the time spent in the presentation, group tasks and visits by children, when asked about rehabilitation, their understanding of the concept was still very limited. If children are to be involved in the design of AT and RT, it is worth exploring how necessary an understanding of the function of the technology is in order to report on the aesthetics of a device. At best, methods in which to deliver information about disability and rehabilitation should be evaluated to ensure that the ability to inform children about these issues is possible in the event that such information is required.

The ratings of participation in the activities were often very positive, although concerns about children’s tendency to report overly positive evaluations of experience have been raised in research involving children in technology design (Read et al., 2002). It was because of these findings that the face scale within this research was modified to ensure that the images were balanced in their appearance, unlike items used by Read et al. (2002). Given the attempts to remove biases within the measure, children continue to report high levels of enjoyment. The difficulty in commenting on this relates to the ceiling effect for responses that are created when evaluating the experience of children. Alternative methods should still be explored for assessing the enjoyment of fun experienced by children during involvement. The enjoyment of children in such methods should also be utilised when involvement is outside the school context. Given the scope of this research is only to conduct research within the school environment, it is important for future work to validate these findings by identifying how the enjoyment of the methods is affected by the context in which they occur.

5.3.2 Overview of the Interview Methods

The first stage of the research has gathered a large amount of information. In order to make the findings more accessible to researchers and practitioners that may wish to involve children in the design of healthcare technology, **Table 10** summarises the results of investigations directly relating to the use of the four interview methods. This research does not recommend a specific method for use by researchers performing similar research, as the significance of the various metrics outlined in **Table 10** fluctuates between projects. Therefore, their presentation here acts only to inform the selection of one of the four interview methods for use in future research involving children in healthcare technology design and development.

Table 10 presents each metric that has been discussed within **Chapter 4** and **Chapter 5**, and presents the methods in an order that is determined by their scoring according to the metric. For example, for 'cost of materials', the methods are reported in an order from the least expensive to the most expensive. The order in which the methods are presented for each of the metrics is determined by the preferred order that could be desirable for manufacturers during a design process (e.g., low cost, reduced time, high quality). The presentation of information in this way allows a quick reference guide to the methods where the information taken from the table can be guided by the priorities of a particular research project.

By tabulating the categories, some of the subtle differences that are described earlier in **Chapter 4** and **Chapter 5** are lost. For example, the number of responses gathered shows the focus group as gathering more responses per participant than any other method. However, the figures for average number of responses gathered per participant for the focus group ($X = 2.27$) were only slightly higher than the figure obtained for the board game method ($X = 2.24$). The results of the table should be approached with caution and not as separate to the detailed outline of findings that are reported above.

One potential difficulty that may arise in selecting methods is the ratings of enjoyment. Although the focus group and one-to-one interview were favoured by a range of metrics relating to quantity of information and cost, the methods with the most favourable enjoyment ratings were the DLI and the board game. This serves to demonstrate the difficulties that may arise in selecting methods in research. Therefore, metrics of greatest importance to a given project should be used to make final decisions regarding the selection of a method.

Table 10 Summary of the information gathered regarding the interview methods during the first stage of the research. The methods are rated from 1 – 4, where there placement in the table is determined by their scoring according to each outlined metric in the left side column.

Metric	1	2	3	4
Robustness: accessibility to children with variants of CP (most accessible – least accessible)	Focus Group	Board Game	N/A	N/A
Efficiency: time taken to setup the area and materials required for the method (shortest setup time – longest setup time)	One-to-one Interview	Focus Group	Board Game	DLI
Completion rates: from a twenty-minute time limit (complete question list – incomplete question list)	One-to-one Interview	DLI	Focus Group	Board Game
Number of obtained responses: the number of responses gathered per participant to a question posed within a method (highest number of responses – lowest number of responses)	Focus Group	Board Game	One-to-one Interview	DLI
Cost of materials: physical cost of materials required to run the method (least expensive – most expensive)	Focus Group	Board Game	One-to-one Interview	DLI
Enjoyment ratings: children's rating of their enjoyment during participation in a method (highest proportion of 'very good' ratings – least number of 'very good' ratings)	DLI	Board Game	Focus Group	One-to-one Interview

5.3.3 Modified Markopoulos and Bekker (2003) Framework

After consideration of the topics of enquiry from this research, alongside topics that are recommended for future research, **Figure 37** highlights the framework that was used in the analysis of child involvement in the design of healthcare technology in this first stage of the research. This is a modified version of the Markopoulos and Bekker (2003) framework. The original framework was used to delineate comparative assessments by considering links across the three branches that formed the framework; the assessment criteria, UTM characteristics, and children characteristics.

The modified version derives from specific topics of interest when applied to the use of interview methods with children. The main modifications that took place on the original framework include i) removing specific factors relating to the characteristics of UTM's from the framework where there is now a focus on the *cost and value* of children's involvement, ii) the introduction of the *cost and value* category meant that *efficiency* could be removed from its original location under *method characteristics* to be considered under the heading of *cost and value*, as shown in **Figure 37**. In addition to this, the *child characteristics* branch has been replaced with a more specific focus on the *personal and environmental factors* related to child participants. This includes consideration of the *presence of disability* and the *school environment*.

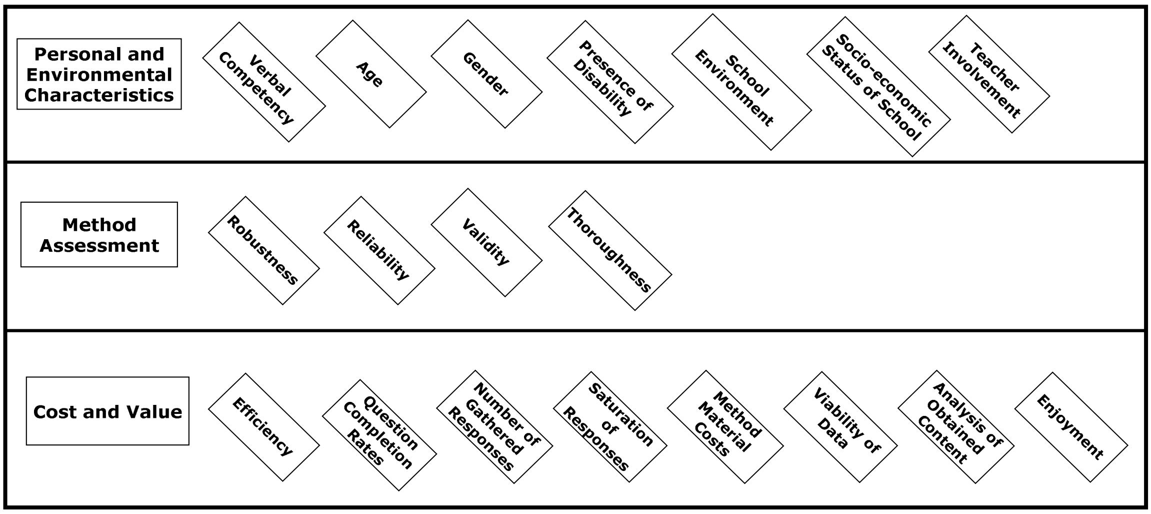


Figure 37 Outline of the modified Markopoulos and Bekker (2003) used to compare methods within this research

By drawing links across the topics highlighted of interest within the area, new research questions can emerge. For example, by drawing together *school environment* from the *personal and environmental characteristics* branch, *validity* from *method assessment*, and *enjoyment* from the *cost and value* branch, and research question can be formed. For example, *to what extent does the school environment affect children's levels of enjoyment during participation in methods?* With an underlying focus on validity, there is scope to examine how differing school environments and setups might influence the validity of responses gathered from children.

Although this framework is not established, it provided a means with which to add structure to this analysis, and offers a basis for exploration by other researchers in the future. The promotion of a structured framework into a new area of investigation encourages a more unified development of the literature to attest criticisms of other design literature (Love, 2000; Love, 2005).

5.3.4 Areas to be Investigated at the Next Stage

Although a range of issues were identified within the evaluations of the topics of investigation from the first phase of this research, not all of the areas can be investigated. From the evaluation of the topics of investigation above, the following areas of research topics were identified for further examination. The scope of the research outlined in **Chapter 1** was integral to decisions regarding the next stages of research. Of particular importance was the need to focus investigations on barriers within methodology, concentrate on research visits that can take place within the school environment, and ensure that the research is led by the work completed in the first phase of the research. Based on these decisions, the following areas were identified for further investigation.

Developing a Method for Validating Information Gathered from Children

Having gathered a large amount of information from research visits to schools, there were difficulties in ascertaining the accuracy or validity of the information. In addition to this, there is a need to consider how to use information gathered from children when applied to designs. Consequently, **Chapter 6** outlines the development of an internet application that was devised to present prototypes of healthcare technology to children. The prototypes were developed from information gathered during **Chapter 3** to **Chapter 5**, which provides insight into the process of converting raw data into designs. In addition to this, the application also provides the opportunity to examine the later stages of the design cycle, as children are involved in the use of the application to evaluate the prototypes. As part of such evaluation visits, the potential of the internet application to be used as a means of validating information that is acquired from children in design research is explored.

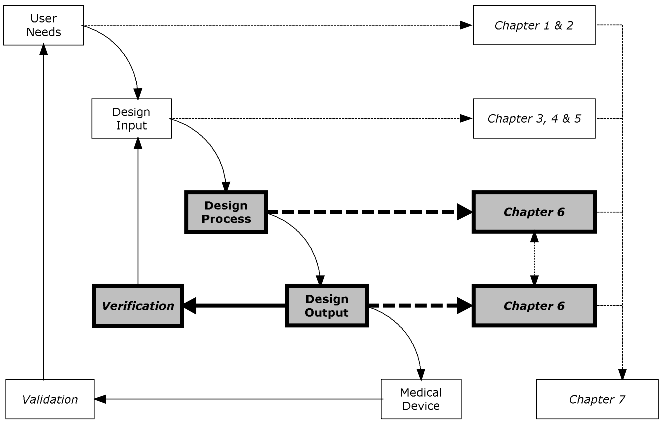
School Involvement Guidelines for Researchers and Practitioners

Before this research took place, it was noted that there was, at the time, a lack of information on the involvement of children in the design of healthcare technology. **Chapter 7** adopts an action research approach to outline the experiences of the researchers involved in the initial visits and the internet application implementation to create guidelines for future researchers. The guidelines are designed for researchers considering research within the school environment and outline practical points about what has worked, and not worked, within this research. Although **Chapter 4** and **Chapter 5** have highlighted several areas of research as requiring further attention in the future, it is important to set up the infrastructure for this to take place. The development of the guidelines is used as a means of encouraging researchers to use the school environment.

The next two chapters outline an internet application to expand the insight into the design process of healthcare technology with children, and the penultimate chapter outlines guidelines to support future research in the area. The findings of the research are then concluded in **Chapter 8** and are discussed in the context of the contribution to knowledge provided by this research.

Chapter 6

An Internet-based Application for Gathering Information from Children



This chapter outlines a novel internet-based application for gathering information from children. As outlined in **Chapter 1**, the application derives from the experience that was gathered during the first stage of the research. The use of the internet application provided an opportunity to gather insight into the later stage of the design process as the focus in the first stage of the research was primarily about gathering requirements. This chapter begins with **Section 6.1**, outlining the context of the internet application within the thesis, alongside detailing the surrounding literature supporting its development. Following this, **Section 6.2** discusses the context of the research, before the role of designers in the design of healthcare technology is explored in **Section 6.3**. This is followed by an outline of the development and structure of the application in **Section 6.4**. **Section 6.5** then describes the implementation of, and data gathered, by the internet application, including observations regarding its use by children with and without disabilities. This section also includes details of the exploration of the internet application as a means of validating data retrieved in the first stage of the research in **Section 6.5.6**. The chapter concludes by summarising the findings regarding the use of the application in **Section 6.6**.

6.1 The Context of the Internet Application

Within this thesis, the first phase of testing investigated methods for gathering user requirements and preferences directly from child users. As part of this, there was a comparison of existing interview methods, gauging the suitability for their use within healthcare technology design. The development of the internet application provided the opportunity to investigate methods that can be applied at the later stages of the design cycle. This expands the focus of the thesis beyond the early stages of the design cycle to begin to consider the role of designers and children in the later, evaluative stages.

Descriptions of the design cycle vary extensively throughout the literature dependent on the product and population to which it is applied. In the development of medical devices, Keates and Clarkson (2003) highlight that a strength of the Waterfall Method (see **Figure 38**) is its focus on the evaluation of emerging products or systems, whether mainstream or assistive. They further highlight that the model accounts for verification ("Are we building the thing correctly?") and validation ("Have we built the correct thing?") during design. By using these two stages, the likelihood of delivering a product that satisfies the needs of the user is increased.

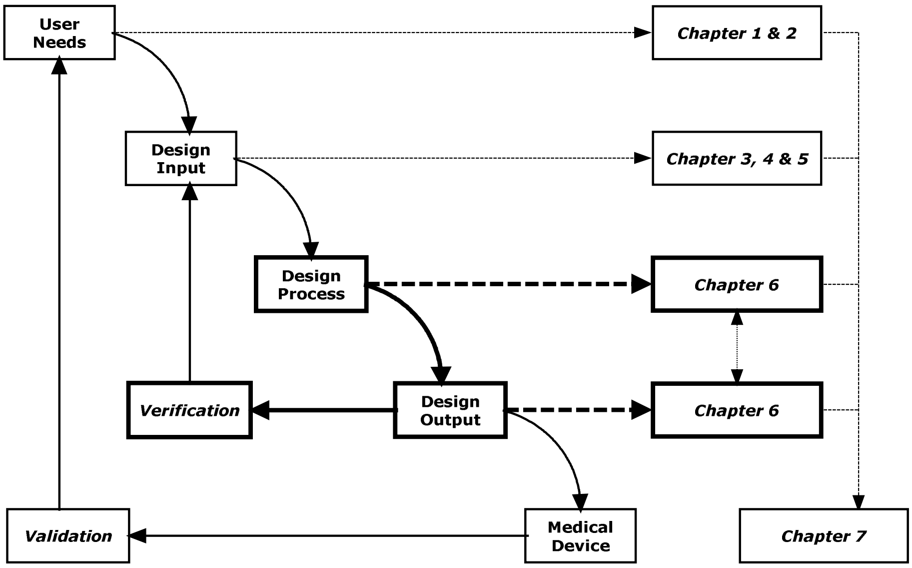


Figure 38 The Waterfall Model, from FDA (1997), outlining the stages of the design process covered by this research

This thesis has explored several of the stages from the Waterfall Model, as expressed in **Figure 38**. The inclusion of a mix of interview methods covering both individual and group interviews, alongside design-based methods, was described in **Chapter 3 – 5**, ensured that children were involved in **design input** to address the specifications that were outlined as **user needs**. In this research, children were involved to consider the extent of information that can be gathered to inform this stage of the research using a selection of interview methods. The information from the children was then fed into the **design process**. Within the thesis, this relates to the handling of the data and development of prototypes by the designers as described in this chapter in **Section 6.3**. This chapter continues to evaluate the latter stages of this design process when considering the verification of the design during the **design output** stage. During this stage, it is important to verify the information and consider whether the device, during development, is being built correctly. The internet application described within this chapter was designed for this purpose, where prototypes developed during the **design stage** were relayed to children for evaluation of social acceptability.

Table 11 An outline of the design cycle for a rehabilitation joystick adopted in this research

Stage in design cycle	**Function within this research**	**Location of research in the thesis**
i) User Needs	The need to improve the appearance of a rehabilitation joystick to increase the likelihood of engagement from end users that are children	In **Chapter 2** the involvement of children in the design of healthcare technology is identified as an important aspect of the design of a rehabilitation joystick
ii) Design Input	To gather preferences and opinions of children regarding the design of a rehabilitation joystick and how to improve the current design	Information relating to children's preferences was gathered with the use of four interview methods in the first phase of research, outlined in **Chapters 3 - 5**.
iii) Design Process	Use the information obtained from users to create a range of possible improvements to the design of the existing rehabilitation joystick. Based on information gathered from children and the views of the designers, the most appropriate solution is chosen and developed.	The involvement of the designers is described within this chapter in **Section 6.3.1**. The use and interpretation of the data is described in **Section 6.3.2**.
iv) Design Output	The creation of a virtual prototype that depicts the chosen solution. Involvement of children in the evaluation of the designs.	The process of developing the virtual prototypes of joystick designs is described in **Section 6.3.3**. In addition to this, the verification of the designs is discussed in **Section 6.5**.
vi) Medical Device	Assessing the acceptability of the device with the end user.	Future research is required to perform a complete review of the acceptability of proposed designs with intended end users (i.e., children with CP)

Although typically the evaluation of acceptability is left until the **medical device** stage, this research differed in that it evaluated the social acceptability at the **design output** stage. Within this thesis, the focus has been mostly on gathering information regarding aesthetics from children, and the completion of the **medical device** stage, requiring consideration of function and usability, has not been possible. However, the majority of the stages have been completed, with this information outlined in **Table 11**. The table discusses the different stages of the research in relation to the rehabilitation joystick device that was one of two devices shown to the children during the group tasks in the first stage of the research. The joystick was used again as the device on which to base the internet site.

This research covered the first four stages of the waterfall model, including the verification of the fourth level; **design output**. For the **medical device** stage, the acceptability must be evaluated in full, with validation of the device. In order to complete the design process, the last stage would have to involve a review of a systems' acceptability. Nielsen (1993) highlights that designers should try to achieve this goal by considering the social and practical acceptability of a device. The social acceptability was considered a central part of the **design input** section of the design process of the design cycle, and involved a large number of children in gathering child preferences. Due to time and scope constraints, the research was unable to fully explore the social and practical acceptability of the device within the context of the **medical device** stage. The validation of the end product would have involved consideration of the aesthetic preferences of end users of the device (i.e., children with CP requiring assistance with upper arm rehabilitation exercise). In addition to this, the practical acceptability of a design would require investigation into the usefulness of the system, covering considerations of usabilit*y* (the extent to which a product can be used by specified users to achieve specific goals (ISO, 1998)) and utility (the provision of the necessary functionality by the product to perform the desired task) with the end user (Keates and Clarkson, 2003). Although there is scope to investigate the ability of children without disabilities to comment on elements of the social acceptability of the device, only end users are capable of providing the details to feed into the practical acceptability of the device.

The ecological validity of this research has been improved by linking the work to an ongoing research project, and its demand for insight into the involvement of children in the design process of healthcare technology. However, the application of both the interview methods within the early chapters, alongside the development and implementation of the internet application all occurred within the school environment. Therefore, although this research provides insight and guidance to researchers developing healthcare technology within the school environment, the application of the methods across different contexts is required to strengthen the external validity of the findings. The internet application, whilst described in this chapter as informing the evaluation stages of the **verification stage** of the design process, is itself a novel method that has yet to be validated. Therefore, the findings discussed in this chapter, although following the development of an ongoing research project, still require further investigation to improve the external and interval validity of the findings.

The next section begins to contextualise the use of the internet application within the design of healthcare technology, particularly within the school environment. The main drive behind the use of the internet application was due to its increasing popularity and use within healthcare, alongside its potential to be used to access a wide range of children with and without disabilities.

6.2 Research Context

The need to involve users in the design of healthcare technology has been emphasised throughout this thesis. In addition to this, concerns surrounding the marginalisation of users with disabilities and particularly the use of proxy information are echoed in related research (Rabiee et al., 2005). This thesis has begun to assess available methods for use to involve children in the supply of information at the level of informants (Druin, 2002). However, this has focused predominantly on the earlier stages of design. There is a need to consider means with which children can evaluate designs, including those that stem from a process with which they have been involved. The first phase of research highlighted that children, with and without disabilities, can successfully supply information relating to preferences for colour and materials for use in healthcare technology design. However, children with certain disabilities, and particularly those with a reduced capability to manipulate design materials, were excluded from the DLI's and mostly from the board game. As a means of examining the involvement of a wider population of children in the evaluation of healthcare technology there was a need to explore an accessible evaluation method for presenting prototypes of designs whilst working within the cost and time limitations of the thesis. There was a need to establish a method for verifying any newly generated designs based on information from the children relating to its social acceptability. In order to achieve this, the research required a means of presenting visual representations of designs created on the basis of information gathered from children in the first phase of testing.

In this instance, the prototype was an experimental prototype, used to determine the adequacy of a solution. Given that aspects of importance during the verification stage were concerned mainly with the social acceptability of healthcare technology, it was important to ensure that the aesthetic properties of designs were given focus over any aspect of functionality. Over the last decade, animation tools and 3D modelling have become popular methods of creating and manipulating 3D models (Halskov and Nielsen, 2006). This method allows a user to portray materials, textures, light and rendering to create animated sequences that clearly express the intended appearance of a device. Such a means of presenting information via a computer provides the opportunity to involve not only children without disabilities, but also utilise available accessibility equipment to involve children with disabilities. Due to the scope of this research, only the school environment was used, where the Disability Rights Commission (2005) ensures that accessibility equipment required by children attending a school will be available. The availability of the equipment facilitates participation and makes visits involving a computer or the internet more accessible for all children. The presentation of information via a computer within the school classroom also supports recent trends in healthcare practice suggesting a move towards the use of information and communication technologies (ICT) to interact with patients including children.

In recent years, the methods used to supply information to healthcare users have exploited the latest in ICT and there are now a number of examples of internet based "e-health" systems (Lakovidis, 2004). Integrating e-health into the development of healthcare technology can provide an opportunity for practitioners and researchers working with children with disabilities to circumvent problems associated with traditional methods of information gathering (Imms, 2008). Such research also supports suggestions by Carlsson et al. (2007), and Lewis and Porter (2004) that technology-based interventions such as the internet provide an alternative means of approaching groups of children posing particular barriers.

Outcome questionnaire completion is an emerging method for measuring healthcare outcomes (Wright and Neill, 1999), and has been applied in adults and teenage populations. Young et al. (2009) report that the reliability of questionnaires for use in healthcare with children is still valid independent of whether they are presented in a paper-based or internet format. This research developed the internet application by shaping its accessibility around children with disabilities. A similar approach was adopted by Young et al. (2009) when gathering healthcare information, although such a use of the internet has only recently emerged in the research literature. To date, no research has looked to involve children in healthcare technology design via the internet; therefore, this presents a novel aspect to this research. However, its development was based on wider supportive literature. For example, published literature exists identifying the potential benefits of using the internet to capture opinions from children with disabilities and their families, alongside enhancing their education, increasing independence at home as well as improving access to healthcare services (Mitchell and Sloper, 2001; Lazarus and Wainer, 2005).

Whilst the time and cost constraints of this research support the use of internet-based methods for gathering information from children regarding the design of healthcare technology, it is important to examine and outline the implications of such practice. Whilst e-health approaches would seem to have a number of advantages there is a need to ensure that practice does not exacerbate the ‘disability divide’. There may be a number of reasons why a person with a disability may experience barriers to access and effective use of the internet. The relatively small incomes of those with disabilities can be compounded by the additional costs associated with improving the accessibility of home computer facilities (Lenhart et al., 2003). Furthermore, there is often a lag in the development of accessibility equipment and AT for computer-based systems, leaving disabled users in a constant state of catch-up (Dobransky and Hargittai, 2006). Such factors partly explain why accessing populations with disabilities via the internet often leads to a sample bias towards higher socio-economic, Caucasian, and well-educated groups (Fyfe et al., 2001). Although contributing factors to the disability divide are poverty and education, current legislation within the UK indicates that educational institutions are obliged to provide the accessibility hardware and AT that is outlined on a child’s statement of special educational needs (Disability Rights Commission, 2005). It seems, therefore, that educational settings may reduce the disability divide for children whilst also providing a suitable environment to apply e-health approaches.

Given the previous data collection and highlighted benefits to using the internet within the school environment, the internet application was deployed in this setting, which further allowed control in ensuring the inclusion of a broad socio-economic cross-section of children with and without disabilities. Therefore, on the basis of the literature and the development of the area of e-health within healthcare practice, the choice to develop the internet application provided a means with which to explore an emerging research method, a means with which to validate information from children, and an opportunity to explore the later stages of the design process.

Although there are disagreements over the extent to which children should be involved in the design process (Nesset and Large, 2004), involving children in the design of technology for their use is advisable. Although an array of design methods for children may involve them at the beginning (e.g., PD) or the end (e.g. usability testing, user-centred design) of the design process, few researchers attempt to involve children throughout the entire process. Despite concerns regarding overexposing children to stimuli by trying to achieve complete involvement (Harbeck and Sherman, 1999), Druin (1996; 2002) continues to involve children as design partners, with the application of contextual inquiry, a tailored method of PD research. Recently Druin’s work (2002) has formed the foundation of a model considering the inclusion of children with special needs in technology design (Guha, 2008). Although Guha et al. highlight brief points to consider when involving children with special needs in design research, information is provided mainly about considerations prior to involvement. No information is provided about design considerations during and after involvement. To begin to address the involvement of children with and without disabilities across the design process of healthcare technology, this chapter provides insight into the later stages of the design process by outlining the participation of both children and designers.

Although Druin (2002) supports the idea of involving child users throughout the entire design process of products, there is not enough literature available to find guidance when applying such an approach to healthcare technology design. This was combined with doubts over developments of theory in design research (e.g., Love, 2000), that led this research to involve adults as designers until more insight is gathered into the involvement of children in healthcare technology development. In the same way that adults established involvement in research prior to investigations regarding the inclusion of children, this research explored the involvement of adult populations before visits with children are attempted. The initial involvement of adults within the design of new joystick designs in this exploration allowed the research to i) imitate current design research to investigate the process that takes place before involving children in evaluation during the design process, and ii) gather an understanding of the extent to which children can be involved when the focus of the research is healthcare technology. As described earlier, the design of healthcare technology can consider both the social and practical acceptability of a device. In this design stage, adults were asked to focus solely on the social acceptability of the device, as consideration of the practical acceptability requires testing of the usability or utility of a device with end users.

6.3 The Design of the Virtual Prototypes

Virtual prototypes were designed from information gathered from the early stages of the research. The prototypes were created by second year undergraduate product design students from the University of Leeds, based on tabulated data from the first phase of the research. This section begins with a discussion of the way that the data was processed for presentation to the designers in **Section 6.3.1**. This is followed by an overview of the data interpretation applied by the students during the development of prototypes in **Section 6.3.2**. **Section 6.3.3** concludes this section by providing an overview of the designs that were generated by the undergraduate students.

6.3.1 Development of the Joysticks

The data from the visits during the first phase of the research was summarised and tabulated for ease of interpretation and presented to the product design students. This included information outlining the colour, shape and textural preferences gathered from the children, including details regarding children's perception of medical devices. The data from each of the methods was assigned to the students as shown in **Table 12**.

Table 12 The distribution of children's data from the first phase of research to the product design students

Student	Data set 1	Data set 2
Student 1	Focus Group	Board Game
Student 2	DLI	One-to-one Interview
Student 3	Focus Group	DLI
Student 4	Board Game	One-to-one Interview

The information was divided according to interview method in the first stage of the research. Each student received data that was obtained via two interview methods from the first stage of testing in this research. By evenly distributing the data from the methods across the students, it prevented the supply of too much information. By applying a systematic approach to the data distribution, it allowed for more control over the analysis of the designs created by the students, particularly in identifying problems with data interpretation.

The data from the earlier research was presented to the students with a project brief. The project brief instructed the designers to use the two data sets independently of one another, producing one joystick design for each data set. By students being asked to complete this process it further informed the use of the data by the designers. Decisions to incorporate single data sets into separate designs make it easier to identify the application of data in the final prototype. The students were informed that the eventual designs would be presented on an internet application and were asked to prepare their designs in 3D computer-aided design (CAD) software. All participants were also asked to render their designs to incorporate texture, lighting, and shading to improve the realism of the designs for presentation on an internet application. The time and cost of developing even a physical visual prototype model, without functionality, was beyond the scope of this research and virtual prototypes were a more appropriate medium to express the ideas for new designs that were created by the designers. Further to this, it reduced the demands of time placed on the undergraduate students, and importantly it standardised the portrayal of the designs. Where typical design drawings or sketches may have been confounded by an individual's ability to draw, the use of CAD software presents a neutral platform on which to depict ideas.

However, controls were not put in place for the variety of skill and experience of the students as designers and in using CAD.

The involvement of the students in the design of virtual prototypes was completed to transfer the data from **design input** stages to the **design output**. Although typically this stage would be the **design process** as depicted in the waterfall method in **Figure 38**, this research is not trying to replicate this process as would be typically practiced in a real world design process. It is not possible to generalise from a small non-representative sample of students to the practice of designers within real-world case studies. However, this research does consider aspects of importance that require consideration during this process. For example, preliminary insight into the difficulties that designers might face when trying to apply information gathered from a population of children to the development of a medical device.

6.3.2 Interpretation of Data by Designers

This section outlines the observations regarding the process adopted in the design of the virtual prototypes, alongside considering difficulties that might be incurred when using data from children. The students were presented with tabulated data as a means of standardising the presentation of information. Due to the split of information according to method when assigning information to the students, there was a lack of responses to a range of the questions. The lack of data was a result of limits to the capability of the facilitators to ask a full set of questions in every method during the first phase of testing in the research. This was related to factors such as time limitations or withholding questions based on the presence of a child with a disability. This led to designers being provided with, for example, information about colours that children reported liking, but no information about what colours the children did not like. This led to instances of deductive designing, as opposed to always following reported preferences. The extent to which this is typical of design research with children is an area for future investigation. The saturation levels explored during the first phase of research indicated that saturation occurred when analysing all of the responses, but further investigations are required to understand this at the level of the methods.

The tabulated information from the children consisted of lists of responses provided to questions in the first phase, as shown in **Table 13**. The difficulty with being presented with such information is the extent to which interpretation is permitted. By grouping the information in such a way, it implied that the category at the top of the list was the most popular option, which it may have been within the given method, but this was not representative of the whole sample. Consideration is required in future research regarding the presentation of the data. Further to this, there may be a need to augment information relating to topics such as children's perceptions of healthcare technology. By coding the responses in this research, the students were provided with lists of how children perceived healthcare technology. Given the emphasis on the social acceptability of the device, it might be tempting for designers to avoid features that are listed as reminding children of healthcare technology for fear of incorporating such characteristics into a design.

Table 13 An example of information provided to student 2 for the question, "What objects do you not like the feeling of?" from the DLI method

What objects do you not like the feeling of?	
Reponses	**Percent of children**
Squashy	20%
Hard materials	20%
Rough surfaces	60%

Currently there is very little research investigating children's perceptions of healthcare technology, and the data needs to be used by adults as is common in practice, before trialling its use with children. The undergraduate students were uninformed about children's perceptions of healthcare technology, and providing lists of information does not provide rich information on which to guide judgements for deciding between highlighted preferences. Future research might consider providing designers with a mix of both tabulated and qualitative research in a manner suited to their role. Gould and Lewis (2003) discuss the key principles and what designers think when designing for usability. They outline that although second-hand information might be suitable for certain standard types of information (e.g., literacy levels, or how long children are typically at school for), direct contact with potential users is essential to develop a basic understanding of what is required in design. Although this is typically aimed at usability, future enquiries might, for example, consider the extent to which designers might be involved in data acquisition. As the scope of users involved with a device becomes broader, so too does the need to consider the user from many dimensions of psychology (e.g., cognitive, behavioural, anthropometric, and attitudinal characteristics) (Gould and Lewis, 2003). Although such a list of characteristics might link directly into usability research, there is a need to consider which characteristics are most relevant for informing decisions in the design of healthcare technology for children, and how this should be used to improve the types of information presented to the designer in the design process. Within the design of virtual prototypes in this research, the logbooks indicated that the information used included colour and material information only, with the use of items in data regarding children's perceptions of healthcare technology only being used as points to avoid or remove from final designs.

6.3.3 The Joystick Designs

Each designer successfully created two designs based on different sets of data. Following the involvement of the designer's, nine joystick designs were available for use in the internet application. These images were then fed into the internet application and used to involve children in the evaluation of the new designs (see **Figure 39**).

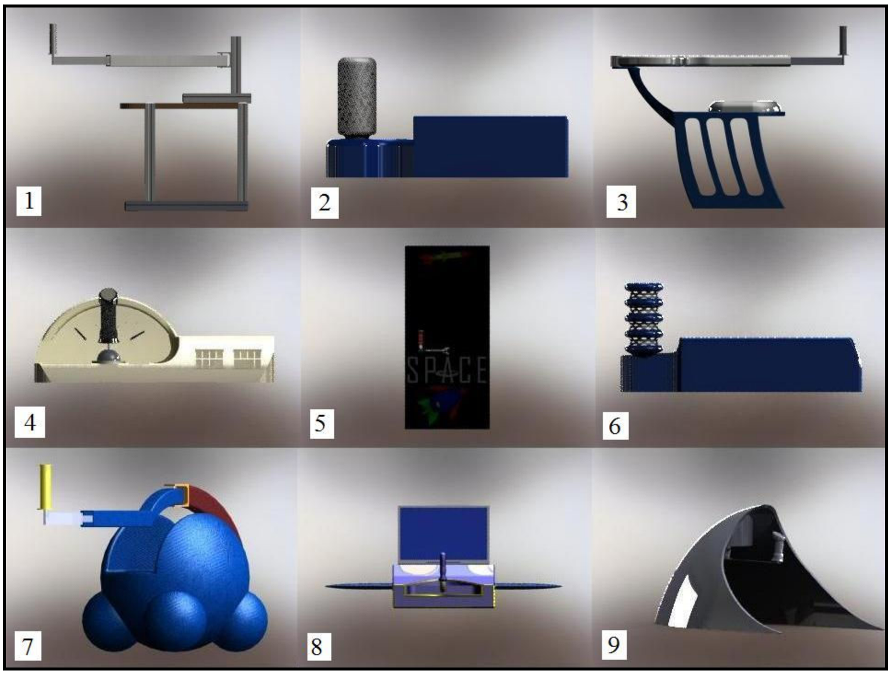


Figure 39 The virtual prototypes produced by the designers

Joysticks 2 and 6 are both supportive of the wrist and have quite simple exteriors. Both joysticks 3 and 7 are similar to the original joystick, but the design has incorporated changes on the basis of the information provided by children (e.g., rounded edges, smooth shape). Designs 4, 8 and 9 are designed to simulate a cockpit, with design 5 being a similar design to an arcade machine. Joystick 1 is a model of the original joystick for comparative purposes.

The creation of virtual prototypes that were incorporated into the internet application came directly from the involvement of adults. The role of children in such later stages of design, beyond the supply of information to this stage, has yet to be investigated. The designers required no functional knowledge of a rehabilitation joystick and only utilised shape and form information from details that children have already provided. Therefore, the possibility of involving children during the development of prototypes for the aesthetics of the device could be considered in future research. Children within the development of the virtual prototypes only acted as informants (Druin, 2002), yet future research may consider exploring the role of child as design partners in the development of the aesthetic of a device.

This would have to be approached whilst considering the findings of the viability of the images produced during the first stage of the research.

6.4 Development and Implementation of the Application

The application was an interactive web-based application that stored information within a central database. The application interface was designed for 5 – 11 year olds with and without disabilities. Common accessibility issues were identified using the Web Accessibility Initiative (WAI, 2009) and then an inclusive design approach was used to attain a usable application interface. The purpose of the interface was to present information visually and as such, the needs of visually impaired users were not considered in the development of this particular application. The content and layout of the interface was enhanced with assistance from five teachers at primary schools in West Yorkshire (England, UK), through interview sessions and demonstrations, alongside usability tests within the research team and guidance from the Academic Department of Rehabilitation Medicine, University of Leeds. The latter group consists of paediatric rehabilitation practitioners, consultant physicians, registrars, psychologists and child physiotherapists. Before implementation in schools, the application was visited with a range of children who were regular testers of software developed by the research team who had been previously involved with other software projects.

The application contained a sequence of screens, with at least one element of each requiring an input from the user (see **Figure 40**). The children predominantly used a mouse to interact with the interface by clicking on an icon to select their desired choice. The only input requiring use of the keyboard was for entering the child's name. In order to begin the task the interface initially gathered consent for participation by presenting a statement approved by the Maths and Physical Sciences Faculty Research Ethics Committee, University of Leeds. This was followed by the selection of an avatar character that would instruct users' navigation throughout the remaining pages.

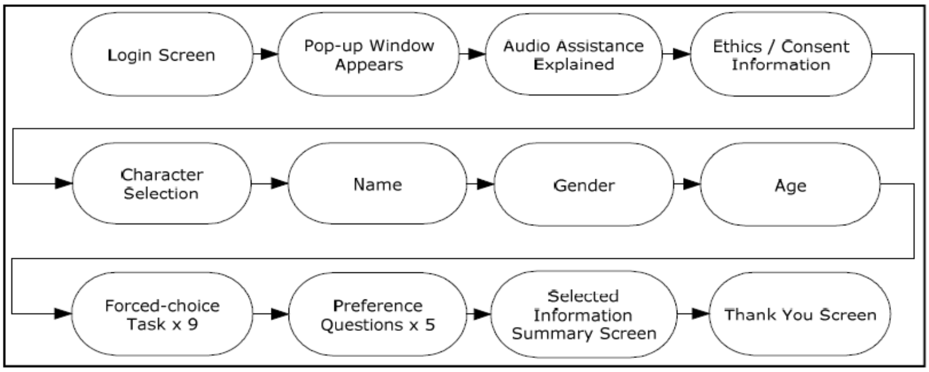
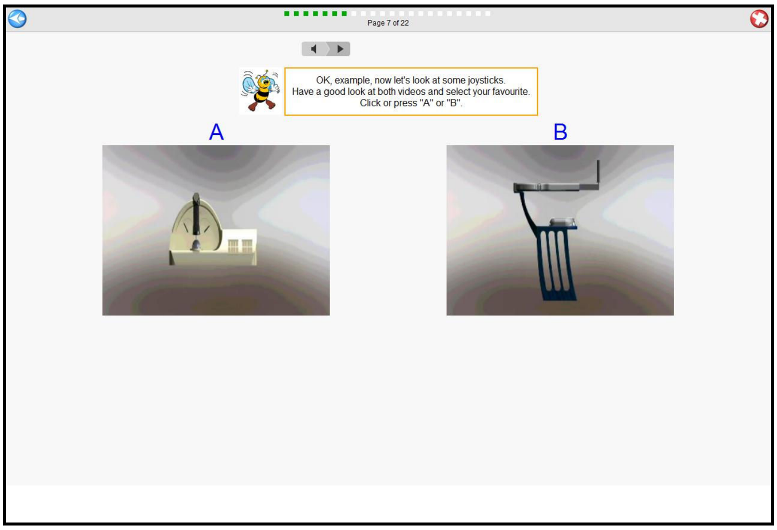


Figure 40 Process diagram of the screens that form the interface for the internet application

After gathering consent information, the application retrieved simple demographic information (name, gender and age). This was followed by a series of nine forced-choice decisions where children selected their preferred joystick design from two possible options. Each decision eliminated the non-preferred joystick from the pool of joysticks that could be displayed. In total, all nine virtual prototypes of the joystick designs created by the designers (outlined in **Section 6.3.3**) were used. A forced-choice task was implemented because it requires participants to utilise item-to-item comparisons within a process that minimises the recognition and decision-making judgements that may be required were all nine joystick images displayed simultaneously. The joystick designs were displayed as rotating 3D objects in video clips (see **Figure 41** for a static example). This stage was followed by four questions regarding the general preferences of the children for certain colours and materials, where these questions were a selection of those originally presented to the children who participated in the first phase of visits within the research. The justification for including the questions is twofold: i) a database of children's general preferences for healthcare technology can be formed for use in future research and analysis at the University of Leeds, and ii) the results can be recorded for children who took part and answered the same questions in the first phase of the research to compare responses. The questions relating to preferences were completed by selecting one text word option from a list of five. The same method was used for questions regarding building materials except that instead of using just words, images were also presented to depict the materials. All written text on the screen could be read aloud by clicking a button at the top of each screen.



OK, example, now let's look at some joysticks.
Have a good look at both videos and select your favourite.
Click or press "A" or "B".

Figure 41 Example of the screen layout for the forced-choice task

Figure 41 provides an example of the screen layout that was used by participants throughout completion of the tasks in the application. The green bar at the top of the screen indicated the progress of the user through the application. The grey icon beneath was used to activate audio playback of written text such as instructions. The orange box outlines instructions to the children, with the avatar character (in this case the bee) positioned to the side of the instructions (the avatar is present throughout all screens following its selection on an earlier screen). The forced-choice task was completed by selecting the large letter (either ‘A’ or ‘B’) above the preferred joystick design. Clicking on the image would cause the rotating 3-D videos to pause so that designs could be observed as a static image.

6.5 Implementation of the Application

This section describes the methodology that occurred when the internet application described above was implemented within the school environment. The section begins by outlining the participants (**Section 6.5.1**), followed by the procedure (**Section 6.5.2**). Following this, there is the outline regarding observations surrounding the implementation of the application within a school environment in **Section 6.5.3**. This section describes any barriers that were observed when using the application. The results that were obtained from the application regarding the evaluation of the new joystick designs are discussed in **Section 6.5.4**, with the exploration of the application as a validation tool being outlined in **Section 6.5.5**.

6.5.1 Participants

Two hundred and fifty seven children used the interface, with both males (N = 123) and females (N = 134). The age range of the children was 4 – 12 years of age (X = 9.71, *SD*

= 1.51). All children spoke English as a first language. Within this population, twenty-one children had one or more disabilities. All children with disabilities were receiving therapy or developmental support services from school-based programs. The scope of disability ranged from mild to severe multiple disabilities, with no control across age or gender. The etiology of the diagnoses was acquired via reports from teaching and support assistants at the schools. The prevalence of medical disorders included CP (*N* = 11), varying levels of deafness (*N* = 7), global development delay (*N* = 2) and Downs syndrome (*N* = 1). Alongside this, a wide variety of comorbid problems in language, speech and hearing were prevalent, including profound deafness and communication aid users. No visual problems were reported by any participants.

In order to explore the use of the internet application as a validation tool, one class of school children who had previously participated in the research during the first phase of testing completed the application. This included both males (*N* = 4) and females (*N* = 4) aged 10 – 11 years of age (*X* = 10.88, *SD* = .354). These children completed the questions whilst a younger, novel class group were involved in the completion of the application at the same school.

6.5.2 Procedure

Visits took place at six local primary schools. One school provided specialised paediatric psychotherapist services that included several students with long-term neurological, neuromuscular and developmental conditions. When arranging visits to schools it was ensured that internet access was available and that they adhered to UK legislation by providing any accessibility equipment required for students to use a computer and access the internet (Disability Rights Commission, 2005). Such legislation also ensured that staff (e.g. support assistants) were available for individuals with additional educational needs.

The application was accessed via the internet within the available ICT resources at each school. The children were introduced to the purpose of the application and its content in class groups, although this was not the case for children who had participated previously. Such children were asked to complete the internet site relating to a project with which they had been involved in the previous year. In five schools, an ICT suite was available, where a subset of children performed the task at one time (in a group of 12 – 15) but worked through the application individually. In one school, laptops were provided to whole class groups in the classroom as an alternative to an ICT suite. Children were directed to the website location of the application and then the researchers and support assistants were available to help any children who indicated that they required support. The time taken to complete the application was recorded automatically for all participants. Throughout testing observations were made by researchers regarding the use of the interface by children with and without disabilities and the problems that arose.

6.5.3 Observations regarding the Use of the Application

All the children successfully completed the application and the average completion time was over five minutes (*X* = 5’31”, *SD* = 3’54”). Children without disabilities on average took around half of the time to complete the task (*X* = 5’22”, *SD* = 3’38”) when compared to children with disabilities (*X* = 9’41”, *SD* = 7’36” minutes), although there was large variability in the times for the latter. For example, one child classified as having a disability, completed the internet application in a shorter time than the average (*X* = 4’56”). The longest time taken by a child with a disability was, in contrast, a far slower completion time (*X* = 27’42”). The classification of children with and without disabilities does not capture the differences between the two groups. The qualitative observations should be used in trying to gauge and understand the variability in the completion times of the children. Children without disabilities had no difficulties in completing the tasks, with the only assistance being directed to the younger children (aged 4 – 5 years) where comprehension of instructions often required verbal delivery. Such support was supplied by the researchers and support assistants by reading the instruction text aloud to ensure that the children understood the tasks.

Most children with disabilities required some level of assistance to complete the application. All children with profound deafness required a sign language interpreter to translate verbal instructions throughout the logging in process. Once logged in, sign language interpreters were still available to answer any questions; however, they were only needed by a subset of children with hearing impairments: i) those with additional learning difficulties, or ii) younger children (4 – 6 years old) who required help with general language comprehension. Because these children were unable to hear the audio file instructions they lacked the alternative assistance embedded within the interface that was available to the other children. Children with hearing impairments in the higher age categories (7 – 11 years old) rarely presented any questions to the researchers or sign language interpreters and, once logged in, completed the task without difficulty.

A limiting factor for some of the children with disabilities was language comprehension. The children who participated with genetic disorders such as Down syndrome or global learning delay often had an support assistant in place because of other language comprehension difficulties that occurred in their day-to-day education. As such, the support assistants continued their role in explaining any aspects of the tasks to the children. The majority of the time this consisted of reading the text aloud. The audio files that were available to provide additional instructions did recite the text at a relatively slow speed, although the rate was found to be too fast to assist some children with comprehension difficulties.

The requirements of non-ambulatory wheelchair users involved setting up the computer in an accessible location for the user, i.e. ensuring that the computer monitor was the correct height and that the peripheral devices were within a comfortable operating distance. Most schools provided specialised desks within ICT suites for such purposes, although in one school two non-ambulatory children of 4 years of age completed the interface on a normal classroom table alongside other children using a laptop.

The extent to which children with CP required assistance was often dependent upon the available technical resources. In one school, two children who had spastic hemiplegia completed the tasks on a computer that had accessibility equipment in place. The equipment consisted of a large accessibility keyboard alongside a modified joystick in place of a mouse. The joystick supported the same precise functionality and movements made with a mouse, whilst ensuring that users only needed to perform small movements thereby reducing any potential fatigue. Similar equipment was used for a further four children at a different school, where two children with quadriplegic CP completed the application. Although the accessibility equipment was in place, only one of these children could complete the application independently. The child who could not complete the interface had high levels of spasticity and had difficulty in pressing the keys on the keyboard. In this instance, the support assistant used personalised methods to obtain the preferences from the response of the child, and held the child's hand to assist them in operating the keyboard.

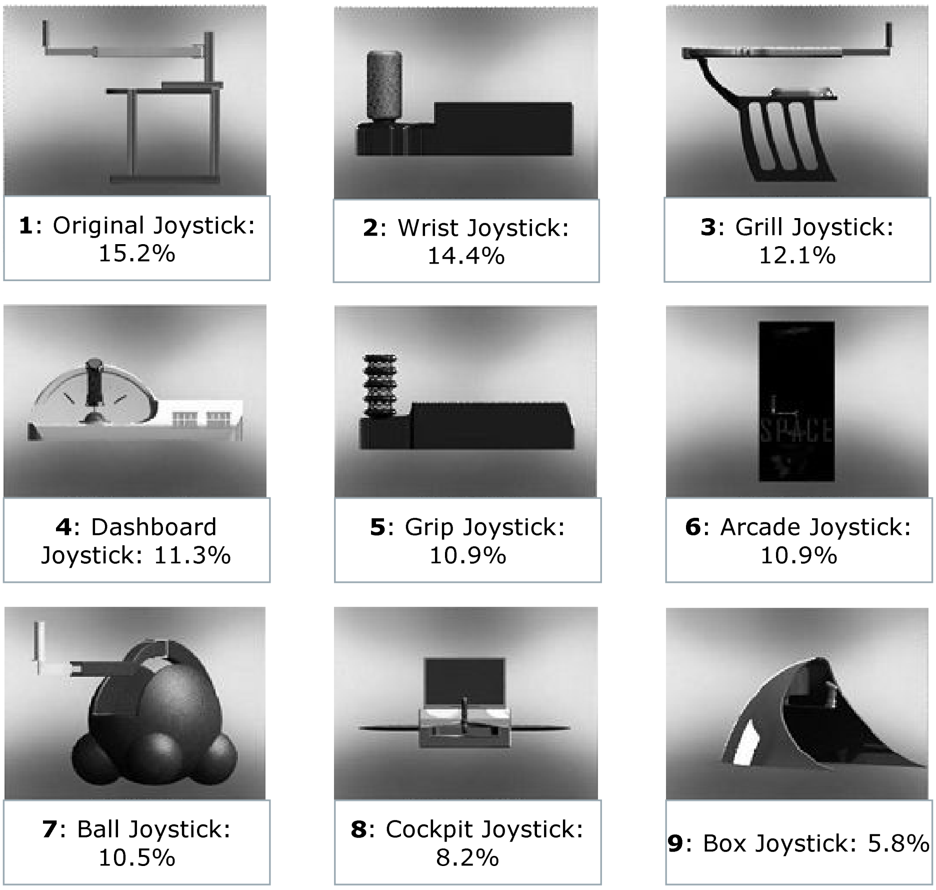
The assistance of support assistants was often very vocal and involved, and they would try to motivate the child to complete the application. Individualised methods were often adopted to provide support to children with learning difficulties. In most cases, the support assistant would read questions aloud to the child, and ensure that they worked through the task in a similar manner to their regular work rate. Although support assistants did not suggest responses to questions, they often discussed and described available options, and this may have altered the experience of the application for these children. The forced-choice task appeared to be completed with the least difficulty for children with disabilities, possibly due to the simple and repeated procedure of selecting their preferred option. Once children started this task, it was completed without the need for further explanation or additional support (with the exception of a child who required assistance to input responses).

6.5.4 Data obtained from the Application for Design Evaluation

The joystick images were presented as three-dimensional videos during the two alternative forced-choice task. For each joystick shown in **Figure 42** there is a percentage; this indicates the proportion of children who specified that the respective joystick was their most preferred, deduced by the application from responses obtained during the forced-choice task. The preferences of children measured in this instance are those relating to the joysticks as they are presented on the internet site (i.e., as virtual prototypes). One difficulty that arises in drawing any conclusions about the children's preferences for the joysticks is the differing modes of data collection used to gather and evaluate the information. Data was gathered through interviews; the evaluation occurred once the information had been interpreted and transformed into prototypes. Therefore, conclusions regarding whether or not child involvement can improve the design of healthcare equipment cannot be made until a more consistent methodology is used.

The children's joystick preferences (gathered using the forced-choice task) are displayed in **Figure 42**, and the general colour, texture and material preferences are summarised in **Figure 43**. Where information in the first phase of research gathered a range of preferences from the children, the internet application constricts the responses of children to those relating to the preferences of information directly presented to them. In adopting such an approach, the difficulties associated with open- and closed-ended questions can be observed. The advantages that arose from the first phase of questioning included flexibility in discussions with children, more detail being obtained to back up disclosed preferences, and the encouragement of co-operation and rapport. In line with Robson (2002), the use of closed questions, as used in the internet application, allowed for more control in questioning, alongside an easier means of analysing the resultant data. In addition to this, the internet application provides an efficient means of obtaining data from a wide range of children with and without disabilities.

Figure 42 indicates that the original joystick was the most preferred joystick design, with 15.2% of the children concluding the force-choice task with the joystick. However, there was very little difference between the most preferred joystick design, and the second most preferred (with 14.4% of children indicating this as their preferred design), alongside the third most popular design, which is very similar in appearance to the original joystick design (with 12.1% of the children indicating their preference for such a design). When observing the preferences for the different designs it is noticeable that the preference for designs is quite evenly distributed amongst the groups, only showing small differences between the percentages of children preferring the individual designs. Further to this, the designs that were created in a style that was different to the original (e.g., the 'dashboard joystick' design and the 'arcade joystick') received lower levels of preference from the children than both the original joystick design and a joystick that was a modified version of the original (the 'grill joystick'). The differences shown by the children serve to support the wide preferences of the child population that participated in this research. Such an array of responses may encourage researchers to reduce the number of preferences that are given to children, as selecting the most preferred joystick design in this instance would serve to satisfy the preferences of less than a quarter of the children. Alternatively, the presentation of joysticks may benefit from more detailed measures of children's preferences for each joystick, but this will increase the time demands on the children.



1: Original Joystick: 15.2%

2: Wrist Joystick: 14.4%

3: Grill Joystick: 12.1%

4: Dashboard Joystick: 11.3%

5: Grip Joystick: 10.9%

6: Arcade Joystick: 10.9%

7: Ball Joystick: 10.5%

8: Cockpit Joystick: 8.2%

9: Box Joystick: 5.8%

Figure 42 Children's final preferences of joystick designs

Similar to the findings of the forced-choice task, there were no clearly defined categories that were preferred by the children when responding to questions relating to colour and material preferences. **Figure 43** presents the graphs that outline the percentage of responses that were gathered for the different categories of preferences at the end of the application. 'Blue' was the most popular colour preference selected by the children, with 'other' being the least selected option. When asking the children about the colour that they would like a joystick to be for school, the most preferred colour was 'red'. The content analysis from the group diagrams in the first stage of the research (outlined in **Section 5.2.1**) highlighted that children preferred ‘blue’, ‘red’, and ‘yellow’. Similarly, brighter colours were identified as being preferred in the content analysis (outlined in **Section 5.2.3**). However, in **Figure 43**, beyond the initial colour for both questions relating to colour, there appears to be a mix of colours that provide an alternative insight into the findings from the first stage of the research.

For the two questions relating to materials, shown in the lower segment of **Figure 43**, there was a small amount of crossover between categories that were preferred by the children. Both ‘metal’ and ‘rubber’ featured within the higher preferences for both questions, although there was a difference between the most preferred materials to make a joystick from (indicated as ‘silk’) and the object that children like the feeling of most (indicated as ‘cotton wool’).

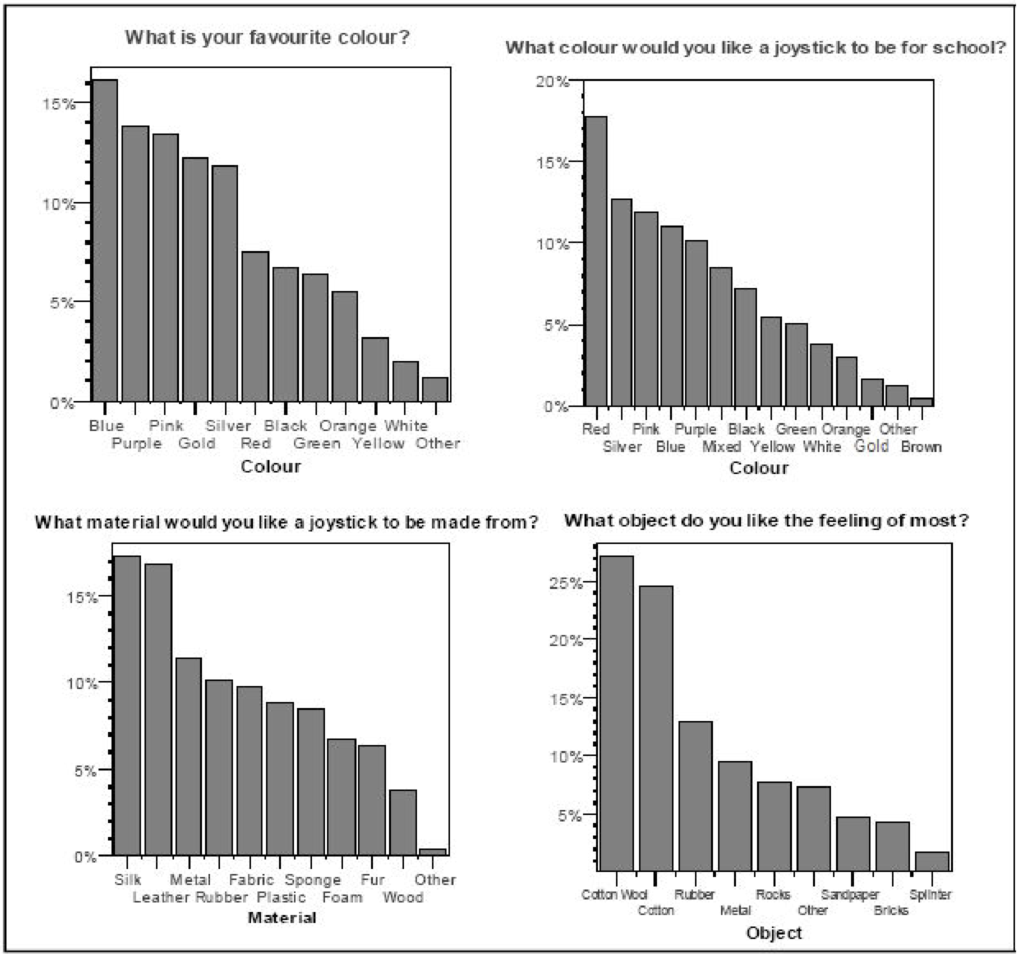


Figure 43 Information gathered from children regarding colour and material preferences for use in the design of a rehabilitation joystick

When the questions regarding the colour and material preferences were presented, four buttons were visible that listed different options for the children to choose from. These were randomly selected from a database of categories that were initially gathered during the interviews in the first stage of the research. However, alongside the four generated options, children were given the option of inputting an individual response that differed to those being presented. Children could do this by selecting the 'other' button that was presented alongside the four options, and manually typing their own preference. As shown in **Figure 44**, the majority of children did not insert their own response and simply selected from the available options, as indicated by '0' response (accounting for 75% of the children). However a range of children also selected '1' individual response (15% of the children), alongside '2' (7% of the children), '3' (2% of the children), and a small number of children selected individual questions on every question (indicated by '4' in **Figure 44**) (this accounts for 1% of the children). There is an evident inversely proportional relationship between the increasing number of individual responses and the number of participants inputting them.

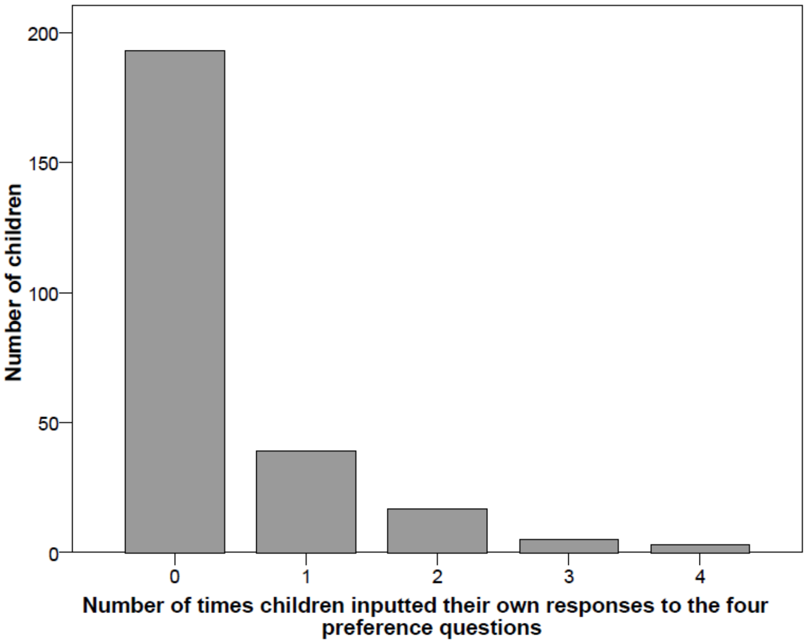


Figure 44 The number of times children typed in their own independent response

Given that three children inserted four individual responses for each of the four questions indicates that the decision to reduce the number of preferences displayed for the children may require revision. However, it also indicates that many children understood the system and were capable of ensuring that the researchers received information about their preferences.

Data gathered from the internet application is capable of portraying the displayed preferences of the children who were involved in completing the application. One difficulty with the obtained information, much like the coded and tabulated information from children given to the designer to produce prototypes, is deciding on how best to use it. The preferences of children that were highlighted in **Figure 44** revealed large variations. Such large variation could cause problems if it was to be applied during the design of a device. For example, if the data relating to children’s favourite colour information was to be used in the design of a healthcare technology device, two possible outcomes of a designers use of the information could arise; i) use of the most popular colour to assign to a device, or ii) incorporate the two most popular colours in the data set into the device design. The two most popular colours as indicated from the data retrieved from the research involving the internet application included blue (accounting for 16% of the responses from the children) and purple (which accounts for 13.6% of responses). If the population of children providing this information were end users, incorporating the two most popular colours in a final design would still only account for the preferences of less than 30% of the children. Additionally, in the first phase of the research, when children indicated their favourite colour, it was not always the same colour as their preferred colour for a piece of healthcare technology. There is clearly a range of factors influencing the decisions made by children, particularly when trying to understand their decisions relating to healthcare technology. This research has begun to address methods that may be suitable for involving children in the design of healthcare technology, but there is still a large amount of research needed to understand the factors affecting decision-making and practice once children are involved.

6.5.5 Cost Information Relating to the Internet Application

It was outlined during the first stage of the research, involving interview methods with children, that the cost and time associated with user involvement were major barriers in the development of medical devices (e.g., causing reluctance to involve users by manufacturers) (Shah and Robinson, 2007). Therefore, this research has begun to explicate the associated costs of involving children in the design of healthcare technology to support decisions made by researchers and manufacturers in future work.

The costs associated with interview methods were outlined in **Section 5.1.4**, where it was shown that the cost per child on average in an interview method was £5.83. This section provides an overview of the costs that were incurred during the development and implementation of the internet application. However, these costs do not account for the additional support that was provided by sign language interpreters or support assistants, as these costs were incurred by the schools in which the research took place. Such information will be useful to gather in future projects to inform similar research that is not taking place within the school environment.

In total, only three researchers were used during the implementation of the internet application in the school environment. In addition to this, one technician was utilised to complete the necessary programming to build the application at the request of the primary researcher. As was the case in **Section 5.1.4**, all researchers volunteered to participate in the research, and the figures provided are estimated costs should they have been employed as part of a research project. The information on which these figures are calculated was provided by the Faculty of Engineering Research Office at the University of Leeds. **Table 14** provides a breakdown of the wages that would have been required for the researchers involved in research relating to the internet application. In total, only two PhD students participated in the trials, with support from an undergraduate psychology student. As discussed in **Section 5.1.4**, the costs relating to an undergraduate student are maintained at the same rate as a PhD researcher, as this is the most likely level at which they would be accounted for in a research bid. The FEC figures are calculated only for the PhD students, as a technician is supplied by the university at a standard rate of £16.84 per hour, and therefore they are not worked into FEC calculations.

Table 14 Costing of hourly rates of the researchers who participated in the development and implementation of the internet application

PhD Student	
Maintenance	£17,875
Fees	£3,633
Indirect Costs	£7,693
Estates	£11,862
Infrastructure	£842
Total Cost (for 1 FTE contract) per annum	*£41,905*
Hourly Rate (inc. FEC, as calculated for 37.5 hours a week for 44 weeks)	**£25.40**
Technician	
Hourly Rate (as standard to cover any work performed on research projects)	**£16.84**

From the information presented in **Table 14**, it is possible to gather an understanding of the cost of staff wages in relation to those who time spent on the project. **Table 15** presents information relating to how many hours each researcher spent on the trials that are reported in this section of the research.

Table 15 The staff wages relating to the involvement of the researchers in the development of the internet application

Staff details	**Number of hours worked**	**Hourly rate**	**Total**
PhD Reseacher	10	£25.40	£254.00
PhD Researcher	9	£25.40	£228.60
PhD Researcher	8.5	£25.40	£215.90
Technician	120	£16.84	£2,020.80
		Total Cost	**£2,719.30**

No resource costs were involved in the development of the internet application because it was designed and implemented online. The costs associated with running a computer suite and spending time supervising the children were further costs incurred by the school. However, should the application be used more widely in the future, consideration of these additional costs will be required.

From the information generated relating to staff wages, it is possible to gather an estimated cost per child for involving children in the implementation of the internet application. In devising this figure, it is more representative of the costs associated with the research by involving the wages of the technician who programmed the application. When accounting for all of the children who participated in the internet application trials (N = 257), the cost per child on average was £10.58. This figure is almost double the cost per child that was calculated for the interview methods. The largest difference in the expense that is incurred for the internet application is related to the initial involvement of a technician. However, once the development of the application is complete, there is no further expense, which leads to the average cost per child being reduced every time it is used. In addition to this, there is scope to develop the use of the internet application in schools with only teacher supervision, and not researchers. Therefore, the potential exists to recruit and involve child participants in research without incurring any additional costs for researcher wages and additional resources. Although the interview methods revealed a lower cost per child, their continued use will also lead to increasing costs. This is linked to the need for facilitators and material resources. However, the internet application will reveal a reduction in cost per child, as the use of the application increases, as no further development and little researcher involvement is required as the frequency of its use increases.

6.5.6 Data obtained from the Application to Explore Data Validation

This section describes the use of the application for gathering information for validation and further exploration. This involved revisiting children who have already provided responses to the research team, and exploring any preference change that had occurred. Although this may not have a direct impact on designs of technology immediately, it will provide an opportunity to gather partial insight into the longevity of preferences and considers whether the internet application could appropriately validate information that was gathered in the first stage of the research. The need to begin to consider ways of validating information and methods used to involve children in design research has been highlighted (e.g., Mazzone, 2007). The internet application presents visual prototypes to children and gathers responses to questions. This means of presenting and gathering information from children could be a useful tool for future research involving design-orientated tasks.

Introduction to the Use of the Application to Explore Data Validation

A number of schools were visited during the implementation of the internet application. One school that was visited had been involved in design tasks the previous year, and the opportunity was available to test the internet application for its ability to gather information from children who had been previously involved in the research. Questions that were posed during early design visits that took place within the first phase of the research were included at the end of the forced-choice task. Questions that had been included in the early design visits enquired about children's preferences. These included asking children to list their preferences for joysticks, including which colour they would like the joystick to be, if they would change colours dependent on school, and gathering material preferences from the children. All of the five preference questions had been asked by the children previously in the first stage of the research.

By involving children who had previously participated in the visits and provided answers, the internet application was provided with a means of gauging its capability to retrieve similar information from child populations as the interview methods. In addition to this, the opportunity existed to explore any differences that were found from the children when providing responses in the first and second stage of the research. Although this does not involve a validation of the gathered information, it provides an exploratory insight into any differences that are found whilst demonstrating how it could be used to validate responses from children in the future.

Method for Investigating the Use of the Application to Explore Data Validation

A class of children who had been involved in the previous design tasks were involved in the assessment of the validation of data. However, of the children who participated, only eight children (4 males, 4 females; mean age (X = 10.88, SD = .354)) had been previously involved in the interviews following design tasks and the internet site completion. The internet application was used in six schools to assess its use for gathering information from children regarding their preferences and their ability to be involved in the evaluation of healthcare technology designs. One school within these visits had been involved in previous research developing the joystick, which was the device on which the application was focused.

Once children had completed the internet application, their reported preferences could be compared to preferences that were acquired the previous year in research that had taken place in the earlier design visits. The analysis of the results was completed by identifying levels of agreement between responses that were recorded during the initial research visits within schools, when compared to the responses gathered by the same children via the internet application one year later.

Results from an Analysis of Responses gathered from the Application

No children with disabilities participated in the visits to explore validation. All children who participated showed no difficulties in the completion of the internet application, and no child required or requested a support assistant. The data to represent the agreement between responses provided by participants in the interview and the internet application are displayed in **Table 16**.

Table 16 Levels of agreement between the responses to questions

Question	Agreement
What is your favourite colour?	**33%**
What colour would you like a rehabilitation joystick to be if it was used at school?	**17%**
What material would you want a rehabilitation joystick to be made from?	**20%**

Table 16 indicates that overall, the level of agreement between the responses provided in the first stage of research and during the internet application was low. The levels of agreement were based on the available data. Although all children who participated in this visit completed the internet application without difficulty, there was a lack of data from the interview method use during the first stage of the thesis research. For the interview methods used during the first stage of the research, not all questions were completed during the twenty-minute time limit. The difficulty in completing a validation investigation came when the questions that had been drawn from the first stage of research for use in the internet application had not received an initial response from a participant in the first stage. For example, for one participant who took part in examining the use of the internet application with this group, no problems arose completing the internet application. However, they had participated in the board game method during the first stage of the research and very few questions had been answered during their method participation due to disruptions. Therefore, there was no original data from the interview methods to compare with the responses that they provided whilst using the internet application.

Conclusions about the Use of the Application to Explore the Validation of Data

The internet application successfully gathered data to explore the use of the internet application to gather information from a previously involved population of chidlren. The overall scores from children, taken from the two different stages of involvement, indicated low levels of agreement. The highest agreement in scores when comparing responses from the interviews in the first phase of research with those provided to the internet application was a child's favourite colour. Although previous research has attempted to understand children's preferences of colour (e.g. Child et al., 1968), currently very little research attempts to explain why differences exist. More recent research linked to colour preferences of children towards AT (i.e., Light et al., 2007) highlights that children generally indicate a preference for bright colours, independent of gender, but the cause for changes over time have still not been explored. Material preferences also failed to achieve a high temporal longevity, and consideration should be given to how such preferences that are prone to change can be used in the design of healthcare technology. Light et al. (2007), in trying to establish the preferences of typically developing children for the design of AT, discusses that children use a range of materials in clarifying their preferences, but the paper provides no detail about this. Further research into the tactile and material preferences are required; particularly for establishing the differences that occur between children with and without disabilities. Such findings can feed into discussions about whether children with disabilities should always be consulted directly, alongside informing the appropriate use of proxies.

This section of research began to explore the ability of the internet application to gather responses from children in the second stage of the research, who had previously participated in the research during the first stage. Although it was only possible to explore the differences in responses provided by the children over time, where it is not possible to draw firm conclusions regarding the implications for designing with chidlren, the application was shown to gather information from the children. Given that the internet site has undergone observational testing and areas for improvement for future research have been highlighted, the application now requires further validation before it can itself be considered for use in the evaluation and validation of information during the design and development of healthcare technology with children.

6.6 Discussion of the Application Use

The principal aim of this research was to determine whether it was possible to gather information from children in a school environment using an internet application. This section firstly concludes about the investigations regarding the use of the internet site in **Section 6.6.1**, followed by an outline of the application of the findings in **Section 6.6.2**.

6.6.1 Overview of the Use of the Internet Application

Children with and without disabilities took part and successfully completed the application with varying degrees of support. This demonstrates that e-health techniques can potentially be used to inform the design and development of healthcare technology. In the

UK, legislation requires schools to provide the necessary support for a child with a disability, and this was essential for the success of the project. The active involvement of mentors and teachers was also an invaluable resource for informing the development of the structure and format of the internet application.

Gathering the views of children with disabilities is not without its difficulties. Despite the available assistance, children with disabilities took approximately twice as long to complete the survey with large differences in their response times indicating a need to further explore any disability-dependent variations in completion times. Care does need to be taken when working in groups to ensure that there is no stigma attached to the need for a longer amount of time to complete the survey. There are also issues with relying on the school-based assistants to aid completion of the survey, since it can be difficult to ensure that the choices of the assisted child are truly their own. It is also unlikely that this technique will be applied more widely if it is reliant upon such assistance, limiting deployment to similar educational settings. The major barrier for completing our survey was the need for assistants to read text aloud. While the audio instructions were used, if the speed of delivery of the audio had been flexible so that it could be adjusted to match the requirements of the individual then this may have allowed some children to be more independent when completing the application. However, the implementation of such a feature requires further investigation. A more difficult problem to address is the communication requirements of children with hearing impairments and learning difficulties. Children with deafness often have lower average reading comprehension scores than children without (Wauters et al., 2006) so it is crucial to improve the accessibility for these children and remove the necessity for a sign language interpreter. It is possible that video-based sign-language instruction would have been a useful addition for these individuals, and future work could look at the efficacy of such an approach.

It was hoped that the application would gather data about children’s general preferences regarding rehabilitation joysticks that was meaningful. Ideally, the children’s preferences would form the basis of the user requirements for developing future rehabilitation devices. Despite the application accurately documenting the opinions of children, the most effective way for designers to use such information remains unknown (e.g., the children selected a different favourite colour than the colour chosen for the favourite joystick so it is unclear how a designer should incorporate this potentially conflicting information into a design). Therefore, assessing the worth of the retrieved data is in need of further research. Though it may seem that such decisions are trivial, the preferences of children may in fact be essential for developing a medical device that will be engaging, and as a result effective. The e-health technique used here provides a general tool for developing healthcare technology and formally ascertaining the preferences of children.

Gathering this information should not be undervalued since it can drive the engagement of children with their therapeutic device, and as a result determine their adherence to the prescribed rehabilitation exercises (Weightman et al., 2008).

Access to the internet is expanding across the population of the UK and this growth provides an opportunity for practitioners and researchers to access a wide range of populations with disabilities (Whyte, 2006). For people with disabilities, the internet is reported to significantly improve quality of life, with increased connection to the wider world whilst allowing communication with people that have similar interests and experiences (Colver, 2005). Our online survey provided a means for children to be involved with developing the technologies that could improve their lives. There are few excuses not to involve children with disabilities in this type of research and there is now scope to continue to refine these methods to develop better medical devices for children.

The tool was used to explore its use as a possible research took for data validation in future research with children. When looking at the acquired data, children supplied different information relating to preferences when compared to information that had been gathered in the research during the first phase. The lack of consistency in responses can be attributed to a number of previously identified attributes of children. Punch (2002) points out that, like adults, children may lie to researchers for several reasons: to avoid talking about a painful subject, to say what they think the researcher wants to hear, or through fear, shame or a desire to create favourable impressions. It is too easy to discredit or fail to accept the accounts of experience provided by children (Morrow, 1999). Although these issues might be better understood by establishing rapport with a group of children, this was not possible due to the time constraints within the internet application visits to schools.

The internet application has yet to be validated as a method alone, before being applied to validate information from interview methods. In addition to this, the potential use of the application beyond a validation tool has yet to be explored. The affect of the different mediums (e.g., computer-based, interview methods) with which children are presented information requires further investigation, particularly in relation to the internet application.

Although previous instances of gathering preferences for use in design of healthcare design exist for AT (Light et al., 2007) and hospital wards (Coad and Coad, 2008) for example, to date there has been no consideration about ways to improve or test the validity of the information prior to its application. This method not only provides a means of beginning investigations into the validity of information, but further it is presented on an application that is designed to be accessible and inclusive to the largest number of children.

6.6.2 Application of the Findings

The internet application provides a feasible means with which to gather information from children to use at the evaluative stages of the design cycle. It provides an opportunity to incorporate designs of devices in a virtual prototype form and involve children remotely, allowing the potential involvement of children in research to occur on a global scale in future projects.

If the application is to be developed for further research projects, its inclusion must be improved to account for a wider range of children with disabilities. Gathering information online in a school environment via an internet application was not difficult for children without disabilities. Greater consideration is required about ways in which to accommodate and facilitate the independence of children who required support during the visit to allow them to complete the application, unconstrained by factors such as the extent of a disability or the setting of a particular environment. The application provided no alternative option for relaying written information to children with hearing impairments. This was not a barrier to the research because it was designed for use in schools where support is often in place. However, children with deafness often have lower average reading comprehension scores than children without (Wauters et al., 2006); therefore, in order to secure this as a plausible means of data acquisition it is crucial to establish a way of accommodating these children without the necessity for a sign language interpreter. Future developments to the application may look towards the inclusion of videos of sign language interpreters where children require assistance.

Children with visual impairments were not considered in the development of the application. Although options such as enhanced sound capabilities and modifications to the size and layout of the screen can be incorporated into the application, further research is required to establish which are necessary, and for which conditions. The original application was developed through a consideration of the potential users, and ensured that it could be used by most children within the school environment. In order to further the application, the adoption of such a bottom-up approach in the future will have to place more reliance on the detailing of impairment specific to children. As discussed by Keates and Clarkson (2003), the most successful products often come from bottom-up approaches with input from top-down approaches focusing on capability. The necessity to account for greater consideration for the capability of users calls for more input from top-down thinking in the development of the application, whilst maintaining the engaging and desirable elements that stem from consideration of able-bodied people and those with minor disabilities. Although inclusive design research outlines the capabilities of the general population, Keates and Clarkson (2003) often apply these figures to older adults when investigating the ageing population.

By beginning to detail capabilities specific to the child population, the design of not only healthcare technology, but also everyday technology could potentially benefit.

The use of virtual prototypes, and particularly the perception of devices and technology portrayed via this medium, needs to be explored with child populations. It is not clear to what extent the appearance of devices differ on the basis of dimension, angle and resolution when the context of presentation is a computer screen, or in fact whether these factors affect the ability of children to make inferences regarding the appearance of a device. Recently research has begun to investigate the mechanisms that underlie contextual inference and scene recognition in humans (e.g., Oliva and Torralba, 2005). The ability of this research to inform the presentation of RT and AT on a computer screen has yet to be fully investigated. However, specific enquiry into the area might catalyse exploration into the perception of features that comprise a medical device, and how this information can be supplied to the design of future devices in healthcare.

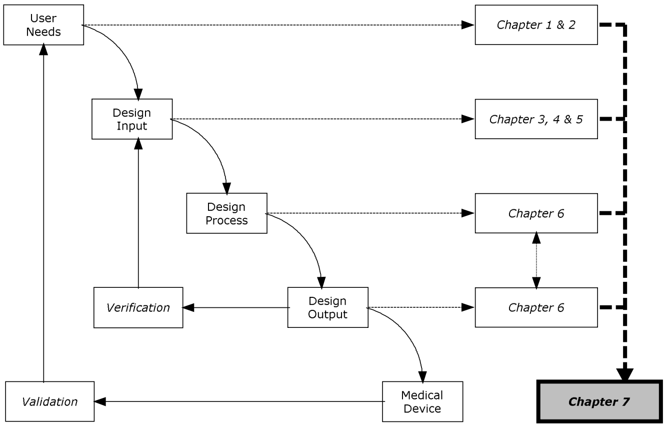
The use of the internet to supply healthcare information has been identified as an increasingly popular method of delivery. However, the relative ease with which people can place information onto the internet has been the source of criticism for its use in healthcare, and particularly for people with disabilities. It has been noted that people with disabilities and their families are easily exposed to misleading information about treatments (Oppenheim, 2006). Dedication to tightening controls on such problems may help to ameliorate the problem, and achieving this is important to realise the full benefits of internet use by populations with disabilities. Consideration must be given to the method used when trying to promote further internet use. For example, children with disabilities do not want to be categorised as separate to other children, and they value personal engagement on a level synonymous with other children (Kaye, 2000).

For people with disabilities, the internet is reported to significantly improve the quality of their lives; it ensures that they keep informed and feel connected to the world, alongside allowing communication to occur between people with similar interests and experiences (Colver, 2005). It must be ensured that developments to make the internet more inclusive for disabled users do not introduce novel methods specific to disability, and ensure that investigations instead continue to develop means with which children with disabilities can access online content to the same extent as children without disabilities. Similarly, applications need to be inclusive, but equally engaging across population with and without disabilities.

Given the prescription of warning that often accompanies the guidance of possible research methods for use with children with disabilities (e.g. Taylor, 2000) this application presents a unique opportunity to gather valuable information from children with and without disabilities on an even platform, whilst simultaneously enriching their lives. However, the use of the application as a means of validating information has yet to be explored in further research. The internet is undergoing vast change and arising with this is a concurrent opportunity for practitioners and researchers to furnish the lacuna of information and research regarding online access to populations with disabilities (Whyte, 2006). Such practice requires future exploratory work to increase and refine the use, implementation and identified barriers associated with such applications for users with disabilities.

Chapter 7

The Involvement of Primary Schools in the Design of Healthcare Technology for Children



This chapter outlines guidelines for the involvement of primary schools in the design of healthcare technology. The guidelines were included to broaden the scope of the research by looking beyond the examination of child involvement, to strategies for performing such research within the school environment.

An action research approach was used to address the need for research guidelines for investigations that involve designing with children in the school environment. The chapter begins with an introduction to research in **Section 7.1**, emphasising the benefits of involving schools in research related to the design of healthcare technology. The following sections then discuss different aspects of school involvement; preparing visits (**Section 7.2**), planning visits with primary schools (**Section 7.3**), running research visits in primary schools (**Section 7.4**) and post-visit information (**Section 7.5**). The concluding section contains an overview of the potential application of the guidelines in practice (**Section 7.6)**.

7.1 Introduction

This chapter presents an action research approach to the development of guidelines for use in healthcare technology design with children. The insight and experiences that were gained by the author and the accompanying research team are presented, along with recommendations to other researchers that are planning or completing similar research. It is hoped that the development and dissemination of the guidelines will provide insight into designing healthcare equipment with children, and promote the use of the school environment for data gathering.

When designing the research activities in the first stage of the thesis, it was noted that very little guidance about how to conduct and run design activities within the school environment existed. This research recognises the value that the school environment has to accessing children and promoting their involvement in healthcare research. Earlier phases of testing made up an action phase that examined current practice, and this chapter consists of the reflective stage, outlining the lessons that were learned. The introduction of guidelines facilitates the involvement of schools in healthcare technology research, providing the opportunity to access populations of children with and without disabilities who can inform the design and development of such technology. This chapter documents the priorities and concerns that have arisen in the research visits during the earlier phases of testing within this thesis, and explicates the considerations that need to be made at the different stages of the research process. The process of delineating and disseminating the research experience gained in this thesis provides the opportunity to critically reflect on one's practice, and discuss the approaches that have proven successful.

The primary school setting is an environment providing the ideal opportunity to investigate healthcare technology design and development research with children. The presence of children with disabilities in primary schools has increased since the development of inclusive education, where the benefits of these settings have been described (Lindsay, 2003). Inclusive education leads to the increased use of healthcare technology within the school environment; therefore, the opinions of children without disabilities are particularly valuable to designers to ensure the social acceptability of healthcare technology deployed within this setting. The design of healthcare technologies directed at improving childhood participation in education and play require the involvement of stakeholders at the prioritisation stage of identifying the technology "gap" and at the inception of the design process (Light et al., 2007). Stakeholders include disabled children, peers without disabilities, and service providers such as teachers (Waller et al., 2005). Teachers can provide invaluable information and insight into the daily factors associated with disability within the classroom and school environment, and they are a critical research resource. Parents can also be included but their role in technology development within educational settings is likely to be less involved than instances where technology is being developed within the home environment.

Smith et al. (2009) highlight that although teachers have been involved in collaborative research projects their engagement in research can vary considerably because of competing pressures on their time. Despite this, there has been a recent identification of the need to increase the cooperation between researchers and practitioners within educational research and practice (Vanderlinde and van Braak, 2009). Although general guidelines can be found for planning and conducting social and educational research (Cohen et al., 2007) there is a paucity of published literature that provides practical guidance on involving children and teachers in technology design and development in educational settings. Approaches to usability testing of computer products (in this instance Microsoft®

software) have been reported (Hanna et al., 1997), but these are not related to research in healthcare or the school environment.

The presence of disabled children within the school context permits open discussions between all children about the design of healthcare technologies, not just technology that has been designed for use with a specific disability. With appropriate planning, those involved in the case studies within this thesis were afforded the opportunity to canvass opinion from disabled as well as able-bodied children, thus avoiding the cost and time associated with dedicated user group meetings or workshops (that take place outside of school settings) to gather data from people with a specific disability. Additionally, previous research alerts us to the danger of people with disabilities feeling that they are “overresearched” (Mitchell, 2003). Therefore, when children with disabilities are involved in research, careful consideration should be applied to their recruitment and treatment in school. However, in using the school environment for larger visits involving whole classes of children, there is an opportunity to disperse the effect of researching only children with disabilities.

Research within this thesis took place within the school environment, where the deployment of formal user-centred design processes has certain advantages. Primary schools within the UK are obliged to provide the accessibility hardware and AT that is outlined on any statement of special educational needs for children with disabilities. This policy ensures that the elicitation of ideas and preferences from disabled children, particularly those presenting physical and communication impairments is supported with appropriate accessibility or assistive equipment. This requirement enables researchers to plan what should be fully inclusive and accessible research by providing the means of ensuring at least basic communication skills from every child (National Disability Authority, 2006). The addition of this technology may require consideration of how best to pose questions to different children.

A key aspect of working in the school environment is contact with teachers. Teachers are clearly knowledgeable about their students, class dynamics and the accompanying environment and are crucial to the success of any user-centred design method used in the school setting. Teachers can also assist in the research process and guide and control a class full of young children in the context of the research project. Design research uses methods on the basis of research interest, the size of the population, and the experience of those performing the methods (Druin, 2002). Providing researchers involve teachers in visit planning and apply initiative and willingness to adapt methods appropriately within this environment, bespoke research designs may be implemented to ensure that useful information is obtained to inform the design process.

Although theorists have questioned the likelihood of success in collaborations between schools and universities (Carlone and Webb, 2005), it is the responsibility of the research team to ensure that the demand placed on any school is not too high. Within the links formed with schools in this research, the aim has been to establish a “collaborative labor” (Zigo, 2001). This approach involved the research team engaging with students in the classroom setting to acquire knowledge that can be used to address problems on a larger societal level. The process contained an element of exchange, where ideas were shared between the researchers and the participants. Within this research, we initiated discussions surrounding what disability means to children, and introduced concepts of rehabilitation. In exchange, we witnessed the generation of novel ideas and perspectives by the children regarding RT and associated devices. This chapter describes the process when involving children and teachers in the design process across six primary schools.

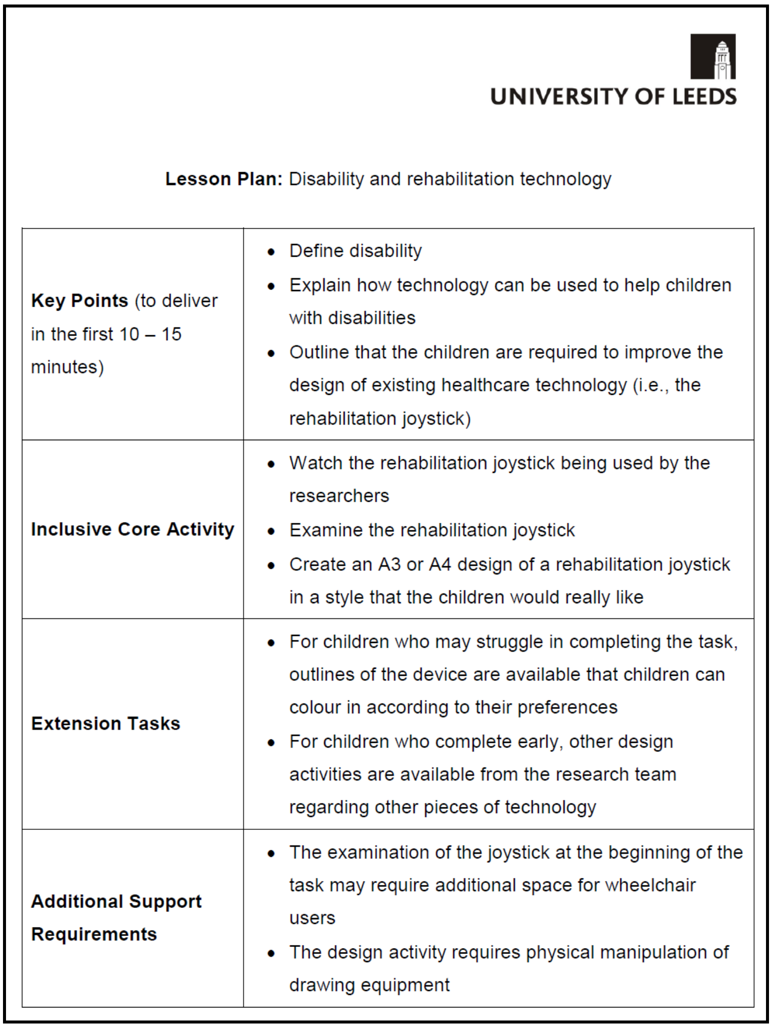
These guidelines present the procedures and practices that were developed during the first stage of testing within this thesis, alongside the implementation of the internet application. The guidelines also take into account barriers that were identified during **Chapter 4** and **Chapter 5**, and address means of overcoming them.

7.2 Preparing Visits with Primary Schools

When contacting primary schools, the receptionists appeared to adopt a variety of methods for dealing with communication from external groups such as the research group. To arrange research visits, telephone conversations were the most useful form of communication, particularly when contact was made with the head teacher allowing for detailed discussion of the research project. Such an approach ensured communication with staff at the school and a faster response than was obtained when communicating via post or email. However, many schools also had special needs coordinators who were equally important to involve in discussions about the practicalities of the research visits. Establishing such initial links with schools was often confounded by the limited availability of staff in both of these roles. However, once contact was made, most schools expressed strong support and approval for the value and application of the research. To develop this support, the direct benefits and potential outcomes of the project were highlighted and any meetings to discuss the project in more detail were arranged around the existing schedules of a school. These early discussions provided an opportunity to discuss the time commitments that would be expected of a school. For this project, most schools were asked to be involved in one visit that lasted half a day. However, many schools were approached with the intention of developing permanent links with the research team. By establishing such links, a research team avoids creating novel links with schools for any new research projects, and teachers begin to feel more comfortable with the researchers. In these instances, it was proposed that visits to the school could take place once or twice a year; multiple visits could be used for follow up research or involving new cohorts of students.

Before any plans for research visits in the primary schools were finalised, members of the research team attended meetings with head teachers from the participating schools. The most effective strategies for integrating research practice into the existing procedures at a school were established at such meetings. The current NC was suggested as a foundation on which to design research visits. Information outlining the programmes of study and the learning objectives of children within this framework can be found online (www.nc.uk.net). The research presented in this thesis linked into the Design and Technology curriculum where learning objectives included developing, planning and communicating ideas, alongside evaluating processes and products. Identifying such objectives allowed the team to arrange research activities that addressed the aims of a project whilst simultaneously contributing to the current practice and teaching within the primary schools.

Lesson plans are often used by teachers to outline the intended learning objectives of a lesson. During meetings with head teachers, the development of a lesson plan to accompany the visits in schools was encouraged (see **Figure 45** for an example). By doing so, it clearly communicated to teachers how the research fitted into the NC and provided them with a succinct outline of the visit in a familiar format. The lesson plans were simple and not over-planned, fitting onto one sheet of A4 paper for ease of reference during a lesson. It contained key points that a teacher or researcher would deliver within the first ten or fifteen minutes of a lesson and detailed an inclusive core activity (i.e. the task that the majority of children should complete). Consideration regarding the dynamic capabilities of a class was important and extension tasks were developed. Extension tasks accounted for the spectrum of learning capabilities within a class by ensuring that there were additional tasks for children who were less able to complete the inclusive core activity, or for those who required further tasks. Head teachers provided an estimated number of three or four children in both of these categories for most classes. By providing teachers with a draft lesson plan the team had an opportunity to discuss the availability of resources for any proposed activities and review the suitability of any extension tasks within a specific school before the visits took place. The lesson plan provided by the research team acted to communicate clearly with the teacher, and was not intended to replace any existing lesson plans that a teacher may have already prepared. Instead, it provided a means with which the priorities of the research team could be expressed within the framework of the teachers practice, and can be extended or reduced following discussions with a teacher.



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Lesson Plan: Disability and rehabilitation technology

Key Points (to deliver in the first 10 – 15 minutes)	• Define disability • Explain how technology can be used to help children with disabilities • Outline that the children are required to improve the design of existing healthcare technology (i.e., the rehabilitation joystick)
Inclusive Core Activity	• Watch the rehabilitation joystick being used by the researchers • Examine the rehabilitation joystick • Create an A3 or A4 design of a rehabilitation joystick in a style that the children would really like
Extension Tasks	• For children who may struggle in completing the task, outlines of the device are available that children can colour in according to their preferences • For children who complete early, other design activities are available from the research team regarding other pieces of technology
Additional Support Requirements	• The examination of the joystick at the beginning of the task may require additional space for wheelchair users • The design activity requires physical manipulation of drawing equipment

Figure 45 An example of a lesson plan used on research visits to the schools

Extension tasks are particularly useful for visits involving children with disabilities. For example, in **Chapter 6** in the early visits with the internet application, typically children without disabilities who had finished completing the tasks lined up at the door. Because children with disabilities took longer to complete the internet application, they often remained the only children left seated with all of the other children watching. Following this experience, the inclusion of extension tasks into lesson plans enabled the addition of further small activities that ensured that children without disabilities were engaged until the end of a visit. Such changes also fed back into the design of the internet application, where it was examined whether simple built-in features such as having evaluation questionnaires, or alternative items such as built-in games would be useful additions.

7.3 Planning Visits with Primary Schools

When discussions with primary schools had been completed and visit dates set, the team focused on issues regarding consent forms and information sheets for parents and guardians. Although it is advised to provide assent forms to children immediately before their participation on the day of a visit (Ungar et al., 2006), schools often required consent to be gathered from parents for any additional tasks that form part of the research activities. Due to delays that can occur with the return of such forms, the team ensured that letters were sent out at least two weeks in advance of the visit day. The parental information sheets were short and succinct and consisted of one to two short paragraphs detailing the general purpose and activities involved in the visit. Initially the research team produced an extensive explanation of the purpose of the research, but head teachers suggested cutting the information down to the minimal amount for ease of the parents.

Although children's knowledge of disability has received attention in research (e.g. Magiati et al., 2002), concepts such as rehabilitation have yet to be investigated. Given that the research visits relied heavily on discussions and activities relating to complex topics, the team ensured that the class teacher discussed these with a class before the day of a research visit. Although research has shown young children to have an awareness of physical and sensory disabilities, it is not until later in development where an awareness of developmental difficulties such as speech and language disorders can be identified (Diamond and Hestenes, 1996). Teachers were asked to hold discussions surrounding a range of disabilities with a class before the research visits, with this information being consolidated in presentations that were provided on the day of the visits. If the opportunity to be involved in such preliminary talks arises then there is scope to gain invaluable insight into the class population prior to a visit. For example, should a child present a severe communication disorder, a researcher can gather insight into the strategies used to communicate with the child in day-to-day activities, alongside focusing on any means with which methods can be adapted to accommodate such a disability.

Insight into a class gathered before a visit can inform the preparation and planning of research visits. In particular, gathering details of the children with disabilities will shape any adaptations that are required to methods to maximise the inclusivity of a specific class population. When developing design research in schools where children with disabilities attend, a consideration of the behavioural capabilities of these children will often be useful in guiding the selection of methods as they could prevent their access and participation. The research visits involved in this research have included children with physical, visual, auditory and communicative impairments, alongside children with developmental disorders. If children present any such impairment there will be a need to consider possible alterations to the running of visits. In the research visits in this research, when children have presented physical impairments due to CP, for example, there has been a need to consider alternative means of gathering assent from the children. An inability to complete paper-based assent forms requiring fine control of pen for example, will require alternatives such as audio recordings of children verbally consenting to participation. This would serve the same function as paper-based forms, but simply require alternative resources. However, the inclusion of additional data collection methods, such as audio recordings, may require revisions to ethical approval.

Involvement with a school prior to research visits will not only offer insight into the population of children that may be involved, but will allow the researchers to document the environment in which the research visits will take place. This process can occur during meetings with teachers and head teachers or during involvement with classes prior to the visits. Factors that are worth noting that may directly affect the visits include the daily time schedule of the school (e.g., duration of sessions, break times), space available in areas assigned for the visits, and the type of area that will be available (e.g., a public corridor, quiet library). A major factor of importance to consider if children with disabilities are present in a class group is whether there are support assistants available to assist the children. Often the presence of a support assistant will have already been decided dependent upon a child's statement of special educational needs. However, in research visits forming part of this research, classrooms have had up to three children with hearing impairments, with the appointment of only one support assistant for any additional support that is required. In addition to support assistants, the presence of classroom assistants can allow researchers to focus solely on data collection in visits where observations are required for example. Knowing such features of the environment in advance allows consideration of any means of reducing problems that may arise, and provides the opportunity to design a research visit that caters for the specific capabilities and needs of a class group.

The development of any collaboration with teachers, support staff or classroom assistants prior to visits has proven to be very useful in designing visits within this research. Such roles within the schools have provided first hand knowledge of the daily activities of children, and highlighted any practical difficulties that they have anticipated. They have also assisted children as they participated in the research and provided guidance to the research team about the idiosyncratic characteristics of a school and the attending children. However, this insight must not supersede information that can be gathered from children directly. The use of proxy information in this instance is ideal for foresight into difficulties that may arise during visits, but ensuring that children are asked about their experiences during and after participation promotes the identification of areas of improvement in future research visits.

Although support staff and workers may attend the visits, the selection of research team members to assist with data collection is important. Within this thesis, the research team has comprised researchers working within rehabilitation engineering, or who have been involved in previous educational research, including undergraduate psychology and product design students. An ability to understand the environment or population undoubtedly promotes more efficient research visits by reducing the need to explain protocols for working with children.

The choice of methods to use in a research visit can have a major impact on its success. Choosing appropriate methods relies on consideration of issues raised relating to the capabilities of the population, environment, and the research team that will complete the visits. Capability should be maximised, and foresight will encourage such an ethos. Prior insight can also inform possible areas of delay in the research and guide the allocation of time to a project. For example, a child with communication impairments might take longer to answer each question, so this should be accounted for in the construction of any questionnaires. Schools are obliged to provide any necessary accessibility equipment to assist with existing impairments that children have, so these should be discussed with a school and utilised where possible. The supply of accessibility equipment is particularly useful for ICT equipment, as mentioned in **Chapter 6** when discussing the internet application. Using ICT resources provides one means of overcoming a range of impairments, and is an area receiving increasing attention in relation to children with disabilities (Wong et al., 2009); focusing on this area will provide promise of possible means of overcoming impairment that might be encountered.

This research would have benefited from the use of pilot investigations before the research visits. For example, the sporadic behaviour of different groups of children during participation in the board game method was not consistent across all gender or age groups. Insight into characteristics that caused such behaviour may have prevented disruptive behaviour occurring. In addition to this, gathering an idea of children's capabilities, such as observing a child with a physical impairment completing daily work would have provided insight to their capabilities and allowed these to be utilised more effectively in a research visit. For example, a range of children with physical disabilities within this research had difficulty in completing design tasks such as group task diagrams. Noting how children typically complete such tasks, or identifying software that can be modified with a computer in a school environment are all possible means of gathering information that might otherwise be ignored.

The use of props within the visits during this research has proven successful. The inclusion of the simulation kit, alongside such props as the material samples in design tasks appeared to have a positive impact on children's participation. As outlined in research by Druin (1999), children's feedback and comments regarding technology need to be interpreted within the context of concrete experiences. Props provide a means of assisting children in the construction of a mental model, which has been reported to assist children in learning (Astrachan, 1998). This is of particular importance in an area such as rehabilitation, where children may not have explored related concepts such as disability before, and require greater insight than a preliminary discussion. This is also the case for materials, for example, where children might be aware of the appearance and feel of an object or surface within the context of a product, but cannot isolate or recall the feeling away from this. Therefore, the use of props within the design sessions within this research were provided as a means of assisting children validate their recall of textures.

7.4 Running Visits in Primary Schools

In the experience of the research team, research in schools should always be approached with flexibility. On occasions, the research team had to perform interviews and focus groups with children in cloakrooms or teaching kitchens. Although such arrangements evoked feelings of uncertainty in the researchers, the children were often familiar with most areas of their school and always appeared comfortable when participating in interviews, independent of the environment. Additionally, when involving children with disabilities there is a need to be willing to change set interview and activity protocols. For example, in an activity within this research where a child with a communication impairment begun to show signs of lethargy, questions were reduced to those requiring only yes and no responses, making the task less labour-intensive for the child. In addition to this, during interview sessions with children with communication impairments, the researchers have occasionally asked participants whether they would like to answer more questions at breaks in questioning. This provides the opportunity to let the children indicate whether they would like to continue questioning as signs of boredom and disinterest are sometimes more difficult to identify in children with communication impairments if you are not familiar with the child. Consequently, the ability to change in accordance with the needs of the children and school was a necessary requirement to perform research within the school setting. Controlling for extraneous variables was often a challenge, and most schools were not naturally suited to research requiring a controlled environment. Having to make do with given settings and last minute changes to visits, means that establishing well controlled and standardised conditions is very difficult to achieve.

Before providing a presentation and outline of visit activities to a school class, the research team have always ensured that they introduce themselves by their first name. Where possible, the team have also worn name badges to identify themselves to children. On occasions where this has not occurred, children have often enquired about the researchers' names, indicating a desire for this information to be typically made available. When delivering information and instructions to children, the team found that presenting year 1 groups (aged 5 – 6 years old) with phonically-based instructions led to less confusion with instructions for the children than written instructions, and applied a similar approach to older groups such as year 6 (aged 10 – 11 years old). This means of delivering information allowed the researchers to observe levels of engagement during explanations and promoted an interactive question and answer session with the children. The approach was also synonymous with methods employed to deliver instructions by many of the teachers.

Research visits led by the team often followed a structure (see **Figure 46**), beginning with a presentation to the whole class of children regarding the purpose of the visit. The opening presentation often lasted between 10 – 15 minutes beginning with an overview of disability and an outline of the visit activities. This was followed by a general overview of engineering and how it can be applied to healthcare, particularly in terms of making healthcare equipment. The inclusion of the topic of engineering has been welcomed by schools and was often integrated into teaching, or themed weeks. The presentation discussed a range of topics within the field of engineering, discussing how they apply to the real world (e.g., automotive, structural and robotics engineering). Props were used to provide examples of engineering applications, such as a Sony AIBO robotic dog, and supporting audio and video materials that demonstrated the content of the presentation. Although most teachers had already discussed the concept of disability with the children, the researchers took the opportunity to draw specific attention to it within the context of rehabilitation. Role-playing was used with the presentation when, for example, children were asked to try to take a jumper off with one hand. This activity was used as a way of relating disability to the daily behaviours of the children and to provide insight into the effects of a physical impairment of the arm. Subsequent question and answer sessions with the children allowed for any queries, although questions were encouraged throughout all discussions. Importantly, when providing explanations of neurological impairment such as CP it was ensured that the existence of other learning-related impairments was not implied.

Figure 46 Summary of research activities completed on a research visit

The group activity (or ‘inclusive core activity’) that followed had clear and simple objectives, beginning with the initiation of discussions with children about disability and rehabilitation. The key points were to highlight the correct use of rehabilitation equipment and discuss how engineering and technology design could assist in the production of equipment that can help people with disabilities. The inclusive core activity involved children working alone or in groups to design their own version of a rehabilitation joystick and often lasted between 60 – 90 minutes. The complete rehabilitation joystick device currently under development at the University of Leeds was presented to the children and they were encouraged to operate the device with the accompanying software. In addition to this, material props (e.g., sponge, leather and cotton) and colour charts were given to the children to assist them with the generation of ideas. For the children who completed the task before time, a selection of other case studies and design activities were available. When children struggled with the task, further assistance was available from the researchers, and if necessary, the children could simply replicate the original design and focus on changing only one aspect of the design such as the colour. This design task incorporated the "developing and generating" aspects of the NC. The children generated ideas based on other people's experiences, talked about their ideas and communicated their ideas using a variety of methods, including drawing and making models.

Another aim of the group task was to encourage children to begin thinking about the idea of rehabilitation and related devices alongside focusing their thoughts on the aesthetic of the joystick. To assist in maintaining children's engagement with the task, researchers moved around the class and further discussed topics and emerging designs with the children. It is worth noting that for such an activity, at least two additional research assistants were required for each class of children. This was the optimum number to ensure adequate support was in place to run the visits smoothly and to assist the teacher where necessary. The researchers who attended the visits often worked within the research team on similar projects and had previous experience working with children, in an educational and research setting.

The final stage of the research visit expanded upon the ideas generated in the design tasks within a range of focus groups, interviews, one-to-one design sessions and board games that took place either during or shortly after the group task activity. The interviews lasted 20 minutes and involved either an individual or a group of children. Children with disabilities often did not require any additional support from the research team in these activities as support assistants were already in place for those who required mobility and speech support. Children with disabilities were happy to be involved in group interviews, although children with communication impairments took longer to respond to questions. There was variability across the schools regarding the number of support assistants that were available to assist with the research. Although typical daily behaviour of teaching assistants has only just begun to be investigated in a systematic manner (e.g., Blatchford et al., 2009), their involvement within the research visits was always positive.

Consideration should be given to the methods that are used when involving schools in research. Although this section promotes the use of interview methods, as were used during the first stage of this research, alternatives are beginning to emerge. For example, **Chapter 6** of this thesis presented an internet application for use in the design and development of healthcare technology with children. Although cost comparisons between the internet application and interview methods revealed a greater initial expense when using an internet application, the costs incurred with such a method will reduce every time the application is used. Conversely, the interview methods will continue to gather cost, as they require the presence of a facilitator and a range of resources in order for them to take place. Alongside cost considerations, the types of information required by researchers can also be used to guide the selection of a method to use in the school environment. Where a small number of trials are required to gather in-depth information from children, the interview methods may be suitable. However, when children are to be involved in an intensive iterative process requiring shorter responses, the internet application might be more suitable.

7.5 Post-visit Information

Where possible, children were asked to complete post-test questionnaires following participation in design tasks and interviews. These questions were designed to gather their opinions regarding their enjoyment of visit activities in addition to questions that try to gauge children’s understanding of the material covered. By implementing a range of methods for gathering post-test information, it has become clear that different methods suit different age groups. The research team often ask younger children more closed questions, as a means of clarifying enjoyment in an activity, with older children being asked more about the process and how this might be improved in the future. However, an awareness of children’s tendency to acquiesce in such questions should be noted (Read et al., 2002), and researchers should encourage openness by outlining the anonymity of children’s responses. The involvement of children in post-test activities also provides the opportunity to de-brief children on the purpose of the visit and emphasise the importance of the children’s information in the process. This also provides the opportunity to thank the children for being involved.

The security of data was of extreme importance in the research. Any electronic data was modified to incorporate unique individual identifiers, and information that could lead to identification of participants was immediately removed or transformed. Given recent issues surrounding storage of data, guidance on its management is emerging (e.g. McGilchrist and Sullivan, 2007). In addition to this, maintaining links with a school is crucial, and all schools that have been involved in the initial research visits have indicated willingness to participate in future studies. The levels of involvement that are possible by a school vary, but every school has been visited at least once throughout the year in relation to ongoing projects. To sustain these links, research updates were sent to the schools for dissemination to students and parents and guardians. These included explanations of how the obtained information was being used by the research team, e.g. discussions of developments that had occurred with the joystick device. The researchers also hosted mini-competitions on the basis of suggestions by teachers that involved choosing one or two children that completed the design tasks in greatest accordance with the instructions that they were given.

De-briefing teaching staff was always very insightful, particularly for identifying and gauging the extent to which proposed activities worked in the classroom, and for noting any difficulties that arose. In addition to teachers, the insight of support assistants and teaching assistants is very useful in that they can provide the subtle details of the involvement of children with disabilities. It is these insights that have proven invaluable in the development of research methodology applied by the research team to accommodate children with disabilities. Although practitioners have been criticised for failing to alter practice in accordance with research findings (Lather, 2004), the use of insight from the aforementioned stakeholders provides a prime opportunity to radically develop suitable methods for research involving children with disabilities.

Table 17 combines teacher observations with insight gathered from the research team to summarise the main points of consideration when involving primary schools within research. Beyond the research visits themselves, such dissemination of findings is currently crucial. By reporting on the experiences of a research team, and particularly information about the process of running visits, the likelihood of establishing best practice of research within the development of healthcare technology taking place in the primary school environment in increased. Given the underlying philosophical contradictions in existing design research (e.g., Love, 2000), the importance of clearly outlining the development of any methodology for use in the area is of high priority. By outlining such intentions regarding the maintenance and documentation of developments in methodology, it is hoped that research in the area will stand a greater chance of remaining grounded in research practice and have greater relevance to the involvement of children with disabilities.

Table 17 Summary of the process used to involve primary schools

Preparing Visits	When contacting primary schools aim to speak to the head teacher or special needs coordinator Highlight the benefits of any outcomes of research on initial contact Ensure the research team is highly flexible with scheduling and visit planning Incorporate research into the National Curriculum where possible Create a clear and simple lesson plan for teachers outlining key points, core activities, and extension tasks
Planning Visits with Primary Schools	Provide schools with clear and succinct outlines of the research project along with consent forms for parents and guardians Ensure that complex concepts such as disability and rehabilitation are discussed by the teachers and children before the research visit day
Running Visits in Schools	Provide children with assent forms before participation in visits Be prepared to change the visit setup Delivery of instructions should be phonically-based Ensure that presentations to children are engaging and interactive: this can include audio, video and interactive products Involve an adequate number of research assistants to account for demands of time within visits
Post-visit Information	De-brief children and do a post-test review (e.g. questionnaire) to gauge children’s understanding and areas to improve Ensure that security measures are implemented with any data Maintain future links with schools through the use of newsletters for parents and guardians and other additional activities De-brief staff and gather insight for improvement in future visits

7.6 Application of Guidelines and Future Research

Children with and without disabilities have important roles in guiding the design and development of healthcare technology. The primary school context is an ideal setting to gather information from all children to create technology that fits into the social context in which it is to be used. This case study has outlined the process adopted by the team to gather data from children within the primary school. The recent history of accessing and performing research visits within this setting has been described and problems that were incurred have been highlighted. The experience of the research team has been outlined to compensate for the current lack of literature covering the involvement of children in the design and development of healthcare technology, and in particular rehabilitation equipment. Research in primary schools can be very insightful, but running clear and trouble-free visits can be difficult, particularly when the content contains relatively complex concepts such as engineering and rehabilitation. There is a need to reflect on any approaches used to deliver such information when presenting to children and it is hoped that explicating the methods used in this research will assist others when performing similar investigations.

Although this chapter provides preliminary guidelines regarding access to primary schools, further attention is still required to identify suitable methods for deployment within this environment. Although gaining access to, and running visits in schools can be mapped to an extent, detailing trade-offs between the availability and resources of schools with the data required by a research team is more challenging. Involving adult users has led to the development of usable and clinically effective devices for use by adults (Ram et al., 2007). Through the involvement of primary schools in research, it is possible to begin the development of devices for children of equal worth, with an expanding capacity to account for the context of their use and the opinions of those surrounding the user.

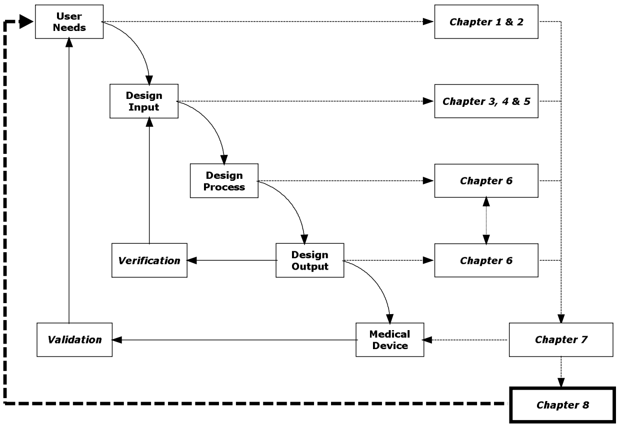
These guidelines were designed for use by researchers and practitioners working within the development of healthcare technology and related devices. The development of the guidelines and insight into practice experienced throughout this chapter comprised action research. The scope of action research as a method can be used in almost any setting to address a problem involving people, tasks or procedures requiring a solution, or where causing change results in improvements to outcomes (Cohen et al., 2007). The aims of preparing an outline of the experiences obtained through this research and the production of guidelines alongside work with teachers includes i) sustaining relationships with schools involved in research at the university, ii) providing an overview to other researchers wanting to undertake similar healthcare technology development research in schools, and iii) extending access to the school environment and increase access to the benefits of collaborations between research teams and participating children, teachers and researchers.

Although different conceptions of action research exist, this research adheres to the definition of Ebbutt (1985) who sees it as a systematic study converging action and reflection with the intention of improving practice. It is hoped that through the experience outlined in this research, the methods that have been utilised can inform future researchers who can build on the experience of the author and the research team.

This section has presented guidelines and insight into conducting research methods within the school environment. By discussing the preparation through to the post-visit information of running visits, it is hoped that this chapter will provide support for researchers working in the area in the future. This section has consolidated the experience that was gained through being involved with the research visits in this thesis. To conclude the thesis, **Chapter 8** outlines the major findings of the different aspects of this thesis and future directions for research, including the application of the guidelines above.

Chapter 8

Conclusion and Further Work



This chapter reviews the findings of this thesis, outlining the implications of the work that has been performed and consolidating directions for future research. The chapter comprises three sections; **Section 8.1** summarises the findings of the two phases of the research, and outlines questions that arose that could not be answered within the scope of the thesis. Following this, **Section 8.2** discusses how the investigations that took place within this research have added to existing literature. To conclude, **Section 8.3** highlights the limitations of this research whilst outlining further research that needs to take place for researchers to acquire a greater understanding of the involvement of children with and without disabilities in the design of healthcare technology.

8.1 Summary Discussion

This section draws together the summaries of the research that was carried out during this thesis. The section is divided into two sections; **Section 8.1.1** outlines the main findings and summaries that were made at the conclusion of each chapter. This is followed by **Section 8.1.2** that outlines the questions that arose during the research in the thesis, but could not be answered due to the time constraints and limitations that were placed on its scope.

8.1.1 Recapitulation

The aim of this thesis has been to explore the involvement of children in the development of healthcare technology. The research aim presented within **Chapter 1** that guided the overall investigation was to:

Explore the involvement of children in methods for use in the design of healthcare technology

In order to understand and address this aim, the thesis has:

1) Synthesised existing literature from healthcare, design research, psychology, HCI and related disciplines, to acknowledge previously highlighted issues that might arise when involving children in healthcare technology design. This was addressed in **Chapter 1**, and was the focus of the first half of **Chapter 2**.

2) Identified existing methods currently used to involve children in the design of healthcare technology from across healthcare and HCI. Additionally, the current trends adopted within the two domains were analysed with the use of a structured literature review. This formed the later part of **Chapter 2**.

3) Designed and carried out exploratory research into the use of four interview methods when involving children aged 7 – 11 years old in the design of healthcare technology. This was the focus of **Chapters 3 - 5**, where **Chapter 3** outlined the protocol and methodology, and **Chapters 4** and **5** reported the results from the investigation.

4) Developed a novel internet-based application for involving children in the evaluative stages of healthcare technology development. The development of the application, results from its use, and considerations regarding its future implementation are outlined in **Chapter 6**.

5) Produced guidelines for researchers to complete similar investigations in the school environment that derived from the experiences gathered during the research forming this thesis. **Chapter 7** outlines the guidelines by presenting an action research approach to the involvement of schools in technology design research.

Chapter 2 reviewed the literature and outlined the drive behind establishing methods for involving children with and without disabilities in the design of healthcare technology. Given the lack of methods in healthcare for use in technology design, research with children in HCI was highlighted as a possible source of methods as several are in existence within the domain. In order to categorise any trends between the investigations taking place across healthcare and HCI, alongside identify any difficulties that might arise by merging methods used by the two disciplines, a structured literature review was completed.

The structured literature review highlighted that a multiplicity of methods exist within HCI, although currently there is no means of assessing their effectiveness, or comparing methods with one another. The choice of methods to use within this research was approached with caution. Two well-established interview methods, alongside one novel method from both healthcare and HCI provided four interview methods for use within the research. The established methods (i.e., interview and one-to-one interview) were chosen due to their reported ability to involve children in research, providing a contrast and point of comparison with the inclusion of two lesser known means of involving participants in research (the DLI and board game method). A comparative framework was then used to monitor the use of the four interview methods within the research, alongside consider means of method comparisons in future research.

Chapter 3 outlined the approach taken to visit the four interview methods with children in the context of the school environment. Alongside outlining the framework used to examine the involvement of the children in the different methods, the other topics of interest within the research were discussed. This included consideration of personal and environmental factors that may cause barriers to children's involvement, and the cost and value of child participation. The chapter concluded with details of the process used to apply the framework to children's participation in the interview methods, and outlined the data analyses that took place prior to the presentation of results in the following chapters.

Due to the quantity of information that was gathered from the visits, the reporting of the results was divided across two chapters. **Chapter 4** outlined the results of the analyses that took place regarding the comparison of the different methods, and highlighted any barriers to child involvement that arose during research visits, particularly in regards to any personal and environmental factors. This involved an examination of the influence of age, gender, verbal competency, and the school environment, on the ability of children to participate in the interview methods. Of particular importance during this chapter was a focus on the influence of disability on a child's ability to participate in one of the four interview methods.

Although age and gender were not shown to influence the involvement of children in the interview methods or design tasks, disability was highlighted as a potential barrier. Where children had severe communication impairments for example, researchers were required to accommodate the children by adapting the questioning and interview methods as appropriate. The interview methods would not have been able to involve these children if they were performed in manner outlined for the standard interviews. In addition to this, the involvement of children is reported by the teachers in **Chapter 4**, when describing the findings from the teacher involvement interviews. Although feedback from the teachers was generally positive, a few suggestions were provided to refine future research practice.

Further insight into the interview methods with the children was gathered from the comparison of the interview methods with the use of the Markopoulos and Bekker (2003) framework. Each of the methods was examined regarding its robustness, reliability and validity, where the differences between the methods were described in detail. The examination of robustness highlighted that the DLI was not suitable for children with disabilities, and that the board game tended to incite distracted responses from the children.

The focus group and one-to-one interviews were the most suited to involving children with and without disabilities. The reliability of the methods examined the ability of the methods to extrapolate similar information across different conditions. The focus group and one-to-one interviews were once again the least troublesome, whereas the development of an individual low-tech prototype during the DLI and different game play in each of the board game methods made the reports of reliability in the latter two less favourable. Consideration of the validity of the methods discussed how the format of the methods might have affected questioning. For example, the questioning in most of the methods relied on children's memory recall to respond to questions in the interviews, but the DLI produced a prototype that allowed children to focus their attention and rely more on recognition memory in responses. Although such differences in memory use have not been shown to affect preferences of colour, their influence on texture and material memory has not been reported.

Chapter 5 focused on the cost and value of child involvement. In this instance, cost referred to an exploratory analysis of the cost-benefit aspects of involving children in the research. This involved looking at times taken by the children to complete the different interview methods, the quantity of information gathered, and physical cost of materials. The topics of value involved an examination of the types of information that children can provide, alongside reporting on the experiences of the children during the research visits. The chapter provides an overview of the transcripts from the interviews with the children, alongside a discussion of self-report ratings of enjoyment that were obtained from the children.

When looking at the completion rates of the methods, the one-to-one interview always completed all of the questions posed within the twenty-minute period that was imposed on the methods. Contrary to this, there were no instances of children completing all of the questions within the twenty-minute period when participating in the board game. The remaining two methods had mixed completion rates. An examination of the time taken to complete a method also showed the one-to-one interview to be most favoured, followed by the second fastest time from the DLI, then the focus group and the board game.

When looking at the number of responses that can be gathered from the different methods, the board game was shown to generate the largest number of average responses to questions posed to the children. This was followed by the board game, one-to-one interview, then the DLI. Consideration of the cost of materials showed that the focus group and the one-to-one interview methods were the least expensive when calculating material cost, whereas the board game required more resources. The most expensive materials were those required for the DLI.

The content of both the images obtained in the group tasks, and the transcripts from the interview methods were examined to try to understand the topics for which children can provide information. The viability and clarity of the images was assessed by engineers, with an overall mix of results. The information provided by the children in the images was often very informative regarding colour and material information, although children appeared to have difficulty in using metrics relating to measurement and cost. Similar findings were gathered when examined the transcripts from the interviews, where children again appeared to struggle with size and cost dimensions. Overall, children could provide information relating to the other topics that the researchers posed; this included questions relating to colour and material preferences, perspectives on disability, and perceptions of hospital equipment.

Chapter 6 – 7 provide the later, applied chapters of the thesis, based on the findings from the earlier chapters. These chapters formed the second phase of the research. **Chapter 6** presented an internet application that was devised to address some of the barriers that were identified in the first phase of the research relating to child involvement, alongside providing the opportunity to investigate the involvement of children in the evaluative stages of healthcare technology development. The internet application also provided preliminary insight into a means with which to validate information that was gathered from children in the earlier phases of the research.

The internet application contained three major sections for children to complete; providing demographic information, completing a forced-choice task, and answering four questions regarding colour and materials preferences. All children without disabilities completed all sections of the internet application without any observed difficulties, although a range of issues were identified when children with disabilities would participate. Although all children with disabilities completed all sections of the internet application, it would not have been possible without collaboration with the support assistants and sign language interpreters within each of the schools.

The demographic and preference information, alongside the information for the forced-choice task was retrieved from the remote database on which it was stored. For the forced-choice task, where children were presented with nine joysticks designs from which to choose their most preferred, preferences were quite evenly spread amongst the nine joystick designs. Therefore, no particular joystick design was clearly preferred by the children who participated. Although the internet application was also intended to examine the validation of information provided by children, further research is required into the internet application before it can be used for this purpose.

Chapter 7 documented the research experiences that were gathered during the first, exploratory research visits and during the use of the internet application in **Chapter 6**. The involvement of children in the design of healthcare technology is only a relatively recent area of investigation, and explicating procedures that were successful or caused problems, with focus on the school environment as a research setting, creates a foundation on which further research can be guided.

The guidelines reported on the different aspects of performing research visits within the primary school environment. This included an outline of relevant research literature, information on preparing visits, planning visits with primary schools, running research visits, and gathering and using post-visit information. To support researchers, an example lesson plan was provided in addition to a table that summarised the key points regarding each of the aforementioned topics relating to research within the primary school.

8.1.2 New Questions

The research within this thesis was used to address the research questions outlined in **Chapter 1**. However, the investigations that occurred have uncovered topics that leave open a number of questions that require further investigation. The areas that have been identified and that are explained beneath are distinct from the research questions that were outlined and addressed throughout this thesis.

1. How can methods from HCI be evaluated for their suitability for use in healthcare technology design with children?

The assessment of the suitability of a method taken from HCI and used in healthcare is inextricably linked to the generic characteristics of the domain from which it derives. The components of a method are determined by functions that are required for success within its own sphere of research. In the case of HCI, methods that have been developed for children in technology design are accompanied by very little consideration of outcome measures or the validity of information, and qualitative approaches are often adopted. Conversely, healthcare upholds a strong emphasis on accountability, outcome measures and the validity of information gathered; this is in addition to applying what are chiefly quantitative research methods. Although HCI may have design methods that have been used with children, the extent to which they can accommodate the needs of healthcare research requires further investigation.

The application of the modified Markopoulos and Bekker (2003) framework was useful in guiding a comparison of four interview methods in this research, in which the DLI, similar to methods used within HCI design research with children, was shown to be restrictive to children with disabilities and the most costly in terms of time and resources.

Although this does not rule out the use of design methods in healthcare, it draws doubt on the ability of HCI design methods to be used effectively in their current state. The application of the structured framework, alongside highlighting difficulties with the methods, also revealed the capability of a method comparison to occur. This comparison revealed the capability to assess novel methods (i.e., the board game) alongside more established methods, such as the one-to-one interview and focus group. There is scope in future research to explore the suitability of other design methods for use in healthcare research by incorporating features that are of use within healthcare research, or alternatively for methods developed solely within healthcare to be utilised in the design of healthcare technology.

2. To what extent do personal and environmental factors affect the participation of children in design methods?

A range of personal and environmental factors was investigated within this research, taking place in the confines set out in the scope of the research. There is still space to explore further factors that affect children's participation in methods when designing healthcare technology. For example, the research revealed barriers in the participation of the DLI's for a small number of children with CP. The children with CP whose participation was restricted the most included children with reduced physical capability. This limited their ability to create a prototype during the DLI, or participate fully in the design tasks during the group activity. There was a highlighted need to consider alternative methods of obtaining designs or prototypes from children with disabilities. Although the use of the internet application during the second phase of the research overcame a range of the physical barriers to involving children with disabilities (e.g., allowing the use of accessibility equipment to provide responses and preferences), the internet method only evaluated products. Therefore, more consideration is needed into the personal and environmental factors that affect children's participation in methods for use in the design of healthcare technology.

The involvement of children with physical and verbal disabilities often required alternative strategies to ensure that they could participate. For example, sign language interpreters from the schools were required for translating instructions between the researchers and any deaf children. Additionally, for children with severe communication impairments, often the use of a speech-generating device required a change to questioning during a visit. Although future research has been suggested to examine personal and environmental factors, there is a need for a more detailed examination of the role of children with disabilities in the design process and how impairment can be accommodated by design methods. Guha et al. (2008) has begun to report on the expected levels of involvement that can be expected from a child with special needs, dependent on the expectations of the research team and availability of support. However, there is a need to consider how support and guidelines can be created for researchers that relate to the practical considerations of involving children presenting a range of disabilities.

3. Can children be involved in all stages of the design process of healthcare technology?

This thesis has examined the involvement of children during the early and late stages of the design process, covering the design and evaluation of healthcare technology. However, the involvement of children was not explored in the stages of the process that involved generating ideas and developing chosen solutions, and instead adult product design students were used. The involvement of product design students revealed that they did not apply any specialist technical knowledge during the generation of prototype designs and relied solely on the information supplied by the children in the first phase of the research. Therefore, there is scope to consider the extent to which children can be involved in the design of healthcare technology beyond the role of providing requirements and evaluation.

By including children during each stage of the design process, the ethos of user involvement in healthcare technology design would be satisfied, alongside providing potential positive effects on the sense of empowerment experienced by users, and particularly those with disabilities. However, this thesis involved child users as informants throughout the design and evaluation stages, and increasing their involvement would lead to their participation as design partners (Druin, 2002). Although such an approach is supported by Druin (2002), several researchers have highlighted reluctance to the involvement of children to this extent (e.g., Scaife and Rogers, 1999). Therefore, there is a need to explore the process that children could be expected to undertake during such involvement, alongside establishing the feasibility of children adopting the role of designer in healthcare technology development.

4. How valid is the information that is obtained from children?

During the first stage of testing, the viability and clarity of information presented in the children's images was assessed by engineers. The overall ratings suggested that a large proportion of the children attained average ratings for both the viability and clarity ratings, although the inter-rater reliability of the raters was not verified. These ratings do not directly inform the validity of the information, but they suggest that children are capable of participating in the design of healthcare technology, and that the information provided by children is of worth to engineers or designers of such technology.

Although the internet application was used to acquire data from children in the second stage of the research who had been previously involved in the first stage of the research, the application requires further development before it can be used for validating data. The validity of the information is important because it feeds into an understanding of the accuracy and reliability of data gathered from children during the design process. Such information can also provide feedback to researchers on the quality of methods being used to inform the design of technology with children. This research described a means of assessing the validity of information over time, although areas such as the convergent validity of information from children and that gathered by the internet application are open to future investigation.

The validity of information gathered from children is important as it directly affects and underpins the ethos of user involvement. This thesis holds the underlying assumption that the inclusion of children in the design process will benefit any resultant product for use by them. By applying user involvement in healthcare, it is suggested that devices will fulfil user needs and expectations. For example, inclusive design suggests that, particularly in the domain of healthcare technology, gathering users opinions will inform a process that creates a device that is less stigmatising and fits into the context in which it will be used. Whether this occurs in practice requires verification through the involvement of children in the development of a real-world product. A range of accurate measures for validating information from children could support such enquiries in the future.

5. How can cost inform the involvement of children in the design of healthcare technology?

This research has identified the cost of involving children by outlining aspects of cost related to the involvement of children in a range of methods to inform the design of healthcare technology. From the research, it was possible to list the cost of materials used during methods, the number of responses that were acquired, and the levels of saturation that occurred for the different interview methods. In addition to this, comparisons were made between the two types of method explored during this research; the interview method and the internet application. Although the internet method was shown to have higher initial costs, once it is established it has the potential to produce a lower cost per child if it is used frequently. The interview methods will continue to incur costs however, as facilitators and material resources are continually required. Alongside further exploring such wage and resource costs, there is also scope to further investigate saturation of responses and explore its benefit to healthcare research.

Guest et al. (2006) highlight that often purposive sampling is used in qualitative research within healthcare, where samples are chosen based on predetermined categories of interest and the size of a sample. Although categories of interest can be guided by previous literature, establishing an adequate sample size is more difficult. Guest et al. point out that currently very little research is available to inform theoretical saturation levels that can be expected from participants. This research has begun to inform the saturation of responses that can be expected in the context of this research, but requires further information to increase its worth for application to healthcare research more generally.

8.2 Research Value

Healthcare technology is being continually developed and implemented, but currently very little research has explored the ability to involve end users in the design and development of such technology when they are children. The largest proportion of children using this technology has disabilities and the implementation of a user involvement approach as driven by medical device manufacturers and healthcare organisations must encompass the consideration of populations of children with disabilities. This thesis has compared a range of available interview methods for their suitability for involving children in the design of healthcare technology. To support practitioners in the area and to promote growth, both an internet application method has been proposed for use in the evaluation of such technology, alongside the production of guidelines for researchers working in the area. This section clearly outlines the contributions of this research and the value in pursuing the findings further.

The approach applied an exploratory approach when reviewing the use of methods during the first phase of the research. By applying deductive reasoning during this qualitative research, the thesis moved away from the typical practice seen in technology design research with children in domains such as HCI, where methods and findings remain untested, to one that promotes structure and validation of data gathering and analysis. In doing this, the benefits and barriers that were observed throughout the use of a range of methods were clearly outlined and acknowledged.

The use of the Markopoulos and Bekker (2003) framework allowed a means of identifying and examining the barriers that occurred during the involvement of children in the research. The framework was initially devised to generate a sound methodological knowledge for involving children as participants in HCI research; namely, UTM's. Given that this research wanted to adopt a similar, structured approach to understanding child involvement and the plausibility of using certain methods within healthcare, the framework was utilised. The framework was used not only to compare the four interview methods in the research, but also to achieve a more clear and transparent approach to method research than has typically been achieved in previous design research with children.

The structure applied in this research was useful for providing preliminary insight into child involvement, mainly due to the lack of research that has taken place before. The continuation of the framework is suitable to ensure that research is well directed in what is currently a sparse literature base. Although a structured approach has ensured that decisions for research directions are explicated it would be unsuitable to suggest a duplication of the use of the framework in all related design method enquiries in the future. Therefore, a specific focus on the personal and environmental factors that might cause barriers to child involvement, in addition to further awareness of the effect of disability within such research may suffice to support future investigations. However, there remains the challenge of developing an outcome metric or methodology that can determine the usefulness of a method for involving children in the design of healthcare technology. Although this was not determined within this research, the framework may be able to assist in identifying a feasible measure that can be used to assess the development of any new methods in healthcare technology development.

Field and Tilson (2006) point out the complexities of medical device development and evaluation. The involvement of scientists, engineers, and clinical experts are supported by resources to support the translation of new ideas into safe, useful and profitable products. However, despite other areas of engineering (particularly those related to safety-critical industries) having already started to consider the incorporation of user requirements, healthcare research has been slower to act (Martin et al., 2006). Delays in the area also extend to the inability of ergonomists to tailor methods to be more in line with the need of medical device developers. Martin et al. (2006) point out that few existing research papers provide any general recommendations outlining factors that should be considered by developers when selecting methods for use within product development. Although this research has begun to explore the involvement of children in healthcare technology development, there is now a need for the development of guidelines to provide general advice and recommendations for researchers and practitioners in academia and industry, which can assist in quantifying the relative costs and benefits of different methods.

8.2.1 Research Contribution

This thesis has demonstrated that children can be involved in the design process of healthcare technology, although several factors still require consideration. Despite the need for future research, this thesis has to date provided a range of contributions that include:

i) Presentation of a systematic review of literature relating to healthcare technology design with children *ii) Identification and examination of methods for use in the design of healthcare technology with children*

iii) Exploration of existing barriers to the involvement of children in the design of healthcare technology

In answering its overarching research question, this thesis has also made three supplementary contributions. It has:

i) Created a framework that can incorporate a range of methods and evaluate their suitability for use with children in the design process of healthcare technology

ii) Developed an accessible internet application that can be used by child participants without disabilities, alongside populations of children presenting a range of disabilities, in the development of healthcare technology

iii) Provided guidelines to assist researchers designing healthcare technology to involve and utilise the primary school environment

iv) Begun to gauge the costs and value of involving children in healthcare technology design

Very few instances exist where children are involved in the design of healthcare technology for which they are the end users. Recent research has indicated that major barriers to user involvement in medical device technology include factors such as resources (e.g., time, money, and labour), user characteristics (e.g., disabilities), strategic considerations (an inability to contribute because the technology is too complex for users to understand) and regulatory controls (such as ethics) (Shah and Robinson, 2007). Many of these barriers have arisen from investigations with adults, and consideration as to whether such barriers exist with child populations has not been undertaken.

This research closely examined many of the barriers typically associated with user involvement in populations of children, alongside identifying means of ameliorating barriers where possible. Both personal and environmental factors, alongside the effect of disability were examined in the first stage of the research. The information gathered from this investigation was used to inform the development of the internet application, as described in **Chapter 6**. In addition to guiding the involvement of children in the internet application, it assisted with the creation of guidelines for conducting design research in the school environment more generally, as described in **Chapter 7**. In exploring and explicating the barriers, practitioners and researchers in the area will be more informed of strategies to overcome them. In addition to this, the thesis describes the use of an internet application that successfully involved children with and without disabilities in the evaluation of healthcare technology by applying knowledge gained through the research visits in this thesis. Before discussing the future work that will be required to extend the research in this thesis, the benefits and progression of research from the thesis are first outlined.

Healthcare technology encompasses a wide range of devices, concepts, and procedures that are used in medicine. This thesis used the term ‘healthcare technology’ when focusing specifically on RT and AT. For older adults, the application of medical devices in healthcare has increased longevity through a reduction in deaths from heart disease and stroke (e.g., Alemayehu and Warner, 2004). As Alemayehu and Warner point out, due to these developments in better diagnosis and treatment, the life expectancy of older adults has increased. However, this increase in the successful application of technology to older adult populations has simultaneously increased pressure on society. The demand on healthcare to supply for the needs of an increasing demographic, now accounting for 60% of healthcare costs, adds to the need for further technological interventions to support care and treatment. For child populations, the application of healthcare technology does not bring with it such an apparent double-edged sword.

The application of healthcare technology to child populations has seen many benefits, not least changes from impairment-orientated models of intervention for children with disabilities to an emphasis that focuses on the child, tasks, and environmental factors (Østensjø, 2009). For example, children with CP affecting upper limbs are often given recommendations to perform therapeutic arm exercises that consist of reach-retrieve exercises, as these have been shown to improve function (Kluzik et al., 1990). However, for an improvement to be shown, an appropriate amount of exercise needs to be maintained (Taub et al., 2004). The difficulty lies in ensuring that children complete the exercises that could be viewed as uninteresting and repetitive. A technological intervention that has been used in this instance is a therapeutic joystick for use by children with CP that is connected to a computer game (Weightman et al., 2008). The actions required by the user to be successful in completing the computer game comprises movements that mimic reach and retrieve exercises. The implementation of such technology holds the potential to improve the lives of children with disabilities, but it is the responsibility of the designers and manufacturers to provide devices that are going to be comfortable, appealing and engaging to the end user. This is particularly the case in RT where user engagement with a device can determine the extent of therapeutic benefit.

The development of RT and AT is often firstly reliant on protocols to ensure that the device has therapeutic benefit, mechanical functionality, and is safe to use. However, following the change to models of interventions, aspects that are increasing in consideration are factors such as social acceptability and motivational factors. The social acceptability of a device concerns the reduction in stigma that might be associated with a device and considers the perception of a device by users' peers. This is of increasing importance with inclusive educational settings. In such settings, there is an increased likelihood of the development of technology for use in the school environment. Such technology does not need to remain a standalone rehabilitation device, and children without disabilities could be worked into the exercise routines, particularly if technology is a device such as a joystick, that can be linked to a computer game.

In order to design, develop and implement devices for children with disabilities that can maintain their engagement and reduce stigma from peers, child involvement is required. It is only from the perspectives provided by child users of such technology and their peers that rehabilitation or assistive devices with these properties can be created. This research has contributed to the area by establishing methods for involving children within this process. However, this occurred predominantly in the school environment. If the area were to be developed further, it would require expansion and investigation of methods that can be used to involve children in the design and development of a range of medical devices. This would include extending research to cover the user involvement of children in a range of settings.

By extending research methods and practice in medical device design and development for children, designers will increase their understanding of the wants and needs of the end user. When suitable methods for involving users have been established, designers will be more informed in their practice, which is hoped to develop subsequent products into ones that are more accessible and desirable. This will contribute towards attaining greater social acceptability for such technology, where users will be encouraged to use products without concern for any associated stigma.

8.3 Future Work

This section expands upon the findings of this research, and discusses how they can be developed in future research projects. It is divided into two parts. The first part discusses the limitations of the investigation carried out in this thesis, including the areas that it did not consider, and remain to be addressed. The second part discusses how future studies can address these limitations and build on the research presented within this thesis.

8.3.1 Limitations of the Study

This thesis has begun to identify and address how children with and without disabilities can be involved in the design process of healthcare technology. However, due to practical constraints of time and cost within the thesis, limitations had to be placed on its scope and a few caveats accompany the findings of the research. When interpreting the overall contribution and applicability of the findings of this thesis to future research, four important limitations and their consequences should be noted: i) the methods, ii) factors that influence involvement, iii) the location in which the research occurred, and iv) the technology on which the design research was focused:

i) This thesis has only addressed a select range of methods in the design of healthcare technology with children. This involved a focus on a selection of interview methods. Although the framework for comparing methods was effective in this research, its capability to involve a range of other methods is not known. In addition to this, the suitability of other interview methods for use in the design process of healthcare technology has yet to be explored.

ii) When comparing the methods used within this thesis, only a select number of variables were explored in detail; cost, value and the barriers posed by personal, environmental and methodological factors. These factors were chosen because of their relevance to healthcare, but in order to involve children in the design and development of a wide range of healthcare technologies, further factors influencing their involvement in the process may be required.

iii) The methods applied within this research were tested within the school environment; therefore, there is a context-specificity to the findings. Although considerations regarding their use in this setting have been made within this thesis, their application beyond this environment requires further research. Future research needs to consider developing comparisons of methods, novel methods and guidelines for the involvement of children within the design of healthcare technology for application to a wider range of environments including the home and healthcare contexts.

iv) The research only reported on the involvement of children in relation to the development of RT and AT under the branch of healthcare technology. In addition to this, a joystick device was central to the majority of the interview methods and the internet application development. A joystick device was a familiar product to many of the children and consideration should be given to any application of this research in guiding the design and development of less familiar devices with children.

This thesis has shown that the involvement of children within the design of healthcare technology can be achieved with the use of interview methods in a school environment. However, the usefulness of such methods within different environments has not been established. In addition to this, the extent to which gathering information from children can improve the design of healthcare technology has yet to be fully explored. However, this research has defined an exploration into the involvement of children and has channelled the focus of a new area for future research. To promote this process, the thesis provided guidelines for researchers working in the school environment.

8.3.2 Directions for Future Research

Although this thesis has established means with which to involve children in the design of healthcare technology, this is only the first step in the larger task of establishing effective processes for involving children in healthcare technology development more generally. Although methods have been compared and conclusions have been drawn about their use within a given context, both the coverage of methods, environment and types of healthcare devices can be expanded to begin compiling a more accurate insight into the involvement of children in the design of healthcare technology.

The research involving children in the design of healthcare technology still sits amidst a compilation of disciplines. The underlying philosophical implications on design research have not been resolved, but merely understood and accounted for during this thesis. In order for the involvement of children within design to continue, future research has to begin to consider how to establish objective measures into future exploration. This research was used as a means of gathering a preliminary understanding into the involvement of children within healthcare technology design, and did not have the scope to achieve such measures. Having gathered a preliminary insight into the area, attention should be focused on considering how to integrate measures such as those based on physiology, as proposed by Love (2000).

This thesis focused on areas of new and emerging research. The involvement of children within the design of healthcare technology has only recently started to receive attention. The reliance on methods to involve users within a design process has provided the need for this thesis to focus on the involvement of children with and without disabilities in this procedure when applied to healthcare technology. Given that the methods for this purpose are in their infancy, it is important to ensure that investigations in these early stages create a foundation of literature that is rigorous and transparent. The development of a framework for comparing methods for example, ensures that the choices to employ certain methods within the area are not formed on arbitrary decisions. Although this research was not able to employ wholly objective enquiries, focusing on the development of physiological processes as suggested by Love (2000), its examination of the area has generated a range of topics that need to be addressed. The unanswered questions throughout the thesis are to be expected in an emerging research topic, and now a preliminary investigation has occurred there is an ideal opportunity to begin to consider how to incorporate methods of enquiry suggested by Love (2000).

This thesis has created a means of exploring the involvement of children within the design of healthcare technology. However, it has also produced a framework, method, and guidelines. Each of these developments within the area needs validation. Although they have the potential to assist with the expansion of the research area, it is crucial to ensure that they do not remain unquestioned. The future research directions below are divided into two topic areas; these include existing methods, and the application and development of existing guidelines. Each considers the future application of methods developed within this research, but also how they might be validated and improved.

Existing Methods

Although a selection of existing interview methods were used to involve children in the design of healthcare technology, a large number of methods that could have been used were ignored. The use of a structured literature review led the identification of current research methods that were suitable for use in healthcare research. Although HCI presented a range of methods, none of these were deemed suitable for application within this research, and instead interview methods were chosen as a starting point. The thesis has provided a foundation on which to explore other methods that exist that may be useful for involving children in the design of healthcare technology. However, a range of other existing research methods still need to be explored for their potential value and contribution to the involvement of children with and without disabilities in healthcare technology design research.

Future research in healthcare technology design with children can assess the appropriateness of methods, beyond interview methods, by examining their use within the framework. These ideas could be explored through the following investigations:

i) Identifying and assessing further methods for use in design and development of healthcare technology for children by applying the methodology and analyses performed in **Chapters 3 - 5** to methods that extend beyond interview methods.

ii) Verification of the framework when used for examining a wide range of methods. The use of the framework as a means of comparing methods for use with children should be evaluated throughout any further applications. Although the framework was useful in evaluating methods in the context of the school environment, its use outside of this environment, and consideration of additional criteria for this purpose need to be explored.

iii) The identification and selection of methods to involve children in healthcare technology design research should be based on their suitability to acquire information. The involvement of users in the design and development of healthcare technology often results in a need to consider how to accommodate children with disabilities. The presence of a disability and its implications were a focus in the review of existing methods in this research when considering the effect of personal factors on involvement. These observations about what were successful means of involving children in design research were combined with literature to form the internet application.

The application highlighted that the synthesis of existing literature with experience can contribute to the formation of useful research tools. Following validation, the internet application may prove to be a useful device for overcoming the existence of disability when involving children in design research. The use of the internet application also fed into current trends to utilise ICT within healthcare. There is a need to explicate the factors that ensured the success of the internet application when applied during **Chapter 6**, and begin to explore whether factors of importance are universal. By identifying factors that improve the chances of a method acquiring information from participants, more appropriate methods can be identified and used in future research.

In addition to identifying the appropriateness of a method, there is a need to consider the validation of methods. A lack of validation in the use of a method could lead to any potential benefit that may exist being ignored where the testing and reporting of any benefits and weaknesses could inform future research. When applying new methods, the process of validation is integral to its development. By establishing ways of validating methods, researchers reflect on the capability to gather relevant and representative information from the population of interest. In the development of existing and novel methods, it is important to continue refining and improving their capability to acquire information to feed into healthcare technology development and look at ways of validating acquired information.

Guidelines

The guidelines developed within this research were done so based on experience. By documenting these experiences accurately and thoroughly, researchers who wish to explore the area are provided with insight before conducting research. This research focused on developing guidelines for designing with children in the school environment, but there is scope to extend the context to other locations (e.g., healthcare settings and the home environment). Each of these different settings may share similarities in the selection and use of a particular method, but the process surrounding this activity (i.e., recruiting participants, processes before, during and after visits, ethics) require an isolated focus. The specific focus on such factors is essential for research involving children in the design of healthcare technology if it is to become more established. Further foundations in the area can be developed by recruiting more researchers into the area. Guidelines for healthcare technology development may increase the likelihood of further research taking place as it provides initial insight into an area that would otherwise be unknown, and provides a key stone to further research literature.

The development of guidelines assists with saving time and resources for researchers, providing that guidelines are accurate. This is important because the guidelines affect the perception of researchers who may not have been previously involved within related research. A focus on accurate guidelines, with an awareness of the influence of expressed opinions, is essential to ensure that the developing areas become accessible to researchers who wish to be involved.

8.4 Conclusions

This thesis has shown how children can be involved in the design of healthcare technology. This has included the comparison of a range of available interview methods to gather information from children to inform the design process. As well as investigating methods, the thesis presents the use of the internet to host an application that is inclusive of many child users, accounting for the presence of a range of disabilities. The use of this application and other methods that might be used with children has been encouraged within the school environment through the creation of guidelines for this purpose. These guidelines facilitate the benefits of child involvement in the development of healthcare technology where they are the end users, alongside presenting a means to improve the experience of both the teacher and the child within the primary school environment.

The findings of future research do not have to be limited to application within healthcare technology design and development, and can be used to inform research and practice across a range of disciplines including healthcare, design, and HCI. The focus of future research should now concern itself with continuing to establish a strong foundation for future developments in healthcare technology design and development with children. This can be supported by increased efforts to identify the suitability of existing methods, and ensure that novel methods are appropriately considered and validated. Of equal importance is the push for dissemination of findings and experience in the form of guidelines. If the latter remains clear and accurate, it will catalyse an open invitation to researchers who have an interest in the development of technology that has a major influence on the lives of its users.

Appendix 1: Taxonomy of Literature regarding the Involvement of Children in the Design of Healthcare Technology (completed April, 2007)

1.1 Objectives of the Taxonomy

The objectives of developing taxonomy diagrams was to i) identify current patterns in research regarding involving users and particularly children in healthcare and HCI literature ii) identify, for all included studies, the intent of the research and the purpose of methodology used iii) identify and review gaps in knowledge within the literature iv) propose ways in which literature from HCI can be adapted to exist coherently amongst the healthcare literature v) to gather an understanding of current research practice across the two areas and consequently better informs the next stages of the research process.

1.2 Construction of the Taxonomy

The taxonomy applied selection and exclusion criteria during the selection of research papers. These papers were then analysed and the details were recorded in a table documenting their aspects of interest. The following sections outline the process of completing the taxonomy in more detail.

1.2.1 Selection Criteria for the Research Papers

Studies for HCI were drawn using the following search terms (the symbol * indicates the use of truncation): “child* design tech*”; “rehab* tech* child*”; “child* AND design”; “tech* user involve*”; “health* tech*”; “rehab* tech*”; and “disab* tech*”. For healthcare the search terms were expanded to include: “rehab* tech*”, “Inclu* health*”, “child* tech*”, “user involve* tech*”, “med* device”, “user disab*”, and “child* health*”.

These search terms were chosen to ensure the inclusion of all aspects of interest to the research, with the final decision to include a study being based upon the inclusion and exclusion criteria outlined in **Section 1.3.2**. The databases used included ScienceDirect, PsycInfo and Compendex, and proceedings from relevant conferences and workshops (e.g., Interaction, Design and Children (IDC), INTERACT, INCLUDE). A book search was also carried out using book search engines (i.e., Google © books, Amazon © etc., British Library).

Studies were also drawn from recent research summarising the area of interest. Nesset and Large (2004) recently performed a review of theories and their applications when children are involved in the design process of information technology. Their paper was examined for further relevant research. It was intended to include one further book but at the time of reporting, the book was unpublished. The book is '*Child Ergonomics*', edited by Rani Lueder and Valerie Rice in 2008.

1.2.2 Inclusion and Exclusion Criteria:

The use of effect size, or another standardised measure would have been ideal to allow for the quality of studies to be either identified, or excluded from the literature database, but the majority of retrieved papers did not contain this metric. Therefore, inclusion and exclusion criteria were developed for both HCI and healthcare. Due to the subjectivity that can arise when the quality of a study is being assessed, only basic inclusion criteria was developed to ensure a thorough analysis (Begg, 1996). The two domains had separate criteria to account for the higher incidence of relevant studies within HCI. The criteria for the separate domains were as follows:

HCI Literature:

The HCI literature that was retained from the literature search included all research that involved testing and designing technology with children. The studies chosen were those related most frequently to methods used in involving children in the design process. Alongside this, more general articles were included that had the involvement of children central to the research when interacting with technology, together with proposed guidelines, research methods (description, evaluation and comparison), and descriptions of research experience with children from the HCI domain.

Healthcare Literature:

The literature that was included in the healthcare domain involved articles that emphasised the role of user-involvement, public- and user-focused approaches, previous combinations of engineering and healthcare research and research looking at inclusive design. The intention of this section is not to give a literature review of healthcare, but to look at those studies of particular relevance to ongoing research. Therefore, the studies that appear in the final literature selection exist because they are grounding in both the inclusive criteria set out, but also high relevance to current research.

1.3 Structure of the Taxonomy

Each study was assessed according to the factors outlined below and were placed into **Table 18**. The papers that are outlined in **Table 18** were then used to form the basis of the taxonomy trees (**Figure 47** and **Figure 48**) where the papers are represented as nodes with individual numbers relating them to the table. The headings of the table include i) Article title ii) The article title column presents the full reference of the research article iii) Domain. At first domain was crudely divided into either HCI or healthcare. With the majority of studies seeming to have derived from the HCI literature, particular attention was paid to how this area was divided. From reviewing all included papers in HCI, the following domain sub-categories were identified: software development, computer product design, methodology, and specific research practice. The healthcare literature was also broken down into further sub-domains, with the following having been identified: multidisciplinary research, rehabilitation research, methodology, and specific research practice. In addition to HCI and healthcare, robotics articles also existed amongst the literature that was gathered, although these papers fitted into the pre-existing sub-domains and did not need their own.

Each of the studies were placed in **Table 18** and assessed according to the following headings:

Artefact Tested: The artefact tested outlines the central element of the research being carried out. This can vary from a product under testing, to the desire to change researchers' perspectives.

Publication Type: The options consist of journal, conferences proceedings, workshop presentation, book or book chapter, or internet site.

Intent and Purpose: This outlines the aims of the research providing the overall aim of a piece of research.

Metric: This column explains the means by which the intent and purpose was measured within a paper.

Intervention: In studies where experimental manipulation takes place, this column outlines the procedure or measures used. This definition of intervention is different to that associated with typical intervention studies within healthcare.

Methodology: This column outlines the methodology used within the studies, whether used in testing, evaluation, or more generally in the research process.

In all columns, where a heading is not appropriate to the research within the taxonomy, the square assigned for information is filled with a "N/A" marking, highlighting a columns lack of applicability.

Table 18 Outline of the literature used in structured literature review

Article Title	Domain	Artefact Tested	Publication Location	Intent and Purpose	Metric	Intervention	Methodology
1 Druin (1996)	HCI	Child involvement guidelines	Journal	Change researchers views adequately for children and not just see them as short adults	N / A	N / A	N / A
2 Druin et al. (1997)	HCI	Intuitive zooming interface (educational software) (multimedia software)	Conference Proceedings	To design an intuitive design interface and explore methodologies that support a child's role in the development of new tech	Intuitive nature of software	Design partnership with children	Brainstorming on paper, design partners
3 Hanna et al. (1997)	HCI	Guidelines for research involving children	Journal	To provide examples and guidelines from one research grouping working to incorporate user data from children in the design process	N / A	N / A	N / A
4 Druin et al. (1999)	HCI	Methodology	Conference Proceedings	Describe the research methods that were developed and adapted for work with children. Provide an example of them in use (KidPad).	N / A	N / A	Contextual inquiry (observation), technology immersion (observation), participatory design (speaking with the children, brainstorming, low-tech prototyping)

5 Hanna et al. (1999)	HCI	Review of history and work practices of Microsoft	Book	Description of methods, guidelines and practice used during stages of product development by Microsoft	N / A	N / A	Expert reviews, site visits, survey construction, card-sorting task, paper prototyping, iterative lab tests, longitudinal tests
6 Kafai (1999)	HCI	Methodology	Book	To argue for the use of LCD and provide a case study	Students' software designs	Usability testing sessions	Teaching through usability sessions, designing of software by students, evaluation of developed software
7 Scaife and Rogers (1999)	HCI	Software / methodology	Book	To close conceptual gaps between a child's everyday experiences and the abstract formalisms used in science with multimedia software	Outcome of design	Informant design approach	Questioning teachers and pupils and getting them to evaluate existing CD-ROMs. Low-tech prototyping with children, high-tech prototyping with children (co-designing)
8 Keates et al. (2000)	HCI	Methodology	Conference Proceedings	To present a methodological design approach for implementing inclusive design	Success of methodology	N / A	5-level design approach, 2 case studies presented
9 Theng et al. (2000)	HCI	Software	Conference Proceedings	Describing their experience working with children as design partners and testers in building a children's digital library (DL) of stories and poems for 11 – 14 year olds. To engage children as designers and testers.	i. levels of trust acquired for PD approach ii. proposed ideas and discussions iii. evaluation of designs	i. brainstorming, team work ii. presentation of design ideas iii. paper-prototyping of ideas	Participatory design, brainstorming, presentations, lo-fi prototyping, participatory evaluation

10 Donker and Markopoulos (2001)	HCI	Evaluation methods	Conference Proceedings	The comparison of three usability evaluation methods (a. think-aloud, b. structured interview, and c. written questionnaire) when used with children	Number of problems found by children using an evaluation method	Counting the number of problems found by children, controlled for verbal ability (WISC-R), and extroversion (ABV-K: the Amsterdam biographical questionnaire for children)	Random selection of parts. from a class, randomly assign to one of three methods, and asked to evaluate a program individually.
11 Druin and Fast (2001)	HCI	Software	Journal	To describe the research accomplished when creating new storytelling technologies for children (KidStory project) when working with children as design partners. Also to discuss the concepts of learner, critic and inventor.	Development of storytelling technology	Children working as design partners	Journal writing, invention activities (using clay and coloured paper), problem-solving exercises, development of virtual objects for the software.
12 Bruckman and Bandlow (2002)	HCI	Literature	Book	The paper outlines research to date (when written) involving designing with children in HCI	N / A	N / A	Literature presentation and description
13 Druin (2002)	HCI	Child involvement in design	Journal	To provide a framework for understanding the roles that children can play in the technology design process, particularly in regards to designing technologies that support learning.	N / A	N / A	N / A

14 Keates et al. (2002)	HCI	Methodology	Journal	To present a methodological design approach for implementing inclusive interface design	Success of case studies (i.e., the application of the design cube)	Use of design cube in case studies	Usability / evaluation visits on prototypes
15 Read et al. (2002)	HCI	Methodology	Conference proceedings	To describe a toolkit that can be used to measure fun (endurability, engagement and expectations) in empirical studies. Also evaluation of the toolkit.	Evaluation visits for a. engagement and expectations b. expectations and endurability, and c. expectations	a. 4 tasks were used to evaluate effectiveness b. children completed nine activities c. web site design project	a. smiley-o-meter, fun-sorter, video recordings. b. smiley-o-meter, fun-sorter, again-again table. c. smiley-o-meter.
16 Read, Gregory et al. (2002)	HCI	Methodology	Conference proceedings	To describe WeDD (Web Site Day Design), a design process modelled on participatory design.	N / A	N / A	Brainstorming, video recording, photography of project taking place, paper prototyping, questionnaires, observation.
17 Barendregt et al. (2003)	HCI	Theory and method	Conference proceedings	The paper aims to identify difficulties encountered by evaluators when they conduct a formative evaluation of both usability and fun in computer games for children	a. the influence of tasks on the behaviour of children playing a game b. to study the use of a combination of usability and fun heuristics	N/A	a. numbers of screen visited, verbal and non-verbal positive and negative comments b. talk-aloud
18 Bekker et al. (2003)	HCI	Methodology	Journal	To describe and assess a novel design method for use in interaction design, for gathering requirements from children.	The success of the design method	Case study: development of a newspaper by children using the KidReporter method.	Making photos and descriptions of photos, interviews, writing articles and questionnaires.

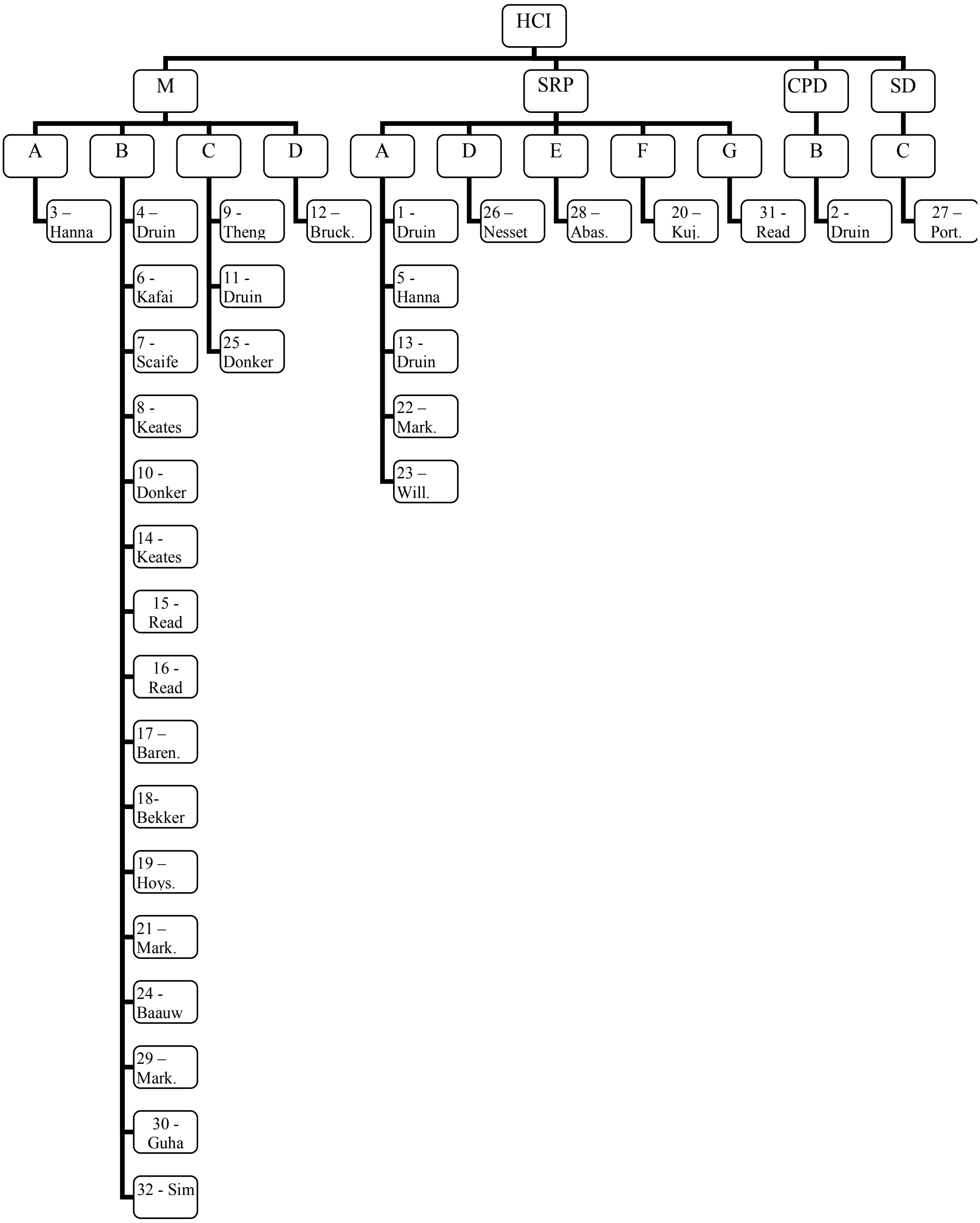
19 Höysniemi et al. (2003)	HCI	Methodology	Journal	To present a novel approach to usability evaluation with children	Effectiveness of new method	a. usability test with a prototype of QuiQui's Giant Bounce b. informal test sessions	Questionnaires, test session used peer-tutoring, recording of playing times, web camera recordings, video recording, and interviewing (with a 'question asking protocol').
20 Kujala (2003)	HCI	Researcher opinions / beliefs	Journal	To clarify the nature of user involvement and its benefits	N / A	N / A	Analysis of literature, literature review.
21 Markopoulos and Bekker (2003)	HCI	Methodology	Journal	To introduce a methodological framework for delineating comparative assessments of UTM's for children participants	Effectiveness of evaluation methods	a. comparison of co-operative evaluation and co-discovery b. comparison of verbal protocol, interview and post-task questionnaire	a. talk-aloud, co-discovery b. interview, questionnaire, verbal protocol
22 Markopoulos and Bekker (2003b)	HCI	Editorial / discussion paper	Journal	To introduce interaction design and children, emphasising not to treat them as an homogeneous group and discusses the various stages to involve children in the design process.	N / A	N / A	N / A
23 Williamson (2003)	HCI	Discussion paper	Internet site	To provide an overview of best practices in the involvement of children in the design of new technology.	N / A	N / A	N / A

24 Baauw and Markopoulos (2004)	HCI	Methodology	Conference proceedings	To describe an experimental study of different strategies for obtaining verbalisation data related to usability testing	Number of problems found	Analysis of problems identified by either post-task interview or think-aloud	Video recordings, think-aloud, post-task interviews.
25 Donker and Reitsma (2004)	HCI	Software	Conference proceedings	a. To identify the difference in problems identified by child experts compared to novices b. to evaluate the suitability of talk-aloud and behavioural observation in usability testing	Usability of a piece of educational software	a. usability test by both novice and expert testing children b. observation of children talking-aloud	Talk-aloud, behavioural observation, usability testing.
26 Nesset and Large (2004)	HCI	Literature review	Journal	Review of the literature on the role that children can play in the design of information technology application intended for young users themselves	N / A	N / A	Outline of relevant theory and practice in designing with children to date.
27 Porter et al. (2004)	HCI	Software	Journal	To present research regarding the development of HADRIAN – a design tool for inclusive design	N / A	N / A	Description of new tool / method development
28 Abascal and Nicolle (2005)	HCI	Theory	Journal	The paper analyses the benefits of the use of inclusive design guidelines in order to facilitate a universal design focus so that social exclusion is avoided.	N / A	N / A	Description of related theories and presentation of case studies

29 Markopoulos et al. (2005)	HCI	Methodology	Conference proceedings	The presentation and evaluation of a new method for evaluating products, using a parent as a facilitator.	Effectiveness of new method	Verbalisation data between child, parent and interactive product.	Verbal recordings, diaries (parents note down observations)
30 Guha et al. (2006)	HCI	Methodology	Conference proceedings	Describe a new technique for working with young children as design partners. Mixing ideas is presented as an additional Cooperative Inquiry design technique used to foster effective collaboration with young children (ages 4-6).	Successfully support young children in successfully collaborating during a brainstorming design process. Also provide recommendations on the basis of the case study.	‘Mixing Ideas’ method: generation of ideas, initial mixing of ideas, mixing the big idea.	Observation (both child and adult), journals kept, brainstorming, group discussions, debriefing children.
31 Read et al. (2006)	HCI	Outline of research group activities	Conference proceedings	To describe the work, vision, and approach of the Child Computer Interaction (ChiCI) group at the University of Central Lancashire, UK.	N / A	N / A	Description of activities of the group, including publications and projects.
32 Sim et al. (2006)	HCI	Methodology	Journal	To describe and evaluate the relationships in an empirical study of fun, usability, and learning in educational software.	Reporting of fun and usability (observed to reported)	Within-subjects single factor with 3 conditions, with children trialling two software applications.	Pre- and post-test questionnaires, smiley-o-meter (pre-test), smiley-o-meter (post-test), observation, and fun-sorter.

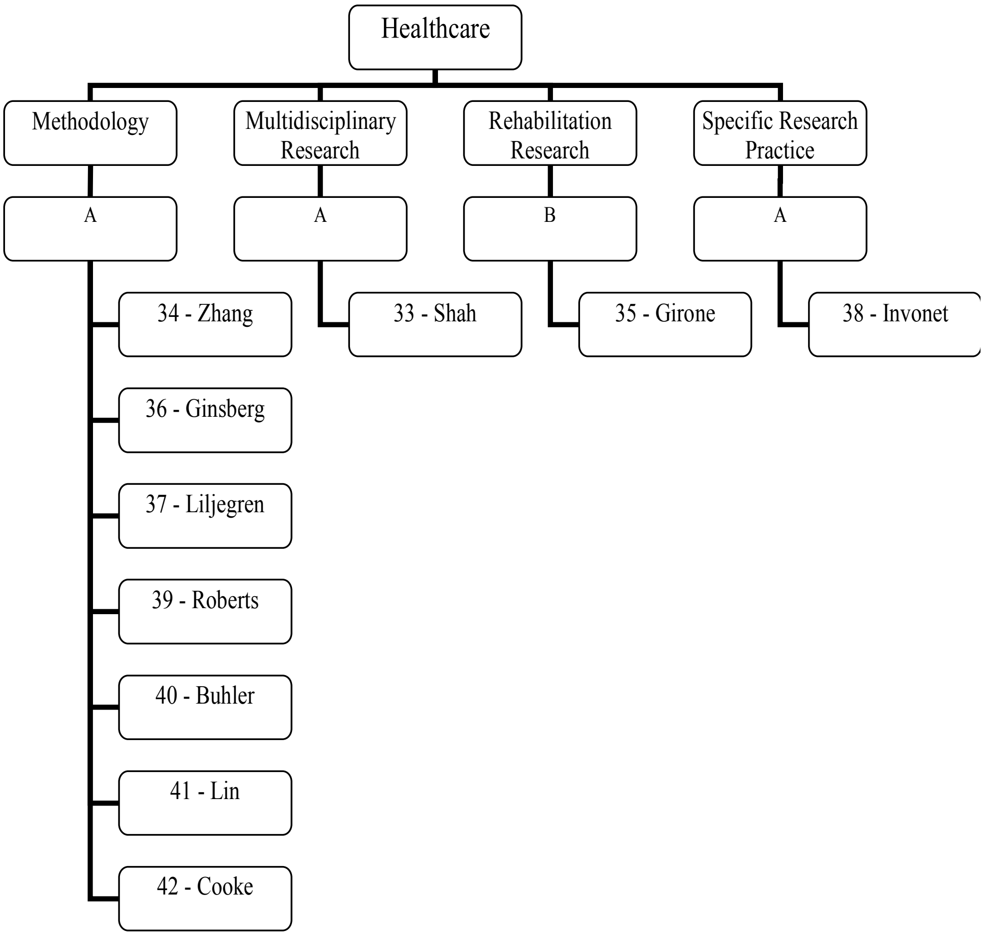
33 Shah and Robinson (2006)	Healthcare	Methodology	Journal	To provide a platform for methodological development and represent a combined perspective on the findings from a survey of published literature drawing on engineering, ergonomics, healthcare and social sciences.	N / A	N / A	Literature survey, literature mapping.
34 Zhang et al. (2003)	Healthcare	Methodology	Journal	To modify the traditional heuristic evaluation method of assessing software usability so that it can be applied to medical devices and used to evaluate the patient safety of those devices through the identification and assessment of usability problems.	Successful application of a modified version of heuristic evaluation to medical devices.	Application of modified heuristics by 4 individuals (2 x Health Information Science graduates, 2 x Psychology graduates).	Expert evaluation
35 Girone et al. (2000)	Healthcare	Hardware and Software	Conference proceedings	To report a proof-of-concept visit to gather therapist and patient feedback, with the system (an ankle rehabilitation device) measuring the range of motion and maximum force output of a group of four patients.	Successful function of the device	Measurement of comfort, collection of patient displacement and torque data, and comparison of ankles.	Prior to device testing: measurement of ROM, strength, balance, sensation, pain and skin condition. After completing visit on device; self-report, questionnaires.
36 Ginsberg (2005)	Healthcare	Methodology	Journal	Human factors heuristic assessment and user testing of five clinical areas to inform hospital procurement decision-making in selecting an infusion pump.	Errors identified in a system, and user preference of a system.	Heuristic evaluations paired with user testing and evaluation.	Heuristic evaluation, questionnaire (comparison form),

37 Liljegren and Osvalder (2004)	Healthcare	Methodology	Journal	To investigate the use of cognitive engineering methods as tools to incorporate into the usability aspect in the selection process of new hospital equipment.	The use, success and modification required of cognitive engineering methods used in the selection process of medical equipment.	User questionnaires (presentation of information, properties and difficulty of tasks), Cognitive Walkthrough (including 5 tasks), and Usability testing (including 7 tasks).	User questionnaires, cognitive walkthrough, and usability testing (including background questionnaire).
38 Invonet (2006)	Healthcare	Methodology	Internet site	To present the events and presentations of a workshop discussing some theoretical and methodological issues around researching public involvement in research.	N / A	N / A	Presentation of research and discussions of the workshop.
39 Roberts and Fels (2006)	Healthcare	Methodology	Journal	To test think-aloud protocols with people with disabilities	Success of methods in performing their function with people with disabilities	Use of method on disabled people	Usability testing, think-aloud protocol method.
40 Bühler (2001)	Healthcare	Methodology	Journal	Introduce empowering participation of users with disabilities in research and development, alongside the discussion of methods	N / A	N / A	Literature discussion, description of both novel methods (e.g., the 'Wizard of Oz' method) and established methods (e.g., focus groups and interviews)
41 Lin and Shao (2000)	Healthcare	Methodology	Journal	Examine the participation-success relationship.	Satisfaction of system users following greater user participation	Survey regarding system	Survey
42 Cooke (2004)	Healthcare	Methodology	Journal	Derbyshire Children's Hospital planning with children.	Success of hospital design	Designing with children	Questionnaires and focus groups.



KEY: *Domain*: M = Methodology, SRP = Specific Research Practice, CPD = Computer Product Design, SD = Software Development; *Artefact Tested*: A = Research Practice, B = Methodology, C = Software, D = Literature, E = Theory, F = Opinions / beliefs, G = N / A; *Place of publication*: 1 = Journal articles, 2 = Conference proceedings, 3 = Book chapter, 4 = Internet paper

Figure 47 Taxonomy structure of the HCI literature



KEY: *Artefact Tested*: A = Methodology, B = Hardware

Figure 48 Taxonomy structure of the healthcare literature

Appendix 2: The Devices used during Research Visits

2.1 Rehabilitation Joystick

The joystick was taken from an ongoing technology development project that was taking place at the university at the same time as the experimental work for this thesis. The project was developing a joystick to assist children with cerebral palsy in the completion of rehabilitation exercises with their upper body (see **Figure 49**). The project designed and produced PC-based computer games that accompany the joystick, alongside testing the joystick in clinical visits. The computer games were played using the joystick that uses innovative software and mechatronics that only work when the correct arm is used. The software monitors the movement of the joystick and facilitates the child's attempts to move the joystick, thereby enabling them to complete any games whilst simultaneously working towards a greater functional reach.

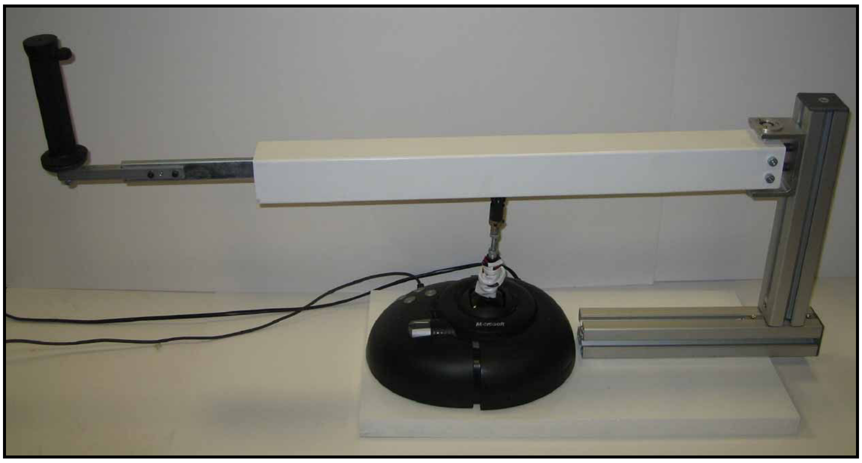


Figure 49 The force-feedback joystick developed at the University of Leeds

2.2 Handwriting Device

The handwriting device was a PHANTOM Omni® Haptic Device, used with accompanying *OpenHaptics Academic Edition* software (see **Figure 50)**. The device contains six degree-of-freedom positional sensing with a moulded rubber stylus for grip. The device has been used for research into the movement and co-ordination difficulties children experience when suffering from Dyspraxia and related disorders. The system directs the forces to a child's arm and hands and promotes appropriate movements whilst discouraging inappropriate ones. Movement made by a child, alongside reaction times and speeds of movement are recorded by the software.

Figure 50 The Omni Haptic handwriting device

2.3 Communication Fixture Device

The communication fixture device was being developed as part of a project being conducted at the University of Leeds. It was being developed during a collaborative project by product design and mechanical engineering masters students. The development of a specific communication fixture device arose when making observations within a classroom regarding existing mounting systems that are used by communication aid users. Alongside reducing the mobility of communication aid users, it was identified that there are no existing product solutions that allow an electric wheelchair user to move an assistive communication device in and out of their line of sight unaided. Therefore, the project began the development of a device to remove some of the barriers caused by current assistive technologies and thus to enable the user to develop increased confidence in both communication with others and wheelchair navigation.

The communication fixture was designed as a means with which to move a communication aid (see **Figure 51**) from an upright, central reading position, through a ninety-degree angle to a horizontal position. This sequence occurs when the device is activated by the user through pressing a button. When the aid is required again, the user activates the button again and the vertical position is restored. This action was simulated during testing by manually rotating the communication aid whilst held next to a child’s wheelchair. This provided children with a demonstration of how the device would work, and provided a prop for children when deciding on which colours and material they would prefer to use.

Figure 51 An example of a communication aid that would be attached to a wheelchair

Appendix 3: Verbal Competency Rating Scale

Teacher Register / Verbal Competency Rating:

A score should be constructed between 1 – 7 for the verbal competency level of each child listed, where 1 is excellent, and 7 is poor. Please use the following items as guidance measures in constructing the score from the information you know about the child:

- Understanding of relationships between words e.g., for common objects, such as table and chair
- Word knowledge through the extent of the child's vocabulary
- Ability of child to use the correct words for expressing themselves

School Name……………………………………………………

Teacher Name…………………………………………………..

Child name	Verbal Competency Rating (1 – 7)

The register highlighted key aspects of the *Verbal Comprehension Index* from the Wechsler Intelligence Scale for Children (Weschler, 2003) so that these features of a child's ability were used to form the basis of scores given by teachers. The use of these criteria was to ensure that teacher's were assessing children's verbal ability on similar criteria.

Appendix 4: Description of Methodology used in Visits

4.1 Focus Groups:

The children were in groups of four, based on guidance provided by Morgan et al. (2002). The facilitator read a question from the list and allowed time to discuss the answer whilst trying to minimise their involvement or expression of opinions. Research by Christensen and James (2008) highlight the lack of guidelines for conducting focus groups with children. ‘Conventional wisdom’ is cited as suggesting i) children should be interviewed in restricted age groups otherwise older children may dominate ii) boys and girls should be interviewed separately as they have different communication styles iii) groups should be small, with no more than eight children.

4.2 One-to-one Interview:

Docherty and Sandelowski (1999) highlight that one-to-one interview methodology with children lacks concrete guidance. Therefore, this research begins to make the experiences of using this method with children more established. The question list was read aloud by the adult interviewer, where the child was asked to provide a response for each question. Guidance provided by Greig et al. (2007) explains potential reasons for selecting structured interviews in research; “Interviews that aim mainly to obtain facts or that look for views on predetermined topics, will have more structure” (pg. 122). Structured interviews allow for “…each person to be asked the same question in the same way. This allows for more direct comparisons and is more amenable to quantitative methodology” (pg. 123).

4.3 Design-Led Interviews:

Read et al. (2002) promotes the use of a participatory design approach to designing with children in research. With this approach, a child works alongside the researcher in the design of a low-tech prototype design for a product or device. The child is asked to create a 3-D prototype alongside the researcher. During the development of the prototype, the researcher asked the list of questions. The children were allowed freedom in the designs they produced and this was to be further encouraged by the adult researcher. The additional materials that were provided included paper and colouring utensils, alongside plasticine and card.

Read et al. (2002) outlines that the difficulty with the literature on participatory design and related topics is the lack of clarity and consistency in the terminology used. This research does not follow a participatory approach in the style intended by such theorists, and the introduction of structured questioning within the method eliminates its original purpose. Therefore, the term ‘design-led interview’ (DLI) was used to describe the structured questioning that occurred during the creation of a low-tech prototype.

4.4 Board Game:

The board game was in the same style as a monopoly board (see **Figure 52**). The questions from the list were presented on individual cards on the periphery of the board. To begin, all cards were face down, where children had to roll a dice and read out the question printed on the card on which their marker landed. The child who rolled the dice answered first, and other children then added further comments and discussed the question if they wished. The game was completed when all questions have been answered or twenty minutes had expired. The premise of using a board game to capture information from children was that previous research had shown that by embedding interview questions into a task situation, the interviewee presents less signs of being self-conscious (Wood, 1995). Further to this, in gathering information from difficult population, Lamey and Bristow (2007) showed that by presenting questions through a board game activity, the participant is empowered in the topics and encouraged to participate.

Figure 52 The base of the board game on which the question cards were placed

In this research, the board was constructed using a laminated A3 design. The questions on the cards that were placed around the board game were presented with text at either 12- or 14-point type, as Bernard et al. (2002) highlight that this is recommended by theorists for the construction of children’s books. The medium for the presentation of questions is an important consideration, as research by Bernard et al. (2002) has shown that certain types of font size are more ‘readable’ than others, and such factors have a direct impact on the time taken to complete the method.

Appendix 5: Question List for Use in the Interview Methods

Issues of interest, identified from the literature review, included social and practical acceptability, texture, and barrier identification. The topics of interest were also led by the ongoing rehabilitation joystick project (see **appendix 2**). Topics of interest included the general social and practical aspects of the device (discussed in **appendix 5.1.1)**, the link with the joystick led to questions specifically relating to the design of the joystick handle and the need to establish children's textural preferences (discussed in **appendix 5.1.2)**.

5.1 Question Construction:

Free recall compared to specific and direct questioning within research involving children has revealed that information that is more accurate is gathered from free recall (Steward and Steward, 1996). However, there are differences in the way children cope with the different types of questions, even between groups with similar language and communicative abilities (Salmon, 2001). It was decided that the best approach would be specific and direct questions with prepared elaborative material available should the children have require further explanations to questions.

5.1.1 Social and Practical Acceptability:

Keates and Clarkson (2003) draw attention to elements that designers should consider. In drawing references to work by Nielsen (1993) they highlight that the acceptability of a system comprises of social and practical acceptability. The two elements contain subsections in their definition. The practical acceptability of a system is defined by its usefulness through usability and utility. Social acceptability on the other hand, is made up of the aesthetic characters of a system. In focusing on these two factors Keates and Clarkson (2003) state that these are very important objectives to account for in a system, and that this can lead to a minimally effective solution in a minimal amount of time. If a system is to be designed, "…it is best to consider the needs of all users with similar conditions during the design process" (Keates and Clarkson, 2003, pg. 216). Therefore, by involving a range of children including those with disabilities, the reduction of stigma that is associated with healthcare technologies such as rehabilitation technology may be addressed in the context of opinions from a variety of children.

Parette and Scherer (2004) identify universal design principles as an area that can provide insight into the stigmatisation associated with a product. Alongside this, the device aesthetics, gender / age appropriateness, and social acceptability all play a part in ensuring that a system being designed is going to be the most effective for a population. Such research has already taken place with older people and assistive technology (McCreadie and Tinker, 2005). There is very little research to date that considers the social and practical acceptability of a device in research with children. Millard et al. (1998) emphasises that when designing technology for children, it should "…sit in a social context and it is vital that any requirements exercise should capture that context" (pg. 66).

Close analysis of the social and practical acceptability of rehabilitation devices will provide an opportunity to design equipment that will not exclude other potential child users, and should contain the same appeal for all child populations. Such an approach has been applied to the design of assistive technology by involving children without disabilities (e.g., Light et al., 2007). Within this research, it is highlighted that "…re-designing AAC technologies to incorporate these types of functions and features may increase their appeal and make them easier for young children to learn and use" (pg. 247).

5.1.2 Texture:

When designing a system, recent trends are leading toward a consideration of the entire user experience (e.g., Vredenburg, 2002). Such considerations should carry through into technology designed for children, where factors such as textural preferences have been mostly ignored. Krumlinde-Sundholm and Eliasson (2002) state that although visual information may provide valuable information, tactile input can impose understandings of the force of a grasp, alongside the control and manipulation of objects within an individual's hand. Therefore, in technology involving rehabilitative properties, where understanding of grasp and tactile sensibility are crucial, sufficient attention should be paid to the factors that affect it. In doing so, it is important to establish the extent to which children can provide an opinion on this topic. The role of texture within the design of rehabilitation is of particular interest given research indicating problems such as tactile sensory deficiencies that are exhibited in populations of children with CP (e.g., Cooper et al., 1995); a common user of this type of technology.

5.2 Question List:

Questions were based around the topics described above, and were analysed for face validity by two further independent researchers in addition to the primary researcher. Asking such questions is based on the assumption that such identified requirements for children do pre-exist the methods that are being applied to capture them (Woolgar, 1994). The construction of the questions involved balancing items, and addressed both positive and negative aspects of the areas of interest.

5.2.1 General Aesthetics / Social Acceptability:

What different types of colour(s) do you like?

What colour(s) make you feel happy?

What colour(s) make you feel sad?

What colour(s) would you want a joystick to be if you used it in your room?

What colours would you NOT want a joystick to be if you used it in your room?

What colour(s) would you want a joystick to be for school?

What colour(s) would you NOT want a joystick to be if you had to use it at school?

What colour(s) are your favourite toys / games?

What do you like about the shape of your favourite toy or game?

What shape(s) could a toy or game be that would make you not want to play with it?

What colour(s) would make you NOT want to play with a toy or game?

Health-related Aesthetics:

What would make you want to use a rehabilitation joystick?

What would make you NOT want to use a rehabilitation joystick?

If you liked a joystick but it made you look silly would you still use it at home?

If you liked a joystick but it made you look silly would you still use it at school?

What sort of equipment do you think disabled people use?

How do you feel about disabled people?

What do you think machines from hospital look like?

What do machines that are NOT from hospital look like?

5.2.2 Practical Acceptability:

Compatibility

How would you make a joystick just for children, and not for grown ups?

Where would you use a joystick at home?

Where would you use a joystick at school?

How big could a joystick be for your bedroom?

How big could a joystick be for your house?

How big could a joystick be for your school classroom?

Reliability (Trust of system)

Would you use a joystick if it moved on its own?

Would you rather have a fast bicycle, or one that would never ever break?

Usefulness

What would make a joystick really fun to use?

5.2.3 Texture

Materials

What should a joystick for your bedroom be made from?

What should a joystick for your bedroom NOT be made from?

Touch

How would you want a joystick handle to feel?

What would you NOT want a rehabilitation joystick handle to feel like?

How do your favourite toys or games feel to hold?

What do you like about the way your favourite toy or game feels?

What object(s) do you like the feel of?

What object(s) do you NOT like the feel of?

How should a joystick feel to make you want to play with it?

What do you think machines from hospital would feel like?

Appendix 6: Parental Consent Form

Appendix 6 provides an example of a parental sheet that was sent home to parents prior to the research visits.

6.1 Parental Information Sheet

This sheet provides information for parents regarding research that will be taking place at your child's school. It will outline what takes place during the research, what activities your child will be expected to complete, and what will be done with the findings. At the end of the sheet there are contact details for the researchers involved.

Purpose of the study

The research will be looking at how children can be involved in the design of equipment and devices. Specifically, this will involve health-related equipment, and a device used for rehabilitation in children with disabilities. The School of Mechanical Engineering and School of Rehabilitation Medicine at the University of Leeds have recently developed a joystick for children with cerebral palsy to use with computer games. This joystick was designed to assist children with cerebral palsy in completing different types of rehabilitation exercises designed by physiotherapists.

Currently we are looking at how children can be involved in the design of these joysticks to make them more appealing to other children. The research will involve the children taking part in a whole class activity where they will produce ideas for the design of a piece of rehabilitation equipment. Children will also take part in small group interviews (e.g., one-to-one interviews, focus groups) to gather further information about the designs that the children produce. These interviews will last 15 – 20 minutes each. The tasks will be incorporated into the existing 'Design and Technology' National Curriculum activities to minimise disruption to the child's education.

During the interview stage, audio recordings will be taken. This will allow the conversations between the researcher and children to be transcribed and reported. In order for the children to take part in the research, we require both the consent of the parent and the child. The attached consent forms **must be returned with a signature by the scheduled date of the research.**

What will happen to the data?

The audio data, transcriptions and diagrams belonging to the children will be stored securely in the researcher’s office. The data will only be accessed and analysed on university grounds by those who are authorized. All data will be anonymised so that children cannot be identified through the data we gather.

The sketches and diagrams drawn by the children during the group tasks will only be used for research purposes. The sketches will be subject to copyright law and explicit permission will be sought from the children and guardians in the event that reproduction of any of this material is required.

How will the data be used?

The data will be used solely within this research project. This project will be an opportunity to inform best practice on how to involve children in the design of rehabilitation technologies. This work will be undertaken at the University of Leeds and will be disseminated to other universities, the NHS and health care professionals and engineers through publications in relevant conferences and journals.

Further information

All researchers involved will have undertaken CRB checks before participating in any research involving the children. In addition to this, the children will remain within the care of the school at all times so that further health and safety considerations do not need to be accommodated.

Consent forms must be obtained from both the parent and child before participation can take place in this research. If any further information is provided by parents before signing consent please feel free to contact the details of the primary researcher provided below. If you are not happy with the information gathered by this means, please further your query to the research supervisor whose details are also provided below.

Thank you for your time,

Matthew Allsop

NB: The original parental contact sheet was followed by an A4 sheet outlining the contact details of both the candidate and research supervisor.

6.2 Parental Consent Form

CONSENT FORM

Using computer technology to assist children with cerebral palsy to undertake arm exercises within their own home

I have read the Parent's Information Sheet about the study	Yes/No
I have had the opportunity to ask questions and discuss the research study	Yes/No
I am satisfied with the answers to my questions	Yes/No
I have received enough information about this study	Yes/No
I understand that the audio recordings will only be used for this research project (and understand that they will be anonymised so that my son / daughter cannot be recognised from the audio recording)	Yes/No
I agree to the digital information stored securely and that it will be destroyed after 10 years	Yes/No
I agree to allow audio recordings to be undertaken	Yes/No
I agree for my child to take part in this research study	Yes/No
I agree that I can withdraw my child and their data from the research at any time	Yes/No

Signature of the child’s Parent or Guardian

....

Name of parent (block capitals)

....

Date…………..

Appendix 7: Child Assent Form

Engaging Children in Health-Related Design Processes

Children’s assent form

My name is …………………………………………….

I understand what this study is about	YES / NO
I would like to take part in this study	YES / NO
I agree to audio recordings taking place	YES / NO
I understand that I can change my mind and not take part if I do not want to	YES / NO

Child’s signature …………………………………………….

Today’s date …………………………………………….

Appendix 8: Standardised Instructions from the Interview Methods

Each set of standardised instructions had space for the facilitator to document the school, group number, and participant numbers for later transcription. Following the instructions there was space for the facilitator to make notes on any questions that were asked during the instructions.

Each of the methods had the following sets of instructions:

8.1 Design-Led Interview:

“You are about to take part in a design-led interview. In this activity, you and I will try to get a better understanding of the design you have already made. You can use any of the materials that are around us to try and build another design of a rehabilitation joystick”

“As you are putting the materials together I will be asking a few questions. When we have finished all of the questions I will let you know. There are no wrong or right answers, just tell me whatever you think about the questions I ask you. The activity is for fun, and will take about 20 minutes”

8.2 Interview:

“You are about to take part in an interview. In an interview, one person ask questions whilst the other person provides answers. I have a list of questions with me and I will be reading them one at a time. After each question that I ask, you will be given the chance to tell me what you think about each question. When we get to the end of the questions I will let you know. There are no wrong or right answers, just tell me whatever you think about the questions I ask you. The activity is for fun, and will take about 20 minutes”

8.3 Board Game

“You are about to take part in a board game. In this board game, the aim is to answer all of the questions around the board. You will take it in turns to roll a dice. When you know what number you rolled on the dice, you move your marker over the same number of squares. The person who rolled the dice should then read out the question on the square where their marker lands, and answer the question first. The other three people can then join in and discuss what they think about the question”

If you land on a square where the question has been answered, you need to pick up the nearest card that has not been answered. When all the questions have been answered, the game will end. There are no wrong or right answers, just say what you think about the questions that are on the cards. The activity is for fun, and will take about 20 minutes”

8.4 Focus Group:

“You are about to take part in a focus group. In a focus group, people discuss ideas with each other. I have a list of questions with me and I will be reading them one at a time. After each question that I ask, you will all be given the chance to discuss the answer to the question together. When everyone has had a turn in telling me what he or she thinks, we will move on to the next question. When we get to the end of the questions, I will let you all know. There are no wrong or right answers, just tell me whatever you think about the questions I ask you. The activity is for fun, and will take about 20 minutes”

Appendix 9: Post-test Questionnaire

Did you enjoy taking part in the activity?

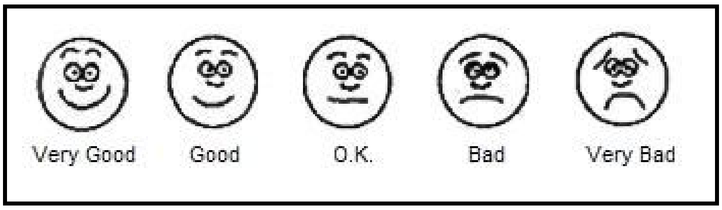
………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

……………………………………………………………………………………………

Which face describes how you felt when you were taking part in the activity?



Comments

………………………………………………………………………………………………

………………………………………………………………………………………………

What did you like most about the activity?

………………………………………………………………………………………………

………………………………………………………………………………………………

What did you like least about the activity?

………………………………………………………………………………………………

………………………………………………………………………………………………

Was there anything you didn't understand in the activity?

………………………………………………………………………………………………

………………………………………………………………………………………………

Was there anything you would like to change about the activity if you had to do it again?

………………………………………………………………………………………………

………………………………………………………………………………………………

What do you think ‘rehabilitation’ is?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

What are your experiences of disability?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Appendix 10: Questions for the Teacher Involvement Interviews

10.1 Questions Used for the Teacher Involvement Email Interview

The following questions were presented within an email to teachers who wanted to complete the teacher involvement questionnaires via email.

1. What have been your experiences of our research team visiting the school to run visits with the children?
2. What are your thoughts on the involvement of primary schools in such research?
3. Are there any concerns that you have regarding the school's participation in research?
4. What motivation do you think the schools have to be involved in research?
5. Does such motivation change when the basis of the research is rehabilitation technology?
6. Do you feel that you have had enough involvement in the decision-making and visit planning?
7. Are there any ways in which you feel research involvement could be improved, or actively involve teachers more?
8. What topics within the primary school curriculum were addressed within the ongoing research projects?
9. Are there any immediate changes in the children following involvement in the research?
10. How could future research visits be improved?

10.2 Questions Used During the Teacher Interviews

The following questions were devised as a foundation upon which to base the questioning within the semi-structured interviews with the teachers:

1. What have your experiences of our research team visiting the school to run visits with the children?
2. What are your thoughts on the involvement of primary schools in such research?
3. Are there any concerns that you have regarding your participation in research?
4. What motivation do you think the schools have to be involved in research?
5. Does such motivation change when the basis of the research is rehabilitation technology based?
6. Has you involvement in decision-making and visit planning been enough?

7. Are there any ways in which you feel research involvement could be improved, or actively involve teachers more?
8. What topics within the primary school curriculum were addressed within this research project?
9. What effect has research had on education of children or day-to-day activities?
10. How could future research visits be improved?
11. What previous experiences have you had when involved in research in the school? (Would you describe them as positive or negative and why?)

Appendix 11: Breakdown of Material Costs for Methods

11.1 Focus Group:

Printing	
Question list	5p
Materials for method	
Paper for question list:	5p
Total:	**10p**

11.2 One-to-one Interview:

Printing	
Question list	5p
Materials for method	
Paper for question list:	5p
Total:	**10p**

11.3 Board Game:

Printing	
Question list	5p
Materials for method	
Paper for question list	5p
A3 colour print out of board game	10p
Laminating board game design	70p
Question list for game cards	15p
Laminating questions	70p

A dice	50p
Player pieces	£1
Total:	**£3.25**

11.4 Participatory Design:

Printing

Question list	5p

Materials for method

Paper for question list:	5p
Plasticine (6 colours)	£7.95
Coloured pencils (12 pack)	£2.20
Sketching pencils (12 pack)	£3.00
Paper	50p
Felt tips (30 pack)	£1.49
Total:	**£15.24**

Appendix 12: Content Analysis

A large amount of information regarding children's preferences and opinions focusing on healthcare and rehabilitation technology was gathered during the interviews. To make the content easy to interpret, the interviews were transcribed. Informal inter-rater reliability checks were performed on the transcripts by providing a research assistant with a number of anonymous transcripts. The transcriptions formed by the assistant were compared with the accuracy of the transcriptions performed by the primary researcher. High levels of agreement were found, with very little difference being documented when comparing the transcriptions of the two researchers.

Following the completion of the transcripts, the qualitative identification of themes and coding took place. This was again verified by the assistant who completed the same tasks on a range of transcripts before comparisons were made. There was agreement between the two researchers on the themes that were finally decided for the qualitative analysis.

In total, two main themes were identified throughout; preferences for technology design, and discussions relating to individuals and their own experiences of healthcare equipment. Although the questions used during the visits were structured according to topics of interest, the responses were analysed to identify larger topics of discussion and to provide a structure with which to present the information. Each main theme contained sub-themes that are illustrated in **Figure 53** beneath. The analysis beneath is structured in the order of the sub-themes which were identified within the main themes. Each of the sub-themes has a range of topics that were discussed and these are displayed in a figure before each topic is discussed. The discussions incorporate quotes taken directly from the transcripts, and they can be seen in italics. Where quotations are used, participants are referred to simply as 'child'. Where multiple children participate, they are allocated numbers to outline the process of the discussion as it occurred at the time.

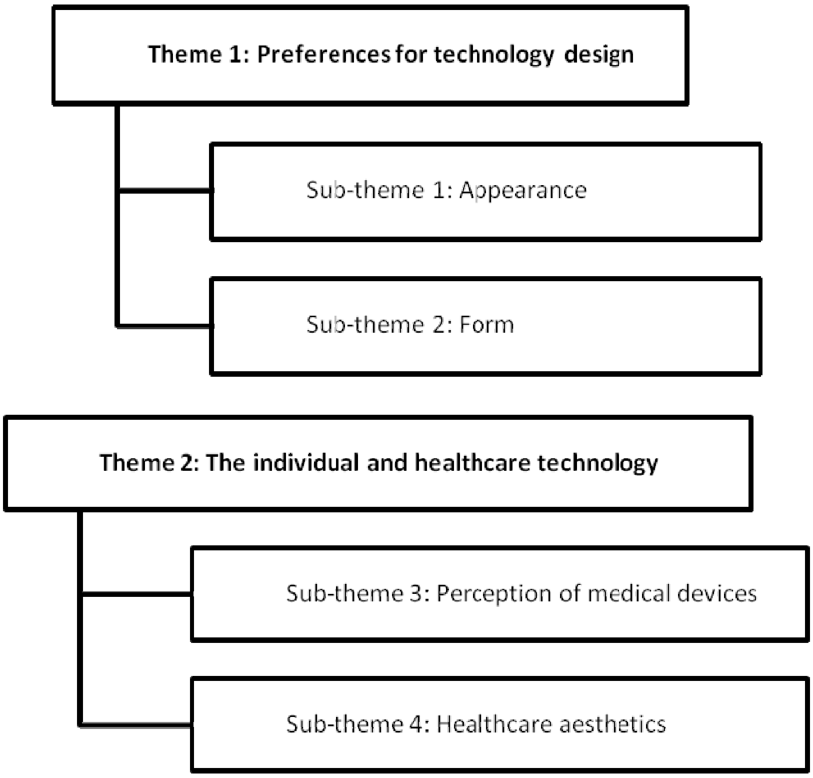


Figure 53 Main themes from the interviews with the children

The first sub-theme to emerge in discussions about preferences for technology design involved topics surrounding appearance. The interviews followed on from a design task that focused mainly on the design of a rehabilitation device and such an emphasis on appearance carried through to children's discussions of technology in the interviews. The majority of discussion about the appearance of technology involved colour, and how children would improve a device to make it more appealing to other children.

12.1 Theme 1: Preferences for Technology Design: Appearance

As shown in **Figure 54**, discussions surrounding the appearance of technology focused on children's preferences for the rehabilitation joystick and handwriting device that was the focus of the group design task. Therefore, discussion relating to technology preferences is a generic label for either rehabilitation device that was being discussed with the children. The majority of discussion surrounding appearance involved a discussion about colour, although there was also discussion about how to improve the appearance overall.

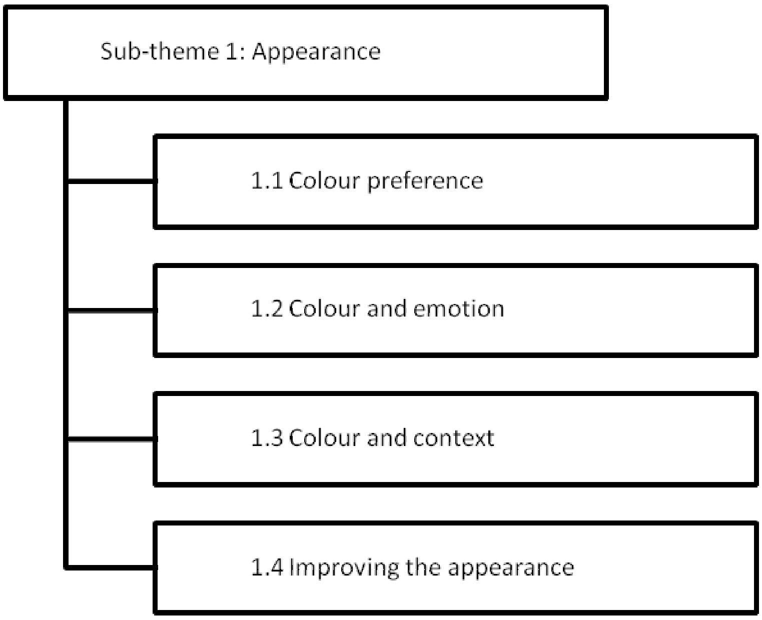


Figure 54 Sub-theme 1

12.1 Sub theme1.1 Colour Preferences

When children were asked questions about their favourite colours, they often recited a list. One-word responses were the most common answer that children used to answer such questions, particularly in younger age groups. Very little interaction occurred in the focus groups and board games when outlining a favourite colour, although discussing why children liked a colour often provoked further details (see sub-theme 1.2 and 1.3).

Facilitator: What different types of colours do you like?

Child 1: Err… I like red, blue, and purple

Child 2: I like yellow, light green, light blue

Child 3: I like purple, pink, and light blue

Child 4: Red, blue, and gold

Children in the older age group of 9 – 10 years of age occasionally extended lists to include global categories that describe colour information, such as pastel colours, or bright colours.

12.1.2 Sub theme 1.2 Colour and Emotion

Some children justified their choice of favourite and preferred colours on the basis of the emotions that it evoked, and that certain colours, particularly bright colours, made them feel happy. The interviews often enquired directly as to which colours made the children feel happy and sad, and they were able to select colours for each of these categories. Some children were capable of providing in-depth responses to explain why certain colours evoked emotional responses, sometimes providing sensitive, insightful information.

Facilitator: What colours make you feel sad?

Child 1: Red, black, green and yellow… because my dad and my step dad he says that red is a warm colour and blue is cold, so it feels like emotions

Child 2: I actually feel, I think orange makes me feel sad because that was my dad's favourite colour until he died. Whenever I see orange it makes me feel sad

However, their ability to explain preferences were reduced for instances when an anchor such as emotion was not provided.

Facilitator: Why do you like certain colours?

Child: It's like I feel it's real… I just like it

12.1.3 Sub theme 1.3 Colour and Context

Although it was not made explicit by the children, it was clear that when asked, many thought that devices should have different colours and designs dependent on the environment in which they were to be used.

Child: To say that we have our school uniform and we have certain colours that we have to wear I'd want the (device) to be light green or a blue so that we know that's it part of the colours of our school uniform

The reference to an environment acted as grounds to include and exclude certain characteristics, with for example the avoidance of certain colours due to negative associations with the school environment.

Facilitator: Same colours… so it doesn't matter then?

Child 1: Black, because school is boring

Facilitator: So, you'd just have a black (device)

Child 2: Dull…

Child 1: Yeah, like school

Consideration of the school environment was common, but so too were modifications that should be made for gender.

12.1.4 Sub theme 1.4 Improving the Appearance

In order to improve the appearance of rehabilitation technology many children suggested incorporating personalised features into the design e.g., stickers, lights, colours.

One child who had CP indicated that in the past when they had been asked to use a device in a hospital in early usability testing they found it boring alongside having no control over its design.

Child 1 (with CP): Yeah, it's a bit dull. When I did it I didn't really want to do it

Facilitator: Why didn't you want to do it?

Child 1: Because it was boring and I don't really like working in hospitals because they're just boring

Facilitator: If you had it at home, how would you want it?

Child 1: Well I had it at home, but no-one would let me customise it. I couldn't paint it pink, or put fluff on it

In such conversations related to colour, children with disabilities provided answers that were similar to all participants. There was a strong preference for bright colours, and often indicated similar personalisation preferences amongst all children.

12.2 Theme 1: Preferences for Technology Design: Form

As shown in **Figure 55**, although the visual aesthetics of the device were discussed in relation to colour, children also revealed preferences relating to the texture, shapes and the size of a rehabilitation device. Children clearly had good knowledge of different varieties of colours as consideration and awareness of these may be an important part of daily creative tasks. However, children's ability to recite their preferences was reduced when less common questions were asked involving materials and size dimensions.

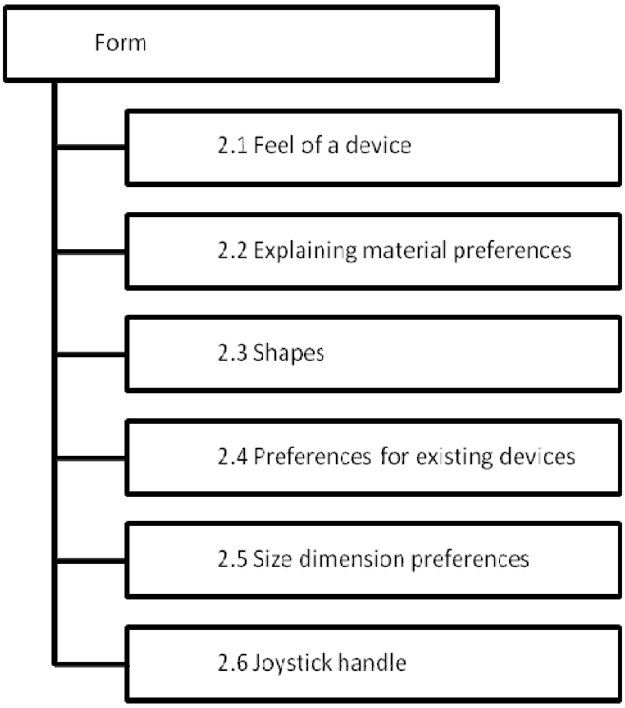


Figure 55 Sub-theme 2

12.2.1 Sub-theme 2.1 Feel of Device

Most preferences for the feeling of a device were related to soft objects, although explanations and discussion of materials was not always clear.

Facilitator: How would you want a (device) to feel?

Child 1 – Soft…

Child 2 – Soft and silky

Child 3 – Soft and squeezey with that foam stuff

Child 4 – I like my brothers, but its plastic but its really comfy

Child 5 – Why? How does it feel when you hold the (device)?

Child 1 – Rubbery, soft and smooth… and silky

The majority of responses from children indicated that soft and comfortable is indicative of items that they like the feeling of, although when asked about materials that should be used for rehabilitation equipment many children indicated metal to be the most appropriate. However, the children were not explicit about where on the device should be made from separate materials, as no attempts were made to label parts of a device, with the exception of specific discussion about the handle.

12.2.2 Sub-theme 2.2 Material Preferences

Children's preferences for materials were often confusing. Although children were aware of a range of materials, they failed to indicate a thorough understanding of their properties. Given that materials have been a central element of the previous design task, children had already begun to think about the materials and incorporate them into their designs. Occasionally concerns for safety arose where softer materials were given preference, particularly in environments where the children might play.

Facilitator: What should a (device) for your bedroom be made from?

Child 1: Fabric

Child 2: Fabric

Child 3: Something soft that you can grip

Child 4: Something that's safe

Child 2: Something that doesn't slip

There was also an awareness of the need to choose materials in line with the product being designed for children.

> *Child : you wouldn't want to make it... you'd have to make it unbreakable really because I know that children end up knocking stuff off and you'd have to make it unbreakable .. and like foamish - because foam doesn't break easily*

Although children with disabilities were mostly in line with the opinions of children without disabilities, a slight preference for softer materials was noted.

12.2.3 Sub-theme 2.3 Shapes

When children listed preferences of shape into the design of rehabilitation technology, there was often no explanation, only the recital of a shape. However, generally children often revealed preferences towards soft, round shapes, with evidence of well-reasoned decisions on a number of occasions.

Facilitator: So on the whole, do you like square shapes or more rounded shapes?

Child 1: Well both

Child 2: I like rounded shapes like eggs

Child 3: Well if it's pointed you might hurt yourself

12.2.4 Sub-theme 2.4 Preferences for Existing Devices

When children discussed what they liked about the devices that they already owned, often comfort entered into the discussion. Comfort seemed to come about as a result of the practicalities of certain shapes.

Interviewer: What do you like about the shapes of these toys and games?

Child 1: It's easy to pick up

Child 2: It's easy to hold onto something… like a toy or something or to hold it up

There was confusion about the way that the texture of the device felt, and children could not provide detailed information about the way that items felt.

Facilitator: How do your favourite games feel to hold?

Child 1: Quite hard but soft

Child 2: All my toys are just everything… soft

Child 3: Hard and bumpy some are soft

Child 4: Some are hard and some soft

12.2.5 Sub-theme 2.5 Size Dimension Preferences

Many of the dimensions used to outline the size of the device were arbitrary and did not provide any useful information. Often the facilitator would enquire about the preferred size of a device and mentioned a measure such as a metre. The children would latch onto this information and provide variations of this metric.

Facilitator: And how big do you think a (device) could be for your bedroom?

Child 1: Quite small

Child 2: About that big

Interviewer: What, just short of a metre?

Child 1 and 2: Yeah

Facilitator: How big could a (device) be for your school classroom?

Child 1: About that big

Child 2: Half a metre… no about twice as big

Child 3: Two metres

Child 1: No, about one metre

Other size information lacked specific detail and often did not make sense, suggesting that children cannot provide useful information relating to the size of a device.

12.2.6 Sub-theme 2.6 Device Handles

The point of contact with a device is perhaps a crucial element for children as the preferences that were indicated for a device handle were similar to the descriptions of the children’s favourite toys and games. The children often preferred soft and comfortable materials for use on the handle. Again, the descriptions of materials were lacking and descriptions of material properties are used instead of specific material names.

Facilitator: What material would you want a (device) handle to be made from?

Child 1: …either rubber or some kind of foamish

For children with disabilities a device handle requires greater thought regarding its design. Although soft comfortable materials were often chosen, children with disabilities often indicated the need for device handles that were easy to grip.

12.3 Theme 2: The Individual and Healthcare Technology: Healthcare Equipment Use

As shown in **Figure 56**, discussion of healthcare equipment use contained four subsections, discussions about disability and one’s appearance as seen by others.

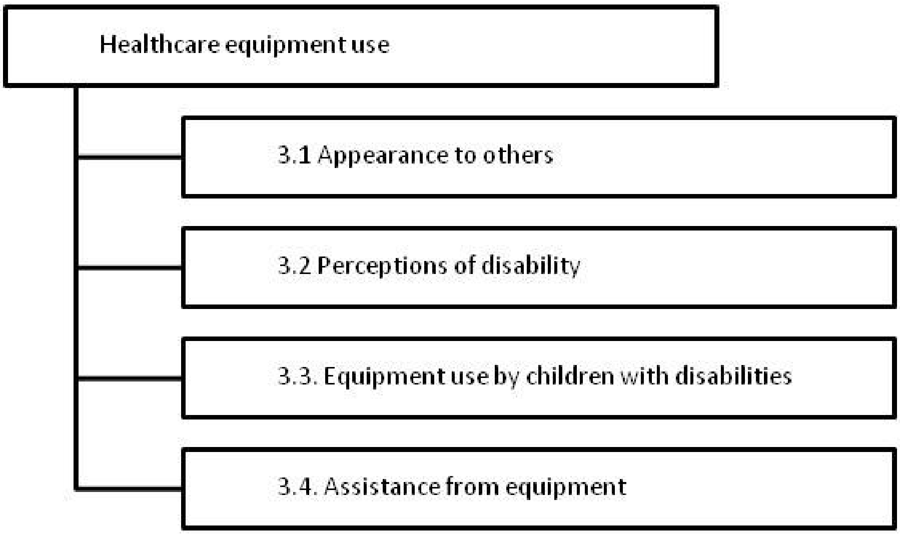


Figure 56 Sub-theme 3

12.3.1 Sub-theme 3.1 Appearance to Others

A large proportion of children indicated that they would use rehabilitation within the home environment even if it made them appear silly. However, when asked if they would use it at school, a large proportion of children showed reluctance.

There was a clear distinction made between using a healthcare technology device with and without the presence of others, and concerns were raised about others witnessing a device making a child look silly.

Facilitator: Would you still use it [a device] at school?

Child: Probably not

Facilitator: Why not?

Child 1: Because I'd look silly obviously

Most children would not use a rehabilitation device in the presence of others, although a small proportion of children indicated that they would if it was required for therapeutic use. However, those suggesting they would be willing to use the equipment around others were often in a focus group with a child with a disability.

12.3.2 Sub-theme 3.2 Perceptions of Disability

When discussion about disability was taking place, often children without disabilities described feelings of sadness towards those with disabilities. There was often a sense of pity that accompanied such statements, and an underlying assumption that people with disabilities are unable to function normally.

Facilitator: And how do you feel about disabled people?

Child: Erm… I feel sorry for them because they're not able to do as much stuff as you are…

Questions about how people felt about disabled people were not asked in the presence of children with disabilities.

12.3.3 Sub-theme 3.3 Equipment Use by Children with Disabilities

When raising questions about disability with the children, lists of equipment associated with children with disabilities were created with ease. In schools with a number of pupils with disabilities, participants were able to list equipment easily. Further to this, when a child with a disability was present in a focus group, the child listed all of their own equipment, with other participants helping to recite any that the child had forgotten. Unsurprisingly the most frequently chosen devices were often the devices that children with disabilities used in their own school environment. Therefore, a child’s knowledge of equipment used by people with disabilities, aside from wheelchairs, was influenced heavily by their own exposure to such technology in their school environment.

12.3.4 Sub-theme 3.4. Assistance from Equipment

When discussing healthcare technology, children were asked questions about whether they would trust equipment that moved on its own. Children seemed to be hesitant about the idea of using such a device, although relating the idea to the rehabilitation devices that they had seen in the group design task helped. However, many children failed to provide to give an answer to such questions unless prompted and simply provided yes or no responses. One child with a disability supported the idea of using such a device, as it would require minimal effort:

Facilitator: Would you use a device that moved on its own?

Child (with CP): I would because I don’t have to do anything

When talking to children away from the idea of assistance it became clear that most children choose reliability of devices over possible fun. For example, when children were asked about whether they would prefer a fast bicycle or one that would never break, many chose the latter.

12.4 Theme 2: The Individual and Healthcare Technology: Healthcare Equipment Aesthetics

12.4.1 Sub-theme 4.1 Perceptions of Hospital Equipment

As shown in **Figure 57**, the first of two sub-themes when looking at hospital equipment aesthetics is the perception of hospital equipment. Children were asked about the way that they think about equipment that is from hospital. Many children seemed to struggle from the need to recall information, and for the majority of children responses were very vague. These often included descriptions of big, white machines, or a few detailed descriptions of more common equipment such as electroencephalograph (ECG) machines.

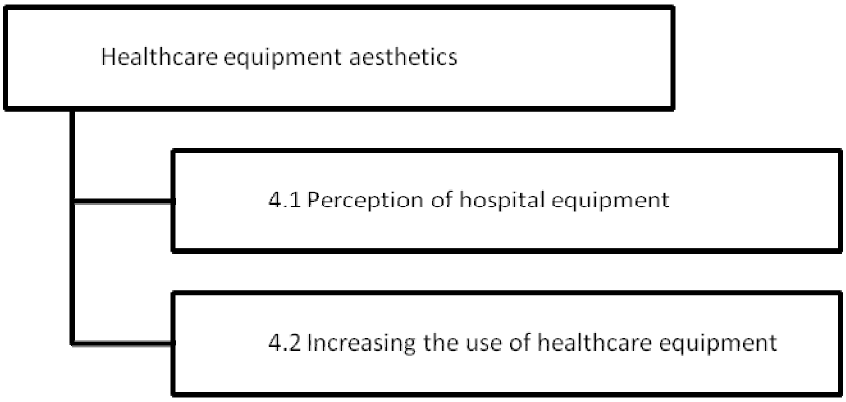


Figure 57 Sub-theme 4

Descriptions provided by children with disabilities followed a similar pattern of describing machinery that they have seen in the past, alongside the use of mostly negative words such as '*rough*' and '*hard*'.

12.4.2 Sub-theme 4.2 Increasing the Use of Healthcare Technology

Children indicated that most popular reason for wanting to use a rehabilitation device would be for use in alleviating the symptoms of an illness or disability. To increase the use of the technology more generally, most children placed importance on the right to personalise it. Ideas for personalisation included a range of ideas for modifying the exterior of a device to suit individuals.

When enquiring further about how children would personalise their device to increase use, many highlighted the importance of ensuring that it was only for children. Many suggestions were made regarding ideas about how to make a device look like it is just for use by children. The majority of children responded with ideas of placing stickers on the device that identified it as for children only, and putting patterns on it, which suggests that children may perceive adult equipment as typically plain. A large number of the children replied with the idea of just making the device smaller.

12.5 Summary of Content Analysis

Overall children provided a large amount of information during the interviews. There was variation in the capability of participants to provide information for certain topics. This may reflect the structure of questioning, as certain questions drew on the direct experience of all children (e.g. colour information) compared to more specialist information (e.g. appearance and feeling of hospital equipment). This was demonstrated when asking questions about the social acceptability of healthcare equipment. Children could answer questions relating to social acceptability without any difficulty when questioning drew on direct, daily experience (e.g., favourite colour or shape of a child's favourite toy). Asking children about features of technology such as hospital equipment caused difficulty, except for a few children with disabilities who are in contact with this equipment more frequently.

When questions were asked regarding disability, groups would use any children with disabilities attending their school as a basis for responses. However, this only occurred if the children with disabilities were not present. When children with disabilities were present amidst interview groups, they were always given the space to voice their opinions and often given the lead in responding to such questions relating to disability.

All children could provide ideas for the compatibility of technology when questions regarding practical acceptability were asked. However, the responses that were provided were often confusing. When children were asked questions about the size of devices, for example how big a device could be to fit into a classroom, children displayed a lack of understanding in the accuracy and representation of measurements. However, children were able to make decisions about how reliable a device should be, and suggest ways to improve devices to make them more fun.

For information relating to textural preferences, children often recited properties of materials and not actual names of materials. However, a number of more commonly used materials were mentioned. Children were also capable of describing the surface of objects that they liked the feeling of, but were unable to explain why they liked a specific texture.

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