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The Evaluation of Methods for Engaging Children in Healthcare Technology Design

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Abstract

Examples of user involvement can be found throughout healthcare literature. This extends to the design and development of healthcare technology where the involvement of users has been found to positively impact the quality and safety of products. However, there is currently little known about which methods are the most appropriate for involving children in technology development. The research applied and developed a framework to guide the use of methods in the design and development of healthcare technology for upper limb rehabilitation in children with cerebral palsy. Utilising an assessment framework to explore the suitability of four interview methods for involving children in the design and development of healthcare technology, research was carried out in primary schools in the United Kingdom. The research team i) used the assessment framework to guide the collection of information for comparing methods for involving children; ii) considered additional criteria for inclusion in the framework; and iii) gathered observations and data to comment on the criteria in relation to the four interview methods. Children were able to participate in all four interview methods, although further consideration is needed to identify how children with disabilities can be involved in design activities forming part of interview methods. Differences were found between the methods relating to their robustness, reliability, validity, efficiency, enjoyment and cost. The involvement of participants with a disability highlighted the need to develop new methods that support their inclusion in healthcare technology design work. The assessment framework applied in this research was useful to inform the comparison of methods and represents a step towards a more unified approach to understanding how best to capture the perspectives of children to develop technology that best serves their needs.

Keywords: user involvement, children, disability, technology design, healthcare, assistive technology

1.0 Introduction

In the United Kingdom (UK), the Government has committed to creating a norm of shared decision making in healthcare between patients and clinicians, and the emergence of new commissioning boards pledge to champion patient and carer involvement [1]. The justification and support behind user involvement (UI), and activities relating to patient and public involvement (PPI) is now well established in the healthcare literature [2], with many examples available from service planning and development and research activity within the National Health Service (NHS) [3]. The increase of UI has extended into areas such as healthcare technology development involving the engagement of end users [4]. This practice is becoming more widespread for the manufacturers of technology (such as medical devices) in the UK, where recently introduced standards [5] require manufacturers to adopt a user centred design process (referred to as a Usability Engineering Process) that spans the design and development life cycle of a device.

UI in the development of healthcare technology can potentially impact its quality and safety [6]. When considering how to involve users in the design of healthcare technology, it is important to consider which methods are suitable, and most beneficial, throughout the medical device development lifecycle [7]. A number of methods have been utilised in healthcare technology development to involve users, where usability tests, interviews and questionnaire surveys are the most frequently used [4], with general guidelines to inform method use in, for example, assistive technology development [8]. The definition of user in healthcare technology development refers to a heterogeneous group of people, including clinicians, patients, carers, family members and persons with disabilities. While the derivation of benefit from a device could be used as a collective characteristic of users, consideration their heterogeneity is necessary for effectively capturing user perspectives for integration into technology development and assessment. This process can also support an understanding of the regulatory, health and safety, and insurance perspectives concerning the development of technologies [9].

While it has been outlined that UI is becoming more common in technology development, particularly assistive technology and rehabilitation equipment, there has been little exploration of methods that could be used to involve children [10]. While recommendations for the use of particular methods at different stages of healthcare technology development exist [11], they are stratified for use at specific design process stages without explicit justification, and do not focus on children. From the healthcare literature, there are guidelines available for involving children in healthcare research [12] [13] but without underlying support behind recommendations of which methods should be used, particularly in relation to technology design and development.

The participation of children and young people in research has emphasised the need to perceive and encounter children as equal human beings in child-centred health care settings [14]. For example, the use of developmentally appropriate methods is linked to minimisation of attrition and improving access [15]. To date, the authors are unaware of research literature comparing different methods regarding suitability for used with children and young people in healthcare technology development. With listening to and engaging with young people proposed in recent reforms to the NHS [1] it is an important time to consider the development of strategies to bolster and evaluate the effectiveness of UI activities involving this group. In doing so it should be acknowledged that this group are not homogeneous and the NHS must be flexible in responding to their diverse needs, backgrounds, capabilities and interests [16].

While literature from healthcare is lacking consideration and guidance on methods to involve children in technology design, human-computer interaction (HCI) literature presents a wide selection of both. Spurred on by the increased interest in the interaction between technology and children, a subfield of HCI has been created specifically to investigate ‘Child Computer Interaction’ (CCI) [17]. Examples of novel technology methods used in design that have stemmed from this discipline (technology design rather than technology evaluation for which a range of methods have also been developed) include the BRIDGE method [18], contextual laddering [19], and cooperative inquiry [20]. Although tempting to draw methods from this domain for use in healthcare technology design, the value and quality of research methods that stem from HCI and CCI have not been evaluated in an empirical way [21]. HCI methods are often developed in isolation for application in the development of a specific device leading to disparate trails of research with ad hoc methods being created for use on one project [22] [23] and making any meta-evaluation of methods difficult. With an increasing drive for involving children and young people in healthcare research, it is important to begin to assess the suitability of available methods from CCI in a way that can be expanded across disciplines.

Within HCI, a framework has been proposed for assessing methods available for use in developing technology with children [24]. The Markopoulos and Bekker framework was developed to assess new methods (with a specific focus on using usability methods with children) for their appropriateness for use with children. Despite the failure of CCI to adopt a systematic approach to evaluating methods, with one exception [25] of research using a framework to describe design methods in terms of required design skills as identified by the Theory of Multiple Intelligences, there is scope to apply the framework within the consideration of methods for use with children and healthcare technology. The framework considers three elements of child involvement in technology development: 1) components of a method, 2) assessment criteria to evaluate a method, and 3) characteristics of children as participants in a method. Markopoulos and Bekker conclude that many comparisons are based on the first two dimensions and the characteristics of children are rarely taken into account [24]. This paper reports on the use of the framework to compare interview methods for involving children in the design and development of healthcare technology for upper limb rehabilitation in children with cerebral palsy.

2.0 Method

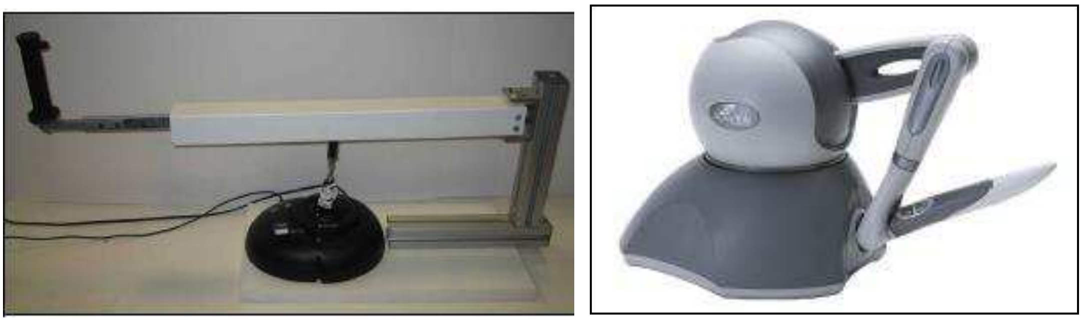
This paper outlines the application of a framework for assessing interview methods when used to involve children in the design of healthcare technology. Continuing previous work of Charterhouse Rehabilitation Technologies Laboratory at the University of Leeds [26], the research took place between 2009 and 2010 in five mainstream primary schools from education authorities in Yorkshire, UK. The research protocol was designed for delivery in a mainstream school environment as it provides direct access to the end users of healthcare technology for children and their peers, alongside providing access to the insight and support provided by teachers [27]. Further, accessibility equipment for children with disabilities is supplied through a child's statement of special educational needs [28], avoiding any access difficulties that might be experienced in alternative environments. Primary schools in the UK typically contain children from the ages of 5 – 11 years of age, although only an older age group (i.e. 8 – 10 years old) was included in this research. An older cohort of children was included as previous research has outlined their ability to maintain concentration and complete tasks as directed by an adult, and that they are often happy to be observed [29] [30].

2.1 Group presentation

The visits began with group presentations that involved a whole class discussion and reflection on disability, rehabilitation and healthcare technology. The teachers and researchers worked collaboratively to provide a spoken dialogue about healthcare technology and how it can assist people with disabilities who require rehabilitation, allowing for questions from children.

2.2 Group task

A group task then took place, with a demonstration and opportunity to try out one of two rehabilitation devices; a rehabilitation joystick or a handwriting device (Figure 1).



The rehabilitation joystick (left) connects to bespoke software that guides a user through upper limb exercises that match movements a physiotherapist would encourage a child to practice, with varying levels of force-feedback assistance available, designed for children with CP. The handwriting device (right) was a PHANTOM Omni® Haptic Device, used with accompanying OpenHaptics Academic Edition software.

Figure 1 The devices introduced to children during the group tasks

The demonstration was provided to ensure that the purpose of a joystick or handwriting device was understood, and particularly how it can be used in rehabilitation. Following the device demonstration, children were asked to create their own designs of a joystick or handwriting device by incorporating their preferred colours, shapes, materials and features into colour drawings. Props were provided to help children identify their preferred colours and materials, including colour charts and texture samples. The texture samples were 3″ x 3″ cuttings of aluminium, brass, plastic, cotton, rubber, sponge and sandpaper. The group task provided a means of integrating the research into the framework of teaching and learning for the schools, outlined in the National Curriculum (NC) [31], by aligning group activities with the existing Design and Technology curriculum ("developing, planning and communicating ideas" and "knowledge and understanding of materials and components").

While the children participated in the group task, the classroom teacher completed a rating form that indicated each child's verbal competence level, comprising a subset of the Wechsler Intelligence Scale for Children (WISC, 4th edition) [32]. The ratings were used to identify children that may have required additional support when participating in the interviews.

2.3 Participation in interview methods

Once the group task was underway, the research team divided a class list into same sex groupings to participate in one of four interview methods.

Table 1 Overview of the interview methods used in the research

Method	**Number of people involved**	**Description**
Focus group	4 – 6 children; 1 adult facilitator	The adult interview facilitator has a list of questions to work through. After reading a question aloud, the children are allowed time to discuss their responses with each other. The researcher provides clarification to questions when requested from the children, and moderates discussions if deviation occurs.
One-to-one interview	1 child; 1 adult facilitator	The one-to-one interview involves a researcher sitting with a child and reading a list of questions to the child. The child is provided with the opportunity to respond to each question in full and ask any questions if uncertain.
Board game	4 children; 1 adult facilitator	A board is designed for use as a platform for placing a number of cards on which questions are written. Each child is given a game piece. The children take turns to roll two die. The children use the sum of the dice to instruct how many question cards their game piece should move over. The card on which the game piece lands should be turned over by the child who rolled the dice. The child reads the question aloud and provides their response to the question. The other children then provide their own responses to the question, and discuss what they have said with one another. A researcher is present during this game to provide initial instructions for the method, provide clarification on uncertainty around any questions or aspects of the game, and moderate discussions if they deviate during the activity.
Design-led interview	1 child; 1 adult facilitator	A child is presented with a range of materials (e.g., modelling clay, coloured pens and pencils, paper, card). The child is asked to develop a low-tech model or drawing that incorporates shapes and form that they would like in a piece of healthcare technology. While the child is building a model or drawing the researcher asks the child questions from a list. The child is given time to respond to each question in full.

The four interview methods included focus groups, board games[1], design-led interviews (DLI), and one-to-one interviews (described in Table 1). For each method, a standardised set of instructions was read aloud to children before questioning, outlining the process of the method, and reiterating consent details. Each method ended when all of the questions had been presented to the children, or when a twenty minute time limit was reached; whichever came first. The same set of questions was used across all four methods. The questions were designed to gather information from children relating to different aspects of technology. The topics around which questions were developed covered the social and practical acceptability of healthcare technology[2] (e.g., What colour would you want a rehabilitation joystick to be if you had to use it at school? What could make a joystick fun to use?), and questions regarding texture preferences[3] (e.g. How would you want a joystick handle to feel?). Following completion of interviews, children were asked to complete self-report questionnaire obtaining information about age and gender, and rating of enjoyment using a visual analogue scale (VAS) (Figure 2). Audio recordings were made during each interview and transcribed after the research visits.

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[1] The decision to use the board game method stemmed from a meeting with the authors from a conference article outlining the use of a similar method to involve residents in the design of a low security mental health unit [33]

[2] The acceptability of a system involves both social and practical acceptability. The practical acceptability of a system is defined by its usefulness through containing usability and utility. Social acceptability refers to the aesthetic characteristics of a system [34].

[3] When designing a system, the entire user experience should be considered [35]. Such considerations should carry through into technology designed for children, where factors such as textural preferences have been mostly ignored. It has been stated 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 [36].

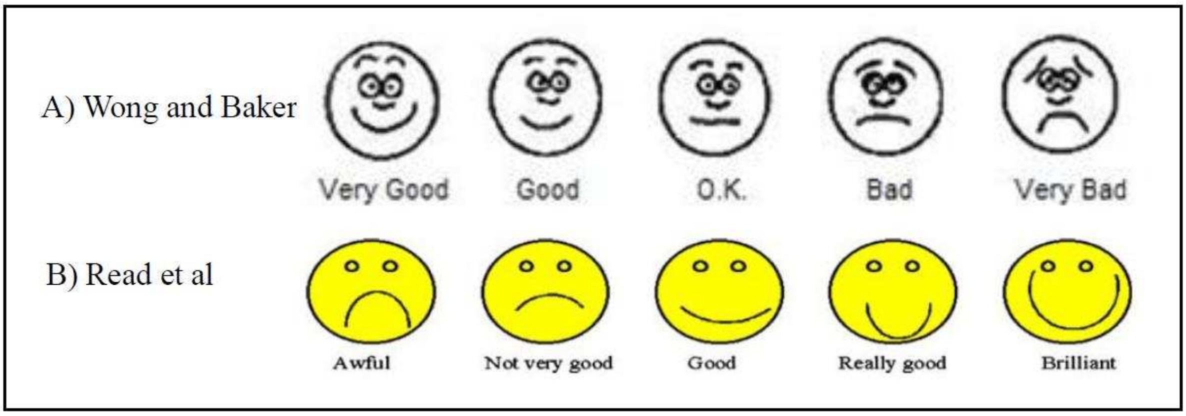

Figure 2 Adaptation of the Wong and Baker pain scale [37] used to assess the children's enjoyment of methods and the smileyometer [33]

2.4 Post-trial Activities

At the close of a school visit, a discussion group was held with all participating researchers. Detailed descriptions of the visit and comments on any issues that had arisen were documented. Specific observations were also documented linked to the Markopoulos and Bekker framework. Once all trials at the schools had been completed, the cost of materials required to run each of the four interview methods was calculated. Additionally, the detailed costs for the involvement of the researchers, in terms of equivalent time and associated cost, was calculated by the research support office at the University of Leeds.

2.5 Analysis of data

The Markopoulos and Bekker [24] framework was used to focus on universal criteria for assessing the methods used during the research visits.

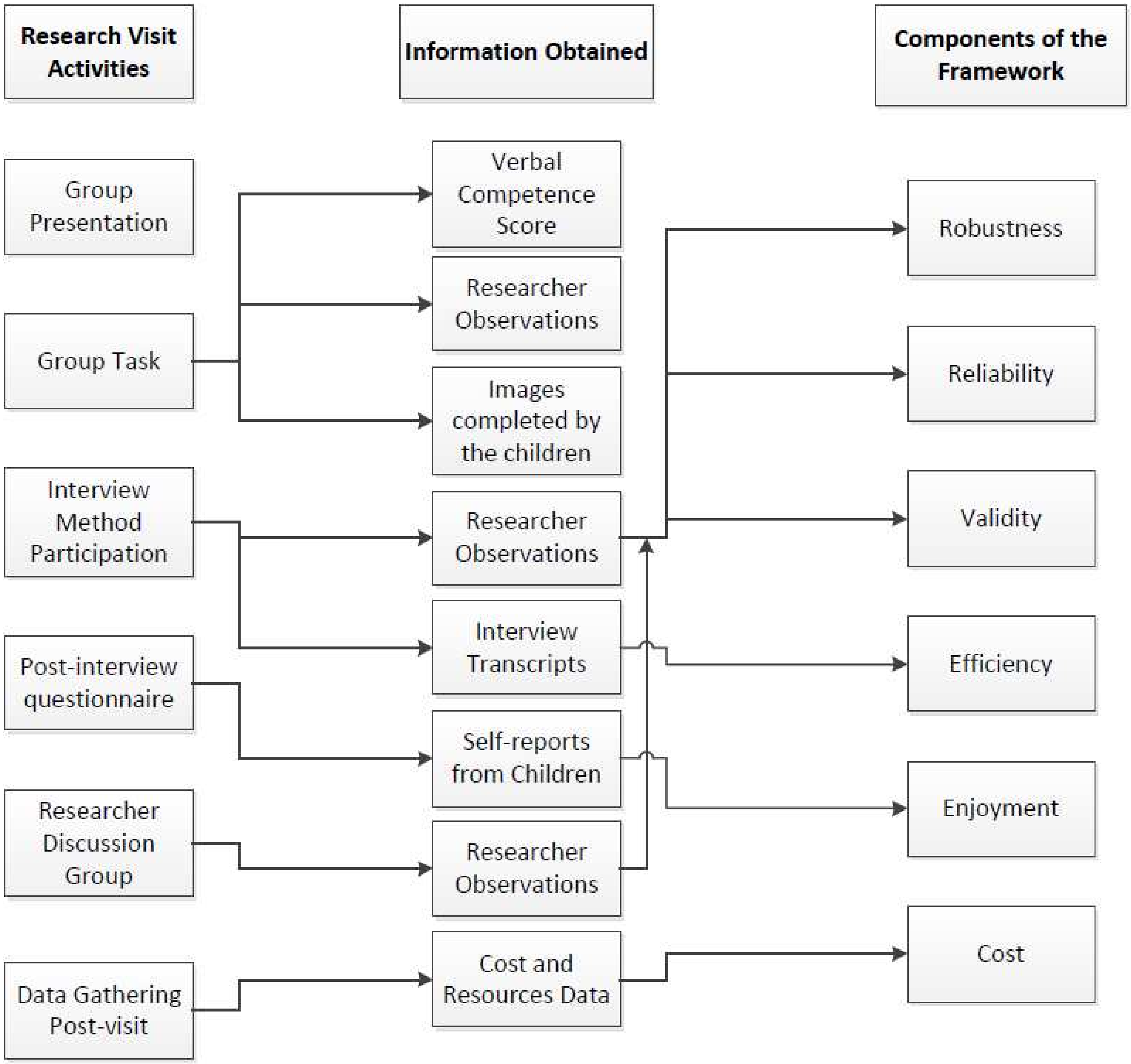

Figure 3 Measures used to perform the process analysis in the method comparison

The five key characteristics outlined in the framework for the assessment of a method are outlined in Figure 3: robustness (the feasibility of a method being applied across different contexts, products, or domains), reliability (whether a method can extrapolate the same information from children in different conditions, such as different settings, schools, and populations), validity (whether responses gathered from children can meaningfully inform the design of healthcare technology), thoroughness (examination of the extent to which a method can obtain information about all aspects of a device being designed), and efficiency (time taken to set up a room for a method, completion rates of the methods, number of responses obtained during the interviews). Thoroughness (referring to the proportion of all usability problems of a product that are found through a test) was not included as it was not deemed appropriate when the focus of the research was design, not usability.

A focus on the characteristics of children led to the development of two additional criteria: cost (resources used and researcher involvement, as this can inform the projection of costs by manufacturers or other researcher's when developing projects in healthcare technology) and enjoyment (enjoyment is linked to engagement [39], and although difficult to measure [40] is an important concept to explore in design research to include a characteristic deemed important in research with children [41]).

Variable	**Data capture method**
Robustness	Researcher observations
Reliability	Researcher observations
Validity	Researcher observations
Efficiency	Observation of time taken to set up each method Completion rates of each method Number of obtained responses
Cost	Resource cost summary / staff cost summary
Enjoyment	VAS scores in the post-test questionnaire

Table 2 Methods used to capture the variables of interest

The source of data used to discuss the variables of interest is outlined in Table 2. Ethics approval for this research was provided by the University of Leeds Research Ethics Committee. Consent from parents was obtained prior to the school visits and children signed assent forms at the beginning of the research visit.

3.0 Results

In total, 107 children aged 8 – 10, including both males (N = 56) and females (N = 51) participated, including five children with CP. Three children with CP had a diagnosis of spastic hemiplegia having moderate functional impairment to the upper extremity. The remaining two children with CP were diagnosed with spastic quadriplegia with accompanying dysarthria, both using text-to-speech communication systems. Table 3 outlines how the participants were distributed across the four interview methods.

	Focus Group	One-to-one Interview	Board Game	DLI
Number of male participants	30	5	16	5
Number of female participants	33	5	8	5
Total Number of Times Used	15	10	6	10

Table 3 The distribution of participants across the four interview methods and the total number of times each method was performed during the visits used

3.1 Group Task summary

All children participated in the group task. The children with spastic quadriplegia received support from classroom assistants who constructed images on the basis of instructions given by the children. When reviewing the images generated by classes working with the joystick device, most of the children incorporated the existing joystick shape in their designs and modified the colour scheme. An example is shown in Figure 4, which includes annotations outlining the key components of the system (e.g., screen) and preferences for materials (such as rubber for the handle).

Figure 4 Example of a group task design obtained following a demonstration of the joystick device

The children who were shown the handwriting device tended to deviate from the shape of the device presented, generating novel ideas for the shape and function of such a device (for example, Figure 5).

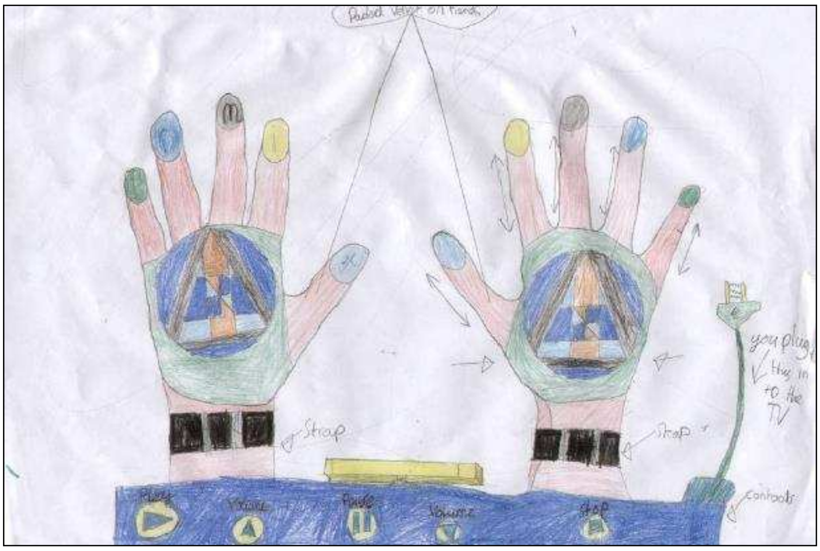

Figure 5 Example of a group task design obtained following a demonstration of the handwriting device

3.2 Markopoulos and Bekker Framework

3.2.1 Robustness

For the DLI, all children without disabilities were able to participate without any reported or observed difficulty. No children with disabilities participated because teachers indicated that they would be unable to manipulate the materials to create a prototype. Focus groups were the most inclusive method for children with and without disabilities, with flexibility in where they can be conducted (e.g. a cloakroom was used in one school with limited space). When children using speech generating devices participated in focus groups, children without disabilities often waited for a device user to respond prior to providing their own reply to a question and appeared to treat children with disability as an authority voice on any questioning related to disability and healthcare.

During one-to-one interviews, all children were very focused in their responses and did not deviate in discussions around the content of the questions. However, responses tended to comprise one word. No children with disabilities were allocated to one-to-one interviews. For the board game, only one child with a disability participated in the method. The child had CP with a mildly affected upper limb and used their unaffected arm to roll the dice and move counters during the game. All children without disabilities had no difficulty physically participating in the method. However, some children required further explanations from the facilitator regarding the instructions for how the game is played. There were also instances of disruptive behaviour from both male and female groups.

3.2.2 Reliability

It was possible to apply all of the methods in different settings, where methods were successful at gathering design information from children. For DLI's, the resultant outcome of the method included a prototype alongside responses to questions from the children. Not all children completed their prototype in the time allocated, and all participants used different combinations of materials during construction of a prototype (e.g., modelling clay, paper and pencil). However, the prototype served an equal function across participants, feeding into responses from the children, and allowing the researcher to ask questions that directly referenced the prototype (see Figure 6).

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 prototype at the same time)

Figure 6 Interview example

With the board game, the behaviour of the children fluctuated, with experience of disruption and distraction in two groups. Children appeared to enjoy participation in the methods, but this led to instances where responses were not in keeping with the question posed across all groups (see Figure 7):

Facilitator: What do machines that are from hospital look like?

Child1: Ok… squary pants

Child 2: Like cookies and that

Child 3: 17 minutes it's been…(looking at the display on the dictation machine)

Child 2: They look like those modern robots and that

Child 1: Who is green? (in reference to the board game piece)

Child 3: If it looks ugly… with a cherry

Figure 7 Interview example

3.2.3 Validity

Validating the responses obtained from the children was not possible in the context of the school visits, but has been relayed to children through an additional research project via an internet application, which has been reported elsewhere [42]. Validity of obtained information, when understood as an attempt to uncover meaningful information that can inform technology design, is not always possible to explore within the timeframe of a short research visit. The need to relay the information back to children, or utilise and embed into the design or development of a device prior to exploring the validity of information, limits the extent to which it could be explored in this research. However, a general note about the validity of the research process, rather than content obtained, was highlighted in the use of props and a prototype in the DLI. This allowed children to interact with materials from which their preferences were being drawn. For the children participating in the other three methods, only recall of preferences for materials and colours information was available to the children. The interaction with materials may impact the validity of responses obtained from children in the DLI. .

3.2.4 Efficiency

When examining the setup time for the DLI, a researcher was required to prepare a range of materials that could be used by the children to create low-tech prototypes, but often these were left unfinished. Figure 8 shows examples of such low-tech prototypes. The image on the left shows a child's design of a joystick, with the image on the right showing an unfinished design by the child who created a similar diagram (Figure 5) during the group task.

Figure 8 Examples of a low-tech prototype that was developed with a child during a DLI

The completion of all of the questions in the set list was used to define whether a method was completed within the twenty-minute time limit for running each interview method. Figure 9 outlines the proportion of complete and incomplete question lists for each of the four interview methods.

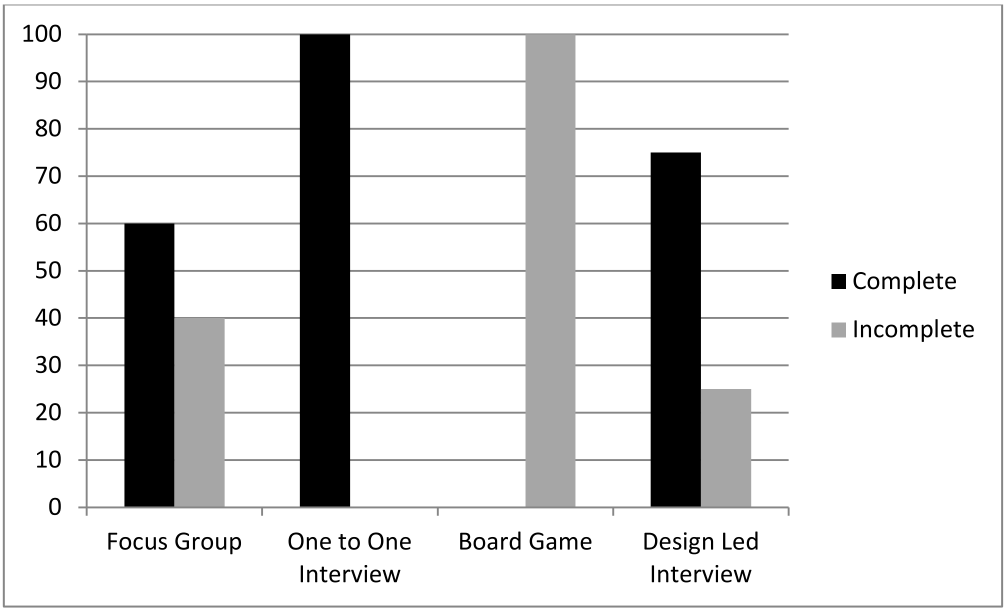

Figure 9 A graph to show the percentage question lists that were completed in the twenty-minute time limit by each of the methods

Children who participated in the one-to-one interview completed all of the questions in the twenty-minute period in each trial. This was not the case for the DLI and focus group, where the question list was not completed on a number of occasions, although the question list was not completed in any of the board game trials. Figure 10 shows the average time taken to complete question lists across the different methods. The board game took the longest average time for children to participate (20 minutes), the focus group took 18.44 minutes, the DLI 15.97 minutes, and the one-on-one interview took 11.89 minutes.

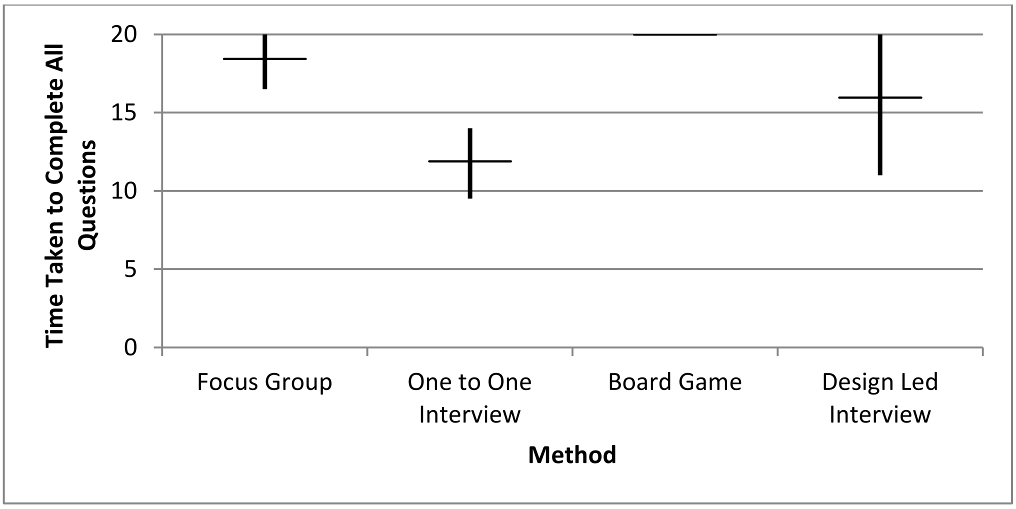

Figure 10 Average time taken to complete each of the different interview methods

To explore the quantity of information gathered from the interview methods, the number of obtained responses to questions was examined. In order to represent the average number of responses gathered per participant, all obtained responses (comprising statements or one word responses) were calculated. For groups comprising more than one child, the total number of responses gathered by a method was divided by the number of children participating. This was completed for each method, from which the mean figures are presented in Figure 10. The focus group was shown to gather the largest number 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 gathered fewer responses than the four-participant methods. Although the DLI (X = 1.29) gathered the least number of responses per question, there was only a small difference when compared to the one-to-one interviews (X = 1.36).

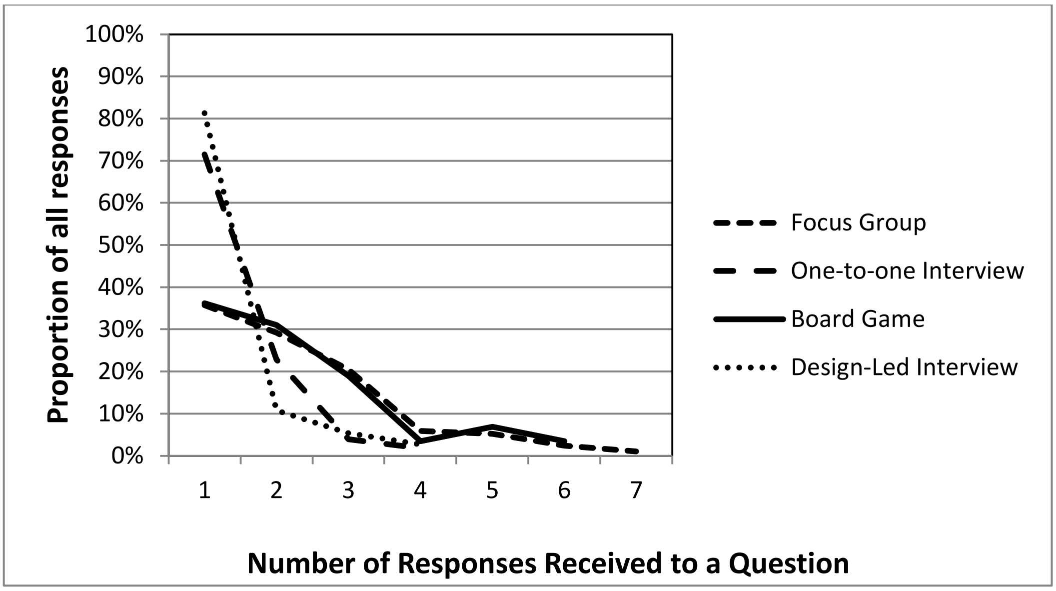

Figure 11 Graph to show the number of responses gathered from each of the interview methods

In order to investigate the number of responses gathered during the methods, the distribution of responses were examined by method. Figure 11 outlines 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. As shown in Figure 15, the methods involving one participant (i.e., the one-to-one interview and the DLI) commonly 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). The focus group gathered the largest number of responses to questions, with 1% of responses providing up to seven responses to a question.

3.3 Cost

Information was obtained to identify both the cost of involving the required personnel to host the research activities described in this paper, and also to identify the costs of resources needed for the interview methods. Costing for the personnel reflect wage costs incurred with all researchers in employment at the University of Leeds during the 2012 / 2013 academic year; costs across different universities can be expected to differ. Wages were calculated for each researcher based on full-time equivalent contracts (i.e., 1 FTE). Before an hourly rate was calculated, it was ensured that full economic costing (FEC) was completed for each of the researchers (shown in Table 4), including information about indirect costs, estates, and infrastructure. 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.

Post-doc mechanical engineering researcher	**Cost**
Salary	£27,319
Pension	£4,371
National Insurance	£2,013
Indirect Costs	£38,464
Estates	£14,828
Infrastructure	£842
Total Cost (for 1 FTE contract) per annum	£87,837
Hourly rate (including full economic costing, as calculated for 37.5 hours a week for 44 weeks)	**£53.23**
Post-doc mechanical engineering researcher	
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 (including full economic costing, as calculated for 37.5 hours a week for 44 weeks)	**£25.40**

Table 4 Overview of the wage costs for research personnel, including FEC

The number of hours spent on the trials multiplied by the hourly rate is shown in Table 5, providing a guide to the cost for involving the researchers in the trials held at each of the schools.

Researcher Role	Number of trials	Number of hours dedicated to research visits	Hourly rate	Total
PhD researcher (main author)	5	25	£25.40	£635.00
PhD researcher (undergraduate psychology student)	5	25	£25.40	£635.00
PhD researcher (PGCE student)	4	18	£25.40	£457.20
Post-doc mechanical engineering researcher (post-doc 1)	1	4.00	£53.23	£212.92
Post-doc mechanical engineering researcher (post-doc 2)	1	4.00	£53.23	£212.92
Post-doc mechanical engineering researcher (post-doc 3)	1	4.00	£53.23	£212.92
				Total cost: £2365.96

Table 5 Financial cost of involving research personnel in the use of the interview methods

The material costs of materials are also reported. The outlined costs include all materials required to perform the interview methods with a child in the school environment. The costs reported in Table 6 accurately reflect those incurred during this research.

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 6 Cost to provide materials for each of the interview methods used in the research

In total, the staff wage costs and the resources used for running the interview methods totalled £623.53.

3.4 Enjoyment

Alongside gathering self-reports of enjoyment from the children, the post-task questionnaire sought to establish areas of improvement in both the research process and the interview methods. The post-task questionnaire was completed by 86% of children, with completers rating their experience of participating in the group task and interviews as 'very good' (64%), with the remaining children selecting 'good' (17%), and 'O.K.' (5%). Reasons reported for not enjoying involvement related to the board game method when other participants were 'behaving badly' and that the pace of the game was consequently too slow. When answering the question, 'What do you think the word 'rehabilitation' means?' less than 5% of the participants provided an explanation of rehabilitation that was similar to descriptions provided by researchers at the beginning of the visit, with most being confused and / or incorrect. From the responses provided by those that were similar to 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', 64% of children reported having a disability, or knowing another person with a disability.

4.0 Discussion

The Markopoulos and Bekker [23] framework was used to inform criteria to be explored when comparing four interview methods for involving children in technology development research. To the authors' knowledge, this is the first reported application of the framework. Although originally developed for usability testing methods, the framework draws on characteristics that can be examined for methods used to involve children in the design of technology. The inclusion of additional items was driven by the need for greater transparency of the cost of involving users in healthcare research, and to counter trends failing to explore the impact of child characteristics in technology development research.

4.1 Application of the Markopoulos and Bekker framework

The findings from the framework provided insight into the process (robustness, reliability, efficiency, cost and self-reported enjoyment) and content (validity) of engaging children in healthcare technology development. A framework was used to guide examination of the involvement of children with physical disability in the design and development and healthcare technology. The focus remained on physical disability and did not include participants displaying cognitive impairment. A wider focus on considerations for involving children with intellectual disability in the development of healthcare technology is needed to ensure that group characteristics (such as reduced motor, communication and social skills and lower cognitive functioning than peers [43]) are adequately considered.

A key finding came from assessing the robustness of the methods, which revealed a need to explore alternative methods for involving children with physical disabilities in design activities and identifying alternative means of designing and developing prototypes for children with disabilities. This will allow the benefits of the DLI to potentially be extended to children with physical disabilities. For example, the direct reference to a prototype does not require recall of preferences, and direct references to materials being used during the methods can improve confidence over the validity of responses from children. Although this is not an issue when obtaining colour information, for which children have shown to be reliable in providing, children's memory for other preferences, such as those relating to texture, have not been examined [44] [45].

4.2 Addition of new criteria to framework

The addition of the cost criterion was to further support design research planning with children, such as method selection and cost projection. The need to report on the impact of UI has been increasing [2], and the inclusion of cost information in this research provides insight into the types of engagement that can be achieved in a primary school setting with a university research team. This information can be used to project costs in grant writing and also supply information to those evaluating the impact of UI in healthcare. However, this research did not account for the cost of planning and establishing links with schools, or costs that could be incurred when research is conducted away from the school setting (e.g. travel costs for participants and their families). Although guidelines exist for establishing links with schools in healthcare technology development research [26], the cost of this process is difficult to capture in financial terms.

Although the outline of financial cost for research may not always link directly to the purpose of a project, it does support the wider need to provide robust measurement around user involvement in research, which can be used to complement existing qualitative explorations [46]. In trying to reflect costs of the whole process, consideration of additional costs, such as resources, time and energy should also be considered [47]. The focus on costs in UI in healthcare research is an opportunity to inform the international evidence base underpinning UI activity that remains partial and lacks coherence [5], and begin to start compiling information on the impact and cost of UI, and the frequency, extent and magnitude of its application [2].

The examination of enjoyment was informed by self-reports by the child participants using a visual analogue scale that sought to verify whether participation in the methods were positive experiences for the children. The majority of children reported their experience positively, although it is common to find a positive response bias in research with younger children [48]. The inclusion of an enjoyment measure stemmed from the current lack of methods for assessing the engagement of children in research activities. Previous research [39] has described the state of ‘flow’ which occurs for an individual when they are engaged in an activity and reach an optimal state of performance, leading to a sense of enjoyment and control that is experienced when the skills of an individual are matched to the challenges of a task. In this sense, enjoyment can act as a proxy to inform whether research activities promote an environment that is amenable to engagement, and further research is needed to understand how this can guide the structure and content of research involving children.

Ensuring that children have enjoyed their experience of participating in research is important due to its bearing on the perception of research by children, their likelihood to participate in the future, and to infer that their contributions stem from a disposed and engaged perspective. Despite positive ratings of participation, and time spent by the researchers outlining the role of rehabilitation to the children, there was an inability of most participants to articulate the role of rehabilitation for a person with disability. This may indicate a need for further clarification about the way in which rehabilitation and the use of healthcare technology is explained to children. Whether an understanding of the concept is required by the children to allow them to provide meaningful insight for the design of technology is a question to be addressed in future research.

4.3 Applying findings from the framework

In this research, the DLI was the most time consuming to set up, the materials were most expensive, and few responses were gathered from questions. However, the use of props, which set is aside from the alternative methods, provides greater validity to the preferences obtained, as they were often in direct reference to materials being used by the children at the time. The board game, which also required set up time and comparably lower material costs, gathered several responses to each question. However, the interaction between the children led to instances of disruptive behaviour, and uncertainty over the validity of certain responses. With a high likelihood of a trade-off when selecting between methods for involving children using the framework, a development team should assign subjective weighting to the framework criteria. This is will guide its use when selecting between methods for involving children in the design and development of healthcare technology.

Criteria from the framework can be used to inform decision making in research with children by constructing a better understanding of the cost effectiveness of using competing methods. Considering the quantity and quality of information alongside the actual cost to obtain the information can provide a means of selecting methods for involving children in healthcare technology design and development. In this research, while the methods varied in the time taken to complete all questions, the number of responses obtained provides an indication of the quantity of information that can be obtained. This can be used as a metric to inform value judgements about the selection of a method on the basis of time to complete versus quantity of information obtained. The methods involving four or more children were found to generate a larger number of responses per child, on average, than methods involving only one child. Therefore, the methods involving groups of four or more children were often found to require more time to answer all questions, and often overran the twenty minute limit, despite generating a larger quantity of responses per child. Such information can be used to inform the planning of future projects by focusing thinking on the resource limits of a research team (e.g., financial, time), and which method(s) best extracts the quantity or form of responses required. With this in mind, future research needs to consider how to assess the quality of information obtained from methods. While some methods can elicit large quantities of information, the quality of these data is difficult to ascertain until it is evaluated. Currently, evaluation of information quality can occur through application of data to a product followed by an assessment of its effectiveness (e.g. ratings of device improvement following integration of user preferences), although this only assesses the quality of the data at a secondary level.

5.0 Conclusions

The use of the Markopoulos and Bekker [23] framework provided a focused assessment of interview methods for involving children in the design of healthcare technology. The criteria used in this research require further investigation to refine measures associated with efficiency and establish how best to assess thoroughness, to generate a framework that can expand to consider a wide range of user involvement activities in technology design. In this research, the technology demonstrated to children is. While user engagement methodologies are being used to elicit information across a range of healthcare technologies [10], the findings from this research outline the selection and use of methods for developing technology for physical rehabilitation, mainly for children with CP (such as joysticks and peripheral hardware to computer systems). The wider call for reporting of cost and reports of enjoyment by children can be applied across all user engagement research in healthcare technology development with children. As technology interventions increase in their application to healthcare, including with children, exploring the boundaries and need to expand a framework to assess the involvement of users with and without disability is crucial. Detailed analysis is promoted here with the aim of producing a unified approach to understanding how best to capture the perspectives of end users in the development of healthcare technology to ensure that it best serves the needs of children, and particularly children with physical disability.

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