Involving Children and Young Adults With Complex Needs in Game Design

Kathrin Gerling

University of Lincoln

Brayford Pool

Lincoln LN6 7TS, UK

kgerling@lincoln.ac.uk

Conor Linehan

University of Lincoln

Brayford Pool

Lincoln LN6 7TS, UK

clinehan@lincoln.ac.uk

Jonathan Waddington

WESC Foundation

Exeter EX2 6HA, UK

jwaddington@wescfoundation.ac.uk

Michael Kalyn

University of Lincoln

Brayford Pool

Lincoln LN6 7TS, UK

mkalyn@lincoln.ac.uk

Adam Evans

University of Lincoln

Brayford Pool

Lincoln LN6 7TS, UK

adevans@lincoln.ac.uk

Abstract

Involving young people with complex needs in game design can be a challenging research endeavor, particularly when working within a school context. In this paper, we discuss findings from two case studies where we worked with young adults with visual impairment, and young people with mobility disabilities. We focus on ethical challenges that emerged during the research process, and we discuss management strategies to foster the establishment of inclusive and engaging field research into video games for young people with complex needs.

Author Keywords

Participatory design; game design; complex needs.

ACM Classification Keywords

K.4.2 [Computers and Society]: Social Issues – *Assistive technologies for people with disabilities, Handicapped persons/special needs*; K.8.0 [Personal Computing]: General - *Games*.

Introduction and Background

Designing interactive technologies such as games for young people with special needs is challenging: it is important to ensure that systems are not only accessible, but also fun to use, providing a positive player experience. Participatory game design offers an

opportunity to empower players by involving them directly in the process of designing technology that will impact upon their lives [1]. It allows developers to tailor solutions to the specific needs and preferences of a participant group and is particularly useful when working with marginalised or under-represented user groups [5]. It has successfully been applied to develop assistive technology [4], and to explore the design of technology for young people with special needs in a classroom setting [2].

However, tailoring solutions to specific needs can introduce a number of challenges, some of which may only arise during the research process, and others being specifically associated with the context in which the research takes place, e.g., working in a school environment. For example, research participants will often talk with their peers about the game design sessions they have been involved in. While these interactions can be beneficial in allowing participants to reflect on their involvement, it may lead to feelings of exclusion for peers who have not been given the opportunity to participate.

In this paper, we outline two studies that take a participatory design approach to developing video games for children and young adults with complex needs. We then discuss ethical concerns that emerged in these studies as part of the participatory design process, and summarize core challenges to provide a foundation for further discussion of ethical concerns when directly involving young people with special needs in the development process of interactive technologies.

Involving Children and Young Adults With Complex Needs in Game Design

Involving children and young adults with complex needs in game design is the first step toward creating interactive experiences that are tailored to their needs and ideas. However, there are a number of challenges that we discuss through two recent case studies.

Case Study 1: Games for Young People With Neurological Vision Impairment
Neurological Vision Impairment (NVI) is a term that describes vision impairment caused by injury to areas of the brain that are responsible for visual processing. NVI detrimentally impacts upon quality of life. Daily activities such as reading are often significantly impaired. Visual search-based therapy strategies for NVI have recently been demonstrated as effective at improving functional vision. However, these therapies require participants to repetitively search an array of monochromatic on-screen stimuli in order to find target stimuli. Therapy must be undertaken in 30-minute sessions multiple times per week for a number of months. Adult stroke patients have previously demonstrated adherence to these types of interventions but this has not yet been demonstrated with children. This project explores the design of a game-based vision therapy programme that aims to support participant engagement and adherence [3].

PARTICIPANTS
Participants all suffer from cerebral visual impairment (i.e., visual impairment caused by damage to brain tissue), and additionally present a range of other related cognitive and physical disabilities. Our primary group of participants, with whom we held weekly sessions over the course of six months, were four

people (3 female, 1 male), aged 18-20, recruited through a specialist education center for learners with vision impairment. Two participants had an undiagnosed neurological presentation with associated developmental delay, learning, speech and language difficulties. One participant had been diagnosed with a tumour on the optic chiasm at 6 years old and had associated optic atrophy at the time of participating, with no light perception in the left eye and visual field loss in the right. Our fourth participant had a confirmed diagnosis of cerebral palsy and left hemiplegia and unconfirmed NVI. Two participants were legally blind and two were described as having low vision. A second group of participants consisted of three young people with acquired brain injury and suspected hemianopia who were part of a local community group organized by an occupational therapist. Each person in this group had relatively minor cognitive and physical impairments. Data was collected from these participants during a one-off design session that lasted approximately two hours.

The research was approved by the University of Lincoln School of Psychology Research Ethics Committee. Initial approach to potential participants was made by their college tutor. Candidates were informed about the study by a researcher who dictated a verbal information sheet, and gave formal consent by initialing (or placing a cross) in a large bold box under a transcript of the information.

RESEARCH APPROACH

Designing game-based therapy tools for people with visual impairments presents a number of significant challenges. For example, 1) Games must be challenging to be fun, but frustrating challenges could disengage people from therapy, 2) Accessibility guidelines for visually impaired users suggest designing to allow the use of other senses. However, therapy must force people to use their vision, 3) Games must be accessible and fun for people with a wide range of physical and cognitive impairments. A researcher met each participant separately, at fortnightly sessions over a three month period. Each session lasted between 20 and 45 minutes, during which time participants were observed play testing the game and were asked to provide feedback.

Case Study 2: Games for Children and Teenagers Who Use Powered Wheelchairs

To explore opportunities in motion-based game design for children and teenagers who use powered wheelchairs, we worked with a school that provides education for young people with special needs. Throughout the participatory design phase, our goal was to better understand how young people using wheelchairs perceive themselves with respect to video game play, their perceptions of motion-based games, and their thoughts on wheelchair-based game input.

PARTICIPANTS

Participants of this case study had a wide range of physical and cognitive abilities. We worked with two groups of children and young adults over the course of four months, during which we held a total of nine sessions. Participants were aged 14 to 22 (3 female). All participants used powered wheelchairs; medical conditions ranged from spinal cord injury as the result of accident to progressive neurodegenerative diseases and developmental conditions such as Cerebral Palsy. While most participants could express themselves through speech, one participant was non-verbal and

required the assistance of staff, and another participant applied assistive technology (iPad application generating speech) to participate in our design sessions.

The research was approved by the University of Lincoln College of Science Ethics Board. Our consent procedure included informed consent from parents which was obtained through the school, paired with assent from study participants that was renewed at each session.

RESEARCH APPROACH
Exploring the design of motion-based video games for young people using powered wheelchairs is associated with a number of challenges. On a very basic level, participatory design needs to understand how young people who use wheelchairs perceive themselves and their wheelchair in the context of game input – this requires careful exploration of their personal experiences, and may bring up negative emotions. Along these lines, the project also explored their relationship with physical activity – again, this could potentially bring up negative emotions, e.g., frustration if a participant used to play sports, but is no longer able to fully participate as a result of disability. Finally, creating games to be deployed in a school setting suggests that games need to accommodate wide range of abilities among users, in our specific case, that meant not just considering physical but also cognitive impairment. This may add another layer of complexity in the context of design as games need to be flexible to challenge players of all abilities, and requires additional exploration throughout the design process.

Ethical Challenges and Potential Management Strategies
In our research, we encountered ethical challenges that can roughly be categorized into three areas: (1) aspects related to formalities of research ethics and consent processes, (2) ethical challenges related to the design goals of the research, and (3) ethical challenges introduced by research setting.

(1) Formal Ethical Challenges
The process of informed consent to participate should in principal be a positive ongoing process from initial approach all the way through to exit from the study, and persons who want to participate in research should be given every opportunity to do so. Procedural ethics often requires participants to perform activities such as reading and signing forms that can be difficult for people with sensory, motor or cognitive impairments to do, and can act as a barrier for candidates who want to participate in research, for example, if persons with complex needs have limited ability to communicate their desires to researchers and staff, but their general behaviour expresses interest in the research activity. This can be a difficult issue to deal with in a school setting, and it is important to consider management strategies that help to avoid individuals feeling excluded from the activity.

Proposed management strategy: We found that it was immensely helpful to be prepared to offer alternative activities that did not contribute to our research project, but nevertheless gave those students who did not participate in our research project the opportunity of learning more about the work we do. While this requires extra time, and, potentially a little bit of extra planning, activities such as allowing students to explore

technology used in our current research (e.g., the wheelchair tracking system to be used as part of case study two), or games that resulted from previous projects, prove to be a valuable way of allowing everyone to feel included in the general research activity, an aspect which we feel is extremely important when carrying out research in a school setting.

(2) Ethical Challenges Related to Design Goals
Particularly regarding the design of games for young people with complex needs, there were two challenging aspects that repeatedly came up throughout our research process. First, with our research interest in disability, we are bound to make enquiries that relate to participants' personal situations, potentially exposing vulnerability. Second, particularly when designing games, challenging players is a core aspect of creating an engaging experience; therefore, some of our work needs to explore the boundaries of players and how to push these in meaningful way. By doing so, this creates another point in research at which vulnerability could be exposed [1], e.g., if participants feel that their disability limits their opportunity of dealing with game challenge.

Proposed management strategy: When working with young people with complex needs, we need to consider carefully the level and points of involvement of end-users in the development process. Direct involvement potentially empowers players, but also exposes them to various risks. In this context, it is important to carry out risk assessment to identify potential pitfalls, liaise with staff to help invite individuals who are likely to be able to cope with questions raised as part of the research process, but ultimately be prepared to look into alternatives to consider end-user needs rather than

direct involvement, e.g., working with experts during general requirements analysis that touches upon potentially difficult topics, and involving end-users during later stages of development, e.g., when assessing player experience.

(3) Ethical Challenges Introduced by Research Setting
During our research, we learned that when working with groups of mixed abilities, it can be difficult to adequately address all participants and facilitate an engaging research process, for example, if some individuals require time to express themselves as a result of their impairment, and other participants grow impatient to voice their opinions. Along these lines, we observed some instances of behaviour that would disrupt the group unintentionally, and later on introduce difficulties when data was to be transcribed, e.g., if one participant had a vocal tic. Additionally, we experienced instances during which the discussion got carried away by participants, which is generally desirable in the context of participatory design, but also led to unanticipated exposures of vulnerability, e.g., with one participant pushing another one on his disability when discussing views on powered wheelchairs in the second case study. Finally, if participants can only be part of the research when supported by their carer who acts as interpreter, this may introduce challenges as participants should be given opportunity to express themselves, yet contributions to the research might be subject to the carer's interpretation.

Proposed management strategy: In our work, we learned that it was beneficial to be flexible in terms of research methodology, e.g., to offer focus groups for some individuals, and engage others through individual

interviews to allow them to express themselves without pressure that may be experienced in a group setting. Furthermore, we found that working with staff to identify groups of participants that would work well together was a helpful approach. In this context, it can be challenging to consolidate the goals of the research (i.e., obtaining high-quality data, and enabling participants to speak for themselves) with an ethical and inclusive research process that invites participation from individuals with all abilities, and researchers are challenged to make responsible case-by-case decisions in collaboration with staff, carers, and participants.

Conclusion

Working with young people with complex needs in the context of participatory game design is a challenging activity. While the involvement of users during game development is an extremely valuable research opportunity, it also introduces a number of challenges that need to be addressed by researchers, designers, and also through the involvement of carers, and liaison with other domain experts. We hope that this paper outlined some of the core challenges when working with young people with complex needs in a school setting, and we hope that it can contribute to the discussion of participatory design in this field.

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