Strategic Use of Technology in Research with Youth with Autism: Ethical Implications

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ABSTRACT

This paper will specifically be focusing on the potential ethical problems behind the use of technology in participatory methods namely creative video ethnography and online participatory ethnography. These methods will be deployed as part of my research with The Lab, a network of after-school technology clubs for youth with autism, to understand how these young people socialise with and within differentiated spaces. Differentiated spaces will be referred to as physical, online and psychosocial spaces. Due to the participatory nature of the research, the ethical concerns are multilayered, from traditional research ethical issues such as informed consent to dilemmas around the use of immersive technological platforms and participant ethics. These concerns, while speculative as the research is still in its infant stages, can be anticipated and will be discussed in this paper along with the broader methodological and ethical issues concerning the use of novel methods.

Author Keywords

Participatory Methods, Autism, Differentiated Spaces, Immersive Technology, Ethics

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Ethical concerns surrounding research involving minors or people with disabilities have largely focused on the well-being of individuals and their capacity to give informed consent. These groups of people have often been labelled "vulnerable" as their impairment or maturity are likely to impede their "capacity to understand what the research entails" which correlates to their in/ability to give consent (NHMRC, 2007). They may also be susceptible to "experience greater burden [emotionally]" in comparison to non-disabled persons or adults due to lack of comprehension, researcher-participant power relations, stigmatisation, communicative particularities, etc. (Yan & Munir, 2004). Despite these concerns, the research community has widely recognised the value in conducting research with

minors and people with disabilities and has continually sought to develop methods and strategies that would engage these groups of people without compromising their well-being. The emergence of participatory research and the incorporation of technology, for example, can be seen as new ways to engage people in research, particularly individuals in the abovementioned groups. However, these strategies present new ethical challenges that will be discussed in this paper in relation to my research.

My research works with The Lab, a network of technology clubs for youth with autism, to understand how *differentiated spaces*, specifically referring to physical, online/digital and psychosocial spaces, enable these young people to socialise and engage beyond the perceived limitations of their disability (Ng et al., 2015). Individuals with autism have often been associated with communicative "deficits" and repetitive behaviour that hinder their sociality (Baron-Cohen, 2004). However, youth at The Lab have evidently been able to socialise with other participants as well as neurotypical individuals such as mentors or stakeholders within and out of the sessions (Donahoo & Steele, 2013). An evaluation of The Lab attributed this success to two main factors: the use of technology and the unstructured nature of the sessions (Donahoo & Steele, 2013). Informed by the evaluation and led by a transformative paradigm, I have developed a qualitative participatory research design which incorporates the use of technology in its administration. However, the marriage between participatory research and the use of technology has presented new ethical challenges from participant ethics to the use of immersive technological platforms (i.e. Game spaces). The following sections will discuss the methods and their ethical implications.

PARTICIPATORY RESEARCH METHODS

Participatory research methods have been associated with the transformative paradigm where the aim is to empower participants through some form of active engagement or dialogue throughout the research so as to allow effective and accurate communication of perspectives. (Banks et al., 2013; Mertens, 2015, p. 31-33). According to MacLeod et al. (2014), participatory methods have been widely used within autism research as they "sought to overcome barriers to [research] participation" for individuals on the spectrum who have been deemed as "problematic" within traditional research settings (eg. Interviews) due to their communication particularities. This is echoed by other researchers within the field of autism studies such as Lewis (2009) and Bagatell (2007) who conducted participatory research with autistic

individuals through engaging participants in a consultative process which I will largely apply as the framework to my research. Stone and Priestly (1996) highlight that structures of traditional methodology invoke unequal power relations between the researchers and their participants, particularly in the case of disability studies. They propose that the participatory paradigm may redress some of these power dynamics and enable researchers to engage in meaningful research with disabled participants (Stone & Priestly, 1996). I will specifically be discussing two participatory methods which will be used in this research.

Creative Video Ethnography

Video ethnography specifically relates to "participatory video", defined as "an iterative process, whereby community members use video to document... issues that affect their environment" (Corneil, 2012, p. 19). Members of The Lab will first be taught different filming and editing techniques to inject elements of fun, learning and creativity – aligning to the aims of The Lab. Then, participants of the research will be be asked to film snippets of The Lab sessions as a form of documenting their experiences within this environment. They may choose to video conversations between members or narrate their own activities and experiences at The Lab. Finally, together with the participants of the research, we will stitch the videos together through a consultative process at the end of all the filming sessions to create a narrative and further our understanding of the culture of socialisation within the specific Lab site.

Online Participatory Ethnography

Online, digital or "virtual ethnography" is an adaptive form of ethnography using digital tools within an online community (Fielding et al., 2008). "Participatory" in this case refer to two different aspects of participation. Firstly, this online participatory ethnography will be conducted in an ongoing consultative process. Secondly, instead of studying an established online environment which is often the case in virtual ethnography, participants will be requested to participate in building this online environment.

To align this research with the interests of the youth at The Lab, I have chosen to conduct this part of the research within a familiar game space called Minecraft. Minecraft is a 3D sandbox simulation game which allows users to build landscapes and items through placing and breaking blocks (Minecraft, 2015).

Participants will have the choice to engage in free-form gameplay or complete a selection of optional tasks within a dedicated, multiplayer server. They will also be asked to give feedback during the sessions about their experience online, their interactions with other players as well as the tasks set by the mentors or myself. Participants are encouraged to give suggestions on how to improve the game space and report incidents that happen online (eg. Cyberbullying). The aim of this method is to understand cooperative gameplay within the online and physical spaces. How do participants engage with others online? Do they communicate beyond the online space if given the opportunity (such as engaging in gameplay during the physical sessions of The Lab)?

While these participatory research methods present opportunities to engage participants and aggregate more accurate accounts of their perspectives, they also present ethical challenges including participant ethics and the use of immersive technology.

ETHICAL IMPLICATIONS

Banks et al. (2013) identified six broad themes relating to ethical challenges in community-based participatory research: (1) Partnership and power relations, (2) Blurring boundaries between researcher and the researched, (3) Democratic representation, (4) Ownership and dissemination of data, (5) Anonymity, privacy and confidentiality, and (6) Institutional ethical review processes. These ethical concerns are not only applicable to this research but also provide a general ethical guideline for participatory research. However, they are not specific to methods and do not address concerns around the administration of data collection. This would particularly be problematic when assessing the use of novel methods in participatory research as data collection involves varied levels of uncertainty. Hence, I refer to Banks et al (2013) guidelines as part of the first two of three tiers within this research's ethical framework. The first tier aligns itself with traditional research ethics and is primarily concerned about the well-being of individuals as illustrated in (5) and (6). The second tier is concerned about the overall methodology, in this instance, the participatory paradigm as seen in (1), (2), (3) and (4). The final tier, which is the primary focus of this paper, is concerned with the specific methods previously mentioned and its use of technology. In this tier, while ethical challenges cannot largely be generalised to other research projects since the methods and technology determine the concerns, it sheds light to the possible outcomes as to how the administration of research methods may affect the research and its participants. This three-tier, multilayered ethical approach may be useful in evaluating other research projects as it provides flexibility in its evaluation which may be particularly applicable with the emergence of new research methods and technology. It is important to note that while I have deliberately discussed this research's ethical concerns in three tiers, they overlap and are not mutually exclusive from one another.

Professionalism and Participant Ethics

Although the participatory paradigm encourages inclusive active engagement, the nature and conduct of research is exclusive to only participants who have given informed consent (Fox, 2013). This institutional barrier presents significant problems within the setting of The Lab where members would consist of both participants and non-participants of the research.

As previously mentioned, the methods of this research were developed to assimilate into the culture of The Lab. They value the learning and use of technology which are the common denominators of all activities across The Lab. However, through giving or declining informed consent to the research, members would have seemingly

included or excluded themselves from activities since the research runs concurrently with the normal sessions. This poses several ethical implications. Firstly, members of The Lab may feel coerced into participating in the research for fear of being left out during the process of the research as it would be difficult to distinguish The Lab's activities from research activities. Secondly, and more pertinently, it may create tensions between participants and non-participants. For example, if a participant was enthusiastically filming the sessions, will it be appropriate to video non-participants who are members of The Lab that make up part of his or her experience nonetheless? Can this data be used for analysis then?

In this case, professionalism not only applies to the researcher but also to participants who have to adhere to certain ethical guidelines and code of conduct. They need to be advised as to who they can or cannot film and how they should approach a non-participant if they require assistance. Professionalism is a skill and a set of values, behaviours and attitudes embedded within a profession (Smith, 2006). Hence, to set up a guideline for research participants, we can adapt the ethical and moral codes from other professions that perform similar tasks – the key is keeping them simple. In this case where the task of research participants involves filming, it could be useful to borrow certain codes of conduct from journalists such as being respectful and sensitive to interviewees (eg. Avoid racial, gender or sexual slurs) or tasteful in the choice of filming content (Carlson and Lewis, 2015). Overall, the goal is to induce a sense of professionalism and pride amongst research participants who have personal agencies and are active contributors to the research.

To achieve this goal, training sessions will be held to teach participants videography and professionalism at the same time to translate guidelines into practice. A specialised release form – similar to those given out by journalists - stating that a non-participant has agreed to be video recorded for the purpose of research on a specific date could also be used to educate participants on the ethics of videography in research.

Ethical challenges in using technology within participatory methods are therefore beyond simply the researcher's responsibility. Participants need to be appropriately educated in their ethical responsibilities as well since such participatory methods give more autonomy and control to participants in steering the direction of the research. As it may be difficult to establish the codes of conduct for novel methods, one useful way is to borrow different guidelines from other professions that may be applicable.

Use of Immersive Technology: Gameplay vs Research
According to Johnson and Levin (2009), virtual worlds and game spaces are inherently immersive. They are not only "highly social environments" but are also "richly expressive environments that immerse participants in the setting" through visual and sound cues, textures and realistic perspectives (Johnson & Levine, 2009). By blurring the lines between research and immersive

gameplay, it may compromise both the well-being of the participants as well as the integrity of the research due to deception.

Although participants will have given informed consent before they are able to access the research game space, the immersive nature of virtual spaces may lead them to forget the purpose of gameplay for research. Instead, they may engage in full-fledged gameplay that disregards the ethics of research. Participants, for example, may utilise the game space for obscene or other non-sociable activities such as sabotaging and cyber-bullying which occur frequently within such game spaces (Donahoo & Steele, 2013). These activities may not only compromise the validity of research data but may also threaten other participants' well-being within both the online space and The Lab.

Aside from inappropriate activities, participants may also feel deceived or spied on within these spaces without an established distinction between gameplay and research despite giving informed consent. The inability to fully separate The Lab's activities from research activities (since the latter was meant to upkeep the spirit of the former in the first place) is a cause for ethical concern which needs to be addressed.

One possible solution of migrating this ethical risk is to create a virtual "gate" before entering the game space that reminds participants of their involvement in the research. Although this may be compared to other online agreements such as the acknowledgement of terms and conditions on social networking sites where they are seldom read or remembered, the repetitive and interactive nature of the virtual "gate" where a set of short and simple fun facts and questions about the research and their well-being will be randomised each time they enter the game space may be able to enforce the values of the research on the participant through, once again, tailoring to their interests. Still, with the immediacy of online technologies where a click of a button would bring you to your destination, the solution of a gateway illuminates other problems with using technology to gain informed consent in research that is unprecedented, particularly with vulnerable populations such as youth with autism. However, these unprecedented issues should be expected when administering novel methods. The key is how as researchers we mitigate these problems and create a safe and vibrant environment for our participants and research. To do so, I recommend to integrate traditional ethical frameworks such as the guidelines set up by Banks et al. (2013) with applicable codes of conduct from relevant industries. In this case, the administration of games and social networking sites may be my point of reference.

CONCLUSION
While participatory methods through the use of technology sought to subvert traditional power relations particularly in research with young people or persons with a disability, it also presents new ethical dilemmas as discussed in this paper. As Rachael Fox (2013) points out, participatory methodologies require "careful critique" around and beyond "social and institutional barriers" to create a more comprehensive understanding

of what it means within ethical frameworks of research to be *participatory* and if *participation* is necessarily beneficial to research, particularly for youth or people with disabilities who are more vulnerable to unprecedented circumstances.

In considering the ethics of novel participatory methods in my work with youth with autism, we must look beyond the traditional ethical frameworks (first tier) and the overarching paradigm (second tier). Specific research methods need to be carefully examined through varied lenses (eg. professions and industries) particularly in its use of technology to comprehend the complexity of ethical challenges that surround contemporary research.

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