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Digital technologies for supporting the informed consent of children and young people in research: the potential for transforming current research ethics practice

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Abstract
Much research at the intersection of technology and ethics focuses on the impact of technological developments and innovation on wider society. This discussion considers the intersection of ethics and technology from the opposite direction; that is, how technology itself can support the ethical participation of people – particularly children and young people – in research. Our central argument is that the use of digital technologies (laptops, PCs, tablet devices, smartphones) offers the potential to support the presentation of information about research topics and methodologies, and children's decision-making about their own participation, more effectively than by traditional, often paper-based, methods.

Informed consent with children and young people

Informed consent in research is one of the fundamental principles of good ethical practice for researchers across all disciplines. The ESRC's Framework for Research Ethics (FRE) (2010; p.28) defines informed consent for research participation as:

> *...giving sufficient information about the research and ensuring that there is no explicit or implicit coercion...so that prospective participants can make an informed and free decision on their possible involvement.*

Children and young people are crucial informants and participants in many research projects and have a right to express their views in matters that affect them (UNCRC, 1989; Article 12). However, there are debates about whether and how children's informed consent can be appropriately gained (Wiles et al., 2005), leading to their exclusion from some research (Dawson & Spencer, 2005). This is especially true for children and young people who have additional support needs due to disability, special educational needs, and / or language comprehension and expression (Lundy, 2007). Consequently, those who are amongst the most vulnerable are often the least likely to be given opportunities to express their views about matters which are important to them, suffering a 'double denial' of their right to be heard (Lundy, 2007p.935). In other words, they are denied expression and participation: firstly because they are children, and secondly because they are disabled.

Guidance regarding children's participation in research emphasises the need to support children's understanding of the research process by tailoring methods and information appropriately (ESRC, 2010; Department of Health, 2001).For example, Dockett and Perry (2011) and Christiansen and Prout (2002) consider the importance of consent as a process rather than a one-off 'tick-box' exercise at the beginning of research projects. Others, (e.g.

Alderson & Morrow, 2004) provide guidance about 'child-friendly' features for providing 'accessible' information, such as using plain language, larger font size and incorporating images; online resources offer useful exemplars of such materials (www.lancs.ac.uk/researchethics/index.html; www.ethicsguidebook.ac.uk/; http://www.easyhealth.org.uk/content/about-website). Whilst younger children are less likely to fully understand their rights when participating in research (Hurley and Underwood, 2002); there is some evidence that presenting information in more accessible formats (including shorter sentences; use of bullet points; increased font size; and pictures) improves 7-10 year old children's understanding of the material, compared to a group that received a 'standard' form (Tait et al., 2007).

Nevertheless, research into the comprehension of research information for children and young people is rare (Lewis, 2010). The examples that do exist tend to be oriented towards medical / clinical contexts and content (Tait et al., 2007; Williams et al., 2011), and exclude children with disabilities (Hurley & Underwood, 2002) and / or comprehension difficulties (Tait et al., 2007). Moreover, there is a widespread tendency to assume that informed consent information (the familiar 'information sheet' for participants), and the process of gaining consent that the information sheet supports, is presented and negotiated as a paper-based exercise, often including the requirement for a child to write or sign their name on a consent form to indicate their agreement. In a world where digital technologies (laptops, PCs, tablet devices, smartphones) have transformed communication as well as the presentation of, and access to, information, this practice seems surprisingly anachronistic and exclusive.

Interestingly, technology of any kind is rarely mentioned in the research and guidance included above and certainly no specific examples of technologies being used in the informed consent process are provided. Research that has explored and developed technology-based presentation of information for consent purposes is, again, very rare, tends to be clinically oriented (cancer research) and with a focus on adult respondents (Wright, 2012; Kim et al., 2008). Thus, there is a significant gap in knowledge and practice with regard to the role that digital technologies could play in transforming current research ethics procedures and approaches for children and young people, including those with learning difficulties and disabilities.

The affordances of digital technologies in supporting informed consent with children and young people

Dye *et al.* (2003) suggest that comprehension, decision-making and communication capabilities are key factors that can impact on the capacity of people with learning disabilities to give consent to take part in research. These factors are likely to be just as important and applicable when the participant is a child or a young person, with or without a learning difficulty or disability. Applying these factors directly to the involvement of children and young people in research, we suggest there are three main dimensions of participation for children and young people in which digital technologies could play an important role, and these are discussed further, in turn, below:

(1) *accessibility* of information presented for improved comprehension;
(2) *motivation* to take part in the research*;* and
(3) *competence and autonomy* to make and express an informed decision.

(1) Accessibility of information presented

Digital technology has the capacity to improve the accessibility of research information provided to potential participants in ways that go significantly beyond the presentation of materials in shorter sentences, larger font sizes, and images for paper-based leaflets. Digital technologies afford the possibility of presenting written text in ways which can be easily transformed and customised according to individual needs, including font size, type and colour, as well as the background colour on which the text is presented. Being able to customise these aspects of written text can make a significant difference to readers with specific learning difficulties (Morphy & Graham, 2012) for example. In addition, many people, without a specific difficulty or diagnosis, have been documented as experiencing visual stress, which can be alleviated through changing the colour contrasts between text and background (Singleton & Henderson, 2007; Smith & Wilkins, 2007). For other users, the addition of graphical symbols, or the replacement of some of the text with symbols, can greatly enhance understanding (Abbott, Detheridge & Detheridge, 2006). This is possible rapidly and efficiently through the use of technology tools, although the eventual product may be paper-based. Thus, presenting or producing even simple information electronically could improve accessibility for a wide group of potential participants.

Written text can also be accompanied or replaced by audio instructions or narratives, for example through the use of text-to-speech technologies, or the recording and supply of relevant audio clips. These audio files can be replayed, paused and slowed down to enable children and young people to check and update their own understanding of the information provided, which can be very powerful in aiding comprehension (e.g. Lange et al., 2006; Parr, 2012). In addition, text and audio that describes or explains a research project can be accompanied by short video vignettes or scenarios to illustrate, for example, which members of the research team the child is likely to meet or what a focus group or an interview actually looks like in practice. This facility for presenting audio alongside images also works both ways: not only can participants be told about or shown different aspects of the research without the need for written text, but they can also provide verbal responses (if appropriate) which can be video or audio-recorded. In other words, the role of technology can be to record verbal assent or dissent, as well as the discussion about the research that precedes it. Thus, the benefits of presenting research information to participants via technology rather than via traditional paper-based means are cognitive and sensory, as well as practical.

Touch interfaces could be particularly powerful in supporting a wide range of involvement of children and young people, including those with learning and physical disabilities, because a touch interface is easy to understand and does not add unnecessary complexity to the learning process. For example, a touch interface is more accessible than numerical keyboards because, if configured appropriately, the interface can be visual rather than text-based. The rapid development of tablet technology, and the availability of Windows 8, has brought touch technology within the reach of all research projects. Technology-based research supports the engaging and communicative benefits of touch technologies; for example Inkpen et al (2005) found that users engaged in more pointing, made more preparatory statements and made more on-task comments when an information display was horizontal (as with a tablet PC or smartphone) than when it was vertical (as with standard PCs or laptops). Kruger et al (2004) also found that the orientation of information in touch technologies was important in determining comprehension, coordination and communication. Specifically, they found that users rotate text or images to help with

comprehension, making text easier to read (making the task easier) or to have an alternative perspective. Finally, and crucially, the principal advantage of direct-touch interfaces is that they are more natural and intuitive for users (Shneiderman, 1982; Ryall et al., 2006) which may make people feel more motivated to use them.

(2) Motivation to participate in the research

Macfarlane (2009) argues that overly legalistic wording of research information within the social sciences could deter potential participants because it could be seen as unfriendly and suspicious. This is something to which children and young people are likely to be particularly sensitive given that they may be very unfamiliar with being approached by University researchers regarding involvement in research. The language and formality of paper-based information sheets and consent forms, even with efforts at accessibility, may feel alienating and odd. By contrast, today's generation of children are being reared on touch technology, and these technologies are increasingly being used with pre-school children. Notably over 80% of the top selling paid Apps are targeted towards children, with 58% targeting pre-school children (Shuler, 2012). Children and young people are, therefore, very likely to have expertise, experience and affinity with touch technologies, particularly smartphones and, in some cases, tablet technology such as iPads and other mobile touch-interface devices. Through using these as a means to communicate about research, we may encourage participation through giving validation to the technology of choice of children and young people.

Additionally, children and young people who may struggle with motivation and participation in other ways are likely to find digital, visual media more engaging (Carrington, 2007). Walker (2008) suggests this is because digital media reflect youth culture, and this further enables young people to manage and explore their identities (Nind *et al.*, 2012). Indeed, Nind and colleagues (Clarke *et al.*, 2011; Nind *et al.*, 2012) found that engaging young women with behavioural, emotional and social difficulties in developing digital comic strips for presenting consent information about their project was highly effective in supporting their knowledge and participation in the research. The prevalence of personalised and portable smartphone and tablet technologies, and their widespread use by children and young people (Rideout et al., 2010), makes them ideal tools for presenting research information to potential participants, not least because young people say internet and mobile technologies offer them greater control over social interactions and given them time to 'stop and think' about their responses (Madell & Muncer, 2007).

(3) Competence and autonomy in decision-making

Nind (2009; p.7) notes that *'researchers can take positive action to increase capacity [to consent]'*. Similarly, the Department of Health (2001) presumes that:

> *'...many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process'* (DoH, 2001:4).

Consequently, there is an onus on researchers to develop appropriate methods to achieve informed consent which can scaffold understanding in order to encourage and maintain voluntary and positive participation. This includes careful consideration of what information about the research is provided and how it can be tailored effectively to meet the information needs of particular children or groups of children (Dockett & Perry, 2011; Wiles *et al.*, 2005). The presentation and accessibility of the information itself is covered above; in addition,

researchers need to consider how children can be reminded and supported over time regarding their rights to participation and withdrawal.

In this regard, touch-screen technologies such as smartphones and tablet devices offer a direct, familiar interface for many children and young people that can be used for supporting and recording decision-making both at the start, and during the research process. For children for whom written or spoken responses may be problematic, demonstrating choice through touch offers an important avenue for autonomous decision-making. In addition, video / audio capture of responses (both verbal and non-verbal) can be easily achieved via digital technologies and revisited as many times as necessary throughout a project to check or aid understanding and memory.

An additional inclusive affordance is around location/presence – many of these technologies are with their 'owners' at all times, whereas previous technologies (PCs, laptops) were sited – and 'owned' – by the school or home. Not only could this be an important feature in helping children to make individual and autonomous decisions, but such 'ownership' (even if temporary within the context of a research project) also offers social kudos for young people trying to protect their image and vulnerable identities (Nind et al., 2012). Digital technologies are therefore likely to be valuable for presenting initial information about research to participants and their families, and also for providing opportunities for capturing visual records of decisions and choices if consent is negotiated over time (Dockett & Perry, 2011).

Some cautionary notes

Of course, as well as the potential that digital technologies may offer in this context there are important cautionary factors that must also be considered. Firstly, the governance of research ethics at Universities, including the requirement for research activities to be insured, means there has been an increasing formalisation of the process of gaining informed consent from research participants (Wiles et al., 2005). This includes an expectation that consent to participate should 'typically' be signalled by a written signature, which is also recommended by the ESRC's Framework for Research Ethics (2010):

> *'...the information should be provided in written form, time should be allowed for the participants to consider their choices, and the forms should be signed off by the research participants to indicate consent' (p.28).*

Whilst alternative means of providing consent are permissible (e.g. verbally recorded; gained post hoc) it is clear in the ESRC's guidelines that these are cases that would require the highest level of scrutiny by committees. We are also currently undertaking a scoping exercise of ethics information provided on University websites (to be reported in due course) and have found that in many cases there is an explicit expectation that informed consent is signed / written (with alternatives being considered as exceptional). Consequently, it is unknown to what extent Universities might be willing to accept alternative means of demonstrating consent such as touching a response option on a screen; selecting a symbol; using eye-gaze technology to signal a decision; or video footage of discussion about the research. However, we suggest that if an appropriate audit trail can be established irrespective of the type of response made the Universities are likely to be more persuaded to trust and accept alternative modes for committing consent decisions. This could be achieved

by storing logging data (e.g. Burton & Walther, 2001) alongside video or photographic records of pointing to or touching a particular response option. Crucially, a positive response consenting to participation can be reviewed and checked at the start of each contact if research takes place over time. Just as with 'traditional methods' for consent, options to dissent or withdraw from the research should also be displayed with equal valence and revisited on repeated contact (if the research design allows for this; Dockett & Perry, 2011).

The valence of response options (attraction or aversion to a specific object or event) regarding participation is the second main area which could give rise to concern. Specifically, the motivational and attractive features of personal digital technologies which might make children and young people feel interested and engaged in their content, may also risk becoming too persuasive. This could mean that children and young people may not feel, or may not be sufficiently aware, that they can exercise their choice to say no to participation. Berdichevsky and Neuenschwander (1999) present a framework for the ethical principles of persuasive technology design, the first principle of which is that:

> *'The intended outcome of any persuasive technology should never be one that would be deemed unethical if the persuasion were undertaken without the technology or if the outcome occurred independently of persuasion.' (p. 52)*

In other words, the same considerations relating to the fundamental principle of beneficence in research ethics (benefits should outweigh harm) applies here too. In addition, Berdichevsky and Neuenschwander (1999) rightly emphasize that it is the creators of the 'persuasive technologies' who must assume responsibility for their use and the creators '…should never seek to persuade a person or persons of something they themselves would not consent to be persuaded to do' (p.52). We fully agree with this and propose that there is some important research to be carried out in this area that systematically investigates the nature of decision-making by children and young people using traditional and technology-based methods.

Conclusions

Overall, we suggest there is a compelling evidence-based rationale for incorporating digital technologies in informed consent processes for children and young people (and others) asked to take part in research. At the simplest level this rationale is based on the ability to easily and quickly customise the colour and size of text and images in order to improve the accessibility of research information. At a deeper level, the affordances of touch, portability, and video and audio capture and replay available through tablet PCs and smartphones, may support comprehension, motivation and engagement with the information presented. This, in turn, could encourage greater autonomy in decision-making and participation in research, which will offer important insights into children's views and experiences. Currently, there are very few available examples of how technologies have been used in this context and we suggest this is an area ripe for exploration and development, not least to explore the extent of the concerns and cautions that may exist as well as the potential positive benefits. Inclusive design with children and young people, including those with disabilities, is a crucial next step (cf. Abascal & Nicolle, 2005) alongside opportunities for greater sharing of exemplars and practice in this area.

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