

Article

## The Potential of Digital Technologies for Transforming Informed Consent Practices with Children and Young People in Social Research

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### Abstract

How children and young people understand and exercise their autonomy, engagement and decision-making is fundamental to learning how to become active and engaged citizens, and to be socially included. Digital technologies are increasingly an integral part of children's everyday lives and, therefore, valuable tools for supporting social inclusion. This paper discusses how digital technologies might positively support autonomy, engagement and decision-making through the lens of informed consent practices within social research. Current research practices are dominated by paper-based methods for obtaining informed consent which could be exclusionary for children and young people generally, and children with additional learning and support needs in particular. Digital technologies (laptops, PCs, tablet devices, smartphones) offer the potential to support accessibility and understanding of ideas and activities, as well as engagement with and autonomy in decision-making and participation. This paper explores this potential as well as the challenges that researchers may face in this context.

### Keywords

children; digital technologies; ethics; informed consent; participation; voice; young people

### Issue

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### 1. Introduction

Children's cultural worlds (at least in developed Western countries) are changing at a rapid pace, reflecting and responding to technological advancements in personal and mobile computing (Rideout, Foehr, & Roberts, 2010). Children and young people's access to information, social communication and interaction, as well as play and creativity are being transformed through increasing access to digital technologies (laptops and PCs, tablet devices and smartphones). For example, in a wide-ranging report from Ofcom (2014a) detailing UK children and adults' confidence with, and use of, digital technologies in their everyday lives, research showed that 14–15 year olds had the highest levels of technological knowledge and confidence in

digital technologies across all of the age-groups surveyed. The report also highlighted that 6-year-old children are as confident as 45-year-olds in their use of technology. Moreover, children are more enthusiastic about, and reliant upon, technologies than adults, showing greater knowledge and awareness about technologies and advocating for their use amongst their friends. Notably, in a conclusion from the press release from Ofcom to accompany the report, it was highlighted that: 'As a result of growing up in the digital age, 12–15 year olds are developing fundamentally different communication habits than older generations' (Ofcom, 2014b).

Such fundamentally different communication habits have important implications for social research, and social researchers, who aim to promote social inclusion by seeking and understanding children's views and ex-

periences. As Farrell (2005; p. 177) reminds us: ‘real-world research...acknowledges the reality of children’s everyday lives’. In this context, then, real-world research into the reality of children’s everyday lives must include consideration of the important roles that digital technologies may or may not play (Parsons & Abbott, 2013). Fundamental to respecting children’s rights to have their voices heard in decisions that affect them (UNCRC, 1989, Article 12) is also their right to ‘share information *in any way they choose*, including by talking, drawing or writing’ (UNCRC, 1989, Article 13; my emphasis). With the strengthened role of children (and parents’) participation in decision-making in the revised Special Educational Needs and Disability Code of Practice in England (Department for Education/Department of Health, 2015), it is very timely to consider *how* such decision-making can be meaningful and authentic, especially for children who may access literacy and communication in different ways.

This paper considers the potential of digital technologies for supporting these rights in the context of decision-making about research participation, especially when the potential research participants are children and young people with additional learning and communication needs. If children and young people are to be included in important social research that values and promotes their views, experiences and preferences then children first need to be supported to understand and access information about what their research participation means, so that they can learn to exercise their autonomy i.e. to give their informed consent. It is argued here that paper-based methods for communicating with children and young people about research may be exclusionary or inaccessible for some children and young people, and that there is potential for researchers to support understanding, engagement and participation of children and young people through utilising the positive affordances of digital technologies. The paper first considers the current state-of-play with regard to gaining children’s informed consent for university-based research participation and the guidance available for researchers in this context. This is followed by discussion of some of the proposed positive features, or affordances, of digital technologies for supporting the accessibility of information, as well as children and young people’s motivation, competence and autonomy with respect to research decision-making and participation. The cautions and challenges inherent in the application of digital technologies to this field are then discussed, followed by conclusions that point towards the need for participatory design approaches with children and young people to gain their views and ideas.

## **2. Informed Consent with Children and Young People in Social Research**

Informed consent in research is one of the fundamen-

tal principles of good ethical practice for researchers across all disciplines. In social research, the Economic and Social Research Council’s Framework for Research Ethics (ESRC, FRE) (2015; p. 29) provides detailed guidance about ethics review and governance at universities in the UK, and 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.’

Typically, at least within universities in the UK, the ‘giving of sufficient information’ is managed by writing information sheets that summarise key aspects of the project, such as what participation entails, the voluntary nature of participation, and how data are stored. The ‘informed and free decision’ made by participants is then usually recorded by a signature on a written consent form so that an audit trail about non-coerced involvement is established. The argument is that such processes protect the participant, the researcher and the institutions involved. Guidelines such as those by the ESRC (2015) also set minimum required standards that should be met in this regard (e.g. the topics and questions that should be addressed in a participant information sheet). However, the extent to which such processes do in fact provide ‘sufficient information’ so that the decisions of participants are ‘informed and free’ is highly contested. For example, concerns have been raised about the cultural and social assumptions embedded in paper-based communication and signed forms (White & Fitzgerald, 2010). Hamid (2010) describes his research in rural Bangladesh, where participants with limited literacy were sent a ‘participant information package’ (p. 265) and asked to sign a written consent form for their children’s participation (processes designed according to the expectations of the institutional research ethics committee). Although signatures were obtained and the consent forms returned, Hamid (2010) confesses that it is difficult to know who signed the forms and whether participants comprehended what was involved.

In addition, some authors have questioned whether participation information sheets really tell people what they need or want to know about research participation, not least because the wording of information sheets may frame research studies in ways that may be off-putting to research participants (Brooks, te Riele, & Maguire, 2014). Indeed, Macfarlane (2009) argues that such forms may be exclusionary because of expectations about their content from research ethics committees. Grayson and Myles (2005) illustrate the problem by demonstrating that the response rate to a survey was substantially reduced when participants received a

more 'legalistic and impersonal' (p. 298) introductory letter and consent form (whose wording complied with institutional requirements) compared to a more personalised and informal one. Brooks et al. (2014) concur with this challenge, noting that: 'the way in which information is presented to potential respondents is not neutral...the formality of some initial consent procedures may alienate some groups, particularly those who are vulnerable' (p. 95).

Indeed, Brooks et al.'s (2014) above comment highlights that concerns about the presentation of research information become magnified and more complex when the involvement of (so-called) 'vulnerable' groups is mooted (Parsons, Abbott, McKnight, & Davies, 2015; Sikes & Piper, 2010); 'vulnerable' groups usually include children and young people and others with potentially reduced capacity to consent such as the elderly, and people with learning disabilities or mental health difficulties (ESRC, 2015). The concerns about free and informed consent arise in relation to these groups mostly in relation to the potential for the abuse of power (knowingly or unconsciously) through participants feeling pressure to participate and/or not really understanding what they are participating in or why their participation is necessary (Cameron & Murphy, 2007; Flory & Emanuel, 2004; Stalker, 1998).

Children and young people are crucial informants and participants in many research projects and, as noted earlier, 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 (Jones & Stanley, 2008; Wiles et al., 2005), leading to their exclusion from some research (Dawson & Spencer, 2005). There are concerns that the insistence of formal procedures and particular forms of wording, often required by ethics committees, can exclude children from research. For example, Scott and Fonseca (2010) discuss a research project where the researchers planned to involve 5–6 year old children as participants; the ethics committee insisted that children be given, and asked to sign, written information sheets and consent forms that were not accessible to them. The children's school principal objected to the formality of the process but the ethics committee would not change their recommendation. As a result, the research was completed without the involvement of the children—a vital group of stakeholders whose views the research was designed to gather (Scott & Fonseca, 2010).

Such concerns about understanding of rights and processes are especially true for children and young people who have additional support needs due to disability, special educational needs, and/or language comprehension and expression (Cuskelly, 2005; 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, 2007; p. 935). In other words, they are denied expression and participation due to doubts about their competence to make decisions and give informed views: 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, 2015; Department of Health, 2001). For example, Dockett and Perry (2011) and Christensen 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 (e.g. [www.ethicsguidebook.ac.uk/](http://www.ethicsguidebook.ac.uk/); <http://www.easyhealth.org.uk/content/about-website>). While younger children are less likely to fully understand their rights when participating in research (Hurley & 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, Vopel-Lewis, & Malviya, 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, augmented by discussion, often including the requirement for a child to write or sign their name on a consent form to indicate their agreement (Parsons et al., 2015; Parsons, Sherwood, & Abbott, in press). For children whose sensory, learning and communication needs may preclude them from accessing written or printed text and images, it is reasonable to assume that the presentation of research information using such forms will be inherently exclusionary for them (Wright, Sheehy, Parsons, & Abbott, 2011). In a world where digital technologies are continuing to transform communication as well as the presentation of, and access to, information, the practice of using paper-based forms seems surprisingly anachronistic and potentially exclusionary.

Indeed, technology of any kind is rarely mentioned in the research and guidance included above nor by the

guidance provided to researchers by research intensive universities in the UK (Parsons et al., 2015); certainly no specific examples of technologies being used in the informed consent process are provided. Although there are some social researchers who report using more technology-based methods for supporting informed consent with children and young people in research (Parsons et al., in press), these methods are rarely reported in the literature and are certainly not common (see Flewitt, 2005, for an exception). Wright et al. (2011) even report that researchers with significant expertise in the development and application of assistive technologies for communication and learning used 'accessible' paper-based forms for supporting the informed consent process rather than the technologies that formed the substantive foci of their projects.

This lack of exploration and use of different methods for supporting the informed consent process led Parsons et al., (in press) to conclude that innovation in informed consent practices with children and young people is much needed because 'the increasing bureaucratization of research ethics governance within UK universities has reified expectations about the methods used to gain informed consent for research participation.' In other words, paper-based information and processes of communication tend to dominate practices because that is what university research ethics committees expect, and this can curtail risk-taking or creativity that researchers may otherwise wish to exercise (Nind, Wiles, Bengry-Howell, & Crow, 2013).

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, Young, Neimeyer, Baker, & Barfield, 2008). One of the few examples of research that has sought children and young people's views directly about how research information should be provided, and informed consent from children and young people sought more effectively, also comes from the context of clinical research (Spencer, Boddy, & Rees, 2014). Spencer et al.'s (2014) research included a small number (c. 18) of children and young people attending mainstream schools and colleges, aged 9–18, in one-off workshops where they were shown a short film showing a (fictional) clinical consent procedure in action and asked to discuss the ethics considerations from their perspective. Among the many useful insights from these young people, it was clear that many favoured the use of videos and websites as ways of communicating with them (and their parents) about research. In addition, the children and young people:

'reiterated their preference for a dialogue and meaningful relationship with the research team across the research process. Identifying ways in which researchers can build trust and respect with young

people in research would appear key to adequate information provision, and points to a pertinent area for future research'. (Spencer et al., 2014, p. 37)

Thus, there is considerable scope for considering how such meaningful relationships can be initiated and maintained, and how researchers can build the trust and respect needed in order to communicate effectively with young people about research. Digital technologies should be considered as potentially playing an important role in this respect. However, opportunities for cognitive and sensory scaffolding of understanding and responding via digital technologies, as well as their potential for engaging interest in participation, have been significantly underexplored in relation to informed consent procedures with children and young people. In the spirit of the innovation called for by Parsons et al. (in press) the following section considers some of the features—or affordances—of digital technologies that may be helpful for communicating and supporting children's decision-making about, and participation in, research.

### **3. Some Potential Affordances of Digital Technologies in Supporting Informed Consent with Children and Young People**

Dye, Hare and Hendy (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, suggests there are (at least) 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.

These categories, and the examples that are used to illustrate them, are by no means intended to be definitive or exhaustive, but offer a starting set of possibilities from which ideas can be further developed and discussed.

#### *3.1. Accessibility of Information Presented*

Digital technology has the capacity to improve the accessibility of research information provided to poten-

tial 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 basic 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). Thus, presenting or producing even simple information electronically could improve accessibility for a wide group of potential participants.

For other participants, the addition of graphical symbols, or the replacement of some of the text with symbols, can enhance understanding (Abbott, Detheridge, & Detheridge, 2006; Detheridge & Detheridge, 2013; Jones, Long, & Finlay, 2007), especially for children, young people and adults with autism and/or learning disabilities who already have some familiarity with symbols (Miranda, 2003; Poncelas & Murphy, 2007). Importantly, Zentel, Opfermann and Krewinkel (2007) demonstrated that the presentation of information for people with learning disabilities using a combination of text + symbols + speech produced the highest levels of understanding. In other words, information made more sense to individuals when they were shown the information in a simplified form and this was accompanied by a verbal explanation. This links closely with the feedback from Spencer et al.'s (2014) participants noted above who emphasised that decision-making about research participation needs to take place in a dialogue rather than simply within an information transaction; something that is also strongly echoed by other researchers (Crow, Wiles, Heath, & Charles, 2006; Nind, 2008).

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, McPhillips, Mulhern, & Wylie, 2006; Parr, 2012). In addition, text and audio that describes or explains a research project can be accompanied by short video vignettes or scenarios (Flewitt, 2005) 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 facili-

ty 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.

Certainly, the potential for the use of video in supporting informed consent processes in research was acknowledged and supported by the participants in Parsons et al. (in press), who were all social researchers (with varying levels of experience) working with children and young people in their research. Participants suggested that videos could be especially helpful for enabling parents and children to jointly view, and discuss, what the research entailed rather than relying on parents to give or translate information intended for young people via paper-based forms. This is also in line with the feedback from the young people in Spencer et al.'s (2014) research who recommended that video could play an important role in supporting discussion between parents, young people and the researchers. Given the widespread availability of video record and playback on tablets and smartphones, video production and access has become much more accessible and easy to use in recent years, making this kind of approach much more feasible than even a few years ago.

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, early research demonstrated 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; Inkpen et al., 2005). Kruger, Carpendale, Scott and Greenberg (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 perspec-

tive. Moreover, the principal advantage of direct-touch interfaces is that they are more natural and intuitive for users (Ryall, Morris, Everitt, Forlines, & Shen, 2006; Shneiderman, 1982), negating the need for lengthy training or familiarisation periods, which may make people feel more motivated to use them and engage in the material presented via them.

There is certainly emerging research evidence that even young children (4–5 year olds) are natural and intuitive users of touch screen technologies, finding them enjoyable and easy to use in the classroom (Clarke & Abbott, 2015). Teachers also report being able to use touch screens (via iPads) to support differentiated learning in class (Clark & Luckin, 2013), highlighting the value of such a flexible tool in helping to meet the additional learning needs of less able children. Clarke and Abbott (2015) also report teachers' observations that children seem to have a greater *readiness* to engage with literacy and numeracy when supported with structured iPad apps, alongside the more 'traditional' input from teaching assistants and full class teaching using whiteboards. These findings suggest that children and young people may be more willing to engage with ideas, and understand them more effectively, when presented via touch screen devices rather than via paper-based methods, although of course there is a need for much more research in this area to explore and observe this potential (Clarke & Luckin, 2013).

### 3.2. 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. Within clinical research, Dawson and Spencer (2005) go further in raising concerns about current research practices regarding informed consent for vulnerable groups, arguing that 'children will be harmed, as vital research will not be performed' (p. 235) because the expected wording on information sheets is too complex and off-putting. This is something to which children and young people may be particularly sensitive given that they are likely to be unfamiliar with being approached by university researchers seeking their involvement in research (Danby & Farrell, 2005). The language and formality of paper-based information sheets and consent forms, even with efforts at accessibility, may feel alienating and odd. Given the increasing prevalence of, and familiarity with touch technologies noted above, children and young people are very likely to have expertise, experience and affinity with touch technologies, particularly smartphones and, in many cases, tablet technology such as iPads and other mobile touch-interface devices in a way that adult researchers may not (Parsons et al., in press). Through using these devices as a means to communicate about research, we may therefore en-

courage 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 and Logan (2008) suggest this is because digital media reflect youth culture, and this further enables young people to manage and explore their identities. Indeed, Nind and colleagues (Clarke, Boorman, & Nind, 2011; Nind, Boorman, & Clarke, 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 (Ofcom, 2014a; 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). The researchers interviewed by Parsons et al. (in press) also indicated that the ability for children to answer consent questions electronically, in their own time, was a valuable and positive feature of portable technologies.

The asynchronous affordance of communication via digital technologies has also been shown to be valuable for those with social and communication difficulties, specifically people on the autism spectrum. Asynchronous communication refers to the ability to send or post a message online and for someone to be able to read and respond to the message in their own time i.e. an immediate response is not needed in the same way as in the context of face-to-face communication. For example, Benford and Standen (2009) interviewed 23 young people and adults with autism about their online communication preferences and found that many preferred the visual anonymity and asynchronous, flexible nature of their interactions. These features helped people to feel more in control of conversations and, therefore, empowered to engage in social interactions on their own terms. Brosnan and Gavin (2015) report similar findings through exploring young autistic people's use of Facebook; respondents reported finding online communication easier because there is less pressure to understand non-verbal social cues and there is time to think through replies.

### 3.3. 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, p. 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, Heath, Crow, & Charles, 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 (cf. Crow et al., 2006; Nind, 2008).

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. At this stage, these suggestions are largely hypothetical although many researchers agreed that these were positive affordances of digital technologies and some (a small minority) reported using social networks to recruit, and maintain communication with, research participants (Parsons et al., in press).

An additional inclusive affordance of portable digital technologies is around location/presence; portable technologies are of course situated 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). Moreover, Clark and Luckin (2013) in reviewing the evidence regarding the use of tablet technologies to support learning report that the individual ownership, and scope for personalisation, afforded by such devices are 'highly motivational' for children (p. 11). 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 individual visual records of decisions and choices if consent is negotiated over time (cf. Dockett & Perry, 2011).

#### 4. Challenges and Cautions

Of course, no discussion about the role of digital technologies in children's lives would be complete without appropriate acknowledgement of the concerns that also arise. The different communication habits between children and adults reported by Ofcom (2014a, 2014b) have also raised concerns about the extent to which children are using technologies and whether this is acceptable and safe. For example, media headlines in the UK have questioned whether children need a 'digital detox' (Woollaston, 2013, no page numbers) and even whether smartphones are making children 'borderline autistic' (Espinoza, 2015, no page numbers); research has also discussed concerns about children's vulnerability and safeguarding online especially in the context of using social media (Weeden, Cooke, & McVey, 2013). Indeed, the public nature of social media (e.g. Twitter and Facebook) is inherently at odds with the confidential or anonymous nature of much research. This means that considerable care needs to be taken with establishing the privacy settings when using such platforms and ensuring that users are aware of the boundaries. Appropriate use of such platforms, with clear planning and support, is nevertheless feasible; for example, Kurtz (2009) describes the careful use of Twitter within his primary school classroom as a way of strengthening home-school communication. He discusses the measures taken to protect pupils' privacy but also notes the valuable learning opportunity about privacy issues created through the use of Twitter in this context.

Concerns about online safety and vulnerability tend to become amplified when children and young people are deemed as more vulnerable or at risk than others (Livingstone & Brake, 2010). For example, Lough, Flynn and Riby (2015) argue that children and adults with autism are at more risk online due to their offline difficulties in social communication and understanding of others' intentions. The Wirral Autistic Society (2015) appears to confirm this in a report about the high level of 'mate crime' reported against people with autism, when their social vulnerability is exploited by others (although the report available is very short and not peer-reviewed). Such concerns give rise to important discussions of the challenges involved in keeping children safe online and how children understand consent regarding the decisions they make (Byron, 2010); as well as balancing the risks of online interactions against the benefits (Livingstone & Brake, 2010), especially in the context of the undeniable strength of social change and expectations inherent in children's use of technologies (Ofcom, 2014a).

Of course, access to technologies in the home and at school varies substantially and is governed by social and economic factors, as well as adult perceptions and decisions about appropriateness (Plowman, McPake, & Stephen, 2010; Thomas, O'Bannon, & Britt, 2014). This means that it may be undesirable, impractical and even unethical to assume technologies can be a part of informed consent processes in some contexts and for some participants; the use of technologies may, therefore, in itself be exclusionary. In addition, the power of adults (teachers and parents) as gatekeepers in the processes of informed consent and research participation must be acknowledged and should not be underestimated (Brooks et al., 2014). The generational divide revealed between children and adults in Ofcom's (2014a) research only serves to add further complexity to these power dynamics, especially if there are different preferences and expectations from adults and children about how information is presented and communication takes place.

However, as Parsons et al. (in press) note, the use of technologies in the informed consent process can be an option that is available rather than the only means of communication with children and families; researchers should not be the initiators of children and young people joining social networking sites (for example). Moreover, as Livingstone and Brake (2010) argue, any risks of using social networking are also balanced by opportunities and 'for most children, social networking affords considerable benefits in terms of communication and relationships' (p. 80). Byron (2010) also cautions that most children are unlikely to experience harm online and that a more balanced debate about children's use of technologies is needed. There is certainly a need to find out from more children and young people what would be appropriate and acceptable in terms of how researchers could and should be communicating with them about research in ways that reflect generational differences in communication (Ofcom, 2014a), and respect children and young people's skills in 'different mediums of communication' (Morrow & Richards, 1996; p. 100). The fact is that children *are* using, and increasingly expect to be able to use, portable digital technologies for communication and interaction; researchers must take these experiences and preferences seriously to understand how the appeal of technologies can be harnessed positively to support understanding, participation and decision-making.

It is also essential to acknowledge, in line with the young people in Spencer et al.'s (2014) research, that decision-making needs to be understood as part of a discussion or dialogue between young people, parents/caregivers and the researchers. Likewise, comprehension of information is not as straightforward as improving accessibility by being able to increase the font size or add images to text (cf. Zentel et al., 2007) but rather depends upon interaction and negotiation in

the context of trusting relationships (Cuskelly, 2005; Nind & Seale, 2009). It is not the intention to suggest here that simple tweaks to presentation of information, via digital technologies, will by themselves support improved comprehension and autonomy. However, it could be that simple tweaks, in conjunction with different modes of engaging with information (e.g. via social networking and websites), which can be multi-vocal (including parents and teachers as well as children and young people) and easier for children to understand and navigate, could be a more effective starting point for scaffolding research relationships and comprehension than traditional paper-based methods.

The governance of research ethics at universities in the UK, including the requirement for research activities to be insured, also provides an important part of the context about how informed consent information is presented, and a decision recorded, so that there is an effective audit trail (ESRC, 2015; Wiles et al., 2005). This includes an expectation that consent to participate should 'typically' be signalled by a written signature, as noted earlier (ESRC, 2015). While 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 full justification and, therefore, a higher level of scrutiny by committees. 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, 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 another 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. Wright et al. (2011) discuss this issue in the context of ensur-



ing ongoing consent during research projects that involve engaging digital content. They caution that researchers need to take extra care to 'make clear delineations between private, public and research spaces' (p. 4) and to remind participants that their interactions and responses are being recorded.

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). This is a position strongly endorsed by this paper and it is clear 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 (paper-based) and technology-based methods in order to better understand how the use of technologies can be used to navigate the line between motivation and persuasion or coercion.

## 5. Conclusions

Overall, there is a compelling rationale for incorporating digital technologies in informed consent processes for children and young people, including those with additional support and communication needs, 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 so 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 positive benefits. Universi-

ties, researchers and research funders all have roles to play in developing and sharing approaches to this important area of research, and critically investigating and reporting the strengths as well as limitations of different methods. An online Observatory of research exemplars, with critical reflections and commentary would be a good starting point for this: a space where researchers can make public their creativity and innovation in research ethics methodologies and share good practices. A separate and dedicated space is needed because there is very limited reporting of research ethics methods in social science peer-reviewed journal articles (Peled & Leichtentritt, 2002) or sharing of examples and practices at the university level (Parsons et al., 2015). Targeted research is also needed to examine the extent to which children and young people, including those with disabilities and a range of communication needs, comprehend and remember the information that is given to them when they are approached for research participation. Compared to the social sciences, there is much more scrutiny of informed consent materials and practices and methods in medicine and health sciences (e.g. Tait et al., 2007), and so it is timely for social researchers to use the societal push towards increasing technology use as an opportunity for research and debate in this area.

In addition, there is considerable scope for much wider public engagement to better gauge and reflect the understanding and expectations of members of the general public, including children and young people, about the presentation of research information and how ongoing research participation can be effectively communicated and supported. Inclusive and participatory technology design processes with children and young people, and their families, would be a very valuable next step (cf. Abascal & Nicolle, 2005) for informing what may be possible, as well as socially acceptable, in this regard. Children and young people have substantial knowledge and expertise to contribute to this arena and we need to hear more from them. For example, universities could establish valuable outreach or public engagement activities with schools and organisations to routinely include children and young people in checking and advising on the accessibility and appropriateness of research ethics methods and information in research that plans to involve children and young people. Such activities could help to identify key principles and practices from the perspectives of children and young people about the things that matter to them. As social science researchers interested in the 'reality of children's everyday lives' (Farrell, 2005, p. 177), this is the very least that we can do if we are serious about pursuing high quality research that has relevance and impact for children and their families.

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### Conflict of Interests

The author declares no conflict of interests.

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