

Safety and Ethics in Technological Participatory Health Research with Adolescents

Children have participated in design processes for a long time, and as techniques have evolved their voices have been better heard thanks to participatory design.

T. Ugras et al., 'New co-design techniques for digital game narrative design'

Chapter Highlights

1. The existing evidence about the impact of technology on children and adolescents is conflictive.
2. Ethical principles of offline research may not be applicable to online and technologically mediated research.
3. The development of ethical guidelines is not happening as fast as technological changes are and therefore there may be a delay or gap between both.
4. Respecting the autonomy of adolescent participants and balancing these with the policies, guidelines and demands of different stakeholders (adults, legislations, jurisdictions) is still a huge challenge.
5. Ethics is not static. It should be adapted to the ethical, cultural, social and developmental abilities of every participant. Special consideration should be given to vulnerable populations and those with complex needs.

Involving children and adolescents in research requires a reflexive, responsible and ethical commitment. I am an advocate of including adolescents in research that is about them; however, researchers have a duty to carefully assess the purpose of their involvement and the possible harm and benefits of doing so. This exercise needs to happen very early on, as it will determine many of the following decisions that will guide the study design and subsequent execution and dissemination. Ethics is also fundamental in technological, participatory health research with adolescents.

Kennan and Dolan (2017) believe that involvement of children and young people should not be the outcome of arbitrary decisions; careful consideration should be given to what constitutes harm and benefit and that it does not lead to exposing participants to exploitation and harm (Society for Adolescent Medicine, 2003). On the other hand, being extremely concerned about protection can instead 'silence' the voices of adolescents and deny society the possibility of generating knowledge informed by the experiences and perspectives of adolescents (Kennan & Dolan, 2017). Finding the perfect balance is, therefore, challenging.

Determining benefit and harm may also not be an easy task. According to Kennan and Dolan (2017), the lines between the likelihood of achieving benefit versus harm are usually blurred. This is particularly the case with social research, as the damage may not be immediately visible as it would with medical research. Emotional distress may happen because of intruding in people's lives or if the participant did not enjoy the research experience, particularly if the outcome was opposite to their wishes and views (Kennan & Dolan, 2017).

Expectations for participants (and their families or carers) must be managed; this means being transparent about study limitations which are beyond the control of a researcher (Kennan & Dolan, 2017). The research can change over time; however, researchers have an obligation to be open and transparent. If, for example, the purpose of the research is purely to enhance adult understanding, this needs to be explicit from the start (Stafford et al., 2003).

In most cases, parents have the best interest of their children at heart and are concerned with their physical, psychological and economic well-being (Rogers et al., 1994). In some circumstances, however, this might not be the case. Adults are usually the gatekeepers of adolescents' lives and, as such, researchers must respect this and work in collaboration with them to gain access to their population of interest but also understand the parental wider social context and their own views of safety and ethics. The Society for Adolescent Medicine (2003) considers that parents and communities are the entities in charge of protecting adolescents, therefore they should be respected, as well as included and informed, while acknowledging and respecting adolescent autonomy. All stakeholders should agree and accept the ethical measures in place.

Due to these clear challenges of balancing and getting it 'right' and setting adequate ethical boundaries, a chapter on the ethics of adolescent health research using technology is pertinent as there are few direct provisions, regulatory frameworks and data protection guidelines for

children and adolescents. Those available rely heavily on parental consent and make no distinction between adolescents and children (Berman & Albright, 2017).

3.1 Ethical Principles

Ethical behaviour could be slightly subjective and dependent on several factors such as context, culture, religion and historical time. There are several ethical guidelines available; for example, the American Psychological Association recommends that, as a minimum, psychologists who conduct research should inform participants about 1) the purpose of the research, expected duration and procedures; 2) participants' rights to decline participation and to withdraw from a study; 3) factors such as potential risks, discomfort or adverse effects; 4) limits of confidentiality (data coding, sharing, archiving); 5) incentives for participation; and 6) contact details. The British Psychological Society also has a code of human research ethics. Academic institutions and professional colleges also have their own ethics committees and ethical guidelines that researchers and professionals must adhere to. There are some ethical principles which are applied to research almost globally and it is good practice for researchers to adhere to them, for example the Belmont Principles.

3.1.1 *Belmont Principles*

The Belmont Report consist of three ethical principles (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1978; hereafter 'The National Commission', 1978) that were submitted in a report known as 'Research Involving Children' which was submitted to the US president in September 1977. At the time, these principles were applied to gene therapy clinical trials with children but have permeated almost all contexts of ethical considerations applied to research studies (Nagai et al., 2022).

3.1.1.1 *Respect for Persons*

The principle of respect entails treating a person as a person (Hodges et al., 2023). It includes two ethical convictions. The first one is that all individuals should be treated as autonomous agents and the second is that any individual who experiences diminished autonomy is entitled to protection (The National Commission, 1978). This principle requires that

individuals enter research voluntarily and with adequate information (The National Commission, 1978).

3.1.1.2 *Beneficence*

Beneficence states that research participants must be safe from harm and enjoy benefits from involvement and a reasonable balance between both (Hodges et al., 2023). This principle also means securing participants' well-being (The National Commission, 1978).

3.1.1.3 *Justice*

Justice entails the risks and benefits of research in the general population to consider the inclusion and exclusion criteria of research subjects (Hodges et al., 2023). An injustice occurs when a person is entitled to a specific benefit and is denied it, or a burden is imposed unduly (The National Commission, 1978). To support beneficence and justice, research questions must matter to participants and benefit their communities (Hodges et al., 2023).

According to the Belmont Report, informed consent is required to ensure individuals are fully informed to decide what happens, or not, to them. Information should be presented in an organised manner considering the individual's level of intelligence, rationality, maturity, language and capacities (The National Commission, 1978).

Incomplete disclosure is only acceptable if it is necessary to accomplish research goals, there are no undisclosed risks that are more than minimal and there are suitable plans in place for debriefing participants. A clear difference should be defined between when disclosure may destroy or invalidate the research and when it is simply an inconvenience for the researcher (The National Commission, 1978).

3.1.2 *Declaration of Helsinki*

The World Medical Association (WMA) developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects and identifiable human material and data from June 1964. The Declaration is clearly targeted at medical research; however, the ethical principles can be useful and applicable to research in other fields. It states, for example, that the researcher has the duty to protect life, health, dignity, integrity, right to self-determination, privacy and confidentiality of personal information belonging to the research participants (WMA, 2008). The Declaration also states that research should conform with scientific

principles and have a guiding research protocol submitted to a research ethics committee. Research must avoid harm to the environment. Potential risk and burden to participants should be assessed and justified if included in research. The benefits should outweigh the risks. Researchers must give consent to provide their data and data management procedures should be in place (WMA, 2008).

3.1.3 Gillick Competence and Fraser Guidelines

Other examples of ethical guidelines, which are very applicable to research in health, are the Gillick competence and Fraser guidelines. The Gillick ruling informs English law regarding children's competence. It does not state an age, but it defines a competent child as one who 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and has 'sufficient discretion to enable him or her to make a wise choice in his or her own interest' (Gillick, 1985, cited by Alderson, 2007, p. 2273). The Society for Adolescent Medicine (2003) emphasised that adolescents who experience chronic illness have been through choices and experiences which have challenged them to have increased capacities.

The Gillick competence and Fraser guidelines consist of a legal case about whether doctors should be allowed to give contraceptive advice or treatment to girls under 16 years of age without parental consent (NSPCC, 2018). Specifically, in 1982, Victoria Gillick used the services of her local health authority and the Department of Health and Social Security to stop doctors providing contraceptive advice to girls under the age of 16 without parental consent. The claims were dismissed but the Court of Appeal reversed the decision. In 1985, this was taken to the House of Lords and Law Lords which supported the original judgement. This indicated that the capability of an adolescent to provide consent depends on their maturity and the nature of the consent (NSPCC, 2018). The adolescent should have the maturity to understand what is involved and have the capacity of making their own decisions (NSPCC, 2018).

3.2 Evaluating and Determining Participant Competence

One of the challenges researchers have is identifying the level of 'competency' in research participants. This is usually determined informally (Schelbe et al., 2014). Competency is a multifaceted concept consisting of the interaction between age, maturity, cognitive ability, moral development, psychological state and social environment (Schelbe et al., 2014).

Competence is a fundamental construct that needs to be explored when considering seeking consent in children and adolescents. According to Alderson (2007), researchers have an initial presumption of children as incompetent. It is challenging for children to question those views from adults, and demonstrating competence over incompetence can be even more challenging (Alderson, 2007).

Competence in health research can have very specific characteristics. As Alderson (2007) argues, children and adolescents who have experienced adversity may have more knowledge, skills and courage than their peers or even adults who may have not experienced serious disability or illness in their lives. Children's competence and autonomy develop through personal experiences and not as a direct consequence of age or physical growth (Alderson, 2007). Alderson et al. (2006) described how children with diabetes, for example, were more advanced than their peers in terms of child development theories. Four-year-old children with diabetes were able to understand the importance of controlling their illness and made decisions towards their best interest. These children were aware that their health depended on their informed commitment (Alderson et al., 2006). Children and adolescents need to be fully informed about procedures, particularly the ones that may be painful or frustrating; otherwise, they may be overwhelmed with fear or anger (Alderson, 2007). This 'sense-making' process should be mandatory, whether consent is being requested or not. Children and adolescents should be informed about the nature, purpose and possible effects of the intervention, as this may reduce misunderstandings and fear.

Alderson (2007) described some of the standards to evaluate competence in a person giving consent:

1. Capacity to understand the relevant information.
2. Ability to retain the information.
3. Capacity to weigh the information to make a reasonable choice.
4. Possibility of making voluntary and autonomous decisions.
5. Ability to communicate the decision.
6. Ability to believe the information.

These criteria are useful; however, they may need to be considered carefully with children and adolescents. For example, for information to be understood, it needs to be explained in an age-appropriate manner. Some children and adolescents may be better with their communication skills, and this may mean they are better at explaining their thoughts and emotions. Others may struggle more to communicate but this does not mean they do not understand the information to make informed decisions.

Chapter 2 described the need to train adolescents in research skills so that they could effectively engage in the research study. Kennan and Dolan (2017) added the need for ethics training, whereby adolescents involved as researchers can learn about their responsibilities towards keeping research participants safe from harm.

Another important component of assessing competence is evaluating the skills and competences of practitioners and researchers who are requesting consent. For example, are they themselves sufficiently able to work with children, adolescents and their parents? This entails being able to help them understand relevant information, resolve misunderstandings and assist them in making informed and reasoned decisions, without putting pressure on them (Alderson, 2007).

3.3 Informed Consent in Health Research

Participant information sheets and consent forms are the most basic and widely used tools of applied ethical principles. These documents are summaries of the research in lay language, which include details about 'the ask' of participants, potential risks of participation, as well as possible sources of support and contact details if they experience distress because of participating in the study. These forms are usually compulsory for academic and clinical research and are widely used. An age-friendly version of these documents can be adapted to the needs and comprehension levels of different ages of children and adolescents. Assent instead of consent is usually sought for those participants under the legal adult age. Seeking children and adolescents' assent to participation in research is valid and important as it has been demonstrated that even young children are able to understand the basic components of research (Crane & Broome, 2017). Including adolescents in the consent process can have benefits for them, for example increased self-control and a higher capacity for decision-making (Society for Adolescent Medicine, 2003).

Informed consent is not a one-time decision participants make; it is an ongoing process that reflects participants' potentially changing perceptions of the study's risks and benefits of the research (Hodges et al., 2023). Adolescents may have limited experience to be able to anticipate the nature and type of questions they will be asked as well as their reaction to these. Schelbe et al. (2014) therefore suggest that researchers should provide written examples of the type of questions participants will be asked in the interview. Parents and adolescents should be communicated with about consent both verbally and in writing (Cook & Krueger-Henney,

2017). The research paradigm and methods should be made explicit as well as their potential benefits and limitations, particularly those local and structural issues which may impede change.

Age-friendly material should be provided but in different formats as well to cater to a variety of reading and comprehension competencies in adolescents (Schelbe et al., 2014). Language is another important aspect that should be considered. Birks et al. (2006) highlighted the need to include information sheets in other languages, which is particularly relevant in pluralistic communities and settings. In some cases, children and adolescents may speak the language of the research but their parents, still in charge of parental consent, may not. Parents are entitled to receive information in the language which they can comprehend and make informed decisions with (Birks et al., 2006).

Crane and Broome (2017) recommend the input of children development specialists in the design of scales for children and adolescents. At the least, scales should be piloted before the study. Quizzes can also be used to determine the level of understanding children and adolescents have of the information provided and they can also be an opportunity to talk more about consent (Crane & Broome, 2017). An interest topic introduced by Hampshire et al. (2012) is participatory ethics. This approach consisted of child and adolescent participants working together with adult researchers to develop guidelines, for example the 12-point Code of Practice which stated, for example, that ‘children should benefit from being researchers’.

Sharpe et al. (2021) worked with adolescents with disabilities and used alternative methods to communicate, instead of written consent forms:

1. An accessible information pack;
2. Visual timetables;
3. Image-based emotion card to support their understanding of and how to convey feelings;
4. Visual aids to support written language;
5. A video information sheet, which could overlay a sheet or be saved on a device, using an augmented reality smart device.

Alderson (2007) argues that consent should not be based on an arbitrary age but should instead consider every individual’s abilities. The statutory age of consent to treatment varies significantly between countries. Some countries consider it to be at 12, whereas others have identified it to be at 19, which suggests a potentially arbitrary approach (Alderson, 2007).

Adolescents themselves should actively inform the process of adolescents’ assent; this must be a regulatory requirement and a critical art of

demonstrating respect for adolescents enrolling in health research (Grady et al., 2014). Participation in health research needs to be very explicit that agreeing or refusing to participate will not affect the adolescents' care or service provision (Grady et al., 2014). In some countries, such as Britain, doctors are protected from prosecution when they treat children under 16 years of age without having parental consent if they claim that the child is competent to consent themselves (Alderson, 2007). The Childcare Act (1989, 1991) states that a competent child and anyone with parental responsibility for the child can provide valid consent. This means treatment can be enforced on a child resisting treatment if it is considered that this is in their best interest (Alderson, 2007). In other countries, such as the United States, adolescents are not legally permitted to consent to specific health procedures such as clinical research (Grady et al., 2014).

The Society for Adolescent Medicine (2003) suggested that researchers should evaluate their own state (country) laws to determine if adolescents should or should not be considered as children under federal regulations. If they are not considered children, then parental consent is not needed. If adolescents are considered children, the researchers and research ethics groups and organisations may still decide that parental permission can/should be waived, knowing this is against federal law.

Birks et al. (2006) included signed letters by all consultants in participant packages to inform participants that they were aware of and supported the study, inviting participants to take part. Although no issues are mentioned in the study, it is important to ensure that participants do not feel coerced into being involved in the study and their decision to participate should be independent of their treatment. Including consultants may have forced participants into taking part due to possible fear of retaliation regarding their treatment. Adolescents' assent needs to be carefully considered as younger adolescents may feel pressured to enrol; however, the reasons are not clear. One reason was parents not giving them a voice regarding their participation (Grady et al., 2014). These adolescents require additional support and protection (Grady et al., 2014). For this reason, continuous consent and check-in with adolescents throughout the research process is necessary. Researchers should be careful to make sure adolescents understand the value of participation without feeling pressured to enrol (Grady et al., 2014).

Even though adolescents want a voice, parental involvement is significant in decisions such as their involvement in health research and clinical trials (Grady et al., 2014). Gatekeepers play an important role in identifying research participants. Coad and Coad (2008) had an adult gatekeeper

who was a senior play therapist and not an active researcher in the project. The role of this gatekeeper was to protect participants and to gain consent without coercion. Research specific to adolescent health identified that adolescents trust their parents to support them when making decisions about enrolment in health research, and this does not vary by age or severity of illness (Grady et al., 2014). Parents, as usual gatekeepers, may also feel forced to be involved in research studies labelled as ‘therapeutic’ for fear of harming their child or adolescent by refusing participation (Alderson, 2007).

Another important aspect to consider is legal status. Adolescents (under the age of 18 in most countries) have a different legal status from adults; therefore, adults have a duty of protection towards them. This introduces a logistical concern, as parents or guardians must give their consent for adolescents to be included in a study (Schelbe et al., 2014). Adults can deny participation for children or coerce adolescents into participating (Schelbe et al., 2014). This usually occurs if families are concerned about their privacy and topics adolescents may disclose (Schelbe et al., 2014).

A study carried out in New Zealand (Martel et al., 2019) decided to include adolescents over the age of 16 only, as this allowed them to include participants without parental consent. Apart from being legally allowed to do this, the authors explained that adolescents often visit clinics without parental or guardian awareness and, therefore, this would have been a breach of confidentiality. Adolescents who were not able to provide consent due to cognitive difficulties were excluded from the study. There is, however, no explanation of how these cognitive difficulties were evaluated.

Protecting participant identity is one of the pillars of ethics in research. It has been argued that anonymity, however, is not foolproof, as data can be reidentified (Berman & Albright, 2017). Data can often be either useful or anonymous (Berman & Albright, 2017). It is important to ensure anonymity in all parts of the study. For example, Flicker and Guta (2008) said that it was important to remind adolescents not to write their name at the top of forms or questionnaires. Surveys may be printed as booklets to ensure answers can be covered answers. Adolescents should be given identical writing materials to avoid being identified; for example, same coloured pens. Additionally, they should be given access to a drop box where they can return the material without it being recognised as theirs (Flicker & Guta, 2008).

Researchers need to be clear and transparent about the limits of confidentiality from the start, regarding for example child protection issues. Researchers have an obligation to report any disclosures of abuse,

neglect, self-harm or if the adolescent poses a danger to themselves or others (Schelbe et al., 2014). Adolescents should be aware in advance of the risks of taking part in research, for example potential child protection issues that may be disclosed by a research participant (Shortt & Ross, 2021). This information should be explicitly included in participant information sheets and consent forms.

3.3.1 Situated Ethics Approach

Situated ethics consists of a constant evaluation throughout the research process to adapt accordingly to the development of the project (Olesen, 2021). Whittington (2019) used situated ethics, where all participants were given the opportunity to consent or withdraw along the life course of the study. The research topic was sexual consent. It was considered that sexual consent had to be 'sought every time' and therefore the researcher decided to model this approach in the research. The researcher described that this approach was not always successful and would sometimes 'get in the way', but she persisted as it was useful in the research process and the research topic.

Adolescents should be made aware that they can revoke their participation at any time, without any consequences for them (Østergaard, 2021). Adolescents may also be willing to engage with the research to protect their benefit entitlements as well as to maintain support from agency workers; however, if this is their motivation, they may disengage from the research very early on (Campbell & Trotter, 2007). Adolescents, however, need to be provided with examples of how to refuse or withdraw their participation, for example periodic check-ins to consider if they are willing to continue the research (Schelbe et al., 2014). Adolescents may also refuse to answer a question and concrete examples of how to do this can be provided: 'just say next please' (Schelbe et al., 2014). Materials and activities should explicitly indicate what participants should do if they feel uncomfortable about any aspect of their involvement in the research (Al Hweidi et al., 2022) or during a specific activity. Overall, it should be clear that refusal to participate in a study does not jeopardise adolescents' access to services (Flicker & Guta, 2008).

3.4 Technology, Research and Ethics

The first ethical consideration about the use of technology in research is that the existent evidence is conflictive about whether technology is beneficial or

harmful for adolescents and in what context. Technology is reshaping research methodologies (Gibbs et al., 2020). The development of new media has been so rapid that research is failing to keep up with the pace (Patton et al., 2016). There is therefore a continuous debate over the impact of digital media, whether it is beneficial or negatively impacting on adolescents' social, emotional and cognitive development (Patton et al., 2016).

One very strong example of how technology has reshaped research methods is the adaptation and transformation of traditional research methods. Netnography is the method of conducting ethnographic fieldwork in virtual environments. It is based primarily on the observation of textual discourse, instead of traditional ethnographic face-to-face interactions.

One of the identified advantages of technology in research is the capacity to bridge the geographic and social distances (Gibbs et al., 2020). Social networking and media enable access to information, communication and sharing information with peers, and they generate contents and draw in resources (Patton et al., 2016). Chen et al. (2010) described how technology was an essential tool to attract adolescents and engage them in their project. It is fundamental, however, that equipment is 'right' for the research design and functioning well. Participants in this study, for example, identified that the use of digital cameras – capturing images, recording interviews and using software to create their final report – was their favourite part of the study (Chen et al., 2010).

Digital content that is age appropriate and viewed with adult supervision can boost academic achievement, literacy and improve social connections (Maftei & Merlici, 2023). Improved social network activity may lead to enhanced self-esteem, improved friendship quality, sense of belonging and identity exploration (Maftei & Merlici, 2023). Video games can also improve attention, visual and representational processing, executive functioning and visual spatial working memory (Maftei & Merlici, 2023). Digital media, such as the use of biometric devices, can foster positive approaches to eating, exercise and sleep patterns (Children's Commissioner, 2017). Seland (2024) found that digital engagement can be a coping strategy for young people who experience problems. Children and adolescents perceive digital media as leisure and pleasure as well as a huge potential for learning (Children's Commissioner, 2017).

Stafford et al. (2003) identified the views of adolescents themselves on online research methods. According to their study, these methods can reach many adolescents who are familiar with online methods and enjoy them. In principle, they offer privacy, and adolescents liked not having to travel to avail themselves of the research; however, they do recognise that

not every adolescent may have a computer or access to the internet at home. Adolescents themselves have awareness of ethical issues, for example privacy as well as differential accessibility.

Potential limitations of technology in research start with the fact that research is struggling to keep up with evolving technologies that are shaping children's lives, and researchers tend to rely on old methodologies to investigate these new developments (Mallan & Singh, 2010). There are great benefits from social digital connections, but this can increase vulnerabilities, including for example social contagion, violence, mental health, suicide and self-harm and being targeted by extremist groups (Patton et al., 2016). Technology may expose adolescents to potential risks online (Gibbs et al., 2020). There is a growing concern for online safety. Adolescents can experience cyberbullying, grooming, exposure to sexual content and social contagion including self-harm, mass shooting, radicalisation and eating disorders (Patton et al., 2016). Digital media can instead become a promoter of consumer cultures and affect adolescent lifestyle, health and well-being (Patton et al., 2016).

Problematic use of media and the internet has been defined in several ways; however, there is overall agreement that these types of behaviours can be detrimental to adolescent mental and physical health (Maftei & Merlici, 2023). Sleep disturbance and gaming addiction have been linked to new media (Patton et al., 2016). Age-inappropriate and violent content can severely impact development and behaviour (Maftei & Merlici, 2023). Additionally, the more time spent online means less time spent on activities such as exercise, healthy eating and sleeping, which are conducive to a healthy lifestyle (Children's Commissioner, 2017).

The other significant challenge is that the capacity to conduct research online has expanded more quickly than the ethical guidelines for digital research (Hodges et al., 2023) that should accompany them. Online research is perceived as lower risk than in-person research and this may lead the risk of disclosure online to be underestimated (Hodges et al., 2023). According to James et al. (2009), for every young person who is an example of good citizenship online, there are many more examples of intentional or naïve misuses – or ethically ambiguous misuses of digital media.

Ethics in technology is fundamental. James et al. (2009) have described how carefully managed and informed sharing can result in an inspiration, an empowerment and building supportive communities for adolescents. The opposite – careless oversharing – may lead to long-term negative effects on adolescents and the friends or people they write about online.

Adolescents who experience empowering social roles online can build a sense of responsibility towards others, their community and society in general (James et al., 2009). The ethical challenge, therefore, is to maximise the benefits of technology without exacerbating risk and exposing children and adolescents to harm (Children's Commissioner, 2017).

3.5 Defining and Evaluating Risk in Health Research

Identifying and evaluating risk is challenging in health research with children and adolescents (Alderson, 2007). There may be extra risks as children and adolescents may be damaged by short- or long-term interventions and may be liable to live with the side effects for many years. Risk can be quantifiable based on incidence; how many people out of 100 may experience a harmful side effect, for example (Alderson, 2007). The other aspect of risk is magnitude. This aspect is qualitative as it depends on a person's evaluation of whether it is severe or minimal, which is subjective (Alderson, 2007).

Risk is not only present because of treatment or intervention but is also potentially present in other stages of the research; for example, research reports may inadvertently lead to humiliation, embarrassment or stigmatise disadvantaged groups including children and adolescents with mental or behavioural issues. Flicker (2008) carried out research with HIV-positive adolescents and highlighted potential risks regarding disclosure and stigma. Their participation in research could jeopardise the respect of their peer group and put them at risk of being tokenised.

3.5.1 Researching 'Sensitive' Topics

Topics that are 'sensitive' require extra ethical thought. It is important to consider what the meaning of sensitivity is. Overall, researchers should ask themselves who is this topic sensitive for? Is it a sensitive topic due to cultural or contextual reasons and, therefore, may not be as sensitive in another context? It may also be sensitive only for a group due to generational differences, for example. Is it sensitive as it may cause embarrassment or sensitive due to potential emotional reactions? And lastly, even if it is socially sensitive, what are an adolescent's approach, views and opinions about this? Is it sensitive for them also and, if so, how? This will help the research team to consider how best to approach the topic to ensure that sensitivity does not lead to upset or any negative consequence for a research participant.

There are, however, topics that have been traditionally considered as 'sensitive' for research, for example sexuality and mental health. According to Petrie et al. (2006), topics such as sexual behaviour in young people is a very personal topic in nature and it is also an area where adults are prone to make judgements and would often seek to control. Due to the research topic, Petrie et al. (2006) sought parental consent for every young person under 16 years of age to take part in their interviews, even though the research was taking place within schools. The research topic might attract adult disapproval and media attention. The topic could also lead to disclosure of information that may require child protection intervention. For this reason, researchers were clear about the limits of confidentiality and had an 'opt in', 'opt out' approach where adolescent could engage on a voluntary basis.

Adolescents with mental health issues are described and perceived as a vulnerable population (Olesen, 2021). Research in this population requires extra precautions; however, they should be given the opportunity to make an informed choice regarding their involvement in the research (Olesen, 2021). Excluding these adolescents without giving them the opportunity would be paternalistic and unethical (Olesen, 2021).

Researchers need to have reasonable expectations of adolescents' capacity to participate according to their abilities. This means that not all adolescents may be engaged in the research to the same capacity or the same way (Olesen, 2021). Whittington (2019) argues that alongside safeguarding procedures, researchers should develop robust participation and engagement strategies that consider the competences of adolescents, their agency and right to participate, independent of the sensitivity of the topic.

3.5.2 *Safety and Vulnerability*

An essential part of ethics is safety and supporting adolescents continuously through the research process by ensuring they are going to be well and feel well through every stage of the research study. There are several examples of good practice from the literature. Beresford and Sloper (2003) prepared 'help packs' for adolescents. These packs had contact details of key voluntary organisations that could provide extra support for adolescents. Independent project advisors were available to support adolescents. These advisors were knowledgeable about the different illnesses and conditions that adolescent participants might have (Beresford & Sloper, 2003). They were available to provide information and advice by telephone. They were also introduced to adolescents on the first group meeting (Beresford & Sloper, 2003).

Sartain et al. (2000) established a support network to help researchers manage research-related stresses to provide appropriate responses for participants and their families. Possible scenarios were discussed with professionals in child protection on how to deal with disclosures of abuse or other situations where confidentiality had to be breached due to child protection issues.

Specific groups of adolescents may have unique needs and characteristics that may leave them in a place of vulnerability in society that permeates any participatory research exercise carried out with them. One of the issues is defining 'vulnerability'. Holmarsdottir (2024) provided a definition of vulnerability which entails a person's lack of ability to protect their own interests with a lack of capacity for decision-making as well as environmental factors that impede their access to rights, opportunities and power. Some of these adolescents also experience significantly unequal access to technology. Some of them experience the consequences of a digital gap which limits the opportunities and the capacity of adolescents to meaningfully engage in the digital world and access the benefits of technology. Digital inequalities include innate vulnerability but also situational vulnerabilities such as gender, sexuality, race, ethnicity, disability, health, education, rural residence and global geographies (Holmarsdottir, 2024). Closing the digital gap is imperative as this would stop social and economic inequalities from worsening. This means that significant efforts are needed to ensure children and young people have access to develop the skills they need to use digital technologies effectively and safely (Ayllón et al., 2024).

Adolescents with healthcare needs may have a disability that requires medical technology to survive (e.g. tube-feeding equipment) (Watson et al., 2006). Watson et al. (2006) described the way they obtained consent from this group of children, which included adolescents also (0–15 years). Ten participants were non-verbal and three had assisted communication. Researchers spoke to participants about who they were, where they came from and used pictures to explain the research questions (Watson et al., 2006). In some cases, researchers relied on parents and carers for interpretation. According to the researchers, despite relying on parents for interpretation they were confident that they gained 'unique insights' from their participants.

Digital research should avoid replicating marginalising social experiences that could intensify participants' vulnerability. Hodges et al. (2023) worked with Black immigrant and refugee participants and consider that it is important to consult experts in immigrant and refugee issues to avoid negligence when designing studies and in the overall research

process. Immigrant adolescents are at a higher risk of participation tokenism, as they are less likely to participate in research, particularly controversial or sensitive topics (Vyas et al., 2022).

Consent with African Americans is not an individual decision but a collective one (Hodges et al., 2023). Regarding research online with this population, Hodges et al. (2023) suggest that researchers must ensure that the recruitment and consent procedures honour cultural decision-making processes. According to Hodges et al. (2023) an iterative consent is appropriate for Black immigrant and refugee families. Iterative consent entails researchers proactively engaging in ongoing conversations with participants about their continuous consent process throughout the research. This becomes particularly relevant in online research where participants may perceive they have fewer opportunities for voicing concerns or queries to researchers (Hodges et al., 2023).

Researchers need to build long-term relationships with Black immigrant and refugee families to ensure community buy-in (Hodges et al., 2023). Recruitment most often occurs in face-to-face community gatherings and places of worship where researchers can build relationships with leaders, community representatives and become partners in the communities. Due to this sense of community, an individual's negative experience in a study may dissuade others from participation by word of mouth or 'snowballing' effect (Hodges et al., 2023). Research teams should include or be led by Black researchers who are cultural insiders as this can provide a suitable pace and direction (Hodges et al., 2023). Additionally, researchers would benefit from training on social positionality and ongoing support regarding their ethnic-racial identity (Hodges et al., 2023).

Another population with specific needs and characteristics is LGBTQ+ adolescents. Gaining access to LGBTQ+ adolescents can be challenging (Schelbe et al., 2014), as some of them may not be 'out' to their family or community. Some may attend LGBTQ+ groups without the knowledge of their parents and guardians, therefore obtaining consent for their participation in research may not be possible. The standard of seeking parental consent could expose LGBTQ+ adolescents to greater harm (Whittington, 2019). Schelbe et al. (2014) described an example where a researcher advocated for a waiver of parental consent. These waivers can be warranted in cases where parental consent may result in harm for the child or adolescent, or parental consent infringes rights to privacy or leads to unjust exclusion. Following the waiver, Schelbe et al. (2014) used 'youth research advocates'. In this case, they were licensed social workers who had individual and collective meetings with the young people to ensure they

understood the research, assess any emotional vulnerability and provide any other support needed.

Some adolescents may come from very specific social and cultural backgrounds. Martel et al. (2019) carried out a research study with Maori adolescents to evaluate a screening tool for early detection of mental health issues in New Zealand. This is an interesting example of research that is designed and carried out within a specific cultural group, respecting their culture and values, specifically, the design and ethical considerations that need to be considered to ensure the research is undertaken with rather than on people. Digital research methods, without careful consideration, could instead distance researchers from communities (Hodges et al., 2023).

This study was not designed as a Maori project; however, most participants were and therefore the researchers opted for a co-creation design where Maori culture, values and beliefs were validated, respected and protected. Non-Maori researchers worked in partnership with Maori, allowing them to understand context, specific requirements and challenges, working alongside each other in bicultural research (Martel et al., 2019). YouthCHAT is an electronic, multi-item screening tool developed in 2016 to assess mental health and risk behaviours in young people. Martel et al. (2019) translated YouthCHAT into the Maori language and tested it among Maori youth and clinicians. The study consisted of the design of YouthCHAT, which was informed by clinicians and adolescents and explores information on sexual health, youth stress, conduct disorder, eating issues, substance abuse, depression and anxiety (Martel et al., 2019). This electronic screening tool helped adolescents prioritise concerns and identify areas where they were ready to accept support. Adolescents completed YouthCHAT using a tablet.

3.6 Rewards and Incentives

Providing rewards or incentives for adolescent participation is conflictive. Children's and adolescents' level of vulnerability should be evaluated before making decisions about the use of rewards or incentives. Crane and Broome (2017) consider that young children may not have a full understanding of the value of money and it would be more suitable to give them incentives such as toys, books and movie tickets. Parents and adolescents may be consulted about suitable and age-appropriate incentives. Careful consideration should be given to children and adolescents who may be homeless or financially disadvantaged (Crane & Broome, 2017). Participants should never be exploited and should never be coerced

into taking part in research (The British Psychological Society, 2021). Researchers may also want to discuss the most appropriate incentives or compensation with organisations involved in the study, depending on what was useful and significant for a research participant, as well as avoiding any harm (Schelbe et al., 2014).

Compensation for participants may go beyond money. It may include technical assistance and training (Israel et al., 2005). Different examples of rewards and incentives have been reported. For example, students received an incentive (e.g. a water bottle or a key chain) for completing the form whether they took part in the study or not (Ozer & Douglas, 2013). Adolescents received two movie tickets (Oridota et al., 2023). Participants were given gift cards after completing their interview (Østergaard, 2021). Participants received cash incentives for completing the survey and for recruiting new participants (Powers & Tiffany, 2006). Valdez et al. (2021) used 'student dollars' to recognise the participations of adolescents in the study. These dollars could be used to purchase snacks and school promotional items (e.g. t-shirts) from their school's student store.

Rewards may be given in more indirect ways as well in exchange for participation. For example, Harragan (2021) spent time running sessions in the youth club. All adolescents, even those that did not want to take part in the research, could benefit from these sessions. Flicker and Guta (2008) administered their research questionnaire with adolescents but provided them with an educational activity. Adolescents could write down questions and they were answered in the workshop by the adolescent advisory team, and an adult member of the research team was present as a support.

The timing of these incentives should also be considered. To avoid participants feeling coerced into participating, they were given a monetary incentive at the time of assent/consent (Schelbe et al., 2014). According to Lightfoot and Sloper (2002), payment for participation should be offered once adolescents have agreed to be involved in the research. Additionally, payment is needed when involvement is high and over a period. Treats, trips and meals make adolescents feel appreciated as much as cash.

Rewards can have a deep societal impact. Hampshire et al. (2012) described, for example, that a 16-year-old participant used the money obtained from his participation to buy textbooks for school. A 15-year-old used the money to buy fertiliser to contribute to the food production business of his household. Adolescents may experience significant benefits when taking part in the research. Adolescents can become paid researchers in the project (Powers & Tiffany, 2006). This role meant adolescents

oversaw surveys, data collection, educational sessions, data analysis and co-authored a journal article (Powers & Tiffany, 2006).

Paying adolescents can also be perceived as exploitation. According to Campbell and Trotter (2007), involving adolescents as co-researchers, paying and training them, has questionable ethical implications as this may not have any use to them, to the extent of possibly exploiting them. Therefore, the benefits and risks should be carefully considered in every case, for a specific group of adolescents and their circumstances.

3.7 Relationships and Collaborations

Research with adolescents requires a systematic communication, collaboration and developing good relationships (Schelbe et al., 2014). Promoting a healthy, working social relationship with adolescents is crucial for success (Vyas et al., 2022); however, the timing and characteristics of these relationships must also be mediated by ethical principles and behaviours.

Different studies emphasise the need to approach and create a relationship with adolescents before starting the research study (Wrede-Jäntti et al., 2021). Whittington (2019) worked with adolescents before ethical approval was sought. The researcher consulted with adolescents over the age of 16 regarding the methodology as well as to determine what was realistic in a collaborative study. Adolescents were also involved in co-developing research methods. This engagement helped develop rapport and interest for the adolescents to participate in the project. It is important to consider the potential risk of approaching participants before seeking consent from them or their parents and carers. In some cases, for example for funders, this might also be considered unethical behaviour instead of good or recommended practice which may jeopardise success in obtaining funding. If, however, there has been an ongoing relationship with an organisation as a worker or facilitator then having pre-existing relationships is expected.

Collaborations are very important in order to access adolescents. These collaborations should be clear about the research objective, risks and benefits. Researchers need to invest time and energy with the gatekeepers before accessing research participants. These collaborative relationships are crucial if problems arise, as mutual decisions can be made based on mutual respect and understanding (Schelbe et al., 2014). Researchers need to identify key personnel who are enthusiastic about the project, have access to the adolescents and are willing to assist in pragmatic tasks (recruitment, obtaining consent, access to physical space) (Schelbe et al., 2014).

From an ethical perspective, organisations (schools, charities, agencies) are usually not compensated with money or any other tangible method, therefore it is crucial to identify how the study will benefit the organisation (Schelbe et al., 2014). Researchers have also worked in partnership with children's charities, for example Children in Scotland (Shortt & Ross, 2021). Researchers were given a contact number for Children in Scotland if they needed to discuss any issues (Shortt & Ross, 2021).

Overall, researchers need to recognise that they need organisations and should negotiate with them as to how the research can be carried out, respecting their culture and ethos as well as ethical practices. If these are compatible with the research then these collaborations will be very powerful and capable of supporting the study and the research team, which is fundamental to the research success and development.

3.8 Inclusion

Inclusion, in Chapter 2, focused on participation in the research process. In this chapter, it is focused on the implications for ethics.

Researchers should carefully ensure children and adolescents involved in research are fully informed about the project and what their participation entails. Having their name or signature on a piece of paper does not mean they have that understanding, but it could be a response to obeying to an adult figure or just assuming it is expected of them. This may translate into children and adolescents dropping out of the study or not participating meaningfully as they were not interested to begin with.

The emotional, cognitive and language ability of children and adolescents varies. Not all adolescents of a similar age function at the same level (Schelbe et al., 2014). Researchers must be ready to accommodate different levels of skills to meet the variety in developmental needs of adolescents (Powers & Tiffany, 2006; Schelbe et al., 2014).

Adolescents can have the capacity of deciding themselves to participate or not in health research; however, this involves an assessment of their cognitive development, psychosocial circumstances, emotional state, judgement and personal circumstances (Rogers et al., 1994).

Rogers et al. (1994) have provided guidelines for adolescent participation in health research; however, these principles are relevant to inform any study with adolescents:

1. Design research in which adolescent identity and data cannot be linked.

2. Ensure the privacy and confidentiality of participants in all stages of the research: a) selection, b) setting, c) question design, d) collecting and storing data.
3. Interact with community representatives.
4. Ensure that researchers have made reasonable effort to obtain parental/adult consent.
5. Unemancipated adolescents can take part in the study if they are already obtaining healthcare services and the research is carried out with these services.
6. Adolescents may only be allowed to consent independently if the study involves minimal risk.
7. Adolescents who will participate without parental consent should be evaluated by a trained professional to ensure they have the cognitive ability to comprehend the research and risks, judgement around their personal health and long-term benefits of participation or non-participation, as well as their sense of health responsibility and capacity to comply with research protocols.

3.9 Data Management Online

This section is not solely focused on adolescent research online, as these considerations should be taken for all research carried out online, but they are mostly applied to child and adolescent research. According to The British Psychological Society (2021), internet-mediated research can make it difficult to adhere to existing offline ethical principles. Online research also means participants may often be in many different countries and therefore situated and governed by different cultures and legal jurisdictions (The British Psychological Society, 2021). The British Psychological Society (2021) provided the following guidelines for online research:

1. Privacy and anonymity. The distinctions between public and private spaces may be unclear. Data that was anonymised could eventually become identifiable when data sets are linked or specific analyses or algorithms are applied to it. The fact that internet communication is often public, visible, traceable and permanent does not mean that it can be used for research purposes. The opinions of users on this matter vary and are unclear. Personal webpages may seem like public documents; however, the copyright remains the property of the web hosting company. Consent should still be sought. Consent online should be simple, as lengthy consent may be quickly skimmed

through or not read at all. The British Psychological Society (2021) also recommends that the General Data Protection Regulation (GDPR)/UK Data Protection Act (2018) information is included: 'I understand that information will be used only for the purposes previously outlined and my consent is conditional upon the university complying with its duties and obligation under the Data Protection Act 2018.' The names of forums or website where information was obtained should not be revealed if this compromises the safety and anonymity of participants. Pseudonyms used by participants online should be treated with the same respect as personal names would be treated. Data transcription services online, such as AI, may not be compliant with participant confidentiality policies and should therefore not be used (The British Psychological Society, 2021).

2. Data storage. Careful consideration should be given to where data is stored. Vulnerabilities can emerge when data is stored in third-party software which may become compromised. This may lead to a higher risk of linking data sets and releasing personal or sensitive identifiable information. Identifiable data collected automatically by software (e.g. location, IP address, email address) should only be used to check for multiple completions and should be deleted immediately. If researchers need to match existing data with participant responses over time, participants should provide a memorable code instead. If personal information is still needed, this information should at least be stored separately from participant responses. Unencrypted emails offer low security (The British Psychological Society, 2021).
3. Scientific integrity. Online research usually means the researcher has less control over the research procedures and environment, for example who has access to participate, the conditions in which participants are responding, participant feelings or reactions to the research process and variations generated by different hardware or software used by research participants. Another risk to research integrity is the use of AI or 'bots' to complete information; particularly if these are paid surveys, these may be false. The use of open-ended questions, captcha or skip logic can help identify false respondents.
4. Social responsibility. Researchers have the duty to act responsibly and, for example, to refrain from intruding in spaces considered private by users. Online research can also, unintentionally, lead to promote inequality by benefiting a privileged sector, which in this case has access to technology and services online. Researchers should make the fundamental decision of whether their research would be better

carried out offline to protect participants or reduce the negative impact on them. Researchers should also mind themselves and reduce risks for themselves and their integrity as people and as researchers. This means refraining from accessing websites designed around illegal services, goods or activities without being compliant with relevant legislation and authorities.

3.10 Big Data and Ethics

Big data is an umbrella term encompassing the vast amount of digital data continuously generated globally, at a high speed, frequency and variety of sources (Berman & Albright, 2017). Big data is a technological issue, but it is also the social and cultural dimensions related to its use, expectations of applicability, robustness and accuracy across several domains and disciplines (Berman & Albright, 2017). It is characterised by several features (Berman & Albright, 2017), being:

1. digitally generated
2. produced passively
3. collected automatically
4. trackable temporarily and geographically
5. constantly analysable.

This rapid development of data and technologies that facilitate collection and analysis means more data will be collected on young people over their lifetime than before. The issue is that the impact that big data will have on their futures is still unpredictable (Berman & Albright, 2017). Ozer and Piatt (2017) say that the possible implications, when disseminating results online, is that big data creates a permanent digital footprint, which remains over time. This must be understood by participants before they consent to posting any materials or images related to the research, but since the long-term impact of the digital print is still unknown, participants' decisions may not be fully informed.

Data collected from children and adolescents may be used and analysed by indeterminate algorithms to create digital identities of which individuals may be unaware of, and digital identities may be created and shared over social media and by digital service providers who may even profit from this (Berman & Albright, 2017). For this reason, online consent is fundamental. Berman and Albright (2017) highlighted that there are no clear guidelines on the nature of informed consent for websites, and the terms

and conditions may be written in legalistic or technical language which makes understanding difficult. Adolescents and parents may be faced with a binary choice to accept these terms without understanding them or forsake the website completely.

The introduction of GDPR has contributed to safeguard children's and adolescents' information. The Right to Erasure is concerned with data being unlawfully processed due to lack of free and informed consent. Additionally, if data were disclosed to a third party, the individual affected must be informed and all links or records of personal data must be erased, unless it is impossible or requires a disproportionate effort to do so (Berman & Albright, 2017).

Empathy Card Game

This game was used by Geppert (2023) to introduce empathy in adolescent research.

Adolescents had a card on their foreheads. The group would treat the person according to the label they had on their forehead but could not see themselves.

This was a fun way to get adolescents thinking about how social systems include or exclude people.

Here is an example of an adolescent consent form used in an online study exploring the impact of maternal cancer on adolescents (Rodriguez, 2016):

Adolescent Adjustment to Maternal Cancer

Participant Consent Form

Purpose of the Study

You are invited to join a study which examines the psychological impact of adjusting to maternal cancer diagnosis. This is a difficult and distressing time for you but the information you provide will be used to enhance understanding of what you are going through and to establish if a web-based intervention is a good way to help adolescents facing this situation.

What will be involved if I agree to take part in this study?

If you agree to take part in this study, you will be involved in four different phases.

The researcher will have an online video chat (Skype) interview with you to understand your current situation further. This session is

audiotaped. Participants will fill in a survey online which will help understand the psychological impact of maternal illness on adolescents. Adolescents will complete an eight-week intervention. Half will complete the intervention first and the other half will participate in the intervention later. The survey will be filled in again at the end of the intervention and at a six-month follow-up.

Can I withdraw from the study?

Even if you decide to take part in all phases of this study, you are free to withdraw at any stage without having to explain why and there will be no consequences for you or your family.

Confidentiality

All the information you provide will be anonymous. Your name or family name will not appear in any report resulting from this study. A research number will identify you in the databases. Findings will only be reported as group data. The researcher, however, must break confidentiality if:

1. Your physical and/or emotional well-being is at risk and another adult (parent, guardian) must be informed to guarantee your safety.
2. You are being harmed or at risk of being harmed by issues specified in the Child Protection Policy NUI Galway (2011) and *Children First: National Guidance for the Protection and Welfare of Children* (2017).

However, the researcher will always inform you first about this situation and the procedure that must be followed after the situation has been reported.

If you have any queries, please contact [add relevant research contact details here] _____

Adolescent Adjustment to Maternal Cancer

Participant Consent Form

I confirm that I have read and understood the information sheet about the study which is examining the psychological impact of adjusting to maternal cancer diagnosis.	Place a circle round either Yes	No
I am satisfied that I understand the information provided and have had enough time to consider the information.	Yes	No

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	Yes	No
I understand that any information I give to the researcher is anonymous and will be treated with confidence.	Yes	No
I understand that I can ask the researcher questions about the study at any time.	Yes	No
I confirm that I have competent reading writing and comprehension skills in the English language to be able to take part in this online study.	Yes	No
I confirm that I have access to the internet and parental/adult permission to use it for the purpose of this research project.	Yes	No

Name: _____

Signed: _____ Date: _____

Please send back one signed copy of this Consent Form. The other copy is for you to keep.