



# ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children  
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# ETHICAL GUIDANCE: PRIVACY AND CONFIDENTIALITY

Respecting the privacy and confidentiality of children participating in research involves close consideration of several aspects, including: privacy with regard to how much information the child wants to reveal or share, and with whom; privacy in the processes of information gathering/data collection and storage that allows the exchange of information to be confidential to those involved; and privacy of the research participants so that they are not identifiable in the publication and dissemination of findings.

# PRIVACY AND CONFIDENTIALITY

## BEST PRACTICE REQUIRES THAT YOU:

- Respect children's right to privacy and ensure that their information remains confidential.
- Securely store, protect and dispose of information/data that has been collected.
- Be mindful that any assurance about confidentiality also includes explicit mention of the limits to this, and always be prepared to act sensitively on safety concerns.

Respecting privacy and confidentiality requires awareness and sensitivity during the planning and data collection phases of research.

## KEY CONSIDERATIONS

Respecting the privacy and confidentiality of children and others participating in research requires awareness and sensitivity during the planning and data collection phases of research. Some of the concerns can be considered and attended to when planning the research, with the development of specific protocols, for example, for keeping information private, responding to disclosures of concern, storing data, and maintaining anonymity. Other issues require researcher flexibility and adaptation during the process, for example, in response to difficulties securing a location that provides privacy and confidentiality, or conducting interviews when others are present.

### ***Privacy with regard to how much information the child wants to reveal or share***

Children participating in research may wish certain information to remain private and not want to share this with the researcher or others. Privacy and the right to be free from intrusion or interference by others is a basic human right, articulated for children in the UNCRC (Article 16). This right underlies the importance of respecting that children share only the information that they wish to when participating in research activities and, if necessary, ensuring that they understand that in some circumstances it may be preferable to keep certain information private.

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The type of data that is collected during research creates various ethical concerns in regard to how much information children wish to share. For example, in biomedical research that involves children, the collection and storage of biological data, such as genetic/ DNA information, raises an ethical issue concerning the child's

understanding about what will potentially be revealed from providing this type of data. In gene-based prevention trials, the implications of the disclosure of the test results needs to be fully considered by researchers, disclosed during the consent process and understood by the parents and the children (Spriggs, 2010).

***Privacy in the processes of data collection and storage that allows the exchange of information to be confidential to those involved***

Privacy means that entrusted information received from children must be respected and safeguarded. Other people, including parents, may be interested in the information that has been collected, but the researcher is ethically obliged to treat the information carefully and retain confidentiality. This obligation extends to all staff involved in the research, including, for example, interviewers, interpreters, translators, drivers, and 'cultural brokers'. Training makes a significant difference in the quality of research and this should incorporate issues related to cross-cultural competence and responsibility, including managing confidentiality.

The location and methods used in collecting data impact on the privacy of the participant and the confidentiality of the research information collected. To ensure confidentiality, the setting should allow children involved in research to impart information privately and freely. For example, children being interviewed should be able to speak without being overheard, and children providing written or visual material should be able to do so without it being seen by others. Sensitive topics may produce social desirability biases and therefore require innovative methods that encourage honest answers and maintain privacy and confidentiality of responses. An example of such an innovative method is provided in the case study by Urvashi Wattal and Angela Chaudhuri, as used in research on early marriage including child marriage in India.

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**Case study 17: Maintaining confidentiality of responses and preventing social desirability bias with an innovative method: The polling booth in research on early marriage including child marriage, by Urvashi Wattal and Angela Chaudhuri (see Case Study section p.152).**

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Maintaining confidentiality in group research requires additional consideration, and cannot be guaranteed (WHO, 2011). Similarly, in RCTs confidentiality is not guaranteed with certain designs and procedures, such as surgical interventions where 'blinding' of medical staff and patients is not possible, or single blinded trials where the medical and research staff know the participant's experimental status but the participant does not. By comparison, in other RCTs where double blind designs are used to minimise participant and observer bias, confidentiality of experimental status is provided and as such, wherever possible, double-blinded designs should be used over single blinded and unblinded designs.

In some research contexts it is important that children's actual participation in the research remains confidential. Privacy is particularly important when the research study is exploring topics that are potentially stigmatising and have secrecy attached, for example, in research related to sexuality (Valentine et al., 2001) or

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HIV/AIDS (Clacherty & Donald, 2007; Hunleth, 2011; Nyambedha, 2008). It may be necessary to avoid children retaining tangible items related to research participation, such as information forms, material produced during the process (such as artwork) or research reports, which may place child participants at risk or cause difficulties if discovered by, or inadvertently revealed to, others (WHO, 2011).

The nature of the information collected has implications for the development of protocols and processes with respect to confidentiality of the information gathered. Research that includes collection of personal information which could potentially lead to identification of research participants (for example, names, addresses, age, gender, ethnic origin, qualifications and experience) requires particular consideration of storage facilities and processes. Personal information should be stored securely and accessible only to those who are authorised (National Children's Bureau, 2003). If possible, data should be kept separate from identifiers, such as name and address.

Consideration needs to be given to the transporting, storage and disposal of information, bearing in mind the different forms of data collected, such as audio and video tapes, handwritten and electronic data, and biological data, such as genetic material. Personal data should be accessible only by those who need to use it, and sensitive data kept in a locked room with controlled access, or kept in a locked filing cabinet or drawer, or in password protected computer files (Shaw et al., 2011). If electronic data needs to be sent through the internet, confidentiality can be secured by the use of encryption protocols. Such protocols involve a process of altering data to render it incomprehensible to any eavesdropper, with the recipient being able to convert the received data back into meaningful information. Specific national and international guidelines regarding transporting, storage and disposal of biological data need to be consulted and implemented by researchers undertaking biomedical research, with explicit consideration of the ethical considerations for children. This includes adhering to guidelines regarding the maintenance, amalgamation and closure of genetic registers, with thought given to the procedures for seeking informed consent, ensuring confidentiality, and security of genetic registers for child participants.

### ***Privacy of the participants in dissemination of research findings***

Privacy includes ensuring that research participants are anonymous and not identifiable in research reports, presentations, and other means of disseminating findings. In certain research sectors, this is a stage where there exists potential to do great harm to children, their families and communities. Harm can occur through participants being identified in association with the research and information disclosed to powerful groups (such as government departments) that may compromise the well-being of individuals in certain situations. Similarly, communities require protection from any adverse consequences that may come about through identification in research. The ethical principle of non-maleficence obligates researchers to ensure that participants are not harmed or compromised through the dissemination of findings. Strategies can be used to help maintain anonymity, for example, removing identifying information from reports, changing the name of communities, omitting participants' names, and using pseudonyms. However, it needs to be borne in mind that the use of non-gender-specific pseudonyms means the data is not analysable in terms of gender (Gallagher, 2009). Particular attention needs to be given to

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the use of photographs containing images of children, other people, location landmarks and other identifying features, as well as to the use of direct testimonies of children.

While anonymity is the norm, it is also important to acknowledge that in some contexts children want to be identified in relation to the research and this should be considered if it does not pose any threat to them and/or provides recognition of their involvement. In addition to this, information provided to researchers that is not 'in confidence' but is given freely, with informed consent, and intended for wider dissemination, is not necessary to keep confidential per se.

## CHALLENGES YOU MIGHT MEET

Privacy is a key factor in ethical research practice, contributing to the authentic participation and protection of children during research. However, in certain situations and contexts, attending to privacy matters can present significant challenges to researchers. Tensions arise when researchers' understandings and expectations regarding privacy and confidentiality are at odds with the customary cultural, community or family practices of research participants or conflict with other ethical considerations, such as child protection. The disparity in power relations between adults and children is reflected in some of the challenges surrounding privacy, with adults not necessarily considering privacy an important or routine consideration for children, and children's preferences being subordinate to those of adults if there is conflict. Social and cultural contexts give rise to different considerations and challenges regarding confidentiality, and require researchers to critically reflect on the potential issues arising in each unique research situation.

### ***How can privacy be provided for children if this is not the usual social/cultural practice?***

In some cultural contexts privacy may not be the usual experience within families and communities and may be difficult to maintain in research. Parents, family members and other children may join interviews because the cultural customs, power relations, conceptualisations of childhood and status of children precludes privacy for children, and/or the belief that adults are more able to provide 'correct' answers (Abebe, 2009; Ahsan, 2009; Clacherty & Donald, 2007). In such contexts conducting research interviews in public places may draw less attention and consequently allow greater privacy than attempting to find a private location (Abebe, 2009).

The importance of public and social network confidentiality (Hill, 2005) is highlighted when members of the research team are from the same or linked communities to the participants. There may be inherent risks attributable to established social relationships and existing power dynamics with interviewers from the same community, which are beyond the awareness of an 'outsider' researcher. These may not be readily resolved, even if the risks are recognised, as selecting interviewers from other communities may see aspects of the research relationship, including those related to confidentiality, influenced by historic rivalries or different social backgrounds.

Parents and others may be interested in the information that has been collected and consequently they may ask about the data collected or the content of interviews, which can put stress on the

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Where possible children should be involved in choosing where the research is to take place.

child and the researcher. However, respecting the privacy of the child requires the researcher to keep information confidential and not pass it on intentionally or inadvertently (for example, by making comments among research team members in open space) to family members, friends or others known to the child.

### ***Which location best supports privacy for children in research?***

The social and cultural context contributes to determining which setting best allows respect for children's right to privacy, assisting them to provide information in research openly and freely. In research contexts in high income countries the usual expectation is that interviewing children in a quiet, private location where it is possible to talk without being overheard or interrupted is the most suitable approach. However, there are practical difficulties inherent in this approach arising across international contexts, as most research occurs in the child's home, at school or in recreational clubs where space may be at a premium (Valentine, 1999), there can be multiple interruptions (MacDonald & Greggans, 2008), adults may feel entitled to join the child participating in the research (Clacherty & Donald, 2007) and children may not be able to refuse to participate. Ideally, children should be involved in choosing where the research is to take place, in order to find a setting which is most suitable for them. However, tensions may arise with such an approach in regard to research costs and convenience.

In some contexts finding a location that allows confidentiality can be further complicated by societal concerns about protecting children from abusive adults, which leads to an unease with research being conducted by lone adults in settings that are not public (Barker & Smith, 2001; Matthews, Limb & Taylor, 1998). It may therefore be advisable to use locations that are visible to others but not within their hearing. However, tensions can arise if there are risks associated with research participation for children which are increased by being visible. The considerations have to be carefully weighed, in the unique context of each research study, to ensure that the risks are minimised and benefits maximised by whatever course of action is taken regarding privacy.

### ***How does the presence of others impact on children's privacy and information gathering during interviews?***

Despite the emphasis on privacy, difficulties with confidentiality in home settings can arise as some parents may insist on being present during research interviews, due to their curiosity or concern for the child (Fargas-Malet, McSherry, Larkin & Robinson, 2010). In some contexts, when interviews are being conducted, the gender of the interviewer may have a bearing on parents' decisions regarding privacy. For example, for a range of personal, social and cultural reasons, parents may feel more comfortable having their **adolescent** daughter interviewed alone by a female researcher, but not by a male. Parental presence can lead to a number of outcomes, both positive and negative, including spontaneous family discussion with more detailed accounts, shy children feeling supported (Powell et al., 2011), parents becoming involved by reinterpreting the questions for children (Hood et al., 1996), or the silencing of children (Valentine, 1999). The individual child's response to the parent's presence contributes to determining if this has a beneficial outcome for the child and with regard to the quality of the data collected.

An additional consideration is that some children may wish to have parents, siblings or friends present during the information gathering process. In such instances, it may be difficult to provide assurances of confidentiality and may also impact on how much information individual children wish to share. Respect for the child's wishes and autonomy would ideally provide guidance, however, this could be challenging and inappropriate in certain cultural contexts in which this is not the accepted custom. The reality is that researchers may not always be able to accommodate children's wishes if they are at odds with the parent's wishes, especially if the researcher needs to negotiate their position as a guest in the child and parent's home (Alderson & Morrow, 2011; Mayall, 2000; MacDonald & Greggans, 2008; Sime, 2008). The reality of the power dynamics in most situations is that when child and adult wishes conflict, children's wishes are usually subordinate to those of the adults.

When parents remain present for interviews, a range of covert and overt techniques can be used to minimise parental involvement (Bushin, 2007). These may include, limiting eye contact with the parent, specifically using the child's name when asking a question, raising subjects it is more likely only the child would know about, and reiterating the importance of ascertaining the child's opinions. These suggestions are subject to an awareness of the local context and, if necessary, discussion with community elders, to ensure that any minimisation techniques are culturally sensitive.

The researcher may need to adapt their expectations of data collection in response to parents who are reluctant for researchers to interview children privately or insist on being present. Respect for children's privacy regarding how much information they wish to share, which may be affected by who is present, should be privileged over the researcher's wish to elicit more information. A degree of reflexivity and flexibility is required on the researcher's part to ensure that they do not encroach on children's privacy in their desire to attain quality data. Some of the challenges that may be encountered in respecting children's privacy are highlighted in research with children with disability, in which traditionally parents or other adults have been expected to act as proxies representing children's voices and interests. In her case study, Berni Kelly discusses challenges to children's privacy in this context.

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**Case study 18: Interviewing children with disability in the presence of a parent, by Berni Kelly (see Case Study section p.154).**

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***How can confidentiality be respected in research with focus groups?***

Respecting individual privacy and confidentiality in the context of focus group consultations is an issue that needs careful reflection. This is particularly important in research within close-knit communities or on sensitive topics. Privacy issues in focus groups are further complicated by research which draws on internet chat rooms and blogs. There may be difficulties maintaining confidentiality in group settings (WHO, 2011) or when children wish to have friends or siblings present during interviews. How other children manage private information shared in the research forum requires agreement within

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the group from the outset and sensitive guidance on this issue by the researcher. There may be a need in some research studies for focused de-briefing of group interview participants with the aim of defusing any potential difficulties for the child once the research group has disbanded.

***What are the limits to confidentiality when there are safety concerns?***

A significant ethical challenge can arise in research involving children when researchers suspect child abuse or other unsafe or criminal activity, or have acquired information indicating this from child participants (intentionally or inadvertently shared on the child's part). This might include discovering that a child is being abused or neglected; is being harmed or threatening to harm her/himself or another person (Schenk & Williamson, 2005); or has a communicable or sexually transmitted disease requiring notification (Avard et al., 2011). The researcher has to decide whether to share the information and with whom, for example, parents, the police or care and protection agencies. This is a particularly contentious matter, and opinions and practice about breaching confidentiality to report suspected child abuse are divergent (Cashmore, 2006). In such instances, respect for the child's autonomy and right to confidentiality may directly conflict with the researcher's ethical responsibility to ensure that children are protected from harm. This issue may be further complicated if the researcher is a practitioner who has a dual role with the children involved in research, and the ethics of confidentiality directly conflict with professional standards.

The challenge involves the prioritising of ethical principles. The principle of respect for children's dignity and preservation of confidentiality underlies arguments against reporting issues such as suspected child abuse. Other arguments centre on the principle of beneficence (King & Churchill, 2000), on the basis that reporting will decrease the risk to the child, which can be perceived as a beneficial outcome (Knight et al., 2000).

There are numerous views about confidentiality and reporting concerns in research involving children. Some researchers recommend ensuring rather than guaranteeing confidentiality, and informing participants explicitly, prior to starting data collection, of the limits of confidentiality, the actions that will follow any safety concerns and which organizations will be involved (Duncan et al., 2009; Meade & Slesnick, 2002). A consequence of being explicit about the limits to confidentiality may be the loss of participants at the stage of recruitment, and attrition during the study, as well as impacting on the completeness and quality of the information obtained.

However, researchers' ethical commitment to respecting children is not diminished by applying limits to confidentiality and being explicit in relation to these allows for respectful conversations with children about the relevant issues. Researchers, ideally, should be able to talk with children before acting on their concerns and, where possible, plan the safest and most effective ways to take action, thus applying good practice in supporting children's participation which promotes the safety and protection of children (Feinstein & O'Kane, 2008). Ultimately though, it is the researcher's responsibility to ensure that the safety of children is prioritised. The case study by Lorraine Radford discusses ethical dilemmas related to protecting children and

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addressing confidentiality, in a UK study about children's experiences of violence, abuse and neglect. It describes a system that was put in place with alert, review and referral processes.

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**Case study 19: Child protection and confidentiality: Surveying children's experiences of violence, abuse and neglect, by Lorraine Radford (see Case Study section p.156).**

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The age of the child and the familial, as well as societal, context may have some bearing on the approach taken by the researcher in regard to child protection. The researcher response needs to take the evolving capacities of the child into account in relation to the perceived concern, potential reporting action, inclusion of the child in deciding this and the possible outcomes. For example, it seems unlikely in some situations that older children or youth would agree to participate in research if they thought that such participation would result in them being referred to the authorities of whom they (and perhaps the researcher) are mistrustful. In addition, researchers need to be aware of both law and customary law on when adulthood is reached, recognising that there are differences between countries in relation to these. This is particularly pertinent with regard to reporting safety concerns regarding children. In peer research it is important that training is given, parameters of confidentiality are clear and that support mechanisms are in place for young researchers. The case study by Clare Lushey and Emily Munro looks at challenges that arose in peer research, with regard to differing degrees of concern and opinions about confidentiality in relation to a specific incident.

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**Case study 20: Peer research and young people in and leaving out-of-home care, by Clare Lushey and Emily Munro (see Case Study section p.159).**

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Researchers need to be aware of requirements with regard to mandated reporting. The decision to report concerns or knowledge regarding harm or potential harm to children may be a legal one as well as an ethical one (Fisher, 1994). Legal requirements with regard to reporting suspected abuse or child maltreatment differ across international contexts (Williamson, Goodenough, Kent & Ashcroft, 2005). In some areas legal or professional requirements may mandate reporting of suspected child abuse (for example, by health professionals, teachers and psychologists), even if researchers as a professional group are not specifically mandated to report. However, these requirements are not consistent internationally, or even nationally in some cases.

Some ethics review committees and institutional review boards require mandated reporting of suspected child abuse, and this mandatory approach is recommended by some researchers to provide clear guidelines, prioritise child protection and ensure uniform research practice (Allen, 2009; Steinberg, Pynoos, Goenjian, Sossanabadi & Sherr, 1999). The lack of consistency across international contexts, within countries and across ethical review boards underscores the importance of researchers considering the issue of reporting prior

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The lack of consistency across contexts underscores the importance of researchers developing reporting protocols prior to starting data collection.

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to starting data collection and creating a plan or protocol to follow if required. Making a contingency plan before the research starts, for providing support or referral to appropriate services for children who reveal themselves to be at risk of harm, provides some relief from the dilemma.

The needs of the research must not subsume ethical responsibilities toward children who may be at risk. However, some researchers intentionally use methods to prevent disclosure, avoid reporting child abuse and assure confidentiality (Socolar, Runyan & Amaya-Jackson, 1995), such as limiting response options, warning participants not to tell, and masking the responses so that the data is anonymous, thus avoiding researcher knowledge of individual disclosure of concern. These methods avoid compromising confidentiality, but clearly the principles of beneficence and justice and the researcher's obligation to act in the best interests of the child are neglected. In addition, children who may have an expectation that disclosure of concern in a research context would lead to help and support, despite assurances of confidentiality, are disregarded.

***What if children (or parents) do not want to be anonymous in dissemination of research findings?***

Various strategies can be used by researchers in order to maintain anonymity, as discussed above. However, children sometimes want to have their real names used in publications and research reports in recognition of their participation. In some situations parents, supported by professionals, also may want to waive anonymity when they perceive that publication, which includes identifying information, will bring about sufficient benefits to warrant this. An example of this is apparent in the case study provided by Andrew Williams, which gives identifying information that is already in the public domain as a means of illustrating benefits of research involving a child with a degenerative condition who is unable to provide consent. [See Case study 2 in the Harms and Benefits subsection of the Case Studies in this compendium.]

However, waiving anonymity presents a challenge for researchers who take the approach that participants are best not identified, for example, in research that is sensitive in nature. One consideration is the extent to which it may be difficult for children to assess the potential risk and/or long-term implications in using their own name. They may not have the experience to know where the material will end up and how it may be distorted by the media (Laws & Mann, 2004). However, this has to be balanced against individual children's ability to make a sound judgement and the reality that children may be better placed to assess the risks to themselves in familiar contexts. Discussing the concerns with children is an important step in this decision-making process.

Anonymity is a means of avoiding harm, however, precautions against recognition of participants (such as removing identifiers) are not always necessary, and may even impede appropriate recognition. Researchers also need to be aware of the importance of ensuring that children's participation is recognised and valued in forms that are discernible and meaningful to the participants. In participatory research where children are actively involved as researchers they may want their names included to recognise and value their important contributions. In such contexts children can be

encouraged to identify any potential risks and advantages (now or in the future) of their names being included, so that informed decisions can be made.

The use of photographs in the dissemination of research raises issues around privacy and anonymity, both at the time of dissemination and also in the future, when the child may have a different opinion about the use of their image. It also raises issues related to power and representation of children (Phelan & Kinsella, 2013). Researchers may use ways to hide the identity of children involved in their research (or photographed by children involved in their research) in order to ensure they are not identified and maintain their anonymity. Strategies may include pixilation, blurring the face or image, or perhaps using only text in representation of the findings (Nutbrown, 2010). However, Nutbrown contends that this raises an ethical debate about children's voice — arguing that if consent or assent has been obtained from children to use their images might researchers be silencing children in attempts to protect them? The issue of anonymity in relation to children's authentic representation raises the tensions between protection and participation that are not easily resolved, particularly with the added dimension of speculating about future (unknown), as well as present, contexts.

### ***What are the privacy and confidentiality challenges related to technological developments?***

Privacy and confidentiality, when conducting research using technological media, such as computers or mobile phones, with children, is an important consideration. There is the potential risk that people known to the children may gain access, intentionally or inadvertently, to the information. Mobile phones and computers may be shared within households or organizations compromising the privacy of participants and their information.

The issues are further compounded in research that uses information and communication networks such as the internet, instant messaging and social media for data collection. The expectations research participants may hold of privacy online may be exaggerated, if not illusory (Lobe et al., 2007). Diverse modalities of online internet communication have different features and, consequently, different practicalities in regard to privacy and confidentiality. For example, some internet forums are intentionally public and therefore anyone can read messages that are posted without leaving a trace of their presence. However, people's presence in chat rooms is more apparent and real time communication makes it awkward to observe without interacting (Lobe, Livingstone, Olafsson & Simões, 2008).

The complexities of obtaining online informed consent, the ability of researchers and participants to assume anonymous or pseudonymous identities, and the potential for them to have multiple online identities, contribute to the ethical concerns in online research with children (Lobe et al., 2007). There is the risk that people not belonging to the group of selected child participants, may give false details and participate under false pretences, threatening the privacy and safety of the group (Alderson & Morrow, 2011).

Research using new technologies requires consultation with communities (including online communities) and children, prior to undertaking research, to reduce risks of breaking confidentiality

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(WHO, 2011). In addition, the challenges around protecting images of children and data collected (for example, children's artwork or photographs) on the internet are an increasing concern.

## WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO PRIVACY AND CONFIDENTIALITY?

- Children have the right to privacy (Article 16).
- Children's best interests should be a primary consideration (Article 3).

## KEY QUESTIONS

### ***How will children's privacy and confidentiality be respected?***

- How will you ensure children and their families cannot be identified?
- How will privacy be attended to in the research setting?
- Do you plan to allow parents or persons in authority to be present when research is being conducted with children? Why? What impact may this have on children's involvement in the research or the information they may share?
- How will you respond if parents or others will not allow children to be interviewed on their own?
- What will the gender and number of interviewers be in relation to the children being interviewed? Why?

### ***How will you attend to concerns about children's safety that arise during the research?***

- How will you ensure children (and parents) understand the circumstances under which confidentiality should be breached?
- What actions will you take in response to a child's disclosure of harm or abuse?
- How will you ensure that children are informed in regard to these and their views taken into account?
- Who else will you need to inform about these actions?

### ***How will you ensure that research findings are disseminated safely?***

- How will you ensure that the identities of children, families and communities are not revealed?

***How will you ensure data is safely stored and destroyed?***

- What strategies do you have in place for the safe and secure storage of data?
- When and how will you ensure the secure destruction of all nominal information?

***Are there additional strategies that would enhance research staff's capacity to respect children's privacy and confidentiality?***

- To what extent would developing and implementing explicit protocols for research staff regarding privacy and confidentiality be helpful?
- Have research staff received training relevant to privacy and confidentiality in research involving children?

ISBN: 978-88-6522-023-8

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