

# PRIVACY AND CONFIDENTIALITY

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## **Negotiating privacy, confidentiality and consent in focus groups with children and young people**

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### ***Background context:***

In 2015, the Australian Royal Commission into Institutional Responses to Child Sexual Abuse contracted us to complete a study to understand what children need to be safe and feel safe in organisations such as schools, sporting groups, religious institutions and holiday camps. In focus groups, children and young people considered what it meant to be safe, what adults and organisations were doing and could do to improve their safety and prevent safety concerns (such as abuse) and to ensure that adults and organisations responded in child-friendly ways.

In our participatory research projects we have worked with a number of child and youth advisory groups to guide and strengthen our practice. We seek their feedback on the nature and purpose of our studies and advice on the ethical challenges of conducting sensitive research with groups often deemed 'vulnerable'. For the Children's Safety Study we recruited three groups of advisers: one was made up of primary-school-aged children (11-12year olds), another from high-school-aged young people (15-16years) and a group comprising young people from an alternate education program (aged 13-17).

### ***The ethical challenge:***

Members of our Child and Youth Advisory Groups spent some time considering the ethical challenges of conducting this sensitive research. Among other concerns they believed that it was important for participants to have as many choices as possible and to be assured that what was shared in groups was kept confidential. They worked with us to develop a consent process which included informing the group about the consequences of sharing their peers' input outside of the sessions. Members thought it might be embarrassing, cause shame and bullying if things like their fears were shared. They also considered it important to complete each session with a group agreement as to what could be discussed by all focus group members outside of the group.



We undertook focus groups with young people in schools, recreational and support programs, early childhood education settings and with children and young people living in out of home care. In many of these settings, an adult observer from the participating organisation sat in focus groups so that they could provide assistance to any child or young person that might feel uncomfortable with the content of the discussions and to meet the organisation's child safety policies. Children and young people in the Child and Young People's Advisory Groups felt strongly that these observers should be bound by the same expectations as researchers and participants. They appreciated, however, that observers may want or need to follow up on any issues arising within the groups (such as disclosure of harm, poor practices, concerns about the behaviours of staff and children, or approaches that made children or young people feel unsafe).

### **Choices made:**

The advice provided by the Advisory Groups informed the choices made. In partnership with adult researchers, a group agreement was developed at the beginning of each focus group which set expectations on how the groups would proceed. At the end of the focus groups, participants and observers were reminded that they had agreed that things shared in the group would be confidential and not shared outside of the group (unless there were concerns for children's safety). This listed all the things (both positive and negative) that the group believed could or should be shared and why and to whom these things could be communicated. In particular, the group was asked to consider what, if anything, observers could share if asked, "How did the group go? What did they say?" and whether there were any concerns raised in the group that observers might act on (realising that it would be months before the findings of the study would be communicated more broadly). Researchers, observers, children and young people came up with an agreement as to what could be shared, by whom and for what purpose. When consensus was found, all children, young people, researchers and observers indicated their agreement either verbally or by signing a copy of the document.

As an example, in one focus group children reported that when they were unsafe they often talked to their stuffed toys about their worries and concerns and felt safer when they could play with them. When asked in the closing exercise what they did not want shared with others outside the group, a few of the children felt that they might be bullied by children outside of the group if it was known that they still played with these toys. The group decided that researchers could share these stories in the research report but that no one in the group should talk about it outside.

In another group, children reported that their school's Easter play (where the suffering of Jesus was graphically depicted) caused younger children some distress. They felt that it was OK for the observing teacher to share this with the school's Principal because they thought that she needed to know and that they preferred that this event be changed to focus more on the positive parts of Easter. They agreed that the observing teacher should not name the individuals who raised this concern but that the group felt that it was something that should be actioned.

When asked if there were any types of information that could be share outside of the focus groups, participants felt that it was appropriate for adults and observers to discuss or take action: when individuals were unsafe; when adults or organisations were doing things that needed to be altered; and on things that would ultimately improve children's safety or their experiences within an organisation.

It is important to note that the groups agreed that if information was disclosed indicating a child or a group of children were at risk of being harmed or had experienced abuse, participants would be informed that action must be taken and a discreet conversation with that individual would occur. A separate agreement would then be negotiated with the participant who would know what was going to happen and what involvement, if any, they wished to have. In the ten focus groups involving 121 participants there was only one disclosure of a past experience of abuse and the agreed process was implemented.

In developing this process for negotiating agreement with research participants, the research team had to reflect on the nature and purpose of confidentiality and its limits. We were reminded that confidentiality is not breached when participants (namely children and young people) explicitly consent to particular parts of their focus groups to be shared and that, in some cases, it is both ethical and appropriate to do so.

### ***Reflexive questions/considerations:***

Although this mechanism was primarily developed to address issues of confidentiality, privacy and consent it also appeared to be empowering for children and young people. Participants reported that it was unusual for adults to be asked to be accountable to groups of children and young people and they observed that the process demonstrated that the research team took their rights seriously and encouraged other adults to do the same. It also gave researchers the opportunity to remind adult observers that they were also expected to

maintain the group's confidentiality, aside from the exceptions negotiated with the group.

In focus groups, children and young people highlighted that a key source of distrust in adults arose from adults passing on information that was shared by children in confidence. Having an explicit agreement that sets out what, when, how and with whom information is shared was considered empowering.

Children and young people were well aware that in many circumstances adults need to share information, particularly when children are unsafe or have experienced harm. They encouraged adults to negotiate with children *how* (not whether) these concerns might be discussed with others.

In the case of the focus group where children talked about toys as being a source of comfort or distraction, researchers and observers were unaware that children might be worried about this information being shared. As such, what adults considered 'sensitive' was different to what children believed might cause them embarrassment or harm (i.e. bullying). In developing a group agreement, adults developed a greater appreciation of the consequences of sharing accounts outside the group and some of the children's concerns were allayed.

On the basis of such considerations the following questions might guide further reflexive engagement:

- How do children and young people understand ethical considerations such as confidentiality, privacy and consent and what expectations do they have of you as a researcher as well as adult observers and others involved in the research process?
- In addition to meeting the requirements of Ethics Committees, what else needs to be done to ensure that children and young people's expectations are met?
- Informed consent requires children and young people to understand what they are being asked to do and why – what do they need to be able to meaningfully make informed decisions?

Further detail about our approach to consent can be found in (Moore, McArthur, & Noble-Carr, 2018).

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## **References**

Moore, T. P., McArthur, M., & Noble-Carr, D. (2018). More a marathon than a hurdle: towards children's informed consent in a study on safety. *Qualitative Research, 18*(1), 88-107.

