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Children and young people's decision-making in social research about sensitive issues

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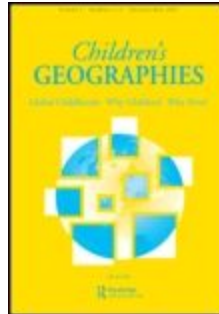
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Children and young people's decision-making in social research about sensitive issues.

Abstract

Limited attention has been given to what motivates and informs children and young people's decision to participate (or not) in social research, especially about sensitive issues. This paper reports the findings from focus group interviews with children and young people aged 9-16 years, undertaken as part of a larger study that explored what constitutes a sensitive issue in social research and the factors considered when deciding to participate.

Participants articulated a range of intrinsic and extrinsic motivations: benefiting others, getting something out of it, getting things 'off your chest' and the role of incentives and trusted adults. While similar to findings about *medical* research, the data from this study provides deeper insight into how children and young people make decisions to participate in *social* research. The critical role that accessible information plays in supporting children's considered decision-making is highlighted, along with rich insights into why research might matter for themselves and others.

Key words

Children and young people's decision-making

Participation in social research

Children and young people's motivation

Introduction

Over the past 20 years, closer attention has been placed on children and young people's participation in social research (Abebe and Bessell 2014; Broome et al. 2003) Contestation over whether children

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3 and young people *should* participate has largely been replaced with debates about *how* research might
4 be conducted in appropriate and ethical ways (Kennan and Dolan 2017). Central to these
5 conversations have been questions about how to best facilitate children and young people's
6 participation, including recruiting them and gaining consent from their parents and others who may
7 support, limit or deny their engagement in research (Campbell 2008; Collings, Grace, and Llewellyn
8 2016).

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13 Researchers report that recruiting young participants can be difficult, often because they are reliant on
14 a number of stakeholders (sometimes referred to as 'gatekeepers') to support, approve and (in the case
15 of parents) consent to the child or young person's involvement (Harger and Quintela 2017; Powell
16 and Smith 2009). The challenging and labor-intensive nature of recruiting children and young people
17 can sometimes be attributed to researchers not adequately understanding parents' and other
18 stakeholders' concerns or factors affecting their decision-making. This process is often more
19 problematic when the topic of the research is regarded as 'sensitive' or the group of children and
20 young people are seen as particularly vulnerable (Campbell 2008; Carter and Osborne 2009; Powell et
21 al. 2018). Exacerbating such challenges is the lack of agreement about what constitutes a 'sensitive
22 topic', despite such phrasing being ubiquitous (Richards, Clark, and Boggis 2015, 26). While some
23 topics appear to be considered sensitive across different groups of people, such as those related to sex,
24 sexuality, drug and/or alcohol use and child abuse, sensitivity is largely dependent on the contexts of
25 children's lives and experiences (Authors 2018).

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Once stakeholder approval and parental consent is obtained, researchers need to communicate (often
through a proxy) the nature, risks and benefits of participation with children and young people, so that
they feel comfortable participating and sufficiently informed to provide assent. This process is often
repeated when commencing data collection to ensure that children and young people have fully
understood what their participation entails.

However, there remains limited attention to what motivates and informs children and young people's
decision to participate or not participate in social research, especially about sensitive issues (Authors,
2018). A clearer understanding is needed of how children and young people conceptualise research
and their decision-making process, given the likelihood of adult decision-makers underestimating
their capacity and/or of overstating or minimising the perceived risks of participating in social
research, particularly about what might be deemed 'sensitive issues'. Understanding both the intrinsic
and extrinsic motivations for children's participation in 'sensitive research' will provide researchers
and those making decisions about how children might engage in research with insights to help
strengthen research design, recruitment strategies and ethical review.

This paper reports the views of children and young people about these decision-making processes. It
is based on focus group data collected as part of a larger multi-phased, mixed-method Australian

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3 study which explored a range of stakeholder perspectives (including those of children, parents,
4 researchers, ethics committee members, government and non-government organisation
5 representatives, and other decision-makers) about the barriers and enablers to children's participation
6 in social research. The study aimed to better understand the tensions between the protection of
7 children and their participation in social research, what constitutes a sensitive issue and how key
8 stakeholders make decisions about children's participation in social research about sensitive topics.
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13 This article draws from the final phase of the project that recruited children and young people to
14 explore the factors that influenced their decision-making and to tease out some of the ethical,
15 methodological and practical implications associated with this. The findings shed light on children
16 and young people's decision-making and provide guidance about the intrinsic and extrinsic motivators
17 that influence their participation and what issues they consider when making a decision to participate.
18 These insights might usefully inform stakeholders, parents, and children and young people about what
19 they need to know before they agree to consent to children's participation in social research (Authors
20 2018b).
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28 Background

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30 Over the past 20 years there has been a growing interest in the factors that influence the decision-
31 making of participants in research. Within the literature there has been much consideration of some of
32 the extrinsic motivations for participation, namely the use of incentives and concerns related to
33 coercion and intimidation (Grant 2015). Increasingly, researchers have also been interested in some of
34 the intrinsic motivations (Carrera et al. 2018) but this literature is less developed. Intrinsic motivations
35 often relate to the personal benefits a participant receives, particularly their sense of altruism, their
36 desire for their views and experiences to be given recognition and validated and their sense of duty to
37 engage (Carrera et al. 2018; Seymour 2012).
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43 Missing from this literature is a consideration of children's extrinsic and intrinsic motivations for
44 participation in social research (a notable exception being a study by Edwards and Alldred (1999)).
45 This is despite a significant body of social research being conducted with children and young people
46 and significant debate about the ethics of their participation. Much of the literature that focuses on
47 children and young people's involvement is linked to medical research (see, for example, Brody et al.
48 2005).
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53 In the medical sphere, studies have shown that children and young people highly value the
54 opportunity to benefit others (Brody et al. 2005; Brody et al. 2012; Varma, Jenkins, and Wendler
55 2008; Wagner, Martinez, and Joiner 2006) and that this is the strongest factor that influences their
56 decision to participate (Barned et al. 2018). Other factors include perceived benefits to themselves
57 (i.e. learning more about their own health or treatment; access to therapies or alternative treatments;
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3 perceived improved relationships with practitioners), opportunities to learn, to have their say and to
4 influence practice, and help build new knowledge (Barakat et al. 2013; Varma, Jenkins, and Wendler
5 2008).

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8 In addition to their own assessments of the value of participation, children and young people in these
9 studies were often influenced by what has been described in the literature as 'extrinsic motivations'
10 (Ryan et al. 2000, 2020). These included their parents' views, the relationship they had with the
11 person recruiting them for the research, and their sense of responsibility to others (Brody et al. 2005) .
12 In some studies, children and young people reported that there were extrinsic motivations for
13 participating in medical research (i.e. for incentives they were promised), while in others, incentives
14 were not identified as being important to children and young people (Brody et al. 2005; Hoberman et
15 al. 2013; Nasef et al. 2014).

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18 In medical studies, children and young people also identified several potential risks, inconveniences
19 and disincentives to their participation. Often these were specific to the different therapies or
20 treatments that were being tested through studies (see, for example, Bernhardt et al. 2003; Wiener et
21 al. 2015). A lack of information about the nature or purpose of a study, lack of clarity about the
22 potential risks and benefits, feeling hassled or having to give up time, being invited by a stranger and
23 not feeling as if the study would be interesting, were other factors that discouraged children and
24 young people from participating (Barakat et al. 2013; Bernhardt et al. 2003; Brody et al. 2009;
25 Hoberman et al. 2013).

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28 Edwards and Alldred's (1999) social research study examined these issues in some depth and sought
29 to understand what motivated children's decision making. The researchers talked to 70 children, aged
30 between 10 -14 years from a range of schools, about whether and why they might participate in a
31 study about parental involvement and home-school relationships. They found that children often
32 believed that research gave them an opportunity to listen and learn from others, to have their say, to
33 inform adults about things adults should know, and to enact their rights to participate. However, they
34 also established boundaries and highlighted things that they thought were private. Some young people
35 were indifferent about research and its value. Edwards and Alldred noted that the responses from
36 children often varied across schools and appeared to be shaped by their school's location and the
37 social class of child participants. Their conclusion highlights the enmeshed set of factors that children
38 and young people are likely to consider when deciding whether or not to participate and some of the
39 contextual factors that also have some influence.

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42 Apart from the Edwards and Alldred study, there remains a lack of knowledge about the factors that
43 influence children and young people's decision-making in social research, particularly around topics
44 that might be regarded as 'sensitive'. It is difficult therefore to determine whether the medical
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findings, flagged above, are broadly applicable to other kinds of research or whether there are other factors that come into play in the context of social research.

Indeed, it is possible that what we know from the research about children's participation in clinical studies may have limited relevance, given specific risks of harm (related to medical intervention) or benefits to children individually or as a group (such as improved health, life saving) are quite different to possible risks and benefits in social research (Morrow 2012; Kennan and Dolan 2017; Alderson and Morrow 2020). Our study attempts to understand children's decision-making processes and motivations to participate in social research on topics identified as sensitive.

Research Approach

This article focuses on findings from the final stage of a large mixed methods study undertaken in Australia. The study involved three stages:

- Interviews with various stakeholders (researchers, ethics committee members, parents, children and other decision makers) to identify what constitutes a sensitive topic in social research with children, and their decision-making processes generally (Authors. 2018).
- The development of a series of online surveys, administered to a wider range of decision makers, to identify the key factors for agreeing to research with children, including the role that incentives and topics play in decision making (Authors. 2019).
- Focus group interviews with children and young people to explore in more depth children's decision-making processes and motivations for participation in the hypothetical studies developed for the online survey. The focus groups were framed by two broad questions:
 - How do children and young people think about 'sensitive' topics?
 - What motivates children and young people to participate in social research about 'sensitive issues'?

Children's Participation

A Children and Young People's Reference Group (CYPRG) was established, with five children, aged 7-13 years, and was co-chaired by two Youth Advisors (aged 16 years). Because the project was about the barriers and enablers to participation in social research and aimed to explore decision making, we invited children and young people who had recently been involved in social research about sensitive issues. Members of the CYPRG had participated in previous studies on projects around safety, living in out of home care and loss. When inviting children and young people to participate we discussed whether they felt their experience in previous studies gave them certain expertise and confidence in understanding the aims of the study.

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3 The CYPRG helped identify some of the ethical and practical challenges of conducting the study,
4 assisted in adapting key concepts into child-friendly language, and guided the development of
5 vignettes and other research tools utilized in the study (Stages 2). They also provided feedback on the
6 themes developed in each of the stages and shared insights into how these themes informed the
7 conclusions of the project. They met on four occasions.
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11 12 Ethics

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14 This study was conducted with the approval of the [researcher's] University (Number 2016-110H)
15 and ratified by partner universities (INSERT DETAILS). Schools and non-government organisations
16 helping to recruit participants contacted parents and provided them with information about the study,
17 the proposed methodology and a description of the anticipated risks and benefits. Consenting parents
18 then provided their children with an information brochure which used child-friendly language to help
19 children make an informed decision about consent (Authors, 2018).
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24 Focus groups were conducted by experienced researchers with expertise in working with children and
25 used child friendly methods (including small group discussions, story-telling, and games, value walks
26 and a computer program¹ to stimulate discussion), enabling participants to opt-in and out of
27 conversations and providing multiple opportunities to withdraw their participation. As children and
28 young people participated in groups, a collective agreement was developed in partnership with
29 participants, which clarified what expectations there were around confidentiality, anonymity and
30 choice. All participants and researchers agreed to the shared terms (see: Authors 2018b, for more
31 detail).
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41 Method: Focus Groups with Children and Young People

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43 Thirty-five children and young people participated in five semi-structured focus groups conducted in
44 two Australian state jurisdictions (Australian Capital Territory and New South Wales). Participants
45 were aged 9 to 16 years and included 17 males and 18 females. Participants were provided with a \$30
46 gift voucher to thank them for their time.
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50 Participants and recruitment

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52 Children and young people were recruited through schools and community organisations. As the
53 broader study focused on 'sensitive topics', children who lived in out-of-home care and participants
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3 who attended a youth centre were also recruited to provide the perspective of those often deemed
4 'more vulnerable'. The sampling approach was purposive and did not attempt to represent broader
5 child and youth populations. Table 1 summarises the demographics of the children and young people
6 who participated.
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13 Table 1 Participants
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		State	Number of participant	Ages
Children (CH)	Children in out of home care system (#FG1, CH IN OOHC)	ACT	3	Aged 9-11 years
	Primary-school-aged children (#FG2, CH IN SCHOOL)	NSW	5	Aged 10–12 years
Young People (YP)	Secondary-school-aged students (#FG3, YP IN SCHOOL)	ACT	10	Aged 12–13 years
	Secondary-school-aged students (#FG4, YP IN SCHOOL)	NSW	10	Aged 12-13 years
	Youth Drop in Centre (#FG5, YP IN YC)	ACT	7	Aged 13–16 years
	TOTAL		35	

Data collection

The focus groups commenced with participants being invited to answer the online survey (used in stage 2), which included a series of vignettes (Authors. 2019). Hypothetical studies were presented which ranged from relatively benign to highly sensitive studies, and participants were asked, if invited to, would they agree to participate or not. The amount of payment and the study methods were also varied to test their impacts on children and young people's agreement to participate. Focus group participants were asked to decide whether they would participate in the proposed studies before engaging in a conversation about how they made the decision. Questions included: 'How would you decide whether you would like to participate in a study?' and 'What might keep you from participating?' As the hypothetical studies had varying degrees of risk associated with the topics this became the basis of the discussion on what constituted a sensitive topic and whether this influenced whether they may participate or not².

We then explored the process through which the children and young people agreed to participate in the focus group – 'how were they invited', 'how parents informed them', 'how they decided whether they should participate or not' and any barriers that might have restricted their participation. It is this exploration of their motivation and decision making around participation that is the focus of this paper.

Data Analysis

The focus group discussions were digitally recorded, with the participants' permission, transcribed and uploaded into NVIVO 12 software program for analysis. Using a thematic analysis approach, each focus group content was coded deductively, based on what children said in relation to each of the key research questions. Each focus group's data were examined in depth and then comparisons made across other focus groups. This provided a comprehensive approach to the data analysis. The strength of the theme was assessed (determined by the number of times they were identified and within how many groups they were raised), based on the meanings and interpretations found in the transcripts (Punch 2013; Silverman 2011). Given we were interested in why children might be motivated to participate, the reasons were grouped into intrinsic and extrinsic motivation. The ideas and themes from the analysis were examined for robustness, by researchers within the team, the project advisory group and the Children and Young People's Reference group, to check that interpretations and conclusions were consistent and accurately reflected participants' data.

² Further detail about the vignettes can be found in Authors (2018)

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3 The qualitative findings were analysed to consider children and young people's motivations to
4 participate in the *actual* focus group as well as whether to participate in a range of hypothetical
5 studies.
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8 9 **Dissemination of results**

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11 Recognising the implications of the study for the various partners, the research provided feedback to
12 groups of participants in different ways. For adults and partner organisations, the research team is
13 developing a series of guides and summaries to present findings and implications. For children and
14 young people, a session at the end of each of the focus groups provided them with an overview of the
15 findings from their session and member-checked the researchers' observations about key themes. An
16 information session was held for members of the Children and Young People's Reference Group
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23 **Limitations**

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25 The focus of the study was to understand what helps and hinders children and young people's
26 participation in sensitive social research. There is some inherent incongruity with this in that the
27 findings presented are from focus groups made up of children and young people whose parents and
28 other gatekeepers agreed to their participation and those children and young people who were keen to
29 do so. Although there was some variability in individual groups of children's preferences and
30 decision-making the data does not represent the views of those who were restricted from participating
31 and those who chose not to engage. As such, the findings must be understood within this context.
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37 Due to the small number of participants in groups and the limited number of groups conducted the
38 analysis did not attempt to consider whether young people from particular backgrounds had different
39 experiences or motivations. However, when considered alongside findings from our online survey
40 (Authors. 2019) the themes can be considered robust.
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48 **Findings**

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50 Children and young people reported several factors they considered when deciding whether or not to
51 participate. This first section examines the significance of the topic and concept of sensitive research.
52 We then discuss factors children and young people identify as key to their decision making.
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Focus of the study and the sensitivity of the topic

Focus group participants spent some time considering the topics in the hypothetical studies as well as having a broader discussion of the types of topics that might either engage them or contribute to their reluctance to participate. There was some variation between individuals in the groups and between the groups as to what constituted a 'sensitive' topic.

The participants in all the groups spontaneously identified sensitive topics when the interviewer asked about the term. In doing so, most also recognised that children and young people differ in what they might experience as 'sensitive'. For example, some young people felt that discussing personal and family relationships might be sensitive for some youth (who had experienced relationship problems or family breakdown) but not for others. The immediacy and the depth of impacts seemed to play a part, with those who were currently experiencing a challenge or who were still upset about an incident (such as a conflict) more likely to see a topic as particularly sensitive and confronting.

I feel like it would also be confronting issues that might not have actually directly happened to you but the idea of it could be disturbing (#FG3, YP IN SCHOOL 12-13yos).³

I've got something else I think it's just more of a really fragile subject that if you think of it as glass, if you keep tapping on it too much, then you're going to break, and maybe have a break down about it. (#FG1, CH IN OOHC : 9-11yos).

For some individuals, 'sensitive' topics were ones that should never be discussed with children and young people, including sexual abuse, problems at home, sexuality and death. They felt that talking about these issues might cause discomfort because they are not things that children are used to speaking about, they might cause embarrassment, or that by talking about them children's fears might be publicly expressed.

Some participants were wary of studies that might ask them questions that were embarrassing, particularly when asked in front of their peers. They felt that when topics were considered sensitive it might be better to discuss those using one-on-one methods (such as interviews or surveys) rather than in group settings. This would enable children and young people to still have their say on important matters but to do it in a way that enabled anonymity:

I reckon people could judge you for your answers, and start bullying you for what you say, and they might have different views and opinions of what you've got to say. (#FG4, YP IN SCHOOL: 12-13yos)

³ The participant codes with each quote indicate: Focus group number (FG#); young person (YP) or child (CH), School or Out of home care (OOHC) group: age group.

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3 *if there was a chance of it making me feel uncomfortable or something, I would*
4 *rather do it anonymously than in front of people. (#FG4, YP IN SCHOOL: 12-*
5 *13yos).*
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9 However, there was a sentiment, across groups, that participants might still choose to participate in
10 studies focusing on these topics if they believed that it was going to benefit others. They perceived
11 that it was important for young people to still be given a choice.
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15 *I think no, because, if it's for a good cause, then there's a benefit to talking about*
16 *it and getting, because after all the research is done, and there can be statistics*
17 *and stuff to show parents and other people what's actually happening, because*
18 *you get sort of like a firsthand experience because the people that've had it happen*
19 *to them can actually say what's really happening (#FG4, YP IN SCHOOL, 12-*
20 *13yos)*
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24 Children and young people reported that they were more likely to participate in a study with a
25 sensitive focus if it considered something that they had experienced, had a strong view about or that
26 seemed interesting to them.
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30 *If it was an issue that I was really passionate, or felt strongly about, then I'd*
31 *probably do it, just as a way of expressing my views and opinions, it's an easy way*
32 *to directly get it out. (#FG3, YP IN SCHOOL: 13-16yos).*
33

34 One of the younger participants was very graphic in his explanation, During an activity that invited
35 participants to identify on a continuum how likely or not they would participate in studies on
36 particular topics. One of the scenarios focused on experiences of bullying and violence. This young
37 man who was currently living in foster care said:
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41 *'I would be right out here in agreeing to participate (indicating a long way down*
42 *the corridor) I would definitely talk about this topic – I've experienced it and I*
43 *would definitely participate'. (#FG1, CH IN OOHC : 9-11yos).*
44

45 Conversely, many participants indicated they would be less likely to participate in studies on a topic
46 that was not relevant to them and when they felt that the research activity itself (i.e. a survey) might
47 be boring. They acknowledged that their disinterest in the topic might be tempered if they were
48 invited to participate by someone who was important to them or if they believed that they might have
49 a duty to. Further detail about these considerations is discussed below.
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53 **Motivating factors**

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55 In their responses to questions and activities about whether they would participate in particular studies
56 the participants provided rich insights into personal motivation for being involved in research. These
57 factors are detailed below.
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Benefits for others

In three of the five groups (including two with young people in schools and one with children and care), participants reported that they would participate in a study if they thought that it was going to be beneficial for others. The benefit could relate to a discovery made, about informing a certain practice or program, or about helping adults better appreciate what children and young people think and feel.

For me it depends on the purpose of the survey and where the information is going to be used, because I think even if it's an uncomfortable topic that I have experience with, I think if it was going to improve that situation for other people and help out people who are facing these situations, then I think I'd participate in the survey (#FG3, YP IN SCHOOL: 12-13yos)

But I understand some people might not want to do it because they just think, if it's not benefiting people or benefiting them, then they just sort of think it might be a waste of time, something like that. (#FG4, YP IN SCHOOL: 12-13yos)

Altruism was such an important factor that some participants reported they would be more likely to participate in a study, even if they believed that it might cause some discomfort, be time-consuming or not be as enjoyable as another topic.

even if the topic might have negatively affected me in the past, I reckon I would still get involved in it to help out other people who might either have gone through that and need help or are going through it. (#FG3, YP IN SCHOOL: 12-13yos)

For me it depends on the purpose of the survey and where the information is going to be used, because I think even if it's an uncomfortable topic that I have experience with, I think if it was going to improve the situation for other people and help out people who are facing these situations, then I think I'd participate in the survey (#FG3, YP IN SCHOOL: 12-13yos).

Catharsis / 'getting things off your chest'

As noted, children and young people often reported they would participate in a study if it considered a topic that was relevant to them or an experience they had encountered. This was particularly the case for children and young people who had a negative experience and had not previously been given an opportunity to talk about their experience or the negative consequences arising.

Yeah, well if say I got bullied and we were on that topic, I would just use it as a way to get all the weight off me, talking about it. So, I find it a good experience rather than a negative experience. (#FG3, YP IN SCHOOL: 12-13yos)

In addition, several children and young people reported that they would benefit from participating by listening to others who had similar experiences to themselves, to learn more about how they had lived through the experience and changed as a result. However, there was some divergence amongst the

group in relation to the best methods for considering important issues. In the previous section, young people stressed the value of listening and learning from others, however some were a little reticent to talk about their fears, concerns or issues in a group setting.

Duty or obligation

Most participants reported that they believed they had a 'duty' to participate in research, particularly when it was of benefit to others, when they held a leadership role in their school or when they had been specifically asked and knew that their school, the researchers or the research project was reliant on them to be involved. This was particularly the case when an organization (namely their school) had given them an official position (such as Student leadership role)– in such instances they believed that it was part of their responsibility in assuming that role to participate in studies, when instigated or recommended by staff at that organisation.

Q If a teacher asks you and you feel like, maybe you don't have to, but you feel like it's your duty, is that a problem, is that a bad thing?

A Yeah, I agree with [another participant] I don't think it's like a problem, but I feel like it can affect your decision making, the way you would do things that you wouldn't normally do, because you feel again like you'd be obligated to do it. (#FG3, YP IN SCHOOL: 12-13yos).

This experience was not shared by all participants, with some believing that they did not feel obliged to take part. In the group from the local youth centre, for example, participants gave examples of times when they had been asked to volunteer to be involved in a project but chose to not join while some school students felt that they would not necessarily agree to participate in a study if invited by a teacher:

To me it doesn't really matter if a teacher's giving me notes to do stuff, if I really don't want to do it, then it's not going to make me want to do it anymore than if I saw it online. (#FG1, YP IN SCHOOL: 13-14 yos)

“Getting something out of participating” other than payment

Children and young people in three groups reported that they would participate in a study if they believed that they would 'get something out of it'. This could be the development of new skills, having the opportunity to discuss topics of importance to them, learning from others, or being exposed to a new experience.

You might take something away from it. You will maybe become more comfortable with speaking your opinion in front of other people, stuff like that. (#FG4, YP IN SCHOOL: 12-13yos)

Could benefit you, like in listening skills, hearing other people's opinions. Sometimes ... you want to tell people, but you don't really have to as well. (#FG4, YP IN SCHOOL: 12-13yos)

Those in the focus group made up of young people who were receiving support from a youth service believed that it was important for the service system to better understand the experience of those receiving support in anticipation this might improve the assistance they were provided. They, and peers in other groups, also anticipated that it would be beneficial for them to hear the views of other young people and to learn more about their shared experience:

Gathering your ideas up, improving your ideas because of what other people have said. (#FG3, YP IN SCHOOL: 12-13yos)

I reckon it's important because it can help kids... It can give info... Important information and can also help me figure out where am I in [relation to others] (#FG4, YP IN SCHOOL: 11-12 yos)

Incentives of payment

Participants had varying views about the influence that a financial incentive might have on their participation. For some, offering a payment for being involved in research seemed like 'a bribe' and may sway some children and young people to participate.

I kind of see where it's coming from, because in some ways, not specifically, and I'm going to do the big frank thing, but it kind of feels like you're bribing us for our opinions, and you feel that we wouldn't willingly give them to you. (#FG4, YP IN SCHOOL: 12-13yos).

Others, in groups made up of vulnerable and less vulnerable participants, felt that a payment might diminish the sense of altruism that participating in research sometimes elicited and, for those who were participating to get the payment, might influence the way in which young people participate:

You should do it out of free will, sort of like volunteer work in a way, I don't think you should be getting paid, I just really don't think we should be getting paid to do it. I don't see the need to be paid. (#FG3, YP IN SCHOOL: 13-14yos).

And there might be some kids who just say what you want them to say, so they can get out and just get the money and everything. (#FG1, CH IN OOHC:9-11yos).

They felt that if offered a payment and informed that they could retain it, regardless of whether they fully participated or not, *some* children and young people would attend for the requisite time but may not stay engaged:

I feel that way as well, because I feel like kids these days, they would only do something if they get something out of it, so I kind of feel the money is just forcing them go into it just for the money, and then sometimes they could just go in, and do the one session, then quit just for the money, instead of actually doing the full participation (#FG4, YP IN SCHOOL: 12-13yos).

Several participants similarly believed that a payment might help to get children and young people to agree to participate, but that it may not have a strong influence on whether they would stop participating if they felt bored, disinterested or otherwise chose to withdraw. However, most felt that

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3 receiving a financial reward for their participation was less of an incentive than the opportunity to
4 participate, to benefit others, to learn or have a mechanism through which they could share their
5 views. These young people did, however, say that they would accept the payment, but that it wasn't a
6 deciding factor.
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10 *If I get offered money just to give my opinion, I'm gladly going to take the money,*
11 *I'm not going to say no to it. (#FG3, YP IN SCHOOL: 13-14yos).*
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13 Being influenced by those inviting them to participate

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15 As discussed in the previous section, some participants felt that they were more likely to participate in
16 a study if they were invited by a teacher or other staff member. Similarly, many reported that if their
17 parents had agreed for them to participate, they would be more likely to engage. They said that they
18 would sometimes gauge the worth of the project by their parent's willingness for them to be involved.
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22 Although they took their parents' and workers' views into account, some believed that they would
23 still spend time considering whether it was something that they wanted to do. They reported, however,
24 that unless they could identify compelling reasons not to participate, they would 'go along' with their
25 parents and participate even if they did not appreciate the benefits of doing so. This was sometimes
26 because they believed that as adults with greater experience their parents might be in a better position
27 to identify issues:
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32 *My Mum she would, ... she would have her reasons for me not doing it, because*
33 *she's quite a knowledgeable person, and she has a lot of memories, so she*
34 *wouldn't feel comfortable with me doing it, then I would respect that, because I*
35 *know she's got her reasons for it (#FG3, YP IN SCHOOL: 12-13yos)*
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38 Conversely, participants reflected on what they would do if their parents did not want them to
39 participate in a study that was of interest to the child. In such instances some indicated they would talk
40 to their parents to try to understand why their parents were unhappy about their participation. This
41 was because they believed that as their parents had 'more experience with these things' they would
42 accept their parents' decision. However, a few give examples of when they would further debate their
43 participation: particularly when they thought that the study had merit, might be interesting or when
44 they felt obliged to be involved.
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48 If they still could not persuade their parents to allow them to participate in studies that they were
49 motivated to join some said they would use strategies, such as 'pestering' to 'wear them down'. They
50 believed that this was an effective way of getting their parents to agree with them, reporting that
51 unless parents felt incredibly strongly, they would be likely to change their position. This
52 demonstrates both a high level of motivation and also a degree of agency within the parent-child
53 relationship with children playing a part in the decision-making of their parents.
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3 *I'd probably just keep annoying my parents until they said yes. (laughing) (#FG3,*
4 *YP IN SCHOOL: 12-13yos).*
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6 Although outside of the scope of this paper's focus on children and young people's perspectives on
7 their decision making, it should be noted that there were some stark differences in the ways that
8 parents and children discussed their possible participation in research: some participants in the focus
9 group described how their parents sat with them explaining what researchers were asking of children
10 before mutually deciding whether a child would participate, while a larger group of participants said
11 parents made decisions with little discussion with their children. Those whose parents had discussed
12 the research with the child were more likely to understand their parent's decision and were more
13 likely to be able to take these into consideration when assenting. Children and young people who did
14 not have these conversations appeared to be basing their decision on what they believed their parents
15 thought or assented without considering their parent's decision-making.
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22 23 The perceived credibility of the researcher and research project

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25 Children and young people felt that they would be more likely to participate in a study if they knew
26 that the researcher was a credible person who had experience and knowledge and who could be
27 trusted. In many instances, children and young people had no interaction with researchers before
28 making a decision, so much of their musing was hypothetical. They did report, however, that they
29 would more likely assent to participate if the researcher worked for (what they sometimes described
30 as) a "legitimate" agency such as a university and, through information resources, shared a little about
31 themselves.
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37 *More experience with kids, not someone who just came in who's never been to a*
38 *survey before. If they do their own research. (#FG4, YP IN SCHOOL: 12-13yos).*
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40 Many were somewhat sceptical about research that recruited participants through Facebook and other
41 social media, reporting that it was common for them to be asked to answer questions and participate
42 in surveys. Most often they would decline if they weren't given enough information about the nature
43 or purpose of these studies and felt that they'd be more likely to participate if recruited through other
44 avenues such as school or a trusted organisation.
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48 There was some disagreement within and across the focus groups as to whether they would be more
49 or less likely to participate in studies if they personally knew the researchers. Some felt that they
50 would be more comfortable talking to someone they trusted, while others placed greater value on the
51 anonymity of being interviewed by someone they (and people they knew) did not have a relationship
52 with. However, across the groups, participants reported that researchers could help children and
53 young people feel more comfortable by spending time with them and building rapport before they
54 began conducting the research.
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(P1) I think from what I've seen ... people like to talk to people that they know, not a stranger, they like to know who they're talking to, because they feel more comfortable. Even as you guys as researchers, if you had an hour or two of sitting down with someone, getting to know them, that could help them to be comfortable.

(P2) I was going to disagree with that, I think it's much better to talk to someone you don't know, because say you're going to get into more embarrassing things, to someone you do know, they're going to still be around you (#FG4, YP IN SCHOOL: 12-13yos).

Discussion

This paper has presented the findings of focus groups with children and young people to explore further what constitutes a sensitive issue and to understand what factors they consider when deciding to participate in social research about potentially sensitive topics. Involving children as active participants in research is now generally accepted as essential to understand the issues and concerns that affect their lives (Authors. 2018; Powell, Taylor, and Smith 2013). However, tensions between children's participation and protection still underpin much research activity (Dan et al. 2019). Researchers continue to note barriers to recruiting children on the one hand due to adult stakeholder's concerns; on the other, children's involvement has become in some contexts routine, with limited assessment of potential risks to participants (Campbell 2008; Powell and Smith 2009). The tensions surrounding children's participation are particularly heightened in social research on 'sensitive' issues. This paper has presented the findings of focus groups with children and young people to explore further what constitutes a sensitive issue and to understand what factors they consider when deciding to participate in social research about potentially sensitive topics.

Sensitive issues in social research

Considerations of research being too sensitive and how the level of perceived sensitivity impacts on decisions to participate in research are important to understand. While participants in the focus groups (like adults in the broader study: see Authors. 2018), could readily identify what constitutes a sensitive topic, they did not always have a shared view of whether a particular topic was too sensitive to be discussed. Sensitive topics were often those that, when discussed (particularly in a group setting) might cause embarrassment, concern or discomfort and lead to ridicule when a child's previously unknown views or experiences were expressed. In addition, participants in this study felt that the context in which research is being conducted and the personal histories of children and young people played a part in determining whether a topic was sensitive or not and whether they would participate. Some felt that if a child or young person had experienced an upsetting or traumatic experience talking about sensitive topics might be challenging, while others (including those who were in care and receiving support from a youth service) held a contrary position: that if they had experienced something and wanted to talk about it that participation in research on a sensitive topic might be

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3 beneficial for them and others. For example, one young person felt strongly that he would participate
4 in a study on bullying and violence *because he had experienced these problems* and wanted to have
5 his say.
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8 9 Decision making factors

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11 Previous research that explored how children and young people make decisions about whether to
12 participate in research has been mostly about medical studies. These studies have stressed children's
13 willingness to engage in studies when they believe that there is some benefit for other children or for
14 themselves. Participants in this study also placed value on these potential benefits but when
15 considering positive effects for themselves, they more often considered whether the experience would
16 be enjoyable or interesting and whether they might learn something from others. Having an
17 opportunity to talk about issues of interest and importance was valued, particularly when children felt
18 like their views were being validated and when they experienced 'catharsis' as they articulated their
19 needs and views. These aspects have been highlighted in previous research with children and young
20 people and within the broader child participation literature (Edwards and Alldred, 1999; McGinley
21 and Grieve, 2009).
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29 Unlike children in medical studies, the social research discussed in the focus groups did not raise the
30 prospect of having access to an intervention or treatment when they agreed to be involved and
31 therefore did not consider this as something that might encourage (or discourage) them from
32 participating.
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36 Like adults, children have different kinds and levels of motivation to participate in research (Ryan and
37 Deci 2020). Understanding what motivates children and young people to participate and the
38 orientation of motivation and decision-making process reflects the underlying attitudes and values that
39 help appreciate why they may or may not choose to participate. The participants in this study
40 identified a range of intrinsic and extrinsic motivations.
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45 Intrinsic motivation is sometimes regarded as altruistic motivation and can refer to self-sacrificial acts
46 intended to benefit others (Schwartz and Howard 1984) or doing something for its inherent
47 satisfaction, doing something for the perceived fun or challenge, rather than for rewards or being
48 pressured (Ryan and Deci 2020). The children and young people in this study reported that they would
49 decide to participate in a study if they thought it might benefit others including if it helped adults
50 better appreciate what children and young people think. Having an opportunity to hear what others
51 had experienced and thought was highly valued as was the opportunity to "get things off your chest".
52 While not the aim of research, this 'getting things off your chest' could be a fortuitous byproduct of
53 involvement, a possible secondary benefit to being involved for some children and young people (and
54 adults too).
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3 Although it is sometimes argued that children and young people are more focused on what is
4 happening in their immediate place and time, participants did have a future focus – reflecting on how
5 they might use what they had learned through their participation in a study and how it might be
6 beneficial to others. This future focus was perceived as a benefit of participating.
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10 Extrinsic motivation refers to behaviour that is driven by external incentives such as money, fame,
11 grades, and praise. As the name implies extrinsic motivation comes from outside the individual in
12 contrast to intrinsic motivation, which is instigated internally for the individual. In this study,
13 participants argued that these external incentives (or extrinsic motivators) played less a part in their
14 decision-making and that they would be more likely to participate if there were benefits to others, if
15 they wanted to have their say or “get things off their chests” or could learn from others.
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20 There is a significant debate in the literature over whether the provision of extrinsic incentives erodes
21 intrinsic motivation (Cerasoli, Nicklin, and Ford 2014). However, Ryan and Deci (2000) argue that
22 ‘there are varied types of extrinsic motivation, some of which do, indeed, represent impoverished
23 forms of motivation and some of which represent active, agentic states’ (p 55). This latter form of
24 extrinsic motivation recognises an individual’s relative autonomy to see the value and utility of the
25 task, and participate willingly through personal endorsement and choice, rather than mere compliance
26 with external control.
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31 This may be particularly important in the context of research where there may be real concerns that
32 children might be pressured into participation by adults or when using payment or other rewards as
33 incentives. Participants had a varied and sophisticated view of the role payments might play in
34 influencing decision making. Some felt it did diminish the more ‘altruistic motives’, other felt that
35 although it was positive to receive a financial reward it was less of a driver for participation than other
36 factors. In the findings from the young people’s online survey from the larger project, payments did
37 increase the participation of children and young people in hypothetical research scenarios without
38 concerns of undue influence. However, in that survey significant numbers of children and young
39 people said they would still participate for no payment, including those with fewer economic
40 resources (Authors. 2019).
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45 There is some conjecture about the ethics of researchers presenting the potential benefits and positive
46 side effects of participation to children and young people as a way of enticing them to engage in
47 research (Spriggs 2015). Some have argued in the context of medical research that highlighting the
48 potential benefits for others and tapping into children’s sense of altruism might be coercive,
49 particularly when such benefits cannot be guaranteed (Spriggs 2015). However, it might also be
50 argued that overstating the potential risks that could be encountered when participating in research
51 (such as experiencing distress, shame or embarrassment) might deter participants unnecessarily and,
52 in doing so, restrict children’s ability to influence and shape knowledge, practice and policy. Findings
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3 from this study do not point to a solution to this ethical challenge but, instead, highlight the fact that
4 like medical research, children value benefits for others when considering whether to participate in
5 social research – a consideration that parents, researchers, ethics committees and others might ponder
6 when deciding whether children participate in research or not. Participants noted the sensitivities
7 associated with some topics and the possibility of embarrassment or bullying - pointing to the need for
8 researchers to effectively attend to confidentiality and privacy and convey this to potential
9 participants.
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15 Finally, the study provided some insights into the ways that parents and their children influence their
16 decision-making in relation to research participation. Some children and young people reflected that
17 they often looked to their parents for guidance as to whether they should participate or let their parents
18 ultimately decide. However, other young people also flagged conversations and negotiations between
19 parents and their children as well as some strategies (such as nagging) that young people utilized
20 when there was a disagreement and young people were motivated to participate. Although this
21 dynamic has been explored in other fields (particularly in consumer science which has a growing
22 interest in children's 'pester power' (Lawlor & Protero. 2011) the implications for decision-making in
23 research is limited.
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30 Conclusion

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33 A substantial body of literature clearly points to children and young people's right to participate in
34 matters that affect them, such as research. This study adds to existing evidence that children have an
35 evolving capacity to make informed decisions, to weigh the risks and benefits, and grapple with
36 complex and competing concerns, particularly if they are well-supported by adults to do so (Evang
37 and Øverlien 2015; Morrow 2012). While some indicate their decision making may be influenced by
38 a sense of duty and/or the opinions of their parents (people they trust), the findings of this study
39 suggest they are nevertheless also capable of making considered decisions when they are provided
40 with the information and opportunity to understand what participation involves.
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47 Adult stakeholders therefore need to be aware and respectful of children and young people's capacity
48 for sophisticated decision-making and ensure that they are provided with sufficient, accessible
49 information in order to make those decisions. The findings are particularly important for raising
50 researcher awareness of the intrinsic and extrinsic motivating factors (in order to mitigate instances in
51 which participation may not be entirely voluntary or well informed), and the need to provide sound
52 information and the opportunities for communication and dialogue. This also points to the importance
53 of researchers establishing relationships with potential participants (children and young people) and
54 other stakeholders, particularly parents as this is the context in which information can be conveyed
55 and discussed, and decisions made.
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3 It is hoped that by better understanding how children conceptualise what constitutes a sensitive issue,
4 and the motivating factors (both intrinsic and extrinsic) informing their decision whether or not to
5 participate in research, researchers and other key decision makers will be better informed in terms of
6 providing information, time and opportunities for children and young people to consider their
7 decisions, including the layered implications of these.
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