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## How do research ethics committee members respond to hypothetical studies with children? Results from the MESSI study

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## How do research ethics committee members respond to hypothetical studies with children?

### Results from the MESSI study

#### Abstract

Hypothetical scenarios were used to assess the influence of the sensitivity of the study topic, payments, and study methods on research ethics committee (HREC) members' approval of social research studies involving children. A total of 183 Australian HREC members completed an online survey. The higher the perceived sensitivity of the study topic, the less likely the study would be approved by an HREC member. HREC members were most likely to approve each of the hypothetical studies if no payment was offered. Payment was the most common reason for not approving the low risk studies, while risks were the most common reasons for not approving the more sensitive studies. Face-to-face interviews conducted at home with children elicited substantially higher rates of approval from HREC members with more sensitive study topics. Both HRECs and researchers may benefit from additional guidance on managing risks and payments for children and young people in research.

## 1. Introduction

Human Research Ethics Committees (HRECs) (Australia), Institutional Review Boards (USA), or Research Ethics Committees (UK) provide ethical oversight of research, and ensure that research is undertaken in accordance with their laws and regulations (Page & Nyeboer, 2017). In Australia, the *National Statement on Ethical Conduct in Human Research*, requires that HRECs abide by the values of: respect for human beings, research merit and integrity, justice and beneficence (NHMRC, 2007, updated 2018). This ethical review role gives them the authority to approve, require modifications to, or reject research studies (Lynch, 2018). Furthermore, HRECs ensure that: the selection of participants is equitable, informed consent is obtained, risks to research participants are minimized and are reasonable in relation to any anticipated benefits, participants' safety is protected, and that provisions are in place to protect participant privacy and confidentiality (Lynch, 2018).

In addition to HREC approval for a research study with children and young people, other safeguards are required: approvals are required from any institutions in which the study is to be conducted, such as schools, followed by informed consent processes with individual participants, including parents or guardians, and the child participants themselves (where they have capacity to do so) (Harger & Quintela, 2017).

While such safeguards and approvals are appropriate and reasonable, research has found that HRECs may be cautious about approving research studies with children about 'sensitive' or 'difficult' subjects, such as sexuality, or with those who are deemed to be vulnerable, such as children in institutions (Sikes & Piper, 2010). HREC concerns about retraumatizing participants may make it challenging for researchers to obtain HREC approval to explore such topics in their research without demonstrating sufficient safeguards (Harger & Quintela, 2017).

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6 Issues such as payments have also been controversial in relation to children's participation in  
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8 research. HREC guidelines, such as those of the Australian NHMRC, generally limit  
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10 payments - for any research participants - to reimbursements of costs or time involved, with  
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12 disproportionate payments or inducements *likely to encourage participants to take risks*  
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14 considered *ethically unacceptable* (NHMRC 2007, updated 2018: Section 2.2.10). When  
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16 children are the research participants, research ethics committees exercise additional caution,  
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18 expressing concerns that child participants will be overly influenced or induced to participate  
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20 if a payment is offered (Bagley, Reynolds, & Nelson, 2007) or that their decision-making  
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22 may be distorted (Wendler, Rackoff, Emanuel & Grady, 2002). It has been suggested that  
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24 concerns about payments have limited their adoption, and, as a result children may be less  
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26 likely to be participants in research; this means that attempts to expand knowledge by the  
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28 participation of children in research may also be curtailed (Sikes & Piper, 2010).  
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34 Comments have also been made about the lack of transparency about HREC processes and  
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36 decisions, which are usually not published or shared, and that few studies have been  
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38 undertaken of HREC decision-making (Abbott & Grady, 2011; Lynch, 2018). Variability  
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40 between research ethics committees' recommendations and approvals of research studies,  
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42 member roles, and the potential for these to adversely impact on the approval and conduct of  
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44 research has also been highlighted as a concern (Abbott & Grady, 2011; Friesen, Yusof &  
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46 Sheehan, 2019; Guta, Nixon, & Wilson, 2013; Lynch, 2018). If, rather than guessing,  
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48 researchers had a better sense of what would likely impede HREC approval, and what would  
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50 not, potentially detrimental self-censoring could be minimized or avoided (Lynch, 2018).  
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52 Obtaining greater clarity about HREC decision-making will assist researchers and others in  
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54 designing research studies that meet ethical requirements. The current study aims to address  
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56 this important issue.  
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3 The *Managing Ethical Studies on Sensitive Issues (MESSI)* study is an Australian study that  
4 explored how adults and children make decisions about children's participation in social  
5 research about sensitive topics. An advisory group, which included research ethics committee  
6 members, provided input into the study design. The *MESSI* study used a mixed methods  
7 design involving four stages. Stage 1 involved semi-structured interviews (n = 64) exploring  
8 with HREC members, researchers, professionals<sup>1</sup>, parents, children and young people, how  
9 they conceptualized and made decisions about research with children; the results of this stage  
10 informed the design of the subsequent stages, in particular, the factors examined in the online  
11 surveys. Stages 2 and 3 constituted online surveys using common hypothetical scenarios  
12 which allowed similarities and differences in responses between the above groups to be  
13 identified. Stage 4 involved focus group interviews with younger children, giving them the  
14 opportunity to explore the factors they considered important in deciding to participate in  
15 social research studies. Findings from other study stages are reported elsewhere [REDACTED]  
16 [REDACTED]  
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35 [REDACTED]

36 Experimental Vignette Methods (EVM) were used to explore the differences between  
37 participants in their provision of approval, consent or assent for children age 7 to 14 years to  
38 participate in social research studies. In Stages 2 and 3 (the online surveys) respondents were  
39 asked to make decisions about approving a series of hypothetical research studies (or  
40 vignettes). The vignettes characterised social research projects involving children and young  
41 people. Using a within-subjects design, we systematically varied the vignette's characteristics  
42 (study topic, method and payment) and were able to identify how each of these characteristics  
43 individually influenced respondent decisions to approve, provide consent or participate in  
44 [REDACTED]  
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56 [REDACTED]  
57 [REDACTED]

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58 <sup>1</sup> Professionals were defined in the study as "a professional or worker responsible for children in Australia aged 7-14. (You  
59 might be a teacher, principal, worker or manager)".  
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3 each of the hypothetical studies. Importantly, we could tell whether the sensitivity of the  
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5 study topic had implications for the observed relationships between payment and decisions.  
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8 This paper explores the factors influencing the decision-making of Australian HREC  
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10 members in providing approval for children aged 7 to 14 years to participate in social  
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12 research studies. It aims to answer the following research questions:  
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- 15  
16 1. How does the sensitivity of the study topic, payment for participation and study  
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18 method impact the likelihood of HREC member approval for a hypothetical study?  
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- 20  
21 2. Do the impacts of payment and survey method on the likelihood of HREC member  
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23 approval differ with the sensitivity of the study topic?  
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## 26 27 28 **2. Method**

### 29 30 31 32 **2.1 Study design**

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37 We conducted a cross-sectional online survey of all Australian HREC members from April to  
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39 August 2017. Each participant was asked to respond to each vignette and all its variations.  
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41 All HREC members were eligible to participate. The survey was administered via Qualtrics  
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43 ([www.qualtrics.com](http://www.qualtrics.com)). The survey was hosted on the [REDACTED].  
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47 Participation was anonymous; no identifying information or Internet protocol addresses were  
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49 collected.  
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54 The MESSI study was approved by the [REDACTED]  
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56 and ratified by the study partners' universities.  
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## 2.2 *Recruitment*

We emailed an invitation to HREC Chairpersons and/or Research Ethics Managers at the 213 Human Research Ethics Committees (HRECs) registered with the Australian National Health and Medical Research Council (NHMRC) at the time of recruitment. The email addresses for the HRECs were sourced from the 2017 public list of HRECs registered with the NHMRC<sup>2</sup>.

The email containing a link to the survey requested that the invitation be forwarded to all committee members. The emails invited HREC members to participate in an anonymous online survey about what influences them to provide consent for children to take part in a non-medical or social research study (or not).

If HREC members elected to click on the survey link in the email they were taken to a Participant Information page and asked to provide their Informed Consent by confirming that they agreed to participate, after which they commenced the survey. HREC members who completed the survey were invited to go into a draw for a presentation of the research findings at their HREC meeting. Participants took an average of 30 minutes to complete the survey.

## 2.3 *Measures*

The survey questions and factors explored in the hypothetical scenarios were drawn from the responses given in the qualitative interviews conducted in Stage 1 of the study, in which HREC members, researchers, professionals, parents, children and young people were asked how they conceptualized and made decisions about research with children. Payment of child research participants, the sensitivity or risk in asking children about particular topics, and the research method used were all of particular concern in decision-making in relation to research

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<sup>2</sup> <https://www.nhmrc.gov.au/sites/default/files/documents/attachments/embryo%20research%20licence/human-research-ethics-committees-registered-with-nhmrc.pdf>

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3 with children. We were also keen to explore the reasons why HREC members would not  
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5 approve research.  
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8 HREC members were asked to provide basic demographic information and information about  
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10 their HREC role, experience and training. They were also asked a range of other questions in  
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12 relation to their considerations of approval for social research involving children. The HREC  
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14 member and HREC manager responses to these questions are reported elsewhere [REDACTED]  
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16 [REDACTED]  
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20 The main component of the HREC member survey was a series of questions asking whether  
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22 they would provide research ethics approval for the participation of children aged 7 to 14  
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24 years in four hypothetical studies or vignettes. This age range was chosen as it related to  
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26 children who were commonly considered in the social sciences to be old enough to provide  
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28 their own assent/consent but also required parental consent. A full factorial design was  
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30 chosen whereby participants were presented with all the scenarios in order to conduct within-  
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32 subject analyses (Ulrich and Ratcliffe (2007). The hypothetical studies presented different  
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34 combinations of factors with the potential to influence consent or participation.  
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39 There were four sets of vignettes with varying levels of risk or the sensitivity of the study  
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41 topic, ranging from relatively benign, covering (i) food choices and (ii) internet safety  
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43 (namely, children's views and the strategies used in relation to internet safety), through mid-  
44  
45 range (iii) children's experience of violence, to highly sensitive (iv) sexting. In the 'highest  
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47 sensitivity' survey, hypothetically participants would be asked about their experiences of  
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49 sexting (defined as sending a sexual or sexually suggestive message, photo or video by  
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51 mobile phone), and to forward a copy of a sext they had sent to the researchers. The design of  
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53 these scenarios has been discussed previously [REDACTED]  
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3 The second factor varied in the vignettes was the level and type of payment. Payment  
4 amounts were presented in Australian dollars (A\$)<sup>3</sup>. For each vignette, the opportunity for the  
5 child to (i) enter a draw to receive a A\$200 voucher was presented initially. Subsequent  
6 presentations varied the payment amount; participants were asked if they would approve  
7 participation if the child received (ii) no payment, (iii) A\$30 (an amount commonly used by  
8 the research team) or (iv) A\$100 (a high payment unlikely to be approved by a research  
9 ethics committee<sup>4</sup>).

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12 The third factor varied in the vignettes was the method of data collection. We included four  
13 methods for each of the vignettes: (i) a 15-minute online survey (the initial presentation) (ii) a  
14 face-to-face interview with a researcher at the participant's home (with a parent or guardian  
15 at home but not part of interview) (iii) a group interview or focus group with a researcher at a  
16 youth centre near home (iv) filling out a survey in class.

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19 The four sets of vignettes were presented in random order. When participants declined to  
20 approve a hypothetical study, they were asked to select their main reason for declining from a  
21 list which include the following reasons: topic, payment amount, lack of benefits, risk,  
22 methods, time, age of the child or other. These reasons were drawn from the Stage 1 results.  
23 In Stage 1, we had canvassed participants' views about reasons for HRECs not granting  
24 approval for research involving children aged 7-14 years (summarized elsewhere [REDACTED]  
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54 <sup>3</sup> As at 30 June 2017, the time of data collection, A\$1.00 was equivalent to US\$0.7692 or 0.673 Euros  
55 (<https://www.rba.gov.au/statistics/historical-data.html#exchange-rates>).

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58 <sup>4</sup> The view that \$100 would most likely not be deemed appropriate by an Ethics Committee was drawn from interviews, the  
59 research literature and the research team's experience.  
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3 The descriptions of the hypothetical studies were presented via a short, animated video and  
4 written text. The survey language was pitched at a Year 6 to 8 (11-14 years old) reading  
5 level, as measured by the Flesch–Kincaid Grade Level test (Kincaid, Fishburne, Rogers, &  
6 Chissom, 1975) to allow for consistent presentation across all participant groups.  
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12 The scripts for the vignettes are provided in Appendix 1.  
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## 16 **2.4 Participants**

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19 Of the 213 HRECs contacted, 208 were operating and eligible to participate in the study. Five  
20 HRECS had been disbanded, seven reported that they received no applications involving  
21 research with children, four email addresses were incorrect and two HRECS refused since  
22 they needed institutional approval to participate (one from university senior management and  
23 the other from their own HREC). Of the remaining 195 HRECs. Only the five disbanded  
24 HRECs were excluded from the HREC population for the purposes of calculating response  
25 rates.  
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35 A total of 255 individual HREC members clicked on the online survey link, 26 of whom did  
36 not continue. A total of 229 HREC members participated in the MESSI survey, giving an  
37 estimated 13.8% response rate.<sup>5</sup>  
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43 The analyses presented in this paper were conducted on the sub-sample of 183 HREC  
44 members who completed all the scenario questions (79.9% of HREC survey participants).  
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48 Basic demographic characteristics are presented below (see Table 1). The characteristics of  
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56 <sup>5</sup> The minimum membership of a HREC is 8 members (paragraph 5.1.30, National Statement: NHMRC, 2007). If we assume  
57 that there are 8 members on each of 208 eligible HRECs, then there were at least 1664 potential respondents (208 x 8). If this  
58 assumption is correct, 229 respondents implies a maximum possible response rate of 13.8% for the member survey.  
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3 the 183 HREC members who responded to all scenarios are similar to the full sample of 229  
4 HREC members who commenced the survey [REDACTED]

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8 The geographic (state/territory) distribution of HREC members who completed all the  
9 scenario questions was similar to the distribution of registered HRECs across Australia, with  
10 the largest proportions from Victoria, NSW and Queensland (78.1% across these three  
11 states). Most HREC members were from either University/College HRECs (50.8%) or  
12 hospital/health service HRECs (31.7% of all respondents).

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15 Table 1 shows that the HREC member respondents covered the range of roles required by the  
16 National Health and Medical Research Council for HREC membership (NHMRC, 2007,  
17 Section 5.1), as did the subset of respondents that answered all the scenario questions. Over  
18 half the members were female (57% of all respondents and 58% of the subset of  
19 respondents).

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36 [INSERT TABLE 1 ABOUT HERE]

## 37 38 39 40 41 **2.5 Statistical analysis**

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46 Combining the study approval responses from all permutations (base case, three alternate  
47 methods and three alternate payment levels) resulted in seven scenario variations for each of  
48 the four study topics. Recall that the method for the base case is an online survey and the  
49 payment is the chance to go into a \$200 draw on completion of the survey. Study approval  
50 data were collected seven times for each respondent for each of the four study topics.

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3 Approval was recorded as a dichotomous variable, set to 1 if the HREC member approved the  
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5 hypothetical study and 0 otherwise. Logistic regression is often used to estimate associations  
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7 with dichotomous outcome variables; in that case, the estimated independent associations  
8  
9 between the HREC member's approval of the hypothetical research project and the research  
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11 topic, payment and method, would be given by odds ratios. Judging odds ratios as difficult to  
12  
13 interpret, however, we instead estimated associations in terms of relative risk (RR) estimated  
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15 via general linear models (GLM) using a Poisson regression with a log link. The estimation  
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17 results are similar to those from log binomial regression but the Poisson with a log link  
18  
19 overcomes convergence problems. Acknowledging the clustering of errors associated with  
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21 repeated measurement of the same HREC member, we accounted for the within-person  
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23 variance using robust standard errors (Schmidt & Kohlmann, 2008; Zou, 2004).  
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29 The HREC member's role in the HREC and the institution in which the HREC member was  
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31 based were included as control variables. We had evidence from the Stage 1 semi-structured  
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33 interviews with HREC members that approval could be related to the type of HREC and role  
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35 of HREC member.  
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39 The RR is the ratio of the probabilities of giving approval between two categories of an  
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41 attribute included as a regressor. A RR that is greater than 1 indicates that the probability of  
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43 giving approval is higher compared to the referent group. A RR that is less than 1 indicates  
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45 that the probability of approval is lower than the reference group. An RR of 2 for women  
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47 versus men, for example, indicates that women are twice as likely as men to give approval.  
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51 In one set of analyses we divided the approval responses into the four study topics,  
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53 comprising 1,281 data points for each study topic. Research questions considered at this  
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55 level included whether for each study topic the approval rating is impacted by payment,  
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57 regardless of the survey method. We denote these analyses "study-topic level analyses".  
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3 In these GLMS we include covariates for payment and survey method, controlling for  
4 type of HREC and role on the HREC.  
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8 Another analysis involved the full dataset of 5,124 responses, combining all four study  
9 topics. By including interactions between study topic and payment, plus study topic and  
10 survey method as covariates in the regression, we were permitted an evaluation of more  
11 nuanced research questions. For example, were payment found to impact on approval  
12 for an online survey in the study-topic analyses, we could evaluate whether the payment  
13 effect varied with the sensitivity of the study topic. Analogously we could consider  
14 whether more sensitive topics were any more likely to be approved were the study to be  
15 a face-to-face interview rather than online. We denote this analysis as “scenario-level  
16 analysis”. For ease of reading, we summarise key findings from this analysis graphically.  
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20 A third “summary analysis” was conducted with the full data set and HREC role and  
21 HREC type controls, plus the study topic covariate, but without interactions. This  
22 allowed us to show how the responses varied on average with the sensitivity of the study  
23 topic.  
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30 Statistical analyses were performed using STATA MP Version 15 (StataCorp, 2017).  
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## 40 **2.6 Descriptive analysis of reasons for not approving a study**

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46 Of the 183 HREC member respondents, 162 (89%) rejected at least one hypothetical study at  
47 its initial presentation (an online survey where participants were offered a chance to enter a  
48 draw for a \$200 voucher); 14% (n=26) rejected only one study and approved all others.  
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54 HREC members who chose not to approve the initial presentation of a study were asked to  
55 select their main reason for not giving approval. These reasons are summarized descriptively  
56 for each hypothetical study. Then we show, as frequencies, the main reasons for rejection by  
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3 hypothetical study topic and number of studies the HREC members rejected. Findings help to  
4 contextualize the findings of the statistical analysis of the scenario responses.  
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### 7 8 **3. Results** 9

#### 10 ***3.1 How does the sensitivity of the study topic, payment for participation and study method*** 11 ***impact the likelihood of HREC member approval for a hypothetical study?*** 12 13

##### 14 ***3.1.1 Does higher risk/sensitivity of the study topic decrease the chance of approval?*** 15 16

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18 The estimated risk ratios and errors between the hypothetical scenarios and approval for  
19 the summary analysis are reported in Table 2: they show a significantly higher rate of  
20 approval for the topics of lower risk or sensitivity compared to those of higher risk or  
21 sensitivity. As shown in Table 2, the average probability of approval for the food choices  
22 scenarios was 57.6%. The probability of approval was 6% significantly lower [(1-  
23 0.94)\*100] for the internet scenarios (54.2%); 47% [(1-0.53)\*100] significantly lower  
24 for the violence scenarios; and 63% significantly lower for the sexting scenarios.  
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28 Results for the association between study topic and HREC approval for the scenario-  
29 level analysis (See Appendix 2) are broadly similar to the results for the summary  
30 analysis. The scenario-level analysis does, however, indicate that there was no difference  
31 in the rate of approval between the two relatively benign topics (food choices and  
32 internet) for the initial presentation (an online survey with the chance to go into a \$200  
33 draw ( $p>0.1$ )). The HREC approval rating for the violence and sexting scenarios  
34 remained significantly lower than that for food choices ( $p<0.05$ ).,  
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### 3.1.2 Do higher payment amounts decrease the chance of approval?

The estimated risk ratios and standard errors from the study topic level analyses are presented in Table 3.

Table 3 shows that HREC members were more likely to approve all four hypothetical studies when no payment was offered, than if entry into a draw for a \$200 voucher was offered (Food choices: RR=1.27, Internet safety: RR=1.32, Experience of violence: RR=2.15, Sexting: RR=3.52;  $p < 0.01$  in all studies). For example, HREC members were 1.27 [27%  $(1.27-1)*100$ ] times as likely to approve the hypothetical food choices study (low risk) and 3.52 times as likely [252%  $(3.52-1)*100$ ] to approve the sexting study (high risk) if no payment were offered (compared to entry into a \$200 voucher draw).

[INSERT TABLE 3 ABOUT HERE]

Table 3 (study topic level analyses) indicates that the payment of \$100 to children (compared to a \$200 voucher draw entry) was the least commonly endorsed with RR's significantly below 1 in all four scenarios. For example, for the food choices scenario HREC members were 79%  $[(1-0.21)*100]$  less likely to approve the study if a payment of \$100 was offered compared to participants being offered a chance to go in the \$200 voucher draw. There was little variation in the RR's for the \$100 payment across the scenarios, with RRs ranging between 0.21 for food choices and 0.24 for sexting.

Not surprisingly, the results for the \$30 payment fell in between those for the no payment and the \$100 payment. Estimation results in Table 3 indicate that compared to the chance to go into a \$200 voucher draw, HREC members were less likely to approve

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3 \$30 payments for the hypothetical food choices and internet safety studies (low risk).  
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5 (For example, HREC members were 41%  $[(1-0.59)*100]$  less likely to approve the  
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7 hypothetical food choices study if a payment of \$30 was offered.) In the higher  
8  
9 sensitivity studies (experience of violence and sexting) HREC members were just as  
10  
11 likely to approve surveys with a \$30 payment as the chance to go into a \$200 voucher  
12  
13 draw.  
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### 16 17 *3.1.3 Does the study method influence approval?*

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20 The study topic level analyses showed that there was no difference in the inclination to  
21  
22 give approval for studies based on the method of data collection amongst the low risk  
23  
24 study topics (either the food choices or the internet safety) (See Table 3). However,  
25  
26 Table 3 shows that for the more sensitive topics (experiences of violence and sexting),  
27  
28 HREC members were more likely to give approval if the study was conducted as a face-  
29  
30 to-face interview in the child's home than as an online survey (Violence  $[94\%(1.94-$   
31  
32  $1)*100]$ ; Sexting  $[168\%(2.68-1)*100]$ ).  
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### 41 *3.2 Do the impacts of payment and survey method on the likelihood of HREC member* 42 *approval differ with the sensitivity of the study topic?*

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45 For ease of interpretation the results from the scenario level analyses are also presented  
46  
47 in Figure 1, which illustrates the approval rates by payment amount and scenario.  
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53 [INSERT FIGURE 1 ABOUT HERE]  
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3 *3.2.1 Did removal of the \$200 voucher payment more incline HREC members to approve*  
4 *an online survey for the more sensitive study topics?*  
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8 From Figure 1 we can see that the ratio of approval between the \$200 draw and zero  
9 payment is very similar for internet safety when compared to food choices, but less  
10 similar for the violence and sexting scenarios.  
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13 The RR for \$0 payment compared to the \$200 draw is 1.27 for the food choices and 1.32  
14 for the internet safety scenario in the study topic level analyses (Table 3). The RR of  
15 1.04 (internet safety, no payment) in the scenario level analysis (Appendix 2) tells us  
16 that 1.32 is 1.04 times higher than 1.27. However, this difference is not statistically  
17 significant ( $p>0.05$ ). Likewise, the RR for no payment compared to the \$200 draw is  
18 3.52 for the sexting scenario in the study topic level analysis (Table 3) and the scenario  
19 level analysis shows that it is 2.78 (Appendix 2) times higher than 1.27 ( $1.27*2.78=3.5$ ).  
20 According to the scenario level analysis the RR of 3.52 for the sexting scenario is  
21 significantly higher (2.78 times) than the equivalent RR for the food choices scenario.  
22 Analogously, the scenario level analysis shows that the RR for the violence scenario is  
23 1.69 times significantly higher its food choices counterpart.  
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42 For all topics, regardless of sensitivity, HREC members were more likely to give  
43 approval for a study without payment than for one offering the chance to go into a \$200  
44 draw. However, no payment was more reassuring to HREC members for the riskier  
45 topics than for the relatively benign topics.  
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51 *3.2.2 Did the \$100 payment discourage approval equally across all levels of topic*  
52 *sensitivity?*  
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56 There was little variation in the RRs for the \$100 payment across the four scenarios  
57 (Table 3). The scenario level analysis shows that there was no significant difference  
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3 (p>.05) between the RR for food choices (0.21) and the other three scenarios (internet  
4 RR=0.20; Violence RR=0.23; sexting RR=0.20). (See Figure 1.)  
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8 Regardless of topic sensitivity, the \$100 payment was a significant discouragement for  
9 approval.  
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13 *3.2.3 Did the \$30 payment discourage approval for the less sensitive but not the more*  
14 *sensitive studies?*  
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19 HREC members were less likely to approve the low risk/sensitivity studies (hypothetical  
20 food choices and internet safety studies) when there was a \$30 payment compared to the  
21 \$200 voucher draw. In the higher sensitivity studies (experience of violence and  
22 sexting), however, HREC members were just as likely to approve surveys with a \$30  
23 payment (Table 3). The scenario level analysis confirmed the difference by topic  
24 sensitivity, finding significantly larger RRs for violence and sexting than for the less  
25 benign topics (Appendix B).  
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35 HREC members saw no difference between the \$30 payment and chance to go into a  
36 \$200 voucher draw for the more sensitive topics but were deterred by the \$30 payment  
37 for the less sensitive topics.  
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44 *3.2.4 Did conducting a face-to-face interview in the child's home rather than the online*  
45 *survey more incline HREC members to approve riskier topics?*  
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50 The scenario level analyses (Appendix 2 and Figure 2) found that that the RR's for the  
51 face-to-face interview compared with the online survey for the violence and sexting  
52 scenarios were both significantly higher (1.94 and 2.68) than the equivalent RR for food  
53 choices (1.02). Whereas HREC members were no more likely to give approval for the  
54 relatively benign scenarios when the study (with the chance to go into a \$200 draw) was  
55 conducted face-to-face, this method proved more reassuring for the riskier topics.  
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### 13 **3.3 What were the reasons for not approving studies?**

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16 As was shown in Figure 1, HREC members were less likely to approve the study the more  
17 sensitive or risky the study topic (online survey where participants were offered a chance to  
18 enter a draw for a \$200 voucher). Although the percentage of HREC members who would not  
19 approve the lower sensitivity studies (food choices and internet safety) was relatively low,  
20 payment was the most common reason for doing so (32% and 26% of those who would not  
21 approve studies respectively). Much higher percentages of members rejected the higher  
22 sensitivity studies. Risks were the dominant reason for not approving the experience of  
23 violence study (64% of those who would not approve study), whereas both risks (45%) and  
24 the age of child (32%) were the two most common reasons for rejecting the sexting study.  
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38 Figure 3 shows the main reasons for rejection by hypothetical study topic and number of  
39 studies the HREC members rejected. These are presented in terms of frequencies. The most  
40 common response pattern was to reject both the sexting and experience of violence studies  
41 (the higher sensitivity studies), but to approve the food choice and internet safety studies (n =  
42 62, 34% of 183). The next most common pattern was to reject all four studies (n = 52, 24% of  
43 183). The third most common pattern was to reject only the sexting study (n = 23, 13% of  
44 183). Around half of the HREC members who rejected all four studies rejected the food  
45 choices and internet safety studies because of concerns about payment. Their concern was  
46 less about payment and more about risks for the higher risk studies (violence and sexting).  
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#### 9 **4 Discussion**

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12 Over the past three decades there has been a growing appreciation of the importance of  
13 children and young people participating in social research on issues that affect their  
14 lives. Rather than excluding children from sensitive research, researchers have been  
15 required to design their research approaches to ensure that they are safe, ethical and  
16 practicable. In particular, researchers have had to consider how to best facilitate research  
17 so that it is palatable to the various parties who facilitate or restrict children's  
18 participation, including parents, agencies with responsibility for children, and research  
19 ethics committees (Powell et al., 2020). The MESSI study was innovative in its use of  
20 hypothetical scenarios to explore how these research facilitators make decisions and  
21 consider the likely influence of the study sensitivity or risk, payments and study  
22 methods, on the decision-maker's approval of children's participation.  
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37 The results from the survey of 183 HREC members using hypothetical scenarios show that  
38 the likelihood of study approval is impacted by each of the three elements of study design  
39 considered.  
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##### 46 *4.1 Does the higher/risk sensitivity of the study topic decrease the chance of* 47 *approval?* 48 49 50

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52 The HREC member responses to the vignettes presented showed that they were much  
53 more likely to approve a study that was considered to be of low risk or sensitivity than  
54 they were to approve a higher risk study. This result held irrespective of the study  
55 method or payment level or amount.  
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3 This finding was also consistent with the responses provided by children and young  
4 people to the same vignettes: the higher the risk or sensitivity the less likely they would  
5 agree to participate [REDACTED]. However, proportionately more children agreed  
6 to participate in both the higher and lower risk studies than did the HREC members grant  
7 approval [REDACTED].

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10 Although the reluctance of HRECs and others to approve high risk or sensitive social  
11 research has been discussed previously, few attempts have been made to define “high  
12 risk or sensitivity”. An earlier stage of the MESSI study, in which a range of Australian  
13 stakeholders were asked the question ‘*what is a sensitive topic?*’ found that while participants  
14 identified a range of sensitive topics, they were less concerned about the topic than with the  
15 *contexts* of children’s lives and experiences [REDACTED]. That is, topics were  
16 generally not sensitive in and of themselves, but may become sensitive to particular children,  
17 depending on their individual experiences and life circumstances [REDACTED]. Some  
18 researchers have commented that, in their efforts to protect children from their perceived  
19 risks from particular studies, HRECs can become risk-averse (Hildebrand et al., 2015).  
20 However, concerns about children becoming distressed or upset from discussing a  
21 particular issue are not well grounded in existing evidence. When children have  
22 experienced negative impacts or distress, researchers have shown that they were minimal and  
23 often compensated by positive benefits (Ellonen & Pösö, 2011; Finkelhor, Hamby, Turner, &  
24 Walsh, 2012; Murray, 2005). The need for researchers to document for HRECs the  
25 methods they will use to mitigate and address any potential risks related to the topic  
26 being investigated should be the primary concern (Powell et al., 2020).  
27  
28 The responses provided by HREC members to vignettes in relation to the sensitivity of  
29 the research are also consistent with those they provided to the other questions in the  
30 MESSI study survey. In a paper from the same study [REDACTED] more than half  
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3 the HREC members nominated particular topics that they would not approve children  
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5 aged 7 to 14 years to take part in under any circumstances. However, nearly half the  
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7 HREC members said that they would approve such research on any topic as long as there was  
8  
9 a benefit arising from the research, the methods were robust, and the risks clearly managed  
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12 [REDACTED]

#### 15 4.2 *Do higher payment amounts decrease the chance of approval?*

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18 This study also found that any payment for participation, in the form of cash (\$30 or \$100)  
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20 or the opportunity to enter a draw to win a \$200 voucher would generally discourage HREC  
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22 members from approving a study, regardless of its level of sensitivity.  
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27 At all study risk levels, HREC approval was most likely when no payment was on offer  
28  
29 and approval fell as the payment increased. Around half of the 52 HREC members who  
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31 rejected all four hypothetical studies (presented as an internet survey with a chance to enter a  
32  
33 \$200 voucher draw) rejected the low-risk food choices and internet safety studies primarily  
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35 on the basis of concerns about payment. This suggests that some respondents were so  
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37 concerned about payments to children that they would not approve any study regardless of  
38  
39 the topic or risk level.  
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44 Around half the HREC members would approve the higher risk studies if no payment  
45  
46 was offered; yet payment was rarely given as the stated reason for rejecting the higher  
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48 risk studies. Instead, the stated concerns were the study risks or topic.  
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52 At the higher risk levels, HREC members approved \$200 voucher draws at the same rate as a  
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54 \$30 payment, while for the lower risk studies the \$200 voucher draw was preferred to the \$30  
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56 payment. In contrast, children and young people were equally likely to participate at the  
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58 different risk levels when offered a \$30 payment or entry into a \$200 voucher draw [REDACTED]  
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3 ██████████ Researchers with more limited research budgets may be encouraged by this finding  
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5 to offer entry into a \$200 voucher draw, as they appear to be acceptable to both HREC  
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7 members and children and young people.  
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11 In examining the children's responses to the same vignettes, we used Singer and Couper's  
12  
13 (2008) empirical test of the "undue influence" of incentives, which tests whether or not there  
14  
15 is a statistically significant interaction between the size of the risk and the size of the payment  
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17 on the decision to participate. We found that neither the A\$30 nor \$A100 payments provided  
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19 "undue influence" in the riskier study – that is, that they were not induced to participate in a  
20  
21 study they may not have participated in without a payment ██████████. Furthermore,  
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23 a remarkable number told us they would participate without payment. However, consistent  
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25 with findings that monetary payments are an effective tool to increase research  
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27 participation rates (Bower et al., 2014; Jennings et al., 2015; Permuth-Wey &  
28  
29 Borenstein, 2009; Singer & Couper, 2008), children and young people were more likely  
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31 to agree to participate as the payment increased ██████████.  
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37 On the basis of our previous findings in relation to the children and young people, "undue  
38  
39 influence" is unlikely to be as much of a concern as HREC members have previously  
40  
41 thought, and should not even be a consideration with low risk studies. The origins of HREC  
42  
43 members' concerns about the appropriateness of payments to children for their participation  
44  
45 in any research study may reflect our previous findings about HREC members' lack of  
46  
47 expertise and training in research with children ██████████ Lower level research  
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49 payments to children, such as \$30 and voucher draws (a \$200 draw was used in this study),  
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51 are more commonly used and provide the benefit of increasing participation rates without  
52  
53 "undue influence" on child participants ██████████ Their use should be supported  
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55 rather than used as a criteria by which a study is not approved by research ethics committees.  
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#### 4.3 *Does the study method influence approval?*

In the lower risk study scenarios, no differences were detected in the HREC members' likelihood of approval for the different study methods tested: online survey, school survey, face-to-face survey in the child's home and a group interview or focus group with a researcher at a youth centre near home. The only difference detected was in relation to the higher risk scenarios, where HREC members were more likely to provide approval if the study was conducted as a face-to-face interview in the child's home.

Face-to-face or in-person interviews are generally assumed to provide more opportunity for the researcher to monitor and discontinue the study if the child participant becomes distressed or upset. However, children may prefer the anonymity of a paper or online survey when providing information about a topic that is sensitive or considered personal, rather than discussing it with a researcher at their home where they may be concerned about being overheard by their parents (Macapagal, Coventry, Arbeit, Fisher, & Mustanski, 2017). Others want to be offered the choice (Hill, 2015). Researchers may need to address HREC concerns by outlining how they would mitigate any risks from conducting (online) surveys with children and young people on potentially sensitive topics, should they choose this study method.

## 5 **Best practices**

HREC members were concerned about each element of the study design, but primarily the risk or sensitivity of the study, and the payment amount. When considering lower risk studies, their decisions to deny approval of the study were driven primarily by concerns about payment. However, when they considered a study to be high risk or of high sensitivity, the motivation for denying approval was largely the risk.



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3 These findings may prompt researchers to conclude that to maximize the chance that  
4 their study is approved by an HREC, they should avoid the use of a payment for the child  
5 participant. However, there are a number of reasons to argue for payments for child  
6 participants, as for adults. Firstly, payments increase participation rates and are also  
7 appropriate as compensation for time spent on research or reimbursements for expenses  
8 (Dickert & Grady, 1999; Gelinas et al., 2018; Rice & Broome, 2004). (Largent & Lynch,  
9 2017) argue that there is also a responsibility on the part of research ethics committees to  
10 ensure that payments are not too low as to be exploitative. Secondly, concerns about the  
11 “undue influence” of payments are unfounded. Children and young people are able to identify  
12 risks and are not induced by money to participate in research that they would not have  
13 otherwise participated [REDACTED]. On this basis, HREC member concerns can be  
14 allayed, and their focus on payments as the reason for denying study approval is unwarranted.  
15 Payments of around \$30 may be appropriate for child participants even for high risk studies.  
16 Furthermore, an undue emphasis by HRECs on payment issues rather than managing risks  
17 and methodological issues can lead to children and young people being denied that  
18 opportunity to consider their own participation.

## 6 Research Agenda

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43 The limited research about HREC decision-making reduces the transparency of their research  
44 ethics approval processes, particularly in relation to research involving children and young  
45 people. Using hypothetical research scenarios is an innovative way to gain insights into the  
46 decision-making of HREC members, particularly in relation to their assessment of factors  
47 such as the level of sensitivity and payment levels that could not tested in a real research  
48 study with children and young people. The MESSI study has also allowed us to compare the  
49 responses of the other groups who responded to the same scenarios (children and young  
50 people, professionals and parents) to provide additional information about questions of  
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3 appropriate payment amounts and the sensitivity or risk. Further research that builds on the  
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5 findings from this study may provide greater clarity in terms of how to optimise the  
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7 participation of children and young people in social research studies about issues that affect  
8  
9 them. Additional research with HREC members in other countries is also needed to better  
10  
11 understand the generalisability of these findings.  
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## 15 **7 Educational Implications**

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18 HRECs would benefit from additional training and guidance on how best to facilitate  
19  
20 children's participation in ethical research and on the issues related to payments for children  
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22 and young people in research. Obtaining children and young people's direct perspectives on  
23  
24 complex ethical issues is an innovative method that could be used more widely to provide  
25  
26 guidance for HRECs. Some HRECs have established a children and young person's advisory  
27  
28 committee to represent and provide advice in relation to research projects involving children  
29  
30 and young people (Navratil, McCauley, Marmol, Barone, & Miller, 2015). Others have  
31  
32 incorporated children and young persons' reference groups to assist with particular projects  
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34 and to integrate their views into the research ethics application (Moore, Noble-Carr, &  
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36 McArthur, 2016). Whichever method is used, additional input to inform HREC decision-  
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38 making about these issues is needed.  
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45 To assist HRECs in their decision-making, researchers themselves would benefit from  
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47 additional training and expertise on how to manage the risks related to their research with  
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49 children, and in presenting that information in their research ethics applications. Better  
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51 researcher awareness of the issues around payments of child participants, including  
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53 appropriate payment amounts, is essential to increase the opportunities for children to  
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55 participate in social research about sensitive issues.  
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## 59 **8 Study limitations**

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3 There are some limitations to the study which should be considered in interpreting these  
4 findings. Firstly, this sample of HREC members is from an Australian study and may not be  
5 applicable to other countries with different research ethics review processes. Secondly, with  
6 a relatively low response rate of around 14%, there could be concerns about selection bias  
7 towards respondents most concerned about research with children on sensitive topics.  
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10 Thirdly, descriptions of the hypothetical research studies provided less information than  
11 would usually be provided in ethics applications. In designing the vignettes we had to balance  
12 the need to provide enough information for participants to decide whether they would  
13 approve a study, and the need for brevity to minimise participant attrition. Fourthly,  
14 following traditional vignette design, the information included was uniform for all groups of  
15 survey participants (HREC members, children, parents and other professionals), which also  
16 restricted the level of detail. Irrespective of these limitations, this is one of the larger studies  
17 examining these issues, and the measures used detected differences both between and within  
18 groups.  
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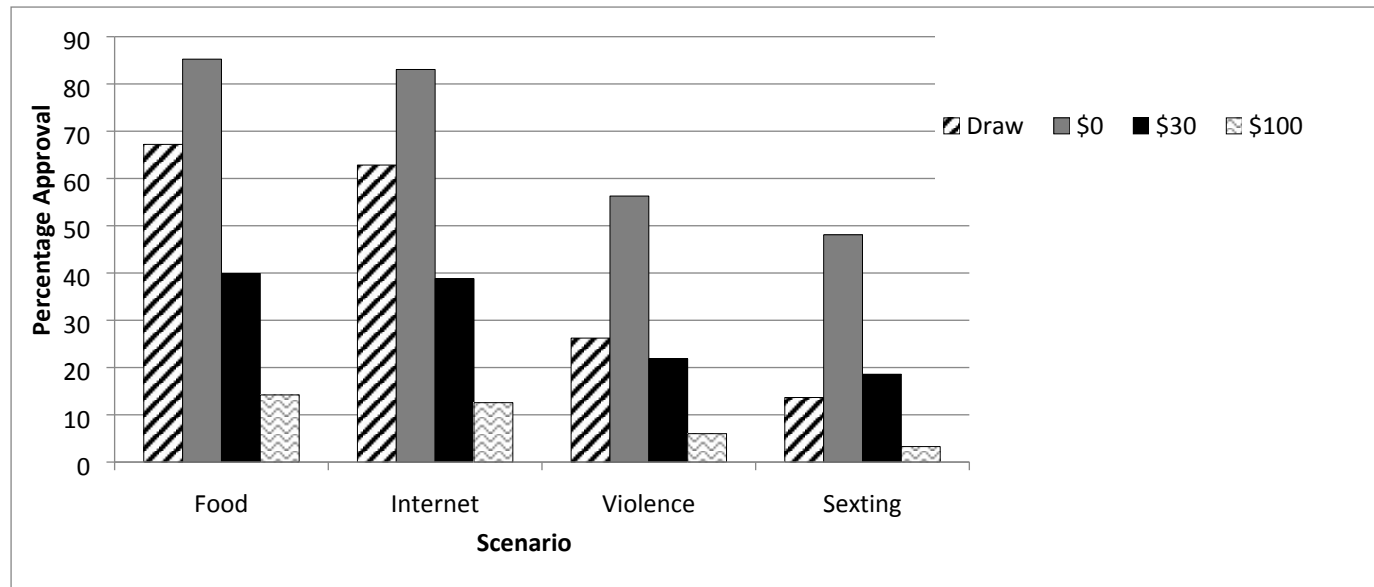


FIGURE 1: Predicted probabilities of approval by hypothetical study topic/sensitivity and payment.

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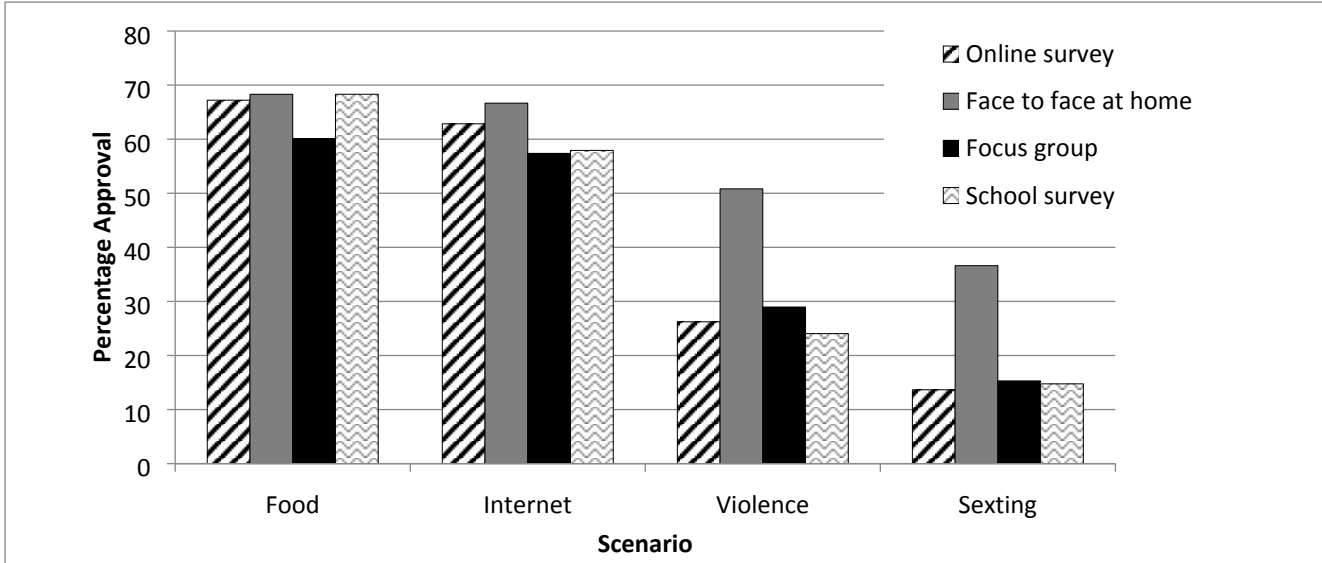


FIGURE 2: Predicted probabilities of approval by hypothetical study topic/sensitivity and survey method.

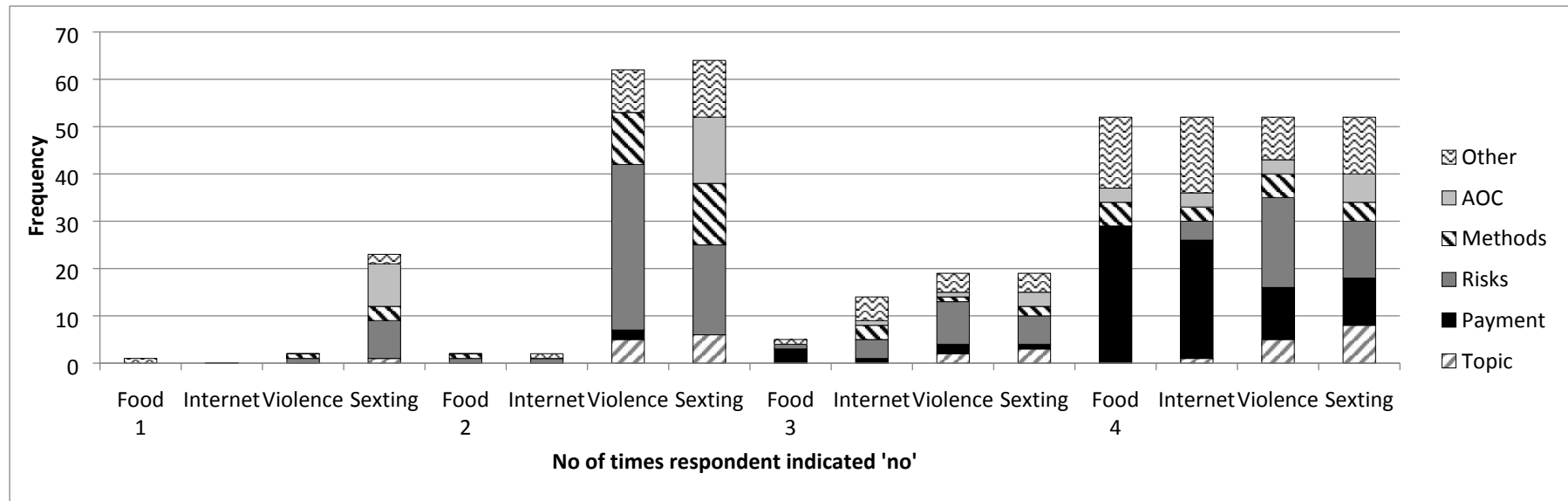


FIGURE 3: *The main reason given by HREC members for rejecting hypothetical studies by the study topic/sensitivity and number of studies rejected*

Table 1: Roles and gender of HREC member respondents

Characteristics	Sample respondents (n =183) %
Distribution of HREC respondents	
NSW/Victoria/Queensland	78.1
Type of HREC	
University/college	50.8
Hospital/health service	31.7
Other	17.5
Role on the ethics committee	
Chair	12.6
Lay person	24.0
Professional	13.7
Pastoral care	10.4
Lawyer	7.1
Researcher	28.4
Other	3.8
Gender	
Female	58.0
Male	41.5
Other/Missing	0.5
Total	100.0

Table 2: Unadjusted results for the association between scenario and HREC approval

			Marginal probability/ Percentage approval
	Risk or sensitivity of topic	RR (SE)	
Food choices	Low		57.6
Internet	Low	0.94(0.02)*	54.2
Violence	Medium	0.53(0.03)***	30.6
Sexting	High	0.37(0.03)***	21.5

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 3: Estimated RRs from a series of general linear model predicting HREC member approval for hypothetical studies by study topic (n=1,281 for each study)

	Experience of			
	Food Choices	Internet Safety	Violence	Sexting
	RR (SE)	RR (SE)	RR (SE)	RR (SE)
<i>Role on HREC</i>				
Chair	Ref			
Lay person	0.91(0.10)	0.80(0.09)*	0.92(0.19)	0.84(0.21)
Professional	0.81(0.10)	0.75(0.10)*	0.80(0.22)	0.81(0.22)
Researcher	1.08(0.10)	0.94(0.10)	1.06(0.21)	0.77(0.18)
Other	0.87(0.09)	0.83(0.10)	0.88(0.18)	0.77(0.17)
<i>Non-university HREC</i>				
	1.00(0.07)	0.97(0.07)	0.98(0.13)	1.14(0.19)
<i>Payment</i>				
Chance in \$200 draw	Ref			
\$0	1.27(0.07)***	1.32(0.08)***	2.15(0.25)***	3.52(0.61)***
\$30	0.59(0.06)***	0.62(0.06)***	0.83(0.13)	1.36(0.28)
\$100	0.21(0.04)***	0.20(0.04)***	0.23(0.06)***	0.24(0.09)***
<i>Study method</i>				
Online survey	Ref			
School survey	1.02(0.06)	0.92(0.06)	0.92(0.12)	1.08(0.24)
Face to face at home	1.02(0.06)	1.06(0.07)	1.94(0.25)***	2.68(0.51)***
Focus group	0.89(0.06)	0.91(0.07)	1.10(0.16)	1.12(0.24)

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

## Appendix A: Text for the hypothetical research studies

### Food choices scenario text:

You are invited to take part in a study about the types of food you do and don't like to eat.

We want to know:

- About the food you eat inside and outside of school
- What food you like and
- If you help to buy and cook food at home.

By asking young people about this, researchers will be able to understand more about young people's food choices and how to make healthy eating more exciting.

The study is an online survey. It will take about 15 minutes and can be done at home. If you finish the survey, you can go into the draw for a \$200 voucher.

It is your choice to fill out the survey. The information you fill out will be confidential, meaning your name will not be used and no one will be able to identify you from what you said. You can stop the survey any time. If you are upset, talk to your parents or another trusted adult. If you have any complaints about the survey, you can contact the researchers or the Ethics Office of [REDACTED]

### Internet safety scenario text:

You are invited to take part in a study about your views on internet safety.

We want to know:

- When, where and how you access the internet
- How you keep yourself safe online and
- What adults have taught you about internet safety and what you think about it.

1  
2  
3 By asking young people, researchers can help schools and adults understand how young  
4  
5 people use the internet. The study will also provide information about ways for young people  
6  
7 to protect themselves online.  
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11 The study is an online survey. It will take about 15 minutes and can be done at home. If you  
12  
13 finish the survey, you can go into the draw for a \$200 voucher.

14 It is your choice to fill out the survey. The information you fill out will be confidential,  
15  
16 meaning your name will not be used and no one will be able to identify you from what you  
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18 said. You can stop the survey any time. If you are upset, talk to your parents or another  
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20 trusted adult. If you have any complaints about the survey, you can contact the researchers or  
21  
22 the Ethics Office of [REDACTED]  
23  
24 [REDACTED]

#### 25 Violence scenario text:

26  
27 You are invited to take part in a study about children and violence.  
28  
29

30 We want to know:

- 31  
32
- 33 • How often you have seen or been a victim of violence (e.g. assault or bullying  
34  
35 between young people and/or adults)
  - 36  
37 • Where it took place and who with
  - 38  
39 • Whether you were hurt and how it made you feel
  - 40  
41  
42

43 By asking young people about their views and experiences, researchers will be able to better  
44  
45 design programs and advise young people on how they might avoid violent situations in the  
46  
47 future.  
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51 The study is an online survey. It will take about 15 minutes and can be done at home. If you  
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53 finish the survey, you can go into the draw for a \$200 voucher.

54 It is your choice to fill out the survey. The information you fill out will be confidential,  
55  
56 meaning your name will not be used and no one will be able to identify you from what you  
57  
58 said. You can stop the survey any time. If you are upset, talk to your parents or another  
59  
60 trusted adult. If you have any complaints about the survey, you can contact the researchers or



1  
2  
3 the Ethics Office of [REDACTED]  
4 [REDACTED].  
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8 Sexting scenario text:  
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10  
11 You are invited to take part in a study about children and sexting.  
12

13  
14 We want to know:  
15

- 16  
17 • How often you have sent or been sent a sext (a sexual or sexually suggestive message,  
18 photo or video) and  
19  
20 • Whether the sexts were sent on to other people.  
21  
22 • We will also ask young people to send examples of their sexts to the researchers.  
23  
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28 By asking young people about this, researchers can understand how often young people  
29 engage in sexting and what type of content is sent. This will help to advise people on how to  
30 maintain their privacy.  
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36 The study is an online survey. It will take about 15 minutes and can be done at home. If you  
37 finish the survey, you can go into the draw for a \$200 voucher.  
38

39 It is your choice to fill out the survey. The information you fill out will be confidential,  
40 meaning your name will not be used and no one will be able to identify you from what you  
41 said. You can stop the survey any time. If you are upset, talk to your parents or another  
42 trusted adult. If you have any complaints about the survey, you can contact the researchers or  
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**Appendix B: General linear model predicting hypothetical approval of scenarios.**

Approval (n=183)	RR (SE)
<i>Role on HREC</i>	
Chair	Ref
Researcher	0.98(0.09)
Lay person	0.86(0.10)
Professional	0.79(0.11)
Other	0.85(0.09)
<i>Non-university HREC</i>	
	1.00(0.07)
<i>Scenario topic</i>	
Food choices	Ref
Internet safety	0.94(0.04)
Violence	0.39(0.05)***
Sexting	0.20(0.04)***
<i>Payment</i>	
Chance in \$200 draw	Ref
\$0	1.27(0.07)***
\$30	0.59(0.06)***
\$100	0.21(0.04)***
<i>Method</i>	
Online survey	Ref
Focus group	0.89(0.06)
Face to face interview at home	1.02(0.06)
School survey	1.02(0.06)

**Scenario topic by Payment***Internet*

Chance in \$200 draw	Ref
\$0	1.04(0.05)
\$30	1.04(0.08)
\$100	0.95(0.11)

*Violence*

Chance in \$200 draw	Ref
\$0	1.69(0.19)***
\$30	1.40(0.19)*
\$100	1.08(0.25)

*Sexting*

Chance in \$200 draw	Ref
\$0	2.78(0.47)***
\$30	2.29(0.44)***
\$100	1.14(0.4)

**Scenario topic by Method***Internet*

Online survey	Ref
Focus group	1.02(0.07)
Face to face interview at home	1.04(0.05)
School survey	0.91(0.05)

*Violence*

Online survey	Ref
Focus group	1.23(0.17)

1		
2		
3	Face to face interview at home	1.91(0.23)***
4		
5	School survey	0.90(0.11)
6		
7		
8	<i>Sexting</i>	
9		
10	Online survey	Ref
11		
12	Focus group	1.25(0.27)
13		
14	Face to face interview at home	2.64(0.49)***
15		
16	School survey	1.06(0.23)
17		
18		
19	Constant	0.75(0.07)**
20		

---

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .