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Making ethical deliberations public.

Some provisional resources for youth research ethics

Kitty te Riele & Rachel Brooks

Abstract

The focus of this special edition of *Youth Studies Australia* is on questions, issues, challenges and (tentative) solutions in relation to ensuring we conduct our research with young people ethically. This introductory paper draws on ethical principles as outlined in the *National Statement on Ethical Conduct in Research Involving Humans* and in the *Fairbridge Code of Ethics* for youth work. The authors explain how these principles can inform ethical youth research. In the process, they weave through comments to and from the remaining five papers in this special issue, thereby providing an authentic touchstone for the principles as well as recommending all the papers to you.

This special issue of *Youth Studies Australia* addresses genuine ethical challenges that the contributors have faced in their own youth research. It is worth noting this is unusual. Publications tend to skim over issues of method and ethics in a rush to get to a discussion of concepts and findings. Although ethics inherently involves grey areas and ambiguity, once official 'ethics clearance' has been granted for a research project ethical dilemmas receive little public attention (see Burke 2007). This does not mean, however, that youth researchers ignore such dilemmas during the course of preparing, conducting, analysing and writing up research. Our awareness of our position of power (due to our position and age) means that as youth researchers we tend to take ethical challenges in our research with young people seriously and deal with them conscientiously. This special issue has its origins in our conviction that it is worth making such ethical deliberations public, so that we can learn from each other. In addition to this special issue, our invitation to colleagues to share their experiences has led to a book to be published by Routledge in early 2013, *Negotiating ethical challenges in youth research*. While the book explicitly draws on research from around the globe, this special issue is focused on Australia and New Zealand.

Codes of ethics

To introduce the special issue, in this paper we begin by addressing some of the ethical principles that play a role in youth work, youth studies, and youth research. These provide a foundation and backdrop not only for the papers in this issue but for youth research more generally. They are offered here as provisional resources. In other words, such ethical principles are not straightforward recipes leading to perfect solutions, but they can support a person's own deliberations in relation to a genuine ethical dilemma in a specific (research) situation. In addition to codes of ethics, ethical theories also provide valuable insights (for example see Bessant 2009 and Daley in this special issue). Lack of space prohibits us from exploring ethical theories in this introductory paper.

Professional ethics, and specifically the usefulness or otherwise of a code of ethics, has received considerable attention among Australian youth workers over the past few years. The issues are captured by the Australian Youth Affairs Coalition (AYAC) on its 'Great Debate' webpages (AYAC 2011). Research ethics is much more established, at least in universities, with mandatory

processes for gaining 'ethics clearance' before being able to embark on the empirical phase of a research project. Nevertheless, there is also ongoing debate about the role of such procedural ethics and of research ethics committees (see Dingwall 2011; Langlois 2011). Lichtenberg (1996, p. 14) points out that codes of ethics tend to be aimed at professionals (such as youth workers and researchers) "who jealously guard their independence and are not generally lacking in the conviction of their intellectual and moral powers". Of course, nobody in youth work, youth studies or youth research would suggest that it is unnecessary to act ethically. Therefore we focus here on the resources that ethical principles offer to those conducting research with young people, which can support their ethical practice.

In Australia, the key document informing human research ethics is the *National Statement on Ethical Conduct in Research Involving Humans* developed jointly by the National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors' Committee (NHMRC, ARC and AVCC 2007, referred to from here on as the National Statement). The National Statement is the basis for the work of university ethics committees. In an explicit recognition that research with children and young people can raise specific ethical challenges, the National Statement has dedicated a chapter to this. A common misunderstanding is that the National Statement requires all research with participants under the age of 18 to obtain the consent of a parent or guardian. The guidance offered by the National Statement is more refined, distinguishing between levels of maturity and vulnerability and unequivocally stating that "It is not possible to attach fixed ages to each level" (NHMRC, ARC and AVCC 2007, p. 55).

The principles in the National Statement will be our starting point here. In addition, we draw on the West Australian *Code of Ethics* (YACWA 2003) developed for youth workers. Such professional codes of ethics, although not explicitly aimed at informing research, can be helpful for youth researchers because they provide more general principles for ethical practice in working with young people. Moreover, much youth research is conducted in the not-for-profit and community sector, where formal research ethics clearance may not be required and a professional code of ethics has a higher profile than academic research ethics. This was the case for Beals, in this special issue, who conducted her research project in relation to the UN Convention on Rights of the Child from within a non-government organization for youth development. As a result of her experiences, she argues the need to "draw a bridge" between ethical youth work and research practices. Apart from Beals, two other authors for this special issue (Daley and Billett) had a background in youth work before embarking on formal academic research. In Australia, youth affairs networks in Western Australia, New South Wales, Victoria, the Australian Capital Territory and Tasmania have (draft) codes of ethics. The code developed by the Youth Affairs Council of Western Australia (YACWA, 2003) was first of the block, known as the Fairbridge Code. The codes in the other states are (closely or loosely) based on this.

Research merit and integrity

The first principle in the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC, ARC and AVCC 2007) is research merit and integrity. Research merit is mostly about the research design, such as ensuring the methods are appropriate both for achieving the research aim and for the children and young people who are the participants. Youth researchers have been quick to adopt new methodologies that are likely to suit young people, such as arts-based methods, youth-participatory and youth-led methods, and internet and mobile technologies. The latter is the focus of the paper by Burden, Aubusson and Schuck in this special issue. They show how research that has 'internet and mobile technology use by young people' as its topic also tends to use these technologies as the research method. As they explain, this raises

specific ethical concerns, for example in relation to the blurring of public/private boundaries of information. In relation to youth participatory research Beals, in her paper in this issue, points out the danger of assuming that such an approach empowers young people. In other words, while it is ethical for youth researchers to choose methods that are appropriate to the young people participating in the research, when these methods are relatively new researchers need to be prepared for the emergence of equally new forms of ethical challenge.

The second part of the first principle, integrity, refers to researchers' honesty and to the commitment to searching for and contributing to knowledge. The focus on honesty is also reflected in the Fairbridge Code through its principles of (anti-)corruption and integrity. The youth work principle of knowledge suggests "Youth workers have a responsibility to keep up to date with the information, resources, knowledges and practices needed to meet their obligations to young people" (YACWA, 2003, p. 2). This is a useful reminder to youth researchers to not only focus on advancing public and scholarly knowledge but also their own, for example by reflecting on the ethical challenges in one's research, in order to meet their obligations as researchers.

Justice

The next principle of justice refers to the fair distribution of both the burdens and benefits of research. For example, this means that all young people should have an equal opportunity to participate in research that is relevant to them. This is also reflected in the Fairbridge Code principle of equity and non-discrimination. The consultation paper of the Youth Network of Tasmania (YNOT, 2012, p. 12) gives a relevant case scenario:

Sarah works for an organisation that aims to help young people engage with decision makers. Sarah hears that a Minister is interested in setting up a youth council to discuss with young people their thoughts on various issues. To participate in this group young people will have to provide a lengthy written application that details why they deserve a place at the table. The advertising material for the positions was being distributed through networks of youth organisations and universities. Sarah is concerned that only young people with a high level of written skills will apply for positions, potentially making the youth council unrepresentative of the population and its diversity.

In this special issue Billett also discusses this problem in relation to her research on young people's social capital. She refers to the invisibility and muteness of some groups of young people when researchers focus on easily accessible groups and warns of the risk of skewed and even unjust research findings as a result. The NHMRC also mandates that within specific research projects benefits must be fairly distributed and no young people should be exploited. This is taken up in relation to ensuring all voices are heard by Beals, and in relation to the equitable use of extrinsic incentives by Seymour in this issue.

Beneficence

In the NHMRC National Statement, the principle of beneficence is used to refer both to encouraging benefits of research and wellbeing of participants and also to the minimization of risk of harm (sometimes referred to as non-maleficence). Practically, the National Statement requires researchers to design the research so that likely benefits outweigh and justify any possible risks of harm. This balancing act is addressed by Beals, in this special issue, who points out the risk that the desire for enabling youth voice (articles 12-14 of the UN Convention on the Rights of the Child) could inadvertently lead to exploitation of young people (article 36).

For youth research, the National Statement specifically suggests: “The circumstances in which the research is conducted should provide for the child or young person’s safety, emotional and psychological security, and wellbeing” (NHMRC, ARC and AVCC 2007, p. 56). In relation to emotional wellbeing, the paper by Daley demonstrates that this is not straightforward and may require the researcher to respond very differently to similar issues (of over-disclosure and tears) depending on the participant. In terms of physical wellbeing, Seymour (also in this issue) makes us stop and think about the food we may provide as an incentive or courtesy for participants, in terms of health and allergies. In the Fairbridge Code these kinds of concerns are reflected in the principles of the young person being the primary client, duty of care and cooperation. In addition, the Fairbridge Code includes the principle of transparency. This relates to the National Statement’s requirement that researchers clarify for participants the potential benefits and risks of harm (as part of beneficence) as well as to ensure consent is genuinely well-informed (as part of respect, see below). In relation to the use of incentives, in this issue Seymour argues that the practice not to disclose to young people that they will receive a gift or reward until the data collection has finished, intended to avoid coercion, can run into problems due to this lack of transparency. Daley suggests the need for transparency about the role of the researcher in qualitative interviews on personal topics, to avoid the appearance of a ‘false bond’ that may appear to offer promise more benefit than the researcher can genuinely provide. Finally, the Fairbridge Code also includes the principle of self-care, stating that “ethical youth work practice is consistent with preserving the health of youth workers” (YACWA 2003, p. 2). In the National Statement, attention for the researcher’s ‘self-care’ is less obvious, but there is a requirement for research institutions to be satisfied that researchers “understand the need to assess risk to their own safety” (NHMRC, ARC and AVCC 2007, p. 77). Australian university ethics forms usually have a question asking applicants to address any potential risk of harm to themselves that may result from the research project. Interestingly, in the United Kingdom the Sociological Research Association has a detailed *Code of Practice for the Safety of Social Researchers* (SRA, 2001). For researchers in non-government and community organisation rather than universities, Beals points to the lack of protection when there is no formal ethics approval process. At a more immediate level, Daley refers to having to weigh up the potential risk of interviewing a potential participant in their home or a similar private location. Although this was just a side issue in Daley’s paper, such attention to self-care also matches the care theory approach that she draws on (see Gilligan, 1982).

Respect

The principle of respect is fundamental to research ethics. It recognises people’s intrinsic value, requires due regard for their welfare, beliefs and customs as well as due scope “to the capacity of human beings to make their own decisions” (NHMRC, ARC and AVCC 2007, p. 13). The latter is clearly reflected in the Fairbridge Code principle of empowerment, which affirms the presumption “that young people are competent in assessing and acting on their interests” (YACWA 2003, p. 2). The complexities around these pronouncements are highlighted through the application of informed consent in youth research. Earlier we pointed out that the National Statement does not necessarily require parental/guardian consent for all participants under age 18. Here it is worth quoting at length the specific exemptions from the National Statement (NHMRC, ARC and AVCC 2007, pp. 56-57):

An ethical review body may approve research to which only the young person consents if it is satisfied that he or she is mature enough to understand and consent, and not vulnerable through immaturity in ways that would warrant

additional consent from a parent or guardian.

[.. and..] if it is satisfied that:

- (a) he or she is mature enough to understand the relevant information and to give consent, although vulnerable because of relative immaturity in other respects;
- (b) the research involves no more than low risk (see paragraph 2.1.6, page 18);
- (c) the research aims to benefit the category of children or young people to which this participant belongs; and
- (d) either
 - (i) the young person is estranged or separated from parents or guardian, and provision is made to protect the young person's safety, security and wellbeing in the conduct of the research (see paragraph 4.2.5). (In this case, although the child's circumstances may mean he or she is at some risk, for example because of being homeless, the research itself must still be low risk); or
 - (ii) it would be contrary to the best interests of the young person to seek consent from the parents, and provision is made to protect the young person's safety, security and wellbeing in the conduct of the research (see paragraph 4.2.5).

This provides more leeway than many youth researchers (and even ethics committees) realise for empowering young people to make their own decisions about consenting to participate in research. In this issue, Billett argues for the importance of this for research on social capital because without such agency for young people research may end up excluding vital contributions, for example from young people involved in 'undesirable' activities.

The National Statement principle of respect finds its application mainly in terms of ensuring consent is well-informed and freely given, and in protecting participants' identity through confidentiality (which is also a principle in the Fairbridge Code). First, in relation to consent (apart from the issue of parental consent as discussed above) the concern that consent must be freely given informs much of the discussion of the ethical use of incentives for participation. In other words, incentives should not put undue pressure on people to participate (see NHMRC, ARC and AVCC 2007, p. 36). In her paper for this special issue, Seymour takes a more nuanced approach, distinguishing between intrinsic and extrinsic incentives. Second, the expectation that research maintains participants' confidentiality poses genuine challenges for some research methods. In this special issue, Beals explains how she solved this challenge in the use of participatory research leading to publicly available audio-visual 'digital storytelling'. In research using mobile and internet technologies, the challenge is perhaps even greater because, as Burden, Aibusson and Schuck explain in their paper, the border between private and public data can be nebulous.

Conclusion

Rather than adopting the traditional approach of a guest editorial paper and concluding with a kind of annotated bibliography of the papers in this issue, we have woven through insights from the five papers in the discussion above. We hope this has served two purposes: both giving you a flavor of the five papers and thereby recommending them to you, and also making both the ethical principles and related challenges less abstract and more real. The latter has been our own guiding principle both for this special issue and for the edited book (Te Riele & Brooks, 2013).

The ethical conduct of youth research requires deliberation on values, exercise of judgment, and an appreciation of context. Ethical principles such as those outlined here can be used as resources to support this deliberation, but they are a step removed from the nitty-gritty of doing actual youth research. We hope that the papers in this special issue will support other youth researchers because they are based on authentic ethical questions, issues, dilemmas and proposals of solutions based on real research projects involving young people.

Our contributors are not moral philosophers but ordinary researchers willing to open their research up to ethical scrutiny in order to add to an evidence base and encourage discussion of how to do youth research ethically. For example, Seymour in this special issue explicitly acknowledges the need to extend researchers' understanding of the ethical use of incentives in youth research. Beals notes that, in the absence of a formal ethics committee, writing their own 'ethics report' and making this public helped build trust by others and confidence for the research team itself. Daley draws on the work of Shaw (2008) to alert us to the problem that a "lack of discussion of ethical issues implies that ethical decisions can be made reasonably uniformly". Self-awareness, one of the ethical principles in the Fairbridge Code, provides a major step towards ensuring our research is ethical. The authors in this special issue have gone one step further by making their reflections public for all of us. We hope that, like us, you appreciate their openness and are inspired to continue the conversation about ethical challenges in your own research practice.

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