

# Co-producing trans ethical research

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This chapter engages with the way in which the emergence of trans discourses challenge conceptualisations and practices encountered within ethical processes in research. Advancing progressive research merits critical reflection and a productive rethinking in sexuality and gender studies. Our engagement with ethical issues here is oriented towards addressing questions of how trans subjectivities challenge and develop understandings of gender and sexuality expressed within research settings, and the extent to which research practices are fit for engaging trans subjects.

Our understandings of trans have been formed through participant engagement within research, such as in that outlined in the case studies in this chapter. We specifically understand trans to include nonbinary, genderqueer and genderfluid people as a result of these engagements.

We begin by outlining concepts, practices and procedures in ethical approaches in a brief summary of scholarship in this area. Following this, we present projects undertaken in UK and Australian contexts to draw out specific issues. Specifically, we discuss: conceptualisation of participants/co-researchers in ethical practices that pose barriers to participation; ethical considerations in relation to space, place and time for online methods; and community or co-researcher collaboration to enhance accountability and participant engagement. This piece does not offer an exhaustive ethical review or proposed guidelines, but instead reflects upon how challenges emerged in our practice and were negotiated, with the intent of contributing to an existing dialogue about creating ethical contexts for engagement.

There are multiple reasons for the focus of the chapter. First, all research requires approval from ethical committees and we argue that it is crucial to develop a better understanding of the facilitating and constraining roles of formal processes in research practices with this community. Furthermore, ethical practices should be continuously evaluated and engaged with by researchers, including co-

developing with community partners, ethical accountabilities and practices, to best serve the interests of the communities and individuals involved in or impacted by research. It is important to locate this endeavour within emerging developments in relation to theoretical frameworks (e.g. Hale 2009; Rooke 2010), guidelines for practice (e.g. APS 2013) and new methodologies (e.g. Adler & Zarchin 2002).

### **Background Literature**

Ethical concepts, guidelines and practices as they relate to research are understood here to be informed by cultural and societal representations of morality, responsibility, risk, harm and benefit and as such are located within specific socio-historical, cultural and geopolitical contexts (Parker 2005; Taylor 2008). Conventional ethical notions and discourses are wide ranging, and this chapter concerns ethical frameworks produced through national research body frameworks and guidelines (Research Councils United Kingdom 2013; National Health and Medical Research Council 2015), professional codes of practice (Australian Psychological Society 2007), research conventions such as qualitative ideas about morality and the individual responsibility of the researcher, and decision-making in institutional ethical committees. Engagement within these frameworks is facilitated and sometimes complicated by the specific ethical principles that underpin the individual research investigation, including the theoretical framework, research approach and the involvement of communities impacted by the project. Within the broad domain of ethics we focus on a commitment to critiquing and developing meaningful forms of engagement with individuals and communities involved in and impacted by the research activity. As scholars existing both inside and outside of the research communities we work with, there are ethical implications for our research projects and our understanding of ourselves as researchers.

Our conceptualisation of ethical issues is aided by the concept of “cisgenderism” – a systemic, ideological and structural violence, often reflected in discourses pertaining to legitimacy (Ansara & Hegarty, 2012). Distinctions are often made between people classified as ‘normal’ and trans people, with trans people requiring explanation (Ansara 2010); the cisgenderism framework enables an

interrogation of this ideology. Cisgenderism alerts us to obligations to question problematic assumptions that may be embedded and enacted through “standard” research practices. For instance, psychology scholarship has a long history of pathologisation misgendering or exclusion based on problematic assumptions about gender (Ansara & Hegarty 2012, 2014).

A few issues have been raised in the literature that assist thinking through the contemporary research context. Often in research terminology is used which ignores or excludes particular identities, or which offers a limited set of ways of describing identities that tend to hold more social currency and are better known (e.g. LGBTIQ). Additionally there are well-noted issues with obtaining representative samples in research; there is a particular concern that findings may over-represent views and experiences of people who are more ‘visible’ or face fewer barriers to research participation (Hines 2013; McDermott, Roen & Piela 2013). Furthermore, Morgan and Taylor (2016) have discussed the differences between trans-specific and trans-inclusive research, with the inclusion of stakeholders helping to achieve meaningful rather than tokenistic engagement. Reflection upon this issue highlights the limitations of understanding experiences more broadly and the necessity of careful consideration regarding what we can assume about community members’ experiences and what we can claim to know based on research.

Moreover, pertinent ethical concepts merit contextualised consideration. For example, in thinking about the notion of risk, we must also consider that risk may be something which is negotiated through daily experience in discriminatory societies (Taylor 2008). Acknowledging this prompts a critical consideration of associated ideas such as ‘vulnerability’. Conventional ethics is bound up in notions that participants are vulnerable and that the ‘professional’ researcher has knowledge and power. When the British Psychological Society’s Code of Ethics and Conduct first mentions an imbalance of power, it is to reinforce rather than challenge this notion: ‘ethics is related to the control of power. Clearly, not all clients are powerless but many are disadvantaged by lack of knowledge and certainty compared to the psychologist whose judgement they require’ (BPS 2009, p. 5). Boyle (2003, p. 27) describes society’s tendencies towards a discourse of vulnerability as a ‘social category

applied... only to those groups who are already socially and economically subordinate'. Boyle (2003, p. 28) argues that describing groups as vulnerable can imply 'a set of behaviours associated with passivity, and possibly gratitude, [being perceived as] seemingly reasonable... [and] just as important, the opposite behaviours [being perceived as seemingly] unreasonable'. Structures in society, discourses, and lack of power are positioned as creating vulnerability more profound than individualising, pathologising and disabling views of biological factors. The notion of 'vulnerability' within this chapter is therefore contextualised to consider structural and social means of disempowerment and marginalisation that result in detrimental impacts on wellbeing.

The literature reviewed highlights many of the challenges encountered in fieldwork and contextualises the contemporary conditions in which the research in our case studies is undertaken. We now move on to describe two studies; one in the UK and one in Australia.

***Study 1: Trans representation in the UK media, UK***

The UK study aimed to analyse the effects that trans representation in UK newspapers have on trans audiences. The impact of this coverage was investigated through online interviews and focus groups with trans people; trans participants were selected because they are the most familiar with the ways in which newspaper reporting and surrounding discourses affects their lives, and because they could offer reflections from lived experience. The questions for interviews were influenced by an analysis of trans newspaper coverage over one year to consider emerging patterns. The articles were published during the final operating year of the Press Complaints Commission (which has since been replaced with the Independent Press Standards Organisation) and the first year of new guidance for reporting and researching stories involving trans people. The focus on newspaper content was influenced by the work of Trans Media Watch and their research from 2009-2010. The interviews conducted within this case study are considered in the context of literature on trans studies, the media and gender theory (Humphrey, 2016).

***Study 2: Collaboration with young LGBTIQ people on survey design, Australia***

The Australian study involved collaboration with young LGBTIQ people on survey design. Current research indicates that members of this community negotiate intersecting forms of disadvantage that contribute to poorer health and wellbeing. The project partner, Headspace, is a national Australian youth mental health foundation and community service provider ([www.headspace.org.au/](http://www.headspace.org.au/)). The Headspace centre in a semi-rural town in New South Wales recently completed a two-year project, titled “Training for Change - Improving the Mental Health Outcomes for LGBTIQ Youth (Lesbian, Gay, Bisexual, Transgender, Intersex and Queer/Questioning)”. This examined health issues for young people who identify with a diverse range of gender and sexual identities, in order to develop training programs for service providers with the aim of improving service provision to this community. Two of the authors (Fox and Nic Giolla Easpaig) provided support with the research components of this project. Community psychology methodology informed the approach. Young people who identified as genderqueer, nonbinary and trans made valuable contributions and provided important insights for service providers through steering group collaboration as well as conventional data collection (see Nic Giolla Easpaig & Fox, 2017 for findings).

One of the first stages of research involved gathering information from young people, and this was done through an online survey and focus groups. The use of a survey measure in the research allowed a larger number of young people to contribute, and to do so anonymously. However, survey measures can also be problematic with particular regard to the way in which data concerning sexual and gender identities and practice are collected, an issue raised by the young people who participated in the project (as we discuss later in this chapter). In order to improve the survey, a steering group of young LGBTIQ people collaborated with the researchers in designing more a appropriate format and set of questions. This collaboration continued through the life of the project and has endured, but this chapter focuses primarily on the valuable insights gained in this initial work on the survey.

Ellis, Bailey and McNeil (2015) highlight that there has been a problematic tendency for trans peoples’ experiences to be subsumed within the more general category of “LGBT” experiences, which fails to engage with the specific and distinct complexities of trans peoples’ experiences. When drawing upon the example presented in this chapter, it is important for us to acknowledge that project

involvement was not limited to young people who identified as trans, and that this may have indirect implications for processes that we examine.

## **Ethical Issues for Engagement**

### **‘Risky subjects’**

We now outline issues that have arisen in our research in regards to inclusion, the characterisation of risk and vulnerability within ethical application processes, and the potential for re-researching.

Research findings are implicated in the practice of constructing knowledge about subjectivities and identities for groups such as trans communities. Given those findings are in turn based upon methodological assumptions, it is important to engage with conventions about the way participants and researchers are positioned and conceptualised within ethical practices.

#### *Limits of inclusion*

In study 2, the ethical positioning of ‘risky subjects’ was twofold, located firstly in working with young people and secondly in the specific intersections of youth, sexuality and gender identity.

Participants in research on sexuality and gender are positioned as ‘vulnerable’ and ‘risky’ by ethics committees, and research with youth compounds this issue.

The steering group of young LGBTIQ people in the project quickly identified a desire to include younger teenagers and simultaneously identified the need for participants to give consent themselves (as opposed to a parent or guardian giving consent on their behalf). The very serious possibility of *creating* risk and vulnerability by requiring parental consent for young people who are not ‘out’ to their parents was identified by these young people, as has been documented in research elsewhere (Taylor 2008). If research does require parental consent, young people who are not ‘out’ to their parents are effectively excluded.

The first crucial stage in this study therefore was to convincingly argue to the relevant ethics committee that parental consent could be waived. This was done using the National Statement on Ethical Conduct in Human Research, which allows for waiver where ‘the risk of research participation is no more than discomfort, the aim is to benefit young people, and there are additional good reasons not to involve parents’ (NHMRC 2007, p.56). This was achieved successfully for young people down to the age of 16 in this study, but regrettably not below.

### *Possibility of re-researching*

Study 1 was informed by Trans Media Watch’s trans audience research (Kermode & Trans Media Watch] 2010) in which several participants were featured in UK media articles, a finding echoed here. As Trans Media Watch assisted with participant recruitment, there was a possibility that some participants had engaged with similar research before. Re-researching participants may put anonymity at risk, especially for those that live stealth or within smaller population demographics within trans communities such as nonbinary, genderqueer and genderfluid people (Humphrey 2016). In this study, demographic information such as race and class was removed to reduce this risk. However, this approach does risk homogenising trans people by rendering invisible intersectional lived experiences. This problem has been acknowledged by Roen (2001, p. 262) who finds ‘perspectives of whiteness echo, largely unacknowledged, through transgender (and queer) theorising’ and calls for more research on ‘racialised aspects of transgender bodies’. This issue was not overcome in undertaking Study 1 and remains something which intersectional researchers need to find practical solutions for.

### *Reformulating consent-giving*

Within Study 1 participants were given three ways to indicate informed consent: signing by hand or electronically typing names on a consent form; replying yes or similar wording that indicated consent in an online interview or pre-interview email; or by logging in and attending the online focus group on the understanding that to click the link and participate was to indicate informed consent to the research. Previous research finds that signatures are hard to obtain online and that participants are

unlikely to print, sign and scan a consent form due to the time and hardware requirements (Keller & Lee 2003). It is notable that only one participant provided a signed consent form; this participant requested forms in alternative formats, so this signature option could be due to an undisclosed disability.

While there are legitimate concerns about being unable to speak to participants face-to-face before they indicate consent (Varnhagen et al, 2005; Gill and Baillie, 2018), including risks of not reading or skimming the consent documents and the lack of indication of research access issues, there are ways to alleviate this through communication about consent in interactions with participants including focus groups and interviews. McDermott and Roen (2012) argue that issues with obtaining informed consent are not unique to online research. For example, Pawa et al. (2013, p. 3) reveal that ‘transgender people in Pattaya would be unwilling to provide signatures or written consent due to concerns about stigma and safety of identifying information’. Trans people who are nonbinary or multigendered may have specific barriers relating to signatures and the name or names they use day-to-day. These considerations are further complicated by emerging nonbinary recognition in certain countries. For example, locating the research online may mean that some participants are in geographical locations in which they are unable to legally change names and rely on using signatures attached to names they do not use day-to-day. Furthermore, if the research will involve multiple sessions then genderfluid individuals may feel that being asked for just one signature is a barrier to participation. Challenging cisgenderist assumptions inherent in research requires attentions to the limits and implications of consent-giving practices.

### **Space, place and time for facilitating safe research**

This section focuses on the ethical implications of decisions we make in research in relation to space, place and time, with a focus on online methods. For Seymour (2001, p. 159) “giving a voice” means more than providing the researched with an opportunity to speak: it involves creating the appropriate means and communication context for research participants. Online methods can provide such opportunities. Online research can offer inclusion for harder to reach individuals (Adler and Zarchin



2002). However, online methods are not accessible to everyone. They require internet access and a device through which to connect.

In Study 1, participants were offered different ways to participate online: either a focus group, or interview using their choice of instant messenger (IM) software. Kamzer and Xie (2008, p. 273) advocate participant choice over the research means of participation to ‘increase retention and rapport’. For trans subjects, these options for participation may not be a simple matter of choice, but the only way they can participate. For instance, stealth participants may require a certain level of anonymity that is not afforded within focus groups.

#### *Decision-making about communication*

Synchronous communication methods were used for the online interviews and focus groups: this allows communication to occur in “real time”, with conversational benefits that are useful to semi-structured interviews. Although only one online focus group software was offered, interview participants could choose the IM software. Participants were also given opportunities to choose their pseudonym and an avatar. Participants were asked not to use a name or avatar with which they were known elsewhere online because these could be identifiable, as Buchanan (2011) notes. This is of particular note for the focus groups in Study 1; participant recruitment was achieved through a number of trans organisations and online community groups, as well as snowball sampling, so there was a risk that participants in focus groups could realise they knew one another due to familiar avatars or usernames.

Dodd’s (2009) reflections on ethical LGBTQ research advocate that researchers discuss the possibility of ‘nonstudy interaction’ between participants or between the researcher and participants beyond the parameters of the research project. This is particularly relevant for Study 1 because the researcher recruited from trans groups and LGBTI groups of which they were also a member, adding further

complexity to the shifting power relations researchers negotiate as community ‘insiders’ (Dodd 2009, p. 482).

### *Finding safe spaces*

With online research, individuals can participate from the physical space in which they feel most comfortable to discuss the issues so long as that space has internet access. However, there are limits to what can be known about the location from which participants respond and it is not necessarily safe. Steiger and Göritz (2006) note that IM and online focus group research offer no clues as to the distractions present. For online trans research there may be issues if what was thought to be a safe space with internet access becomes unsafe quickly due to the changing environment of public spaces. Making participants aware of the expected length the focus group or interview, as well as scheduling a time that suits them, can alleviate some scenarios but in certain instances participants may log off for their own safety. Safety is particularly important for ‘stealth’ participants who might not have participated in an offline environment.

The Internet itself is not always a safe space for trans individuals and it may be associated with experiences of transphobia, especially in relation to online newspaper article comments. Atkinson and DePalma’s (2008) research on gender and sexuality with young people suggested that online environments could reproduce inequalities. The focus groups in Study 1 attempted to offer an environment in which to challenge these inequalities without reproducing other inequalities, so private messaging facilities within the focus group software were used to ensure all members felt included. For instance, disabled participants felt able to provide details about ableism in media articles within private messages; a topic that was not discussed in the group conversation. The one-to-one interviews faced less of a problem in this regard because the interviewee and the researcher could communicate more directly; however there is no way of knowing what other activities participants could be engaged in and how this affected their participation in their interview and/or the focus group.

Seymour (2001) suggests that online research might not necessarily be more accessible to participants than face-to-face research because some barriers to participation may not be apparent or be less obvious. Locating research online allows participants greater control over information disclosure but it does not remove participants from their bodies, genders or other lived experiences, so comparable contexts and research experiences should not be presumed on the basis that each participant was able to access the research setting. Locating research online may allow for safer spaces for some trans subjects but these settings must be continually critiqued and scrutinized to best serve the needs of trans participants as a research method.

### **Promoting participation and working collaboratively**

For us, serving the needs of participants includes participant engagement with how the research is undertaken, to what ends, and by whom. This allows for more insightful information and constructs progressive research processes that can be of benefit to those impacted by it. We address the following areas for ethical consideration: collaboration to foster expertise; explicating the research rationale and purpose; and validation of research accounts produced.

#### *Collaboration to foster expertise*

In Study 2 a broad community psychology approach was taken in relation to the project. Here a steering group was formed, comprised of young people who identified with a range of sexual and/ or gender identities, the researcher and the project manager. The researcher and project manager consulted and received feedback from the young people belonging to the steering group in the design of the research, specifically with regards to the survey design. Working closely with the young people revealed a range of practices that from a research perspective tend to be assumed as ‘standard’, but which are problematic and may create barriers to participation.

For example, when advising on the questions within the online survey, the young people’s steering group discussed the problems that standard demographic questions pose. The demographic section

represented the most significant site for issues and suggestions of change. The first suggestion was to put that section of the survey at the end rather than the start: for the young people it always felt like it was the first thing they had to do in many situations and the most problematic. On the advice of the young people, survey respondents were also invited to include their own description in relation to both gender and sexuality status. The inclusion of the young people's own terms and descriptions allowed these young people to challenge the othering typically associated with the cisgenderism inherent within the categorisation of trans identities, and enabled them to articulate their identities in a way that was relevant for them. In a shift away from a limited range of set options, this could include multiple terms and combinations of terms. To represent the responses to this question in the research report, a word cloud (based on the word frequency) was used to ensure that, while more frequently used descriptors were highlighted as such, the full array of identities was also acknowledged. This range of terms used by young people to describe their gender identity was helpful in the training that was developed for health professionals to improve service provision to young people (based on the survey as well as focus groups conducted with service providers).

#### *Explicating rationale and communicating purpose/ benefits*

When grounding Study 2 in a broad community psychological methodology, there was a desire to work transparently with participants and contributors, communicating purpose and desired outcomes. There was also a desire to consider participant benefits in a more meaningful fashion. Significantly two issues were also raised by the young people's steering group, particularly when designing the survey. The young people were in favour of much more description for participants to read at the start of the survey. This description included reasons for conducting the survey, a careful explanation of who was conducting the survey and what the survey results would be used for. It was also important not to overstate the benefits of participation. The following text was therefore inserted into the survey: "there are no direct medical benefits or significant risks for participating in this study, but your participation is likely to help us find out more about how to improve health services for LGBTIQ young people". This may seem a simple and basic action to take, but both the researchers and the

young people felt information like this is often absent; the inclusion of such information helps to construct a safer survey space where participants feel comfortable to share their information.

Transparent reasoning and communication of value was further woven into various sections and questions of the survey. For the demographic section, the following introduction was inserted:

We are sure that you get asked these all the time and it's ok if you don't want to answer them, but we would like it if you could. This information will help us understand a little bit more about the issues facing young LGBTIQ Australians. It will help us to know for example where there are bigger gaps or problems in services or where young people face greater difficulties, and help us to tailor our program to address these issues. To do this, we need to understand a little bit about you.

Here the steering group felt it was important to communicate that the researchers were aware of the sensitive nature of demographic questions, and to explain why we had still chosen to ask them.

Sensitive questions were also contextualised, as in the following example: "Please write the postcode/town in which you live (this helps us to know for example which areas might have more or fewer services)". These alterations to the language in the survey were undertaken for a community who sometimes find that information about their gender and/or sexuality is used against them, not least by researchers. This improvement in communication with participants is therefore an example of how collaborative work at margins can improve research, with wide reaching consequences for our understandings of methodology.

#### *Participant validation of research accounts produced*

As previously noted, it is crucial to engage critically with the representation of trans individuals, communities and accounts in research. As researchers, power differentials arise in our role of reporting on findings, analysing accounts and representing participants within written statements. In this sense ethical considerations arise from ensuring the promotion of an accurate participant 'voice' and from attending to the power differentials that are deeply embedded within the traditional role and practice of research reporting. One approach taken in Study 1 was to include validation which, while of broader use in qualitative research (Namaste 2000), we regard to be of particular importance when

working collaboratively with trans participants and LGBTIQ participants who have historically had their bodies written on largely for the benefit of medical discourse (Oosterhuis 2000).

The definition of validation we have adopted is taken from disability research in which Barnes (2009, p. 467) highlights that ‘taking fieldwork data back to respondents for verification is generally regarded as a key criterion’. For Namaste (2000, p. 266), ‘validating the interpretation of research data remains a crucial component of any reflexive sociological practice’ (which also adjusts the power imbalance between researcher and researched at the analysis stage. Namaste adds that:

transsexuals and transgendered people must be actively involved in the construction of academic knowledge about our bodies and our lives: anything less advocates a position wherein knowledge is produced, in the first and last instance, for the institution of the university (2000, p. 267)

In order to avoid the use of trans lives to benefit only academic discourse, this research was also shared with a number of trans organisations that may benefit from it. Many of the organisations that wished to see a results summary were also active in seeking participants, so ensuring participants could not be identified from the research was of great importance. The validation request asked that participants check that they did not feel misrepresented and that they had not revealed anything they no longer wished to or had given responses that they thought were unique enough to identify them to the organisations that may see the results. Three participations offered this validation via email to say they felt accurately represented by the findings. One further IM discussion was conducted, resulting in rewording to reflect participants’ feedback. This IM discussion was the most in-depth of the validations received and allowed for a conversation to occur that resulted in repeated checking of that participant’s views. For online research, there is a benefit in seeking validation via synchronous communication rather than asynchronous communication so a conversation can develop about the analysis.

## **Conclusion**

The case studies present contextualised, imperfect work which is problematic in a number of ways; however, we hope they capture some of the complexities negotiated when working in the fieldwork. In seeking to contribute to what Seymour (2001) discusses as *creating conditions for ethical engagement*, we found the following elements to be useful in our research practice, and propose these may form starting points for the practice conditions we aspire to. We argue that it is crucial to reform knowledge-making processes in research, especially methodological components such as rethinking design in Study 2, in order to better align the aims of gender and sexuality studies research to the tools adopted. We propose that examinations and critique of methods should not only share theoretical and epistemic orientations but should also actively resist cisgenderism. Within these case studies, research methods that positioned knowledge-making *about* trans lives were considered secondary to knowledge-making *with* trans individuals. Active participation includes a say in how the research is undertaken, to what ends and by whom. These are important considerations, not only for producing “accurate” or insightful information, but also for ensuring progressive research processes that are of benefit to those impacted by them. In gender and sexuality research, ethical concepts and practices used to engage with frameworks such as institutional committees can be contextualised through critiquing and developing meaningful forms of engagement with the individuals and communities involved in and impacted by the research activity. Moreover, we believe that the challenges presented to ethics in research by trans communities and with trans individuals offer ways to strengthen and improve research practice more widely.

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