Creative research methods and ethics

Introduction

Ethical considerations need to permeate the whole of the research process. Ethical issues in research are most often thought of in terms of data gathering and risk of harm to participants, perhaps because historically that is where most harm has been done in notorious studies such as the Tuskegee syphilis experiments and Stanley Milgram's studies of obedience (Iphofen 2011: 53). However, ethics should underpin every single step of research, from the first germ of an idea to the last act after dissemination. And ethical problems require ethical decision making – which allows for creativity, even in places which may seem unlikely, such as research ethics governance committees (Stark 2012: 166). Also, perhaps surprisingly, there is a close link between working ethically and thinking creatively.

> Michael Mumford and his colleagues, from the University of Oklahoma, in the US, studied the relationship between ethical decision making and creative thinking among scientists (Mumford et al 2010: 1). The ethics literature suggested four domains of ethical behaviour which between them could account for most instances of ethical misconduct. These domains were: study conduct, data management, professional practices and business practices (Mumford et al 2010: 2). Mumford and his colleagues studied 258 doctoral students from the physical and social sciences with 4–60 months of university experience. Participants were asked to complete a range of tests and measures assessing their cognitive abilities, personalities, creative-thinking skills and ethical decision making. Of course this study did not assess – could not have assessed – all types of creative thinking and ethical decision making. But it did find, conclusively, that among doctoral science students there are strong and consistent relationships between creative-thinking skills and ethical decision making (Mumford et al 2010: 13).

The work of Mumford et al (2010) suggests that taking a creative approach can help to make your research more ethical. It has also been suggested that being open about the creative aspects of your research, such as acknowledging that your research design is new or your writing is semi-fictionalised, is an ethical position (Piper and Sikes 2010: 572). This is because such a position recognises that research is constructed, with aesthetic aspects; something that was hidden by the traditional styles of social science writing and presentation (Rhodes and Brown 2005: 479).

Research governance

Research ethics, particularly in biomedical research, is governed by groups of people known as institutional review boards (IRBs) in the US, research ethics committees in the UK and by other names elsewhere (McAreavey and Muir 2011: 391). This system developed in reaction to notoriously unethical research such as the Tuskegee and Milgram studies noted above. Nowadays, most universities, health authorities and other bodies researching people in society have their own ethics committees, which scrutinise applications from researchers for ethical approval. These committees aim to ensure that research is conducted ethically and, in particular, to safeguard potentially vulnerable research participants. However, as we will see, researchers and committee members hold a variety of ethical perspectives and standpoints. This means that, in practice, the ethics of some committees can conflict with the ethics of some researchers.

Librett and Perrone found that the requirements of IRBs actually hindered the ability of ethnographers to conduct ethical research (Librett and Perrone 2010: 742). There were a number of reasons for this, such as that IRBs required informed consent to be obtained in the form of a contractual agreement between each individual participant and the researcher, while an ethnographer usually acts as a participant observer of a group, community or organization (Librett and Perrone 2010: 742). This makes it pretty much impossible to gain consent from every individual member or resident, let alone all the visitors the ethnographer might encounter. For example, Philippe Bourgois lived and worked in a ghetto neighbourhood of New York for five years while he conducted an ethnographic study of urban social marginalisation (Bourgois 2002). Also, Nigel Rapport worked as a porter in a Scottish hospital for a year, to study national identity (Rapport, N 2004). It would not have been possible for Bourgois to obtain informed consent from every adult, child, shopkeeper, drug dealer and so on, or for Rapport to obtain informed consent from every doctor, nurse, patient, visitor and others. Also, any ethnographer who tried to obtain informed consent in this way would disrupt the fundamental ethnographic method of participant observation, which aims to observe and experience natural behaviour rather than to influence the situation (Librett and Perrone 2010: 729).

> Laura Stark (2012) turned the tables by conducting ethnographic research of IRBs at American universities. She found that, quite independently of each other, different IRBs used very similar techniques to reach their decisions. These were:
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> • looking for signs of good character in researchers' applications
> • claiming justifications for expertise on which they were drawing, such as personal or professional experience
> • relying on their previous decisions as precedents for making future decisions
> • using meeting minutes as a tool for managing relationships, both with researchers and between board members themselves.

> This methodological commonality didn't lead to IRBs making the same decisions as each other: different IRBs reached different conclusions about similar studies, because they were made up of different people using their own discretion in different contexts. Stark argues that the methodological commonalities exist because the IRBs all have their roots in the same medical research scandals, such as the Tuskegee syphilis experiments. Stark's conclusion is that there are flaws and inequities in the way IRBs enable and restrict research, and that IRBs serve to protect institutional interests as much as – sometimes more than – the interests of potentially vulnerable research participants or even the overall quality of research.

A **YouTube playlist** is available with a range of videos on how to navigate research ethics committees.

Some scholars have concluded that IRBs, and their equivalents in other countries, are unable to address all the possible ethical difficulties that social researchers may face during the research process (Blee and Currier 2011: 401; Sieber and Tolich 2013: 46). In the UK, the Academy of Social Sciences, which is the umbrella body for the UK social science community, has called for a move away from the regulatory approach to research ethics and towards a more educative approach, so as to equip researchers more fully for managing the ethical difficulties they will face. **Information about this initiative** is available online.

Creative research can be highly ethical on the micro level, facilitating improvements in the lives of participants. For example, MacKenzie and Wolf's use of collage as inquiry with student teachers in America reduced the loneliness of participants and helped to create an inclusive community of learners who had deeper relationships with one another (MacKenzie and Wolf 2012: 17–18). Foster's use of drama with parents of pre-school children, in a Sure Start programme in a deprived area in the UK, empowered participants, reducing isolation and increasing their confidence (Foster 2013: 46). At follow-up, three years later, this positive impact had been maintained and also extended to some of the children, 'several of whom continued to attend dance and drama classes – which, [participants] admitted, would have been inconceivable prior to the drama group' (Foster 2013: 49). However, it can be more difficult for creative research to make an ethical impact on the macro level. For example, Foster found that national Sure Start evaluators weren't interested in seeing the parents' production, and that 'those in the position to make changes on a larger scale did not hear the stories that we intended them to' (Foster 2013: 50).

Theories of ethics

Ethics is a branch of philosophy that deals with the rights and wrongs of human behaviour. There are lots of books on ethics and research ethics that outline

different types of ethical theory. Theories include deontology, which suggests that acts are good or bad of themselves, regardless of their consequences, so that telling a lie is bad even if it makes someone feel better. Then there is the opposite view, consequentialism, which argues that the outcome of acts is what matters, so if you make someone feel better, that's good, even if you had to tell a lie to achieve that outcome. These translate into research ethics such that those with a deontological perspective support a universal code of ethical practice that should guide research in any situation, while those with a consequential perspective believe ethical practice should be determined with respect to the particular research context (Kiragu and Warrington 2012: 176). A third position is virtue ethics, which tries to argue that if you're a good person you are likely to do good things, but doesn't really manage to convince anyone; there are too many instances of good people doing bad things, and vice versa. There is also value-based ethics, which suggests that people base ethical decisions on their personal values rather than on external principles such as those proposed by deontologists (Liegeois and Van Audenhove 2005: 453). In practice, most people draw on a combination of theoretical perspectives when they are faced with specific ethical difficulties, depending on the matter at hand (Sieber and Tolich 2013: 37).

The literature also covers different ethical standpoints, such as ethics of justice versus ethics of care. Ethics of justice is a deontological standpoint that emphasises the importance of obeying rules and sticking to principles, while ethics of care is a consequentialist standpoint that focuses on the context of a situation as paramount in resolving any ethical dilemma. Some people regard these as two opposing standpoints, while others see them as complementary (Edwards and Mauthner 2012: 21–2).

The most commonly cited ethical dictum is 'do no harm', which stems from the Hippocratic oath taken by doctors since the 5th century BC, and fitted well with the traditional view of research as a neutral, observational activity. However, more recently some social researchers have decided to include a social justice element within their research, seeing it as their responsibility to use research as a force for good.

UK-based researchers Susan Kiragu and Molly Warrington took a social justice approach in their study of girls' school attendance in Kenya. They were very aware of their privileged position as educated, comparatively wealthy women, and responded as positively as possible to requests for help from teachers and pupils. They gave food, water and pens to the schools and raised funds for a dormitory at one school to help protect girls from a very real threat of rape by local boys. The researchers shared their findings with people in power, successfully negotiating for practical support, such as sanitary towel provision, and mentoring by successful women. Some requests for help were particularly difficult to respond to, such as those from girls who feared, or had been traumatised by, forced genital mutilation, but the researchers did what they could to sympathise and support. 'All in all, we believe it is imperative for researchers to contribute in whatever way possible

> (material and/or non-material), not because they will benefit professionally from publishing participants' data, but because of the imperative of a social justice agenda' (Kiragu and Warrington 2012: 186).

It can be helpful for researchers to review ethical theories and standpoints if they want to deepen their understanding of the philosophical basis for their decisions. Researchers may also find it useful to review ethical codes and other resources that suggest ways of putting these theories and standpoints into action. Many professional groups and associations have codes of ethics, codes of conduct or similar documents. There are also a range of resources online to help with ethical decision making (for example RESPECT for research ethics, which synthesised a range of ethical codes of practice into a single **document**, and the **Association of Internet Researchers' Ethics Wiki**, which contains a wealth of resources for ethical decision making in online research).

Theories and resources are helpful only up to a point. It is not possible to plan for every eventuality (Bowtell et al 2013: 652), so doing research ethically means constantly making and reviewing decisions in a changing environment (Iphofen 2011: 7). As children, we're taught to make moral decisions in a binary framework: our behaviour is defined as good or naughty, we are expected to know right from wrong and the goodies always beat the baddies. Yet this won't serve us well as researchers, because the application of ethical principles to research practice is much more subtle and nuanced than simply favouring what is good or right and rejecting what is bad or wrong (Seal 2012: 698). Researchers are likely to find themselves facing situations where there is no perfect ethical solution. Nevertheless, they have to decide how to act – and, as we have seen, decision making involves creativity.

Creativity is morally neutral, being as applicable to crime as it is to good works (Schwebel 2009: 319). How people use their creative powers is their own choice. As we have seen, traditional research was viewed as value neutral and objective, existing purely for the pursuit of knowledge (Gergen and Gergen 2012: 30). However, traditional positivist research wasn't nearly as value neutral as it claimed to be, effectively privileging the privileged and contributing to a climate where terrible abuses such as the Tuskegee syphilis experiments could occur. By contrast, most researchers in the 21st century aim for some kind of social benefit to accrue from their work. Transformative methodological frameworks such as feminist, emancipatory, decolonised and participatory research are creatively designed to be more ethical by addressing and reducing power imbalances between researcher and researched. The 'transformation' aimed for is a move from oppressive to egalitarian practices, thereby supporting a wider shift from oppressive to egalitarian societies. These frameworks privilege researchers' insider knowledge, which has been shown to help in elucidating and contextualising the subjective experiences of research participants (Stierand and Dörfler 2014: 255).

There have also been claims for the ethical basis of arts–based research, in particular the use of expressionistic and performative methods of presenting and disseminating research. Gergen and Gergen (2012: 30–1) assert that 'If the social sciences are to play a significant role in society, it will not be through increased sophistication in their research methods, but rather through a multiplication in their skills of expression.' I wonder whether it might in fact be through both.

Feminist research

Feminist research has been described as using 'gender as a lens through which to focus on social issues' (Hesse–Biber 2014: 3). In the 1970s, UK researchers in the second wave of feminism, such as Liz Stanley, Sue Wise and Ann Oakley, began studying aspects of society relating to women, such as the family, housework, motherhood and lesbian experiences of homophobia. In the same decade US researcher Laurel Richardson was investigating the effect of gender on everyday customs such as opening doors for people – and regularly having academic papers rejected because her subject matter was seen as 'too strident' or only interesting to women (Richardson 2014: 65). These and other feminist researchers around the world were challenging the traditional research principles of objectivity and neutrality, and asserting that the identity and context of both researchers and participants was central to the research process (Ryan–Flood and Gill 2010: 4–5).

In the 1990s, third-wave feminists moved beyond using gender as a single lens, recognising that gender interacts with other sites of inequality such as ethnicity, sexual orientation and socioeconomic status (Ryan–Flood and Gill 2010: 4). This is known as 'intersectionality', a concept used to acknowledge identity as both multifaceted and closely linked with its social and geographical contexts (Naples and Gurr 2010: 24). After all, nobody is 'only' a woman, or a person of colour, or someone with a disability. An intersectional approach does not attempt to take into account every aspect of someone's identity, but aims to accept and reflect the complexity of identity and examine the relationships between different aspects of identity and their implications for power relations (Frost and Elichaoff 2010: 60).

The intricacies of intersectionality pose a considerable challenge to research methods (Hughes and Cohen 2010: 189, drawing on Denis 2008). For second–wave feminists, qualitative methods seemed most appropriate, and there is still a strong belief that this is the case (Hughes and Cohen 2010: 190). However, some feminist researchers, particularly in the US, recognise the value of quantitative and mixed–method approaches for answering some research questions (Hughes and Cohen 2010: 190–1).

> Marianne Hester and her colleagues in the UK were involved in a mixed-method investigation of domestic violence within relationships, including focus groups, interviews and a questionnaire. Domestic violence is a complex phenomenon that occurs in same-sex as well as heterosexual relationships and may be perpetrated by women or men, although women and men have different experiences of abuse

(Hester et al 2010: 255–6). The researchers used a feminist approach to develop a questionnaire, informed by data from the focus groups, which was designed to be 'sensitive to the gender and power dynamics of domestic violence' in heterosexual and same-sex relationships (Hughes and Cohen 2010: 256). They received 746 usable responses that, when analysed, enabled them to 'differentiate between forms of abuse and their relative impacts' and 'provided reliable data on domestic violence in same-sex relationships' (Hughes and Cohen 2010: 261).

Emancipatory research

Emancipatory research, sometimes known as activist research, is a form of insider research where, for example, gay and lesbian researchers will investigate the effects of homophobia (Telford and Faulkner 2004: 549–50). This research framework grew from political activism and changing conceptions of human rights across Westernised nations in the second half of the 20th century (Morrow et al 2012: 8–10). Emancipatory research is intended to empower disadvantaged people.

A pivotal point in emancipatory research came from the disability movement. Paul Hunt used a wheelchair, as a result of muscular dystrophy, and lived in the first Leonard Cheshire home (Tankana 2007: 21). Hunt was a researcher and an activist (Tankana 2007: 38), so, in the 1960s, when the then Ministry of Health commissioned some research into the participation of residents in Leonard Cheshire homes, he and other residents expected the researchers to support their attempts to have some control of their lives (Barnes and Cotterell 2012b: 143). Sadly, the reverse was the case, as, on the whole, the researchers supported the status quo, in which people living with disabilities were regarded as unfit to participate fully in society. The residents were understandably upset and angry, and Hunt wrote a searing critique of the research, arguing that it was 'profoundly biased and committed *against* the residents' interests' (Hunt 1981, cited in Barnes and Cotterell 2012b: 144; emphasis in the original).

The creative work of Paul Hunt and of other disability researchers, such as Mike Oliver, laid the groundwork for the creation of the 'emancipatory research' model. Emancipatory research developed new ethical dimensions by questioning how social research is conducted and who controls its resources (Cotterell and Morris 2012: 61). This anti-oppressive research practice spread into the fields of mental health, feminist research, community research and numerous other areas.

Diana Rose and her colleagues in the UK carried out a piece of emancipatory/activist research in the early 21st century, reviewing the effectiveness of electro-convulsive therapy (ECT), in which electric shocks are applied to a patient's brain to induce seizures (Rose et al 2002). Several of the researchers had experience of mental illness and mental health services, including ECT (Lloyd, Rose and Fenton 2006: 265). The research team gathered 26 reports of research into ECT by academic researchers, nine of which were produced in collaboration with or led by researchers who had experience of mental illness and mental health services.

They also gathered 139 individual accounts of receiving ECT that they found on the internet. They found that purely academic research identified much higher levels of satisfaction with ECT than either the research involving researchers with experience of mental illness and mental health services or the individual accounts. The highest levels of satisfaction were reported when data had been gathered by a clinician immediately after treatment. Combining this finding with their own experiences, Rose et al concluded that patients at this stage were likely to overstate their satisfaction, in the hope of avoiding further treatments and consequent negative side-effects, but would be more honest in discussion with other people who had experienced mental illness and mental health services, or when giving their own account online (Thornicroft and Tansella 2005: 2). This research was widely disseminated, and its findings and conclusions influenced both change to the UK's national guidelines on ECT and a review of training and information given on ECT by the Royal College of Psychiatrists (SCIE 2007: 9–11).

Two videos about user-led research, presented by Diana Rose, are available online.

Decolonised research

Decolonised research is an approach that aims to detach research from imperialism and colonialism (Tuhiwai Smith 2012: 4–5). Colonised people do not want their story told for them by academics from other, more powerful cultures, however well-intentioned those academics might be. Nor do non-Western people necessarily accept Western views of situations or concepts (Smith, Fisher and Heath 2011: 499). Indigenous people the world over would prefer to tell their own stories and give their own views in their own ways. Traditional research methods, such as surveys, interviews and focus groups, are rooted in Western colonial cultural ways of knowing (Gobo 2011: 423–7). As with emancipatory research, indigenous academics and researchers are working to redress social injustice and increase self-determination (Tuhiwai Smith 2012: 4–6). This involves considerable creativity in approaching research projects. A **seminar** on decolonising methodologies with Linda Tuhiwai Smith, and a **conversation** on decolonising knowledge with Linda Tuhiwai Smith, Michelle Fine and Andrew Jolivette, can be viewed online.

Bekisizwe Ndimande investigated education in Gauteng province, a heavily populated and racially diverse region of South Africa. Although apartheid had been abolished, there were still many social inequities, with some townships remaining segregated, black areas lacking resources and black students experiencing racism in formerly white-only schools. Nevertheless, an increasing number of black students were moving into formerly white-only schools. Ndimande wanted to

understand black parents' support for their children's attendance at discriminatory schools. He used a decolonising research framework 'in order to privilege those whose epistemologies have been marginalized and colonized, in this case the black parents who live in the impoverished townships' (Ndimande 2012: 220) (although not all those parents were impoverished themselves). This framework included:

- treating participants with respect
- being aware, and considerate, of indigenous cultures
- conducting the research in community languages
- being open and honest about his own life and beliefs
- identifying with participants' needs, experiences and concerns
- treating participants as partners in the research, rather than as data sources
- being aware of power imbalances between researcher and participants
- making an effort to connect the academic research world with the participants' world.

Ndimande concluded that while South Africa can legitimately be described as 'post-apartheid', it is not yet 'post-colonial', as the marketisation of education, in which parents and children are encouraged to choose between different schools, is in itself a colonial system (Ndimande 2012: 224). Using a decolonising methodology was intended to disrupt this system, but of course it usually takes more than one research project to make a significant change. However, Ndimande was able to identify this aspect of the colonial legacy and to make recommendations for ways to bring South Africa's indigenous communities back to the centre of its children's education.

In the research world, the English language is dominant (Perry 2011: 906–7). This is a colonialist situation that privileges English-speaking researchers and disadvantages those who do not speak English, no matter how clever or skilled they may be (Gobo 2011: 419–20). Within research projects, non-English speakers may be seen by researchers and research ethics committees as vulnerable or incompetent participants, when in fact they may be entirely able to participate in research if the research is conducted in their native language or a translator is provided (Perry 2011: 906–7).

Another colonialist aspect of research is that Western methods are often regarded as universal, when they may not be appropriate in other regions (Smith, Fisher and Heath 2011: 485–6). For example, Western researchers may take it for granted that consent should be given in writing, but this can prove problematic in cultures where oral communication is privileged and writing rarely used even by the few people who are able to write (Czymoniewicz-Klippel, Brijnath and Crockett 2010: 335–6). Ndimande conducted research in his native South Africa in indigenous languages including IsiZulu, Sesotho, IsiXhosa and IsiNdebele, which helped him to build rapport with his participants and enabled them to contribute more fully than if the research had been conducted in English (Ndimande 2012: 216–8).

However, Ndimande found that he had to be very careful in translating research questions, originally formulated in English, into indigenous languages that had no research discourse (Ndimande 2012: 219; see also Swartz 2011: 61). Similar problems arise with cross-national surveys and are complex to solve, requiring 'multiple skilled translators and survey specialists within each country working to arrive at an optimal translation' (Smith, Fisher and Heath 2011: 492).

As Ndimande's experience shows, these points are relevant not only to anthropologists and others who are likely to conduct social research beyond the boundaries of their home country. Many parts of the world are now multicultural, yet many research methods are monocultural (Gobo 2011: 418). It is important for any researcher to be sensitive to the potential for the cultural norms and experiences of participants and colleagues to affect the research process. For example, it is often taken for granted by Western researchers that participants should remain anonymous. However, working with young Sudanese refugee boys in America, Kristen Perry found some of her participants highly resistant to having their names changed, as her IRB required (Perry 2011: 899). On further investigation, she discovered that 'forced name-changing was a common tactic of repression by the Sudanese majority' (Perry 2011: 911). Perry's participants had – and, in at least one case, exercised – the choice of refusing to take part in her research. But surely it would have been more ethical for the IRB to work in a way that enabled researchers to respond flexibly to the needs of potential participants, rather than effectively excluding them as a result of its strictures. It has been argued that research governance organisations such as IRBs need to be 'decolonised' so as to enable researchers to be responsible to participants rather than institutions (Denzin and Giardina 2006: 35).

Although, as we have seen, there is some ethical decision making within IRBs (Stark 2012: 166), there is also considerable conflict between the values and priorities of research ethics committees and those of researchers (McAreavey and Muir 2011: 393). It can help if researchers are creative in presenting their plans to committees (Czymoniewicz-Klippel, Brijnath and Crockett 2010: 339).

> Gloria González-López, from America, conducted research on incest in Mexico. Her IRB required participants to sign a formal document, including a detailed description of the study, and be given a copy to keep. This worried González-López: 'Would those who lived in extreme poverty have a private place to keep things like this document? What if someone in the family found the document, someone who had not known about the abuse? What if the person who committed the abuse found the document?' (González-López 2011: 447). Instead of trying to complete the ethics application form, González-López contacted the director of the IRB to discuss her concerns. The director was receptive, and presented her case to the IRB, which agreed that González-López could recruit participants on the basis of verbal consent (González-López 2011: 448).

A **video** giving more information about Gloria González-López' findings can be viewed online.

Participatory research

Participatory research, also known as participatory action research, is another transformative framework. Participatory research focuses on communities or groups and emphasises the full involvement of participants at every stage of the research process (Bhana 2006: 432). The research should benefit these communities or groups, as well as the researchers (Wassenaar 2006: 69). The aim is to empower disempowered groups, communities and individuals (Bhana 2006: 432). A **video introduction** to participatory action research can be viewed online, and a **website** with resources for participatory research is also available.

Critical communicative methodology (CCM) is a particularly ethical type of participatory mixed-method research. Developed by the late Jesús Gómez in Barcelona, Spain around the turn of the century, CCM is based on the Habermasian principle that everyone has the right to participate in intellectual discussion, whether or not they are 'an intellectual' or can speak intellectual language. Gómez's view was that everyone has critical analytic abilities, and we can learn a great deal from people who have different backgrounds from our own. In CCM, every research project has a multicultural research team reflecting the diversity of the society being investigated, so as to ensure full involvement throughout the research process, from proposal development to dissemination of findings. The team is supported by an advisory committee made up of representatives from groups that are directly affected by the research. Thus, research participants play an active role throughout, although this changes rather than reduces the role of researchers, who are responsible for communicating academic knowledge to participants. Data is gathered using communicative methods, such as stories of daily life, focus groups and observations that are dialogic and involve the researcher sharing their knowledge and interpretations with participants. Quantitative data may also be gathered and analysed communicatively. Analysis is designed to identify what perpetuates, and what changes, inequalities, and to find solutions to society's problems. This method has already had a significant positive impact on some of Europe's most excluded groups, such as the Roma (Gómez, Puigvert and Flecha 2011: 239).

Outside a participatory framework, participants' views on the research process are rarely sought, though they may differ from researchers' views, even on key issues such as the value of anonymity (O'Reilly et al 2012: 220). However, even when using a participatory framework, there are limits to participation – ironically, most particularly in research governance, where participants' voices are largely silent (McAreavey and Muir 2011: 403). A short **video** about a participant's experience of taking part in dementia research can be viewed online.

Critiquing transformative research frameworks

It is not the case that using a transformative research framework will, in itself, iron out any potential ethical difficulties. For example, using a transformative research framework does not remove power imbalances between people of different races, genders, socioeconomic status and so on. Nor does it mean that all involved will have the same kinds of knowledge (Lomax 2012: 106) or the same understanding of what is, or is not, ethical (McAreavey and Muir 2011: 395). Researchers' experiences of oppression, as in the case, for example, of disability activist or feminist researchers, does not automatically mean that those researchers will understand how oppression is experienced by other people with disabilities or by other women (Mason 2002: 193). A transformative research framework may help all concerned to address power imbalances and differences within the research project, but doing so will still take time and effort above and beyond that needed for core research tasks. In some cases, such as when researching highly sensitive topics with vulnerable groups, it may be better to offer a flexible approach to participation, with options for participants to move through different levels of involvement at different times to suit their needs (McCarry 2012: 64). While this could bring accusations of misuse of researcher power, it is also true that researchers are trained and supported to make research, and are likely to have many more professional and personal resources than most vulnerable participants, and so have an ethical responsibility to know when and how to offer involvement or participation (McCarry 2012: 65). And practicalities can get in the way, because full participation involves a great deal of investment in support, training and inclusion, particularly with vulnerable participants (Gillard et al 2012: 252).

Also, transformative research frameworks can bring ethical difficulties of their own. For example, using a participatory approach may seem like a marvellous idea to a researcher, but considerably less marvellous to participants, who have much less to gain. This becomes even more of a challenge in longitudinal research, which has to compete with demands from participants' families and employers, among others (Weller 2012: 123). Conversely, little is written about the extent to which participants may expect researchers to continue their relationships with them after the end of a project, and the difficulty this can cause for all concerned.

> UK researcher Carla Reeves carried out ethnographic research with sex offenders in a probation hostel. For many participants, the researcher was the only person they could speak to in confidence. Anticipating this, Reeves had planned when and how she would leave the research site, but unforeseen factors caused an earlier exit. Some participants asked if they could keep in touch with her, and she explained why this would not be possible – she would no longer have permission to enter the hostel, and consent for meetings outside was unlikely

> to be granted. However, as Reeves lived nearby, she did sometimes run into her former participants. This caused anxiety at times, such as when she was with a female friend and met a male high-risk sex offender with a history of raping adult women; Reeves couldn't warn her friend, for reasons of confidentiality. This made her wary of her former participant, which left her feeling ashamed, as if she had simply used her participants for the benefit of her research. This internal conflict was resolved only very gradually as her former participants were moved out of the area (Reeves 2010: 328).

A **video** with more information about Carla Reeves' research can be viewed online.

Participants are not often involved in the writing or presenting stages of research – although again there are notable exceptions, such as Ellis and Rawicki (2013) (discussed in more detail in Chapter Seven – also, relevant videos can be viewed online). And participants may be further marginalised, in a variety of ways, by the publication process. For example, in the long and thorough text on participatory action research by Chevalier and Buckles (2013), some participants are mentioned, such as Alberto (on pages 239–42) and the female forestry officer (300–3). However, these names do not appear in the otherwise comprehensive index; there are many names in the index, but only the names of research professionals.

Structural aspects of research, such as project design, timescale and budget, may need to be in place before a transformative research framework is implemented. This effectively sets up potential inequalities for any research encounter, with a framework being imposed on participants rather than agreed with them (McCarry 2012: 60–1). There is also 'the question of who participates and how' (Lomax 2012: 107). Factors that may exclude potential participants include logistics (meeting times and locations, access to technology and communication systems, languages spoken and so on) and the requirements of the research, for example level of commitment and abilities required. This raises questions about the extent to which participants are, or can be, representative of wider communities.

It is not always the case that more participation automatically leads to greater inclusion and empowerment of participants (McCarry 2012: 65), or that using decolonising methodologies actually 'decolonises' the research process. Transformative research frameworks are always worth considering but, if their use is appropriate, need to be used with thought and care, not 'bolted on' to put a tokenistic tick in the diversity box. Also, it is important to remember that not everyone views these approaches as ideal. For example, some researchers have called not for decolonisation, but for cultural integration in research through a 'geocentric' approach (Li 2014: 28).

Managing ethical dilemmas in creative research

Academics, particularly those in the field of education, are often encouraged by others to conduct activist research with the aim of reducing inequalities based on

prejudice and so helping to create a more just social world (DeMeulenaere and Cann 2013: 552). A **video** that explores research justice through transformative research frameworks can be viewed online. While these transformative frameworks are designed to be more ethical than traditional top–down research frameworks, people working within them will still experience, and need to find ways to solve, ethical problems.

> UK researchers Suzy Braye and Liz McDonnell conducted participatory research with young fathers acting as peer researchers to investigate the experiences of other young fathers. The researchers offered support in the form of training as needed and debriefing after interviews, and all participants were paid for their time. The team encountered several ethical difficulties. Peer researchers were unclear about whether they were 'peers' or 'researchers', which caused some difficulty for them in managing confidentiality, especially during the post-interview debriefing sessions. Also, the peer researchers found it difficult to be in a position where they were not supposed to give advice to research participants because, as peers, they wouldn't hesitate. They also didn't understand the rationale and need for the debriefing, thinking at first that they just had to pass on anything serious, rather than understanding post-interview debriefing to be a regular part of research practice, both for harm reduction for researchers and participants and for reflection on the interview in particular and the research process in general. As the researchers had taken the peer researchers' understanding for granted, this led to a few problems. The researchers concluded that becoming peer researchers changed people's experience of power in relationships, and that the reasoning behind some aspects of the research process needed to be more fully explained and discussed, including 'the political nature of the interview relationship' (Braye and McDonnell 2012: 278).

People who are new to ethics often expect a 'top down' approach, with a set of rules or guidelines that can be applied to different research situations. More experienced ethicists are likely to take a 'bottom up' approach, with each new research project being ethically assessed in its own, unique terms and context. Further, while there are some ethical absolutes – for example, causing harm in the name of research is never justifiable – experience also brings more recognition and understanding of the 'grey areas' in ethics, and acknowledgement that different ethical decisions may be equally defensible and legitimate (Lomborg 2012: 21).

> Danish researcher Stine Lomborg studied the ways in which Danish people use personal blogs and Twitter, and how those social media were integrated into their users' everyday lives. Personal blogs and Twitter are publicly accessible and fall under the Data Protection Agency of Denmark's definition of 'non-sensitive information', so they could be regarded as freely available for researchers to use as data. However, they do contain a lot of personal and identifiable information, which some social media users might regard as comparatively private. For

> example, they might intend their blog posts and tweets to be read by people they know personally, for their own information and interest, rather than by an unknown researcher for career advancement. Considering this, Lomborg decided that she needed to ask permission from potential participants before using their words as data (Lomborg 2012: 25).

Using direct quotes from people's data, however that data was gathered, poses a range of ethical difficulties. How do you frame the quote? Do you introduce the person, give some of their key characteristics? Or would that lead your readers to respond in a particular way? Should you use a pseudonym? This is another of the many areas where the 'bottom up' approach to ethics is likely to be most useful, giving full and careful consideration of your unique research project in its own, individual context. When using direct quotes, it is helpful to clarify the reasons for the selection of each quote (Taylor 2012: 393). There are many possible reasons, such as: a single quote to illustrate a point in the narrative; a pair of quotes to show the widest range of a spectrum of viewpoints; a series of quotes to demonstrate a pattern in the data. Explaining the reasons for your decisions is good ethical research practice because it enables your readers to make well-informed judgements about the quality and rigour of your work.

Some ethical arguments have an equal and opposite argument. In her research mentioned above, for ethical reasons Stine Lomborg offered participants the opportunity to read her write-up in draft and gave them the option to ask for any of their direct quotes to be removed. As it happened, just one participant asked for one excerpt to be removed, and Lomborg granted the request. However, in Lomborg's view, this request was likely to have been made on account of personal feelings and wishes, rather than as a result of considered judgement about the extent to which the excerpt, in context, would add to the body of human knowledge (Lomborg 2012: 28). This was problematic for two reasons: first, it had the potential to undermine the quality of Lomborg's research, and second, it reduced the extent to which research decisions were the researcher's responsibility (Lomborg 2012: 28). The principle of 'interpretive authority' suggests that the researcher is a type of cultural interpreter, who is responsible for the rigorous analysis and interpretation of data (Markham 2012: 15). If this principle were applied to Lomborg's work, then granting her participant's request for an excerpt to be removed could be seen as unnecessary and inappropriate (Lomborg 2012: 29). Use of a participatory framework might have forestalled this problem – but it may be difficult to use participatory frameworks in conjunction with this kind of online data gathering.

Ethics in arts-based research

It can be argued that arts-based research requires a dual ethic: research ethics, of course, and also the ethics of authenticity (Parker 2004: 70–1; Leavy 2009: 151). Authenticity implies recognition. People may recognise authenticity by

external factors: an artist's signature on a painting, or a certificate of origin from a trusted authority. Or people may recognise authenticity by internal factors, which are harder to describe: the experience of the artwork chimes with existing cognitive and emotional knowledge to create a resonance, a feeling of rightness. Of course, not everyone will experience an artwork in the same way, which is a potential problem for arts-based research. But if enough people can reach a similar understanding, through discussing and considering their individual responses in the process of creating research, then arts-based research may be deemed authentic (Clark, Holland and Ward 2012: 40). There are also micro and macro approaches to ethics in arts-based research. The micro approach focuses on ethics within the research project where, for example, it is particularly important to make 'full methodological disclosure' (Leavy 2009: 20) by explaining which methods you have used, why you chose them and how you have used them. This enables your audiences to understand your research more fully. The macro approach focuses on wider issues affecting the research project, such as political considerations and balances of power. Research is an inherently political activity, and many artists – writers, musicians, actors and so on – are socially and politically engaged. These artists may use research for 'the artful posing of questions regarding important social, political, and cultural issues by allowing them to be seen in a previously unavailable light' (Barone and Eisner 2012: 128). This is not in itself unethical, unless researchers also try to convince or coerce people to share their point of view.

Ethics in mixed-methods research

As we saw in Chapter Two, mixed-methods research can present some complex ethical dilemmas. Interestingly, some researchers have used qualitative methods to study quantitative techniques in practice, with results that highlight the ethical implications of the methods used.

Polish researchers Dariusz Galasiński and Olga Kozłowska made a qualitative study of a quantitative research technique: people's experiences of completing questionnaires. The research participants were unemployed Polish people, and the questionnaire was designed to examine feelings, behaviour and attitudes around unemployment. The researchers asked each participant to 'think aloud' while filling in the questionnaire. This was not their original plan, but the first participant did so spontaneously and the researchers found his comments so fascinating that they asked all the other participants to do the same. The aim was not to praise or criticise the particular questionnaire, or indeed to make a qualitative attack on a quantitative method, but to show how participants manage the tensions between their experiences and the answer categories in the questionnaire. Questionnaires effectively assume that people are, or can be, simply providers of information. Galasiński and Kozłowska found that participants would 'strategically navigate through the reality created by the instrument, attempting to satisfy their own "life story" and their strategic goals

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while, at the same time, completing the task of choosing the options provided by the questionnaire' (Galasiński and Kozłowska 2010: 280). This experience had a significant emotional dimension, often leading to outbursts of frustration. As a result, Galasiński and Kozłowska suggest that it may be unethical to use questionnaires to investigate difficult personal experiences such as mental ill-health, divorce or bereavement (Galasiński and Kozłowska 2010: 280). They also suggest that questionnaires may not be ideal for investigating 'highly contested, ideology-rich topics or events' (Galasiński and Kozłowska 2010: 281).

These kinds of ethical issues can also cause problems for research.

Kariann Krohne and her colleagues, in Norway, studied the administration of standardised tests by healthcare professionals. They focused on several tests of cognitive and physical abilities administered by health professionals to hospital in-patients. The administration of such tests is supposed to follow a rigid procedure, right down to the health professional's script, to ensure reliability and validity (see Chapter Four for more on these quality criteria for quantitative research). However, Krohne et al found that health professionals regularly deviated from these procedures and scripts in response to patients' needs (Krohne et al 2013: 1172–3). The tension between the research requirement of standardisation and the care requirement of meeting individual patients' needs is always present for health professionals administering standardised tests (Krohne et al 2013: 1174). The health professionals who participated in the research prioritised the care requirement over the research requirement (Krohne et al 2013: 1176). This may have led to bias in the test results.

This is an interesting example of navigation between deontological ethics of justice – that is, the standardisation – and consequential ethics of care in a specific practice context.

Ethics in research using technology

Technology can be helpful in overcoming ethical difficulties. For example, audio or video 'podcasts' (short audio or video files published via the internet) can be used to help ensure that research participants are able to give fully informed consent (Haigh and Jones 2007: 81; Hammond and Cooper 2011: 267). A podcast can be made age appropriate when seeking consent from children. Podcasts are also useful for people who have memory or attention problems, as they can be played over and over again. Because they don't rely on the written word, podcasts are also useful for people with literacy problems or some forms of learning disability. Technology is also useful as a tool in teaching research methods. For example, a **video** example can be viewed online of a researcher working through a consent process with a research participant who has moderate aphasia (reading) and limited verbal output.

However, the use of technology for research purposes also raises a whole new set of ethical problems for researchers to solve. For example, mobile devices such as smartphones and tablets are increasingly used to communicate with research participants and record audio and video data for research purposes. However, these digital interactions can be traced by third parties, which may compromise participants' anonymity (van Doorn 2013: 393). Also, research using social media can compromise participants' safety if they are unaware of the extent to which social media sites such as Facebook, Twitter and Pinterest can be linked together. This means that someone giving their consent to participate in research via one such site may inadvertently provide the researcher with access to their content on other social media sites (Rooke 2013: 267).

The expansion of technology has created a lot of new opportunities for researchers, with associated new ethical difficulties. For example, online research can be passive, where people providing information online are not aware that it is being used for research, or active, where participants are aware of and have consented to be involved in the research. It would seem, at first sight, that active research is more ethical. However, it can be difficult to ensure that consent given online is fully informed. You can provide any amount of information about the research, the participant's opt-out options and so on, but it is impossible to be sure that the participant has understood and accepted this information. This is because a participant may give their consent through a single mouse click, without actually reading the information you provide. For example, in the summer of 2014, while this book was being written, researchers from Facebook published details of an experiment manipulating Facebook users' exposure to emotional content in their timelines (Kramer et al 2014: 8788). This research was in accordance with Facebook's data-use policy. However, many Facebook users felt that they had not given consent – certainly not informed consent – to participating in such research. The outcry on social media was so vehement that the researchers rapidly apologised and the editor of the journal that had published the research printed an 'expression of concern' about its ethical status.

The Facebook research may have caused only alarm to most of those affected, but research online that is not carefully carried out can put participants in actual danger. For example, whether the research is passive or active, if researchers do not maintain their participants' privacy, anonymity and confidentiality they can jeopardise those people's personal safety by leaving them vulnerable to crime through hacking or stalking (Rooke 2013: 267). It is essential for researchers to be fully aware of the potential implications of the use of technology within any research they conduct. For example, it is important to know that many participants are unaware of the size and nature of their personal digital footprint (and this probably applies to many researchers, too). Also, direct quotes from online research can be traced back to participants by using a search engine, so semi-fictionalisation can be particularly useful in reporting online research (Markham 2012: 5). If you are ever in doubt as to whether you might compromise the safety of an online research participant or cause any other unethical outcome, you should err on

the side of caution (Rooke 2013: 268). It is essential that researchers should do as much as possible, proactively, to act ethically when working online (Markham 2013a: 69).

Well-being of researchers

A great deal of attention is paid to the need for researchers' duty of care to vulnerable research participants during data gathering – and rightly so. Historically, rather less attention has been paid to the potential vulnerability of researchers (Librett and Perrone 2010: 739; Bowtell et al 2013: 654), with many codes of research ethics failing even to mention that researchers need to protect themselves and take care, both when working in the field and elsewhere. Also, some research institutions fail to implement even the most basic health and safety regulations in managing the potential risks to the researchers they employ and send out to do fieldwork (Bahn and Weatherill 2013: 25).

> Australian researchers Susanne Bahn and Pamela Weatherill studied the lives of people with rapidly degenerating neurological diseases. In the process, they considered the potential emotional impact for researchers gathering sensitive data and the difficulties for researchers in recognising risk, and developed some strategies for increasing researchers' personal safety. They found that gathering data in people's homes can be risky, as the researcher is a stranger who does not know who will be in the house, their state of mental or physical health or what dangers may exist, such as aggressive dogs, or cables lying across the floor. There is also emotional risk from the experience of interviewing people in very distressing circumstances. Bahn and Weatherill offer a seven-point checklist to help with identifying and managing risk.
>
> 1 Has a mobile phone call-in system been established?
> 2 Is the researcher experienced in working with these types of participants?
> 3 Can researchers work in pairs?
> 4 Can researchers be given personal alarms?
> 5 If data is to be gathered in participants' homes, are other colleagues aware of researchers' whereabouts, and can researchers plan an exit strategy, for example parking in the street for an easy getaway?
> 6 Is debriefing support or counselling available?
> 7 What types of safety training are needed? (Bahn and Weatherill 2012: 33)
>
> Bahn and Weatherill's final recommendation is that safer data gathering practices should be included in research project plans, and budgeted for, and policies should be developed to support this (Bahn and Weatherill 2012: 33).

Even the more mechanical aspects of research, such as applying for ethical approval or using technological methods, can come with a heavy emotional cost

(Monaghan, O'Dwyer and Gabe 2013: 73; Moncur 2013: 1883). Suggestions for ways to manage this include: advance preparation, peer support, working reflexively and seeking counselling when necessary (Moncur 2013: 1885). A **video** offering a few thoughts on the emotional well-being of researchers can be viewed online.

It is important for each of us, as researchers, to take care of ourselves throughout the research process. Doing so will help in a range of ways, including promoting our creativity. Empirical research has shown that self-compassion, or being kind to yourself, is linked with higher levels of original creative thinking, while self-judgementalism, or being destructively self-critical, reduces original creative thought (Zabelina and Robinson 2010: 292). So taking good care of yourself will help you to think creatively, which in turn will enhance your research.

CONCLUSION

You cannot rely on rules to help you to act ethically in research. Principles such as 'use research to do good' and 'guard against bias' can be helpful. But ultimately, to be an ethical researcher, you need to think ethically before, during and after you make your research. Even this won't protect you against mistakes along the way and taking actions which, on later reflection, you will realise were not the most ethical option. But if you're making the best decisions you can, on the basis of the information available to you at any given time, then you're doing all that anyone can ask.

This chapter has given an overview of *what* an ethical researcher should do. The scope for creativity lies in *how* that is done. There are ethical dimensions to each aspect of the research process, so each of the remaining chapters in this book will include a short ethical section focusing on ethical issues of particular relevance to that stage of your research.