Chapter 1: Ethics in participatory research

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Abstract

This chapter introduces the topic of ethics in participatory research, providing a rationale for the book, discussion of the nature of ethics and ethical theories, suggestions for using the book and an overview of its contents. Participatory research involves people whose lives are the subject of study in some or all aspects of research design, process, dissemination and impact, with a focus on generating socially just change. As such, it raises distinctive ethical issues linked with the challenges of collaboration; sharing power; co-ownership of data, findings and impact; attribution of authorship; changing roles and relationships; handling institutional ethical review processes; and collective organising for change. This chapter elaborates briefly on some of these issues, discussing a range of different approaches to conceptualising and practising ethics in participatory research. It considers theoretical approaches to ethics, arguing for an approach characterised as 'everyday ethics'. This takes account of the character traits, motives and relationships of the people involved, the particularities of the situations in which they are acting, and the 'ethics work' that people do to maintain their integrity, act with compassion and work out right courses of action. The chapter ends with examples of case-based exercises for teaching and learning, and an overview of each chapter.

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Introduction

This chapter introduces the topic of ethics in participatory research (PR), providing a rationale for the book and an overview of the subject matter of each chapter. PR involves people whose lives are the subject of study in some or all aspects of research design, process, dissemination and impact, with a focus on generating socially just change. As such, it raises distinctive ethical issues linked with the challenges of collaboration; sharing power; co-ownership of data, findings and impact; attribution of authorship; changing roles and relationships; handling institutional ethical review processes; and collective organising for change. In this chapter we elaborate briefly on some of these issues and discuss a range of different approaches to conceptualising and practising ethics in the context of PR.

We argue that an approach to ethics that takes account of the character traits, motives and relationships of the people involved and the particularities of the situations in which they are acting, provides a helpful framework for PR. This contrasts with approaches to ethics in research that are abstract and principle-based, as well as those that are regulatory and compliance-based. We explore character- and relationship-based approaches to ethics, including the ethics of care, virtue ethics, communitarian and covenantal ethics and their contribution to an 'everyday ethics' for PR. We discuss the role and nature of the 28 cases from real-life research practice that feature in the book, which are used to illustrate the day-to-day ethical challenges faced by participatory researchers working in the fields of health and social well-being.

The book focuses on health and social well-being, as it was developed as a project of the International Collaboration for Participatory Health Research (ICPHR). However, 'health and social well-being' is very broadly conceived, encompassing research involving medical interventions to more overtly radical social justice projects, which give voice to people experiencing oppression, and taking action for change. Much PR, even if not carried out by people who self-identify as health or social researchers, has an impact on the health and social well-being of those who participate. Hence the book is also relevant to research that may be identified as educational participatory research, citizen science or organisational action research, for example, although we do not include examples from all these fields. It is a companion book to *Participatory research for health and social well-being* (Abma et al., 2018), which was co-authored by members of ICPHR and designed as an introductory text.

Rationale for the book

While PR is well-established as an approach that involves people with a direct interest in, or experience of, the issues being studied in carrying out some aspects of the research, it has until recently been a minority interest. It is now growing in popularity worldwide, particularly in the university sector, with academics and students increasingly undertaking research in partnership with civil society organisations, often with a view to stimulating social change or 'impact' (changes in thinking, policy or practices attributable to the research).

However, the complexities of PR are often not fully appreciated, nor are the unique and challenging ethical issues it raises. Traditional concerns in research ethics about respect for the rights to confidentiality, consent, privacy and protection of research 'subjects' or informants do not translate easily into PR, where boundaries between researcher and researched may not be clear, the trajectory of the research may be emergent and unpredictable, and major ethical issues revolve around partnership, power, equality and respect for diverse knowledges. Hence our aim in this book is to delve more deeply into some of the complex ethical issues that arise in the everyday practice of PR, with a view to stimulating readers' ethical awareness, and improving their capacities for ethical reflection and dialogue.

The book was conceived as a curated collection of ethics cases. The inclusion of real-life cases contributed by participatory researchers is designed to ground consideration of ethical issues in the contexts in which they arise. This enables us to take account of the hopes, anxieties and dilemmas experienced by those involved, as well as the decisions made, actions taken and the post-hoc ethical evaluations of participants and readers. However, the 28 cases in the book do not necessarily speak for themselves, nor do they encompass the full range of ethical issues that might arise in PR. Hence there are substantive introductions to each chapter, offering an overview of one or more broad themes, before four cases are presented, written by different authors from a range of countries and contexts. Each case is followed by a reflective commentary and the chapter then closes with some final remarks regarding the issues raised throughout the chapter.

Before summarising the content of the book at the end of this chapter, we will first discuss the history and nature of PR and outline the conception we are using in this book. We will then discuss briefly our understanding of 'ethics' and the history and nature of concerns about

ethics in research, before considering the distinctive ethical issues that arise in PR and what kinds of theoretical and practical approaches to ethics may be useful in this context..

Participatory research

Participatory research is a collaborative effort in which people whose lives are affected by the issues being researched are partners in designing, undertaking and disseminating research to influence socially just change. The process aims to be democratic, participatory, empowering and educational. There are many different variations, with different names and histories. Here we offer a very brief and partial overview of some of the varieties and their origins.

PR is often categorised as a form of action research, which can be thought of broadly as a family of collaborative research methodologies focused on achieving positive change in communities and organisations (Reason & Bradbury, 2008). Its origins lie in a number of different social movements and practices concerned with liberatory and anti-colonial struggles, popular education and literacy, community development, and organisational change. Although the term 'participatory research' only came into common use from the mid-1970s, community-based participatory research practices were developing in the 1960s and early 1970s (organisation-based action research from much earlier). One of the most notable and radical strands is associated with Orlando Fals Borda (1925-2008, political activist and sociologist at National University of Bogotá), who undertook what he called 'action research', working for social and economic change alongside people living in 'peasant' communities in Colombia. He is credited with coining the term 'participatory action research' in the late 1970s (for details of his work, see Fals Borda, 1987, 1988, 2001; Fals Borda & Rahman, 1991). However, by then the term 'participatory research' was already in use, the orgins of which Budd Hall (2005) traces to Tanzania, linking to the work of Marja-Liisa Swantz, with whom he worked when undertaking community development and adult education at the University of Dar es Salaam in the early 1970s. Swantz (1974) wrote a paper about 'participant research' with women, while the following year Hall (1975) used the term 'participatory research' as 'a descriptive term for a collection of varied approaches which shared a participatory ethos' in a paper published in a special issue of the magazine *Convergence* (Hall, 2005, p. 7). The International Participatory Research Network was founded in 1976 by Hall and others, gaining inspiration and momentum from the first conference on action research held in Cartagena (Colombia) in 1977 organised by Fals Borda (Hall & Tandon, 2018). Global links began to develop from this point, linking the practice

and thinking of many different movements around the world, from the work of Paulo Freire in Brazil to Rajesh Tandon in India (Freire, 1972; Tandon, 2005).

Given the 'participatory turn' beginning in 1970s and growing rapidly in the 1990s in the fields of development work, popular education and liberatory movements, the time was ripe for the adoption of participatory approaches to research, which gained momentum as networks developed. Early accounts of participatory research in North America were published in the volume *Voices of Change: Participatory Research in the United States and Canada* (Park, Brydon-Miller, Hall, & Jackson,1993). This included descriptions of projects being carried out at the Highlander Research and Education Center in Tennessee focused on using participatory methods and adult education to address problems in the Appalachian region of the American South (Gaventa, 1993; Horton, 1993; Merrifield, 1993) and a discussion of feminist participatory research by Patricia Maguire (1987). Alongside feminist PR, there was also a growing awareness of the potential of PR in Indigenous communities in the global North, including Australia and New Zealand (e.g. Smith, 1999), and the need for a high degree of critical awareness and humility amongst non-Indigenous researchers working with First Nations people, as exemplified in Cases 4.3 and 5.2 in this book about work with the Inuit and Aamjiwnaang in Canada.

Already this brief account of the origins of PR demonstrates how different terms are used for similar practices, depending upon the tradition and context in which they developed. PR has always had a close relationship with community development and community activism, and is often practised in international development contexts where particular approaches have developed, including participatory rural appraisal (PRA, later Participatory Reflection and Action), linked with the influential work of Robert Chambers (1994), and participatory learning and action (PLA). The term 'community-based research' (CBR) is used widely in North America, particularly Canada, while 'community-based participatory research' (CBPR) has come to be used largely in North America to refer to participatory health research (Coughlin, Smith, & Fernandez, 2017; Wallerstein, Duran, Oetzel, & Minkler, 2017). In the UK, Banks et al. (2013) use the term CBPR more literally to encompass any type of research (not just health-related research) that is based in communities of place, identity or interest and engages community members as co-researchers in some way The International Collaboration for Participatory Health Research (founded in 2009 with the aim of enhancing the quality and reinforcing the impact of PR in the health field) uses the term 'participatory health

research' rather than CBPR (International Collaboration for Participatory Health Research (ICPHR), 2013).

Our conception of PR in this book is of research that is community-based (its rationale and key stakeholders lie in communities of place, interest or identity rather than in large institutions such as universities or hospitals) and value-based (it enacts principles of mutual respect, collaboration, equality and social justice, for example). We draw on Durham University's Centre for Social Justice and Community Action (CSJCA) ethical principles for CBPR, reproduced later in this chapter in Table 1.2, using the term 'CBPR' literally to mean PR that is community based (Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2012). We also draw on the first position paper produced by the International Collaboration for Participatory Health Research (ICPHR) outlining the key characteristics of 'participatory health research', which are applicable to all PR, including that it is locally situated, collectively owned, and promotes critical reflexivity (International Collaboration for Participatory Health Research (ICPHR), 2013).

However, despite the fine rhetoric of social justice found in academic texts and practice manifestos, it is important to stress that the extent to which PR adopts genuine power-sharing models or seeks to challenge radically the structures that embed poverty and inequality in societies varies enormously. It can be used as a tool to reach and control marginalised people and communities as much as for the 'powering of knowledge from the margins' to transform their lives and livelihoods (Thomas and Nararayan, 2015, p. 3). The current popularity of community-university research partnerships, which in some areas are becoming relatively 'mainstream' and institutionalised, brings with it the benefits of opening up universities and promoting 'knowledge democracy', alongside the dangers of co-option and control (Bivens, Haffenden and Hall, 2015).

The role of 'the community' in participatory research

Since 'community' is a key focus of attention in PR, and is also such a contested concept, we will say a few words here about 'community', whilst also drawing readers' attention to Chapter 4 of this book, which critically explores community rights, conflict and democratic representation. While there are numerous characterisations of 'community', a useful generic description is: 'collectivities of people with some but not necessarily all characteristics in common' (Banks, Hart, Pahl, & Ward, forthcoming, 2018). While 'community' has connotations of homogeneity and closeness, the idea that the collectivity may share only

certain characteristics in common allows for elements of heterogeneity and diversity. Communities may comprise people living in the same geographical area (e.g. an urban neighbourhood, or a village), people with common interests (e.g. a hockey team, birdwatchers) or identities (e.g. Hindu religion, or lesbian women). 'Community' falls into the category of what Plant describes as an 'essentially contested concept' (Plant, 1974), with multiple descriptive meanings as listed above and an evaluative meaning, generally with positive connotations linked to care and cohesion (Banks & Butcher, 2013; Crow & Allan, 1994; Somerville, 2016). While this makes it a very problematic concept, it continues to be deployed in everyday life and public policy as a way of promoting social inclusion and stressing commonality. Yet the sense of identity and being cared about that is felt by members of communities can also amount to pressure to conform, and relies on members differentiating themselves from others outside their communities. In addition to solidarity with each other, members of communities also need to practise tolerance of non-members, seeing themselves as part of broader society in order to combat stigma, marginalisation, and violence based on characteristics such as ethnicity, religion, gender, sexuality, class, age or ability (Banks, Hart, Pahl, & Ward, forthcoming 2018). These issues of inter- and intra-community conflict and the tensions between individual and community rights, needs and interests are discussed and exemplified in Chapter 4.

As the case examples in Chapter 4 demonstrate, communities take many forms and the types and levels of participation involved in PR must be designed to respond to these differences. While most examples in this book involve academic or other 'professional' researchers working in partnership with people in communities, PR is often undertaken by members of community organisations themselves, without outside partners. In other cases, communities or organizations already well-established before a research partnership begins may seek an outside researcher themselves to provide support, as was the case in Michael Kral's work described in Case 4.3 with the Inuit in Canada. In such cases the role of the outside researcher may be grounded in skills development and data generation and analysis. In other situations, a particular issue or concern may be known to members of the community, but without an attempt to organize around it having been undertaken. In such instances a professional researcher coming into a group must first serve as community development worker or organizer in order to bring people together around a particular concern, as exemplified in Case 8.1 about isolated women of minority ethnic origins in a Dutch city. In still others, members of the community may be divided or in conflict regarding an issue, in which case

the outside researcher's role may focus on mediation and conflict resolution, as in Case 4.4 about work with Roma people in the Czech Republic. Each of these roles requires a specific set of skills and each situation raises particular ethical challenges (Brydon-Miller & Ortiz Aragón, forthcoming, 2018). The roles may also change over time and people may find themselves taking on several, sometimes conflicting, roles (see Chapter 3 of this volume on blurring boundaries).

The cases in this book exemplify the many forms, 'community participation' may take, from communities in control to community members engaging in participatory exercises designed by outside researchers. As discussed in Chapter 2 of this volume (on partnership, collaboration and power), in designing and undertaking a piece of PR, it is important that those involved give consideration to the types of research they wish to do and how the different parties will work together. In a scoping study of CBPR, Durham Community Research Team (2011, p. 6) identified four points on a continuum of community participation in research:

1. Community-controlled and -managed research, no professional researchers involved.
2. Community-controlled with professional researchers managed by and working for the community.
3. Co-production – equal partnership between professional researchers and community members.
4. Controlled by professional researchers but with greater or lesser degrees of community partnership, e.g.
   - Advisory group involved in design, dissemination.
   - Trained community researchers undertake some/all of data gathering, analysis, writing.
   - Professional researcher uses participatory methods (e.g. young people take photos).

In assessing the accounts of research in the literature reviewed for the scoping study (mainly in academic journals), the majority appeared to fall into the fourth category (controlled by professional researchers, with some degree of community participation) (Durham Community Research Team, 2011, p.5). However, as the cases in this volume show, at different stages of the research process (in the recursive cycle of generating ideas, planning, contributing and

analysing data, learning, taking action, and generating new ideas) degrees of community participation may differ and change over time.

Ethical issues in research

In this section we will briefly outline what we mean by 'ethical issues' and then describe the growth of concern about ethics in research, outlining the main issues and how these are being tackled in policy and practice through the growth of research governance systems. Following ordinary usage in English, we use the terms 'ethical' and 'moral' interchangeably in this book.[1]

To put it simply, we use the term 'ethical issues' to encompass matters of harms, benefits, rights, duties, and responsibilities experienced by humans in relationship to each other and the ecosystem. What is identified or noticed as being harmful or a right, for example, varies between cultures and countries, and has changed over time.

Concerns regarding ethics in the context of research with 'human subjects' grew initially out of responses to biomedical research conducted by doctors in Nazi Germany on people held in concentration camps during the Second World War (Mitscherlich & Mielke, 1949). This led to the development of the Nuremberg Code (1949), presenting 10 principles for medical research, the first of which was voluntary consent. This code shaped the Declaration of Helsinki, originally drafted in 1964 and most recently amended in 2013 (World Medical Association, 1964/2013), which outlines the basic principles for medical research involving human subjects. Another later scandal which had a major influence on the regulation of research was the Tuskegee Syphilis experiment in Alabama, USA, in which poor African American men with syphilis were denied treatment in order to allow medical researchers to study the long-term effects of the disease over a 40-year period, only ending in 1972 when the scandal broke (Reverby, 2000).

The main ethical issues raised by these cases and others like them related to the need to prevent harm to the 'human subjects' involved in any research, ensuring that they were not exploited or physically or emotionally damaged. The importance of giving full information to people who were participating in experiments, or to their carers or proxies, treating them with dignity and respect, and gaining their informed consent came to be regarded as a *sine qua non*

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[1] Some philosophers and other theorists distinguish 'morality' (concerned with societal norms) from 'ethics' (concerned with internally generated (personal) norms) (See Banks, 2012, pp. 5-6 for further discussion)

for ethically sound research. The Tuskegee scandal in the USA led to legislation and the establishment of a commission in 1974, which produced the very influential Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). This report outlined three key ethical principles for research: respect for persons, beneficence, and justice, along with guidance regarding their application with respect to: informed consent, assessment of risk and benefits, and selection of subjects.

These principles and guidelines are still highly influential and have come to dominate not only biomedical research, but also research in the behavioural and social sciences. One of the criticisms of this growth in regulatory ethics across the board is that there has been insufficient input from scholars in these latter disciplines (Schrag, 2010). Hence there is an over-emphasis on protection from harm and risk aversion, which does not necessarily fit with the circumstances of social research, let alone PR. This essentially 'top-down' approach to ethics in research is premised on a distinction between researcher and researched, assumes all research fits this ethical framework and reinforces systems of power and expertise which are actively challenged in PR. In recent years there has been a tendency to generate many more detailed rules and complex systems of research governance deriving from these principles, including systems of ethical approval by review boards and committees, which can lull us into believing that the successful completion of an official form constitutes the end of our obligation to engage in ethical thinking and reflection (see Chapter 7 of this volume). Or as van den Hoonaard has wryly observed, 'paperwork, as we have seen, distracts committees from doing ethics work and researchers from pondering ethical considerations' (2011, p. 290).

In this book we provide an alternative ethical framework from the 'bottom up', which better reflects the realities and values of PR, acknowledging that we need to cultivate researchers with the skills of good communication and relationship building, along with moral qualities of trustworthiness, honesty and care, who are committed to dialogue based on the nuances of the particular situations and people they encounter. It is our hope that this volume, particularly the thoughtful and honest reflections provided by the authors of the cases, will serve to promote greater critical reflection on the ethical issues in all research, and in PR in particular.

Ethical issues in participatory research

In designing the structure of the book we drew on a literature review undertaken as part of a scoping study coordinated by Durham University's Centre for Social Justice and Community Action (Durham Community Research Team, 2011).The common themes under which the ethical challenges in PR might be grouped were outlined in Banks et al. (2013), from which the list below is a summary.

- *Partnership, collaboration and power* – all PR involves some degree of collaboration, whether between professional researchers and community partners or a range of different community researchers. This means it is important to attend to how partnerships are established, power is distributed and control exerted. Some of the ethical issues and dilemmas noted in the literature included: tackling the mismatch between timelines and expectations of community organisations, funders and academics; awareness that closer research relationships also bring greater potential for exploitation; and taking account of the fact that co-researchers may experience moments of inclusion and exclusion in the research process.

- *Blurring the boundaries between researcher and researched, academic and activist* – insofar as PR involves some degree of co-production of research and an action-orientation, this may entail community members taking on roles of researchers, and professional researchers may take on roles commonly associated with health, social care or community development work. Tensions may arise for people who find themselves in the role of both researcher and community advocate or academic and activist. Community researchers studying their own communities or peer groups may find themselves in the roles of both researcher and researched, and have to consider whether and where to draw the lines between being researcher and friend or neighbour.

- *Community rights, conflict and democratic representation* – while most ethical codes and guidelines for research are concerned with the rights of individual 'human subjects' (to safety, privacy, freedom of choice to participate or withdraw), PR in community-based settings raises the challenge of extending rights to communities or groups. This creates issues in defining 'community', taking account of conflict within and between communities and groups and deciding who represents a group or community interest. If the topic of research is controversial, for example, attitudes towards assisted suicide amongst disabled people (see Minkler et al., 2002) there are complex matters relating to democracy and community relations to be considered.

- *Ownership and dissemination of data, findings and publications* – if multiple partners are involved in research, there may be conflicts of interest in terms of who takes credit for the findings and what channels are used for dissemination. These may manifest themselves in decisions about co-authorship, publicity and claims for research impact, particularly as academic pressures to publish and give evidence for impact on policy and practice increase.

- *Anonymity, privacy and confidentiality* – whilst these matters are common concerns in all social research, the close relationships developed in PR preclude straightforward solutions. If community or peer researchers are involved, and wide dissemination is planned within the community, identities of research participants may be hard to conceal. Some participants may wish to be named and credited, others may not. There may be matters that some representatives of a community or group do not wish to be revealed, such as survival strategies of asylum seekers, sex workers or indebted families.

- *Institutional ethical review processes* – a noticeable theme in some of the literature is the difficulty of fitting PR into the process and procedures for institutional ethical review (Brydon-Miller, 2009; Flicker & Guta, 2008; Love, 2011; Manzo & Brightbill, 2007). Whilst many of the assumptions underlying the ethical review process – including the predictability of research trajectories – are problematic for all social research, they pose specific challenges for PR. Ethical guidelines for research and forms to be completed are often premised on a clear distinction between researchers and subjects of research; require individual consent to participate; and make assumptions that an academic or professional researcher ('principal investigator') has primary control over and responsibility for the research.

These form the themes for Chapters 2-7 of the book. The topic for the final chapter (social action for social change) was suggested by one of the authors (Cathy Vaughan) as important in PR, which generally has a social change commitment that goes beyond simply creating 'impact'.

- *Social action for social change* - The theoretical underpinnings of PR emphasise its action-orientation, and that it is an approach to research that strives for social change. However what constitutes appropriate and sufficient 'action' is not always clear, with different partners holding varied views on what types of outcomes could be described as social action. That PR will involve social action is often assumed, with limited guidance

available to research partners about the need to consider the nature of action, to plan for it and to reflect on where responsibility for this action lies. Research partners experience different constraints upon their social change efforts, including time, resources, control and institutional mandates.

While there is obvious overlap between these issues, we felt they provided a useful organising framework for the book. They are a mixture of the types of ethical issues that are identified in 'traditional' (non-participatory) research (such as anonymity, privacy and confidentiality) and those that are more distinctive to PR (blurring boundaries, community rights and social action). Most cases were not written for a specific chapter in the book, so they give relatively holistic accounts of the research process and may raises issues relevant to the themes of several chapters.

Theoretical approaches to ethics[2]

So far we have focused on describing and categorizing ethical issues in PR based on commonly accepted understandings of what counts as 'ethical'. We have said little about theories of ethics, particularly those emanating from moral philosophy, which tend to be concerned to identify what lies at the heart of the 'good life', what counts as 'right', 'wrong', 'good' or 'bad', or what responsibilities humans have for each other and the ecosystem.

Such theories can be useful in offering frameworks within which to conceptualise ethical life, yet they can be also be problematic if we try to use them in making decisions and choices, as many ethical theories tend to focus on one feature of ethical life and it is often hard to link the practice on the ground with a high level theoretical system. For example, on the basis of Kantian deontology, a key principle of right action is that each person should be respected as a unique individual, treated with dignity and never used as a means to an end (Baron, 1995; Kant, 1785/1964). Alternatively, according to utilitarianism, we decide what is right by calculating which course of action will promote the greatest well-being of the greatest number of people (Mill, 1863/1972; Singer, 2011). Both Kantianism and utilitarianism are theoretical systems based on universal ethical principles of right action, with decision-making based on impartial, rational deliberation.

Aristotelian virtue ethics, on the other hand, focuses attention first and foremost on the motives and moral qualities of human agents (the people doing the actions) as opposed to the

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[2] This section draws on Banks (2012).

actions themselves. According to Aristotle, the cultivation of virtuous character traits (such as respectfulness, courage, honesty, compassion) is essential for human flourishing (Aristotle, 350 BCE/1954; Snow, 2015). More recently the ethics of care has been developed, particularly (but not exclusively) by feminist philosophers, paying attention not just to people as moral agents, but above all to relationships between people and the responsibilities they have for each other based on their particular situations and contexts, such as mother and child (Held, 2006; Noddings, 1984). Other variations of more relational approaches to ethics include communitarian ethics, where the focus is less on the individual and more on the 'community', seeking solidarity, harmony and the common good (Gyekye, 2010; Kuczewski, 1997), and the 'ethics of proximity' based on the demand or call of the other person (Levinas, 1989; Løgstrup, 1997). These have resonances with covenantal ethics, as outlined by Hilsen (2006) and Brydon-Miller (2009) in the context of action research, which centres on the deep commitment, relationship of trust and unconditional responsibility between people, drawing on the religious notion of the convenant with God, but redefining this within the context of human relationships with one another as 'community coventantal ethics'.

These relational approaches, particularly communitarian ethics, are much closer to those that are more prevalent in the global South and in Indigenous communities in the global North, where the individual is defined in relationship with others (Chuwa, 2014; Gbadegesin, 2005; Keown, 2005; Li, 1994). Virtue ethics, the ethics of care and communitarian ethics do not attempt to articulate universal abstract principles that apply to all people in all places, at all times. Rather they adopt a more situated (contextual) approach to ethics, starting from the realities of everyday life, as opposed to applying abstract principles, They regard emotions as an important feature of ethics, arguing that empathy and compassion, for example, are essential to ethical being and acting.

There are many other approaches to ethics that start with everyday practice, including narrative ethics, involving the use of stories to sharpen ethical sensibilities (Nelson, 1997) and case-based ethics (casuistry), which takes analysis of particular cases as a starting point, categorising and comparing them (Arras, 1991; Jonsen & Toulmin, 1988). These can more accurately be described as methodologies rather than theories, as they do not attempt to create normative theoretical systems based on foundational principles or concepts. Table 1.1 summarises these approaches to ethics in a simplified form.

Table 1.1: Some theoretical and methodological approaches to ethics

I.   *Principle-based ethics* (ethical theories)

    a) *'Kantian' principles*, for example:
- respect for persons as rational, self-determining beings;
- Impartiality and consistency in choice and action …

    b) *Utilitarian principles*, for example:
- promotion of welfare/goods;
- just distribution of welfare/goods …

II.   *Character- and relationship-based ethics* (theoretical approaches)

    a) *Virtue ethics* – development of character/virtues/excellences, such as:
- honesty;
- compassion;
- integrity ...

    b) *Ethics of care* – importance of particular relationships, involving:
- care;
- attentiveness;
- responsibility ...

    c) *Communitarian ethics* – the primacy of community:
- solidarity;
- harmony;
- inter-connectedness …

III.   *Narrative and case-based ethics* (methodologies)

    a) *Narrative ethics* – collection of approaches that value and use stories:
- Listening to/reading stories to sharpen moral sensibilities;

- Telling stories to define and develop one's identity;
- Invoking stories as moral explanation …

b) *Casuistry* - analysis of cases as a starting point, with a focus on:
- specific circumstances of the case;
- paradigm cases;
- categorisation and comparison of cases …

Taken from Banks, S. (2012) 'Global ethics for social work? A case-based approach' in Banks, S. and Nøhr, K. (eds) *Practising Social Work Ethics Around the World: Cases and Commentaries*, London, Routledge, p. 10.

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Although these many different ways of theorising about ethics, analysing cases and making ethical decisions may seem (and are sometimes presented by their proponents as) mutually exclusive, in fact they can usefully be regarded as complementary facets of a complete account of ethics. The idea of impartial principles of fairness and universally held rights and freedoms is an important way of looking at how people should be treated, especially in professional and international contexts. Principles provide a benchmark against which to assess decisions, actions and policies and highlight unjustified differences in treatment based on favouritism, prejudice, oppressive use of power and unfair legal, social and cultural laws, customs and norms. Our earlier discussion of the Nazi and Tuskegee experiments, which led to the development of principles for research ethics, are a case in point.

However, principle-based approaches do not capture all dimensions of what might be regarded as ethically important features of situations, especially in parts of the world or cultures where individual rights and freedoms have less prominence than family, group, tribe or community relationships and responsibilities. People's motives, character and emotions are also important, as are their particular relationships and responsibilities to each other and within their communities. Careful examination of specific features of each case or situation is vital, as is the ability to recognise morally relevant issues, to compare with other cases and to test against commonly accepted principles and rules. This capacity or quality is what Aristotle termed 'phronesis' or 'practical wisdom'. It is a quality that needs to be nurtured

and developed, through working alongside experienced role models or teachers and entails the ability to notice, pay attention and see morally relevant features of situations (Banks, 2018b; Eikeland, 2008).

Attention to relationships and character is important in all realms of life, not just PR (see Banks, 2018a; Banks & Gallagher, 2009). Otherwise what we regard as the domain of ethics becomes very 'thin' – decontextualised from particular people and places, ignoring important features of human life. It is our view that the ethical domain is inseparable from other aspects of everyday life (the practical, technical and political). Although we necessarily abstract certain features from their context in order to compare and evaluate, it is important to start from the details of the situations in which people are living and working, seeing ethics as deeply embedded in particular circumstances and embodied by people in their daily lives (Banks et al., 2013). Hence we regard cases (stories or narratives) as an invaluable aid to encouraging ethical sensitivity and reflective learning. This is particularly important in PR, which is a highly collaborative and relational practice, lending itself to theorising drawn from virtue, care and communitarian ethics, rather than abstract, universal principles.

Given our concern with the particularities of situations, people and relationships, then using narratives or cases is a useful methodology for developing ethical understanding. 'Casuistry' or case-based ethical reasoning (Jonsen & Toulmin, 1988) draws on a medieval Christian practice of providing moral guidance in particular situations. Rather than beginning with an ethical theory, casuistry starts with particular cases, taking account of the specific circumstances of each case in deciding on an ethically correct response. It works by taking a case and comparing it with a paradigm case, which is relatively straightforward and about which most people would agree in their ethical evaluations, determining differences and similarities. This is similar to legal reasoning, and requires skills in determining the morally relevant features of cases and in creating taxonomies of types of cases and issues. Casuistry is not a normative theory (prescribing what is good or bad), rather it is more akin to a method for making ethical assessments and decisions. In case-based ethics 'moral reasoning' plays a crucial role, with 'reasoning' in this sense including the use of moral intuition and practical wisdom, as distinct from rationality based on abstract principles (Toulmin, 2001).

Since this book draws on cases from many different countries, this approach to ethical evaluation, which starts with the case and pursues a detailed and careful analysis, is very useful. Sometimes people who espouse very different ethical and religious values may come

to agreement about what should be done in a particular case, by focusing on the details of the case. Their differences emerge when they come to justify their ethical evaluations with reference to different values or theories.

The nature of ethics cases and what we can learn from them

This book was conceived as a book of 'ethics cases'. In learning and teaching about practical ethics, it is common to use case examples as a way of encouraging students and practitioners to envisage how particular ethical challenges arise in practice and how they can be handled. It is less common to find longer real-life cases, extending over several pages, narrated by one or more key actors in the story, with a first person account of what they felt and thought, as well as what they did. The typical ethics case tends to be relatively short, often fabricated, told in the third person, focusing on action and encouraging the reader to consider what decision should be taken or to give an ethical evaluation of what happened (Banks, 2012; T. Chambers, 1997). The cases in this book are more diffuse, less focused on simply highlighting de-contextualised dilemmas, and more concerned to offer textured vignettes depicting key features of the characters, motives and emotions of the people involved, and the places and background circumstances germane to the stories. Of course, each case is selective, written by an author or co-authors from a specific perspective, telling a particular story. That is what makes each story both a case and, specifically, an ethics case. A case is framed as an extract from a whole set of experiences, situations and incidents to tell a story that might make some sense to the reader as well as the teller. And since the authors were all asked to offer 'ethics cases', they have constructed them so as to foreground matters thought to pertain to ethics – issues relating to human well-being, harm, or promotion or infringement of rights and responsibilities.

Collecting cases

The cases were collected over several years, inspired by the projects on ethics in CBPR at Durham University in 2011-12, which involved initially collecting UK-based cases (Banks & Armstrong, 2012). It was decided to expand the collection to include cases from around the world, inviting people at international conferences and through international networks to contribute. It became a project of the International Collaboration for Participatory Health Research in 2013, through which we made calls for cases. However, it was hard to get people actually to submit cases. Although relatively short compared with an article, a good case requires considerable work to tell a compelling story, clearly articulated, with the right

amount of detail to give readers a good enough impression of the relevant circumstances, but not to overwhelm them. It also requires some courage – to expose the authors' practice to scrutiny, particularly in cases where on reflection the authors wished the outcomes has been different or they felt implicated in unethical practice. Even when the story ostensibly presents the authors as 'hero/ines' or 'innocent victims', there is still a danger that readers will see other 'hidden' aspects of the cases and may call into question decisions and actions undertaken in good faith by the protagonists. Moreover, for this book, authors were asked to offer cases about which commentaries would be written by strangers, who knew nothing of them or their situations.

Our guidance to case authors included the following information:

> Case examples usually focus on a particular situation or event that raised an ethical dilemma or problem for the person writing the case example. They are usually written from the author's perspective and give an account of the issues as she/he saw them and may include reference to their feelings and thoughts.

> We are looking for case examples about real situations, preferably written in the first person (that is, using 'I'). This should be a short description of a situation, an event or a piece of work - describing the important features. A case example may describe everyday events and actions that an academic researcher, community researcher or other partner or participant encountered in practice that have ethical implications – or it may be a description of a situation that is constructed as problematic – involving a difficult decision, a dilemma, or a situation where 'mistakes' were made.

Many of cases were commissioned as a result of face-to-face contact at meetings and conferences, when people had given presentations about PR projects. Others were gained through calls via the web or email and a few were invited through correspondence with people we thought likely to have suitable material.

The balance between the Global South and North

We made large efforts to commission cases from as many different countries as we could, but nevertheless found it difficult to get as many as we would have liked from the global South. This clearly reflects the limitations of our networks, as well as the fact that the request was written in English, and although we offered support with translation, it would be time-consuming to construct a case in English. It may also reflect the fact that 'ethics' and

specifically 'research ethics' are topics that are well-defined and high on the agenda in the global North, but less so in the global South. This is not to say that issues of harms, benefits, rights and responsibilities are not important, but the concept of 'ethics' that abstracts these matters from everyday practical life is often less recognisable. Apparently, in some languages, for example sub-Saharan African, there is no direct equivalent of the term 'ethics' (Gyekye, 2010). A concern with 'ethics' may be introduced, ironically, in the guise of regulatory practices as part of the research colonisation process of the global North.

Our argument in this book is that the impartial, detached approach to ethics that emphasises fairness and dominates in the research ethics literature, policies and codes, is inadequate on its own as an ethical framework for PR, which is essentially a relational, embedded and embodied practice. This same argument applies to any kind of research or professional practice in many areas of the global South or Indigenous communities in the global North, where particular and partial human and ecological relationships and responsibilities are paramount. Hence Case 3.1, told by Pinky Shabangu, a community researcher working on an externally initiated project in Southern Africa, is particularly telling. She recounts her dilemma about whether to follow the research protocols as stressed in her training (always asking everyone the same survey questions), as opposed to refraining from asking when she knows the answer (her informant's mother is dead), and she knows it will hurt the feelings of her informant (also a neighbour) to have to reply. Similarly, in Case 6.3, PhD researcher from Australia, Michelle Brear, recounts tensions between naming a group of community researchers from a southern African community at their request, and the condition of the Australian ethics committee approval based on maintaining anonymity. As Kalsem suggests in her commentary on this case, this would amount to the academic community, with its position and rules, getting the final say. Interestingly, between submitting the case and the completion of the final draft of the book, a decision was made to name some of the community researchers as co-authors of publications and the case was amended accordingly.

The focus of the cases

As readers will notice, the cases in the book are very varied in terms of:

- how much background information is given;
- the balance between descriptions of events and reflective accounts of cognitive and emotional processes;

- whether or not the account focuses on a specific problem or dilemma; and
- whether the author explicitly or implicitly invites readers to make their own evaluative judgements about what happened and what could have been done differently.

We (as editors) wanted to keep as far as possible to the original accounts and forms of expression of the case authors. However, in all cases we asked for some further information and clarification about the circumstances and actions. In some cases, particularly when the first language of the author was not English, we initiated some fairly substantial revisions, often over several iterations in dialogue with the case authors.

Degrees of participation

A few cases did not make it into the book as after some dialogue it became clear that the research being undertaken was not what we judged to be 'participatory'. Indeed, a common question we asked several authors on receiving their first drafts was 'Can you explain how this research was participatory?'

Given there are so many different views about what exactly counts as 'participatory research' it is not surprising that this issue came up. Researchers may use participatory techniques (such as PhotoVoice or participatory mapping), but unless the people producing the photos or maps then go on to interpret their meaning in the context of the wider research project, then the extent to which the research project can meaningfully be described as 'participatory' may be limited. In some cases the original intention of the initiating academic researcher was to be participatory in some stages of the research process, but the community researchers or other stakeholders were not interested in 'deep' participation. This was the situation described by Jenevieve Mannell in Case 2.3, as she reflects on her struggles to engage fully the community-based researchers with whom she was working in Rwanda:

> As an academic I value the idea of trying to bring about social change through my research consistent with a community-based participatory research epistemology, however for the local researchers involved in this project, research participation is just another piece of paid work.

This raises the well-known dangers of participation imposed from outside (Cooke and Kothari, 2001). In other cases, a research project may become more participatory than originally intended, as the initiating professional researchers realise what 'genuine'

participation and power sharing with 'participants' or 'community researchers' could mean in practice. This happened in Case 2.4 as Candice Satchwell, the academic researcher, describes how she and her colleagues decided at the start of a project about young people's voices that they should involve young people as interviewers for the research assistant post.

Learning from mistakes

One of the matters on which we had to agree as editors was that these cases were not meant to be examples of 'best practice' – either in PR or in handling ethical issues. They were designed to be fairly honest accounts of what happens in everyday PR practice, which includes ethical infringements, wrong turns, mistakes and what might even be construed later by the case authors or by readers as 'bad practice'. A significant number of the cases end with a reflective comment from the author wondering if they did the right thing, commenting on what they have learnt from the incident they have recounted and how they might act differently in the future. Doing 'good' PR, with a high degree of ethical sensitivity, takes time to learn. Learning by doing fits very much with a participatory epistemology (theory of knowledge), which values experiential as much as propositional and theoretical knowledge gained through reading books or listening to lectures (Heron & Reason, 2000). So, for example, in Case 3.2 Catherine Wilkinson describes how she thought it appropriate to become 'friends' with young people in a UK radio station where she was conducting PR. Towards the end of the case she offers this reflection:

> I suddenly began to question my entire approach to this participatory research project, which had drawn me into friendships with young people which I considered to be inevitable due to our comparable age, our liking of the same music, and our mutual interest in radio. I was left asking myself a series of questions: Is it ethical to build friendships with research participants?

Struggles for doctoral students

Wilkinson was a doctoral student, inevitably facing the challenges of inexperience and also having to meet certain criteria for writing a dissertation which contained her own work and reflections as well as the products of the collaborative research with young people. She undertook ethnographic research (observing young people in the radio station and interviewing them) as well as PR (working alongside them as researchers). Hence the young people were research subjects and informants as well as co-researchers, which added to the

'layering' and complexity of the relationships, as MacFarlane and Roche note in their commentary on this case in Chapter 3.

Several cases are about doctoral research (see Cases 3.2, 3.4, 4.1, 4.2, 5.1, 5.2, 5.4, 6.2, 6.3, 6.4, 7.2, 8.1, 8.3), often written by people looking back several years to the challenges they faced as students. Some of these authors give accounts of themselves as struggling, like Wilkinson, to work out their roles and how to position themselves in relation to their co-researchers. For example, Duis (a doctoral researcher) and Baur in Case 8.1 recount how their original intention of acting as facilitators of social action amongst isolated women of Turkish and Moroccan origin in an urban neighbourhood in The Netherlands was modified to becoming advocates on behalf of the women. Finally they question their role altogether as it appeared that participation in the project was 'disempowering' for the women. Case 5.2, written by Wiebe, gives an account of her doctoral research with Indigenous young people in a heavily polluted industrial part of Canada. Not wanting to dominate or undertake 'extractive' research, Wiebe felt the young people should decide how to disseminate and use a film they made together documenting the environmental and social injustices of the area. However, at the point when Wiebe left, having completed her doctoral research, no decision had been made about dissemination and this resulted in the documentary not being widely available. The issues described by these authors provide a reminder to those who mentor or supervise doctoral students to provide thoughtful and timely support as they attempt to negotiate these challenges.

The emergent nature of PR

All research is designed to generate 'new knowledge' and researchers expect (and indeed may hope for) unanticipated findings. However, the process of conducting 'traditional' research is usually 'designed' in advance, with methods identified and a timescale of 'milestones' to be achieved along the way. In practice some of the detailed plans usually prove unrealistic in any research, but in PR unpredictability and 'messiness' are almost defining features (Brydon-Miller, Greenwood, & Maguire, 2003; Cook, 2009). This inevitably proves challenging for institutional review boards/ research ethics committees, as outlined in Chapter 7, and can lead to unhelpful constraints on PR, when academic researchers do not feel able to change their original plans, or are wary of going back to the review board/ethics committee. The emergent nature of PR, and the need for flexibility and creativity on the part of the researchers involved, is a noticeable theme in many of the cases

in this book. This is why PR can be particularly challenging for doctoral researchers, both due to their lack of research experience and the constraints of producing a doctoral dissertation to a timescale and in a prescribed format. The film produced by Wiebe and the young people in her doctoral research (Case 5.2) was not planned and occurred at the very end of the PhD study period. Geralyn Hynes (Case 3.4), an academic researcher who was also a qualified nurse, realised during the course of a PhotoVoice project with people with respiratory conditions in an Irish hospital that she was, in fact, acting as a therapist as she worked with participants to make sense of their illness stories and their lives. This was not what she had expected, nor had participants signed up for 'conversations that exposed [their] deepest feelings'. Yet they found the experience positive. Hynes felt that an ethical review board would not look favourably on a project that was both a therapeutic intervention and research, so the therapeutic element remained 'covert'.

In research projects initiated by professional researchers, or by professional (academic) researchers and partner NGOs, who then go and find people to act as co-researchers, there is no guarantee that people will sign up and if they do, they may not deliver what was anticipated or promised. There are several cases in the book where community researchers have challenged academic researchers. For example, in Case 8.4 a researcher with feminist values working for an NGO on domestic violence finds one or two of the women community researchers expressing views with which she disagrees (blaming some women for the violence they experience). She then has to decide how to handle this – as a professional researcher (respecting the women's views), a domestic violence NGO worker (challenging the women) or even as a friend driving the women home (having a creative conversation). These are not mutually exclusive, of course. Deciding what to do in this case is not just a matter of picking a role and following a set of norms linked to that role. It involves sensitivity to the circumstances and feelings of the women, recognising the social and political milieux that influence their thinking, considering when and how to challenge (if a decision is made to challenge), and reflecting with co-workers at the NGO and other co-researchers. In short, it requires a considerable amount of cognitive and emotional work – the first stage of which is recognising that there is an ethical issue in the first place.

Ethics work and everyday ethics

These cases depict their authors, along with their collaborators, undertaking cognitive, emotional and practical work. The authors give accounts of themselves striving to be

sensitive to the feelings and views of others, reflecting on their identities as ethical researchers, questioning injustices, and reasoning about the right courses of action. Of course, these are retrospective accounts, written for a book on ethics in PR. So we would expect the authors to construct cases that tell some kind of ethical story and feature themselves as moral agents. Nevertheless, the cases are interesting in that they tell us something about what the authors view as ethical issues (often focusing on everyday relationships) and how they give an account of their reasoning and actions afterwards (showing themselves as ethically aware and reflective - in effect, performing through their writing as ethical agents). What the authors depict themselves doing in these cases, and what they are doing when writing the cases as reflective narratives, is a certain kind of moral labour, or what Banks (2016) calls 'ethics work', which refers to:

> the effort people put into seeing ethically salient aspects of situations, developing themselves as good practitioners, working out the right course of action and justifying who they are and what they have done. (Banks, 2016, p. 35)

Banks (2016) suggests that ethics work is a major component of 'everyday ethics' – a term that encapsulates a concern with the small everyday ongoing practices that influence how people treat each other and how they contribute to the well-being and harm of each other, broader society, and the environment. 'Everyday ethics' is premised on the idea that the topic of ethics is about more than facing ethical dilemmas and making difficult decisions. It is about who we are as people (compassionate, just, wise, respectful) and our responsibilities to each other as inter-dependant, fellow human beings (see Banks et al. 2013 for a discussion of everyday ethics in CBPR).

A framework for ethical practice

We have argued that ethical practice in PR depends as much on the cultivation of good qualities of character and a sense of relational responsibilities as it does on applying abstract ethical principles or following rules. Nevertheless, a set of principles may serve as a useful framework to guide participatory researchers setting out on a project. The list of principles in Table 1.2 was developed by a group of community partners and academics in the UK, specifically with PR in mind. It has a relational focus, with the first principle being 'mutual respect' and subsequent principles very much reflecting the values of PR as described earlier (e.g. equality, democratic participation, collective action). This contrasts with the more individualistic focus of many codes of research ethics. Accompanying the statement of

principles are practice guidelines that cover practical matters such as working agreements, ownership of data, and so on.

Table 1.2: Ethical principles for community-based participatory research
(taken from Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2012).

1. *Mutual Respect: developing research relationships based on mutual respect, including a commitment to:*
- agreeing what counts as mutual respect in particular contexts.
- everyone involved being prepared to listen to the voices of others.
- accepting that people have diverse perspectives, different forms of expertise and ways of knowing that may be equally valuable in the research process.

2. *Equality and Inclusion: encouraging and enabling people from a range of backgrounds and identities (e.g. ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research, including a commitment to:*
- seeking actively to include people whose voices are often ignored.
- challenging discriminatory and oppressive attitudes and behaviours.
- ensuring information, venues and formats for meetings are accessible to all.

3. *Democratic Participation: encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need, including a commitment to:*
- acknowledging and discussing differences in the status and power of research participants, and working towards sharing power more equally.
- communicating in language everyone can understand, including arranging translation or interpretation if required.
- using participatory research methods that build on, share and develop different skills and expertise.

4. *Active Learning: seeing research collaboration and the process of research as providing opportunities to learn from each other, including a commitment to:*

- ensuring there is time to identify and reflect on learning during the research, and on ways people learn, both together and individually.
- offering all participants the chance to learn from each other and share their learning with wider audiences.
- sharing responsibility for interpreting the research findings and their implications for practice.

5. *Making a Difference: promoting research that creates positive change for communities of place, interest or identity, including:*

- engaging in debates about what counts as 'positive' change, including broader environmental sustainability as well as human needs or spiritual development, and being open to the possibility of not knowing in advance what making a 'positive difference' might mean.
- valuing the learning and other benefits for individuals and groups from the research process as well as the outputs and outcomes of the research.
- building a goal of positive change into every stage of the research.

6. *Collective Action: individuals and groups working together to achieve change, including a commitment to:*

- identifying common and complementary goals that meet partners' differing needs for the research.
- working for agreed visions of how to share knowledge and power more equitably and promote social change and social justice.
- recognizing and working with conflicting rights and interests expressed by different interest groups, communities of practice or place.

7. *Personal Integrity: participants behaving reliably, honestly and in a transparent and trustworthy fashion, including a commitment to:*

- working within the principles of community-based participatory research.
- ensuring accurate and honest analysis and reporting of research.

- being open to challenge and change, being flexible and prepared to work with conflict.

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These principles, also available in an *Easyread* version with pictures (Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2013) can be used at the start of a research partnership to help all those involved develop a bespoke ethical framework for a piece of work (see Abma, et al., 2018, Chapter 3). They can also inform institutional review boards and research ethics committees about the ethical issues of concern in PR, and provide support in teaching and learning – including when analysing and discussing some of the cases in this book in class.

Using this book

There are many ways this book can be used in learning and teaching contexts, both with students studying PR, and practitioners wishing to develop their understanding and skills. Table 1.3 summarises some exercises that can be used (further examples can be found in Banks and Armstrong, 2012; Banks and Nøhr, 2012).

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Table 1.3: Case-based exercises for use in learning and teaching

A. Analysing a case. Students/practitioners can be given a case from this book, without the accompanying commentary, and asked to discuss and analyse it in groups or individually. The following set of questions might be useful:

1. What is your initial reaction to this case, including any feelings you might have about it?
2. What are the ethical issues involved in this case?
3. What action would you take if you were the researcher(s)/practitioner(s) involved?
4. How would you justify this ethically?

B. Writing a commentary. Students/practitioners can be asked to write their own commentary on a casefrom the book, or one written by a colleague. The following points can be used as guidance:

1. *Audience.* Consider who will be the audience for your commentary and ensure you write in language the audience will understand.

2. *Ethical issues*. Highlight what you think are the key ethical issues in the case - how can they be understood?

3. *Reflection on context*. If you are from a different country than the country of the case, or a different area of work, you might like to reflect on similar issues in your own country or area of work – to what extent are these universal/general issues in a particular context?

4. *Think about how critical or judgmental you should be*. Consider how the author(s) of the case, or other people who feature in the case, might respond to your comments.

5. *Ending.* End the commentary with a conclusion which could be your own position statement ('My opinion about this particular case is …' or 'at the heart of this problem lies ….') or a proposed solution to the problem or another suitable ending to the commentary.

C. Writing a case example. Students/practitioners with experience of PR could be asked to write a case example (about two pages) based on an ethically challenging situation they have faced, using the following guidelines:

1. *Background information*. Start with a short introduction about the context in which the case takes place – the setting, the people involved.

2. *Description of events, thoughts, feelings.* Describe what happened, including accounts of any thoughts or emotions and short reflections, if desired

3. *Anonymity.* Consider whether the names of people, organisations and places should be changed and any identifying features removed or changed, in order to protect the identity of those involved.

D. Other case-based exercises. Cases or short vignettes about specific situations with ethical implications can also be used as the basis for other kinds of exercises. Here are two examples:

1. *Dilemmas cafés* – This method asks participants to offer cases for discussion in small groups in a safe, yet critical, group of peers. A guide for facilitators is available (Centre for Social Justice and Community Action, 2015).

2. *Participatory theatre* – short episodes from PR practice where an ethical transgression or experience of oppression has taken place can be used as the basis for groups of people to act out short scenarios, and then rehearse different options for action. A guide based on Augusto Boal's Theatre of the Oppressed is available (Banks, Rifkin et al., 2014).

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Overview of the chapters

Having suggested some practical uses of the book, we will now briefly summarise each chapter, so readers may identify themes and cases of relevance to their particular interests.

Chapter 2: Partnership, collaboration and power. The Introduction by Groot and Abma discusses some of the challenges of partnership working in PR, including: establishing, sharing and exerting control and power; tackling the mismatch of timelines and expectations between partners; anticipating the risks associated with participation in PR; and ensuring sustainability of partnerships. Four cases are presented and discussedrelating to: institutional challenges in conducting PR with older people nursing homes in Denmark; co-researching with people with Asperger's syndrome in the UK; tensions between community and university-based researchers working on gender-based violence in Rwanda; and including young people in a PR project in the UK. Commentaries on the cases are offered from two community co-researchers, alongside Groot and Abma.

Chapter 3: Blurring the boundaries between researcher and researched, academic and activist. In the Introduction, McFarlane and Roche explore three inter-related tensions: challenges for community researchers regarding their 'insider' status as it clashes with the integrity of research methods; difficulties in social relationships between academic and community partners as they navigate personal and project boundaries; and dilemmas about unanticipated action and change. Four cases describe issues concerning: data collection on sensitive matters from people known to a community researcher in Southern Africa; relationships of friendship between a doctoral researcher and young people in a UK PR project; working with people with intellectual disabilities as co-researchers in Denmark; and recognising a PhotoVoice project with people in an Irish hospital as both research and therapy.

Chapter 4: Community rights, conflict, and democratic representation. This chapter engages questions regarding issues of power and privilege within and across communities involved in PR projects. In the Introduction, speaking from her many years of conducting community-based research in marginalized communities in Bangladesh, Meghna Guhathakurta discusses issues of voice, positionality, intersectionality, and institutional power. These same themes are reflected in cases focused on: work with temporary foreign workers in Canada; persons with disabilities in rural Zambia; Inuit and *Qallunaat* (non-Inuit) community workers in Artic Canada; and Roma and non-Roma residents of a 'socially excluded locality' in the Czech Republic.

Chapter 5: Co-ownership, dissemination and impact. In the Introduction Gustaaf Bos and Tineke Abma present an overview of ethical issues relating to: complexities of co-ownership; participatory dissemination; and ensuring social impact. Four cases are presented, which include descriptions of: ethical disagreements over ownership of data and findings from community-based research in Tanzania; decolonizing research through documentary film in Canada; conflicting realities between young service-users and policy-makers in Finland; and the meaning of 'co' in co-writing between an academic researcher and his co-researcher with an intellectual disability in The Netherlands. Commentaries on the cases are offered from two community researchers, alongside Bos and Abma.

Chapter 6: Anonymity, privacy and confidentiality. The Introduction examines the notions of anonymity, privacy and confidentiality from the perspective of a legal scholar and participatory researcher, Kristin Kalsem, providing a thoughtful framing of the ways in which these concepts—so often assumed in traditional research contexts—are problematised in PR. The cases deal with: breaches of confidentiality following the theft of project equipment in Canada; challenges faced by Canadian researchers working within an institutional setting in guarding privacy while insuring the participants are able to contribute to the research process; negotiating anonymity within the context of community-based participatory research in Swaziland in southern Africa; and supporting the rights of participants with disabilities in Vietnam to get credit for their contributions to the research process—both in local contexts as well as in the global arena of academic publishing.

Chapter 7: Institutional ethical review processes. Drawing upon experience as both community-based participatory researcher and ethical review board member, in the

Introduction to this chapter Adrian Guta provides a review of the many challenges these two groups encounter in trying to understand and negotiate the specific issues PR presents, including conflicts of interest and coercion, the involvement of peer researchers, participant recruitment, and data management. Cases describe: issues raised for a research ethics committee chair when considering approval of a PR project relating to healthcare of migrants in Ireland; issues of parental consent for teenagers involved in a doctoral research project in the UK; concerns about participant burden and vulnerability in action research on palliative care in Ireland; and dilemmas in a UK PAR project involving mental health service users and providers.

Chapter 8: Social action for social change. In the Introduction, Erin Davis and Cathy Vaughan explore the action-orientation of PR by examining the relevant theoretical underpinnings, conceptualisations and impacts of power on action and social change outcomes. A framework drawing on the ethics of reflexivity and solidarity is discussed as a means to maximise the possibilities for action and change. Four cases cover issues relating to: challenges in trying to facilitate social action in a multi-ethnic neighbourhood in The Netherlands; how to ensure sustainability following PR on sexual and reproductive health of women with disabilities in the Philippines; researching for social change in rural livelihoods in a conservation area in rural South Africa; and conflicting views on socially just change in research on community-led responses to family violence in Australia.

We hope readers will find the material contributed by the many authors in this book as stimulating, educational and inspirational as we do.

References

Abma, T. A., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. (2018). *Participatory Research for Health and Social Well-Being*. Amsterdam, The Netherlands: Springer.

Aristotle. (350 BCE/1954). *The Nichomachean Ethics of Aristotle, translated by Sir David Ross*. London: Oxford University Press.

Arras, J. (1991). Getting Down to Cases: The Revival of Casuistry in Bioethics. *Journal of Medicine and Philosophy, 16 (1)*, 31-33.

Banks, S. (2012). Global Ethics for Social Work? A Case-based Approach. In S. Banks & K. Nøhr (Eds.), *Practising Social Work Ethics Around the World: Cases and Commentaries* (pp. 1-31). Abingdon: Routledge.

Banks, S. (2016). Everyday ethics in professional life: social work as ethics work, *Ethics and Social Welfare, 10*(1), 35-52.

Banks, S. (2018a). Cultivating resarcher integrity: Virtue-based approaches to research ethics. In N. Emmerich (Ed.), *Virtue Ethics in the Conduct and Governance of Social Science Research (Advances in Research Ethics and Integrity, Vol. 3)* (pp. 21-43). Bingley: Emerald Publishing.

Banks, S. (2018b). Practising professional ethical wisdom: The role of 'ethics work' in the social welfare field. In D. Carr (Ed.), *Cultivating Moral Character and Virtue in Professional Practices* (pp. not yet available). London: Routledge.

Banks, S., & Armstrong, A. (Eds.). (2012). *Ethics in community-based participatory research: Case studies, case examples and commentaries.* Durham and Bristol: Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement, available at: www.durham.ac.uk/beacon/socialjustice/ethics_consultation.

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., . . . Strachan, A. (2013). Everyday ethics in community-based participatory research. *Contemporary Social Science, 8*(3), 263-277.

Banks, S., & Butcher, H. (2013). What is community practice? In S. Banks, H. Butcher, A. Orton, & J. Robertson (Eds.), *Managing Community Practice: Principles: Policies and Programmes, 2nd edition* (pp. 7-30). Bristol: Policy Press.

Banks, S.,& Gallagher, A. (2009). *Ethics in professional life: Virtues for health and social care* Basingstoke: Palgrave Macmillan.

Banks, S., Hart, A., Pahl, K., & Ward, P. (forthcoming 2018). Co-producing research: a community development approach. In S. Banks, A. Hart, K. Pahl, & P. Ward (Eds.), *Co-producing research: A community development approach*. Bristol: Policy Press

Banks, S., Hart, A., Pahl, K., & Ward, P. (Eds.). (forthcoming, 2018). *Co-producing research: a community development approach*. Bristol: Policy Press.

Banks, S., Rifkin, F., Davidson, H., Holmes, C., & Moore, N. (2014). *Performing ethics: Using participatory theatre to explore ethical issues in community-based participatory research*. Durham, UK: Centre for Social Justice and Community Action, Durham University, www.dur.ac.uk/beacon/socialjustice/ethics_consultation/

Baron, M. (1995). *Kantian Ethics Almost Without Apology*. Ithaca, NY: Cornell University Press.

Bivens, F., Haffendden, J., & Hall, B. (2015). Knowledge, Higher Education and the Institutionalization of Community-University Research Partnerships In B. Hall, R.

Tandon, & C. Trembley (Eds.), *Strenghtening Community University Research Partnerships: Global Perspectives* (pp. 5-30). Victoria, Canada: University of Victoria.

Brydon-Miller, M. (2009). Covenantal ethics and action research: Exploring a common foundation for social research. In D. Mertens & P. Ginsberg (Eds.), *Handbook of social research ethics* (pp. 243-258). Newbury Park, CA: Sage.

Brydon-Miller, M., Greenwood, D., & Maguire, P. (2003). Why action research? *Action Research, 1*(1), 9-28.

Centre for Social Justice and Community Action. (2015). *Dilemmas cafés: a guide for facilitators*. Durham: Centre for Social Justice and Community Action, Durham University, available at: www.durham.ac.uk/beacon/socialjustice/ethics_consultation.

Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement. (2012). *Community-based participatory research: A guide to ethical principles and practice*. Bristol: NCCPE, available at: www.durham.ac.uk/beacon/socialjustice/ethics_consultation.

Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement. (2013). *Doing research together: How to make sure things are fair and no one is harmed*. Durham: Centre for Social Justice and Community Action, available at www.durham.ac.uk/socialjustice/ethics_consultation

Chambers, R. (1994). The origins and practice of participatory rural appraisal. *World Development, 22*(7), 953–969.

Chambers, T. (1997). What to Expect from an Ethics Case (and What it Expects from You). In H. Nelson (Ed.), *Stories and their limits: narrative approaches to bioethics* (pp. 171-184). New York and London: Routledge.

Chuwa, L. T. (2014). *African Indigenous Ethics in Global Bioethics: Interpreting Ubuntu*. New York: Springer.

Cooke, B., & Kothari, U. (Eds.). (2001). *Participation: the new tyranny?* London: Zed.

Cook, T. (2009). The purpose of mess in action research: Building rigour though a messy turn. *Educational Action Research, 17*(2), 277-291.

Coughlin, S., Smith, S., & Fernandez, M. (2017). *Handbook of Community-Based Participatory Research*. New York: Oxford University Press.

Crow, C., & Allan, G. (1994). *Community Life: An introduction to local social relations*. Hemel Hempstead: Harvester Wheatsheaf.

Eikeland, O. (2008). The ways of Aristotle: Aristotelian philosophy of dialogue, and action research (Studies in Vocational and Continuing Education, Vol. 5). Berlin: Peter Lang.

Fals Borda, O. (1987). The application of Participatory Action-Research in Latin America. *International Sociology, 2*(4), 329–347.

Fals Borda, O. (1988). *Knowledge and People's Power: Lessons with Peasants in Nicaragua, Mexico and Colombia*. New Delhi: Indian Social Institute.

Fals Borda, O. (2001). Participatory (action) research in social theory: Origins and challenges. In P. Reason & H. Bradbury (Eds.), Handbook of action research: Participative inquiry and practice (pp. 27-37). London: SAGE.

Fals Borda, O., & Rahman, M. (1991). *Action and knowledge: Breaking the monopoly with participatory-action research* New York: The Apex Press.

Flicker, S., & Guta, A. (2008). Ethical Approaches to Adolescent Participation in Sexual Health Research. *Journal of Adolescent Health, 42*(1), 3-10.

Freire, P. (1972). *The Pedagogy of the Oppressed*. London: Penguin.

Gaventa, J. (1993). The powerful, the powerless, and the experts: Knowledge struggles in an information age. In P. Park, M. Brydon-Miller, B. Hall, T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp. 21-40). Westport, CT: Bergin and Garvey Press.

Gbadegesin, S. (2005). Origins of African Ethics. In W. Schweiker (Ed.), *The Blackwell Companion to Religious Ethics* (pp. 413-422). Oxford: Blackwell.

Gyekye, K. (2010). African Ethics *Stanford Encyclopedia of Philosophy*: http://plato.stanford.edu/entries/african-ethics/, accessed December 2010.

Hall, B. (1975). Participatory Research: An Approach for Change. *Convergence, 8*(2), 24-32.

Hall, B. (2005). In From the Cold? Reflections on Participatory Research From 1970 - 2005. *http://www.participatorymethods.org/resource/cold-reflections-participatory-research-1970-2005*.

Hall, B., & Tandon, R. (2018). From action research to knowledge democracy : Cartagenia 1997- 2017. *Revista Colombiana de Sociología, 41*(1), 227-236.

Held, V. (2006). *The Ethics of Care: Personal, Political, and Global*. Oxford: Oxford University Press.

Heron, J., & Reason, P. (2000). The practice of cooperative inquiry: research 'with' rather than 'on' people. In P. Reason & H. Bradbury (Eds.), *Handbook of Action Research* (pp. 179-188). London: Sage.

Hilsen, A. I. (2006). 'And they shall be known by their deeds': Ethics and politics in action. Action Research, 4(1), 23-36.

Horton, B. (1993). The Appalachian land ownership study: Research and citizen action in Appalachia. In P. Park, M. Brydon-Miller, B. Hall, T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (85-102). Westport, CT: Bergin and Garvey Press.

International Collaboration for Participatory Health Research (ICPHR). (2013). *Position Paper No. 1: What is Participatory Health Research?* Berlin: ICPHR, www.icphr.org/position-papers.

Jonsen, A., & Toulmin, S. (1988). *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley: University of California Press.

Kant, I. (1785/1964). *Groundwork of the Metaphysics of Morals,* trans H. Paton. New York: Harper and Row.

Keown, D. (2005). Origins of Buddhist Ethics. In W. Schweiker (Ed.), *The Blackwell Companion to Religious Ethics* (pp. 286-296). Oxford: Blackwell.

Kuczewski, M. (1997). *Fragmentation and Consensus: Communitarian and Casuist Bioethics*. Washington, D.C.: Georgetown University Press.

Levinas, E. (1989). Ethics as First Philosophy, translated by Seán Hand. In S. Hand (Ed.), *The Levinas Reader* (pp. 75-87). Oxford: Blackwell.

Li, C. (1994). The Confucian Concept of *Jen* and the Feminist Ethics of Care: A Comparative Study. *Hypatia: A Journal of Feminist Philosophy, 9*(1), 70-89.

Løgstrup, K. (1997). *The Ethical Demand*. Notre Dame, IN: University of Notre Dame Press.

Love, K. (2011). Little known but powerful approach to applied research: community-based participatory research. *Geriatric Nursing, 32*(1), 52-54.

Manzo, L., & Brightbill, N. (2007). Towards a participatory ethics. In S. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: connecting people, participation and place* (pp. 33-40). Abingdon: Routledge.

Merrifield, J. (1993). Putting scientists in their place: Participatory research in Environmental and occupational health. In P. Park, M. Brydon-Miller, B. Hall, T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp. 65-84). Westport, CT: Bergin and Garvey Press.

Mill, J. S. (1863/1972). Utilitarianism *Utilitarianism, On Liberty, and Considerations on Representative Government,* London: Dent.

Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L., & Rogers, J. (2002). Ethical dilemmas in participatory action research: a case study from the disability community. *Health Education and Behaviour, 29*(1), 14-29.

Mitscherlich, A., & Mielke, F. (1949). *Doctors of infamy: the story of the Nazi medical crimes*. New York: Schuman.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research* Washington, DC: Department of Health, Education and Welfare, www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html.

Nelson, H. (Ed.) (1997). *Stories and their limits: narrative approaches to bioethics*. New York and London: Routledge.

Noddings, N. (1984). *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley and Los Angeles: University of California Press.

Park, P., Brydon-Miller, M., Hall, B., & Jackson, T. (1993). *Voices of change: Participatory research in the United States and Canada*. Westport, CT: Bergin and Garvey Press.

Plant, R. (1974). *Community and Ideology*. London: Routledge and Kegan Paul.

Reason, P., & Bradbury, H. (2008). Introduction. In P. Reason & H. Bradbury (Eds.), *The Sage Handbook of Action Research: Participative Inquiry and Practice* (pp. 1-10). London: SAGE.

Reverby, S. (Ed.) (2000). *Tuskegee's truths: Rethinking the Tuskegee syphilis study*. Chapel Hill: University of North Carolina Press.

Schrag, Z. M. (2010). *Ethical imperialism: Institutional review boards and the social sciences*, 1965-2009. Baltimore, MD: The Johns Hopkins University Press.

Singer, P. (2011). *Practical Ethics, 3rd edition*. Cambridge: Cambridge University Press.

Smith, L. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.

Snow, N. (Ed.) (2015). *Cultivating Virtue: Perspectives from Philosophy, Theology, and Psychology* Oxford: Oxford University Press.

Somerville, P. (2016). *Understanding Community: Politics, Policy and Practice, 2nd edition*. Bristol: Policy Press.

Swantz, M.-L. (1974). *Participant Role of Research in Development (unpublished paper)*. Dar es Salaam, Tanzania: Bureau for Resource and Land Use Productivity, University of Dar es Salaam

Tandon, R. (Ed.) (2005). *Participatory research: Revisiting the roots*. New Delhi: Mosaic Books.

Thomas, T. and Narayanan, P. (2015) Introduction: powering knowledge from the margins. In T. Thomas and P. Narayanan (Eds) *Participation Pays: Pathways for post-2015* (pp. 1-4). Rugby, UK: Practical Action Publishing.

Toulmin, S. (2001). *Return to Reason*. Cambridge, MA: Harvard University Press.

van den Hoonaard, W. C. (2011). *The seduction of ethics: Transforming the social sciences.* Toronto: University of Toronto Press.

Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (Eds.). (2017). *Community-Based Participatory Research for Health: Advancing Social and Health Equity, 3rd Edition*. San Francisco: Jossey Bass.

World Medical Association. (1964/2013). *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects,* https://www.wma.net/what-we-do/medical-ethics/declaration-of-helsinki/.