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Introduction: Encounters with Systems Within Which Critical Research Is Conducted

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How can critical researchers simultaneously work within and resist systems and institutions that often do not comprehend critical methodologies? The aim of this introduction is to set the scene for the stories from the field featured in this section. These stories focus on how critical research is shaped by researchers' encounters with systems. Each chapter in this section tells a story of encounters with an ethics committee or committees. But many other systems are also encountered by critical researchers, and the chapters in this section raise questions about how critical researchers navigate hierarchal power relations inherent in the variety of systems and institutions within which critical research is conducted. These systems and institutions include hospitals and larger healthcare organisations, non-governmental organisations (NGOs), schools, and universities. Many of these systems and institutions have formal policies on research with a range of specificity and complexity all the way up to an ethics committee.

Ethics committees have many different names and specifiers in international settings. For example, in Canada they are known nationally as 'research ethics boards' (REBs), and within US academic institutions they are commonly known as 'institutional review boards' (IRBs) (van den Hoonaard, 2011). In Aotearoa/New Zealand, there are the Health and Disabilities Ethics

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Committees (Ministry of Health, 2017). Like some other nations, these health-only ethics committees work in parallel with ethics committees of tertiary institutions, with evolving boundaries around which kinds of research are reviewed by which committee (Ministry of Health, 2017). In England specifically, the term 'research ethics committee' has been formally adopted by Research Councils (e.g., Economic & Social Research Council, n.d.) and the National Health Service Health Research Authority (n.d.). The label of 'research ethics committee' is also applied in South Africa within the national guidelines on ethical health research (Department of Health, 2015). These names and constitutions have solidified over recent decades but will continue to shift under changing climates of research, and so we use the shorthand label of ethics committee.

Ethics committees are the lynchpin of ethics approval assemblages (Reubi, 2010). These assemblages of bureaucratic processes are known also as 'the ethics regime' in some critical scholarship (see van den Hoonaard, 2011). The approval processes of ethics committees are not necessarily equivalent across countries, institutions, or disciplines. But health and social researchers are now almost universally required to go through a process of seeking approval for research, and a certain neoliberal bureaucracy has become normalised in academic research involving human participants (van den Hoonaard, 2011). This bureaucracy, as Denzin and Giardina (2007, p. 27) highlight, may reflect a troubling shift in which 'there seems to be a move away from protecting human subjects and toward increased monitoring and censuring of projects that are critical of right-wing ideologies'.

In this introduction we draw on four thematic distinctions that underlie the stories shared in this section. These distinctions help to demonstrate some of the very real implications for critical researchers when inevitably working within systems and institutions. The first of these distinctions is a comparison between the realms of research that are broadly labelled as health research and social research. Within both of these realms we also highlight a second distinction: the contrast between research and practice. To practice can refer to the provision of healthcare and other caregiving professions. But to practice can also refer to critical praxis: the politically conscious work done to challenge the status quo through radical ethical methods (Denzin & Giardia, 2007). The third distinction we make is between risk avoidance models of ethics bureaucracy and relational models of ethical researching that support situational adaptation in the field. In the fourth and final distinction we return to the abrasion between critical research and biomedical models of research. We also summarise recommendations that arise across the chapters in this section by outlining how the authors speak to working within, and resisting, constraining research ethics systems that critical researchers encounter.

Regardless of the global location or name of a particular ethics committee, health and social researchers commonly become all too familiar with the process of proposing research, receiving feedback, and amending or defending the proposed protocol. For critical researchers, the ethics review process is often marred by a disconnection between critical research methods and the research ethics assemblage, a concern that features across the stories in this section and subsequent sections. These stories are reflexively critical of the authors' own research practices whilst also revealing ways in which critical research can come to be constrained through the ethics review processes. As Denzin and Giardia (2007) note, ethics committees have a reputation for being 'routinely ignorant of or unsympathetic to new developments in interpretive approaches' (p. 13). This misunderstanding of critical research often spills over into the encounters critical researchers' experience when accessing or working within systems other than the ethics committee (e.g., the hospital that is required to follow research 'governance' or the NGO with diverse formal or informal responses to research).

Another diverse but central aspect of the ethical approval assemblage is the ethics codes and principles that serve as the benchmarks used by ethics committees when reviewing proposed research. These codes include national projects such as the 'ethical standards' determined by the National Ethics Advisory Committee in Aotearoa/New Zealand (Ministry of Health, 2017), Canada's Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014), and the principles outlined in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978) and enacted by the 'Common Rule' procedures that are applied by IRBs in the US (see also van den Hoonaard, 2011). Denzin and Giardia (2007) critique the Belmont Report's three principles for drawing on conflicting moral philosophies and for being decontextualised from local settings and international declarations such as the United Nations (2006) Convention on the Rights of Persons with Disabilities. The three principles are respect (commonly achieved by informed consent processes), beneficence (commonly achieved by attempting to predict a balance of useful outcomes outweighing risk of harm), and justice (attempting fairness in participation and distribution of benefits). These closely reflect the four principles of biomedical research ethics proposed by Beauchamp and Childress (2001): autonomy, beneficence, non-maleficence, and justice. Likewise, there are international principles that speak to the ethics of healthcare and health research such as the Hippocratic Oath and the Declaration of

Helsinki (World Medical Association, 1964). But what ethical challenges occur when these principles are applied to critical research on health or social issues?

Critical Research on Health or Social Issues

The chapters in this section of the handbook feature stories on a range of critical research projects on health and social issues. There is no simple distinction between health research and social research because health research is socially located and social research so often addresses well-being. But what is evident in these stories is how biomedical research governance has 'crept' (Haggerty, 2004) into critical research. Pam Carter, Sarah Chew, and Elizabeth Sutton (2018, this section) discuss their experiences of the 'pseudo-ethics' of the English research governance of clinical trials that has crept into a requirement that critical researchers engage in tangentially relevant training. Natalie Edelman (2018, this section) critically analyses her experience of multiple ethics approvals from a university, the UK health system, and an NGO all of whom had to review and approve and thus shape her research with a 'vulnerable' group of participants who were users of illicit drugs. This exemplifies the important questions about which health and social issues are considered 'problematic' and by whom. Likewise, Tracey Feltham-King, Yolisa Bomela, and Catriona Macleod (2018, this section) provide a Foucauldian perspective on their experiences of recruiting 'problematised' subjects (i.e., subjects in the discursive sense, not just people subjected to biomedical research). Their work on teenage pregnancy in South Africa again involved multiple research ethics systems in gaining approval from a university ethics committee and a state healthcare organisation; this necessitated navigating contradictory social constructions of teenage pregnancy and ongoing challenges in recruiting women through gatekeepers within the healthcare organisation.

The later chapters in this section move outside the regulatory realms of clinical research governance but continue to detail encounters with systems underpinned by the 'ethics creep' (Haggerty, 2004) of objectivist biomedical research into the diverse fields of critical research. Jessica Cockburn and Georgina Cundill (2018, this section) outline transdisciplinary approaches to research in sharing their research on environmental stewardship in South Africa. Transdisciplinary research requires a participatory form of research that is inherently social, often action oriented, and again requires encounters with multiple research ethics systems in working with community organisations whilst being governed by academic research ethics committees. Their work speaks to the wider project of critical research in asking who benefits from research and what improvements communities desire.

Catherine Smith, Emma Tumilty, Peter Walker, and Gareth Treharne (2018, this section) question the differentiation between the ethical attention paid to human participants and non-human animal participants with a focus on domestic and service dogs. Research on the interactions of humans with other animals is by no means new but it frequently foxes disconnected research ethics systems that are attuned to protecting either human participants or non-human animals subjected to experimental methods. In asking what research ethics might look at within a system that could support an integrated ethical approach to human–animal interaction research, Smith et al.'s work highlights some of the intricacies of research ethics systems and assumptions about sentience and ethics. Will van den Hoonaard (2018, this section) closes the section with a focus on the state of sociological research and argues that such research inherently is, or should be, critical. Drawing on his research alongside Canadian REBs and an analysis of the ethics code laid out in the Canadian Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2014), van den Hoonaard provides a tour of the facets of critical research that raise ethical challenges in a range of examples from health and social research.

Research as Praxis but Distinct from Practice

Engaging in research is distinct from engaging in practice when fulfilling roles such as a health professional or NGO worker. In addition, critical research is a form of praxis in the Marxist tradition and more recent interpretations (see, e.g., Barnard, 1990; Lazar, 2005). Critical research moves beyond the model of research as merely serving to inform evidence-based practice, although healthcare practice can itself be a fruitful focus of critical research. Health professional practice and health research praxis have ethics systems that are often organised around a split between 'clinical governance' and 'research governance' (Carter et al., 2018, this section). But health professional practice and research praxis might be described as sharing a goal to change the well-being of an individual or a community. The methodologies applied by the authors in this section of the handbook include a range of qualitative and ethnographic approaches leading to a multiplicity of perspectives on research embedded in healthcare practice and other social settings.

Carter et al. (2018, this section) analysed how good clinical practice training is a form of 'ceremonial conformity' (Dingwall, 2008). This semi-regulated and very brief form of training is commonly required of health researchers who are not employed by the UK National Health Service but is not about inducting researchers into the world of healthcare practice. Instead, it is a way of attempting to ensure that all researchers know the ethics and bureaucracy of a 'good' clinical trial regardless of their own intended methodology. Edelman (2018, this section) reflects on the pragmatic aims of her research in which she explored the reasons women with 'problematic drug use' do not attend sexual health services. Edelman's aim was not directly to provide the women with a clinical service, although through critical research it is possible to reorient services to better meet the lives of marginalised groups. Feltham-King et al. (2018, this section) reflect on their research praxis in experiencing gatekeeping of pregnant teenagers receiving care in a clinical setting that medicalises and problematises young women. The aim of the research was not to provide a second layer of care for the young women but this was a presumption that needed to be corrected and which shaped the accessibility of participants. Likewise, van den Hoonaard (2018, this section) outlines critical sociological praxis and reiterates many of the broad concerns critical researchers have about how their research is viewed by ethics committees as a colonising bureaucracy.

Cockburn and Cundill (2018, this section) share their experiences of transdisciplinary praxis including the pre-proposal phase during which academics and community members discuss the problems both parties want to address. Building relationships and opening the conversation about what participatory research might achieve is a form of praxis as are the ongoing phases of transdisciplinary research and many engaged forms of participatory research. Smith et al. (2018, this section) explore the place of interactions between dogs and humans. This raises questions about how researchers might reconceptualise sentience and attend to signs of assent or its absence during research with those who cannot verbalise or necessarily understand conventional notions of consent to participate in research.

Reactive Bureaucracy Versus Proactive Ethics

Another tension across the chapters in this section is the way that ethics committees as we know them arose in reaction to 'unethical' research with the aim of avoiding the same injustices being repeated (see Denzin & Giardia, 2007; Neill, 2016; Smith, 2012; van den Hoonaard, 2011). Rather than instilling ethics in a way that is appropriate for all forms of research, the ethics systems that have emerged enforce a constrained set of recommended research procedures to avoid unethical research. Moreover, authors in this section argue that these procedural ethics have become a barrier to proactive ethics during the journey of critical research. Although not an absolute beginning to unethical research, it is possible to trace the current state of concerns about research ethics to the atrocities of research carried out on prisoners in Nazi death camps in the name of science and in ways that apply many of the principles and narratives of experimental research as being for the benefit of the people (Smith, 2012). Medicine, psychology, sociology, and other disciplines all have their own subsequent fables of unethical research that are cited as warnings and woven into the fabric of ethics systems. Two of the fabled examples of unethical research in psychology are somewhat ironic as Zimbardo and Milgram were attempting to understand how 'regular' people could be responsible for wartime atrocities using a mock prison or attempting to convince people they were punishing someone with deadly electric shocks (see Neill, 2016, for details of these fabled studies). The fable of unethical research has a corollary that researchers need to consider the balance of harm enacted against knowledge gained. The argument goes that if the research enhances our understanding of issues such as compliance and torture then the gain in knowledge might be said to be worth it. But who does the resulting knowledge serve? When we ask who benefits from research and from the knowledge that is generated and disseminated, then we can often be left with the concerning realisation that commonly only academia and academics benefit from research findings whilst individual participants or communities bear the brunt of harm from unethical research practices.

The chapters in this section all speak to some of the ways that research ethics are upheld by critical researchers resisting the rigid ethical procedures that originate from biomedical research by engaging in proactive ethics, also known as micro-ethics, everyday ethics, ethical mindfulness, or applying an ethical sense (see in particular Carter et al., 2018, this section; Cockburn & Cundill, 2018, this section). In the same way that critical researchers often cannot know the scope of their findings before the research is undertaken, it is not always possible for critical researchers to know what ethical challenges they might face. These challenges cannot be categorised in the same way as can 'adverse events' in pharmaceutical research, and yet that very model is all too often applied to critical research, as emphasised by Carter et al. (2018, this section).

In many of the chapters in this section, the authors also discuss research with people who might be labelled 'vulnerable' and thus problematised. This includes people with moderate literacy (Carter et al., 2018, this section), women who use illicit drugs and are likely to be inebriated during participation (Edelman, 2018, this section), pregnant teenagers (Feltham-King et al., 2018, this section), non-human animals who cannot speak for themselves (Smith et al., 2018, this section), and researchers who stick to ethical principles in the face of legal action (van den Hoonaard, 2018, this section). Research with vulnerable people rightly deserves ethical mindfulness in order to avoid exploitative procedures. But critical researchers must also resist insinuations that: (1) all vulnerable participants are better off not taking part in research and (2) absolutely all participants are vulnerable merely because they are not privy to the training afforded to researchers. Can researchers ever bridge the divides between communities with a different perspective on research, sometimes a deep and understandable distrust of research following historical injustices under colonialism (Smith, 2012)? Working with communities and from within communities to bridge these gaps in familiarity with what research involves and can achieve is particularly pertinent in research using participatory or emancipatory critical methods. This bridging is another theme across many of the chapters in this section and lends itself to making recommendations that may transfer from the experiences of the individual authors of chapters.

Recommendations for Ethical Critical Research as Distinct from Objectivist Research

The chapters in this section have a wealth of recommendations ranging from small procedural insights to bigger picture insights into the aims and value of critical research. One feature of critical research that stands out in the stories shared in this section is a sense of being an outsider to research ethics systems that are not set up to recognise such approaches to research. Carter et al. (2018, this section) note that as critical researchers, we often have to self-regulate our ethics and our own well-being in the face of ethical challenges. This might sound like a lonely existence but Edelman (2018, this section) notes that one critical researcher's ethical realisations can have ripple effects locally, and these ripples are widened by the stories shared in this handbook.

Another way of facilitating the ripple effect of ethical realisations is to form an epistemic community of practice, as highlighted by Cockburn and Cundill (2018, this section). How might decentralised communities of research practice be organised? Perhaps they might best be formed for an individual project (see Treharne & Riggs, 2015), or perhaps they might be coordinated around a discipline or particular method. Perhaps communities of research practice might be local to a particular place or perhaps they might include national or international colleagues. And who might these communities of practice include? In addition to academic colleagues, communities of research practice are a way of applying participatory approaches to critical research included in many of the studies featured in the chapter in this section.

When formal community engagement is part of an approach, it comes with many challenges. Firstly, how can critical researchers get started with community engagement? Cockburn and Cundill (2018, this section) discuss how ethics systems do not typically account for a consultation phase before the 'main' research phase. Who to consult is another challenge of community engagement addressed by Edelman (2018, this section) in describing how she worked with two experts-by-experience. Edelman also noted the difficulties of maintaining engagement over time which might be heightened in her work with women who use illicit drugs. The issue of engagement over time also applies in all forms of community engagement when the often slow pace of research becomes evident, coupled with the reliance on finite and insecure sources of funding that require a researcher to plan for the ethical conclusion to a line of research when a community may pin its hopes on long-term research or solutions that are not forthcoming.

Having established that the homogenising objectivist biomedical models of research upon which research ethics system are built are not always fitting for critical research, what guidance do the chapters in this section offer to critical researchers who are about to submit an application to an ethics committee or to those who have received approval but face challenges in the field? Carter et al. (2018, this section) discuss how they critiqued homogenising terminology in their answers to a 'study outcome monitoring form'. Acts of protest on an ethics application form might delay an individual application but an organised form of petition might be a better way of supporting critical researchers who encounter that same system.

Many of the chapters in this section raise hopes for ethics systems that can account for community consultation and critical methods. Likewise, Smith et al. (2018, this section) discuss how new forms of ethics review might be necessary for research on human–animal interactions, and if that can be achieved in a way that simplifies existing bureaucratic confusion then it will be a valuable model for enacting progressive principles. Edelman (2018, this section) raises questions about the ethical requirement of conducting studies that are methodologically sound. This notion of soundness or quality is often the concern raised by research ethics systems formed of people with limited knowledge of critical research. There are ways of considering the quality of qualitative research (see Treharne & Riggs, 2015) but there are many complexities in taking a critical perspective on the issue of methodological soundness without forming a new homogenising of critical research that stifles methodological creativity and ethical responsiveness.

Conclusions to This Introduction

Critical researchers encounter a nexus of systems that shape research. At the centre of this nexus are ethics committees that draw on systematised ethics codes and mandate how the principles within those codes should be met. But a wider assemblage comes together to form an ethics system that claims oversight of research often with many unique features in response to historical atrocities, national rulings, and local idiosyncrasies. There is no one universal ethics code but the chapters in this section demonstrate some common concerns and unique learning in relation to four organising themes that help to characterise critical research and achieve ethical critical research. There is a subtle distinction between critical health research and critical social research. Both aim to challenge the status quo, but health and social research may call for distinct locations that bring distinct forms of research governance to be navigated. Within both health and social research there is a need to contrast research and practice, but the two processes intertwine when critical research is conceptualised as praxis or engages with systems of 'routine' practice such as healthcare, teaching, and NGO work. Many ethics committees and other systems apply a risk avoidance model of ethics bureaucracy; in contrast, the authors in this section raise a need for situational adaptation in the field when conducting critical research and call for relational models of ethical researching. The inevitable relationality of critical research praxis is perhaps harder to codify than 'good' biomedical research. The stories shared in this section of the handbook serve as good examples to stimulate critical engagement with ethical issues by critical researchers working to adapt ethically to the systems they encounter.

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