The point is, in short, to make a difference – however modestly, however partially, however much without either narrative or scientific guarantees.

Donna Harraway

A CAT'S CRADLE OF FEMINIST AND OTHER CRITICAL APPROACHES TO PARTICIPATORY RESEARCH

A CAT'S CRADLE OF FEMINIST AND OTHER CRITICAL APPROACHES TO PARTICIPATORY RESEARCH

Niamh Moore



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Also in this series

CONNECTED COMMUNITIES Foundation Series

oday we are increasingly seeing calls for universities to collaborate with communities in designing and conducting research. While such calls are to be welcomed they tend to suffer from a historical blind-spot that ignores the fact that research collaboration – partnerships, participation (call it what you will) – is a deep and powerful research tradition that dates back beyond the recent emergence of calls for 'co-produced' knowledge.

This series of reviews developed as part of the AHRC's Connected Communities Programme, sets out to make visible some of these traditions of collaborative research. In doing so, the series aims to:

- help those who are new to the field to understand the huge wealth of history and resources that they might draw upon when beginning their own research collaborations;
- help those who seek to fund and promote collaborative research to understand the philosophical and political underpinnings of different traditions; and
- support those working in these traditions to identify points of commonality and difference in their methods and philosophies as a basis for strengthening the practice of collaborative research as a whole.

Research collaboration is a deep and powerful research tradition that dates back beyond the recent emergence of calls for 'co-produced' knowledge.

The eight reviews in the series were developed to provide eight very different 'takes' on the histories of collaborative research practices in the arts, humanities and social sciences. They do not pretend to be exhaustive, but to provide a personal perspective from the authors on the traditions that they are working within. As we worked together as a group to develop these, however, a number of commonalities emerged:

- 1. A critique of the mission-creep of scientific knowledge practices into the social sciences and humanities, and of the claims to produce universally valid forms of knowledge from specific limited institutional, cultural and social positions.
- 2. A commitment to creating research practices that enable diverse experiences of life and diverse knowledge traditions to be voiced and heard.
- **3.** A resistance to seeing research methods as simply a technocratic matter; recognising instead that choices about how, where and with whom knowledge is created presuppose particular theories of reality, of power and of knowledge.
- **4.** A commitment to grapple with questions of power, expertise and quality and to resist the idea that 'anything goes' in collaborative research and practice. There are better and worse ways of developing participation in research practice, there are conditions and constraints that make collaboration at times unethical.

At the same time, a set of names and events recur throughout the reviews: John Dewey, Paolo Freire, Raymond Williams, Donna Haraway appear as theorists and practitioners who provide powerful philosophical resources for thinking with. Critical incidents and moments reappear across the reviews: the rise of anti-colonial movements in the 1950s and 1960s, of second wave feminism and critical race theory in the 1960s and 1970s; of disability rights movements in the 1970s and 1980s; of post-human and ecological analyses in the 1990s and 2000s. Read as a whole, these reviews demonstrate the intellectual coherence and vibrancy of these many-threaded and interwoven histories of engaged scholarship and scholarly social action.

The first of the reviews, by **Kevin Myers** and **Ian Grosvenor**, discusses the long tradition of 'history from below' as a collaborative enterprise between researchers, archivists, curators, teachers, enthusiasts, local historians, archaeologists and researchers. They discuss the emergence of the 'professional historian' alongside the rise of the nation state, and the way in which this idea was challenged and deepened by the emergence of activist histories in the mid-20th century. They investigate the precedents set by the rise of groups such as the History Workshop movement and trace their legacies through a set of case studies that explore feminist histories of Birmingham, disabled people's histories of the First World War and the critique of white histories of conflict emerging from the work of black historians and communities.

Two of the reviews explore currents within participatory and critical research traditions. Niamh Moore explores these traditions through the lens of feminist philosophies and methodologies, while Tom Wakeford and Javier Sanchez Rodriguez explore the history of participatory action research (PAR) and its ties to social movements outside the academy.

Niamh Moore's review highlights the strategic contributions made to participatory research through the traditions of feminist and indigenous methodologies. Drawing on Donna Haraway's metaphor of the cat's cradle, Moore explores the way that these different traditions have learned from each other, fed into each other and been in (productive) tensions over the years. Importantly, she makes visible the common threads of these traditions, including a concern with questions of power, matters of voice, agency and empowerment and reflexivity. She identifies examples that include: popular epidemiology and women's health; the controversies and emerging insights arising from the publication of the book 'I Rigoberta Menchú' (a collaboration between Rigoberta Menchú, a Guatemalan activist and Peace Prize winner and anthropologist Elisabeth Burgos-Debray); and the online Mukurtu platform for sharing and curating community stories.

Wakeford and Sanchez Rodriguez's review is written from the position of individuals who situate themselves as both activists and academics. From a perspective both inside and outside the academy, they make visible the traditions of participatory action research that have evolved in social movements and their interaction with academic knowledge. They explain how PAR emerged as a practice that seeks to intervene and act on the world through disrupting assumptions about who has knowledge, and by building intercultural dialogue between those whose interests have historically been marginalised and those experts and institutions in dominant positions. They discuss the contributions of Paolo Freire and Orlando Fals Borda, as well as the emergence within universities of centres for Action Research and indigenist approaches to research before exploring recent examples of PAR from the Highlander Folk School in the US, to the Cumbrian Hill Farmers post Chernobyl, to questions of Food Sovereignty in India (amongst others).

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Central to many attempts to build collaborative research practices is a turn towards the arts and arts methodologies as a means of engaging with different forms of knowledge.

Central to many attempts to build collaborative research practices is a turn towards the arts and arts methodologies as a means of engaging with different forms of knowledge. Such a turn, however, can often overlook the distinctive and sustained tradition within contemporary arts of reflecting upon the question of how publics can come to participate in arts practices. Our series therefore includes two reflections on this question from different perspectives:

First, **Anne Douglas'** review offers a 'poetics of participation in contemporary arts', locating the turn to participation in contemporary arts within a wider history of 20th and 21st century arts and politics. She highlights the huge range of work by artists and arts co-operatives who are seeking to make work through participatory forms, and the deep scholarly tensions and debates that surround these practices. She explores through this rich history the debates over whether participation has become instrumentalised; whether the art/life divide should be preserved or eroded; the links between participatory aesthetics and cybernetic ethics; and the capacity for participation to challenge alienation and neoliberalism. Recognising arts practice as itself a form of research and inquiry into the world, she concludes with a set of powerful reflections on the role of the freedom to improvise and the importance of participation as a moment of care for and empathy with the other.

Second, **Steve Pool**, community artist and academic, reflects on the related but different traditions of community arts as they might relate to social science research. He considers what researchers in the social sciences might need to know and understand about artistic traditions if they desire to mobilise arts practice within the social sciences. He discusses the increasing democratisation of tools for making, the potential for them to open up artistic practice to publics as well as the importance of recognising that such practices are part of wider traditions and philosophies about the value and purpose of art. In particular, he discusses the tension between the idea of artistic autonomy – art for art's sake – and artistic democracy – the democratic creativity of all individuals. He foregrounds the way in which the community arts movement was also allied to a wider politics that moved towards cultural democracy and explores the contemporary practice of artists working in and with social science through examples such as Nicola Atkinson's 'Odd Numbers' and the Community Arts Zone's 'Being Cindy Sherman'.

More recent traditions of collaborative research characterise our final three reviews which take on, respectively, the way that design theory and practice are playing an important role in reshaping society, products and services; the emergence of new technologies to facilitate new forms of collaboration; and the increasingly urgent injunction to develop research approaches that enable collaboration with the 'more-than-human' others with whom we share the planet.

Theodore Zamenopoulos and Katerina Alexiou discuss the field of co-design and its underpinning theories and methods. They argue that Design as a process is always concerned with addressing a challenge or opportunity to create a better future reality, and explore how co-design has evolved as a process of ensuring that those with the life experiences, expertise and knowledge are actively involved in these making new tools, products and services. They observe how the participatory turn in this field has been concerned with both changing the objects of design – whether this is services or objects – and with the changing processes of designing itself. They highlight four major traditions and their distinctive approaches, before exploring the politics and practices of co-design through case studies of work.

Chiara Bonacchi explores how the internet is enabling new forms of collaborative knowledge production at a massive scale. She locates this discussion in the traditions of citizen science and public humanities, and examines how these have been reshaped through the development of hacker communities, open innovation and crowd-sourcing. In this process, she discusses the new exclusions and opportunities that are emerging through the development of projects that mobilise mass contribution. She examines the cases of MicroPasts and TrowelBlazers that demonstrate how these methods are being used in the humanities. In particular, she explores the ethical questions that emerge in these online collaborative spaces and the need for a values-based approach to their design.

Tehseen Noorani and Julian Brigstocke conclude the series with an exploration of the practice and philosophy of 'more-than-human research' which seeks to build collaborative research with non-human/ more-than-human others. They discuss its philosophical foundations in pragmatism, ecofeminism and indigenous knowledge traditions and identify some of the theoretical and practical challenges that are raised when researchers from humanist traditions begin to explore how to 'give voice' to non-human others. In the review, they consider how researchers might expand their 'repertoires of listening' and address the ethical challenges of such research. To ground their analysis, they discuss the work of the Listening to Voices Project as well as accounts of researcher-animal partnerships and projects that draw on Mayan cosmology as a means of working with sustainable forestry in Guatemala.

This collection of reviews is far from exhaustive. There are other histories of collaborative research that are under-written here – there is much more to be said (as we discuss elsewhere) on the relationship between race and the academic production of knowledge. Each of these accounts is also personal, navigating a distinctive voiced route through the particular history they are narrating.

Despite this, at a time when politics is polarising into a binary choice between 'expert knowledge' and 'populism', these reviews show, collectively, that another way is possible. They demonstrate that sustained collaborative research partnerships between publics, community researchers, civil society, universities and artists are not only possible, but that they can and do produce knowledge, experiences and insights that are both intellectually robust and socially powerful.

Professor Keri Facer Dr Katherine Dunleavy

Joint Editors: Connected Communities Foundation Series

ABOUT THE AUTHOR

Niamh Moore is an interdisciplinary feminist scholar based at the University of Edinburgh. She has written *The Changing Nature of* Eco/Feminism: Telling Stories of Clayoquot Sound (2015), and has published an online archive of oral history interviews which the book draws on (http://clayoquotlives.sps.ed.ac.uk). She has also co-authored The Archive Project: Archival Research in the Social Sciences (2017) and co-edited Participatory Research in More-than-Human Worlds (2017). She has been engaged in participatory research for over ten years. Her work spans ecofeminist theory and activism, community food growing, grassroots community archiving and involves a wide-range of methods, including oral history, qualitative interviewing, ethnography, participatory research, and using creative methods.

BIOGRAPHICAL NOTE

I am a feminist researcher, working now at the University of the Edinburgh. My first significant encounters with participatory practice came through researching and participating in feminist activism – and, in particular, through the practices of consensus-building and the non-violent philosophy and activism which informed an ecofeminist peace camp in Clayoquot Sound on the west coast of Canada in the early 1990s, where protestors were campaigning against clear-cut logging of temperate rainforest. I was impressed with the organisation of the camp, which was visited by over 1200 people over the summer of 1993, with over 800 arrested for non-violently blockading the road into the logging area. While my own research was ethnographic, and involved recording oral histories of activists, it was not participatory. 1 Later I encountered the Young Women's Project and The Proud Trust (TPT) in Manchester, in the North West of England. It was on the TPT allotment that I felt a sense of continuity, even if a different kind of activism, in this muddy growing together of vegetables and young and older lesbians and bi women. I became fascinated by the participatory practices of feminist youth work, about which I knew nothing, despite my long years at that stage reading about feminism. These participatory practices felt so tangible at the allotment, but I was also struck by how often it might appear as if nothing was actually going on, often barely even vegetables, but, at the same time, by how much 'invisible work' was happening.2 It seemed to me that one of the first jobs of TPT was in fact to enable young people to participate, to teach participation, to provide skills, and then, and only then, could young people actively choose to participate, or meaningfully choose to refuse to participate. I was pleased then to become more actively involved with TPT and related projects – becoming involved in Feminist Webs (www.feministwebs.com), an open-ended project about histories of feminist youth work, where I provided oral history training, advice about creating an archive, and together we created a book, as well as exhibitions, a zine, and a tour of the archive. I have continued to be involved with TPT and a range of follow on projects (eg., LGBT Youth North West 2014), and now as a trustee. I enjoy the challenges of working collaboratively, of being challenged, of the ongoing learning from how others work together, the, unavoidable, being pushed out of comfort zones, of having questions posed that I would not, and could not, have asked myself, on my own, of the surprise of what it is possible to produce together, of being able to contribute my skills as a researcher, sharing methods skills, oral history and interviewing, of participatory community archiving and the importance of creating archives to sustain community histories and futures.



INTRODUCTION

Feminist scholars, critical race scholars, critical disability scholars and indigenous methodologies have had a profound role in the emergence and development of participatory research (PR). Those who have come more recently to participatory research might easily remain unaware of these, and other, histories and politics, with recent reviews of participatory research often neglecting to point to these influences.⁴ Yet understanding these histories is crucial because they inform current practices of participatory research, and offer critical insight into contemporary challenges around participation. While many of the radical practices of feminist and other liberatory politics have become mainstreamed in participatory research, in the process they may have had their transformative potentials flattened. A 'participatory turn' has been followed rapidly by concerns about the 'tyranny of participation'.5 Revisiting these radical histories provides new opportunities for rethinking the potential of participatory research.

Here, while the main focus is on feminist contributions to the

development of participatory research, I necessarily draw on and interweave my account with other threads of critical participatory research. This is neither an attempt at a history or a genealogy, though these would be valuable projects, but a partial and strategic intervention to foreground crucial contributions these fields make to participatory research, and might still make. I focus on pulling out some key concepts and practices which emerge as shared across these fields, as well as trying to hold on to differences, and pointing to explicit points of tension within and between these practices. This approach echoes the way these fields have themselves emerged – as in conversation with each other and as, often, insistent on the inseparability of issues, before intersectionality became a more commonly known and used term. For instance, writing in the 1990s, disability scholar and activist, Tom Shakespeare cited feminist scholarship and research as a key influence in opening up a challenge to positivist approaches to research. Evans et al., in their discussion of indigenous methodologies and Participatory Action Research (PAR), speak of 'common insights, differing methodologies'.7 Black feminists have been key in insisting on the importance of coalition politics, from the Combahee River Collective statement, the anthology This Bridge Called My Back and Berenice Johnson Reagon's influential essay Coalition Politics: Turning the Century. 8 What feminist, critical race, critical disability scholars and indigenous methodologies have in common is not necessarily a shared experience of oppression, but rather a far-reaching critique of the practices of Western science and philosophy which produce inequalities and marginalities.

For example, Bergold and Thomas 2012

Cooke and Kothari 2001.

Shakespeare 1996.

Evans et al. 2009.

Combahee River Collective 1977; Azaldua and Moraga 1981; Reagon 1983.

This review aims to introduce some of the key practices of participatory research, and some of the debates that surround these:

- Section 2 looks at some of the key issues for those undertaking critical participatory research, both in conducting the research and planning the outputs of a project.
- Section 3 explores participatory research as an approach that focuses on carrying out research with and alongside the people the research is about.
- Section 4 provides some case studies to illustrate some of the issues, questions and controversies raised throughout this review.
- Section 5 summarises some of the challenges of participatory research and considers some possible future directions for this approach.

1.1 Playing cat's cradle

In writing this review, I draw on Donna Haraway's evocative account of playing the string game cat's cradle, as a way of approaching both the *process* of participatory research, as well as the *relationships* between feminist, and other critical approaches, including critical race, critical disability studies and indigenous methodologies.⁹ The cat's cradle is evocative for many reasons here – it resonates well with the dynamic process of many participatory projects and it is accessible, as many of us have played some kind of string game, but it can stretch enough to provide a rich account of process and a dense conceptualisation of participatory work. Haraway used the cat's cradle to describe her own work which she saw as 'part of a larger, shared task of using antiracist feminist theory and cultural studies to produce worldly interference patterns', and the range of practices she intended to encompass might well be taken to include participatory research. 10

While the cat's cradle can be played alone, Haraway is most interested in what happens when it is played together, when our stories become bound up with others. Her cat's cradle is all about 'passing patterns back and forth, giving and receiving, patterning, holding unasked for patterns in one's hands, response-ability'. 11 It is about the serious play of making patterns in the world, which allows for and recognises spaces and knots, tensions and slack, movements towards and away, distance and webs of connection. In this sense, the cat's cradle offers a useful redescription of the focus on iteration and re-cycling through processes which are common in many accounts of participatory research. 12 The cat's cradle is about movement; it disrupts any easy notion of inside/r or outside/r, demonstrating that in the dynamics of play, who or what is inside or outside is frequently in flux, a matter of perspective or location or temporality. The cat's cradle destabilises linear accounts of the research process.

Haraway 1994

Haraway 1994: 60.

Haraway 2013.

For example, Pain et al. 2011

Haraway draws on the game of cat's cradle to emphasise the materiality of the work of making stories real in the world, insisting: 'The point is, in short, to make a difference – however modestly, however partially, however much without either narrative or scientific quarantees.' 13 Paying attention to the cat's cradle allows a focus on what connections are enabled, which ones are refused, what is valued, and what is made; 'worlding' in Haraway's terms. It allows for alterity and otherness to be understood and apprehended as not outside of any system, as always inside, always involved in the making. For Haraway, the cat's cradle enables attention to efforts to make interference patterns in the world, which seems a useful way of thinking about participatory research, as often having the ambition of interfering in the world.

Haraway: 1994: 62.

The cat's cradle is about movement; it disrupts any easy notion of inside/r or outside/r, demonstrating that in the dynamics of play, who or what is inside or outside is frequently in flux, a matter of perspective or location or temporality. The cat's cradle destabilises linear accounts of the research process.



KEY ISSUES

Key issues which recur in different forms across feminist, critical race. critical disability work and indigenous research include: a critique of scientific knowledge and claims to objectivity and neutrality in research practices; attention to issues of power in the research process, particularly questions of who is included and who is excluded and who or what is the object of research; attention to the question of what counts as knowledge; matters of voice, agency, empowerment; and reflexivity in the research process. Critical participatory concerns extend to research outputs too - who determines the form of outputs, who has access to them, what do the outputs of research do, and what are they intended to do?

2.1 Critiquing knowledge – and how it is produced

Feminist, critical race, critical disability studies and indigenous methodologies share a strong critique of the assumptions and effects of research based on a positivist philosophy. Challenging accounts of research as an objective, neutral, value-free way of examining and making sense of the world has led to vital questions about the research process. Critical researchers ask who gets to carry out the research, who is the object of research, who is made (in)visible, who is made silent, who gets to speak, what counts as truth, and, crucially, what assumptions about knowledge and the world shape the entire research process. For Linda Tuhiwai Smith, positivism is only part of the story of conventional research. She also locates research as founded on distinctly Western philosophies, opening her now classic text, Decolonising Methodologies: Research and Indigenous Peoples, by reminding readers that 'the term 'research' is inextricably linked to European imperialism and colonialism', and that, for people whose value was once measured by the size of their heads, 'research' is one of the 'dirtiest words in the indigenous world's vocabulary'. 14

There are many examples of the damages caused by Western and positivist research practices, which provide evidence of the ways in which a stated commitment to objectivity, neutrality and truth emerges as fatally undermined in practice. In the now infamous Tuskagee syphilis study (1932 – 1972), 600 agricultural workers in rural Alabama, all black men, were enrolled in a study to explore the effects of untreated syphilis. 15 The men were tested for syphilis, but those who tested positive were never told of their diagnosis, were never provided with information about how the disease was transmitted, and were not offered any treatment, even after penicillin was identified as an effective cure in the 1940s.

Smith 1999: 1.

Reverby 2009.

Some of the men in the study died of the disease and many passed syphilis on to their wives and partners, as well as to their children, with devastating effects on many lives. The research only ended when a journalist exposed the study, and its assumptions – that syphilis affected black and white people differently; that black labourers such as those enrolled in the study were unlikely to seek treatment; and would not make any changes to their behaviour even if they did learn of transmission routes. The study thus reproduced and enacted a series of assumptions about race, gender and sexuality with fatal consequences.

However, the Tuskagee syphilis study is only one of a number of cases of research with dubious methods and devastating impacts, many of which have involved testing drugs in developing countries without adequate consent before they are approved for use in the Global North; or prescribing poorly tested drugs, which then emerge to cause significant further medical problems. The contraceptive pill was tested on women in Puerto Rico without their knowledge that they were experimental subjects. Norplant was a long-term contraceptive implant aggressively promoted to young black women in the US, who were offered financial incentives to take it. Thalidomide was a drug given to pregnant women to treat morning sickness, and which led to babies born with shortened limbs. DES, a synthetic estrogen, a 'wonder drug' for preventing miscarriages, led to vaginal cancer and other gynaecological and reproductive difficulties in daughters of women who took the drug. 16 Forced sterilisation and coercive use of contraceptive devices, in the guise of research or health projects, have been used to control the fertility of black women and disabled women, and have been linked with a long history of eugenics which has sought to control fertility and manage population, while at the same time, the very testing of these technologies and drugs is part of a narrative that allows the West to proclaim its own development, progress and scientific advances. 17 Given the numerous examples of the devastating impacts of medical research, it is unsurprising that there is a wariness and sometimes an outright refusal to become involved in some research projects.

Bell 2009.

17 Roberts 1999.



Blood samples taken from participants in the Tukasgee Syphilis Study

Academic research also encompasses more mundane practices of being marginalised and ignored. *Middletown: A Study in Modern* American Culture, was an ambitious landmark sociological study in its efforts to research across a whole city, carried out by Robert and Helen Merrell Lynd, and published in 1929.18 'Middletown', later revealed as Muncie, Indiana, was chosen because it was seen to be a typical US city. Retired state legislator, Hurley Goodall, described the origins of the original project by reading out a description of the city from the resulting publication, where Muncie was described as having a 'homogeneous native born population, a small foreign born and Negro population that could basically be ignored'. 19 Yet, although the African-American population was small, it was growing, and was larger, proportionately, than cities such as Chicago. New York or Detroit. It was this casual neglect of the African-American communities of Muncie that gave rise to the collaborative ethnography, and subsequent book, *The Other* Side of Middletown: Exploring Muncie's African American Community, developed to 'fill that void'. 20

In these critiques, scientific and medical studies, as well as mainstream social science, emerge as neither neutral nor objective, rather all knowledges are revealed to be situated and located, and with the potential for far-reaching effects on the everyday lives of people across the world. 21 These accounts of the ongoing damage and devastation caused by research are a reminder of why some turn to participatory research as a way of reconfiguring knowledge practices as a practical way of remaking the world, often arising out of individual and collective experience of the harms that Western research practices have produced. Critique of existing knowledge practices and knowledge production required attention to research methods, to the ways in which knowledge was produced. In this sense, the power and performativity of methods often attributed to scholars in science and technology studies has long been well-known to many involved in critical liberatory politics.²²

2.2 Experience as method and knowledge: consciousness-raising in feminism

Many participatory methods have initially developed outside of academia, in political activism, social movements and everyday life. 23 Some then criss-cross activism and academia, often because participants themselves are students, or turn to formal study in order to have dedicated time to document and understand the actions in which they have been involved. And some go on to work in universities as researchers and teachers.

Consciousness-raising (CR) emerged as an important practice across many movements. Paulo Freire, working with radical movements in Brazil, stressed the importance of conscientisation, of critical consciousness, a process of developing an awareness of the world, involving cycles of reflection and then action on the basis of this reflection, in order to intervene in the world to create change – in oneself and in the world.²⁴ The practice of consciousness-raising was developed particularly in the feminist movement in North America in the late 1960s and 1970s. and was a key site for the development of feminist theory and activism. It was through the process of coming together and sharing stories of their experiences that women realised that their own experiences were not unique, isolated or personal, but rather were collective, shared and political – captured in the feminist slogan that 'the personal is political'.

Lynd and Lynd 1929.

Lassiter et al. 2004: 1.

Lassiter et al. 2004: 2.

Haraway 1998

For example, Law 2004.

See examples also in Bonacchi; Myers and Grosvenor; Wakeford and Sanchez Rodriguez in this series.

Freire 1972; see also Wakeford and Sanchez Rodriquez, this series.



Feminist consciousness-raising groups redefined what counted as appropriate topics for political intervention, whose knowledge on these matters counted, and who got to set political agendas.



CR groups were very popular and spread rapidly in the late 1960s from New York where they first emerged, to other parts of the US, the UK and beyond, with many women remaining involved in groups over a period of many years. CR groups commonly involved small groups of women coming together in someone's home, meeting regularly, often weekly, with discussions often based on an intense analysis of a particular topic. These were subjects that might not otherwise appear on the political agenda, focused on the everyday, on the personal – on relationships, domestic labour, childcare, experiences in the labour market and workplace, sex and intimacy, health and opportunities for education, gender differences in everyday life. Discussions involved going round a circle, with everyone having the opportunity to voice their own experiences, to be listened to, and also to listen to and hear other women's stories. The idea was that there was no one designated leader, that no one should dominate, that every woman's experiences were valid and worth sharing, and there was no expert who would define the stories or experience.

Feminist CR groups redefined what counted as appropriate topics for political intervention, whose knowledge on these matters counted, and who got to set political agendas. Meetings were also women-only, aimed at creating a safe space where women could begin to articulate experiences which many had not yet spoken about, including around relationships with men. CR groups provided an important site of support for women sharing often difficult stories for the first time. The aim of sharing stories was to craft political analysis and to develop feminist theory. Catherine McKinnon described CR groups as an important site for the 'collective reconstitution' of the social meaning of women's experiences.²⁵ Drawing attention to the method, she argued that CR was 'the major technique of analysis, of structure of organization, method of practice, and theory of social change of the women's movement'. 26

CR groups were a crucial site of theorising, of developing collective understandings of the world, developing new concepts and theories, and thinking about ways to transform the world. The methods and practice of CR continue to reverberate through feminist theory and activism, as well as social justice activism more broadly. The commitment to theorising experience is captured well in Joan Scott's argument that 'experience is at once always already an interpretation, and something that needs to be interpreted'. 27 The commitment to both validating the importance of women's experiences, as well as to critically interrogating those experiences in groups, and understanding them as not only personal and individual but rather as shared and collective, has been central to much feminist research, theory and activism.

McKinnon, cited in de Lauretis 1990: 122.

McKinnon, cited in de Lauretis 1990: 122.

Scott 1991: 797

2.3 Women's environmental activism: the anti-toxics movement and popular epidemiology as participatory research

The emergence and growth of a diverse women's health movement and related environmental and ecofeminist activism can now be seen as an early manifestation of participatory feminist research. While many in these movements have been critical of mainstream science, they have also developed complex relationships with science and the medical, pharmaceutical and other industries. A commitment to embodied knowledge and valuing experience does not necessarily eschew scientific research methods completely. One powerful example is the grassroots research and activism of communities living around toxic waste dumps in the US, and the practice of what Phil Brown has termed, 'popular epidemiology'. 28 Love Canal in Niagara Falls remains one of the most well-known and 'successful' of these communities, and appears as an iconic struggle in many accounts of ecofeminism, and the story, as told by Lois Gibbs who initiated local activism, appears as an archetype for other struggles.²⁹ Gibbs became concerned about her son's illnesses, and of those of other children in the neighbourhood, as well as problems in pregancies. Subsequently, she learned about how the neighbourhood had been built on the site of a toxic waste dump. The 'popular epidemiology' many communities carried out can be seen to parallel scientific epidemiology in many respects: activists try and gather data, often with rigour, robust and standardised methods in mind, not least as one of the aims is often to try and draw scientific, public and political attention to what is understood as an unseen issue – thus quality research is essential for this. While popular epidemiology appears as a precursor to more recent interest in public participation in health research, and crowdsourcing of scientific data, 30 for Brown popular epidemiology is more than this because of the emphasis it places on social stuctures as part of the causes of illness and because 'it involves social movements, utilizes political and judicial approaches to remedies, and challenges basic assumptions of traditional epidemiology, risk assessment and public health regulation'. 31

Popular epidemiology does not make an outright rejection of scientific objectivity. Rather it insists that local health problems, documented by local people, is evidence that should be considered as part of the scientific record. It calls into question scientific research which relies on the *a priori* exclusion of personal, experiential knowledges, and everyday experience and emotions. Activists insist that being distraught about the illnesses and deaths of children, to be emotional, is entirely rational, and indeed that any knowledges which seek to exclude emotions are irrational. As Brown notes, because of different needs, goals and methods, lay and professional researchers often have 'conflicting perspectives on how to investigate and interpret environmental health data'. 32 Challenges emerge when grassroots communities try to replicate the methods of scientific research. It is not a simple case of adding new community-generated data to existing scientific knowledge to produce a fuller picture of the world. Rather the process of applying scientific methods in community-based activist research reveals the extent to which these supposedly objective, neutral, value-free processes are also context-specific and contingent.

Brown 1987; Brown and Mikkelson 1990; Brown 1992; Brown 1997.

Gibbs and Levine 1982.

Also see Bonacchi on online participation in this series.

Brown 1995: 147-148.

Brown 1992: 269.

While popular epidemiology begins with local communities, often with those who do not identify as activists, or as part of a movement and without any academic involvement at all, it is also the case that such communities tend to be resourceful and to make use of connections with academics or other experts that they have. Thus, any characterisation of this kind of participatory research as involving lay knowledge against expert knowledge would simplify the more complicated way in which this activism seeks to challenge and reconfigure scientific knowledge. In particular, such work highlights how scientific knowledge is itself plural and contested, that there are disagreements among scientists, particularly when it comes to emerging scientific knowledges, and, as some activist scientists have found, that they can be marginalised by other scientists. When local communities worked in collaboration with scientists who got involved in supporting community research or carrying out their own testing, these scientists found that their own research was often challenged, as scientist Dr Beverley Paigen found when she carried out some studies in Love Canal.

It is little surprise that community-based research which seeks to surface the health effects of the 'medical-industrial complex' has been a site of vibrant and creative approaches to knowledge creation. What is also worth noting here, is that while much of the academic literature now focuses extensively on the process of setting up participatory projects, many of these earlier examples of participatory and collaborative research emerged organically, from the ground up, outside of universities, and so did not have an intense preparatory phase of research design. Instead, they had intense phases of actively working out process as projects emerged, and often had a commitment to collaborative analysis and intervening in the world, something that is not always so explicit in writing on participatory research now.

Popular epidemiology insists that local health problems, documented by local people, is evidence that should be considered as part of the scientific record. It calls into question scientific research which relies on the a priori exclusion of personal, experiential knowledges, and everyday experience and emotions.

METHODOLOGIES AND METHODS: 'BY, FOR AND ABOUT'

Critical participatory research is commonly described as an approach to research; that is, it is not always understood as a method in itself. but rather a perspective that informs how research is carried out. While some methods are by definition participatory, for example, community mapping, more commonly participatory approaches are understood as a form of doing research with and alongside the people the research is about.33 Similarly, feminists have rejected any notion that there are any specifically feminist methods, arguing that feminism is an approach to research, rather than any particular method or tool, however, indigenous researchers tend to be more explicit about using methods from indigenous traditions.³⁴ Evans et al. describe indigenous methodology as 'research by and for Indigenous peoples'. They specify that indigenous methodologies use 'techniques and methods drawn from the traditions of those peoples'. They reject 'research on Indigenous communities which use exclusively positivistic, reductionistic and objectivist research rationales as irrelevant at best, colonialist most of the time and demonstrably pernicious as a matter of course'. 35 Thus, some communities and research traditions are focused on circumscribing research on and with their communities, in an effort to resist the damage of previous research and to maintain some control over knowledge production.

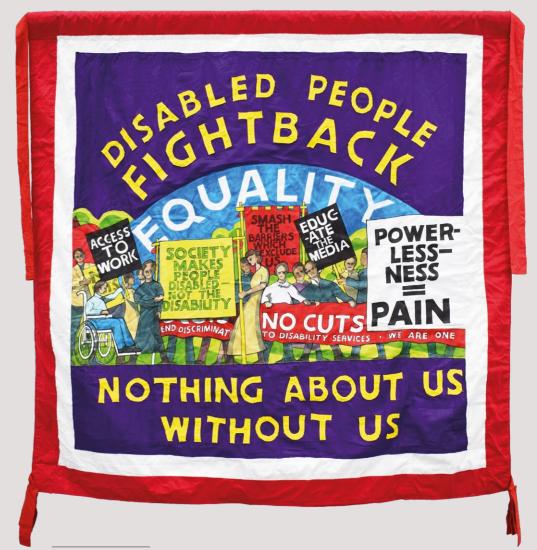
The slogan 'nothing about us without us' has come to characterise much disability activism – an ethos which was swiftly adopted following the publication of a book of the same name by James Charlton. 36 It resonated strongly with already existing critiques of policy processes which made decisions about people's lives without involving any of those who would be impacted by such policies. The slogan has also been adopted by other activist groups and researchers; and has come to inform not only policy work, but also the process of doing research, enacting a shift from research in which disabled people are objects of research, to where disabled people are involved in the research. While this slogan perhaps came late in the emergence of participatory research, it was picked up quickly because of the ways it resonated with existing commitments in the disability rights movement. Charlton also linked this slogan with other slogans and movements: 'power to the people' used by the Black Panthers and 'our bodies ourselves' of the women's health movement, again establishing the links between different traditions of participatory research, identifying a shared commitment to drawing on collective experience to challenge dominant insitutions and inequalities, and drawing attention to the importance of remaining alert to the question of who is involved in creating knowledge and to what (political) ends. 37

Pain 2009 Harding 1996.

Evans et al. 2009: 4.

Charlton 1998.

Charlton 1998: 3.



Banner designed by Ed Hall as part of the Disbanners Project working with disabled people across the North West.

3.1 Research relationships

Attention to who was involved in research has also involved consideration of relationships between researchers and research participants. British sociologist Ann Oakley drew on her experience as a woman interviewing other women to discuss the rapport that can develop between researcher and research participant (1981). Oakley was critical of models of research in textbooks which presented rapport as instrumental, extractive, hierarchical and non-reciprocal. For her, this was indicative of a scientific. professional, masculine approach to research, and not a model which fitted with her own experience of interviewing. She argued that women interviewing women were insiders to the research, with minimal social distance, which she suggested produced a stronger connection between interviewer and interviewee enabling feminist researchers to gain closer rapport. Oakley herself already anticipated some of the complications of this argument - that with this closer rapport came huge ethical challenges, and this was rapidly picked up by others. Her apparently uncritical acceptance of an easy rapport between women was quickly subjected to revision, in a way which might be understood as typical of feminist and other fields, where issues are raised, and intensely and rapidly worked through. Judith Stacey followed swiftly with questions about whether easy rapport might leave feminist interviewing and ethnography even more exploitative than more mainstream research, as participants might 'forget' they were being interviewed for a research project, and disclose more than they might to a male researcher. 38

Others pointed out that gender might not be the only experience mediating the interview context. Nirmal Puwar's work interviewing elite women MPs provides a pointed illustration of this where she recognised that her experience at times:

echoed Ann Oakley's description of interviewing women as a cosy, friendly and sisterly exchange of information.³⁹ Whilst at other times I could relate to Stephen Ball's description of interviews with MPs as '...events of struggle, as a complex interplay of dominance/ resistance and chaos/freedom.'40 Often the same interview shifted between these two types of scenarios. 41

These concerns capture the vibrant, lively and attentive debate around these matters in feminist research, where they are understood as central questions meriting considered attention, engagement and reworking. This keen attention to matters of privilege and power in the research encounter clearly translates well to thinking about encounters in participatory research.

38 Stacey 1991.
39 Oakley 1982: 55.
40 Ball 1994: 113.
41 Punwar 1997

3.2 Authorship and anonymity

A commitment to thinking about power relationships in the process of research also infuses a broader rethinking of wider research practices especially for feminists – for example, to experiments in authoring, and authorising, published texts. Academics have tried to challenge the convention that books are produced by single authors, and signalled that through creating names which undo the conventions of academic authorship and gesture to the collaborative nature of much work. 'The Personal Narratives Group' was the name for a collective of feminist academics who collaboratively created and edited the collection Interpreting Women's Lives: Feminist Theory and Personal Narratives. 42 Feminist geographers, Katherine Gibson and the late Julie Graham wrote under the pen name J.K. Gibson-Graham, from their first book, *The End* of Capitalism (as we knew it), even before they set up The Community Economies Research Network and the Community Economies Collective, networks with a commitment to collaboration in their efforts to create new visions of economy. 43 The moniker 'mrs kinspaisby' (2008) was described as acknowledging gratitude to academic geographers Mike Kesby, Rachel Pain and Sara Kindon, rather than directly attributing authorship. I use these examples to show how these questions are raised within some strands of academic research more generally, although it is often researchers who are interested in the collective nature of social life who are committed to rethinking these kinds of collectivites throughout the whole lifecycle of the research process. 44 Thus, these kinds of commitments are not exclusive to participatory work, although the intensification of auditing of research in universities arguably compounds the challenges posed by participatory research to conventional notions of who owns the research, who writes it up, and what forms of outputs will be produced.45 However, participatory research does push questions of authorship beyond academic collectives to collaborations with community members. For instance, the book *The Other Side of Middletown:* Exploring Muncie's African American Community is edited by four researchers, including academics and community members, with chapters written by students, academics and other research participants. 46

Yet this attention to naming extends beyond the authorship of publications; much social science has a convention that ethical practice involves keeping research participants anonymous as a way to ensure safety and avoid harm. For many members of marginalised communities denying the right to use one's name, to own one's own words, and to be recognised and acknowledged in the research is a kind of violence and they want their own name used in the research. 47 In these ways, critical participatory research practices are challenging a range of conventional research practices – from authorship to ethical procedures.

The Personal Narratives Group 1989

43

Gibson-Graham 1996.

See also Cook et al. 2008.

Cahill and Torre 2007.

Lassiter et al. 2004; see also People's Knowledge Editorial Collective 2016.

Gluck and Patai 1991: 4; Moore 2012; Tilley and Woodthorpe 2011

3.3 Dilemmas over theory and activism

The form of research outputs has also been reworked. Academics have faced challenges from activists that the abstraction of academic language can be complicated to understand – although activists can also be embedded in their own communities of practice, with their own specialist languages. Barbara Christian offered one much cited intervention in this discussion, where she made an important point about the different forms in which theory comes:

I am inclined to say that our theorizing (and I intentionally use the verb rather than a noun) is often in narrative forms, in the stories we create, in the riddles and the proverbs, in the play with language, since dynamic rather than fixed ideas seem more to our liking. 48

This attention to alternative forms of knowledge is part of the critique of scientific knowledge practices, pointing to an important role for the humanities and more narrative-focused social science in supporting participatory research. As mrs kinspaisby note in their conversation, participatory research also offers a way of transforming theory, where the research does not become 'atheoretical', but rather outputs can be 'intellectual projects but more accessible'. 49 Accessible here does not mean simplified. Writing about the collaborative and participatory work of feminist scholar-activist Richa Naga, Elora Halim Chowdhury points out that '[i]nstead of cancelling out, prioritizing or even suppressing competing agendas, narrative analysis, and storytelling enable the weaving of a more nuanced and even politicized telling'. 50 While, for some time, this reliance on narrative and story-based methods has raised questions about whether participatory research can ever encompass other methods, including quantitative and scientific methods and the use of big data, the emergence of strands of research such as citizen science and other forms of internet-enabled collaborative research (see Bonacchi in this series) continues to push at the possibilities of research which again reconfigure notions of the expert and where expert researchers might be located.

48	
Christian 1995: 457.	
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kinpaisby 2008: 297.

Chowdhury et al 2016: 1802



Although there have been questions about whether participatory research can ever encompass other methods, including quantitative and scientific methods and the use of big data, the emergence of strands of research such as citizen science and other forms of internet-enabled collaborative research continues to push at the possibilities of research which again reconfigure notions of the expert and where expert researchers might be located.



3.4 Knots of histories

While pointing out that feminist, critical race, critical disability and indigenous scholars and activists have profoundly shaped the emergence and development of participatory research, it is also salutary to note that versions of participatory research also produce canons and authorise some voices more than others. Patricia Maguire, a pioneer in feminist participatory research, recounted how:

it became really clear that the feminist critique of traditional social science which was so robust in the late 70s was pretty well ignored in participatory action research. So here you had these men – and as much respect as I have for Paulo Freire, Orlando Fals Borda, Rajesh Tendon, Budd Hall, this string of really liberatory guys – they weren't paying attention to gender. 51

As she continued, 'Well then, if you want to change the world, but you exclude half the people, what kind of world is that? We got that world already, thanks'. 52 At the same time, when she came to writing about feminist participatory research in the 1980s, she found precious little directly in feminism to inform her work. She argued that, despite sharing similar central concerns, 'mainstream' feminism has not necessarily been quick to bring participatory research to the centre of its practices. Despite feminism's profound influence on participatory research, perhaps paradoxically, it is not clear that the influence is mutual.

Feminists have ultimately faced analogous critiques – from black, queer and disabled feminists, amongst others - who felt that their lives and contributions to knowledge were not always acknowledged, and that white feminists remained unaware of the ways in which they were implicated in reproducing privilege. It is intriguing that that the professionalisation of some of the interdisciplines where questions of participation and democracy have been most central (women's studies; development studies; science and technology studies) appears to have resulted in a retraction from participatory practices. 53 Arguably, the fields of disability studies and indigenous studies have not been beset by such cleaveages between a participatory ethos and more mainstream approaches to research, which may reflect the marginal status of these fields of inquiry.

Horwitz and Houghton 2016: 105.

Horwitz and Houghton 2016: 105-106.

Eubanks 2009: 109.

CASE STUDIES

The following case studies are intended as examples of participatory research, illustrating some of the issues raised throughout, showing that some of the questions, concerns and controversies about participatory research have been around for some time, as well as pointing to new affordances and possibilities of participatory research as communities seize more control over the research process, and the production of knowledge.

4.1 Our Bodies Ourselves

The limitations of mainstream medical and scientific knowledge ultimately led to the emergence of many vibrant and far-reaching health movements. One of the most successful initiatives has been the women's health movement, exemplified by the book Our Bodies Ourselves (OBOS). 54 Initiated by the then Boston Women's Health Collective, what ultimately became the infamous book, OBOS, was the result of a group of women coming together to discuss health issues. Initial conversations began round frustrations in doctors' offices and the failed attempt to create a list of local doctors who would be sympathetic to women's experiences and listen carefully to their issues in the Boston area. 55 The project then transformed into a research and self-education project, as women identified a need to create their own resources. Importantly they drew on research, but also their own experiences and stories; in this way the women's health movement also used the strategies of consciousnessraising, namely, of story-telling and sharing experience and knowledge.

OBOS is also an intriguing example of the global travels of feminism. Kathy Davis, who studied the global travels of the book, argued that OBOS would never have been as successful if it was just a handbook; she showed how the methods of the project were crucial. The book relied on women's experiences as a resource for producing knowledge about women's bodies and women's health, revealing how much was left out of mainstream medical discourse. 56 As well as women active in the Boston Women's Health Collective carrying out their own research, they were also responsive to their readers, and open to learning and revising knowledge. 57 OBOS invited women to use their own experiences as resources for producing situated, critical knowledge about their bodies and health, that allowed the book to speak to so many women within and outside the United States: 'it was the method of knowledge sharing and not a shared identity as women which appeared to have global appeal'.58 OBOS inspired a dialogue between those who produced the book and the book's readers, who wrote in to the OBOS collective with stories, experience and requests for attention to issues not covered in the original text.59

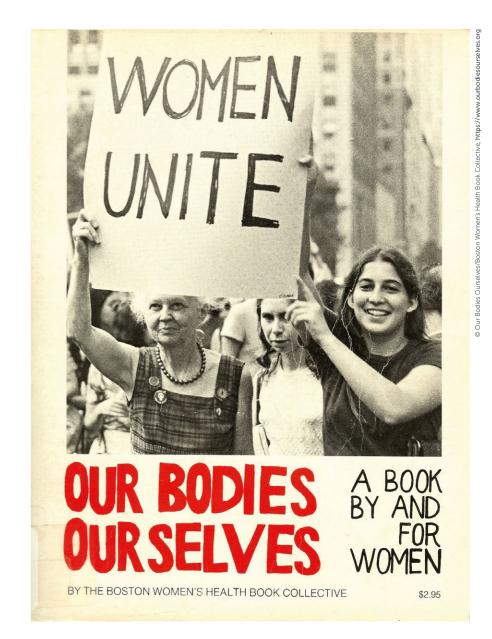
See www.ourbodiesourselves.org Kline 2005. Davis 2007. Kline 2005. Davis cited in Kline 2005.

Kline 2005.

Ruzek 2007

Figure 3 Cover of Our Bodies Ourselves 1973.

OBOS began as a call for dialogue between women and the mainly male-dominated medical profession at the time but transformed as women doctors became involved, and OBOS became a movement where women doctors could also meet and share experiences, with OBOS transforming relationship between 'patients' and 'doctors' in ways not initially anticipated. 60 OBOS remains an ongoing project to learn more about women, and women's bodies, through sharing and connecting medical and experiential knowledges.



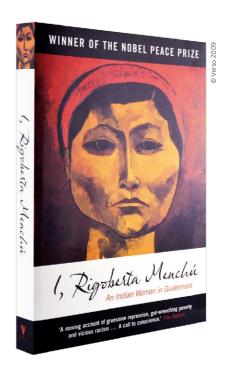
4.2 I Rigoberta Menchú: An Indian Woman in Guatemala

This example is not a recent project and will be new to some readers, while for others, its high visibility in the global news in the 1980s and 1990s may mean that it is a familiar story.

Rigoberta Menchú is a K'iche' activist from Guatemala, who won the Nobel Peace Prize in 1992 for her activism with indigenous peoples in Guatemala, at a time of a violent civil war (1990 – 1996). Arguably, Menchú's global presence was considerably enhanced by the publication of the 1983 book I Rigoberta Menchú: An Indian Woman in Guatemala, published to much international acclaim, as well as controversy. 61 The book was the result of a collaboration between Menchú and, Venezualanborn anthropologist, Elisabeth Burgos-Debray, and was based on over 24 hours of interviews and conversations which took place over a week in Paris, where Burgos-Debray lived at the time and Menchú was visiting. The English translation (by Ann Wright) became an international best-seller, catapulting Menchú (and Burgos-Debray) into the limelight.

This collaboration and the resulting book offer a powerful case which raises many of the issues outlined above. Focusing on this older text serves both as a reminder that collaborations and their complexities have been around for some time; that not all the questions are new; and that they have an international valence, pointing as well to the importance of Latin America in histories of participatory research. 62 Haraway's cat's cradle seems well suited to the knots and turns of this story. It is a text which is incredibly complex on matters of voice. The text of the book appears to be a first person account by Menchú of her life, which risks erasing that it emerged out of a conversation. It is not presented as the conversation that it would have been; there are no questions from Burgos-Debray included; Menchú's voice appears to be centred. Burgos-Debray's name does not appear on the front cover, but rather on the back and inside where she appears as editor. Is this a form of honesty – an appropriate modesty for a story that is really Menchú's, with Burgos-Debray keeping herself out of the limelight? Or is this subterfuge, erasing Burgos-Debray's role as interlocutor and editor, who did considerable work to arrange Menchú's text so that it might be accessible for Western readers? The interviews were carried out in Spanish; Menchú first language is Queche and, supposedly, she had only recently learned very basic Spanish (the language of the coloniser in this context) and, when translated into English, the language can appear very simple, almost naïve. This is a text of multiple mediations, leaving us with the guestion: who really authored the book?

Figure 4 Cover of I, Rigoberta Menchú.



The book was first published in Spanish as Me llamo Rigoberta Menchú y así me nació la conciencia, which translates directly as My name is Rigoberta Menchú and this is how my conscience was born - with rather different connotations to the English title. Some of the criticisms of the text argue that the experiences recounted are not Menchú's own, misreading the text through a Western lens of autobiography, as a story of 'I', an individualised Western self, which the English translation of the title would encourage. But, Menchú's story is considered one of the major texts of Latin American testimonio, where the focus is on the telling of a *people's* story, in which collective and shared experiences are centred, and which is a genre with quite different connotations to Western, individualised, biographical narratives. This might mitigate tendencies to read Menchú as an unreliable narrator, who risks leaving the reader feeling duped and having fallen for a story which emerges later as not guite true. The book has raised guestions of truth and authenticity; Menchú's story has been disputed and she has acknowledged not everything might be accurate: perhaps she had more education than she implied; perhaps she was not always present at some of the violent incidents she recounted. Yet Menchú explicitly rejects a tell-all approach. She writes against the proliferation of confessional cultures; in the book she reminds us several times that she will not tell the reader everything, because not all knowledge is to be shared. The last lines of the book read: 'I'm still keeping secret what I think no-one should know. Not even anthropologists or intellectuals, no matter how many books they have, can find out all our secrets'. 63 While a book entitled *I Rigoberta Menchú* sets up expectations about what the reader might hear and learn about the intimacies of her life, the questions which circle around this text are reminiscent of postcolonial theorist, Gayatri Spivak's powerful question; 'Can the subaltern speak?' Can Menchú be understood as authoring her own story?

Menchú with Burgos-Debray 1983; see also https://www.versobooks.com/ blogs/1826-rigoberta-menchu-a-newcourt-ruling

See also Wakeford and Sanchez Rodriguez, in this series.

Menchú with Burgos-Debray 1983: 247.

4.3 Creating an inclusive archive of learning disability history

The Inclusive Archive of Learning Disability History was created by a team of researchers including those with learning disabilities and without, academics and non-academics, and a number of partner organisations. 64 The project involved co-designing an accessible digital living archive of history of people with learning disabilities. In aiming to create a new archive, the project identified existing archives as important sites of knowledge about people with learning disabilities – but sites which often excluded the voices of learning disabled people themselves and sites which also are often not accessible and inclusive for those with learning disabilities. The project employed an inclusive approach to the research. In an article about the archive, the team not only talk about their collaborative methods, but also demonstrate them too. The text is published in a peer-reviewed journal, *The International Journal of* Heritage Studies, and is authored by 16 people, named in alphabetical order. 65 The text takes the form of a loose dialogue, with different participants speaking to the issues which concern them most. This kind of experimentation with form and authorship characterises much participatory research.

The article also identifies some challenges that the project throws up about inclusive research. One key commitment of the learning disabled self-advocacy movement is 'speaking out in public'. For many the archive was important as a way of putting the lives of learning disabled people in the public domain, and in their own words, as a counter to how people with learning disabilities have often been named, labelled and described by a range of institutions, medical, legal, educational. The project also identified a second key commitment which is 'being person-centred' which they understood as making sure that participants had a lot of say over what went into the archive, having control over content and a say over how content was to be used, in a way which questions the logic of formal archiving practices.

These challenges are also addressed in the next case study where indigeneous and non-indigenous researchers worked together to create a digital platform which would allow public sharing of some stories, as well as enabling some stories only to be shared with those for whom cultural protocols allowed the sharing of knowledge.

See https://inclusivearchive.org and http://www.inclusivearchiveproject.org

Brownlee-Chapman et al. 2018.

Figure 5

Objects from Apex Choir in 'Pop up Museum' – part of the process of co-designing the archive.



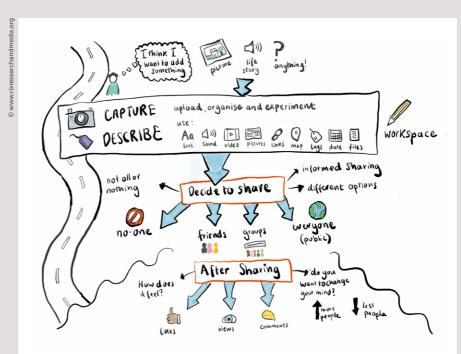


Figure 6 A plan of the user journey for adding to the archive.

Figure 7 Co-researchers with objects used to explore how the digital archive would work.





Figure 8 Plateau Peoples' Portal on Mukurtu.





Traditional Knowledge Labels available on Mukurtu.

4.4 Mukurtu

Mukurtu (pronounced MOOK-oo-too) is a digital platform which allows the curating and sharing of stories. More specifically, 'Mukurtu is a grassroots project aiming to empower communities to manage, share, and exchange their digital heritage in culturally relevant and ethicallyminded ways.'66 Mukurtu is a collaboration between Kim Christen, a North American academic based at Washington State University (and Mukurtu Project Director), the Warumungu Aborginal Community in Australia, and the Center for Digital Archaeology at University of California, Berkeley.

Christen and the Warumungu Aborginal Community had been working for many years together; the project emerged out of a need for a system to archive Warumungu cultural heritage, cultural stories, traditions and resources and which was also able to be responsive to the demands of their cultural protocols which specify with whom certain knowledges can, and crucially cannot, be shared. 67 Mukurtu was the resulting platform, which enables archiving, and sharing, of digital or digitised cultural heritage resources. At the centre of Mukurtu is a profound attention to guestions of ethics and power, and to meeting cultural protocols about knowledge sharing. As a collaborative project, Mukurtu can be seen in a lineage with Menchú's text. Mukurtu takes up Menchú's commitment to public address while at the same time reminding us that there are secrets, that not everything can be made public, while offering a more explicit account of the process of collaboration, of its own making. Thus, Mukurtu excels in its consideration of ethics, in its attention to questions of privacy, and of multiple publics. This emerges both in the commitment to creating a free open source platform, which is accessible and easy to use, while at the same time remaining equally committed to attending to the specificities of knowledges, and who is and is not allowed to access knowledge and stories. Mukurtu then is also an fascinating example of the kinds of projects which Bonacchi recounts in her review in this series, but one where indigenous communities, and their values and commitments, drive the the creation of the digital platform and its affordances, where the platform is free and open source, but the 'data', or stories, are not 'open' for all. 68

Michael Shepherd provides an account of using Mukurtu with Coast Salish Communities in British Columbia, where he notes how, 'particularly in oral societies, knowledge was power and what you knew about place names, genealogy, resource rights and spiritual powers were directly connected to status, wealth and influence'. 69 Here cultural protocol dictates how cultural information is shared and determines that certain types of knowledge may only be appropriate for community elders, or women, or for particular families. If stories, songs and names are recorded and openly shared these might break protocols where some stories are only to be shared with specific community members. Shepherd argues that these kinds of platforms, and the archives that they make possible, in affirming cultural values like protocol, facilitate processes of decolonisation and Native self-determination. In the context of an active open data movement, Mukurtu's attention to guestioning who knowledge is open to is a sharp reminder of the complicated politics of 'openness'.

Brownlee-Chapman et al. 2018.

67

Christen 2008.

Christen 2012; Bonacchi in this series.

Shepherd 2014: 315.

4.5 Participatory Arts and Social Action in Research (PASAR)

Participatory Arts and Social Action in Research (PASAR) was a project involving academics and a theatre practitioner working together with migrant families, particularly mothers and daughters. PASAR was 'based on the principles of inclusion, valuing all voices and action-oriented interventions'. 70 It was also strongly based on arts and creative methods for doing research, generating data/stories and creating impactful outputs and outcomes for the project and those involved in it. In using the methods of participatory theatre, including forum theatre (following the work of Augusto Boal) and playback theatre, as well as walking as a method, the project sought to discuss and dramatise the intense impacts of a government policy in the UK, called the 'no recourse to public funds' policy, which means that people who are subject to immigration controls are not allowed access to various benefits and housing, leaving many families in situations of dire poverty and homelessness. The project also sought to demonstrate how appropriate methods and research practices can support marginalised groups to engage in research as co-producers of knowledge.

The project used walking stories and participatory theatre as methods for generating stories about migrant women's everyday lives and experiences of living with the impacts of the 'no recourse to public funds' policy. Specifically, participatory theatre methods were used to develop 'short theatre scenes shared at a workshop with policy makers and practitioners'. With the explicit aim of allowing 'women to be actors, directors, story tellers, who can imagine and try out social interventions, rather than simply showcasing their vulnerabilities as a result of this dehumanising policy'. 71 The project produced an extensive and diverse range of outputs including academic papers, short films, a policy briefing, some online training, a toolkit on using theatre and walking methods, as well as other short public writings including a blog and contributions to various newsletters and a podcast. There was also a final conference and an event at the House of Commons where migrant families performed some of the forum theatre scenes where they conveyed their experiences of living with 'no recourse to public funds'.

See http://fass.open.ac.uk/ research/projects/pasar

Erel et al. 2017.

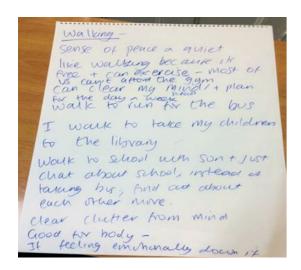








Figure 10 Participatory theatre and walking methods from the PASAR project.



The project was funded by the Economic and Social Research Council/National Centre for Research Methods in the UK and was also intended to make an intervention into academic practice and build capacity among the social science community in the potential of artsbased methods. In acting as a demonstrator project to show the potential of arts-based methods in social science research, and in working with marginalised communities, the project also produced resources which would enable other academics to take up these kinds of practices, including a toolkit, Participatory Theatre and Walking as Social Research Methods, and a film, Participatory theatre as a social research method.

In showing the value of arts-based methods for the social sciences, and for making policy interventions, the project can be seen to enact its ambitions through producing a range of outputs which address different audiences, as well as in a range of formats - policy briefings, toolkits, academic articles, as well as audio-visual material, blogs and short newsletter - all with different intended effects. While there does not appear to be explicit co-authorship with participants, the diversity of outputs from the project shows another way of doing participatory research which can meet the different needs of participants and the research team.

4.6 Learning from case studies

These projects demonstrate an ongoing attention to voice, to who speaks, who listens, who gets to speak and who gets to be heard, who listens and who gets listened to, who and what determines the conditions of which stories are spoken, and which remain unheard. There is an ongoing concern about who is the rightful owner of knowledge, who knowledge should be shared with, and who knowledge should not be shared with. At a time of a growing open data movement, these case studies potently remind us that not all knowledge is for everyone.

These projects demonstrate different ways of enacting accountability and responsibility towards diverse participants. This might mean a commitment to co-authorship of academic publications, or to listening to participant-readers and reworking outputs as a result, or producing varied forms of outputs so that all participants have diverse needs from the project met. The contingencies of different projects means that questions of authorship of outputs, or the nature of outputs are not to be settled but that rather each project throws up different configurations of participants, with different needs around outputs.

These cases also demonstrate how the impacts of colonialism shape the production and circulation of knowledge, and how institutions such as science, medicine, education and the archive act as benchmarks of knowledge that continue to provide sites of intervention for collaborations of academics and activists. Some projects begin with what seems like a small task – e.g. creating a list of women-friendly doctors – but morph into something much more significant, as the very need for such projects leads to the unravelling of some of the assumptions of medicine.

Short-term local tasks can grow into decade long transnational projects; a book can grow out of a conversation carried out over a matter of a week; controversies can be provoked, and can endure.

Perhaps most strikingly, revisiting early examples of participatory research serves as a reminder of the power of participatory research. Lois Gibbs' anti-toxics activism led to the relocation of over 800 homes, and Gibbs continued her activism, leading to the setting up of the 'Superfund' in the US, with companies forced to contribute to the costs of cleaning up the effects of toxic waste; she was subsequently awarded a Goldman Prize for her environmental activism. Our Body Ourselves has become a feminist classic, with an enduring impact on development of feminist work on science, technology and medicince, as well as thousands of women's lives globally.



Short-term local tasks can grow into decade long transnational projects; a book can grow out of a conversation carried out over a matter of a week: controversies can be provoked, and can endure.



CRITICAL PARTICIPATION: CHALLENGES, LIMITS AND **FUTURE DIRECTIONS**

While the ideal of participation emphasises inclusion and empowerment, critics of PR have pointed out that it can often be mobilised in highly programmatic and narrow ways – an argument that has been applied both to activism and to more institutional versions of PR. While many who might have been seen to be on the margins of mainstream research have embraced the possibilities of participatory research, there are those who oppose it. Disability scholar Tom Shakespeare, though also involved in activism, declared himself opposed to emancipatory research even while he admired the 'motivation and commitment of those engaged in it'.72 He saw no point in developing transformative research when there was little chance that it would be enacted by government. He also argued that he wanted the freedom to engage in research which was not instrumental – which suggests interesting assumptions about the nature of participatory research. Against arguments which would insist that academics use their privilege to challenge dominant forms of knowledge and try to improve people's lives, feminist academic Angela McRobbie has also provocatively asked whether women have the capacity or the right to intervene in other women's lives. 73

Criticisms of PR have emerged particularly in the development field, where participatory approaches have been taken up by a range of institutions with considerable enthusiasm, often with a specific focus on involving women in development projects to support women's empowerment. Bill Cooke and Uma Kothari produced an influential book, Participation: The New Tyranny?, providing a critique of participation from the perspective of development professionals. They argue that participation has been appropriated by institutions that are not necessarily committed to transformative politics, and that participation can be enacted in ways which do not always open up research and challenge power differences, but rather entrench hierarchies.

Challenges remain around participation, particularly when it becomes institutionalised. Writing in the context of working with poor communities in the US, Virginia Eubanks observes that 'participatory methodologies have become hot topics because these practices currently serve to fill the gap left by the withdrawal of the state under globalized neoliberal regimes'.74 A similar point is made by Maia Green, specifically with reference to participatory work in development contexts, who notes that 'the fact that participation can operate within statist top-down or devolved neo-liberal programming, as well as emancipatory discourses of liberation and learning, makes it especially durable' – both full of potential and always vulnerable to co-option.⁷⁵ In the UK, discussions of PR are in part framed by recent political turns to austerity, as well as commitments to auditing of research in universities and demands that research, especially that which is publicly funded, deliver public impact. This has led to some trenchant

Shakespeare 1996: 118.

73 McRobbie 1982

Eubanks 2009: 107.

75 Green 2010: 1242. criticisms of PR, which (mis)take it as a process 'where academics become cheap consultants to policy elites looking for evidence to support decisions they have already made'. 76 This is not an account of PR which will be recognisable to critical participatory researchers. 77 Restating participatory research's radical histories, therefore, becomes an important project. While Patricia Maguire noted the lack of attention to gender in the work of those driving participatory research in the 1970s and 1980s, the fact that these absences can still be found in more recent reviews suggests that histories of PR can be subject to the same erasures as mainstream research.⁷⁸ At the same time, the growing attention to intersectionality, decolonising knowledge practices, and decolonising the curriculum. may spark a renewed interest in precursors of intersectionality in the field of participatory research.

Relatedly, juxtaposing Cooke and Kothari's account of participation as it is institutionalised in a development context with the possibilities afforded by indigenous methodologies may offer some insight on the spaces of possibility for critical participatory practice now. Indigenous research is not caught up in the same way with development logics. Indeed, much writing on indigenous research does not specify a direct commitment to participatory research, arguably because those many indigenous researchers are now acting as careful gatekeepers of access to their communities and determining some of the conditions of research.⁷⁹

While some of the central questions for participatory research are ongoing, and intended to be, - matters of power, reflexivity, of inclusion and exclusion, are not to be answered, resolved and put away, rather they are the very ongoing stuff of the doing of participatory research – the contexts in which these questions emerge is always changing. While participatory approaches have tended to focus on documenting marginalising stories and providing alternative accounts of the world, recent work has turned its attention elsewhere. 80 In a twist on the resonances with 'hidden histories'. researchers are now paying attention to lives which are hiding in plain sight, and bringing a critical lens to bear on whiteness and using this to 'expose where PAR runs the risk of re-inscribing dfference'. 81 Evans et al. thus propose that PR 'shifts its gaze from an internal focus on those who are marginalised, to redirect the focus of research to an explicit interrogation of whiteness'. 82

This redirection to guestions of privilege may also be supported by the affordances of digital technologies. Participatory methods have tended to rely extensively on face-to-face projects, which has meant that PR has often been seen to be constrained by a problematic localism. 83 Yet it is now being reshaped as new movements provide compelling examples of digital participatory research and activism, which may open up PR to new ways of enacting global interconnections and interdependence.84

The questions facing participatory researchers now are not whether to persist with participatory approaches or not – but rather a renewed focus on the how. There is an ongoing need to better understand the politics and tensions, the challenges of living up to ambitions in the hopeful values of much PR, when confronted with the sheer hard work and vulnerability of all in the practice of PR, and the difficulty of tracing how academic and popular research practices continue to transform and be transformed in the process of doing PR. Attention to the complex histories of PR offer potential for redirecting us away from instrumentalising approaches, and opening of more uncertain and exploratory, and perhaps sometimes, radical potentials of participatory research.

Slater 2012: 118.

See, for example. Fine 2018 for one recent account of paticipatory research which can hardly be reduced to the kind of 'critique' implied by Slater 2012

Bergold and Thomas 2012.

Smith 1999: 175-179.

See Wakeford and Sanchez Rodriguez, this series.

Evans et al. 2009: 11.

See Myers and Grosvenor on 'History from Below', this series

See Document the Now on the Black Lives Matter movement www.docnow.io; and the Syrian Archive, https://syrianarchive.org

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GLOSSARY

Consciousness-raising

A process that involves a group sharing experiences that may be overlooked by political discourse, for the purposes of generating theoretical insight and political analysis. In the group everyone has the chance to share and their experiences are equally valid. It is particularly associated with the feminist movements of the 1960s and 1970s.

Indigenous methodologies

Research approaches based on the methods and knowledges of indigenous peoples, often highly critical of positivist theories and colonialist practices and their consequences.

Liberatory politics

A politics that seeks to to free a group or individual from social or economic constraints, or discrimination. Associated with selfdetermination, equality in representation and participation in politics.

Participatory research

An approach to research that seeks to research 'with' (rather than 'on' or 'for') communities through collective inquiry and democratisation of knowledge.

Popular epidemiology

Research undertaken by communities (ie. lay experts) to identify patterns in local illness and social and environmental factors that may contribute.

Positivism

A philosophical theory that reason and logic, based on empirical evidence, forms the basis of valid knowledge.

Scientific Objectivity

An approach to research grounded in Enlightenment thinking and positivism that aims to uncover 'truth' by removing all emotion, bias and belief. Results must be testable and reproducable. This approach has been criticised as impossible to achieve and lacking in responsibility to the world it studies.

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