

Tineke Abma · Sarah Banks · Tina Cook
Sónia Dias · Wendy Madsen
Jane Springett · Michael T. Wright

Participatory Research for Health and Social Well-Being

 Springer

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Tineke Abma • Sarah Banks • Tina Cook
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Tineke Abma
Amsterdam Public Health Research
Institute
VU University Medical Centre
Amsterdam, The Netherlands

Tina Cook
Faculty of Health and Life Sciences
Northumbria University School of HCES
Newcastle upon Tyne, UK

Wendy Madsen
School of Health, Medical & Applied
Sciences
Central Queensland University
Rockhampton, QLD, Australia

Michael T. Wright
Institute for Social Health
Catholic University of Applied Sciences
Berlin, Germany

Sarah Banks
Department of Sociology
Durham University
Durham, UK

Sónia Dias
National School of Public Health
Universidade Nova Lisboa
Lisbon, Portugal

Jane Springett
Centre for Healthy Communities, School of
Public Health
University of Alberta
Edmonton, AB, Canada

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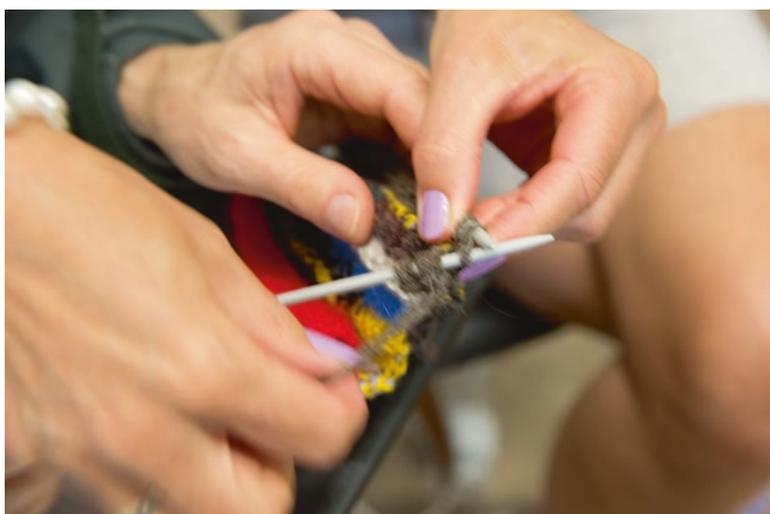
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Tineke Abma, Sarah Banks, Tina Cook, Sonia Dias, Wendy Madsen, Jane Springett and Michael T. Wright

Foreword: An Invitation to Knit Our Worlds Together



Participatory research processes, and those who take them on, have a learning-for-change agenda. They want to make the system in which they are researching better. In this book, that system is health care and community well-being and “better” means meeting the needs of its key stakeholders, not least the service users. Change is produced by the stakeholders in the system as they learn together to rework the current system so that it is improved. In participatory research processes, intended change is therefore the outcome and social learning is its mechanism. Often learning-for-change results in an entirely new system being created. More often, there are smaller improvements, which over time will make for a new system.

Participatory research processes are not especially new, but they have not been adequately described in accessible ways. This book makes a contribution in that it goes deeply into the various elements that make up the learning and change process of participative research. The authors open up the so-called black box of how learning for change actually happens and where it can get (un)stuck. That makes it

a welcome addition to the larger field of action research and, indeed, to social science more generally.

Much that is in this book is typically shared in conversation between mentors and students, change agents and stakeholders. Rarely has it been written for a public audience. At this very time when we are increasingly burdened by systems designed by and for a disappearing era, this book invites a deeper look at how more of us can engage in participatory processes. Attention to the kinds of details that produce a higher chance of success are all here and as such it is an excellent volume for students of research methods, but also for change agents who wish to bring more of a reflective practice to their efforts with systems change.

For those already familiar with participatory change, there will be enthusiasm to see the detail, the stories, the hints and applications. For those who are new to the practices and concepts of participatory research, perhaps the biggest requirement for appreciating this book is to give up what you think research processes should be. The conventional “shoulds” have usually been shaped by logics and methods that supposedly (but never actually!) ensure objectivity. These “shoulds” are part of our inherited academic research protocols that have served and continue to serve as excellent standards by which we can *understand* our current systems *as if* objectifiable. Unfortunately, they are largely useless for changing those systems in the direction of where the stakeholders wish to go. Our human systems are always interpersonal and therefore never entirely objectifiable spaces. Understanding alone does not bring change. We naturally engage and must also account for that. Hence the need for social proliferation of the kinds of knowledge for action in this book.

Health Care and Social Well-Being Revolutionized Through Community Engagement

Think back to the hazy days of the 1980s and early 1990s. Back to the escalating HIV/AIDS crisis. In the USA, a group of mostly educated gay men watched horrifying numbers of their friends die. They received little in the way of care they needed and began to feel they had nothing left to lose. In New York City, a group calling themselves “Act Up!” changed the course of the disease. Less understood, however, is their impact on how we increasingly do health care research. And while this book is neither about AIDS nor gay rights, it is about “acting up”-organizing and changing the momentum of disinterested science.

When Act Up! organized themselves, they took it upon themselves to insist on working as *partners* with health care researchers. Each brought different knowledge forms but together they began to experimentally treat HIV. By working with the leading researchers and physicians, Act Up! developed a model of participative research that transformed health care. No longer would patients simply wait and hope. Their very marginalization and despair was turned into a resource through mobilization and self-education. Community activation resulted. After all who better than the gay community itself could recruit the appropriate service users for

needed studies? Who but community members could make sure there were no blanks in the epidemiological network maps? Act Up! could quickly mobilize the requisite social capital. Interesting to note is that they used deeply creative, theatrical but deathly serious, methods as part of this demand to have voice in their own treatment: for example, staging funereal rites in a church filled with conservative politicians who simply refused to witness their suffering. Eventually Act Up! turned the tide. Today HIV is a chronic condition that even allows for a high quality of life. Related, because social organization is deeply entwined with the organization of science as an activity, the gay population has won the right to full citizen rights through much of the civilized world. Their new participative science of HIV has since saved millions of lives in sub-Saharan Africa. How science is done, how scientists relate to their “subjects” and how empowered the average citizen is, had made the difference between life and death. At that time participative research processes began to become mainstream. While we don’t necessarily have life-threatening illnesses to address, we have community and health care systems that are straining to break free of what might simply be called a credal hierarchy of experts and decisions-makers largely removed from the local concerns of people they serve. The very system of “power-over” organization must change to “power-with”. This book tells us how.

The same social liberation, the democratization of knowledge production calls science to become responsive to its stakeholders, placing people at the center. And so partnership between scientists and citizens is increasingly productive.

As our populations age, and chronic illness escalates, cost of care rises and families and communities are under increasing stress, the participatory research process will become more popular. Foremost perhaps in our unlearning of old protocols is the need to cultivate tolerance for ambiguity, concern for relationship building, and an understanding that collaborative experimentation is part and parcel of participative learning together. Learning is related to, but not the same as, understanding. Learning is a much more messy social process and it may often include mistakes. Learning is grounded necessarily in (inter)personal experience; it is not grounded solely or primarily in abstract concepts. When learning processes are done well, as they need to be in participatory research, we often experience delightful surprise, unforeseen success where the costs of upholding the current centralized systems can be redeployed to a stakeholder-centric model of emergent learning and coordinated action. This model of “researching *with*” is perhaps what people have always done for themselves before inquiry became the sole property of an ivory tower, which in turn had stakeholders become consumers of experts’ knowledge. Thankfully, we are increasingly liberating inquiry from that “banking” model, to use Paulo Freire’s term, which conveys the interdependence of capitalism and conventional research.

In the opening story of this book we meet Hilda, who puts it simply. She points out how perverse our funding system is that wants health care research goals defined *in advance* by researchers—before they have even bothered to hear from patients about what they actually want! What’s refreshing is that Hilda actually voices her

concern presumably in the belief that it could somehow be different. So many citizens have just come to expect to be ignored; they don't even imagine another way.

We learn through the book that what is good for one set of stakeholders is so often good for all involved. Involving service users, it turns out, is as practical as it is ethical. In fact, way too much money has been wasted because researchers have presumed to already know the solution in advance of hearing from stakeholders. Early benefits of inclusion show increasing trust (the social glue for all success in this domain), which then correlates with better data collection and often with the analysis of data when processes can include key stakeholders.

This book is not just about health care as it is practiced in a clinic, but about well-being more generally. For example, we learn from the coalition of engaged citizens and social workers who happily included stakeholders in their initial framing of the problem of how to better address homelessness in their community. After discussions together and taking input from several people who have experienced homelessness themselves as well as those who had worked for years on the issue, they realize that there are many causes. As several had nothing to do with the community directly, the research group decided to focus their resources on affordable housing, because there they have the opportunity to influence urban planning in their district (Chap. 4).

In addition to greater clarity of framing (Chap. 2) all the way to acting for change (Chap. 6), we learn some handy rules – the kind we may even know but of which we need reminders. How can we have our participatory research work be more accessible? How can we formulate questions that are less technical? Again it turns out that when we solve these conundrums, it is good for everyone. Who loses with a more clear understanding of the work? Often the proof of clarity is the ability to speak in nontechnical ways. These and many more “rules of thumb” are the kind rarely seen in the public domain. They are passed along in private conversations in apprenticeship-type settings. This mirrors the encouragement to talk explicitly and repeatedly in the research team about competing responsibilities, thereby identifying as early as possible what cannot be accomplished. This apparently simple rule around transparency in fact is setting new cultural guidelines for progressing the field of participation. When we first come to it we might imagine that everyone will be involved in everything, transparency will replace the guilty silence with honest estimates of limitations. A happy result will be less torment among participatory researchers!

For those with conventional training in social research methods, there is an invitation to repurpose those methods, interviews, focus groups, etc., by bringing an attitude for inclusion and a little innovation. This is what the researchers refer to, by way of Gadamer, as developing *a receptivity to others*. In this practice of receptivity, people with direct experience of the issues under study are not just “research subjects” or containers of data waiting to be squeezed. There is something in it for them too. Ironically, a more participatory process with others requires a more clear-headed understanding of oneself as an instrument of research too. Reflexivity is therefore key to enriching how we see the world. The authors stress how dialogue-centered the praxis of participatory research is and as we

might also consider how developmental this is, we turn in a way from the “I–It” relationship default of conventional social science to “I–You”. To a degree we are all colonized by a modern-industrial era worldview that is less and less human-centric. We are all an “it”, a cog in the dehumanizing systems we have created, but forgotten that we created them. By bringing emphasis to the relational quality between people, we get to meet ourselves as “we” and build a bridge to a new and more adaptive way of organizing ourselves socially.

This means that interviews become a suitable way to enhance the personal understanding of the person being interviewed. Focus groups can be opportunities for consciousness-raising, for opening a space in which not just rationalistic discourse is allowed. I see a reckoning here with the demands of epistemic injustice (which has pushed away all but an intellectual elite from inquiry processes that design our society). And so we see a welcoming to multiple ways of knowing. Naturally, this welcome can lead to especially rich ways of making sense of the generated data within a participatory process and so participation enriches sense-making as a prelude to coordinating action.

Acknowledging Problem “Knots”

In the greater democratization of knowledge there is a shift from “Power-Over” to “Power-With” models of organizing. As we have inherited deeply conditioned views and little practice with a new way of enacting power, we cannot expect an easy slide into participation. The book notes that and highlights the problems of what has been called “astroturfing”, a kind of fake participation, where artificial astroturf replaces authentic grassroots, as in a superficial consultation. We may need to guard against that as participatory research becomes more popular. Indeed this very book can help with that problem.

Deeper though is also the recognition that people – stakeholders – can and do also turn against each other when invited into an empowering process of learning. There is therefore a caution that this work is not for all, but it is for those who are both personally aware of their own shadow side around power as well as committed to transforming old dynamics. This takes patience and developmental effort. Where patience flags we can end up with fake participation or a fall-back to the way things were before the learning processes began. After all, collaboration is the new buzz word. Unfortunately, many like to use the word and then not follow it with any action.

The authors teach through many examples that illustrate the many stages: from defining the topic of research all the way through creating new structures. We see over and over the task of one lone researcher previously has become that of a collaborative process among the various groups of people affected by the issue to be studied: community leaders, professionals whose job it is to address the issue (e.g., social workers, nurses, educators, community workers, public health professionals), and administrators or public authorities who can make changes at the structural level.

I see in this book the power of the old core assumption of what it means to do research – be distantly objective – turned on its head. I see the power of the idea of what it means to be a citizen in the increasingly democratizing twenty-first century put into practice.

This book fits under the tent of action research and I see this book as a companion in the new stories and resources that are coming out as interest in action research rises in response to a need for more intelligent – rather than destructive – approaches to change, in which I have played a role for over two decades to help make the action paradigm more evident and accessible. One discount factor is that I do not bring an especially objective lens to this work! The authors share the premise that action research is not a neutral affair, neither ethically nor politically. All make explicit their efforts and their strategies. These cohere with basic principles of action research: the key principle being the participation of multiple stakeholders in the process of producing actionable knowledge, with an awareness that objective results are dependent on intersubjective processes. In this book, these colleagues in action research have opened up their practice of action research in health care and social well-being for others to learn from their difficult work. Can we be different? Yes! Can our systems become sustainable? Yes. It is good to see more of this work emerging.

Knitting and Cooking Action Research

Many women, in stepping into the field of social science, had necessarily adopted men's rationalistic perspective and individualistic orientation to research process. In fact, we learned that is what science *is* – that is, approaches that impute primacy to distancing, to rationality and thinking over relationship, and the so-called irrational (i.e., emotional-subjective) aspects of relational experience.

If understanding and then measuring is what's important in individualistic, rationalist research processes, why even bother with interpersonal (emotional/relational) experience? Indeed, the privileging of objectivity, since Descartes, has meant *not* dealing with (and not valuing) our subjective and intersubjective experience of people. That is a real problem when working with human systems, especially with regard to any kind of change agenda! Indeed, any movement to embrace the relational and the subjective remains largely taboo in the scientific endeavor today. This choice of a one-sidedly logical, mechanistic orientation to science represents, unfortunately, an overvaluation of the "masculine" and devaluation of the "feminine" in the original action research approach too. With books such as this one, gendered aspects of inquiry and scholarly practice are slowly swinging back toward a middle ground. We may proceed with "walking on two feet" of "head and heart" together. I am pleased to see this book is inviting back the feminine, which speaks of women

and men bringing their best (each of us has masculine and feminine, if usually in different ratio) in relationships that coordinate learningful action toward better human systems. That the emphasis of this book is on the experiential/subjective and relational is very welcome. Happily it turns out that the results of such processes can be good for all (including the ones with the purse strings). Let us knit our efforts together!

2018 Jubilee Professor at Chalmers Institute
of Technology, Sweden

Hilary Bradbury PhD

Preface: The Idea of the Book



Participatory Research for Health and Social Well-Being is an essential textbook designed to be accessible for people starting out doing participatory research. It is a practical guide to help readers become familiar with research for social change and well-being. The chapters cover all phases of the research process from its initiation to the creation of social change and impact. The book is intended for a range of readers, including undergraduate and postgraduate students, doctoral researchers, academics and practitioners in the fields of health and social welfare. It will be useful in generic introductory courses in research methods, specialist participatory research courses, PhD programs and education and training for community-based workers.

One of the unique features of the book is that it takes the participatory *process* of participatory research as a key thread. Its format helps readers understand the essence of participatory research as an *approach* to research (rather than a set of

methods), underpinned by a set of fundamental values. Participatory research involves people engaging and collaborating in a process of researching issues that affect them, including their own lives and communities, resulting in action-oriented learning and understanding (at both an individual and collective level) and transformational change. This is a context-bound, complex and dynamic process, which tends to bring together people from diverse backgrounds and different types of experience and knowledge. The text really capitalizes on our experiences. As a result, it is rich with reference material that comes from our participatory practice. In addition, it strives to articulate many of the previously overlooked aspects of participatory work; recognizing the compelling aspects of this work and alerting readers to the struggles or points that require active and ongoing reflection in practice.

We, the authors, are all engaged in teaching and research in academic institutions in various countries (The Netherlands, UK, Germany, Portugal, Canada, Australia) and are members of the International Collaboration for Participatory Health Research (ICPHR). The impetus for writing this textbook arose from our experience of teaching participatory research without such a book with which to support student understanding. One of the common obstacles when teaching participatory research is first that students tend to think of participatory research in terms of just another set of methods or techniques, rather than a philosophy based on a participatory worldview. Second, being socialized into a rather narrow view of what counts as research in the mainstream literature, students often find it hard to see that organizing and capacity building with co-researchers is part of the research process. Finally, the role of the participatory researcher can be confusing. Students might think a single researcher is or should be in control of the participatory process. In participatory research, however, control is shared and many people are co-owners of the research process. The content of the book anticipates these obstacles by making the process central. Students are invited to think in terms of critical questioning, acting for change, reflecting and learning.

The book was conceived in Amsterdam in February 2015, when Michael T. Wright, Tina Cook and Sarah Banks spent two weeks teaching and sharing participatory research experiences with Tineke Abma and her colleagues at the [VU University](#) Medical Center and Public Health Research Institute. More colleagues from ICPHR were invited to participate and the content was refined at the ICPHR annual working meetings in Berlin (2015), Malmö (2016) and Limerick (2017). The collaborative process of preparing the book has been inspiring, challenging, and, above all, an opportunity to learn from each other and weave together diverse and colorful ideas and experiences from a range of perspectives.



Working on the book, Malmo, ICPHR 2016

Knitting and Knots

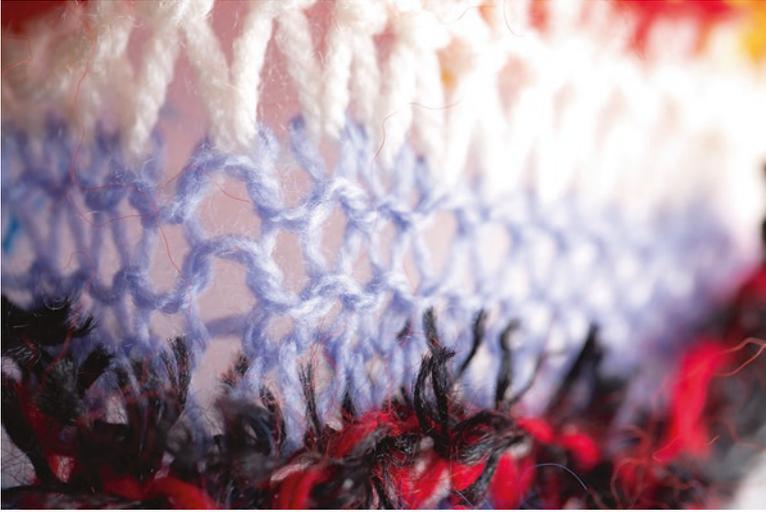
During our first meeting in Amsterdam, Sarah introduced the concept of collaborative knitting as a way of characterizing the participatory research process. She described an exercise involving someone bringing knitting needles and different types of wool, casting on some stitches and people in a group picking up the knitting and adding to it using different stitches and different colored wools. She had engaged in such a process during a collaborative research project and it had struck her as a powerful experiential method for both feeling and analyzing a participatory process. The knitting combined diverse wools and stitches into a patterned whole, and it was very messy on the reverse side, where different strands of wool had been knotted together and there were tangles of wool. The idea of knots resonated with the book’s co-authors, as these are often hidden on the reverse side – as in participatory research, where a lot of the hard work, conflicts and challenges are not written about or made visible in presentations of the research, but it is these knots that hold the whole process together. Without knots our work would unravel. So we decided to feature “knots” in the book to highlight where the critical and vital elements of participatory research can be recognized but also as points where dilemmas or difficulties arise in the participatory research process. At these points, we invite readers to stop and reflect.

To experience this ourselves and to involve more members of ICPHR in the book process, Sarah suggested we do some knitting at the ICPHR annual working meeting in Limerick in May 2017. Tina provided the wool and needles, and many people participated from across the world – including some who had not knitted since childhood, and one who had never knitted before. People helped each other to learn and contribute. They playfully added new colors, cast on and cast off stitches to expand and contract the width of the knitting. When Tina took the knitting to Cartagena, Colombia, in June 2017 to the Fifth Annual Action Research Network of the Americas (ARNA) Conference, the back became the front and there were knots on both sides. Then it came back to Durham, UK, where Tina, Sarah, and colleagues were teaching a Participatory Action Research course for doctoral students in July 2017, and it grew and changed shape some more. Finally it was sent to Tineke in Amsterdam in the state depicted in the photograph below.



There are many ways in which collaborative knitting is not like participatory research. For example, in the knitting process people usually add their contributions

individually without discussing or agreeing with others, although, because some people were less experienced knitters, the need to collaborate and learn together was often evident as you will see in other photographs of the process of knitting in later chapters of this book. However, we feel there are other features of knitting that also encapsulate the participatory research process, including: weaving together diverse strands of experience and meaning, with each strand retaining its own integrity while also contributing to the bigger picture; building on the contributions of others; being conscious of a shared project, owned by everyone; the unpredictability and messiness, and especially the tangles and knots.



Aims of the Book

This book provides guidelines, steps, and actions to craft a colorful pattern, but does not avoid showing the knots that stand for the dilemmas and difficulties in the process and the elements that hold the process together. Throughout the book, readers will find stories with critical reflections on the messiness, “co-laboring” and learning processes of participatory research. This honest presentation will help readers to come to grips with these processes and open up new horizons.

Offering a set of principles for practice distinguishes it from the more traditional “cookbook” approach with recipes for readers to follow. It also differs from other books on participatory and action research in that the participatory process is described in detail with an eye for the humanity and relational character of the process. Central throughout the whole research process is participation, that is, the engagement of those whose life or work is the subject of the study. Including case stories and vignettes from the fields of health and social well-being, the book pro-

vides an international spectrum of experiences in community-based and practitioner-oriented work for students who wish to use participatory research.

Following the metaphor of the knitting process, throughout the book there are points where “knots” are marked in the text, asking the reader to reflect on a challenge or problem to stimulate this spirit of inquiry. In that sense, this book offers a new language and discourse to understand the centrality of the process, which is a particular form of pedagogy. Theories of change, learning, knowledge, critical theory and group dynamics will help to understand processes, and the participants’ roles (including researchers as participants or informants and participants as co-researchers). Attention will be paid to challenges related to working with the expectations of mainstream research, including getting published, funded and accepted/legitimated within institutions.

On the Nature of the Book and How to Use It

In this book, we draw on our personal histories with participatory research and bring these histories and ideas together. Some of us led on the writing of a particular chapter, but snippets of each of us can be found throughout the book. One of the consequences of this choice is that there are differences in style. Also, while we have tried to present the book in a way that allows the nature of participatory research to slowly unfurl, given that it is not a linear process, the chapters do have some overlap. The book is written to work chronologically through the main phases of a participatory research project, but as in this form of research, this provided us with some challenges. It cannot be neatly packaged. The chapters vary therefore in terms of their focus, with some being more practically orientated and others discussing more complex theoretical and conceptual underpinnings. It may be that for you, some chapters will take priority when you first begin engaging in participatory research, and there may be certain chapters that help you start your research collaborations with more confidence. When you have experienced some of the joys and the issues in participatory research you may wish to come back to the book in the light of your new understandings. The best way to understand this form of research is of course to engage with it. But returning to this book in the light of your experience, to delve deeper into chapters that at first may not have seemed to offer you a starting point or seemed so immediately relevant, may now be the springboard for further development of your practice.

Contextualizing Our Work

Each chapter includes stories to illustrate and contextualize the topic, and/or scenarios that invite the reader to compare a more conventional approach with a participatory research approach. The vignettes, examples and case stories cover

community-based projects (involving volunteers, residents or service users as researchers, for example) as well as practitioner-oriented projects (where health, social or community workers, for example, are co-researchers). Some examples come from the public health field (including health promotion, mental health, disability, rehabilitation and elderly care), others from the field of social and community work (covering topics such as violence, debt, poverty and unemployment). Thus, the book covers a broad terrain, including a range of communities of place, interest and identity, advocacy groups and populations (e.g., children, older people, migrants, refugees, people on low incomes, and people who self-identify as belonging to different ethnic groups or as LGBT+).

These examples are situated in various parts of the world, including Europe, North and South America, Australia and New Zealand. While we have attempted to include material that is relevant across the world, we acknowledge that all authors are from the ‘global North’ (including Australia) and we inevitably draw on our own experiences in our writing and examples. Wherever you are in the world, we hope this book will help you to shape your ideas, organize and act for change. It aims to provide guidelines to navigate through the participatory research process, sensitize you for complex and dynamic learning processes and offers lots of internationally relevant creative examples.

Acknowledgements

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The idea of collaborative knitting was inspired by the experience of a community–university research project in the UK, of which Sarah Banks was a member. We would like to acknowledge this project, which was called *Ways of Knowing: Exploring the different registers, values and subjectivities of collaborative research*, funded by the Arts and Humanities Research Council (see <https://waysofknowingresearch.wordpress.com/2013/05/24/knitting-and-knowledging-between-metaphor-and-reality/>).

We are grateful that Janine Schrijver, community partner and professional photographer, shared her photos which she took of our knitting at the ICPHR meeting in Limerick. We are also grateful to other partner organizations that have provided photographs for the book.

Amsterdam, The Netherlands
Durham, UK
Newcastle upon Tyne, UK
Lisbon, Portugal
Rockhampton, Australia
Edmonton, AB, Canada
Berlin, Germany
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Tineke Abma
Sarah Banks
Tina Cook
Sónia Dias
Wendy Madsen
Jane Springett
Michael T. Wright

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About the Authors



Tineke Abma is a full professor of “participation and diversity,” co-head of the Department of Medical Humanities at the VU University Medical Centre, and research leader in the Amsterdam Public Health Institute, Amsterdam, the Netherlands. Formerly, she was an endowed chair in the field of “client participation in elderly care.” In 2013, she received an Aspasia laureate from the Dutch Council for Scientific Research (NWO). Her work is grounded in the interactive and responsive evaluation and empirical ethics. She has been involved in long-term projects in the field of psychiatry, elderly, and chronic care, and her work has been awarded for its high societal impact. Abma is the author/editor of a number of books, including *Evaluation and Narrative* (JAI Press, 1999) and *Evaluation for a Caring Society* (IAP Press, 2018).

Sarah Banks is a professor of applied social sciences in the Department of Sociology and co-director of the Centre for Social Justice and Community Action, Durham University, UK. She teaches and researches in the fields of professional ethics, community development, and community-based participatory research. She

has been involved in developing guidelines and case materials on ethics in participatory research and is the author/editor of a number of books on professional ethics, youth work, and community development, including *Critical Community Practice* (2007, The Policy Press) and *Managing Community Practice* (2nd edn, 2013, The Policy Press).

Tina Cook is a professor of education at Liverpool Hope University. At the core of her work is a focus on inclusive practice in research and evaluation. She teaches research approaches to students and community partners and has published on methodological issues in participatory research and its impact. She is an executive committee member of the ICPHR, an editor of the *International Journal of Educational Action Research*, and a founder member of the UK Participatory Research Network. Her own research focus is with people with learning disability and people with cognitive impairment.

Sónia Dias is a Professor at the National School of Public Health, Universidade NOVA de Lisboa. She teaches postgraduate courses and supervises PhD and master's students in the field of health promotion and disease prevention. Much of her research has focused on health of vulnerable populations, sexual and reproductive health, access to healthcare services, and migrants' health. She has been involved in the conceptual and methodological development in research and interventions with vulnerable populations, using community-based participatory research, combining quantitative and qualitative methods and evaluation approaches. She acts as a consultant for several international organizations.

Wendy Madsen is a senior lecturer in health promotion (CQ University, Australia). She teaches undergraduate health promotion courses and supervises postgraduate research, including participatory research. While much of her research has focused on the history of public health, she has been increasingly incorporating the use of participatory approaches in historical research and exploring how history and the humanities contribute to healthy communities and community resilience.

Jane Springett is a professor and former director of the Centre for Health Promotion Studies at the University of Alberta, Canada. She has been involved in participatory research and evaluation for over 25 years. She currently teaches participatory research within the graduate programs at the University of Alberta, School of Public Health, and has published extensively in the field of health promotion on participatory evaluation. She is co-author with Emeritus Professor Margaret Ledwith of *Participatory Practice: Community-Based Action for Transformative Change* (2010) published by Policy Press. She has coached over 20 PhD students.

Michael T. Wright has been involved in community-based health initiatives since 1984 in the United States and Germany, having served as a psychotherapist, program manager, clinical supervisor, researcher, workshop leader, and consultant. He was formerly the director of International Relations at the Deutsche AIDS-Hilfe and coordinator for the research areas HIV/AIDS and participatory research in the Research Group Public Health at the Social Science Research Center Berlin (WZB). He is currently professor for research methods at the Catholic University of Applied Sciences Berlin and heads the central office of both the German Network for Participatory Health Research and the International Collaboration for Participatory Health Research. In addition, he is coordinator of PartKommPlus, a national research consortium in Germany applying PHR for health promotion in German municipalities.

Chapter 1

Making the Case: The Arguments for Participatory Research



Chapter Summary

Abstract This chapter introduces the pleasure and the challenges of doing participatory research. It covers the origins and background to participatory research for health and social well-being, the underpinning paradigm and underlying principles and values. It introduces the notion of participatory research as a process dependent on context rather than a technical exercise. It provides an outline to the book and what to expect. Finally, it cautions about pseudo participatory research, finishing with some reflections on the demands and the surprises that this approach to research brings to those who engage in it.

Purpose To make the case for doing participatory research.

Central Question What is Participatory Research and why do it?

1.1 Introduction: The Fictional Case of Hilda in Liverpool

Hilda lives in an inner city area in Liverpool in the UK. She has lived there all her life but the area has seen many changes, none, in her view for the better. Many houses are boarded up or in need of renovation, young people are into drugs and the corner shop she used to buy her food in has closed down and she has to take the bus to the supermarket. That is, when she can make the effort to do so, as she is constantly tired and always seems to have a cold or feel ill. Everyone she talks to, if she ever sees them, does nothing but complain. Day to day life seems grey and monotonous, the back road behind her terraced (row) house is always full of rubbish and she lives in constant fear that someone will commit violence or burgle her house. She is particularly fed up with outsiders, often students from the local university or “posh” speaking people from elsewhere, doing what they call research. “Always asking questions that seem to have no relevance at all. One year it was all about what I ate, another about how often I went to the Gym! Questions, questions but never any answers nothing changes”, she muses. “Another year it was a psychiatric morbidity survey, whatever that is...I am not mentally ill,” she continues. Most of the people round her tell the outsiders to go away or provide made up answers to the questions. More recently, however a friend of her niece who was working at the local doctor’s surgery asked her for a chat and took her for a cup of tea at the only remaining cafe. She said she also wanted to do research but she wanted to involve Hilda. She had this research project to do for her course but she wanted to work with local people to explore something that would interest them. “Well”, Hilda thought, “you can start with looking at why we feel stressed.”

Hilda is not unusual in being skeptical about research, many people who are categorized as “marginalized” or living in poverty are often the subject of research but rarely see anything happening directly in their lives as a result. People living in poverty dependent on development aid often have programs imposed on them without reference to local conditions because of research done in a country with different

circumstances. Indigenous people everywhere have often complained of having opened up to graduate students about their issues, but have subsequently heard nothing and continue to live with poor health and struggling with their day to day lives they have shared with them. So much so they have refused to cooperate in any research unless they have equal say in the research process (Leeuw et al. 2012; Pyett and Waples-Crowe 2008).

In this book we want to take you on a journey through the experience of doing research *with* people not *on* them, in order to help bring about social change for health and social well-being. We hope that by the end you have a compass of the sort of questions you need to ask yourself at different stages of the process to help you deepen your knowledge and explore the practice of participatory research. By doing research with the people who are the center of any research topic, focusing on exploring issues that concern them and by involving them directly in all aspects of research, we all become co-researchers and co-creators of new knowledge that will benefit all.

1.2 About Us: Coming to Participatory Research in Different Ways

We all came to participatory research in different ways and our work has developed in various local contexts and with a rich variety of peoples. These backgrounds and experiences shape the book.

1.2.1 Through Health Promotion

Jane Springett For me, it was over 30 years ago when as part of the World Health Organization's Healthy Cities project, I became involved as an academic member of the intersectoral committee in a participatory research project exploring the health needs of people in a deprived area of Liverpool. It was led by Grindl Dockery and her experience was published in a book that came out in 1996, one of the earliest books on participatory research in health (De Koning and Martin 1996). Participation was a core philosophy of those involved in the Healthy Cities project (Dooris and Heritage 2013) and at the time as an urban geographer the approach resonated strongly with my democratic values, my interest in adult learning and my concerns about social inequality. But perhaps, if I was honest, what I liked most was developing a real connection with people. It also appealed because it was a more fluid process than the structured academic practice I had been brought up with, there was room for ambiguity, for intuition and a wonderful recipe for learning. Also, there was the kick of the light bulb moment when a group of people or individual has a sudden profound insight. It took me time, however, to develop the facilitation skills

to enable those moments to happen as I had to let go of the need to control and allow such insights to emerge.

Michael Wright I was attracted to participatory research because of the values which it incorporates. I studied theology and was very influenced by the social teaching of the Roman Catholic Church and by liberation theology, both of which emphasize the perspectives of people in society who are marginalized and the imperative of social justice. I went on to become a social worker, a profession characterized by the values of empowerment, advocacy, and giving voice to those in need. As an academic in Germany, my work has focused on the intersection of social work and health, particularly in the field of health promotion. The international health promotion movement has emphasized the importance of citizen action and community mobilization, both of which can be directly supported in the context of participatory research. As a participatory researcher, I am able to integrate the personal, the professional, and the political in a unique way to make a positive contribution to a more just society.

Wendy Madsen I also came to participatory research when I started to get my head around health promotion – properly, not my rather individualistic take on behaviour change that passed for health promotion in the gym and nursing worlds that I had been previously associated with. I stumbled across participatory research in 2010 while reading about community-based health promotion in David Buchanan's (2000) *An Ethic for Health Promotion* where he advocates a bottom-up approach to health promotion. From there I started looking specifically for authors who took similar positions and naturally came across Meredith Minkler's (2005) community development book and Minkler and Nina Wallerstein's *Community Based Participatory Research for Health* book (2008). As no one I knew did participatory research, it was very much a case of searching the online bookstores and seeing what I could find. There was little rhyme or reason to my searching because I didn't really know what I was looking for. However, in time I came across those who have contributed greatly to the field. I remember getting quite excited by Paulo Freire's *Pedagogy of the Oppressed* (1970), particularly the idea of action and reflection being held in balance. I decided to jump in and give participatory research a go. My first participatory health research project involved an academic colleague and myself driving a 600 km round trip in Australia to a rural community once a month for over a year (see Chap. 11). I have not looked back since as I was so impressed with the learning.

Sonia Dias I spent my early years as a researcher in health promotion working with vulnerable migrant populations in Portugal, and gradually came to realize that links between academics and those communities was frequently missing. Indeed, over time it became clear that there was a profound gap in public health between what was researched and what was relevant for health in those communities. My concern and drive to achieve concrete changes in the lives of people I met made me look to develop research in a different way; one in which empowering communities to build

capacity for their health promotion was key. The experience of being involved in several participatory research-intervention projects showed the extraordinary potential of the participatory approach. What motivated me the most was to witness communities getting stronger and taking and demanding action on health inequities.

1.2.2 Through Action Research

Tina Cook My route to participatory research was through action research. I came to action research having experienced frustration as a practitioner (teacher), that research about the people I worked with (children with special needs and their families) did not help myself or them with their daily lives. I wanted to find better ways to research real experiences, ways that valued the rich complexity of children, their education and their family lives. When I signed up for a Master's Degree at the local Polytechnic in the UK, I was introduced to action research by Professor Colin Biott, who in turn had been inspired by the work of Lawrence Stenhouse and enquiry based courses for teachers (Stenhouse 1968). I loved the way that in action research you did not have to define a situation before you researched it, that the focus of the research could unfold as people worked their way into knowing more and that the values of action research were embedded in respecting forms of knowledge grounded in practice. When carrying out an action research project I was, however, brought up very short one day by a parent who in the middle of a project said "why are you telling me all of this – it's not what I want to know."

As a teacher of children with special needs my mantra had always been to start from the child and take the lead from them. The comment from the parent made me realize that I was not applying that same mantra to research. I was not starting from where the parents were but where I thought they could be. Reading the work of people such as Robin McTaggart (1991) on participatory forms of research, Stephen Kemmis (2006) on becoming critical in the communicative space and Jennifer Greene's (2000) work on democratic evaluation has offered me a lifeline. Their work provided me with some home-ground from which I felt I could now develop my research in a way that offered deeper insights and relevance, that valued the experience and expertise of the people I worked with: it started from them.

1.2.3 Through Community Development

Sarah Banks My route was also from practice. I was working as a community development officer in the rural areas of County Durham, in the UK, in the mid-1980s. One aspect of the work involved supporting community groups and organizations to identify issues of local concern (closure of a shop or school, need for affordable housing, better transport) and take action for change. Inevitably this

involved elements of collaborative research, although they did not name it as such, including gathering opinions, assessing needs and making a case for change. In several areas local groups undertook “village appraisals” (locally-designed surveys of residents’ opinions, mapping of services, identification of needs). I facilitated these groups, working together with a range of people and organizations to co-design and analyze surveys, make recommendations, write and disseminate reports. Community development work is premised on principles of participation, empowerment, shared learning and collective action for change, so participatory research was a natural development of this.

Later, working at Durham University, although much of the research I did was fairly traditional research on professional ethics, I also got involved in a number of projects commissioned by, or in partnership with, NGOs. This included work on faith and young people and young people in rural areas, which had elements of peer research and an action orientation. The main boost to this approach to research was when Durham University became a “Beacon for Public Engagement” in 2008 and as theme leader for social justice I worked with others to set up the Centre for Social Justice and Community Action in 2009, which supports and promotes participatory action research for social justice. Since then I have worked with others on a range of community-based participatory projects and this work has come to dominate my life.

1.2.4 Through Responsive Evaluation

Tineke Abma I too came to participatory research via the day to day experience of doing research and evaluation and finding short-comings in common approaches. Back in the early 1990s when I started my career as an evaluator in The Netherlands, I grappled with how to do justice to the multiple perspectives and plurality of values of those affected by a program or policy to be evaluated, including those whose voice does not usually get attention in decision-making processes. At the time I worked in a psychiatric center, evaluating their rehabilitation program and initially was drawn to responsive evaluation as a way forward. The work of Bob Stake (2004), Egon Guba and Yvonna Lincoln (1989), Thomas Schwandt (2002) and Jennifer Greene (2006) served as a source of inspiration.

Responsive evaluation takes the multiple issues and concerns of various stakeholders as a point of departure to determine the quality and worth of a program or practice. It favors personal experience and draws upon the ordinary ways people perceive quality by listening to their stories. Then, pushing the boundaries still further, I started to engage stakeholders as partners and co-researchers and actively steered towards the inclusion of marginalized voices to prevent “epistemic injustice” (Fricker 2007). I did not want to engage participants for the information they were able to provide; their participation was of intrinsic value. This participatory strand to evaluation reflected a value-committed stance which I also

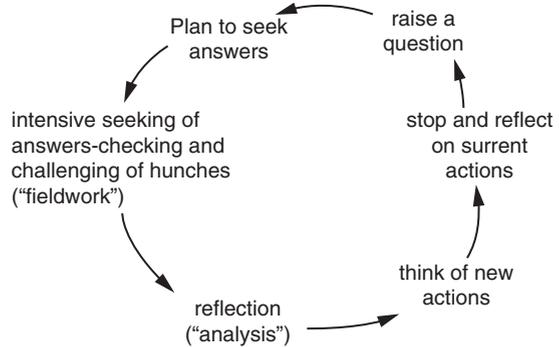
recognized in participatory research; working for social justice, equality, empowerment and emancipation. There is a commonality in working towards a sharing of power and control over the process of evaluation instead of uncritically privileging certain values and certain voices over other. Responsive evaluators navigate like participatory researchers relationally, dialogically and democratically in concrete practices to balance various value commitments and spur moral learning (Visse and Abma 2018).

1.3 So What Is Participatory Research?

First of all, participatory research is not a research method so it cannot be classified as quantitative or qualitative, indeed as we will show, it potentially can use both groups of methods. It is an *approach* to research. It sees research as a relational process through which new knowledge is produced collectively rather than by an individual on their own. The purpose of that new knowledge is to bring about some form of change or action, while the process of doing so is a continual one of learning, reflection and action. It means involving people whose lives are at the center of research in making the key decisions of any research project: what should be the focus of the research, what are the research questions, how to answer these questions, what information to collect, how to make sense of the information, how to share it and what action to take as a result.

How those people are involved is critical. What Stephen Kemmis (2006) calls “communicative spaces” need to be established, that is, spaces in time and place where people are brought together in circle to share their understandings and experiences, to reflect and to question. People understand the world in different ways but we do not know what those differences are until we have an opportunity to share and discuss. Often the starting point is people’s own stories of the situation and in listening to those stories with openness and respect, we demonstrate our respect for those different ways of knowing. This produces local knowledge and forms of action that can make a unique contribution to addressing health and social issues. What that knowledge is, depends on existing relationships and the way relationships develop between the people involved. Moreover, since the direction of the research may change as new knowledge is created, the process is an emergent and cyclical one. Being open to the experiences of people involved implies that the design cannot be pre-ordained. The design develops in conversation with the people. Therefore, although we can identify key stages of a research process in a linear manner, these stages are not played out in that way. It unfolds as you ask questions and put into practice the underlying principles and values. Knowledge is dynamic, changing with new experiences and information, it is always in the making. This is what makes this type of research so rich, exciting and expansive, that acknowledgement of flux. See Image 1.1, which is taken from the work of Yoland Wadsworth.

Image 1.1 The research process



1.4 The Main Underlying Values and Principles of the Approach

While we all come from different places, what connects us are the underlying values and principles of Participatory Health Research (International Collaboration for Participatory Health 2013). It is these underlying principles and values that shape our practice. Although we explore this in greater depth in Chap. 3 on Getting Started, it is worth looking at those principles and values here.

1.4.1 To Maximize Participation

The primary underlying value is to maximize the participation of those whose life or work is the subject of any research (Whyte 1991). So, as well as involving people regarded as poor and marginalized as identified above, it means involving people with illnesses and diseases in researching those diseases and illnesses, health workers in researching improvements in working practices or conditions, local citizens in researching how to make their neighborhoods safer, ethnic minorities in improving their living conditions, people with learning difficulties improving their health education and so on. Participation therefore becomes the key research method. This means that existing qualitative and quantitative research methods have to be adapted to promote participation and it also means developing new methods for collecting and analyzing data. We elaborate on making methods more participatory and data generation in Chap. 7 on Engaging.

1.4.2 To Enable People to Take Action

Another underlying value is that the research should help people take action and do that in a way that potentially empowers them. Paulo Freire, a Brazilian educator whose ideas have had a profound influence on participatory research, pointed out

that if people are consistently told how something should be, this can lead to the internalization of the negative images people have of themselves (Freire 1970). Bringing this to the surface and making people aware of this is a key part of the process of change. Moreover, since participatory research values all forms of knowing, local understandings are not dismissed but incorporated and explored. One form, such as academic knowledge, is not given primacy over other forms. This non-hierarchical approach to knowing is also reflected in how people relate to each other during the research process. Sometimes this can be difficult in health sector contexts where biomedicine and particularly the medical profession have a great deal of control over what is deemed as health, what causes ill health, what constitutes science and research and what services should be provided. While this is gradually changing as patient groups and others are seeking involvement in research and action, hierarchical approaches remain and exclusion rather than inclusion is the norm. So the participatory research practitioner has to use creative ways to change this.

1.4.3 To Add Local Value

Another principle of participatory research is that research should add local value rather than just extract knowledge for the edification of someone else. The research and the action also should be sustainable, in other words something needs to be embedded in the local community or organizations involved. This may be skills such as research skills, learning, a sense of empowerment or the results of a specific policy or action. It could be the process itself.

Example: Social Change as a Result of Participatory Research in Daily Activity Centers in Sweden

Some years ago Jane did some participatory research training in Sweden. Here she gives an account of what happened.

One of the course members initiated a participatory research project with a group of Daily Activity Centers in the local area. The aim was to improve the quality of the work offered to people with learning difficulties. Over a period of time the service users, their helpers and their family members developed a project whereby each activity center interviewed and collected information on another one and then they got together to analyze the results. I returned to Sweden some years later and asked the student, now a lecturer, what happened. She visited the organization and found that three years on they were still following the process and had embedded it in their continual improvement process.

This example (Dychawy Rosner 2015) is an illustration of social change that focuses on issues of practice but it can involve issues of policy. In either case the intention in the research process is everyone learns. Social learning is actively

encouraged through the cycle of look, act, reflect to create a connected knowing (Freire 1970; Ledwith and Springett 2010). This means trying to understand the other person through dialogue from relations of trust and empathy (Goldberger et al. 1996). Ideally the process engages people in transformative learning (Mezirow and Associates 1990). This is when people come to see themselves and the world differently and also how they can act in the world. This in turn often creates unexpected outcomes. Thus, the results of the research process can often be impossible to predict. This, of course, can be quite scary if you like to control everything. It is also somewhat at odds with current funding of projects which are tied to specific outcomes. So, again, a thirst for creativity is required.

1.5 Where Does the Approach Come From?

Participatory research is not new, it has been around for some years in a number of fields including education, environmental science, agricultural science, management science and development studies, as well as in a number of different traditions and cultures. In Sweden, for example, the idea of study circles goes back 100 years (Lundberg and Starrin 2001) while Indigenous groups would argue that we are merely re-remembering older more holistic ways of knowing (Cochran et al. 2008). The contemporary seeds to the approach come from a variety of sources.

1.5.1 *Building on a Rich History*

In Latin America, Africa and Asia, the common ground for a push for this type of research approach came from cumulative concerns for both the persistent inequalities in power and resources and the processes that kept people living in poverty in communities oppressed and dependent that originated in colonialism and the primacy put on Western science. Participatory research was seen as a way of challenging these dominant ways as to how knowledge is produced (Bradbury and Reason 2008). It is from these contexts that community development workers working for aid agencies and NGO's brought back to North America and European countries with a colonial history, experience of working in a participatory way largely outside established institutions (Jackson and Kassam 1998). Indeed, the first edited volume on participatory research in health was co-authored by two researchers with such a background, while its content reflected that international experience (de Koning and Martin 1996). The driver of this type of participatory research was the need to engage the voices of local populations in development initiatives and their evaluation alongside a deep sense of social justice. An example is the work of the Institute for Development Studies (IDS) founded in 1966 at the University of Sussex particularly the work of Robert Chambers who during the 1970s spearheaded participatory

approaches to development (Chambers 1997). It is also reflected in the work of the Canadians, Jacques Chevalier and Daniel Buckles (2013).

At about the same time people working in adult education were becoming concerned that the ongoing distancing of research from learning undermined the premise of their approach that the learner should be in control of their own learning and it was in this field that the words participatory research were first used (Hall 1975; Lykes and Mallona 2008). These ideas were reinforced at the time by the work of Ivan Illich (1975) and Paulo Freire (1970) both of whom were highly critical of mainstream education and reaffirmed the basic human faculty of knowing, learning and reflecting while David Kolb (2014) demonstrated the importance of experiential knowing for changing practice. The work of Paulo Freire (1970) has remained a major influence both on participatory research and community development, with his emphasis on a unity between theory and practice (“praxis”) as fundamental to the development of effective action for change based on teaching people to question and hence encouraging a process of what he called “conscientization.” A key feature of Freire’s approach is the role played by emotion, as this motivates community action. In parallel at this time the tradition of phenomenology was being applied to qualitative research with its emphasis on the importance of feelings and emotions as valid ways of knowing. These notions received reinforcement from developments in feminist research (Belenky et al. 1986).

Meanwhile, social psychology was providing us with an increased understanding of how groups flourish and learn together (Heron and Reason 1997). This built on the experience of action research, developed in the 1940s in management science. Action research challenged the notion of research as a static form of inquiry, arguing that “acting” was the basis of learning and knowing. Kurt Lewin (1948), usually seen as the founder of action research, concluded there can be “No action without research; no research without action” (quoted in Adelman 1993, p. 8). Lewin’s particular concern was to develop action research as a means for improving conditions for minority groups, to help them seek “independence, equality, and co-operation” and “to overcome the forces of exploitation” and colonialization that had been prominent in their modern histories (Lewin 1946 in: Adelman 1993, pp. 7–8). Thus we have come to see action research as a form of inquiry, embedded in action, that uses the experience of trying to improve some practical aspect of a real situation as a means for developing our understanding of it. Peter Reason (1994) further developed these ideas, distinguishing between first person, second person and third person action research and promoting the idea of collaborative inquiry. The first person level referring to inner feelings of discomfort and outrage of a person setting in motion a process of inquiry. The second level referring to sharing personal findings in a group to further stimulate the process of collective inquiry, which can be later placed in a broader socio-political framework (third person level). Along with John Rowan he also discussed different forms of knowledge: propositional, practical, experiential and presentational knowing (see Table 1.1 for description) and Reason coined the term: “new paradigm research” (Reason 1998; Reason and Rowan 1981). The notion of action research also found traction in education from the 1970s as a tool for developing teaching in schools.

Table 1.1 Different forms of knowledge

Propositional	Propositional knowing “about” something, is knowing through ideas and theories, expressed in informative statements.
Practical	Practical knowing is knowing “how to” do something and is expressed in a skill, knack or competence.
Experiential	Experiential knowing is through direct face-to-face encounter with person, place or thing; it is knowing through the immediacy of perceiving, through empathy and resonance.
Presentational	Presentational knowing emerges from experiential knowing, and provides the first form of expressing meaning and significance through drawing on expressive forms of imagery through movement, dance, sound, music, drawing, painting, sculpture, poetry, story, drama and so on.

Source: Reason and Rowan (1981)

The results of combining these different rich traditions became the basis of participatory action research, which was popularised by Orlando Fals-Borda (1987) as the descriptive noun, and perhaps also by Marja Liisa Swantz, who used the term “participative research” in the 1970s in her anthropology in Tanzania, which became her life work (Swantz 2015). These ideas converged around the 1970s during a period when the failures of “top down” expert designed projects were beginning to be exposed, particularly in the development field, but also in other contexts too. Local knowledge had been ignored with disastrous consequences resulting in crop failures, radioactivity contamination and natural disasters. Since that time people’s participation became a key issue on many different fronts fueled by a number of social movements around feminism, HIV/aids, ecology, indigenous traditions and community development. For further information on the rich history of participatory research see Hilary Bradbury and Peter Reason (2008).

1.5.2 Participatory Research in the Fields of Health and Social Well-Being

The field of health was slower in adopting this approach to research. Given the value put on the professional knowledge, particularly in some highly specialized areas it is not difficult to see why nor that early adoption has been in the areas of health promotion and primary health care, particularly in regions that are under resourced or where there are fewer established health care systems (Cornwall and Jewkes 1995). In these areas participation in some form is encouraged. It is a necessity in poorer resourced areas and part of the philosophy of health promotion and a key element of the Ottawa Charter on Health Promotion (World Health Organization 1986).

More generally in the health sector, while the rhetoric of “public participation” has been increasing over the years, how that is defined and executed varies considerably. Health professionals historically have been trained in giving information and advice based on “evidence” with evidence quite narrowly defined and based on Randomized Controlled Trials developed in clinical medicine. Expert knowledge

was considered to be the only “truth” and all other forms of knowledge suspect. It was believed that where the evidence was not translated into practice this was because either the researcher has not communicated it correctly or the practitioner/community member has not understood. Increasingly, however through work done in the area of knowledge translation it is now acknowledged that the knowledge into action process is complex (Wimpenny 2013; Bowen and Graham 2013). Advances in public involvement in science demonstrate the value of user involvement in research (Boote et al. 2015). Debates on research impact as the academic sector seeks accountability are also moving the discourse on impact as being more than research publications.

In recent years there has been a movement in some countries to increase the participation of people whose lives are affected by health issues by consulting them over the course of developing and implementing health research studies (e.g. Cropper et al. 2010; National Health and Medical Research Council 2002). People affected by the issue being studied are, for example, consulted in advance regarding research topics and priorities (e.g. Stewart et al. 2012; Abma and Broerse, 2010). This has led to an increasing repertoire of more innovative data collection methods to engage study participants in a more active way in research. Reasons for the involvement of people with experience include:

- to improve the study question (make it more relevant);
- bring in experiential knowledge;
- improve recruitment (a better sample);
- establish trust: especially among those who felt uncertain, suspicious, skeptical or vulnerable;
- to improve the quality of the data by having a wider set of perspectives to draw on;
- to develop new perspectives: dialogues and mutual learning processes may generate new perspectives;
- to check that the analysis seems appropriate (face validity).

So, there is a shift taking place that is building momentum and therefore books like this one are becoming more important in demonstrating how to be a successful participatory research practitioner.

1.6 How Do We Make the Case for a Different Approach to Research and Why Is It Important to Do So?

Traditionally the researcher has been defined as the “expert”, a distant external observer who uses certain variables and research methods and large samples of “subjects” in order to establish the “truth”. In participatory research, however the researcher, as in anthropology, effectively “joins the tribe”, and facilitates the process of the research with “participants” as co-researchers. The process is a relational one, in that it does not work if you do not create trusting relationships at the start. Together you create a circle of inquiry. The primary criterion for quality is

authenticity, that is, the results are recognized and confirmed in terms of mutual benefits by the participants.

Outcomes at the personal and professional and community/organizational levels include:

- acquiring problems solving;
- communication and lifelong learning skills;
- self-confidence;
- transformational change.

It might also include published contributions to knowledge.

These elements, the integration of learning into the research process, improved capacity in those who are involved and authenticity in that the research results are more meaningful and relevant to people generate actions that are timely, appropriate for the context and potentially sustainable, that is, get results. Not only do decision-makers who have power to make changes get to gain a better understanding because new voices are heard but action is actually taken. Moreover, the literature on participatory research in health indicates this results in not only efficiency savings and more relevant services but also the filling of research gaps, indeed improving the quality of the research overall (Jagosh et al. 2012; Viswanathan et al. 2004). In other words participatory research adds value, improving the processes of decision-making. Moreover, the cementing of relationships and understanding can lead to on-going work in other areas beyond the original project.

These, then, are the pragmatic reasons for engaging in participatory research but there are other reasons too, those relating to social justice and democracy. Engaging in participatory research is engaging in possibility, acknowledges the potential in people and seeks empowerment and capacity building through the research process and beyond. It makes no sense if you are interested in contributing to changing the social relations that lie at the bottom of health inequalities if you practice research in a way that reinforces the existing power relations that created the problem in the first place. Thus, if you believe in social justice, democracy and social change for the better then participatory approaches to research are a natural choice. However, sometimes in order to gain support for this approach you have to argue for the more pragmatic consequences. At the very least there is the political and moral imperative that as owners of publicly funded research, citizens have a right to have a say in the research process. The processes of decision-making to achieve that are important for the quality of the decisions. If involvement becomes a goal in its own right, how participation is executed becomes key.

One of the main criticisms of the approach is that it takes a long time to build the relationships and the trust that lie at the foundations of good quality participatory research. However, it depends how time is distributed across the timeline of a research project. It is like long term capital investment, only in this case, social capital, the greatest returns come over time. Certainly, there is evidence to suggest while greater time is spent setting the scene for participatory research, the process goes much quicker and without glitches later on down the line. For example, respondents are recruited quicker, data provides information that has more meaning

and relevance and action takes place sooner rather than waiting for a knowledge translation process.

1.7 “Beware the Greeks Bearing Gifts” or Participatory “Green Wash”

It is important to not embrace all research that is labelled as participatory as being true to participatory research’s underlying values and principles. Like “sustainability”, participation is somewhat of a buzz word in contemporary society. You need to be alert to the way the term is appropriated, in the same way companies that are endangering the environment cloak their real practices in apparently environmental ways through advertising, sometimes labelled as “greenwash.” When participation is not properly understood or implemented it can merely reinforce the status quo and be ameliorative rather than transformative (Ledwith and Springett 2010, p. 15). Various writers have attempted to identify different levels and modes of participation either as a ladder or a continuum (Arnstein 1969; Cornwall 2008). Sherry Arnstein (1969), for instance, critically assessed forms of citizen power in order to distinguish between real power and an “empty ritual of participation”. She developed a participation ladder to make visible the diverse levels of citizen participation (and thus of power), ranging from nonparticipation (manipulation, therapy) to tokenism (informing, consultation, placation) to citizen power (partnership, delegated power, citizen power).

It is recognized that various forms are valid at different times during the research process and this has to be negotiated. However, there is a difference between the notion of participation as a manipulated consumer, which is a passive role, and being actively involved and engaged. There are a series of critical studies that have demonstrated how participation can be used to reinforce power of large corporations and agencies (Cooke and Kothari 2001), but if engagement is done in the right way it can be a source of beneficial social change. Only real involvement can lead to the changes in consciousness, that is changes in perceptions, beliefs, abilities and sense of self (Staley 2015; Gaventa and Cornwall 2006).



KNOT

***Inauthentic or pseudo-participation** can occur when people who are told they could participate in the research process are not really involved or their involvement at many of the stages of the process is merely tokenistic.*

***Reflect** on the causes of inauthentic or pseudo-participation, and the consequences for potential co-researchers. How might they feel? And how one can one identify and deal with pseudo-participation?*

The frameworks for assessing participation help you to be aware in yourself and in others and, indeed, many organizations, of the tendency to believe that there is participation when a group is consulted on something already decided, for example.

Certainly levels of participation vary and often reflect a particular context. However, since participation means the more powerful giving up power, there is an understandable reluctance to do so or even a lack of awareness of one's own power. By maintaining an intent of participation throughout the process and through reflection you can engage practices to ensure maximum participation in the circumstances you find yourself and also find ways to encourage others to give up power and allow people to be involved. This sensitivity will also enable you to develop a "nose" for inauthentic participation claims.

Example: Inauthentic Participation

Jane recalls being asked to undertake a participatory evaluation with a primary care team around a children's environmental project. She comments as follows:

When seeking to develop a stakeholder group to take the evaluation forward, I was told in no uncertain terms that that was not necessary, telling (not asking!) the children involved to take photos was sufficient. This experience taught me to always have a conversation before I started on a project about what people understood about participation. On this occasion they had actually advertised for a participatory evaluator.

There are some damaging consequences if something that claims to be participatory actually is not, as this can lead to an undermining of trust, further confirming to people who feel marginalized that their voices are not being heard or paid attention to. Illich (1975) talks about the ill effects that can be caused by medical treatment itself ("iatrogenesis"), but we also need to be alert to iatrogenic effects of participatory green wash.

1.8 What to Expect in This Book

In this book we will take you gently through the process of doing participatory research, helping you along your way through highlighting the questions you need to ask yourself as you set out on the journey of inquiry with others. We cannot offer you a formula, because by its very nature participatory research is not predictable, but we can offer you a navigation system to help you on your way. Participatory research is cyclical, iterative and dynamic by nature. There are a number of threads that run through the process and gradually you learn how to weave them together. Like a piece of Fair Isle knitting (which has a complicated pattern), you need to focus on the individual stitches while keeping in mind the overall pattern. Moreover, while at the front, the pattern of the completed piece looks beautiful, at the back of the knitting there is a complex of overlapping threads and knots. The knots are important. Knots symbolize problematic issues that arise but without which everything would unravel.

Knots signify different kinds of connections and strengths depending on their specific form; they can always be untied and re-tied, made and remade.

Keeping in mind this metaphor of creating a piece of knitting, in **Chap. 2** we introduce you to one of the threads, **Framing**, in which we explore the collaborative process and steps that need to be taken to frame the research. Framing is essentially a way of looking at the world; a frame is a lens of understanding so in this chapter we explore ways to surface our own and others' ways of seeing the world and how to come to an understanding that takes the process forward. In **Chap. 3, Getting Started**, we help you to embark on the research process exploring what practical and ethical issues you need to think about. In **Chap. 4, Shaping**, you will be led step-by-step through the process of defining the focus of the research, together with your local co-researchers, some of the challenges and stumbling blocks you might face and possible solutions. In **Chap. 5, Organizing**, we will explore how to facilitate, negotiate and lead on the various tasks and roles within the project, how to estimate the resources needed, how to match the strengths of the participants to the tasks at hand, and plan together how the project will be done.

In **Chap. 6** we introduce you to another thread that is woven throughout the process, **Acting for Change**, in which we explore the ways action and change is both embedded in the research process and can take place after the research has finished, as well exploring the resistance to change that might occur. In **Chap. 7, Engaging**, we examine the notion of “method” – what it is for, and in what ways we might collect and generate data in line with the values of a participatory approach, including recognizing the value of the messiness that comes with learning and change. In **Chap. 8, Sens Making**, we explore ways of collaborating to make meaning out of any data generated in the research process; this includes how to organize a group process to make sense out of the data, taking into account various data forms and the different competencies and skills of the various stakeholders and community members, while ensuring a high level of participation in the process. In **Chap. 9, Telling and Showing**, we look at ways to share knowledge with our co-researchers and also how to present research findings to others. In **Chap. 10** we take the final interwoven thread within the research process, **Capturing and Reflecting for Change**, in which we examine the key role of reflexivity in the research process and its role in generating change. We also examine ways formally to evaluate the research and its impact, together. Finally, in **Chap. 11, Continuing the Journey**, we look at what might happen next, beyond the end of your project, for yourself and for others.

1.9 Change Through Participatory Research: So What Happened to Hilda?

Five years on, Hilda has taken a college course to become a community health worker. The community group that came together with some new people to undertake the original research are now organizing research in collaboration with the local environmental health officer and public health nurse to collect data on air

quality along the road that leads to the local primary (elementary) school as the result of a local meeting of parents concerned with pollution from trucks transporting coal from the local dockyard. Following the original approach from her friend at the doctors' surgery, Hilda contacted some friends and six of them met in her house over a cup of tea and some food. Together, and subsequently with other people who gradually got involved, they decided the focus of the research. Initially they did a local survey asking people what they thought the key health needs were. Fear of crime came at the top of the list. Actual crime statistics were obtained from the police and these challenged local perceptions of crime. In the interviews with local people a key issue had been the back roads or "alley ways" behind the row houses, which were largely perceived as places where young people and drug dealers might congregate. A solution was proposed in the form of what was called "alleygating". Householders in rows backing on one another were given the opportunity to have gates at each end of their back roads. The long-term effect was that many of the back roads became communal spaces where people met and created community gardens or play spaces. This increased the sense of community. A follow up survey showed an increased sense of well-being and a reduction in the perception of crime. The scheme was so successful Hilda was featured in a local video about the "alleygating scheme". The video story subsequently formed part of a local political campaign.

As can be seen from the story, Hilda benefitted alongside many others in her community group from participating in the original research project and the relationships they and other participants developed through the research process. This in turn led to new initiatives and changes. The example also shows how the initial research idea, in this case initiated by a local primary care nurse transmogrified into a co-created project about housing, well-being and crime. Similar examples can be found in the literature. On the other side of the Atlantic in Canada, for example, what originally started as a diabetes prevention project initiated by the Mohawk tribe in collaboration with the local family physician has led to a series of ongoing community led projects covering a range of health and community issues (Potvin et al. 2003).

1.10 Finally: This Comes with a Gentle Warning

Hilda's positive experience demonstrates how what you start with in participatory research may look very different at the end. When starting participatory research you engage in a process that will leave you changed as a result. Everyone whom we have ever taught participatory research, and who has stayed with it, has said they cannot return to the way they did research before. Not everyone, of course, is comfortable with this type of research or can do it. That is fine. If you like structure, concreteness rather than ambiguity, prefer data to people, need predictability and control, then this is probably not for you. If you are open to change, are comfortable

with not always knowing where things are going, like people, and above all have an innate belief in social justice and democracy and a faith in the humanity of people then this is may feel comfortable for you.

You learn best about participatory research by doing it as it is as much about experience and practice than theory and method. In writing this book, we had to address this challenge so eloquently described by Elizabeth Lindsey and Liza McGuiness (1998):

It's like trying to describe how to paint a Picasso. You can teach people about color, you can teach them about form, you can teach them about structure and the paint brush, and what bristles are like. And you can talk about different kinds of paper, and you can talk about what kind of music to play in the background to inspire them and you can talk about all sorts of things. But the bottom line is that when the image unfolds on the paper there is flowing of creativity from the wholeness of the person.

It is about looking at the world through a different lens, one that sees the world in relational terms. By this we mean a world where everything is interconnected, including self and other. Doing participatory research involves you as a whole person and you will be changed by the process. It will become embodied as a commitment and a way of being in the world. This is Patricia Maguire's description of doing her PhD:

The participatory research process is invigorating, and likewise exhausting. But then that is the beauty of it. You will not be detached. You too, not merely the participants, will be rehumanized. Participatory research is not only about trying to transform social structures "out there" and "the people", it is about being open to transforming ourselves and our relationship to others. Just as I examined the dilemmas and contradictions in participatory research, I was challenged daily to consider the dilemmas and contradictions of my own life choices. I was forced to question my part in the social construction and maintenance of large social structures, systems and relationships. And, relentlessly, I found myself asking: How am I choosing to be in the world. (Maguire 1993)

So if you are ready: let the journey or knitting begin!

1.11 Questions for Reflection and Discussion

In this book we want to take you on a journey through the experience of doing research *with* people not *on* them, in order to help bring about social change for health and social well-being. We hope that by the end you have a compass of the sort of questions you need to ask yourself at different stages of the process to help you deepen your knowledge and explore the practice of participatory research.

At its core this chapter aimed to introduce you to participatory research as an approach and to make the case for doing participatory research. We'd like you to reflect and discuss the following questions:

1. Why are you (or your group) personally interested in doing participatory research?

2. What are your underlying values and how do they relate to those underpinning participatory research?
3. What argument would you use to persuade someone to fund a participatory research project?

Further Reading and Sources for Inspiration

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Chapter 2

Framing: The Search for a Lens of Understanding



Chapter Summary

Abstract In this chapter you will be shown the collaborative process and steps that need to be taken to frame the research. Framing is essentially a way of looking at the world; a frame is a lens of understanding. Frameworks are critical for the interpretation and understanding of practices and lives. The process of framing consists of exploring various, sometimes unarticulated, frameworks and choosing those that are relevant to critically analyze the problems at hand, and offer insights to promote critical collective action. Exercises are presented to assist you in facilitating a group process for framing the research. Short examples throughout the chapter illustrate the concepts discussed, the challenges frequently faced when adopting this approach, and possible solutions.

Purpose To guide you in framing the research together with the local research team.

Central Question How do we choose relevant frameworks for critical analysis in our research?

2.1 The Framing Process and Its Importance in Participatory Research

The Map is not the territory. (Gregory Bateson 2000)

We see the world, not as it is, but as we are – or as we are conditioned to see it. (Steven Covey 1996)

These two quotes – one from a biologist and the other a management guru highlight how when coming together with our co-researchers to decide what research question we want to explore, everyone including ourselves comes with a particular lens through which we view the world.

This lens provides a framework that will determine what we see and do not see. Quite often we are not aware of such worldviews and that these frame the picture we have of the world. This is because they are a product of our up-bringing, education and our social position. The following often quoted urban myth illustrates this particularly well:

One dark evening a man was on his hands and knees under a street light looking through the grass. A pedestrian asked what he was looking for. “The keys to my car.” replied the man. Having some time and feeling helpful, the pedestrian joined the man in his search. After a while, with no success, the pedestrian asked: “Where were you when you lost your keys?” “Over there by my car.” the man gestured. The pedestrian was puzzled. “Why are you looking for them here?” The man without keys explained: “The light’s better!”

In this myth we can see that “the light” functions as an unarticulated worldview that frames the situation. The frame in this case for finding the keys of the car, is, however, not particularly helpful in solving the problem. However another person’s question helps articulate what was taken for granted (searching is easier in the light),

and offers a new lens to frame the situation and solve it (looking elsewhere, where the keys were lost).

So, the challenge is to bring the frameworks through which we view and “know” the world into the light so we can see them, but also to share and explore each other’s ways of knowing. To do so is to set the stage for the knowledge co-creation process that lies at the core of the participatory research process. This is important, because how we view the world shapes the research questions we ask, and directs the solutions.



Terminology is not mere description. Terminology and language is shaping worlds.

Reflect on the use of terms like co-researcher and academic researcher. Why should we differentiate? What does the co mean if we are using it to mean one set of researchers?

2.2 Making the Unconscious Conscious Through Critical Questioning

How we view the world shapes the research. However, we often are not aware of how we construct our understanding of the world. The challenge is to ask questions, like the pedestrian in the myth above brings in a new perspective, in order to make the unconscious and taken-for-granted clear to everyone involved and come to a common understanding as to what we want to know and why. This process of questioning and reflection does not stop as the process continues, since as we move

Example: Studying the Meaning of Sport in Times of Illness

One of Tineke’s PhD students, Mirjam Stuij, is studying the meaning of sport and physical activity for people with chronic diseases. Internationally, sport and physical activity are increasingly considered as a “medicine” to prevent illness and promote health. Numerous medical and epidemiological studies point towards the positive effects and several treatment and physiotherapy programs have been developed to promote health. Also, in current health care policies, it is assumed that people with chronic conditions, like diabetes patients, will benefit from sport and physical activity (for example controlling their sugar levels), and should be motivated to become physically active. The biomedical idea of “sport-is-good-for-health” has, however, been critiqued by sociologists, who draw on the philosopher Michel Foucault, highlighting how this is a form of “healthification” or “healthism” (Lupton 1995; Fusco 2006).

(continued)

Implicitly or explicitly current health policies expect people with health problems to strive to become healthy again by becoming physically active; they are expected to self-manage, discipline and control themselves. Some illness narratives of patients point, however, in another direction: not every patient is able to fulfil the norm of becoming physically active. Patients express, for example, feelings of pain, loss, sorrow or chaos that hinders them to become physically active, or they feel ashamed if they aren't able to live up to the norms, while some patients feel insecure about their body after diagnosis, don't understand their illness and suffer from complications. These so-called "counter-narratives" (Peters and Lankshear 1996) challenge the dominant healthism discourse. Counter-narratives are the stories "of those individuals and groups whose knowledges and histories have been marginalized, excluded, subjugated or forgotten in the telling of official narratives" (ibid, p. 2)

through the research process, the information we get and the resulting analysis may change our frame. The following example illustrates the socio-political and relational dynamics of this process.

Mirjam was well aware of the healthification discourse as a medical sociologist. She was able to ask critical questions of the co-researchers (people with chronic illnesses, advocacy organizations, health care professionals) in her research project, and foreground some of the issues that challenged the "sport-is-good-for-you" discourse. For example, not all patients have the intrinsic motivation, resources and capabilities to fulfil the norms set by contemporary policies to become physically active. However, she also had to work with people who believed it was important and meaningful for each and everyone, not withstanding their our own ideas, to become physically active in order to achieve control over their illness or to better respond to medical treatments. These stakeholders, including physiotherapists and medical doctors as well as some advocacy organizations, were not always aware that they reasoned from a biomedical framework, and that this was just one of the frameworks to approach the issue (versus the only, right or best framework, the factual truth, or something natural).

In other words, these groups tended to reason that what they thought, was reality. This is a common human error, and Bateson's quote – "The Map is not the territory" – alerts us that the map (the frame, what we think, see, find), is not the same as the real world. The world is bigger and more complex than the chosen frame or lens. The map is only an instrument to navigate through the world.

2.3 So, What Are Frameworks and Where Do They Come From?

Sociologist Erving Goffman (1974), under the title of *Frame Analysis*, argued that people interpret what is going on around their world through their primary framework. This framework is regarded as primary because it is taken-for-granted by the

user. Frameworks are ways of understanding our world and tools for meaning making and discovery. They are employed whenever we recognize an event as occurring in some context. The goal is to recognize and organize occurrences in meaningful ways. Frameworks can be more or less formally structured; theories and model are highly structured frameworks, metaphors are loosely structured frameworks.

A paradigm can be considered a particularly strong framework held by a particular (research) community. In his landmark book *The Structure of Scientific Revolutions*, Thomas Kuhn (1962) described a paradigm as “research firmly based upon. . . achievements that some particular scientific community acknowledges for a time as supplying the foundation for its further practice” (p. 10). Paradigms, in other words, help (scientific) communities to focus and define areas of relevance. In the first chapter we have explained that participatory research is based on a particular paradigm, which has a set of underlying principles and assumptions. This paradigm can be called transformational, that is to say we strive for social justice, for the reduction of health disparities, and do so via the sharing of power and ownership. Power is not used unilaterally, but shared in mutually transformative power relations. It is also a way of knowing that sees the world as a complex dynamic system that is the product of the interactions and decisions of the people that are part of it. So, as participatory research practitioners we ourselves work from a particular framework.

The French philosopher Michel Foucault (1982) alerts us to be aware of how discourses – particular ways of talking and use of language – are also framing and structuring what we see. Discourses are not neutral, but are shaping what we see and how we act. If we, for example, adopt the business language of performance measurement, consumers, output, safety, efficiency, productivity etc. into the field of health care and well-being this will influence the practice and identity of workers and service-users. The business discourse is tied to a rational, economic world-view. Workers come to see themselves as managers who need to legitimize their work in these terms, and thus not in terms of a care-logic of loving attention, responsibilities, relationships. Discourses are tied to power, because norms (such as efficiency, productivity, safety) are embedded in discourses. These norms reflect and re-establish hierarchies in societies. Power issues are at stake here. Indeed, when people do not meet the ideal norms they are excluded. So, discourses frame the world.

The concept of framing comes from the field of communication studies. There framing is also understood in relation to power, and the power of mass and social media. We all know how journalists and the media frame messages, and how this can distort and bias our understanding of events or persons. In one of the latter chapters on dissemination, Chap. 9 Telling and Showing, we share an example of a journalist who frames a neighborhood with children and their parents with low incomes and eating habits in a stereotypical way – eating food that is not considered healthy, parents not acting in a responsible way – thereby not doing justice to their creativity, resilience and agency. Michelle Fine (1991) nicely shows how framing is also done in policy documents, statistics and research reports. In her study of drop-outs from schools she noticed these adolescents were typically framed as “losers”; helpless, hopeless, depressed and ever without options. Those who stayed in school

were fulfilling the norms of being healthy, assertive and achieving. This contrasted, however, with what she found in her study. Fine showed that dropouts were actually critics of educational and market arrangements. So she began to ask: What is obscured by a portrayal of dropouts as *deficient* in a *fair* system? (p. 5). She goes on:

If youths who dropout are portrayed as unreasonable or academically inferior, then the structures, ideologies, and practices that exile them systematically are rendered invisible, and the critique they voice is institutionally silenced. (p. 5)

The concepts of framing and reframing are particularly helpful in participatory research, because these draw our attention to the relationship between what we see and label or frame, including how language, power and action are interrelated, and often taken-for-granted and unconscious, as Goffman alerted is to. Understanding processes of framing and reframing helps us to make the unconscious conscious, and to be able to ask critical questions that challenge and reframe processes and power embedded in practices and lives. Gender studies experts and feminists Petra Verdonk and Ineke Klinge (2013) explain, in the context of health care and public health, how framing is crucial in the “translation” of dominant knowledge structures via forms of communication and interaction into concrete social practices:

In the framing process, aspects of reality are selected that play a role in how [...] knowledge is interpreted, communicated and received. (...) frames select and draw attention to particular aspects (inclusion and emphasis), for instance by the presence of keywords, stereotyped images, sources of information or judgments, whilst they simultaneously direct attention away from other aspects which may than be overlooked, ignored, or considered less important (exclusion and downplaying). (Verdonk et al. 2013, pp. 53–54).

Thus, we see that framing in some contexts can be seen as the concrete, communicative form of discursive power, with which actions, behavior and views of people become labeled (“framed”) in a specific way according to dominant assumptions. Discursive theories of power alert us this can keep certain issues off the agenda while silencing the voices of some groups.

In the next section we draw attention to the importance of articulating and choosing relevant frameworks for critical analysis and surfacing tacit concepts.

2.4 Becoming Aware of Frameworks-in-Use

In participatory research people are invited as co-researchers to inquire into their own lives and work. One of the challenges everyone faces is that we not only come with our personal perceptions of situations, but are also always influenced by socially and culturally constituted and collectively shared frameworks. These frameworks-in-use determine partly how we understand our lives and practice, and are often taken for granted. If we want change and transformation, this cannot be reached without a critical investigation of taken-for-granted frameworks-in-use. As Stephen Kemmis (2008) puts it:

The person wishing to understand their own practice/praxis clearly must also attempt to understand the prejudices and perspectives built into their own ways of understanding – a task which may seem impossible. (p. 124).

Kemmis goes on to explain that understanding – from a hermeneutic or interpretive perspective – requires of each of us that we reflect on our frameworks-in-use. In other words, we all need to become conscious of our framework-in-use. How can this be done? How can we become reflexive and critical?

Sometimes formalized theory can help to make the unarticulated visible.

Example: Becoming Critical Reading Critical Theory During a Maternity Leave

Take, for example the experience of a PhD student of Jane, Cecilia Lindskov (2009). In partnership with a local family center in Sweden, she was helping them explore how they worked together to provide early childhood support services. In the first part of the research they asked her to interview each of the practitioners that made up the workforce about how they saw the family center, its aims and their role in supporting families. Having collected the data as agreed and having analyzed it, and having engaged the participants in reflecting on what was being said, Cecilia took maternity and parental leave to have her fourth child. Now a service-user of the care system she became increasingly aware of the prevalence of the notion of risk driving everything that was done to support her child. This led her to explore the notion of the Risk Society and to read Ulrich Beck's (1992) work on risk aversion and Anthony Giddens (1991) on Modernity. In turn, this led her to view the data from the interviews through a different lens.

Cecilia had not been aware that her personal framework-in-use was in fact a collectively time and culturally context-bound way of approaching pre and post-natal care, one that was informed by a biomedical perspective and an obsession with risk prevention. One also that was tied up with particular kinds of interests. The medicalization of prenatal and maternal care is promoted to be of interest for mothers and babies (less pain, less complications, less mortality), but one can critically interrogate whether medicalization primarily serves the biomedical system and its actors. With the help of Beck and Giddens – whose work provided her with a new lens and language, and hence enabled her to ask other questions – Cecilia was able to start challenging the status-quo and to realize her deep wish to create better, more just social conditions for the women and their children. Beck helped her critical self-reflection but also helped her collaborators who in subsequent dialogue sessions started to recognize certain aspects in their work within the new framework she shared with them. For this student, her co-researchers were open to new ways of seeing the world. We can see that the works of these scholars brought in new perspectives, through which the existing framework-in-use was questioned.

2.5 New Perspectives and Hermeneutic Dialogue

In participatory research we can see framing as a process of developing a framework while researching, in conversation with the participants through exchanging and changing perspectives. Philosopher Hans-Georg Gadamer (1960/2004) helps us to understand this process of exchanging perspectives, drawing our attention to the interpretative and hermeneutic character of understanding our world. Gadamer compares this process of understanding with a dialogue between the world and ourselves. In dialogues we try to make sense of and understand situations and experiences. From a hermeneutic perspective, our understanding is always partial. A person can never fully grasp the meaning of a situation; we can see only parts, because what we see is framed by our background, education, standpoints, moods etcetera. This implies there are always more perspectives, and this is not something we decide, but which is bestowed upon us, for instance when another person turns out to have experienced the same situation completely different. As understanding always takes place within a specific perspective, it can be enlarged by a change of perspective. This is not a rational and conscious decision, it is again a process we go through when our expectations are not being met. According to Gadamer (1960), hermeneutic understanding means extending one's perspective, or broadening one's horizon, for example by reading a book, like Cecilia did, or in a conversation when we are confronted with unexpected statements or expressions. Hermeneutic understanding means being open to what the other has to say, that means being prepared to accept it as relevant and valid for oneself (Widdershoven and Abma 2007).

Gadamer argued that a successful hermeneutic dialogue will lead to personal transformation because in dialogue it is not the full self-expression of self or bringing to the fore one's standpoint that is important, what is important is that shared expression holds the potential for the transformation of all. In dialogue the recognition of differences in perspectives and possible tensions between participants and stakeholders is an essential ingredient (Gadamer 1960/2004). It requires an orientation on the understandings of other people, the reflection on one's own values, and the willingness to be transformed by the other. Such a dialogue can lead to *Bildung*: a German term with a long history but which is taken here to convey moral development or cultivation (1960/2004, p. 10).

Gadamer considers this venturing into the position of others through dialogue to be crucial to this process. He defines *Bildung* as "trained receptivity to otherness", and argues that not thinking about one's own standpoints, concerns and interests for once, but rather making an empathetic and honest attempt to understand the other, brings about a transformation of the self through which one cultivates oneself (Gergen et al. 2001; Widdershoven and Metselaar 2012; Widdershoven and Abma 2007). Hermeneutic dialogue therefore needs to be at the center of our participatory research *praxis*, to bring about moral learning processes and a *joint* and *moral* understanding of what good care (or well-being, teaching etc.) entails. It concerns a learning process that entails reflections on moral issues, that is issues relating to Socratic questions about what is good, whether it is a good life or good care.

However becoming critical as a participatory research academic researcher is one thing, engaging others in this collaborative inquiry in order to generate mutually transformative power is another thing. Academics as participatory researchers are not experts standing above practitioners and co-researchers, thus they cannot hierarchically and unilaterally explain power structures, like the medicalization of pre- and postnatal care in the case of Cecilia. That would be patronizing, and authoritative, and thus contradictory to the underlying participatory research principle of sharing control and power. However, academics also cannot ignore the differences in educational background and experience among those who become co-researchers either. In the example of Cecilia the practitioners of the family center were socialized in a biomedical framework and not aware of the increasing focus on safety and security and its impact on the lives of mothers and children. Therefore, they needed to be invited and engaged in a process of collaborative learning. As we will see and elaborate on in Chap. 6, Engaging, this is about respect and valuing their unique ways of knowing while helping them to reflect on those ways of knowing just as Cecilia reflected on hers. This means choosing respectful involvement of people in a horizontal way to critically reflect on frameworks-in-use and face their preconceptions and perspectives.

2.6 Freirian Pedagogy

This is precisely what the Brazilian educator Paolo Freire meant when he suggested a plan for liberating oppressed people through education. According to Freire (1990) this entails three progressive phases:

- Conscientizing;
- Inspiring;
- Liberating.

Disadvantaged or oppressed people can become empowered by learning about social inequality (i.e. conscientizing), encouraging others by making them feel confident about achieving social equality, and finally liberating them. This has both an individual component (develop power *from within*), as well as a collective component, that is working together to politicized power *with others*, and to generate *power to* bring about change. It can also generate resistance and recalcitrance to oppose changes generated top-down by others.

Freirian pedagogy is powerful, because it engages individuals and groups in the process of questioning, and challenges people regarding their role in the world and their identity. Such process is often characterized by “messiness” (Cook 1998, 2009), and may include tension and conflict because frameworks-in-use are tied to interests and power relations. In the case of Mirjam there were situations when the “sport-is-good-for-you” discourse created tensions. For instance, Mirjam often felt that she called a study participant to account when she asked if he or she participated in sport and physical activity. Although she never intended to confront some-

one with “unhealthy” behavior or be normative, she did experience doing so sometimes. Another tension was created by health professionals emphasizing that patients should be more active, complaining about patients who were not motivated to change their lifestyle. These were typically called “couch-sitters.” Although these normative statements – telling people how to behave from an external point of view – were not very respectful, Mirjam discovered underlying tensions experienced by practitioners which helped her to understand these frustrations. One of these tensions was the highly protocolized, standardized and manufactured diabetes care on the one hand, and the expectation (and wish) to work person-centered on the other hand. Illuminating this underlying tension helped to create a mutual understanding among practitioners: that they can be successful in motivating patients to become physically active, but that this requires a more person-centered approach. This means that practitioners have to “liberate” themselves from the standardized and slavish following of protocols, and form alliances with patients and other stakeholders, such as health care management and health care insurers, to bring about change.

Yet, this sometimes included heated discussions. For example, during one discussion, two nurse practitioners became a bit angry because the research team put the “hard truth” of RCT research on the effectiveness of sport and physical activity interventions into perspective and emphasized the social aspects of walking. Walking appeared for several patient groups to be a very attractive way of becoming physically active, yet, from a biomedical framework was not considered to be effective. Interestingly and unexpectedly, one physiotherapist being around in the group, brought to the fore that going for a walk was better than doing nothing at all. So, the physiotherapists became the ones who introduced a new perspective, which appealed to all, and the idea of “small steps are also steps” was also found in the interviews with health care professionals treating people with diabetes.

This example shows that through confrontation and dialogue we may develop consensus about the meaning of situations and develop shared knowledge on how to act. Below we further explore the stumbling blocks that may need to be faced during the research process.

2.7 Stumbling Blocks in the Process of Framing and Reframing

So, while change and transformation requires a process of framing and reframing, including critical reflection, this can be difficult. Here critical does not mean being “negative” or being “against” something. A critical attitude refers to being open to new understandings and interpretations, which includes the courage to question presumptions, worldviews or frames and accepted and commonly held “truths” (see also Chap. 7, Engaging the (Sect. 7.4)). Some stumbling blocks in this process of critical reflection are the following:

2.7.1 *Dominant Frames and Resistance*

The frameworks we use are often developed over time, and have become quite familiar to us. If we live and work in contact with like-minded people, this further solidifies our framework. We have already mentioned how certain frameworks become dominant, and serve vested interests. Think of the medicalization of prenatal care in our Western world. While children were formerly born at home, we now think this is risky business. Therefore most children are born in hospitals, and therefore many women tend to think it is safer to give birth in medicalized context. The biomedical framework has become dominant in prenatal and maternal care. In The Netherlands gynecologists and midwives are, for example, debating whether this is the best framework. Midwives have especially been critical arguing that the biomedical framework is disempowering for women (they are no longer in control of their own body), and that, for example, pain medication, has implications for the relationship between mother and child. It is not hard to see how frameworks can conflict, and how they are tied to power and interests. The voice and framework of the midwives is weaker than the voice of clinicians, because the latter is supported by a stronger network and dominant discourses in society.

Quite often one becomes aware of one's framework, and its relative worth, when confronting a new one. Like Cecilia who needed Beck's work to discover her own way of seeing, or Mirjam who experienced in a more profound way that not everybody shared her stance when she met people who held solely a biomedical model on the meaning of sport and physical activity. Raising critical questions can lead to resistance and defensive responses by those who believe the status-quo should be continued, and who have an interest in the continuation of the status-quo. This becomes particularly difficult when a person's identity is tied up with a role engendered by that status quo. Like the medicalization of maternal care is in the interest of the biomedical system but also the roles of doctors and may lead to resistance when this is questioned. Mirjam also met resistance when she questioned "the sport-is-good-for-you frame." Some practitioners dearly wanted to implement physical and sport activities in their practice, and felt disappointed that this was not completely embraced by everybody. They simply thought that every patient should and could change their life-style by becoming active. This was what they believed, and this was tied to their job, unilateral use of power and professional identity. They could not see that this was quite normative and patronizing.

2.7.2 *False Consciousness*

Resistance can also stem from those who may not benefit from the status quo, but do not realize that change could be beneficial to them. The term *false-consciousness* is used to emphasize that what we observe and how we interpret what we see, is not necessarily complete or correct. Sometimes we have illusions. A simple picture can

Image 2.1 What do you see?



illustrate this (Image 2.1): some see in this figure the face of an old lady with a big nose, others see a young woman. The cue is that you cannot see them both at the same time. You really need to switch in order to see one of them. It requires a real shift – sometimes referred to as a paradigm shift – to start looking the world from a different framework than the one used regularly.

We may misunderstand situations and/or have an inconsistent or unrelated interpretation of reality. One way to deal with false-consciousness is education, another is the sharing of knowledge from diverse sources (propositional and experiential). In dialogue such misconceptions and inconsistencies can be discovered and discussed. Like the physiotherapist helped to open up the discussion on the “sport-is-good-for-you” frame by proposing that doing minor physical activities, such as going for walk, was not ideal from a biomedical perspective, but was far better than doing nothing at all, and therefore should not be treated negatively but rather be stimulated in patients.

2.7.3 Stigmatization and Self-Stigmatization

The process of questioning one’s life or work can also be difficult due to stigmatization and self-stigmatization. Stigma’s are generalized perceptions of certain groups of people. For example, in Western societies older people tend to be framed as being passive, complaining, without a role in society, economically unproductive etc. (Barnes 2005; Mehotra and Wagner 2009). Other groups that encounter

stigmatization include people with severe mental illness and learning disabilities. Stigmatization includes the experience of rejection, and it can lead to coping strategies of secrecy and social withdrawal, or energize persons into anger about stigmatization, whereas others seem indifferent to the impact of stigma altogether. Self-stigmatization is a process wherein people internalize these generalized perceptions (Corrigan 1998; Corrigan and Watson 2002).

In the case of older people this can lead to a situation wherein they identify themselves with the negative notions of becoming older, that they should not bother others with their lives. In a participatory research project with older people in nursing homes this was one of the greatest barriers to involving older people (See the case example in Empowerment in Chap. 6 for details). They thought they should be grateful for the care given to them. While they were not satisfied with certain aspects, especially the food and meals, they felt that they could not be critical. There was also fear; that being open about their concerns might perhaps have consequences (being dependent, not getting the right help and support). It was only after a collective process of relational empowerment in which they became aware of the frames they had internalized – that older people should just accept everything – that they could feel inspired to act collectively to change their lives. Crucial in this process was the civil disobedience of one of the older women. At one moment in time she stood up and refused the meal. Saying that it was awful, and that she was not going to pay for that. This act awakened all residents: they did not have to accept everything. They had a voice, and the power to resist certain things that they did not like.

2.7.4 *Colonized Mind*

We are swimming in an ocean of whiteness. (Di Angelo 2011)

This quote from Robin Di Angelo reminds us of our colonized mind. That is to say that we are raised with the myth that whiteness is superior; this colonizing framework is deeply ingrained. So much that we are not aware of it. We are simply “swimming in an ocean of whiteness.” Simple experiments have demonstrated that even small children are already infused with these colonized notions and white-privilege. For example, having to choose between a white and dark-skinned doll most of the children in the experiment, both white and colored children, preferred the white doll, and said that the white doll was more beautiful. This is even true for black and colored children, and thus comparable to self-stigmatization. This affects people on a deep emotional level. Taj Johns (2008) talks about “internalized oppressions”, and describes a process “learning to love our black selves” to heal from these internalized oppressions. Johns, facilitating, a participatory research process, discovered how he was evaluating himself “from a white standard, a standard that influenced my relationships, my presentations in the world, and my love of self.” (p. 477). This awareness prompted a process wherein he started working with a

group of called SASCHA (Self Affirming Soul Healing Africans) One, exploring how the mind, body and spirit responded to racist experiences, and how important it was to reframe situations to become free and liberated:

We have a big wound that we carry with us from racism. We will not be healed until we heal that racial wound. There is something about these racial issues we have internalized. (p. 478)

The mind can react by interrupting or denying the experience; the body may take a fight or flight stance; or the spirit can cause one to feel hopeless. These encounters offered temptations to numb or withdraw from the experience by using addictive patterned responses. We identified racism as the common variable that we needed to reframe. (p. 476–477)

The issue of colonization is not only important for black people in the US, as Johns shares, but also important in Canada and other parts of the world, because of the impact of Western thought on Indigenous populations and issues of racism. This also leads to a privileging of Western concepts of health at the expense of the more holistic models held by Indigenous populations.

2.7.5 Dominance of Abstract Models over Life-world Experiences

To define is to exclude. To mark what is inside and what is outside is to draw a line. This is the frame (Hopfl 2006).

What researchers as experts tend to do is to study the world using definitions and abstract models. Heather Hopfl (2006) nicely illuminates what definitions do: they draw lines, make distinctions between what is inside and what is outside. Definitions and models are simplifications of reality (Maps of the territory, to phrase Bateson), and have an enormous attraction. Models and causal relations help to control and predict, and are generally valued higher than other ways of knowing. Most prominent in the field of health care is the trend toward evidence-based medicine aiming to implement reliable, objective and scientifically sound research findings in clinical practice. The trend to evidence-based medicine was meant to counter the influence of bias and unfounded opinions in health care and to protect patients from arbitrary or ad hoc decisions made by health professionals. Yet, it has also led to a hierarchy wherein practice-based and experiential knowledge are considered as less valid and reliable than professional, expert or termed as scientific knowledge. Sara Ahmed (2017), a feminist theorist, says how within academia “the word theory has a lot of capital” (p. 8), but is often very narrow and isolated from the real world and difficult issues like violence, inequality and injustice. Likewise Heather Hopfl (2006) alerts us that to use theory and a reference to theory is often a move to establish authority. She says: “Here is a frame of reference which both announces our authorship and authority, and establishes this authority by reference to other authorities which conform the standing of our authority.”

Privileging scientific evidence as the gold standard and highest form of knowledge leads to a situation in which some people and groups – those with less powerful positions – will find it harder to have their voice heard. Their life-world knowledge can easily be disregarded as “just another anecdote”, “an emotional outburst”, “subjectivist” or “irrational.” In participatory research we believe that academics are not the superior group with the best framework. The voices and experiences of other groups are also valid sources of knowledge. Moreover, and most important in participatory research is not to privilege one framework over the other.

Participatory research is about finding practical solutions to real life issues. Real life is complex and messy. By examining our potentially conflicting theories and frameworks we can then use them as tools to understand the world and help build new solutions. This places mutual learning and knowledge development at the center of the research process as we test our ideas and put them into action. As such we are active participants in a transformative process whereby we change practice in order to inquire into it. This intertwining and combination of theory and practice is called *praxis*; it is through the effort to transform the world that we generate knowledge. Ahmed (2017) calls the notions and ideas generated through action “*sweaty concepts*” (p. 12). A sweaty concept might come out of a bodily experience that is trying:

Concepts are at work in how we work, whatever it is that we do. We need to work out, sometimes, what these concepts are (what we are thinking when we are doing, or what doing is thinking) because concepts can be murky as background assumptions. But that working out is precisely not bringing a concept in from the outside (or from above): concepts are in the world we are in. (p. 13)

Like Ahmed (2017) participatory research privileges the practice, and is grounded in pragmatism, a tradition that departs from the notion that we can never be certain of the truth, and only work with beliefs and ideas as long as they “work” in practice. Pragmatists are also very keen not to use theory in a dogmatic way. They argue, for example, that people should be able to “unstiffen” their beliefs and principles and to put them into play, by confronting them with the situation at stake. Hilary Putnam adds that practical problems are always “messy”. Unlike theoretical problems, analyzed by philosophers, practical problems cannot be solved via well-defined solutions. There are plausible approaches, but these will never show themselves as scientific or definitive (Putnam 2004). In other words we should stop considering our beliefs and theories as fixed and start using them: conflicting frameworks and theories should not only be discussed, but rather be used as tools to build new solutions. This implies that in participatory research people learn and develop knowledge by putting ideas and theories into action. So unlike traditional research in participatory research researchers are active, transforming a practice to be able to inquire it, leading to what Ahmed (2017) calls “sweaty concepts.”

2.8 Ways of Exploring Various, Sometimes Unarticulated Frameworks

There are several ways of exploring unarticulated frames that are held by those who are engaged in the research, and choosing those that are relevant to critically analyze the problems at hand. A practical and simple tool is the 5 W's, which we will illustrate with a participatory research project on the power relationship between management and client councils (Baur et al. 2010). It concerns a large elderly care institution in the Netherlands with eight separate locations: two nursing homes, and six locations with residential care. Every location had its own local client council, consisting of residents, relatives and volunteers. In addition the organization instituted a central resident council consisting of two representatives from each local resident council. Only relatives and volunteers were allowed to serve on the central council, because it was considered too much of a burden (in terms of energy, time, and content) for residents to participate.

2.8.1 *Practical Tool: 5 W's*

1. What's going on here?
2. Who is involved?
3. Where is this taking place?
4. Why is this happening?
5. When is this happening?

In this case these questions resulted in the following answers by the main stakeholders.

1. What's going on here?

Management: The law requires that we have a client council. It is hard to work with them. They are complaining about small matters. Their functioning needs to be evaluated.

Client councils: We feel we are not taken serious, we have not much influence. We are involved too late in the decision process. We feel overwhelmed by reports that contain difficult jargon.

2. Who is involved?

Management: The client council has some legal rights. When it comes to certain decisions we need their approval, like outsourcing the kitchen or a merger. It is hard to inform the council about these complex issues.

Client councils: We do not feel involved in the process. We are consulted in very late stages of the decision-making; it is hard to adjust things at that stage.

3. Where is this taking place?

Management: The legal context requires us to install a client council. The health insurer will cut down our budget if we do not have a client council.

Client councils: This is a nursing home. People are old (aged over 80+) and it is hard to engage them for this council. Too much responsibility. So, we have family members and volunteers in our councils.

4. Why is this happening?

Management: We want an evaluation to improve the client council's functioning.

Client councils: We are not happy with how things go. We want to have a say. We want to serve the residents and their quality of life and well-being. It might seem small, but residents find matters such as food important. They complain about their potatoes being old.

5. When is this happening?

Management: Today, people enter a nursing home when they are quite old and frail. Yet, it is expected that we involve people.

Client councils: We are confronted with more complex matters all the time. All those big issues, we hardly have any time left to listen to the residents, with their problems.

Both stakeholders felt that resident councils lacked influence. Managers ascribed this lack of influence mainly to resident council members' limitations in thinking and speaking about complicated policy issues. Resident councils attributed their lack of influence to the fact that they were given information too late, after policy decisions had already been made. These aspects were also illustrative of the communication problems between resident councils and managers. Resident councils wanted to speak about the "small" issues that affect the quality of life of clients (such as the temperature of the potatoes served at meals), whereas managers found themselves in a difficult position where they were obliged (by law) to speak with resident councils about amalgamations, budgets and annual accounts. The comingling of these shortcomings and legal expectations of the collaboration were never expressed in public, but were evident behind the scenes through numerous complaints and reproaches.

As one of the researchers involved, Tineke and others had to bring these issues out in the open in a way that would bring resident councils and managers closer together instead of driving them further apart. The participatory researchers started to help to articulate the framework held by management and framework held by the client councils. They used Jurgen Habermas' (1987) theory on systems and life-world to help to understand the tensions (Baur and Abma 2011). Habermas' work can be considered as a critical theory. While traditional theory is aiming to represent reality and build up scientific knowledge through causal "if-a-than-b" relations that enable prediction and control, critical theory (Max Horkheimer cited in Kemmis 2008, p. 125) can be described as follows:

Critical theory has no special influence on its side, except concern for the abolition of social injustice ... Its own nature ... turns it towards a changing of history and the establishment of justice.

Being critical in critical theory means inquiring whether and how the status quo is leading to situations that are inhuman, alienating, unjust and irrational.

Habermas (1987, 2003) constructs a two-level concept of modern society that integrates the domains of the life-world and the system-world. The life-world is the realm in which we as persons are oriented to the perseverance of interpersonal and communal values like love, friendship and solidarity. It is guided by communicative action (co-operative action taken on the basis of mutual deliberation and argument), and the search for mutual understanding. Differently, the system-world is oriented towards the continuation of material goods and welfare, and values the market, efficiency and effectiveness. Strategic action is leading in interactions here. In Habermas' view modern society has resulted in an imbalance between both worlds, meaning that the system components of economy and technology penetrate all aspects of daily life, repressing chances for communicative action in the life-world. We saw this happening in the elderly care organization example. Management held a framework derived from the system-world and acted strategically. The client councils reasoned from the life-world of residents and felt frustrated not being taken seriously. The system world dominated the life-world, and this led to problems in communications. Experiential knowledge and stories of residents were considered not important, considered subjective and anecdotal from the perspective of the system-world that privileged expert knowledge and created a realm of distance, reducing residents to consumers or numbers in a bureaucratic system, it valued professional protocols and instruments, leading to an asymmetry of knowledge in the organization.

During dialogues, resident councils and managers learned from each other that they shared an important interest, namely the well-being of the residents. Since they mostly focused on their differences before, hearing the perspectives and experiences from the other stakeholder group created a new understanding and possibilities for the future. This discovery motivated the participants to jointly sketch some prerequisites for a good and constructive participation process in the form of a joint action agenda. Thus, dialogue served as a vehicle for finding common ground in the context of asymmetrical relations. This joint agenda could only be formulated on the basis of mutual understanding and on the new insights of the resident council members and managers related to the acknowledgment that they needed each other to further develop their collaboration. This was not seen as an instrumental need (in terms of dependency), but as an intrinsic value of interdependence and the mingling of diverse forms of knowledge and experiences.

2.9 Social Change Begins with Reframing

A frame is a lens toward understanding. In participatory research framing means exploring various, sometimes unarticulated frameworks, and choosing those that are relevant to critically analyze problems and gain insight, in order to promote critical

collective action and liberating social change. That is to say, social change begins with reframing. In this chapter we have explored how to surface our hidden and not so hidden frames that we all bring to a research process. We have shown you the value of theory and the value of sensitive critical questions in teasing out our differing world views as we engage with practical action. It is not just about exploring others' frames but also critically reflecting on our own as we deepen the inquiry process.

2.10 Questions for Reflection and Discussion

The core of this chapter aimed to guide you in framing the research together with your local research team. We'd like you to reflect and discuss the following questions:

1. What are the taken-for-granted frameworks you use in your research? And those of the people you work with.
2. Think of another perspective that you can bring in to broaden the horizons on your subject of study.
3. Imagine how framing can silence the voice of (groups of) people.

Further Reading and Sources of Inspiration

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Chapter 3

Getting Started: The Initiation of a Partnership



Chapter Summary

Abstract This chapter discusses what to consider at the start of a process of participatory research. This includes clarifying what different parties understand by “research”, what type of research they want to undertake for what purpose, and the value of making a “working agreement” based on discussions about how to conduct research in a way that is fair, respectful and beneficial to all co-researchers and research informants. The chapter introduces a set of ethical principles and practical guidelines for conducting participatory research, considering the specific ethical issues in participatory research relating to partnership, use of power and blurring of boundaries between researchers and informants. It also considers how to handle ethical concerns common to all social research about informed consent, privacy, anonymity, falsification of data, and what these mean in a participatory research context. Illustrations are given from examples of participatory research projects.

Purpose To offer an overview of practical and ethical (including relational) considerations to bear in mind at the start of a participatory research project.

Central Question What are the main practical and ethical considerations to bear in mind and prepare for when getting started with participatory research?

3.1 Introduction: Starting Carefully

One of the features of participatory research is that the processes and outcomes are unpredictable. This is partly because at the beginning we may not know exactly who all the co-researchers will be and what interests, experience and knowledge they will bring. The “start-up” phase may be quite extended, or there may be “new starts” in the project as new avenues are explored and more people become involved. The process may gather momentum slowly, from an initial idea to a full research project. Hence it is easy to forget the importance of taking time to check out exactly what each party understands by “research” and what they want to get out of it; whether they share the same values and if not, whether this is an impediment or a creative tension; and what each person and/or organization might be able to contribute and what they are expecting from others.

Although it may seem very formal, there can be a value in all parties making an agreement about how to work together (or at least having a clear conversation), including defining responsibilities and roles, and anticipating practical and ethical challenges that may arise during the research process.

3.2 How Does Participatory Research Start?

Participatory research may start in many different ways, which may influence the track it takes and who takes a lead and becomes involved. Here are a few examples:

3.2.1 *A Small Community-Based Organization or Group*

A small community-based organization or group wants to examine and improve a health/social well-being issue and invites service users/community partners to join a research team and/or approaches larger organizational partners.

Example: Debt on Teesside: Pathways to Financial Inclusion

Thrive Teesside, a small organization working on poverty issues in North East England, identified worrying levels of high-cost debt linked with stress and mental health issues amongst local residents. Thrive initially undertook its own research in partnership with two national non-governmental organizations (NGOs) (Church Action on Poverty and Oxfam) and local volunteers. Later Thrive contacted nearby Durham University for help in organizing and analyzing data they were continuing to collect. After several years the relationship between Thrive, Church Action on Poverty and the University developed, and they submitted a joint bid for funding for a larger action research project, Debt on Teesside, involving university researchers, Thrive community organizers and local volunteers (see Image 3.1). The University was the fund-holder, the project was based in Thrive's offices and a partnership agreement was drawn up outlining allocation of funding and responsibilities. The project was co-managed and delivered. This project exemplifies the slow development of a partnership over several years leading to a co-designed project. (See Banks et al. 2013a; Banks 2015, and www.durham.ac.uk/socialjustice/researchprojects/debt_on_teesside/).



Image 3.1 Members of Thrive Teesside planning together. (Photographs: Thrive Teesside)

3.2.2 *A Large Organization*

A large organization (e.g. hospital, school, NGO, university) seeks to examine and improve a health/social well-being issue and invites service user/community partners to join a research team.

Example: *Imagine North East*

Durham University's Centre for Social Justice and Community Action (UK) was part of a bid with several other universities for a large government research council project on civic participation (how people get involved in their own communities and influence decisions in public life). The idea was that each university would lead on a different aspect of civic participation, with the expectation that some of the research would be co-produced with community partner organizations. Durham University was to undertake research on historical aspects of civic participation, focusing on two areas of the nearby Tyneside conurbation that had been the sites of well-known national community development projects in the 1970s. The University therefore contacted key organizations and individuals in these areas, and eventually 12 organizations joined the funding bid, each with their own self-designed project to undertake as part of *Imagine – Connecting communities through research*. A “co-inquiry group” of all partners was formed to share ideas and monitor the research as it proceeded. However, the concept of the project had come from the University, and with such a large number of small partner organizations, the overall coordination and management remained with the University. This example illustrates research initiated by a university, which then engaged local community organizations to undertake aspects of the research. (See www.durham.ac.uk/socialjustice/imagine/).

3.2.3 *A PhD Student or Academic Researcher*

A PhD student or academic researcher interested in a topic may invite community partners/service users to join a research team.

Example: *Researching Conservation and Rural Livelihoods in Kosi Bay, South Africa*

A South African PhD student (Philile Mbatha, University of Capetown) wished to conduct a participatory study into how Indigenous people's livelihoods interacted with complex governance systems in an ecologically diverse conservation area in Kosi Bay. In order to pursue the research she first gained permission of the traditional tribal leaders, the Chief and the Headman, then

(continued)

visited the local villages. Here she discovered that the villagers did not recognize the authority of the traditional leaders (who had let them down in the past). She therefore needed to call village level meetings to explain the purpose of the research and gain formal consent from people of the villages. They were initially suspicious, but then agreed to participate and local community research assistants were engaged in the research.

3.2.4 Practitioners in an Organization

Practitioners in an organization see a need for some research and then initiate this themselves, inviting service users to participate as researchers.

Example: Women’s Health Improvement Research (WHIR) Project

A researcher and a policy officer working for Scottish Women’s Aid (SWA) identified a need to undertake research on the impact of homelessness as a result of domestic or sexual abuse on women’s health and well-being and identify solutions. SWA is a third sector organization that supports women, children and young people in Scotland who have experienced domestic abuse, and has a particular focus on campaigning for responses that actively prevent violence against women. A community-based participatory action research project was developed as a partnership between Fife Domestic and Sexual Abuse Partnership and SWA, with the SWA researcher and policy officer facilitating and supporting women with experience of domestic abuse and homelessness to act as community researchers. (See www.scottishwomensaid.org.uk/policy-research/research/women%E2%80%99s-health-improvement-research-project/).

3.3 Building Trust and Developing Ideas

It is important for potential co-researchers to take some time to get to know each other, organizationally and individually, to see if it is going to be feasible and/or desirable to work together. Sometimes research partnerships develop out of existing relationships amongst individuals or groups that already know each other and have worked together in other ways. For example, several of the community partner organizations that joined the *Imagine North East* project already had relationships with the part of the University that was leading on the research through having provided student placements for Community and Youth Work students over several decades. This meant there was a degree of familiarity and trust. In the case of the relationship between Thrive and Durham University, Thrive initiated this from scratch through searching on the University website for people involved in community-based research. However, Thrive and the Centre for Social Justice and Community Action worked together on several small projects over a few years before submitting the research funding bid together for *Debt on Teesside*. In addition to the University

staff and students assisting with small pieces of research, they also attended Thrive's community organizing training and Thrive provided a student placement.



Building trust among people from diverse backgrounds who do not know each other at the start of a participatory research process can be challenging.

Reflect on what the potential co-researchers need to know about each other. How would they share their motivations, interests and organizational commitments?

Some of the preparatory work that needs to be done for building trusting relationships is listed below.

3.3.1 Sharing Motivations, Values, Ideas, Concerns and Possibilities

It is important to consider what values and motivations the individuals and organizations involved have, their concerns and ideas for the future, and whether these are compatible with each other. This can be gleaned from having conversations, attending events/meetings with each other, examining what other work the potential partners are doing and what they say in their reports and websites.

Example: Are Our Values Compatible?

In the *Debt on Teesside* project, the anti-poverty mission and community organizing approach of Thrive Teesside seemed to fit well with the interests and commitments of Durham University's Centre for Social Justice and Community Action. On the other hand, Thrive Teesside was a Christian-oriented organization, affiliated to Church Action on Poverty. The University research center was secular and the academic working most actively with Thrive was not Christian. Working with each other over several years enabled both parties to feel confident that this was not a problem, and that their networks and expertise were complementary.

3.3.2 Clarifying Understandings of Research, Types of Research, the Issues to Be Researched and the Goals of Each Partner

It is useful to explore what each party thinks research is, what participatory research involves, what can be achieved by means of research and what makes "good" research. For example, is research desired to reinforce existing pre-conceptions; to

explore underlying processes and causes of situations and events; and/or to evaluate a practice or intervention to show whether and how it is working? If different partners have different ideas about what research is, what type of research might be desirable in a particular situation or what counts as valid research, then perhaps a research partnership will not work.

3.3.3 Agreeing Broad Aims and Objectives of the Research

Example: Lack of Trust in Research

At the village meeting where the PhD student (Philile Mbatha) was explaining the purpose of the research in Kosi Bay, she comments that the villagers said:

how troubled the word “research” made them feel, as they stated that during colonial and apartheid eras, their land and resources were taken away from them under the guise of research, and ever since they do not trust researchers. I therefore had to carefully explain the objectives of this research to the people. After discussing the objectives, the people expressed that they appreciate this type of research that includes them because, oftentimes, researchers have come into the area to research about plants, forests and fish; but ignored the people living in the area.

After getting to know each other, it should then be possible to decide whether or not to work together. It is not always easy to pull back from a potential piece of participatory research, but it may prevent difficulties in the future if a tough decision is taken early on. If it seems like the partners are going to be able to work together, then they can begin to develop some broad aims and objectives for the research. Or if one party has already got a set of aims, as in the case of Thrive Teesside’s aims to understand and counteract the negative effects of problematic debt, then it will be important to share these carefully with all participants at the outset and ensure that everyone understands and agrees with the purpose of the research. If necessary, some modifications may need to be made to accommodate the different interests and needs of various people and organizations. Although in participatory research the ideal is for all parties who will be involved to co-design the research together, sometimes this is not possible. New people may join a research team after the planning and design process has started. Or one or more individuals or organizations may apply for funding for a project and seek to engage co-researchers for particular parts of the research when they have gained funding. This may commit the research team to a particular research design in advance, although it is usually possible to make modifications later and it is important to build in flexibility as far as possible.

Example: Modifications Along the Way

In the *Imagine North East* project there was a gap of several years between the original bid for funding and the start of the research. For some community organizations the contribution they had originally planned to make no longer fitted their program of work. Therefore changes were made before the signing of an official partnership agreement between the University and 12 partners at the start of the project.

3.4 Is a Participatory Research Approach Suitable or Possible?

We should not assume that participatory research is necessarily the best approach for examining or exploring the issue to be studied. It may be too practically or ethically difficult to undertake participatory research, or it may be that a “traditional” approach will achieve the desired outcomes more effectively. By ‘traditional’ we mean research that may be quantitative or qualitative but takes a more distanced approach to gathering data and making meaning from that data, with ‘objectivity’ being a central tenet. Some questions that can be asked in considering whether to take a participatory approach are listed below.

3.4.1 Do the Respective Partners Have Sufficient Time, Commitment and Resources?

As outlined in Chap. 1, participatory research has many advantages, but it is also very challenging and requires commitment, patience, time and a particular set of skills. So it is not to be entered into lightly. Very often participatory research entails some of the co-researchers undertaking training, or at least being mentored or supported by more experienced researchers. It may involve attending many meetings to plan and discuss the research together. These meetings may be long and complex, as people from diverse backgrounds learn how to work together, communicate well and take decisions. They may have different ways of learning and knowing. There may be situations where potential researchers have limited time, or the research involves methods that the majority of the co-researchers are not competent to undertake and they are not keen to engage in training, or there may be a shortage of keen co-researchers. In such cases, more traditional approaches to research might be suitable, with an academic or professional researcher taking the lead, perhaps guided by an advisory or steering group.

Example: Unrealistic Timeframe

A Master's student (Mark Hudson, Durham University, UK), who was also a youth worker in Sweden, started to plan a participatory research project involving young people undertaking peer research on inter-faith relationships in a Swedish town. He then realized that the time taken to plan the project with the young people, train them and work with them on data analysis was unrealistic for a short Master's dissertation. So he changed his research design.

3.4.2 What Organizational Supports and Barriers Exist?

If the parties involved decide to go ahead with participatory research, it is important to identify the organizational support that may be needed and available, as well as any potential barriers. If a university or large organization is involved as a partner, then the institution will have specialist staff with expertise in drawing up budgets and partnership agreements; they will have libraries, access to information sources, technical equipment, meeting rooms and data analysis packages; and they may have contracts with travel agents or suppliers of reprographics. Yet these advantages may also prove to be barriers – if the legal team does not understand the nature of participatory research; the finance department is not willing to provide immediate cash reimbursements for community researchers' travel; the procurement team requires a contract to be made with a university-accredited film-maker; and the ethics committee judges it is too risky for some community researchers to play a role in the research. Community organizations and NGOs may be well-located in the area where the research will take place, offering a good meeting point for community researchers and networks with potential research informants. But is there enough space, how will confidential interviews be conducted, do the organizations have the infrastructure to support and manage a research project? All these issues arose in the *Debt on Teesside* project (see Image 3.2), but only some were anticipated.

Example: Delays Due to Long Negotiations Between Organizations

Having been awarded the funding for the co-designed *Debt on Teesside* project, the Durham University Legal Team had to draft an agreement with Church Action on Poverty. This included outlining the responsibilities of each party, and the payment for the part of the project to be delivered by Church Action on Poverty and Thrive Teesside. This agreement took several months, leading to the project starting late and a delay in appointing the University researcher. The Legal Team was concerned that the Thrive community organiser and volunteers, who as part of the action element of the project were to act as mentors to indebted households participating in the research, could be regarded as offering “financial advice”. Hence Church Action on Poverty should have a “consumer credit license”, otherwise there might be a risk of legal action against the University if poor financial advice was given to someone. It took a long time to convince the Legal Team that money mentoring was not the same as financial advice.



Image 3.2 Money mentoring, Thrive Teesside. (Photo: Thrive Teesside)



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Sometimes participatory research is not the best approach to use.

Reflect about the circumstances in which a more “traditional” approach might work better. How would you tell your potential research partners that you have decided not to go ahead?

3.5 Considering What Ethical Issues May Arise and How They Can Be Overcome

Participatory research generates a range of ethical issues over and above those expected in traditional research. An ethical issue is a matter that relates to people’s rights, responsibilities and roles. This may involve questions of human, animal and environmental benefits and harms and making decisions about what is right and wrong action, good or bad attitudes. While unanticipated challenges will always arise, it is important to be aware of potential ethical issues in advance in order to handle them as well as possible when they occur. In traditional research, the main ethical issues covered in textbooks, codes of ethics and research ethics approval procedures tend to be about ensuring participants are not harmed, that their rights to confidentiality and anonymity are respected, that they give consent to participate based on full information about the research process and purpose, and that data and findings are collected and presented honestly (for an overview of research ethics see Oliver 2010; Iphofen 2011; Banks 2012). These issues all occur in participatory research, but they tend to be more complex as the dividing line between researcher and researched is not always clear, and how the research will develop is often not known in advance (for a discussion of the distinctive types of ethical issues in participatory research see Banks et al. 2013b). Furthermore, because of its collaborative nature, one of the key issues in participatory research centers on the use and balance of power between the parties involved.

3.6 Ethical Principles for Participatory Research

Drawing on the work of Durham University's Centre for Social Justice and Community Action (CSJCA), the International Collaboration on Participatory Health Research (ICPHR) agreed a statement of ethical principles and some guidelines for conducting participatory research (Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2012; International Collaboration on Participatory Health Research (ICPHR) 2013). These documents can be a useful starting point for discussing ethical issues in advance, and also for preparing an application to a research ethics committee or institutional review board. Alternatively, for small NGOs conducting their own research which does not require approval by a research ethics committee, working through the ethical principles and guidelines can be a useful internal process for planning ethical research.

Example: Developing an Ethical Framework

The community research team supported by Scottish Women's Aid on the Women's Health Improvement Research Project used the ethics guide and principles to develop their own ethical framework for the research.

Below we list the principles from the ethics guide. There is also an EasyRead version of the document available on the web, which is very useful when working with people who find plain language easier, for example children or people with learning disabilities (Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2013).

Ethical principles for participatory research (Taken from Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2012)

These principles are at a relatively general level, with the bullet points offering brief illustrations of what each principle might include

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

(continued)

2. *Equality and inclusion: encouraging and enabling people from a range of backgrounds and identities (e.g. ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research, including a commitment to:*
 - Seeking actively to include people whose voices are often ignored
 - Challenging discriminatory and oppressive attitudes and behaviours
 - Ensuring information, venues and formats for meetings are accessible to all
3. *Democratic participation: encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need, including a commitment to:*
 - Acknowledging and discussing differences in the status and power of research participants, and working towards sharing power more equally
 - Communicating in language everyone can understand, including arranging translation or interpretation if required
 - Using participatory research methods that build on, share and develop different skills and expertise
4. *Active Learning: seeing research collaboration and the process of research as providing opportunities to learn from each other, including a commitment to:*
 - Ensuring there is time to identify and reflect on learning during the research, and on ways people learn, both together and individually
 - Offering all participants the chance to learn from each other and share their learning with wider audiences
 - Sharing responsibility for interpreting the research findings and their implications for practice
5. *Making a difference: promoting research that creates positive change for communities of place, interest or identity, including:*
 - Engaging in debates about what counts as “positive” change, including broader environmental sustainability as well as human needs or spiritual development, and being open to the possibility of not knowing in advance what making a “positive difference” might mean
 - Valuing the learning and other benefits for individuals and groups from the research process as well as the outputs and outcomes of the research
 - Building a goal of positive change into every stage of the research
6. *Collective action: individuals and groups working together to achieve change, including a commitment to:*
 - Identifying common and complementary goals that meet partners’ differing needs for the research

(continued)

- Working for agreed visions of how to share knowledge and power more equitably and promote social change and social justice
- Recognizing and working with conflicting rights and interests expressed by different interest groups, communities of practice or place

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

- Working within the principles of participatory health research
- Ensuring accurate and honest analysis and reporting of research
- Being open to challenge and change, being flexible and prepared to work with conflict

3.7 Using the Ethical Principles as a Focus for Discussion

Looking at this set of principles (or the EasyRead version) together at the start of a participatory research process can be a useful way of developing shared understandings and commitments. A research team might discuss what is meant by some of the principles, whether they agree with them and how they might put them into practice in their specific research contexts. They may wish to use these principles as a starting point, modifying some of them and developing more of their own.

Example: Women’s Health Improvement Research Project

This participatory action research project facilitated by Scottish Women’s Aid was led by women with experience of domestic or sexual abuse, involving 10–15 women as community researchers. They used the EasyRead version of the ethical principles to talk about working together as a team:

We handed out the seven core principles and we used the EasyRead version which has more accessible language. We also used Ketso [www.ketso.com] which is a tool useful for participation. There are branches of a tree and people write their ideas on leaves to add to the branches. So each member of the group is able to contribute their own thoughts and we developed a working agreement using that.

3.8 Developing a Working Agreement

The second part of the ethics guide offers some more practical guidance about how to put the ethical principles into practice. One suggestion is that the research partners draft a working agreement about how to work together.

Example: Community-Based Research on Sustainable Lifestyles

A PhD student (Will Wilson, University of Lincoln, UK) undertook research with local communities to develop a framework to encourage people to shift towards more sustainable lifestyles, especially in relation to energy use. He found the suggestion of producing a working agreement particularly useful, in order to share the principles on which the project would be based with all co-participants. This helped him in preparing his application to the University research ethics committee:

The crucial element of this was the plan to produce a working agreement, to be issued to all potential co-researchers at first contact, outlining the principles upon which the research was being undertaken. At this point I did not produce the working agreement, but identified what it would cover ... This submission was highly commended by the ethics committee as an “impressive, well-thought submission that demonstrated a clear commitment to ethical research”.

A working agreement about how the research partners will work together would normally be a written document, unless culturally inappropriate or explicitly not wanted by the partners. However, the agreement need not be regarded as fixed or unchangeable – as participatory research often develops in unexpected ways. The working agreement may be used as a framework to be reviewed and revised on an ongoing basis. It may include practical details of working relationships, as well as an outline of how to ensure that people who provide research data are protected and credited. The process of developing the research agreement is as important as the written end product. The conversations needed to develop the agreement allow all partners to understand better everyone’s needs and concerns, which helps to build the openness and trust essential for good partnerships. Scottish Women’s Aid described the process they adopted:

We used the questions as a way of starting discussion with our Steering Committee around some difficult issues, particularly with respect to ownership, control and use of the research data and protocols for handling difficulties and conflict.

Possible headings for a working agreement

(Taken from Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2012)

- *An agreed set of ethical principles* (such as those listed earlier)
- *Guidelines for communications*, including preferred ways of communicating (e-mail, skype, face-to-face meetings), expected frequency of communications and meetings, how to ensure that a few participants do not dominate and that people speak in plain language

(continued)

- *Guidelines for safety*, including procedures for researchers working on their own
- *Guidelines for handling difficulties and conflict*, including ways to sort things out if people disagree, fall out or if things go wrong
- *The agreed aims and objectives of the research*
- *The methods to be used*, including how these will reflect a commitment to participation
- *The management of research*, whether by a research team, partnership, steering group or other means, including acknowledgement that leadership roles may change throughout the research process
- *What funding is available* to whom, for what, and who will allocate and be accountable for the budget. If some researchers are volunteers, it will be important to agree payment for time and expenses
- *Whether training is needed* for any of the research partners (e.g. professional researchers needing training in the specialist field of the practitioners or community partners or practitioners/community partners in specialist research methods) and how the training will be provided
- *Descriptions of each person's role*, including practical details of who will take responsibility for what – e.g. research design, data collection, analysis, interpretation and dissemination
- *When and where* meetings will be held

Processes for reflection, evaluation and learning from each other and from the research during the process of doing it

3.9 How Will Researchers Handle Information and Treat People Who Provide It?

The working agreement might include more details about handling and using information of the kind usually required by research ethics committees or institutional review boards (indeed, the following might provide the basis for a submission to a research ethics committee). These cover the more traditional concerns of any research project where researchers (whether professional or community-based) are collecting and using data about people (themselves or others). In participatory research there is the added complication that co-researchers may also provide data about themselves, as well as collecting and analyzing data about fellow researchers and people they know.

Example: Dealing with Personal Information

In the *Debt on Teesside* research, local people with personal experience of indebtedness were trained as mentors and researchers, playing a role both in supporting people to get out of debt and collecting data for the research on the financial situations of participating households and changes over time. This has potential for breaches of confidentiality and over-emotional involvement on the part of the community researcher-mentors, who empathise with the people they are researching and supporting. One of the community researchers described how troubled she felt during her work on a previous project when a fellow researcher-mentor and a woman they were interviewing were in tears about the financial, personal and emotional issues they both faced in their lives. Further details of this situation are described in Carter et al. (2013).

Drawing on the ethics guides (CSJCA 2012; ICPHR 2013) the following are some of the main issues to take into account:

- *Informed Consent* – Ensuring as far as possible that people who provide information or allow access to aspects of their lives as part of the research are given information about the purpose and uses of the research data. They need to know enough about it to be able to decide whether to participate (or for their parent/guardian/consultee to agree). Working with people with learning disability on a collaborative research project one of us (Tina) and her co-researchers discovered that a barrier to informed consent was that people had not really understood, and so did not recognize, what research and research data might be (Cook and Inglis 2012). Sometimes people have very specific understandings of what research might look like and it is important to ensure that people are familiar with different types of data that might be included (for instance data that comes from talking together, drawing, taking part in films or plays etc). In participatory research those who may need to give consent might include practitioner, community and professional researchers (who may be both collectors of information from others and providers of information themselves), as well as people who are invited to participate in information-collection aspects of the research only. Sometimes it is not only the consent of individual people that is required, but also collective consent (e.g. of a community, group or organization). It is also important to acknowledge that the purpose and uses of the research may change and develop over time – so consent may need to be continually reviewed and renegotiated, especially as specific plans for publication and dissemination develop.
- *Anonymity* – it is a good idea to discuss in the research team, and with others involved in the research, the advantages and disadvantages of identifying people, places and organizations (by their real names, appearances or voices in written, visual or audio records or social media) – whether this is in team discussions or dissemination of the research. If research relates to sensitive topics or contexts

(e.g. mental health, domestic violence, drug use), it is often important not to name or give identifying features of individuals. This was particularly important in the Scottish Women's Aid research with people who experienced domestic violence, for example. In some situations, participatory research may be conducted in the workplace of practitioner researchers – for example, in a hospital or community center. In such cases, the nature of the research (open, dialogic, participatory) may mean that although researchers make every effort to ensure anonymity, it cannot be guaranteed. In such cases it may also be advisable to give organizations and places different names as real names may help identify people. However, in some cases, individuals and organizations may wish to be named – to have their opinions, achievements or challenges credited or highlighted. This needs to be discussed fully and consideration given to the implications of naming one person for the anonymity of others.

- *Confidentiality* – when practitioner or community researchers are collecting data from and about people they know, work with or live near, it is advisable to be very careful about confidentiality and written confidentiality agreements might be useful. If someone tells a researcher something that is personally compromising or that they do not wish to be passed on to others, it is important to honor this. It may mean that information cannot be directly used in the research, and should not even be passed on to other members of the research team. Alternatively, it might mean the information can be used, but people's names and other identifying features need to be removed. At an early stage it is worth discussing the ways in which using social media (e.g. Facebook or Twitter) affects issues of confidentiality. It is important to be as clear as possible about how confidentiality will be handled in order to avoid causing harm or embarrassment to people. Usually, in social research, a limit is placed on confidentiality in circumstances where researchers get to hear about unlawful or risky behavior, suspected child/adult abuse and/or where there may be a risk of serious harm to other people. The circumstances of disclosure should be made clear to those participating in the research in advance.
- *Handling Personal Information* – in all research, it is important to ensure that identifying information (e.g. names and addresses) is stored separately from other personal information collected as part of the research (e.g. interview transcripts, questionnaire responses) and securely (e.g. in a locked filing cabinet, password protected computer). In participatory health and social care research it is vital that researchers who are also community members, neighbors or relatives take particular care in safeguarding personal data that could be stored in community centers or neighborhood projects.
- *Ownership, Control and Use of the Research Data and Findings* – when research is a collaboration between several people or partner organizations it is important to be clear who “owns” any data, new knowledge or collaborative outputs that have been produced. By “ownership” is meant the right to use it and pass it on. If it is jointly owned, then it is important to decide what rights each partner has to use the data to inform their work or produce publications and whether the permission of all partners is required. Sometimes a funder may control the use of data and findings – and all parties need to be clear about the implications of this

from the outset. It is particularly important that recognition is given to new knowledge made by communities, that they have the right to own and use it and that when appropriate they receive financial rewards. It is important also to decide who has the right to have in their possession the data generated by the research (e.g. to hold copies of transcripts or data files) and to access the data (which may be held by one organization).



Deciding whether to anonymize places and people, and what information should be kept confidential is not easy.

Reflect on the variety of possible consequences of either anonymizing or not anonymizing people and places, and consider what types of information should be kept confidential.

3.10 Anticipating the Later Stages of the Research

At the outset of a piece of research, especially if it is exploratory research, it might not be clear exactly what data will be collected and how they will be analyzed, interpreted and shared. It may not be known when the research will end, as it turns into action and may generate further research and learning. However, it is still important to think ahead, and in some cases (e.g. with a time-limited, funded project) to anticipate how the research will develop and what responsibilities will need to be allocated. Details can be found in later chapters on Shaping, Organizing, Acting for Change, Engaging, Sens Making, Telling and Showing, and Capturing and Reflecting on Change. At this point it may be helpful to consider these questions:

1. How might we analyze and interpret research data and findings?
2. How might we share the research?
3. What might we share?
4. What might be the formats for dissemination?
5. How might authorship and credits be allocated?
6. How might the research findings be implemented?
7. How might we encourage learning from the research?
8. How might we ensure we make good endings when the research finishes?

3.11 Concluding Comments

How a piece of research starts can set the tone for how it develops. So it is important to pay attention to exploring commonalities and differences between potential co-researchers and developing relationships of trust before rushing into getting started.

Thinking through aims and objectives and how to ensure research is ethically sound can pay off later. Even when the unexpected happens, it is easier to handle challenges if there are good relationships and some structures in place to support the research partners.

3.12 Questions for Reflection and Discussion

At its core this chapter aimed to offer an overview of practical and ethical (including relational) considerations to bear in mind at the start of a participatory research project. We would like to invite you to reflect on or discuss the following questions:

1. What might be some good reasons why you might decide not to enter into a research partnership with a particular person, group or organization?
2. What do you think are some of the advantages and disadvantages of drawing up a working agreement at the start of a piece of participatory research about how the parties involved will work together?
3. Imagine you are a partner in a new participatory research project, what would you do to ensure that everyone's different skills and knowledges were respected and everyone felt valued and able to contribute?

Further Reading and Sources of Inspiration

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Chapter 4

Shaping: The Co-creation of a Research Design



Chapter Summary

Abstract In this chapter you will be led step-by-step in the process of defining the focus of the research, together with your local research team comprised of key stakeholders (community members, service providers, decision-makers, academics, etc.). This consists of formulating research questions and goals which take into account the various perspectives of those involved. Exercises are presented to assist you in facilitating a group process for defining the focus. Short examples throughout the chapter illustrate the concepts discussed.

Purpose To guide you in setting the focus of the research together with key stakeholders (community members, service providers, decision-makers, academics, etc.) by defining common questions and goals.

Central Question How do we define our research questions and goals?

4.1 When Research Can Help: The Role of Information in Creating Change

When things aren't the way we think they should be regarding issues of well-being, health, and social justice, we can join with others and become active in making the world a better place. But if we don't understand why things are the way they are, we don't know what we can do to change them. We can lose ourselves in a flurry of activity which doesn't change anything because it isn't focused on what really matters (Ledwith 2007). The result is that we and others become exhausted and discouraged. By conducting collaborative research, we can find out what lies at the heart of the issues we are concerned about, and we can find out how best to move things in a positive direction. We can also find out what our strengths are, and we can learn from those who are in a similar situation to ours and who have successfully addressed similar problems. Participatory research provides the information we need to find out these things and thus to act more effectively.

There are many reasons for wanting to do a participatory research project. Some typical reasons are presented here with examples from various countries:

- Documenting a Need;
- Building and Empowering Communities;
- Making One's Own Situation Visible;
- Improving a Care System.

4.1.1 Documenting a Need

Homelessness is a social problem that affects a large number of people across the world. Research has shown that homeless people have much poorer health and higher mortality rates than the general population, and they often experience difficulties obtaining the health care and social services they need. They are also largely excluded from official health and census surveys, which often depend on people having an address or telephone number. Even when these surveys reach homeless people, they do not address the unique circumstances and needs of this group. As a result, there is a serious lack of comprehensive information on the health status and needs of homeless people.

In Toronto, Canada, the organization for homeless people Street Health teamed up with St. Michael's Hospital, the Wellesley Institute, and homeless peer researchers to produce the Street Health Report, first published in 1992 and updated with new data in 2007 (Khandor and Mason 2007). It was the first of its kind in North America and is cited widely. The report presents the results of a survey on the health status of homeless people in Toronto. It discusses the nature of homelessness and its root causes, followed by an exploration of the daily living conditions of homeless people in that city. Findings on the physical and mental health status of homeless people, how they use health care services, and the barriers homeless people face when using these services are also presented. Where possible, the report compares the health of the interviewed homeless people with available information for the general population. The report from 2007 shows how the health status of homeless people has changed in the 15 years since the report in 1992. Based on these findings, the authors present an action plan to improve the health of homeless people and to end homelessness in Toronto.

4.1.2 Building and Empowering Communities

The populations considered most at risk for HIV infection include sex workers (SW). However, in many countries there is lack of knowledge on the burden of HIV among this population and on the multiple complex and interrelated factors (including biological, behavioral, sociocultural, economic, structural, and political) that increase SW vulnerability to HIV infection (Dias et al. 2015). Also, there are several difficulties in accessing “hard-to-reach” and “most-at-risk” populations such as SW.

In Portugal, academics teamed up with health professionals, political decision-makers, representatives of non-governmental organizations, community-based organizations, and SW communities to develop the participatory research/intervention project PREVIH. This project aimed to promote sexual health, reduce the transmission of HIV infection, and improve access to health care among SW in Portugal, as well as to empower SW communities for health promotion and to promote capacity building of NGOs for advocacy and policy making. At the beginning of the

project, establishing the partnerships and organizing the community advisory board was a challenging process. SW were relatively isolated and dispersed, not linked or organized in any kind of association, and they were out of reach for health services. Also, SW demonstrated little interest in taking part in the project and becoming involved in the partnership.

The experience of working collaboratively in all the phases of the project contributed to raising the SW community's awareness of the importance of evidence production for improving their health, increasing knowledge on sexual health and access to health care, and enhancing their capacity for HIV prevention and sexual health promotion. The participatory research project generated data and served as an intervention at the same time: the involvement of SW triggered a process of community empowerment, especially regarding advocacy for sexual health rights and safer working conditions (Dias et al. 2016). In particular, the participatory process enhanced the development of community-based initiatives such as the Sex Work Network. Prior to PREVIH, sex workers were a relatively disconnected and disorganized group; through the research process local networks of SW and community-based organizations were established, building capacity for the exchange of information, tools, and resources. Moreover, in a joint collaboration with a non-governmental organization a community-based center for HIV testing and counseling targeted to SW was established.

4.1.3 Making One's Own Situation Visible

There is a disproportionately high number of immigrants among the people infected with HIV in Germany. Several of these people experience both the stigmatization of being HIV positive and of being an immigrant. The Deutsche AIDS-Hilfe (2013), the national German AIDS organization, partnered with the national network AfroLeben plus, to conduct a Photovoice project documenting the experience of HIV positive African immigrants. The project had the goal of strengthening the participants through a process of sharing their stories of discrimination, uncovering their hardships and also their strengths in facing difficult situations. An additional goal was raising awareness in the general population about the situation of HIV positive immigrants for the purpose of addressing the causes of discrimination. Over the course of the project an academic was consulted regarding how to use the Photovoice method. The project resulted in a collection of photographs accompanied by texts telling the stories of the participants. The photos and texts were professionally reproduced in the form of a publication available at no cost online and an exhibit which toured nationally and was presented at several international conferences. The publication and the exhibit also report on the transformation process experienced by the participants over the course of the 2-year project, documenting a growing awareness and empowerment. The project resulted in several recommendations targeted toward decision-makers, the media, health care providers, and HIV prevention initiatives. The recommendations describe how discrimination can be addressed at various levels and in different settings.

4.1.4 Improving a Care System

The intensity and complexity of the international migration phenomenon has made the use of health care services by immigrants a major international political and public health issue, particularly regarding access to health services. Portugal is no exception; traditionally a country of emigration, it has become in the last decades a country of immigration. Research has indicated that, even in countries where access to health care is guaranteed, such as Portugal, immigrants do not regularly take advantage of the services available. There is a need for more knowledge on the patterns of utilization among immigrants and on the persistent barriers to access.

In Lisbon, academics, representatives of immigrant communities, and health professionals formed a partnership to develop a research project on promoting access and use of health services among immigrants (Dias and Gama 2014). The project intended to identify and explore immigrants' and health professionals' perceptions toward utilization of health services by immigrants and associated factors. It was comprised of quantitative and qualitative studies among immigrant communities and health professionals (Dias et al. 2011). Following the research, the project partners gathered to discuss the results obtained in order to identify intervention needs and to propose action strategies at both the service provider and community levels.

The participatory process strengthened the partners' awareness about the difficulties experienced by immigrants in accessing and using health services, and about the difficulties experienced by health professionals in their attempt to provide quality care. The partners identified steps to improve health care delivery to immigrant populations. The policy makers involved in the project learned about the difficulties encountered in policy implementation, and the health professionals in the project had the opportunity to apply the proposed actions in their practice. The project team was invited to present their work at the National Health Forum to a broad audience of health professionals, health care managers, and policy makers which helped to promote the initiative for replication in other cities.

As these four examples illustrate, defining the topic of research isn't the task of one person, but rather the result of a collaborative process among various stakeholders. Regarding issues of health and well-being, the stakeholders are typically those people whose lives are directly affected by the issue, including people with an unmet need; service users; community leaders; professionals whose job it is to address the issue (for example, social workers, nurses, educators, community workers, public health professionals), and administrators or public authorities who can make changes at the structural level.

4.2 Moving from a Topic to a Research Question

Once the topic of the research has been identified, the next step is to formulate a research question. The goal of the research project is to answer that question and thereby to increase knowledge on the topic. In non-participatory approaches to research, the question often comes from academics at universities who are

interested in developing new concepts and theories. Their questions can often be highly technical and very general, for example: How can child protection services improve their outcomes in family case work? In participatory research projects the question is most often focused on specific, concrete problems that a group of people experience at their workplace or in their everyday lives. For example, on the issue of child protection a social worker may ask: How can I better assist families to cope with the many challenges they face? Or a service user may ask: What can I do, so my child will attend school regularly? This example shows how the different people involved have different perspectives on the issue and therefore different interests, so they ask different questions. Participatory researchers hope to find answers to their questions that will help them, and those like them, to do their work or to live their lives in a way that is more meaningful, effective (whatever that means for the various participants), and satisfying.

Research on health and well-being can be criticized for focusing too strongly on problems, as opposed to solutions (Gergen 2014). It often has the goal of finding out what is wrong, as opposed to finding out what works or how people can create positive social change. This problem-focus tends to highlight deficits, and thus contradicts the resource-orientated approach found in social work, education, and health professions. It can thus actually add more pressure to staff who are already feeling overwhelmed or, in the case of marginalized communities, add to the stigma which they already experience (Zandee and Cooperrider 2013). People who are working or living under difficult circumstances often overlook the positive aspects of their situations and how they can build on these strengths to make things better. Participatory research is interested in exploring problems, but for the purpose of identifying the strengths and potentials of those involved and the opportunities for positive change as found in the current moment. This strength-based or “generative” approach to research, also called Appreciative Inquiry, is future oriented as it invites people to imagine “*what could be*” by focusing on the following questions: “*What gives life? What are our strengths?*” “*Who are we at our best?*” (Cooperrider and Srivastava 1987; Ludema et al. 2001). These elements from Appreciative Inquiry are increasingly used within participatory research (Boyd and Bright 2007; McKeown et al. 2016; Sharp et al. 2017).

A research project works best when the research team can decide on a topic which is clear and meaningful for all those involved. This includes defining a question or a group of questions which have a direct connection to what people have experienced and what they need to know to make positive changes.



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In participatory research, questions should directly connect to what people have experienced and what they need to know to make positive changes.

Reflect on a situation where the various people involved (community members, service users, practitioners, managers, etc.) could have different experiences and ideas regarding the subject of the research. What happens if they do not come to a commonly shared question and goal? How can you as a facilitator assist the group to develop a question that is meaningful for all participants?

4.2.1 *Types of Research Questions*

There are many different types of research questions. Following the work of Cyrilla van der Donk et al. (2014) we list here the types of questions most common in participatory research projects.

Descriptive Questions These questions seek to describe the current state of affairs regarding the issue under study. Needs assessments are a common form of research which falls into this category. Some examples:

- What kind of support do the people in our health center need who are living with cancer?
- Where do homeless people find help in our city?
- Is there a problem with violence in our school?
- What information do refugees in our region need about health and social services?
- What are the most important places for members of our community to meet and socialize?
- What do our young people know about drugs and their effects?
- What are the major strengths of our organization?

Defining Questions These questions seek to define an important idea or concept from the perspective of a particular group of people or several different groups of people. The definitions of important terms such as *poverty*, *homelessness*, or *refugee* most often come from people who aren't directly affected by these issues and the definitions can be associated with negative connotations. A focus of participatory research projects can be defining an issue from the perspective of those affected. Some examples:

- What does it mean to be healthy from the perspective of people with learning difficulties?
- The people in our district are described as being poor. How do we define ourselves? Do we see ourselves as being poor? What do we mean by the word *poor*?
- A goal of our clinic is to be *patient-centered*. How do our patients define that term?
- What is a *safe neighborhood* from the perspective of those who live in this district?
- How do youth in our neighborhood define *violence*?

Comparative Questions These questions compare one thing to another in order to find out what the differences and similarities are. Some examples:

- How healthy are homeless people as compared to others in our community?
- What problems do girls need help with, as compared to boys?
- Where do new parents prefer to get information about raising their children, from midwives or from other parents in their neighborhood?
- In which district of our city are people healthier (comparison of all the districts)?
- Which form of counseling most helps youth with their drug problems, peer counseling or outreach work by social workers?

Evaluative Questions These questions aim at determining the value of a particular action or service, usually in terms of the goals which were set by those conducting the action or service. Evaluation questions often are focused on the effectiveness of a particular action. Some examples:

- How successful were our efforts to mobilize residents in taking action for better housing conditions?
- Does our counseling program help women who have experienced domestic violence?
- Has our neighborhood action resulted in safer streets?
- Have we been able to reach more older people living alone?
- Has the health of our community improved over the last year since we have launched our health campaign?

Explanatory Questions These questions are usually focused on finding out why something is the case. Finding out why can be key in knowing how best to take action for improving a situation. Some examples:

- Why are people in our neighborhood less healthy than people in other neighborhoods?
- Why have all our efforts to stop youth from dropping out of school failed?
- Why is the new family center so successful?
- Why do so few people come to our drop-in center?
- How can we explain the rise in violence in this district over the last year?
- What is the reason for the large number of people developing respiratory problems in our building?



Image 4.1 Jointly knitting, ICPHR, Limerick, 2017

The various types of questions may be combined. For example, in an evaluation of a certain service (evaluative question) we may be interested in finding out if there is a difference between men and women in terms of effectiveness (comparative question). We may also want to find out why the service was effective in some cases and not in others (explanatory question). Or in describing the types of assistance homeless people need (descriptive question) we may be interested in how the homeless people define what they consider to be a useful service (defining question).

4.2.2 What Makes for a Good Research Question?

A good research question reflects the underlying values of participatory research by incorporating the following features:

- The interests of the various stakeholders have been taken into account;
- The question can be answered in the allotted time with the allotted resources;
- The focus of the research is clear;
- The language is understandable for all participants;
- The question takes into account what we already know as well as our assumptions.

Below we elaborate on these aspects while providing examples.

4.2.2.1 The Interests of the Various Stakeholders Have Been Taken into Account

Academics can tend to ask questions that are more abstract. Practitioners can tend to ask questions that are more technical, focusing on structures and methods for service delivery. Service users and others are interested in prompt responses to the specific and tangible problems they face in their everyday lives. These differences

reflect the various interests and perspectives found in a typical participatory research team. To take this into account, more than one question can be asked, each question reflecting the interests of a particular group of participants. Or participants can join together in finding a question which is relevant for all those concerned. The metaphor of knitting applies here, as in the all stages of the participatory research process, as we weave the many perspectives together.

Example: Improving Services for Youth

An organization serving the needs of youth is wanting to improve its services. The staff are wanting to know how to get service users to come regularly to appointments. Service users are wanting different forms of contact with staff, not just the usual office visits. The families of the service users are feeling left out of the services, not really knowing what role they can play. Asking the question, “How can we get service users to come regularly to appointments?” would not take into the account the perspectives of service users and their families. A research team composed of staff, service users, and family members decides to focus on the question, “How can staff, service users, and family members work together so as to improve services?” By asking this question, the various interests can be taken into account.

4.2.2.2 The Question Can Be Answered in the Allotted Time with the Allotted Resources

Every research project has limits in terms of the time and resources that are available. Even experienced researchers can tend to formulate questions which are too big.

Example: Needs of Immigrants in the Community

A community group wants to know what immigrants in their neighborhood need. They would like to reach all or at least most of the immigrants, so that the diversity of the residents can be taken into account. They only have a total of 1 month for the research which will be managed by a social worker who can dedicate 8 h a week. The group decides to conduct interviews with key persons in the immigrant communities instead of trying to ask a large number of residents, as this fits better with the time and resources available.

4.2.2.3 The Focus of the Research Is Clear

It can be a challenge to define clearly what we really want to know. Often people can identify a problem and something they would like to change, but they are not sure what the focus of the research could be. Most social and health issues are complex, touching

on many aspects of people's lives and involving bigger issues at the local, regional, and national levels. Focusing on an aspect that is important to the stakeholders involved and which offers possibilities for change will keep the study manageable.

Example: How to End Homelessness

A coalition of engaged citizens and social workers wants to find out how they can end homelessness in their community. They do some reading about the causes of homelessness and ask for input from several people who have experienced homelessness themselves or who have worked for years on the issue. They realize that there are many causes, several of which have nothing to do with the community directly, such as unemployment. The research group decides to focus on the topic of affordable housing, as they see the opportunity to influence urban planning in their district.

4.2.2.4 The Language Is Understandable for Everyone Involved

Academic researchers and practitioners can tend to formulate questions which are technical or general and which are therefore not easily understood by others. Service users and other concerned citizens can tend to formulate questions which are highly specific to their everyday lives, so that academics and practitioners have a difficulty seeing what is relevant for their work. Formulating a question that is understandable and meaningful to everyone involved can be a challenge. If the question is not something people want to know or otherwise find relevant to their lives, they won't want to be part of the participatory research project. By working together, key stakeholders can find a common language which everyone understands, thereby increasing trust, credibility, and legitimation for all partners.

Example: Improving a Service Delivery System

The director of a service organization for people with psychiatric problems is interested in the question, "How can we restructure the service delivery system so as to better retain people in services who are in need of help?" She invites staff, service users, and members of their families to a meeting to organize a participatory research project on the topic. She has trouble explaining her concern about the "service delivery system" to the others. The issue of interruptions in care is, however, important to everyone. All the participants recall situations in which the contact was broken between the organization and the service user and his or her family. The following question is agreed on, "How can we prevent a break in care for those who need it?" The issue raised by the director is addressed in such a way that all can see the relevance for themselves. As is often the case, the reformulated question not only makes the issue at hand more understandable, but also the scope is broadened beyond a social service provider perspective.

4.2.2.5 The Question Takes into Account What We Already Know as Well as Our Assumptions

Seldom are we the first ones to ask a question about any particular social or health issue. By finding out what others have learned about the issue, we can focus our question more clearly. And we avoid re-inventing the wheel. We may be able to take on the results of other people's work, sparing us the trouble of developing our own project. A further aspect is taking into account our assumptions about the topic at hand. Based on our experience and what we have learned from others, we usually already have ideas about the situation we are studying. We need to take these assumptions into account when formulating our question. Our research can help us to find out if our assumptions are true.

Example: Sexual Health Needs of People Whose First Language Is Arabic

A nurse is wondering how to address the sexual health needs of new immigrants whose first language is Arabic. He assumes that the immigrants would prefer receiving services in Arabic from someone with the same or a similar cultural background. He does a search of the published literature and of documented health services for new immigrants. The result is mixed: In some communities the staff are bilingual and bicultural; in other successful projects there is more a dependence on translation. The nurse brings together a team of other medical staff and members of the immigrant group who have been living longer in the country. The team decides on the question, "How can health services be improved from the perspective of new immigrants whose first language is Arabic?" The study will include questions addressing the issues of language and cultural background of the service providers.

4.3 Setting the Research Goal

The goal of every research project is to answer the research question. In participatory research projects there are usually other goals which reflect why the stakeholders are interested in the project. These goals often are about collective action, empowerment, and creating positive change based on the results of the research and thus often have a political dimension (See Chap. 6, Acting for Change). These can include:

- Improving the living conditions for a group of people;
- Improving social and health care services;

- Building a case for taking action;
- Showing the needs of a particular community;
- Raising awareness on the relevance of social well-being or health issues by translating them in terms of a community’s immediate needs;
- Building capacity for all stakeholders to generate new knowledge for taking effective action.

As with the formulation of the research question, the research goal should also take the interests of the various stakeholders into account, should be realistic in terms of the resources available, should be clearly focused, should be understandable for all participants, and should take into account what we already know as well as our assumptions. To achieve this, a deep discussion needs to take place among all partners so as to build consensus and to set the project’s boundaries (See the section Communicative Space, Chap. 7, Engaging).

This involves a process of dialogue and negotiation and, often, compromise on all sides. For example, academic partners may insist on certain standards for research in the name of “scientific rigor,” (see Chap. 8, Sense Making, for quality criteria for participatory research) while community partners have their priority on problem-solving and advocacy for their rights. And it is typical that the problems to be solved are much larger than what a project can achieve, so the limits of what can be done need to be defined so as to avoid raising unrealistic expectations and causing frustration.

4.3.1 Harmonizing the Question with the Goals

The research question and the goals should complement each other, while reflecting current knowledge and assumptions. The following exercise can help a research team achieve this end. A table with three columns is drawn, each column having the following headings:

Research question (what do we want to know?)	Research goal (why do we want to know it?)	Assumptions and prior knowledge (what do we know or think we know already?)
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The team can start with the question or with the goal.

For example, a research team might know that they want to make their school a safer place. That would be the goal: To conduct a study which helps us to make our school a safer place. What do we need to know in order to reach that goal? That is the research question. For example: How can we prevent bullying? The assumptions could be, for example: Bullying is more common among boys than girls; or students with disabilities are usually the targets of bullying. A search in the literature will show what others have found out about the causes of bullying and how to prevent it;

successful prevention programs may also be found which could be useful in finding out what to do at the school of the research team.

Starting with a question, another research team at a youth center might ask why very few girls come to the center. The goal would be to make changes so that both girls and boys make use of the facility. Assumptions might include: Most of the activities are team sports which are not attractive to girls; or groups of boys dominate all the common spaces, giving the message that girls have no place at the center; or all the current staff are male, which means girls have no women with whom they can identify. Here, as well, a look into the literature and existing projects can provide information about what others have learned, in this case about how gender differences affect the leisure activities of young people.

It often happens that the goal and the question don't fit together. The usual reason is that the interests of the research team haven't been taken fully into account. The interests are usually reflected in the assumptions column. For example:

Research question (what do we want to know?)	Research goal (why do we want to know it?)	Assumptions and prior knowledge (what do we know or think we know already?)
Which health care services are most used by African immigrants?	To improve health care for African immigrants	African immigrants often experience racism African immigrants don't feel understood by service providers Service providers make certain assumptions about African immigrants instead of listening to their needs

In this example, the assumptions column suggests that the research team is interested in barriers in the health care system due to racism and prejudice as reflected in the service providers. The research goal, although very broad, has a clear intention. The research question, however, has no direct connection to either the goal or the assumptions. Finding out about service use patterns wouldn't improve services, it would only show which services are being used. And service use may or may not be affected by how staff act. The following is more consistent with the intention of the research team to address racism and discrimination in the service system, while testing their assumptions:

Research question (what do we want to know?)	Research goal (why do we want to know it?)	Assumptions and prior knowledge (what do we know or think we know already?)
Are African immigrants treated differently than other service users? If so, how does that affect their care?	To improve health care for African immigrants by reducing discrimination on the part of the service providers	African immigrants often experience racism
		African immigrants don't feel understood by service providers
		Service providers make certain assumptions about African immigrants instead of listening to their needs

Here is another example:

Research question (what do we want to know?)	Research goal (why do we want to know it?)	Assumptions and prior knowledge (what do we know or think we know already?)
How can we support parents in our neighborhood in raising their children?	To strengthen the families in our neighborhood	There are more fast food places in our neighborhood than in other parts of the city
		The families of our children have trouble providing balanced meals and regular eating times
		Some of the families in our neighborhood don't know how to prevent obesity in their children
		The children don't know how to control their weight

Clearly, the research team in this example is interested in the health of children in their neighborhood. From the assumptions column, it appears that the main concern is about obesity which is apparently more of an issue there than elsewhere. The goal of the research is, however, very broad. A goal which better fits the assumptions would be: To reduce the number of children in our neighborhood with obesity. The research question is also very broad. Supporting the parents in their role may be part of the solution, but we don't know that. A more fitting research question would be: Why are so many children in our neighborhood obese? With this question the team could test their assumptions. An additional question might be: What can we do to reduce the number of children who are obese? This question would directly address the newly formulated research goal and the concerns expressed under the assumptions.

4.4 Challenges and Stumbling Blocks in Shaping a Participatory Research Project



4.4.1 *Boundaries Set by Others*

Often research projects are financed by public authorities, research funders, or foundations which have a certain focus. For example, money is provided to do research on obesity, but the local community isn't interested in working on that issue. In such cases, it can be very difficult to conduct a participatory research project because there is no one willing to work on the funded topic. Or if a research team can be organized, it is difficult to shape a project which can have a lasting impact on those involved.

To avoid this problem, it is important to hold conversations with potential research team members in advance to determine whether a meaningful project can be organized on the topic of the funder. These same people should be part of writing the proposal for the project so that there are no surprises should the project be funded. A common problem is that someone, often an academic researcher, successfully applies for funding to conduct a participatory research study, but without active input from the people who are supposed to participate in the project. Once the project has been funded, the academic researcher is faced with the challenge of getting people involved in something which was not their idea.

Some funding may have a particular focus, but there may be flexibility for a local research team to specify a topic which makes sense in their local context. This should be clarified in advance with the funder. For example, funding may be provided for HIV prevention. A local community sees the problem in a lack of access to health information and health care services, more generally, and would like to

work on this issue. The funder may agree to this broader focus if the connection to HIV prevention can be shown. Typically, funders are interested in very specific topics; whereas, the practitioners and people affected by social or health problems are interested in more comprehensive solutions addressing a range of issues.

4.4.2 Boundaries Set by Limited Resources

Participatory research projects often face the problem of limited resources. Many projects have no funding, but are rather dependent on the time and energy provided by people and organizations using the resources that they already have. It is important to stay within the bounds of what is doable. For example, a group of wheelchair users may want to research the accessibility of all public spaces in their city, but they only have their own volunteer time and a few hours staff support from a local organization working on access issues. They decide to focus their work on a specific neighborhood which could serve as an example for how to look at accessibility in other parts of the city. This is doable, given the resources they have.

4.4.3 Working with the People Who Are There

Those who initiate a participatory research project are often concerned with the question of whether they have found the “right” people to work with. In building the research team, it is important to have a diversity of perspectives representing the views of key stakeholders (see Chap. 5, Organizing). Academic researchers often are worried that the people who shape the research are not “representative” of those whose life or work is the topic of the research. Participatory research is not about drawing a sample from a population, but rather about initiating a process of change by finding answers to important questions which are meaningful to those involved. Initially, the group of people in the project may not be as diverse as expected, but that can change as the project expands to include others (see also the section on Forming a Research Team, Chap. 7, Engaging). It is very important to ensure that the research team remains flexible and open enough to include those who can most contribute to obtaining an in-depth knowledge of the topic being studied.

4.4.4 Working with the Skills of the Research Team

In shaping the research project, it is important to take into account the skills of the people involved in the research team and their networks. Academic researchers bring skills on applying specific methods of data collection and analysis. Community members bring their local knowledge and experience, which includes their own ways

of gathering and understanding information from their lives and the lives of those around them. Practitioners bring their professional skills and knowledge, which can include skills in facilitating meetings, knowledge about how social and health care systems work, and the experience of helping people in a variety of situations. Service users and people with chronic illnesses or disabilities may bring in their experiential knowledge. Finding out what the people involved in the research project can bring to the work is an important step in deciding what is possible. A common mistake is focusing on a narrow set of skills associated with formal research methods, thus overlooking the range of talents and knowledge found in the research team and among those they know. Often people are unaware of what they can contribute, taking for granted the skills and knowledge they have, or thinking that only certain special skills are useful for participatory research (see also Chap. 5, Organizing).

4.4.5 Difficulty Defining Common Questions and Goals

It is a major advantage when those involved in a research project come from different backgrounds, representing different perspectives on an issue, but this can also provide a challenge for agreeing on common questions and goals. For example, a research team is formed in a diabetes clinic for improving services. On the team are a physician, a nurse, three patients, and a social worker. The physician may be interested in improving the compliance of patients in following the recommended treatment plan, including diet and exercise; whereas, the nurse may be interested in issues related to everyday operations in the clinic. The patients may want their individual needs to be taken more into account in the care they are given. And the social worker may be interested in engaging families in helping people with diabetes manage their illness. These various topics reflect the different perspectives on diabetes care.

One solution may be addressing several questions within the same study, each party involved being able to pose their question. Or a common question may be found through dialogue (see Chap. 2, Framing for Hermeneutic Dialogue; and Chap. 7, Engaging on Communicative Space). For example: How can we improve the communication between physicians, nurses, patients, and social workers? This question assumes that better communication will make a contribution to the topics raised by all those involved. Despite being a complex, challenging, and lengthy process, adopting a participatory approach to define common questions and goals can be an effective way to obtain coherent evidence on specific needs and to identify relevant research priorities.

4.4.6 Loosely Defined Questions and Goals

A common problem in participatory research projects is that the questions and goals were not really defined. For example, a research team launches straight into creating some sort of questionnaire without spending time to figure out what they really want

to know. The participants want to improve their neighborhood and they try to address all possible issues that residents may have in the questionnaire. The usual result of such a project is that it has no clear focus and it thus becomes frustrating or confusing for those involved.

4.4.7 Losing Sight of the Questions and Goals

Once a participatory research project really gets going, the research team and the others involved can quickly lose focus on what they wanted to find out in the first place. Changing questions and goals may be necessary as the project evolves and grows. For example, a project with the goal of making public areas in a neighborhood safer may begin with questions on how these areas can be better policed. As knowledge is gained about the problem, the focus may shift to how these areas can be renewed so as to attract more people and businesses. A problem occurs when the group becomes lost in the process, thus losing its focus completely. In this example, the group researching public safety may find out that several people using public spaces have unmet needs, such as homeless people or young people who are unemployed. These issues are also important, but may not be connected with the issue of safety. No one research project can take on all topics. It is better to stay focused and to find ways in which the others issues can be addressed by other people or in future projects.

4.5 Summary

This chapter presented step-by-step how a local research team can give shape to their project by defining their research questions and goals. Five different types of research questions were identified: descriptive, defining, comparative, evaluative, and explanatory. The characteristics for “good” research questions and goals were offered to assist the local research team in avoiding typical pitfalls. An exercise was introduced to help the team harmonize research questions with research goals. Finally, challenges and stumbling blocks were presented to make the team aware of problems which can occur in shaping their project.

4.6 Questions for Reflection and Discussion

This chapter aimed to guide you in setting the focus of the research together with key stakeholders (community members, service providers, decision-makers, academics, etc.) by defining common questions and goals. We would like you to reflect on the following questions:

1. Define the research questions and goals in a current project or a possible future project by using the exercise described in this chapter.
2. Reflect on your research questions and goals using these questions:
 - Do the questions and goals take into account the interests of the various stakeholders?
 - Are the questions and goals realistic in terms of the resources available?
 - Are the questions and goals clearly focused?
 - Are the questions and goals understandable for all participants?
 - Do the questions and goals take into account what we already know as well as our assumptions?
 - Do the questions and goals fit together and do they reflect what is really interesting for us?

Further Reading and Sources of Inspiration

Cyrilla van der Donk, Bas van Lanen and colleagues have published a textbook on practitioner research in social work and health care: Dutch Edition: van der Donk, C., & van Lanen, B. (2015). *Praktijkonderzoek in zorg en welzijn*. Bussum: Coutinho. German Edition: van der Donk, C., van Lanen, B., & Wright, M. T. (2014). *Praxisforschung im Sozial- und Gesundheitswesen*. Bern: Huber. American and Brazilian editions forthcoming.

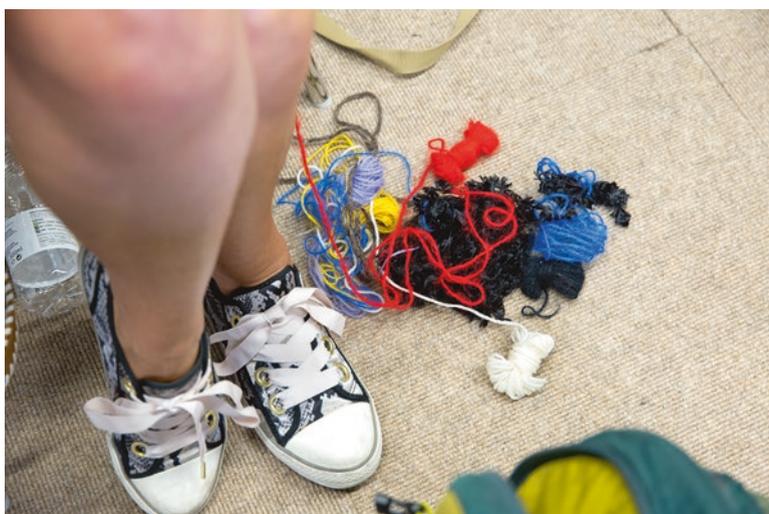
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Chapter 5

Organizing: Making Plans Together



Chapter Summary

Abstract In this chapter you will be led step-by-step in how to organize a participatory research project. This includes identifying the various tasks and roles within the project, estimating the resources needed, matching the strengths of the participants to the tasks at hand, and planning how the project will be done. Issues of capacity building and sustainability are also addressed.

Purpose To guide you in organizing the research process.

Central Question How do we organize the research process?

5.1 The Myth that Participatory Research Doesn't Need to Be Organized

One of the most common mistakes in participatory research projects is assuming that “participatory” means the project doesn’t have to be organized. In reality, every project is initiated by someone and this person or group of people needs to invest considerable energy and time in the beginning to get others engaged (Chap. 7, Engaging) and to manage the process. If the participatory process is successful, the other members of the research team will increasingly take on ownership and responsibility, so that the person or persons who initiated the project can assume a less active role, usually that of coordinating the various activities that are happening and facilitating research team meetings (Image 5.1).

5.2 Setting Up a Structure

Organizing a participatory research project starts with setting up a structure. This includes:

- Organizing a research team;
- Forming an advisory board;
- Negotiating arrangements.



In participatory research we engage those whose life or work is the subject of the study.

Reflect on the roles and labels assigned to the people involved. What do terms like “participant,” “partner-stakeholder,” “insider,” “peer,” “co-researcher,” “community researcher,” or “volunteer” signify? What does it mean when researchers from universities are called “academic researchers,”



Image 5.1 Planning ICPHR, Limerick, 2017

“outsider researchers,” “university-based researchers,” or “professional researchers”? How do you identify yourself? Do others have the right to identify themselves? How do we name our roles and the roles of others? Do we exacerbate or reduce power differences by the names we choose for the various roles?

5.2.1 Organizing a Research Team

Participatory research is not conducted by one person, but rather by a group of people representing different perspectives on the issue to be studied. The person or persons who initiate a participatory research project need firstly to talk to potential partners about organizing a research team, exploring issues of feasibility and ethics (see Chap. 3, Getting Started; section Forming a Research Team and Chap. 7, Engaging).

The team will define more specifically the topic of the research and the various other steps in the research process, as described in the following chapters. The team should be of a manageable size—as a general rule, at least three, but not more than ten people—and should have members who can commit over the length of the project to working closely together. The time and other resources which the members bring to the project will be important in deciding the scope and focus of the research. By answering the following questions, those who initiate a research project can clarify whom they should initially invite to be part of the research team. These questions can also be discussed by those who come to an initial meeting in order to consider who may be missing (Image 5.2).



Image 5.2 Working in teams in the International Collaboration for Participatory Health Research

1. *Whom should I invite to be on the research team?*

(a) *Who should benefit from the research?*

Another way of asking this question is: Whose work or life is the topic of the research? Consider those whose life or work should be improved, based on the results of the project. These may, for example, be practitioners if doing research at a workplace or residents if doing research in a neighborhood.

(b) *Who could prevent or promote a positive change regarding the topic being studied?*

This is the level of people who have the power to make a difference. These may be decision-makers in the formal sense (public authorities, directors and boards of social service agencies or clinics, school principals, etc.). They may also be key persons in communities who are recognized authorities and whose advice people value. This includes religious leaders and other community spokespersons, with or without a formal title.

(c) *Whose voice is not usually heard?*

Participatory research wants to give voice to the people who are not usually heard when it comes to making decisions about how organizations are run, services are provided, or everyday life is organized. These are often groups of people who experience discrimination or who have few resources. They may also be professionals at lower levels in an organization whose experience and knowledge can often go unnoticed.

(d) *Who could bring a new perspective to the topic?*

Research is about uncovering new information. If the research team is composed of people who have the same opinion and the same experience regarding the topic being studied, the likelihood of finding out something new is small. By bringing together a diverse group of people—for example, neighborhood residents, service providers, and public authorities—a research team can better reflect the diversity and complexity of an issue and can thus create a research project with a higher level of credibility and relevance.

Example: Community Leaders Partnering to Promote Health

An academic researcher wants to study how to reduce the rates of smoking in a neighborhood where the percentage of smokers is larger than in other parts of the city. He talks to community leaders in the neighborhood and invites them to an initial meeting. The leaders are a social worker at a neighborhood center, an imam who is very active on social issues, and the president of a neighborhood association. At the meeting, the leaders agree that the smoking rates are high and they see two reasons for that: Many residents come from cultures in which smoking is more common than in the majority culture of the country; and smoking is a way to cope with the stress many of the residents experience due to their difficult living situations. The leaders would like to work together on how to mobilize people for improving their health, in general, and not just regarding smoking. They also want to have members on the research team who come from different cultural backgrounds so as to reflect the diversity of the neighborhood.

Identifying potential research team members is only the first step. People only respond to an invitation to join if the project speaks to their interests.

2. *Why would potential team members be interested in working together on the project?*

(a) *Whose interests are represented in the project and what are these interests?*

Typically, the project idea represents the interests of the people who initiate the project. If they are academics, the topic can be abstract and general (see Chap. 4, Shaping). If they are members of a community, the topic can be very immediate and concrete. The person or persons who initiate a participatory research project need to be open to expanding or changing their idea so as to get more people involved. Adapting to the interests of the various stakeholders is an important part of shaping

the research project which is reflected in the composition of the research team (see also Chap. 3, Getting Started).

(b) *How can I speak to the interests of those I am trying to reach?*

The initiators of a project need to find the right language and the right form of communication to reach the people they want on the research team. This often means working with others who understand the needs and interests of potential members. For example, a social worker may not know how to approach the local public authority about becoming involved. But perhaps the director of her agency or a recognized community leader has personal contact to those who work at the authority.

Example: Asking for Help in Recruiting Others

The academic researcher in the example above realizes that a project on smoking will be difficult to conduct in a participatory way because people are not interested in this specific topic. He follows the advice of the community leaders to broaden the topic by focusing on improving health, more generally. He asks the leaders for help in recruiting others to work together. The community leaders also raise the question of how and where to meet in order to attract people's interest. The social worker offers the neighborhood center as an alternative to the university, where the first meeting was held. Most residents have never been to the university, although it is within walking distance, but many come to events and meetings at the neighborhood center. It is also decided to organize a meal when the group meets and to apply for funding so that the residents receive some sort of monetary compensation for their time.

5.2.2 Forming an Advisory Board

For larger research projects an advisory board can be useful. The size of the research team is limited, and several stakeholders do not have time to participate in regular meetings, even if they are very interested in the project. Inviting people to serve on an advisory board is another way to engage stakeholders in the research process. The commitment is less time-intensive and detail-oriented than the work of the research team. And by serving on an advisory board the members can still identify with the project and its outcomes.

5.2.3 *Negotiating Agreements*

Some participatory research projects are based on formal agreements between existing organizations, for example, a university and a community organization. In such cases, it has become standard practice to negotiate formal agreements in which the various roles and responsibilities of the organizations are clearly defined, including how decisions over the course of the research project will be made. Guidelines exist for drafting such agreements (see Chap. 3, Getting Started).

5.3 Identifying Resources

It is important to consider from the beginning what resources are needed so that the research team and others involved can plan a project which is actually doable. A common mistake in participatory research projects is taking on more than what the participants can handle in terms of time, energy, and expertise.

The majority of participatory research projects are conducted without any external funding. The advantage is that the researchers don't need to conform to the topic or approach specified by a funder. The disadvantage is that the researchers need to conduct their project over and above that which they are already doing, without being compensated for the time involved. Several potential research team members cannot commit to a project without some sort of compensation, given their limited time or monetary resources.

Each project is different in terms of size and scope. Participants with prior research experience can be very helpful in estimating the amount of time and effort a project needs. As the project develops, it can be useful to list each of the project components as found in the chapters of this book and estimate the amount of time and resources needed (see Table 5.1):

Table 5.1 Resource planning

Project component	Resources needed (material and personnel)	Time needed
Framing		
Getting started		
Shaping		
Acting for change		
Engaging		
Sense making		
Telling and showing		
Capturing for change		
Continuing the journey		

As shown in the table, for each component the team can consider the materials needed (paper, computers, office space, etc.) and the number of people who will be needed to do the work. Under the column for time should be listed the total time needed for the activity.

Participatory processes always take longer than you think. It is difficult even for experienced participatory researchers to estimate how much time is actually needed for each project component, because you can never know in advance where the biggest need will be for discussion, debate, or reflection. An initial work plan is, however, necessary in order to organize the steps to be taken.

In identifying resources it is important not only to think in formal terms about who has academic research experience. This experience can be very useful in participatory research for all phases of the project, including the organizing phase. Research team members often have many other types of skills and knowledge which can easily go unseen. Therefore, it is recommended at the beginning to take an inventory of what each research team member brings to the project. This list can be referred to throughout the project as the team plans and implements the various activities.

The following (see Table 5.2) shows an excerpt from a list of resources generated by a research team looking at the issue of green space in a city district. The research question is: How can the amount of green space for recreational purposes be increased in the district? The goal is to improve the quality of life in the district by providing more spaces to be active outdoors. The project was initiated by Maria, one of the district urban planners. The members of the research team include four residents from the various neighborhood associations, two representatives from local youth groups, two members from district sport clubs, and a university researcher.

The table shows that the first three team members have a strong reach into the communities in the district. In addition, they have experience in areas which may be of use to the project: gardening and skateboard park planning. Without conducting an inventory, this expertise may have gone unnoticed. The reach into the community may have also been underestimated. Typically, the members of the research team concentrate too narrowly on what ideas they bring to the project, not looking at their existing skills and experience.

Table 5.2 Inventory of research team resources

Member	Resources
Amalia (resident)	Active contact to many residents through a neighborhood association Owner of a local beauty salon (longstanding contact to many residents) Active in the parents' association at her daughter's school
Toni (trainer at a sport club)	Runs a football program (using an old, rundown football field in the district) Worked as a gardener before becoming a trainer
Sebastian (leader of a local youth group)	Knows many of the youth in the district Took part in designing a skateboard park in another district
Thomas (university researcher)	Experience doing research Did a project on planning urban parks in another city
Etc.	

Several strengths are often considered to be of no consequence because they are taken for granted by the members, such as their many contacts. By conducting an inventory, Maria is setting the stage for the team to identify its resources and to use these in a participatory way over the course of the research project and ultimately for the betterment of the district.

5.4 Clarifying Roles and Decision-Making

As the team takes up its work, roles need to be defined. Typically, those who initiate the project coordinate and facilitate the work of the research team, at least initially. Over time, members take on different responsibilities and thereby develop an increasing sense of ownership regarding the project and the research process.

As stated above, most participatory research projects are conducted without external funding. The project is accountable only to the members of the research team and to an advisory board (if one exists). Where external funders are involved, it is important to clarify what role they will play. Most funders do not have experience with participatory research and do not understand the importance of the participatory process and the flexibility and time it requires. Those who initiate the research project need to clarify to the funder what participatory research is, how it is organized, and the many positive effects it can produce.

It is a common mistake in participatory research to think that everyone on the research team needs to be involved equally in all parts of the research process. Tasks should be matched to the resources, interests, and competencies of the team members, while also providing opportunities for members to learn new skills. In any case, it is important that the team as a whole decide who will do what. It is not the role of the person or persons who initiated the project to act as a director, telling the others what they need to do, but rather to facilitate a process of mutual planning and implementation.

Example: Negotiating Roles and Responsibilities in Urban Planning

In the urban planning example above, the team decides to conduct focus groups with different constellations of residents regarding how current green space is used and what residents need. A list of questions is developed by the team. Thomas has years of experience planning and facilitating focus groups, so he provides input and guidance on how to organize the groups, how to develop a list of questions, and how to conduct and record the discussions. Maria has offered to provide maps of the district and other material to be used in the focus groups. Toni and Sebastian work a lot with groups and are interested in being facilitators. Amalia can't imagine taking on the facilitator role, but knows people in the neighborhood who are active in many groups. She offers to speak to them as potential facilitators. It is agreed that the facilitators will run their own meetings and record them. The data will be sent to Thomas who will put them together and organize a meeting at which all members of the team will take part in the data analysis.

5.5 Planning for Sustainability

Participatory research works best when it is embedded in ongoing cooperative relationships between the respective partners.

A common problem arises when the person who initiates the research—often an academic—seeks to plan and implement a participatory research process in a limited period of time with no means for follow-up. This so-called “helicopter research”—the researcher “flying” in and out of a research setting with no previous or lasting commitment to the people there—is not conducive to participatory research. It is nearly impossible to develop trusting relationships and there is very little chance for sustainable change based on the work.

When organizing a participatory research project, it is important to engage existing networks and structures which will continue to be important after the project has been completed (see Chap. 11, Continuing the Journey). This ensures that, even if no further project can take place, there are people and organizations who will be able to learn from the research process and act on that knowledge.

An important element of every participatory research project is building the capacity and skills of all participants. As we will see in Chap. 6, Acting for Change, the capacity and skills can subsequently be utilized in other contexts to mobilize people regarding other issues (Laycock et al. 2011; Walkers 2009; Wicks et al. 2013).

In the above urban planning example, this could mean that the urban planner develops her capacity and skills to engage citizens in planning processes. The university researcher can learn to value other forms of knowledge outside of academia. And the residents can gain more in-depth knowledge about where they live and how to work with new groups of people in the interest of improving their living environment. All members can experience empowerment in terms of their own ability to effect change.

The learning that goes on among the participants is an important impact factor in participatory research (see Chaps. 6, 7 and 10). This learning is the foundation for sustainable improvements regarding the issue under study.

5.6 Challenges and Stumbling Blocks

5.6.1 *Lack of Organization*

As stated at the beginning of the chapter, even participatory research projects need to be organized. It is important that someone or a group of persons takes on the responsibility for coordinating the various tasks decided by the research team. This means organizing meetings, documenting various decisions and outcomes, reminding members of their responsibilities, and seeing that the project is brought to a satisfying conclusion. Many projects fail due to the lack of someone being in charge of organizing the various activities.

5.6.2 *Lack of Accountability*

It is important to clarify who is responsible for what. It is also important that those involved are held accountable for what they agree to do. The research team commits to seeing the project through and should share responsibility and accountability for the various activities. In the case of outside funding, an organization assumes formally the responsibility for managing the funding and assuring the quality and timely implementation of a project.

5.6.3 *Lack of a Clear Agreement on Central Processes*

The motto “just do it” is useful to get momentum going in a project. But the devil is in the detail. Based on the enthusiasm of the initial meetings, it can seem deceptively simple regarding how a project will be carried out. It is important to reach a clear agreement on all components of the research and to take the time to reach such agreements. This means specifying the various tasks and timelines. Where partnerships between institutions are involved, this can mean drafting formal agreements regarding who is responsible for what (see Chap. 3, Getting Started).

5.6.4 *People Taking on More than They Can Do*

It is a common problem in participatory research projects that members of the research team take on more they can handle. One reason is that participatory research often takes more time than initially thought. Another reason is that people commit in the moment to taking on certain tasks, but that other more pressing responsibilities take precedence in their everyday lives. As a rule of thumb, it is better for people to take on less than they think they can handle. There is always room to take on more! Another useful rule is to talk explicitly and repeatedly in the research team about competing responsibilities, thereby identifying as early as possible what cannot be accomplished. The team can then decide whether to drop the task or to find someone else to do it. The open dialogue avoids a rude awakening later in the project to the fact that many of the activities won't be accomplished as planned, thus jeopardizing the success of the project.

We also need to be alert to signs of emotional burden due to the issues/topics being studied. One of the authors of this book (Tineke) was involved in a study on a sensitive topic, emergency care for people with psychiatric problems, that triggered older traumas among some of the co-researchers, which in turn also affected the other team members (for more on the role of emotions see Chap. 6, Acting for Change). It seemed that at times some of the co-researchers did not exactly know themselves what they needed, that they sacrificed their health and well-being for the project, and that their various needs changed over time and were sometimes in conflict with each other. Although all co-researchers had said they would ask for help

when needed, several did so only when things had gotten out of hand. The unwritten norm of being strong, tough, and self-determined didn't appear to leave much room for being vulnerable.

5.6.5 Hesitating to Seek Help

It can be difficult for people to admit that they can't accomplish the task they set out to do. Enthusiasm for an issue can result in taking on tasks which are too difficult. In many participatory research projects, several team members are doing certain tasks for the first time. Many have never done participatory research before. Creating a climate of mutual aid in the research team is an important preventive measure. People should be asked regularly how it is going with their tasks, so that the team can help as early as possible. This may mean that the task be given to someone else.

5.6.6 Insisting that Everyone Be Involved in Everything

As stated above, "participatory" does not mean that everyone is involved in everything. Such an idea is grounded in a notion of sameness, and doesn't do justice to the differences between people. Expecting people to be and do the same can be disempowering; for example, expecting academic researchers to do community outreach or people with learning difficulties to hold to certain academic norms (Woelders et al. 2015). It does, however, mean that decisions in the research team are made in a democratic and fair way. Not everyone can or wants to be involved in all aspects of the project. The dividing of tasks based on interest, ability, and experience is a reasonable way to share the workload and to have the best possible outcome.

5.6.7 Underestimating People's Abilities

It is important that the members of the research team not be pigeon-holed into certain tasks, based on what or whom they represent. Stereotypically, academic researchers can be in charge of defining the procedure of collecting and analyzing data, practitioners can be in charge of organizing data collection strategies, and community members work on the ground to collect the data. Although a team may decide on such a division of labor, participatory research means shared decision-making regarding the central components of the research process. The team needs to work in such a way that all the members can participate in that process, sharing their knowledge and expertise. Relegating certain members to certain roles from the start cuts short the potential gains of participatory research.

5.6.8 *Managing the Unexpected*

Participatory research projects are full of surprises and are, at their core, “messy” (see Chap. 7, Engaging; Cook 2009). It is the nature of participatory research that projects take on the complexity of different perspectives and experiences in the real-life settings where people work and live. The research process demands a high degree of flexibility and patience on the part of the research team and other participants in order to constantly adapt the project to the realities of the process.

5.7 Questions for Reflection and Discussion

This chapter aimed to guide you in organizing the research process. We’d like you to reflect on and discuss the following questions:

1. Using the questions regarding building a research team, decide who should initially be invited to take part in the research project.
2. Work together with the research team to identify each member’s resources. If you do not yet have a team, put together a list of potential team members and list the resources which are known to you.
3. Work together with the research team to identify roles and responsibilities, realizing these will likely change over the course of the project. If you do not yet have a team, put together a list of potential team members and list possible roles and responsibilities, based on what you know about the members.

Further Reading and Sources of Inspiration

- Cook, T. (2009). The purpose of mess in action research: Building rigour through a messy turn. *Educational Action Research*, 17(2), 277–291.
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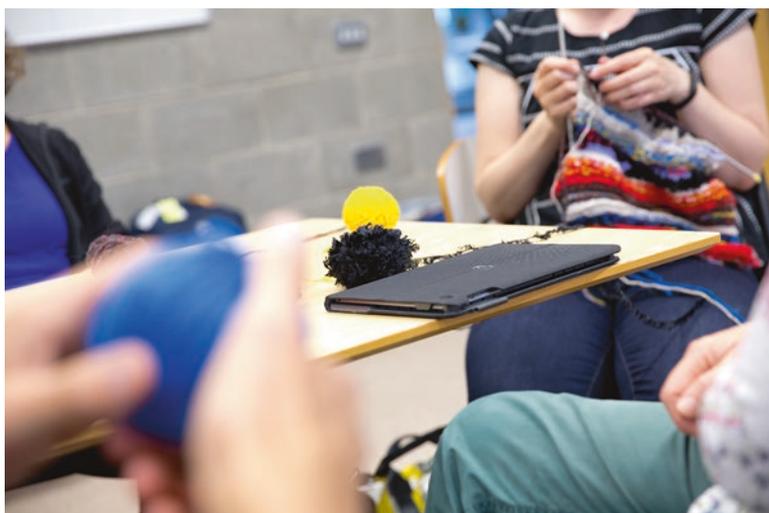
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Chapter 6

Acting for Change: The Generation of Transformative Action



Chapter Summary

Abstract Participatory Research is orientated towards change. This chapter explores the types of actions that generate change in the research process both during and after a research project has finished. It covers the conditions that need to be nurtured to encourage action and some of the impediments to that action.

Purpose Developing insights into understanding types of change and change processes.

Central Question When does action and change take place and what types of action can we expect?

6.1 Introduction

In our knotted weave, change threads its way through our material. It can be found in every fiber. It is what gives it life, strength and purpose. Without change our material would be purely decorative.

While research for its own sake is a worthy endeavor, a prime motivation for doing participatory research is to improve the health and well-being of people. This requires action in some form. That action can be small or it can be profound. Sometimes it will involve individual action, sometimes collective action. It may seek to generate change at the local level of the neighborhood, within an organization or at the policy level. Action may be invisible and intangible, such as changing a person's belief or understanding of a situation as the result of the learning that has taken place. Action can also be more tangible, such as building a community center, introducing changes in the way a service is delivered or persuading policy makers to change a clause in a policy document. Acting for change is unpredictable and often we cannot know how the actions will affect the way changes will manifest. Action is like a small pebble that is thrown in a pond, the effects ripple out to the edge and even beyond. In essence all actions start with a thought. So, if people change the way they think, they will also change how they act in the world. Changing our perspective and making meaning is fundamental to learning. When we learn, a cornerstone of that learning is changing the way we think about something and learning for all is at the core of participatory research.

Participatory research thus does two things at once, it gathers information and creates social action. The knowledge created does not need "translating" or "mobilizing" and action does not only take place after the data collection, generation and analysis. Rather, the research process sets in motion a process of acting together, which ideally culminates in people acting in concert on matters even more bonding than collecting and analyzing information. Similarly, the values and principles that frame the quality of the research process ensures the heart and mind are not dichotomized. As a result, the passion for change can emerge quite strongly, moving people to act when previously they have not seen how or why they should do so (Lather 1986a; Melucci 1996). The meaningful dialogue and relationship building that is at

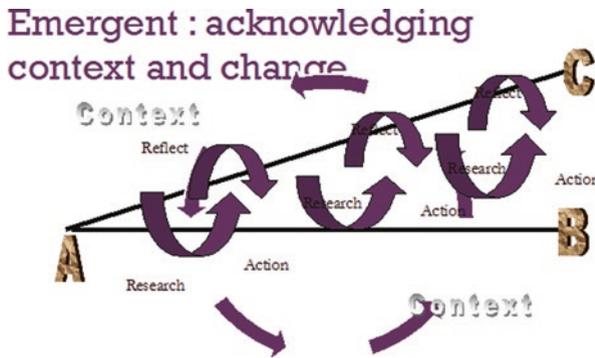


Fig. 6.1 Acknowledging context and change

the center of the research process is predicated on the belief in the capacity of people to transform their lives and the world (Freire 2010; Fals-Borda 1988; McNiff 1988).

Moreover, as we have seen, participatory research is a cyclical and iterative process, thus acting for change takes place throughout the process, sometimes with consequences for the direction of the research process as those involved reflect on actions taken and evaluate them.

Although at the start of the research process you and your co-researchers (see Chap. 5 Organizing for knot to reflect on the terms) may be clear on what outcomes you want, it is important to keep an open mind. At the beginning, you may be clear you want to get to B but where you actually end up is C. Rather than seeing C as the wrong outcome or implementation process, through the action and reflection cycles you will have been led to C as it is the most appropriate outcome than the one originally intended. Since you have engaged in those cycles you will know why (See Fig. 6.1).

We will be exploring reflection and evaluation later on in Chap. 10. In this Chapter, we are looking at a key thread in the participatory research process, acting for change. We will explore where we can expect change and how we can support acting for change during the research process and after. Finally, we look at some of the stumbling blocks that we need to address in doing so, remembering that action is emergent, a product of negotiating fluid understandings.

6.2 What Does Action for Change Look Like in Participatory Research?

Change is at the core of why and how participatory research takes place, “it is what brings people together, what drives them and what drives the twists and turns of the process” (Pain et al. 2015: 6). In participatory research change is usually recognized as the contribution that research makes to the people involved in the research and the communities and organizations they are part of, although change on the wider society, policy making and the academy may also occur. Change is the benefit participatory research brings to individuals, communities, organizations (and even nations). It is both the intended and unintended consequences of the participatory research process.

Change may include, but is not limited to:

- individual, organizational and/or community transformational learning;
- building personal, organizational and/or community capacity;
- changes in practice;
- knowledge that catalyzes individual and collective empowerment to make decisions concerning health and well-being;
- the strengthening of organizational/community structures;
- network building, deepening and extending relationships and acquiring new partners;
- the creation of new and multiple forms of local knowledge and evidence;
- the advancement of existing theories or development of new paradigms;
- policy change.

It can be both potentially positive and negative. Both can lead to significant learning and therefore change (ICPHR 2018).

The nature of change often includes elements that are conscious and concrete but equally important are the less tangible elements. Participatory researchers argue that because certain changes are less tangible, this does not make them less important. We recognise that a change such as the change in the way someone thinks about something can have a very deep, ongoing change on the way they might act in the future.

Diverse changes from participatory research may occur at micro (local) as well as meso (regional) or macro (national, international, global) scales, from individual attitudes and learning, to community or organizational capacity building, through to institutional or policy change. We should not automatically assumed that some scales of change are more important than others or that they will occur in isolation. Different changes often do not happen in isolation, but are co-dependent, existing at numerous scales simultaneously, each contributing to an overall effect and might occur at any stage of the research process and at any level in the system. See the example below:

Example: Solomon Islanders Enacting Change

In 2008, a group of community leaders and health staff from Atoifi Adventist Hospital were joined by a small number of international public health researchers to form the Atoifi Health Research Group. Based on a “learn-by-doing” approach to research, this group aimed to build research capacity within the Solomon Islands through undertaking a number of participatory research projects that range from increasing detection of Tuberculosis cases in the community to controlling soil transmitted parasitic worms (these and other projects can be found at <http://www.atoifiresearch.org.sb/projects>). David MacLaren et al. (2015) point out the success of the group is based on its initiation by Solomon Islanders who had a desire to learn about how to conduct health research through the full involvement of local individuals and institutions to collectively learn and find local solutions of benefit to the Islanders. It was hoped this would lead to local evidence “trickling-up” to inform policy and practice at provincial, national and international levels.

6.3 What Counts as Action for Change?

What counts as change in participatory research is largely defined by the people and communities involved. Different communities, partner organizations, groups of participants, etc., may have different priorities for change. It is they who know the context and are therefore well placed to state what changes can be made to their work or lives and also to be able to tell whether or not the research has had an effect. Changes cannot be identified by academics (or researchers external to the context) alone, it has to be a collaboration. This is not to deny the contribution external researchers, working in partnership, might make to helping communities of practice deepen their understandings in relation to desired, expected and potential changes, but in participatory research the change debate is a collaboration. This differs from more traditional forms of research where the types of change expected of the research can be both determined and assessed by external agents who do not have such lived experience. As participatory research starts from the local it can, and will, take into account that different groups of people, communities and organizations are likely to have different priorities for doing the research based on their own context, and hence have particular understandings of change. Here is an example.

Example: Improving Coronary Heart Disease Services for Maori Clients in New Zealand

Using a participatory research process in conjunction with Kaupapa Maori Research (based on three principles: by Maori for Maori; Maori worldviews as the normative frame; research is for the benefit of Maori), a study by Sandy Kerr et al. (2010) outlined several strategic actions that were implemented in Te Tai Tokerau, New Zealand, to address the issues around heart disease services identified in phase 1 of the study. The Maori-led advocacy and actions included: (1) reserving a set number of angiography appointments for Maori clients that saw a significant increase in the number of Maori accessing these services; (2) community fundraising to implement pre-hospital fibrinolytic therapy within ambulance services for those living more than 60 min from the main hospital; (3) development of a new home-based cardiac rehabilitation service; (4) improved systems for outpatient appointment booking and communication that resulted in improvements in attendance by Maori clients; (5) development of a proposal for the purchase of automated external defibrillators for use within the community; and (6) development of an audio-visual resource to support Maori in cardiac rehabilitation. All these actions were going above and beyond the “normal” service provision in order to address inequity associated with Maori needs and ways not being adequately addressed within health services. The actions were Maori-led. The research identified problems but also possible solutions from within and by the community. It was noted that the actions were predominantly system-oriented to reflect the service provision inequities impacting Maori clients.

6.4 Where Might Change Be Found?

(i) Within the Process

In participatory research, action is understood as being on a continuum. It is not just an expected outcome found at the end of a research process, it is interwoven into the fabric of the research and might be found in any stage of the research process, including the initial planning stage. As Yoland Wadsworth (1998) states:

...while there is a conceptual difference between the “participation”, “action” and “research” elements, in its most developed state these differences begin to dissolve in practice. That is, there is not participation followed by research and then hopefully action. Instead there are countless tiny cycles of participatory reflection on action, learning about action and then new informed action which is in turn the subject of further reflection. Change does not happen at “the end”—it happens throughout. (p. 7).

For example, at the beginning of the process when having discussions about the focus of the research (the design phase); from the data generation process (loosely called methods, See Chap. 7 Engaging); through meaning making processes (analysis, See Chap. 8 Sense Making), or be taken up in the more traditional way, as change that comes as a consequence of the “findings” of the research.

(ii) Who Changes or Acts for Change?

Traditionally we might expect change to occur in the subjects of research and their communities/organizations. When research is carried out in a participatory manner, the potential for change sits on much broader foundations. In participatory research change is not something that happens to communities after external researchers have given them their findings. When people from different backgrounds (which includes external researchers working with communities) come together with a common focus, this transdisciplinary collaboration can create additional value. In this way, everyone has the potential to learn from the process, to make a change, to have an impact in their own sphere of activity. Change can therefore ripple out and be found in people and places beyond the immediate research processes. That includes the researchers, as the quote from Patricia Maguire’s description of doing her PhD in Chap. 1 illustrates so well.

(iii) When Does the Change Occur?

The processes of participation and the spaces for dialogue, reflection and engagement created in the course of participatory research heighten the possibility of varied change occurring in the health and social well-being of those involved and beyond, but social change takes time. Sometimes change is so subtle that it is imperceptible in the short term. For instance, it may consist of hidden changes occurring within the way people perceive their context and might only become visible in the long term as these small changes in thinking and knowing ultimately lead to changes in acting leading to more discernible effects. This means that change is just as likely to occur after the initial research project has been completed (that is outside timescales shaped by the original research plans).

(iv) At What Level Does the Change Occur?

This depends on the context of the research, the original purpose and who is involved. Many participatory research projects operate at a local level bringing about changes in practice. In the example drawn from a participatory research study among Cook Islanders in the southern Pacific Ocean we can see change as an intrinsic part of service delivery but in the example “Health in All Policies” in South Australia the change was at the policy level.

Example: Cook Islanders Evaluate Rehabilitation Services

People who live in remote areas often need to travel to access health services. For those living in the Cook Islands in the southern Pacific Ocean, accessing health services often means relocating to New Zealand. The study undertaken by Rebecca Washbourn and colleagues (2016) outlines a community based rehabilitation service that provides a “bottom up” approach to services for those with disabilities based on local community knowledge and resources. Members of Te Vaerua (translated as meaning “a spirit of giving without expecting return”) board and Western therapists and academics undertook a participatory research study to explore how rehabilitation was valued by Cook Islanders and to generate guidance for Western therapists who primarily provided the services. The central concept that emerged from the research related to a shared view of responsibility of the community in easing the burden of others. This was articulated through three themes: (1) that rehabilitation be locally accessible and pragmatically useful for people who require it (so families didn’t need to relocate to New Zealand); (2) that rehabilitation be built on interpersonal relationships and involve shared responsibility between individuals in a community, expressed as a cultural expectation of giving and providing support; and (3) that rehabilitation provide hope by offering the possibility of a better life. Actions and outcomes were an intrinsic and ongoing part of service delivery but included: presentation of findings to the Ministry of Health; data used by the board to better understand the extent of rehabilitation needs on the island and to inform the strategic planning and service delivery.

Here is the other example illustrating policy change:

Example: Health in All Policies

Health in All Policies (HiAP) is an approach to health policy that is intersectoral and focuses on action addressing social determinants of health. HiAP was adopted in South Australia in 2008 and funding was gained in 2012 to undertake a major evaluation (Baum et al. 2014). This project was based on

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participatory action research whereby co-researchers included staff from a dedicated HiAP unit within South Australia Health and academics from Flinders University. The evaluation involved developing program logic models and detailed case analyses, interviews with key political and non-bureaucratic actors who have knowledge of HiAP implementation, online surveys of policy actors from all sectors involved in HiAP over the 5 years of the project. The findings suggest HiAP has facilitated increased understanding of health outcomes by policy makers, changes in policy directions, and stronger partnerships between health and other government departments. The evaluation process allowed the researchers to track ways HiAP activities may be addressing health and equity outcomes.

6.5 Planning for Change

Given that our values base in participatory research forefronts relational knowing, the way in which we understand change reflects this way of being. As participatory research embeds shared knowledge generation, and hence action, within, throughout and beyond the research process, the key characteristic is that knowledge is always in a process of becoming, it is never fixed and therefore neither is the action required. As Wadsworth (1998) states:

A hallmark of a genuine participatory action research process is that it may change shape and focus over time (and sometimes quite unexpectedly) as participants focus and refocus their understandings about what is “really” happening and what is really important to them. (p. 5)

Some change will be expected in advance and can be planned for. These are the changes researchers set out to work towards as the focus of their research, for example improved local knowledge of key public health issues, better ways of communicating across sectors, improved delivery of preventative health systems. However, it is important for an early acknowledgement by all those involved that this trajectory may not be the eventual outcome. In other words, plan for and be open to what emerges. Being at ease with ambiguity and things emerging or going in a different direction is a skill a participatory researcher needs to develop.

As the research unfolds the relational experience that develops begins a process that starts to “separate rhetoric from well-rehearsed notions of practice” (Cook 2006: 429), since it provides a forum for people to not only share, but reflect and critique their own knowledge in the light of that brought to the table by others. The new knowledge created by those involved, rather than been delivered by external “experts,” often creates an “insider imperative” for change (Cook 2006: 430). In this way change is viewed:

not as an outcome of research but as a praxis (after Paulo Freire) – a collaborative process of critical reflection on reality in order to transform it (Pain et al. 2015: 5).

Change is actually a pragmatic response to the new understandings engendered through the practical processes of thinking together, and can occur at any stage of the project. From the dialectical processes at the heart of participatory research come discoveries and ways of knowing that have not been planned for: they appear to pop out of no-where. This raises questions for participatory researchers if, as Tricia Greenhalgh et al. (2016) points out, participatory forms of research are:

...built on multiple interacting entities that are emergent, locally adaptive, self-organizing ... which generate outcomes that cannot be fully predicted in advance. (p. 405)

The message generally given to researchers, be they a PhD candidate or a researcher bidding for funding to carry out a larger project, is to be specific about what they are going to do during the lifetime of the project to facilitate the pathways to change. How can we provide a plan for change if changes are unlikely to be fully foreseeable before the research process starts? Rachel Pain and others (2015) suggest that people who regularly engage in this relational way of researching often speak of serendipity:

Chance encounters, anecdotes, snippets of learning leading to unintended impacts. The small things – for example, an unplanned conversation over coffee – sometimes lead to large shifts (p. 7).

We know, however, that serendipity is not just about chance, there are conditions that underpin serendipity which can be fostered. To allow for both the expected and the unexpected, pathways to change cannot be totally fixed in advance; flexibility is vital but if we know what fosters “serendipitous change” we can plan spaces to help facilitate that. There are known principles for shaping spaces within the research process that create the conditions to facilitate change. Some of these are outlined in the next section (Image 6.1).



Image 6.1 Discussing the topic “knowledge ecologies” in the ICPHR, Limerick, 2017

6.6 Principles for Facilitating Acting for Change in Participatory Research

6.6.1 Empowerment

For people to act for change, they need what is called *agency*; that is the ability to act, the confidence to do so and the resources to make it happen. This inevitably raises the issue of power and control in any society. A central tenet of participatory research is to encourage the voice of the marginalized to be heard. People who have been historically marginalized may have at their disposal many resources to act but are unaware of those resources because they have not been valued by the “higher ups.” As Peter McLaren (2006, p. 63) says, “knowledge is a social construction deeply rooted in the nexus of power relations.” They also feel unable to act because they have been disempowered by the social system, made to feel worthless and incompetent. These feelings get internalized leading to apathy and passivity. This is known as *internalized oppression* (Tappan 2006).

Since participatory research, by its intention and the way it is practiced, values all knowledge and experience it thus empowers communities, organizations and individuals to analyze and take action to solve their own problems. However, bias needs to be built into the process in favor of the interests of the “have nots” or putting the first last. The powerful can be decisive and act for change but steps need to be taken to avoid their voices dominating and also to ensure those less powerful are empowered to act and are authentically involved. Indeed, the emancipatory tradition of participatory research grew out of the work of people like Paolo Freire (2010) and Orlando Fals-Borda (2006) as a vehicle for encouraging marginalized people to construct a countervailing power (balancing of the power of one group by that of another) to their oppressors through the acquisition of serious and reliable knowledge. The participatory researcher, therefore, has to be constantly attentive to empowering processes. They need to facilitate processes that create a safe environment where those involved can speak freely and not fear retribution. It also means paying attention to the process of capacity building. This can mean anything from helping people feel confident to develop at their own pace, enabling people to come together to share and discuss progress, to ensuring those who cannot continue still have their voice included.

Empowerment is not something one does for, or to, people.

Empowerment is a reflexive activity, a process capable of being initiated or sustained only by the agent or subject that seeks power or self-determination. Others can only aid and abet in this empowerment process. They do so by providing climate, a relationship, resources and procedural means through which people can enhance their own lives (Simon 1990 p. 32).

Similarly, one cannot enforce action for change. As people come together and learn, they become more aware (*conscientization*) and gain the collective knowledge on how to act for change. Below is an example of people with Parkinson’s, a marginalized group in The Netherlands, who got engaged in setting priorities for

research. It shows how they overcame internalized oppression through mutual encouragement in a safe environment (See also Chap. 7, for more details).

Example: Relational Empowerment of People with Parkinson's

One of us (Tineke) was part of a participatory research study in which people with Parkinson's set research priorities. They came together in a situation of mutual encouragement to develop their own voice and agenda. Through dialogue people with Parkinson's became more aware of their own situation and the impact of the illness on their lives. Via conversations with peers they became more critical of disabling environments and processes of exclusion in society. This critical awareness prevented a reproduction of internalized oppression and existing professional standpoints and knowledge hierarchies. Jointly, they developed a sense of power to realize their goals via group solidarity and joining of forces. The dialogues and "deep" deliberations among them resulted in a broad array of research themes, that were grounded in their life-worlds. Those involved experienced their involvement as very positive, special and intensive. After the meetings, they said they were tired and "empty" due to the hard work and thinking. They liked working with peers to inquire, deepen, name and describe experiences. One of them noticed the mutual and emotional recognition: "*You are doing that with peers and you feel that other persons exactly know what you're talking about.*" Participants also stressed the importance of mutual contact, and the possibility to talk about sensitive topics like addiction, which were normally hardly discussed. Almost seven years later the Dutch Parkinson's Association considered the agenda setting project as one of the major events in their organization over the past ten years and devoted in their 40th anniversary special issue newspaper two pages on the merits of patient involvement in research. The research agenda is still in use by the Association. (Source: Abma 2018)

Here the concept of relational empowerment is relevant (Christens 2012; Freire 2010; Sprague and Hayes 2000; Hyung Hur 2006). It regards empowerment as a mutual supportive process mobilizing the strengths of participants. Relational empowerment indicates that power emerges through interaction and narration with others (Rappaport 1995). People with Parkinson's in the example above explicitly stated that deliberation was a meaningful and empowering process to develop their voice and research priorities. To a lesser extent internalized domination/privilege was challenged, but professional researchers and health care professionals did admit funding was one-sidedly invested in fundamental biomedical research and limited knowledge to appraise applied research and agreed to change their programming in line with the priorities of people with Parkinson's (Abma 2018).

The very process in which people come together to understand the world in order to change it can, however, also be challenging. In the process of empowerment, people may turn against each other in acts of *horizontal violence*. When participa-

tion leads to equalizing power, the need to possess power and abuse it as the dominant mode of being in the world, rooted in scarcity and competitiveness can be challenging. Disrupting the existing system inevitably means such challenges. Knowing this helps the participatory research practitioner to just see it as such and, if they do not possess it themselves, engage the help of someone with conflict resolution skills to move the dialogue from unilateral win-lose power and conflict to mutual understanding and mutual transformative power between groups (Torbert 2013). Here is an illustration of mutual transformative power (Baur and Abma 2012; Abma and Baur 2014) (Image 6.2):



Image 6.2 The taste buddies and collage

Example: The Taste Buddies Aligning to Improve Meals in a Residential Setting

Vivianne Baur and one of us (Tineke) initiated a participatory research project to involve older people in a residential setting in decision making processes concerning their life and well-being. After a series of conversations a core group of seven women aged 82–92 were dedicated to work on improvements of the meals. The group explored problems they identified, relating to the meals, including the ambiance, nutrition, taste, variety, preparation, out-sourced kitchen, etcetera. In later gatherings the group began through the process of making a collage, to dream of solutions.

It was during this stage in the process that the older people felt they had become one cohesive group with an own collective identity, and they named themselves *The Taste Buddies*. To verify whether their plans also were recognized by other residents a meeting was organized open to the whole resident community. Informally they also validated their ideas: “*I have put out my feelers to know now whether other residents also want change.*” Later, the Taste Buddies met with team leaders, kitchen staff, cook, restaurant personnel, the local manager and a resident council member to discuss their ideas for improvements. The Taste Buddies used their collage – reflecting their dream –

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to show their plans for improvements: reopening the kitchen and hiring a cook in the residential home, fresh food, well-composed menus, and a quiet and cosy atmosphere. Common ground was found in the well-being of residents. A care staff member expressed their sympathy: *“I do see the problems you have, and it also bothers me. We also want to change something.”* The manager was even stronger in his wordings: *“You are not a hundred percent right, but a thousand.”* Both acknowledged that The Taste Buddies were right about their complaints and concerns with regards to the meals and they encouraged The Taste Buddies to go into dialogue with other groups as well. Their ideas also resonated with the kitchen and restaurant staff who wanted to serve good food. For example a member of staff from the kitchen said: *“Yes, that is something we often talk about, that the combination [of different parts of the menu] is not always good.”* Finally The Taste Buddies participated in the job interviews for the two new cooks. The kitchen was reopened, and meals cooked fresh at the location. Later positive responses from fellow residents were felt by the group as an encouragement to continue: *“If residents say that the food has improved a bit, then I think: Well, see what we have realized!”* Therefore, The Taste Buddies decided to continue as a group for several years to monitor the changes and take up new issues. (Source: Baur and Abma 2012)

6.6.2 Ownership, Roles and Responsibilities

One of the many merits of participatory research is people are much more likely to own the results and the actions required because of their involvement as co-researchers.

Example: New Initiative in Primary Care

This became very clear in a research project one of us (Jane) was involved in with Lynne Graver some years ago in Liverpool. We had been engaged to research the effect of a new initiative in primary care, focusing on local multidisciplinary facilitation teams (LMFTs). There were representatives of the disciplines involved in primary care who were working with primary care clinics to improve health in their populations. Ironically, the research originally started not being participatory, the steering group approved by the Chief Executive of the primary care overseeing body at the time insisted on a team that did not include the LMFTs or the clinics themselves but did include herself. However, over a year we were able to persuade the original steering group to expand its membership and to become more participatory as the value of doing so emerged as a result of the initial dialogue and a learning process. How effective this was for instituting change became clear when we waited outside the CEO’s office having presented our final report three years

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later. We were quite nervous, not knowing quite how it would be received despite an excellent working relationship in the research process. The door opened and she welcomed us in, congratulating us on the report and adding, “of course we have already been implementing the agreed recommendations across the Primary Care Trust as a result of what I was learning during the research!” She already owned the research and was moving to implementation long before the research process had ended. There was no knowledge to action hiatus as is often the case in other types of research. What is often called knowledge translation had already happened.

This example also illustrates how as part of the dialogue in the early stages of research, conversations are required as to who has the role and the responsibility to take action as a result of the research (See also Chap. 3 Getting Started). This can be renegotiated as the process continues and as new forms of actions emerge. It requires an open and honest conversation about power and who has the power to act. As the process continues, notions as to who has the power to act may change and it is worth reflecting on this as a group as the research takes place. Being clear on who can act and how, can form part of the governance process of the research and any agreement as to ground rules. It might even form part of a formal memorandum of agreement, recognizing that this can be reviewed at any time. This helps with clarity on expectations too, because often you can perceive other people having more power than they actually have and vice versa. Again, these differences often emerge as the research progresses. Previous absence of agency and autonomy can be often being restored through a mutual reciprocal process that draws people together in conditions of dignity and respect (Ledwith and Springett 2010).

6.6.3 *Make Space for Relational, Democratic, Dialectical Processes*

Respect and reciprocity are key elements in generating spaces for knowledge production that enable inclusive processes for diverse stakeholders to engage in critical conversations for communicative action. (Greenhalgh et al. 2016).

Time frames for all types of research almost inevitably seem impossibly tight. An approach that necessitates the building of relationships as a pathway to acting for change can be compromised by tight time frames and perceptions of where, in the process, time needs to be built in.



Time is essential in participatory research to develop good relationships among participants and to discuss and return what really matters to people.

Reflect on what relationships mean for you. What are important relationships in your life and work? How can you make friends and nurture relationships in your research? How might time frames (deadlines of funding agencies etc.) affect your research? How can you create enough space for deliberation and dialogue and reflection?

In participatory research, this time for development and exchange of ideas, whilst necessary across the lifetime of a project, is particularly important when starting out if strong, trusting relationships are to be established. It is also a space for early action as new ideas are surfaced in the process of project construction. The shared tabling and critique of varied assumptions, perspectives and knowledge at the beginning of the research facilitates new meaning making among participants. Without the engaged participation of insiders, research is less likely to reveal underlying theories and beliefs that underpin any action. This builds on Patti Lather's (1986b) notion of "catalytic validity", that is, the degree in which the research process energizes people towards a closer knowing of reality in order to transform it. This dialectical collective process of formative co-construction is, therefore, the "hotbed" for impact.

Different partners within the research are, however, likely to operate under different time pressures and on different timescales. It is important to discuss the true nature of these, and the time requirements for working together, at the outset. This process also helps with articulating the value of a "slow start" which is often the area people struggle with, wanting to "get on with the project" and seeing slow as a negative. The strength of participatory research lies in its ability to create spaces where people work together to uncover and examine different points of view (ICPHR 2013) and this slow start is necessary for building trust across those involved to enable this to happen.

6.6.4 Spaces for Recognizing the "Human"ness of Working Together

...working relationships may stimulate care and empathy, hope or despondency may accompany the presentation of findings, and a range of impacts may take place via the emotional registers of the people who they target, including those who hold most power. (Pain et al. 2015: 8).

Rachel Pain et al. (2015) go on to note that "feelings produce impacts produce feelings" and that emotional dimensions are "not as side-effects, but are active in generating impact" (p. 8). Here impact is seen as action or change. See Chap. 8 for an example that nicely illustrates how findings can have an emotional impact on decision-makers (Emergency Care for Clients with Psychiatric Clients in Crisis). The role of emotions in engendering change is in line with social movement theory. Alberto Melucci (1996) argues that collective action stems from the emotional recognition among people that something is not right and needs to change. The longing for a better world motivates people to act collectively, especially if they share a dream, a loved future. Time is needed for emotional support, to attend to "experi-

ences” that occur within the research process, particularly “emotional touch points.” All participants have emotional responses (including academics). These can be productive when that response leads to passion that drives research and action, for instance the passion for creating social justice, knowledge democracy and addressing health inequalities. Active attention to engaging with strong emotions can be productive and rewarding. It is important, however, to recognize that emotions can also be disruptive to research processes and damaging to communities. When things go wrong it can create alienation, resentment, disappointment, disillusionment, a feeling of exploitation, or divisions. This emphasizes the need to build in time for the non-tangible, to attending to emotional drivers that can affect action.

6.6.5 Planning for “Mess”

Empirical research has been characterized historically as a science with tight planning and exactitude as its trademark. The natural tendency, under these conditions, is for mess to be seen as an indicator of failure, as something that needs to be hidden away from public view. As discussed in the next Chap. 7 Engaging, certain forms of “mess” enhance the transformatory powers of a participatory research approach. It has been argued by one of us (Tina) (Cook 2009) that mess is the “driving force for revealing tacit or hidden realities that frame actions” (p. 287). Given that for many people ambiguity is quite difficult to live with, to see it as a positive and actively encourage it necessitates confidence and space. The function of this space is to both acclimatize people within projects to the fact that it will not follow a neat, linear model and that it is this lack of linearity, alongside their own ability to come to terms with “not always knowing what they are doing” (Atkinson and Claxton 2000), will provide the project with opportunities to generate deep, relevant and transformative understandings that facilitate action. We need to incorporate time and space for mess as an integral part of our researching and allow ideas to be cultivated, distorted, fermented and processed.

6.6.6 Creativity

Given that learning, particularly shared learning, is considered fundamental to creating conditions for action, engaging with more creative approaches to generating data provides a fertile context for change processes (Munn-Giddings and Cook 2016). Embedding creativity, creative methods, and different forms of expression, into research pathways, is a positive means of disrupting linear traditions of research and bringing uncertainty and “mess” into the research process. As has been discussed in previous and forthcoming chapters, participatory research can draw on a variety of creative methods such as photographs, films, drawing, scrapbooks, poetry, Forum Theatre etc. to generate data in different ways. Creative methods can open

out the ways in which people can contribute in a more democratic space. By removing discomfiture that can be provoked by direct questioning, creative methods offer a space for those who are less likely to engage in traditional forms of communicative engagement. “Collaboration” rather than “data gathering” underpins these approaches (Gubrium et al. 2016). The aim is to democratize the authorial voice when engaging with communities and the diverse members of those communities. By offering different ways of enabling people to articulate their experiences, creative approaches increase the potential for us to challenge our assumptions and perceptions as we start to see them through a different lens. The blend of experience and reflexivity offered by creative methods facilitates the connections between personal experience and collaborative reflexivity. This in turn creates the in-built transformational potential that externally devised and delivered, single loop methods lack, positioned as they are to collect rather than generate data and to do not build in space for reflexive critique (See the next Chap. 7 Engaging: Method, for collecting and generating data).

By disrupting the “usual” and allowing for multiple interpretations to emerge without diverse interpretations being stigmatized for their difference, creative methods not only unearth what is different, they allow it to be valued. Such disturbance is critical to providing the points in research that allow our usual understandings to be “pricked, disturbed and wounded” (Cook 2009) to offer new insights into our practices. Creative methods can also be fun. Having fun is a powerful driver for creating conditions for enabling the hard work to happen en route to seeing, and accordingly acting, differently. In the photograph below we see the joy of children in a participatory research project, called KLIK, using Photovoice to inquiry, experiment and taste healthy food and living means. See also Chap. 8 Sense Making for a further description of KLIK (Images 6.3 and 6.4).



Image 6.3 Making a picture of somebody moving



Image 6.4 Making sense of pictures

6.6.7 *Building Networks*

Participatory research is a network in itself. It brings people together and the very nature of this is that it is likely to connect beyond the context of the research. People taking part in the research will be linked to others who are liable to have an interest in the research, its outputs and outcomes and the agency to act. It is important to make explicit, within the group, what these networks might be and how they can be used. These networks will be personal, local, national or international; they can be based in practice or policy for practice. Active links to policy makers need to be nurtured if they are to be purposeful. Relationships need to be extended outward for those who have the power to make wider changes to be part of the process of learning for change. If the research has advisors, or an advisory group, it is important to consider who might need to be on that group in the light of where the research hopes to make a wider difference and bring about action for change. Inviting people with influence to act as consultants, having recurrent and timely meetings with those who could be important in championing the research, can, if done by sharing agency in the research, build pathways for change. The process of shared knowledge building in this way creates its own impetus for change. If an effect of the research process is the development of existing, or even new, networks of relationships, social and economic systems and/or policy systems as well as learning amongst the original research actors, action for change is likely to extend beyond the systems we are seeking to change.

6.7 Stumbling Blocks

As indicated in the section on empowerment, acting for change and change itself can face some challenges. Agency comes from available resources and where those resources are few, empowerment is difficult to maintain over space and time. It is important to remember that the broader social structures and power relations also influence the space for democracy that the research process has created and may curtail empowerment. Outside the process, participants may find it difficult to use their newly acquired skills and experience when they return to other aspects of life governed by hierarchical systems.

This touches on two things. Firstly, through our research process we may have to confront the politics of hate, fear, racism, disablism, sexism and homophobia as well as the social and economic inequities of the context. This will mean engaging with the emotions provoked by our research (Torre and Fine 2007), including our own. We will be challenged to balance despair with a sense of agency. Secondly, we have a deep ethical responsibility to create safe and supportive spaces for not only raising critical questions, but for collectively processing the bleak realities of structural racism, sexism and global inequities (Ahmed 2017). Indeed, there is an ethical obligation to challenge what Paolo Freire identifies as “the scourge of neoliberalism, with its cynical fatalism and its inflexible negation of the right to dream differently, to dream of utopia.” (Freire 2001, p. 22). There is, Paolo Freire, argues, nothing inevitable about our social-historical reality.

Resistance to change can be personal, organizational or social and is related to capacity in those areas to engage with it. At the personal level, challenges to status, identity and to previously strongly held beliefs can act as blocks on the process of learning and change. It can give rise to strong emotions and generate conflict. Freire argues the pain is necessary as part of the process of *conscientization*, the awakening of the critical consciousness and “becoming more fully human” (Freire 1997). Not everyone is ready for change and the pace at which it takes place can vary greatly from person to person.

Example: Strengthening the Collaborations Between Health Care Sectors in Sweden

A participatory research project was initiated which focused on nine research and development (R&D) networks set up to promote a professional approach to care and strengthen the collaboration between health care sectors in a Swedish health care setting. The participants were the network coordinators', their facilitators and the network participants together with a PhD student from the local university. Initially the focus was exploring the role of the networks and their ways of working, particularly in relation to knowledge transfer as the networks had originally been set up to encourage evidence based practice. Data was collected by use of a multi-method approach consisting of

(continued)

interviews, observations, document review and reflexive notes on the part of the student with continual dialogue and feedback taking place within the core group of facilitators who had initiated the research. Despite the research revealing a need for different ways of working to be adopted, the participants continued to adopt a didactic and top down approach to knowledge transfer. It became clear that the context, a hierarchical decision-making environment dominated by a key decision-maker was at odds with the interactive network concept and the participants were unable to break away from their dominant discourse and mind set. The reasons for this were eventually explored in the doctoral thesis using Bourdieu's theory of practice as an explanatory framework (Johansson 2011).

It is at the institutional level that action for change often receives its greatest challenge. Institutional capacity for change is consistently reported in the literature as a stumbling block to achieving the changes needed to enhance health and well-being (Habermas 1977; Goffman 1961; Foucault 1965, 1973). Many social institutions such as health and social care have been created to provide services to support people by focusing on needs and deficiencies rather than fostering skills and identifying resources to support people and seem to have difficulty in adopting an asset based approach. As in the vignette, health institutions are hierarchically constructed where professionals' identities are tied up with expertise and this can act as a significant brake on change. On the other hand, such command and control systems can also bring about change quickly across an organization. However, perhaps the greatest stumbling block is attitudes to time. Time to reflect, to dialogue and to attend meetings is scarce in organizations that value doing and monitor that doing through performance management systems that privilege activity, even if it is mindless. Here the action is negotiating that time with those further up in the hierarchy and seeking out key change agents and engaging them early on in the research process. The Taste Buddies and next example show how partnerships can be developed.

Example: Engaging Key Decision-Makers to Bring About Change

A group of home care assistants in Bromölla, a municipality in the south of Sweden, supported by an academic were exploring their practice in providing care for people with multiple chronic health issues at home through story dialogue. As a result of the process, a number of key changes were identified but no one felt able to take action on them because they felt that they had no agency within the community care system. The academic therefore worked participatively with the key decision-makers at a policy level to look at change possibilities. Out of this process, a whole system world café event was held involving everyone including clients and their relatives and actions were identified that were required at all levels in the system.

Stumbling blocks to change depend very much on context and the type of participatory research project you are undertaking. For projects at the more emancipatory end of the spectrum, where you are working with the oppressed and exploited to change their everyday lives, the blocks can be hidden such as institutional cultural conditions like ageism, racism, sexism and homophobia and therefore difficult to pinpoint for specific action (Cameron 2007; Ahmed 2017). Where those institutions are directly involved because they have commissioned the work or are working as co-researchers, it is better to plan ahead and engage with champions within the institutions, laying the groundwork for the necessary action. Even so, you are always at the mercy of organizational change and political change that may mean you lose your champions at a key stage. For an example, see the Towards Inclusive Living project in Chap. 10. This was exactly what happened in this project, a major re-organization within the Trust removed all key change makers who had connected to the project. That means engaging a wide range of people and not just relying on one or two in an organization, developing bonds and connections, and finding the energy and resources to keep going.



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Engaging decision-makers early on and throughout in the participatory research process is essential in order to enact change.

Reflect on who the key decision-makers are in your project. How can you involve them in a meaningful way in the process? What are the potential “brick walls” of resistance you might encounter? What connections do you need to keep going, to keep you energized?

6.8 Activism, Advocacy and Change

Thus far in this Chapter, we have spoken of action as a change in thinking and more tangible changes in behaviors, services, systems and policies, which result as part of participatory research. We have also intimated that significant effort is often required to bridge the gap between identifying what change may be required and actually achieving that change. Those who have the power to implement structural changes sometimes need a little persuading to act. Ideally, those in positions of decision making are included in the participatory research, as outlined above, but this is not always the case. This is when the action that emerges from the research is one of activism or advocacy, especially when the co-researchers come from communities that have been traditionally disempowered. Such activism may include lobbying, writing media releases and letters to those in positions of authority.

Activism, of course, is embedded in participatory research. By doing this type of research we are engaging in processes that encourage solidarity and direct forms of democracy (Barber 1984; in ‘t Veld 2010; Chatterton et al. 2007; Gergen 2003; Hall 2012). This comes in the way we share knowledge without hierarchy and oppression, and offer radical critiques, engaging in and encouraging critical reflection

(Ahmed 2017). It is achieved through the spaces we create for such reflection and for encouraging people with different backgrounds to connect and explore their commonality and their differences. For academic researcher/facilitators who do participatory research, this activism dimension can raise issues of lack of neutrality and impartiality. However, more fundamentally it can also raise issues related to role. The desire to act and see change can so easily mean a departure from a researcher role to one of total activist; this may even be an expectation from co-researchers.



Activism and advocacy are integrated in your work as a participatory action researcher. You want change, you identify with a political agenda, you feel solidarity with those who are marginalized, you are critical of societal structures of inequality.

Reflect on how your will to change and transform institutions and/or society can get in the way of being respected as a researcher. How can you deal with accusations of being partial, not neutral? And vice versa, how can you cope with accusations of not being political and activist enough.

Example: Becoming a True Co-researcher as an Academic

Angela, an academic researcher from Salford University, had been asked to work with a group of citizens who had been invited to be community representatives on what at the time were the local Primary Care Trusts. These Trusts were responsible for the strategic direction of primary health care. They had obtained a grant to research their experience of being a “lay” member. One year into the project they were reviewing their progress. Suddenly one of the co researchers rounded on Angela and upbraided her for not participating and sharing her knowledge while they struggled. Initially shocked, Angela, on discussion, realized that in an effort to be as participatory as possible she had restricted her role to facilitation rather than acting as a true co-researcher sharing her research skills and local knowledge. She subsequently became an equal partner.

There is another direction advocacy and activism may take, and that is arguing for participatory research itself. Participatory research has formed a key part of decolonizing methodologies for many First Nations people, but this needed to be advocated by Indigenous and non-Indigenous researchers over a number of years in countries such as Australia, New Zealand and Canada (see for example, Kendall et al. 2011). Participatory research continues to be held as “not real research” by some traditional researchers and funding bodies. Indeed, part of the reason for the formation of the International Collaboration for Participatory Health Research (ICPHR) in 2009 was to advocate for participatory research at an institutional level; for financial support and recognition of the benefits associated with participatory research.

Participatory research has a role to play in social movements; a core feature of both is collective action (Melucci 1996). What participatory research does is build capacity amongst community members which they can subsequently utilize in other contexts (Laycock et al. 2011; Walkers 2009; Wicks et al. 2013). The skills, resources and networks established during the process can be used to socially mobilize on other issues. When they connect with others, strong social movements for change can develop.

6.9 Transformation or Transition

Participatory research has within it the potential for transformative action. It can bring about change within the system or may even change the system. However, you should not be daunted. While every participatory researcher aspires to a Freirean type transformative process, in most cases what you can achieve is a small change in practice within you and your co-researchers scope and influence. However, that small change may well be the step in transitioning to something more sustainable. Any member of a co-research team could end up bringing about fundamental change in a totally different context as the result of the thinking and knowledge that was produced by your collective research endeavors. Action is unpredictable, not time bound by a project and cannot be controlled. As Paul Chatterton and others (2007) eloquently argue:

the ideology of change, therefore, is about movement in which the journey is more important than a hoped-for utopia.....There are no simple answers nor should there.

6.10 Questions for Reflection and Discussion

At its core this chapter aimed to develop your insight in understanding ongoing change processes – what kind of change it needs to be and how we do that. In participatory research change is usually recognized as the contribution that research makes to the people involved in the research and the communities and organizations they are part of, although change on the wider society, policy making and the academy may also occur. Change is interwoven into the fabric of research, and grounded in feelings of (social) injustice, and activism when those in power need persuading. Change requires agency, which requires attentiveness to empowering processes, which requires capacity building. It is essential to build in time to reflect and space for relations, networks, “mess” and creativity. We’d like you to reflect and discuss the following questions:

1. How would you address commitment to action and change at the beginning of a research project?
2. What does action for change mean for different types of stakeholders?

3. Describe ways in which action can ripple through and beyond a research project.
4. How might you use participatory research to achieve policy change?
5. Rebecca Solnit (2016) states that activists can never really go home, because the problem never goes home. When outcomes, and type of change, cannot be defined in advance, and when moral indignation and social justice are ultimate goals, then what can be “claimed” as successes of the project?

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Chapter 7

Engaging: The Choice and Use of Participatory Methods



Chapter Summary

Abstract The process of engaging people in the research of their lives or work involves a participatory approach to data collection, or what is often understood in participatory research as “data generation.” Engaging people in data collection or generation requires the creation of “communicative space”, and the use of methods that facilitate learning and mutual understanding. Such a process is often non-linear and messy, which is not a threat but a natural part of the process. Reasons for a participatory approach to data collection and/or data generation are set out and examples are given. Data generation evolves through storytelling, questioning and dialogue and critical reflection on action among those participating.

Purpose Most people know about more conventional research methods, methods such as surveys, interviews, focus groups. There are many good text books that will help you with this. This chapter will help you think about the notion of “method”, what the purpose of method is, and in what ways we might collect and generate data in line with the values of a participatory approach.

Central Question How to facilitate the process of engaging people in data collection and/or data generation as inquiry into their own lives and work?

7.1 What is Method in Participatory Research and Why Do We Use It?

Fundamental to participatory research and other community and participatory forms of research is the

shared recognition that science is more than adherence to specific epistemological or methodological criteria, but is rather a means for generating knowledge to improve people’s lives (ICPHR 2013:5).



Participatory research is more than the adherence to specific epistemological or methodological criteria.

Reflect on what this means? That we don’t need conventional methods? If so, how do we gather data? And what do we exactly understand when talking about “data”?

Within participatory research the idea of method is redefined because a central aim of participatory research is social transformation and collective learning. Method in participatory research is not just the application of a neutral technique or instrument, but is recognized as a disciplined and systematic way to study our life or work by learning through action. People themselves generate data through the use of certain methods to study their lives and work, to construct understandings of

practice, actions and ways of being that transcend what may have become accepted without questioning. This includes asking critical questions, listening to others, framing and reframing problems, widening perspectives, and searching for deeper underlying structural patterns that cause a problem or restrict change. This is about reflexivity, a notion we deal with in Chap. 8.

When using methods in participatory research we need to ensure that voices, particularly those that are traditionally marginalised, are heard. By *voice* we mean the ability to speak up, to participate, to experience oneself and be experienced as a person with the right to express yourself and to have the expression valued by others. So, an important principle is that the methods chosen are both suited to the needs of the research focus and to the needs of those involved in the research. There must be flexibility in the research design to be able to choose and adapt a method for best fit rather than using a method as a standardized approach to be adhered to without deviation.

Example: Kneeling in the Mud Story

When I (Tineke) started my PhD many years ago among psychiatric patients, I discovered soon that interviews were frightening. Participants hardly said anything in response to the questions I had, and the transcripts were meagre, only a few pages. The face-to-face situation and question-answer script did not work; it was felt as a sort of examination, leading to uninteresting, superficial, socially desirable answers. So I decided to first build a relationship. These people were working in the garden, so I knelt in the mud with them, working, talking, building up a relationship. They began to trust me, and in the proximity and during the activity of gardening together, their illness stories came to life. I learned I didn't need to ask lots of questions, I merely had to listen. This was a much better way to gain insight into their experiences, how it felt to live with a chronic psychiatric disability (Abma 1998).

The example illustrates that in order to facilitate participation and mutual learning in the process of data collection/generation more common methods can be adapted and re-thought so they are approached in a participatory way. Methods for gathering and generating data in a participatory way need to be crafted to allow people, including those with impaired communication and processing skills, to participate in a way most suitable to their preferences (based on their own choice, not impairment led). We also need to ensure that the use of methods in participatory research heightens the consciousness and personal and mutual understanding of those involved. Engaging in participatory research is a relational and moral praxis (See Chap. 2) guided by the underlying values of participatory research: participation, joint learning, change, striving toward social justice.

In participatory research it is not only data “out there” which is important (knowledge “about” the world, what we might call “facts”). Lived experiences and personal as well as mutual understandings that develop in the learning process are equally important. Lived experiences include our feelings, sensations and moods.

We can make meaning of these experiences through the telling of our stories. Imagine a person who becomes chronically ill. He or she may experience feelings of insecurity. The body was always healthy and thus familiar, now suddenly becomes unfamiliar and strange. To make sense of such bodily experience, a person needs to endow meaning to it. This is typically done through sharing and reflecting on that story, giving voice to it so that we hear it for ourselves but also others hear it and have the opportunity to consider and discuss the meaning of the story. So, engaging in participatory research is about voice, collective voice and meaning making, and providing opportunities for meaning making together. In participatory research we do not just collect data/experiences, rather meaning is “generated” through this storytelling. Relationships form the basis for joint learning in participatory research (see Chaps. 6,10 and 11 for more on this). Collective relational dynamics can, however, be unequal for a variety of historical and socio-cultural reasons such as hierarchy, power issues, perceptions of space and place and the aim is to be aware of these (see Chap. 6, 10, 11, and below).

The meaning making in participatory research is equivalent to interpretation in data analysis. In traditional research the distant researcher makes the meaning, that is, interprets the data but in participatory research the interpretation is embedded in the way the data is generated collectively.

7.2 Data Collection in a Participatory Way

We will start with what this is, and why we might do it in a participatory way. But let us first set out the reasons why it is important to approach methods of data collection in a participatory way.

The following reasons can be given to develop a participatory approach to data collection:

- When we work with different groups of people with different life experiences, ways of communication or ways of understanding the world, it is important to work together to find methods that “fit” with different life worlds. Reason: if we impose a way of doing things that those we are working with cannot understand, we will not be able to find out what their views, ideas and thoughts might be;
- Common data collection methods can be used in a more interactive and participatory way by making more room for the expression of experiences, for example by doing narrative interviews to elicit stories or by having co-researchers or peers interviewing each other. Reason: The control over the process is more shared. It is not the researcher who determines the issues and questions to be asked, but the participants themselves also steer the process by bringing in their own issues;
- Talking about one’s life or work, for example in a focus group where you feel comfortable, can foster heightened awareness of the situation one is in and different ways of thinking about that situation. Reason: By making the data collection participatory it can become “an intervention”, the data collection generates social change, the ultimate goal of participatory research.

This does not mean participatory researchers to not engage with more conventional methods. Traditional tools can be used as a way to stay connected to the received view of science and the canon, for example using a questionnaire/tool before and after an intervention implemented by practitioners in their work environment to evaluate the effectiveness of the intervention. This may be needed in situations where these methods are necessary for gaining external legitimacy of one's work (managers, research councils etc.) to enable you to move forward. In addition, sometimes people whose lives are at the center of the research, also find it hard to engage in something new and need this element of something that they recognize as research to help them feel secure in the process.

Drawing on a range of approaches is part of the commitment of participatory researchers to flexibility to meet the needs of the whole researching group.

7.3 Data Generation

We use this term when we are not only collecting knowledge about issues/experiences/ways of thinking that are currently held by people involved in the research, but when the process of developing relational engagements (communicative spaces) is expressly designed to have an effect on understandings: when learning is an expected and planned core of the process of research. Data generation is a way of mobilizing and creating knowledge for change.

Below we discuss some of the reasons for embedding data generation as part of a participatory research process.

- Data generation is based on strong relationships that offer spaces for delving between and below the common rhetoric we hold about our experiences/lives/work;
- Engaging various people and perspectives will help to gain a deeper and more informed understanding of a practice/problem, acknowledging complexity and context;
- Data is not only found “out there” but lies within ourselves, in our experiences, in intuitions, emotions. We can mobilize that knowledge and learn together;
- Mobilizing knowledge “within us” makes the personal political. The connection between private domain and the public domain;
- Learning together grows new knowledge. New knowledge is the bedrock for new actions (see Image 7.1).

7.4 Starting Point for Data Generation: Communicative Space

The starting point for data generation is building a space where people can feel comfortable and safe. This is true whether we use a participatory approach for data collection or data generation because key to the process of engaging is dialogue and



Image 7.1 Learning together in the ICPHR, Limerick, 2017

dialectics (a form of dialogue that draws on reason and logic to find personal understandings of truth) to create personal and mutual understanding as the basis for social transformation. It is, however, central to data generation because people need to be sufficiently comfortable and trusting of each other to engage in meaningful critical dialogical processes. The concept of communicative space has its roots in the work of Jürgen Habermas (2003) who identified the ideal place for people to come together as a place of

...mutual recognition, reciprocal perspective taking, a shared willingness to consider one's own conditions through the eyes of the stranger, and to learn from one another (p. 291).

The aim of the communicative space in participatory research is to enhance mutual understandings among all those engaged in the research process, to build new knowledge rather than to strive for simple consensus about current knowledge. The intention is to create a platform for dialogue, learning together and change, what Bridget Somekh (2002:92) termed “the construction of knowledge with its enactment in practice”. Thus to foster learning processes, as researchers we do not stand above practices but are embedded and engaged in practices and life situations, stimulating critical questioning and aiming for a joint understanding of the situation and development of plans for action. This all starts from the belief in the creative power of human beings and their critical and reflexive capacity (Freire 1972).

To facilitate a space where people are able to contribute in an open manner, participatory research and related research starts with building relationally based partnerships, either formal or informal. Essentially this requires an “open communicative

space” to discover jointly what moves and intrinsically motivates people to commit themselves to work together. This type of communication does not seek harmony as a means of engagement, but challenges traditional asymmetric relationship between those with lived experience (life or work experience) and external researchers, shifting towards an inclusive approach where the focus is on learning together to create new ways of acting. Key is the quality of deliberation that takes place brought about through equal participation and recognition of all perspectives. Crucial to this is the critical awareness towards, and balancing of, hierarchical relationships, the use of language that enables everyone involved to understand the arguments, values that support various validity claims and the expression of experiences and opinions. Only then is genuine dialogue possible in which people, through deliberate argumentation, are able to contest validity claims, gain moral insight and join in collaborative meaning-making.

Habermas (1984) sees this as an “ideal speech situation” and assumes that in this interactive process the best, that is the most authentic arguments will prevail. Essentially this requires the cultivation of an ethos of critical thinking, listening, and dialogue (Abma 2005; Abma et al. 2016; Freire 1972; Wallerstein and Auerbach 2004). Reflexivity is part of this process, including self-reflection about our identity and positionality of power, such as by race/ethnicity, education, role, research knowledge, etc. (Muhammad et al. 2014; Wallerstein and Duran 2006). Reflexivity includes openness, receptivity, sensibility and critical reflection upon our assumptions, limitations, blind spots and discourse.

In the process of collaborative learning and reflection it may well be that the whole group will come back to the initial questions several times, seeing them again through a new lens formed by mutual critical reflexivity. This is part of the recursive, and often messy process of community and participatory research necessary to develop the shared learning that is the seed bed for action (Cook 1998, 2009). This “messy area” is where participants have

deconstructed well-rehearsed notions of practice and aspects of old beliefs; are aware of the dawning of the new, but as yet have not made sense of it. It is where “mutually incompatible alternatives” (Feyerabend 1975) are debated and wrestled with and become the means for moving beyond normative states of fitting happenings into previously experienced frameworks (Cook 2009: 286).

The purpose of such activity is to move towards a vision of what could be constructed from the discourse to harvest new meanings for practice. This prerequisite for co-laboring, working together with all those involved in the research, serves to break down the more traditional notion of research where professional knowledge is separated from, and valued above, situational, visual and experiential knowledge and the knowledge of tradition and how we live together and relate to one another.

Many types of knowledge need to be recognized and valued as legitimate as they provide necessary elements that underpin actions needed to guide the solving of major problems. As people always have a standpoint or frame of reference, knowledge is always partial and embodied. Knowledge is related to our feelings and emotions and situated-ness. It is essential to involve, understand and integrate multiple perspec-



Image 7.2 Weaving threads of knowledge, ICPHR Limerick, 2017



Image 7.3 Weaving threads of knowledge, Action Research Network of the Americas conference, Colombia, 2017

tives to arrive at joint and shared understanding, the starting point being that each person and perspective can illuminate only part of reality. The aim of involving multiple perspectives and different forms of knowledge (experiential, practical, traditional and scientific) is to develop a richer and more meaningful portrayal of the investigated practice or lives of people and to facilitate a learning platform for representing the multiple experiences, hopes and fears of those with direct experience as a route for transformation (Images 7.2 and 7.3).

7.5 Telling Our Stories to Jointly Generate Data

At the heart of data generation is the facilitation of the communicative space for participatory learning in communities of practice. This is the space where people can talk about their perceptions, experiences and understandings and, through that

process work to co-construct knowledge. Here the focus shifts from methods and techniques in the classical sense to the dynamic of the relational-hermeneutic process of learning together. However, co-construction does not just happen spontaneously, we have to facilitate ways of enabling it to happen and this is where we can use “methods”. As we have stated above methods in participatory research are not, however, prescriptive dictates to be slavishly followed. Their purpose is to facilitate ways of producing data in ways that are contextually relevant, that forefront local knowledge and allow for learning together and the generation of new ways of thinking, knowing and acting.

In the case of generating data in participatory research an important element in telling our stories is that it goes beyond the mapped, the chronicling of the static and the objective. Story is a way in which people can enter and re-enter their own world of experiences. The telling of a story once, can leave it fixed. If that is then analyzed by an external researcher, the extra overlay of that researcher’s understandings can build a path away from rather than towards a deeper understanding of the key elements of that story. Working collaboratively with stories told and retold, as illustrated in the example from the Parkinson’s project below (p. 135), can move us towards a shared process of making meaning from our stories (see also Chap. 8, Sense Making). The shared deliberation of a range of stories allows us to celebrate elements of that story together, study connections and dissonances emanating from the stories (both from within one person’s story and across the stories of others) (Abma 1998, 2005; Abma and Widdershoven 2005).

People shape their stories according to the way in which they both interpret their world and want to have their world interpreted. Once the story is told, rather than being held within oneself, it becomes visible and knowable. Through stories people are able to “show how they hold themselves accountable for what they are doing and why they are doing it” (McNiff 2007, p. 308). This implies that stories can help us develop a more nuanced pathway into people’s constructions of their experiences (Clough 2002).

Moving between different landscapes of experience, when done in the spirit of shared engagement, can support the process and experience of being in the messy area (Cook 1998, 2009), the place where the disruption of long held beliefs and understandings leads to uncertainty and the need for new understandings to be created based on new knowledge. This process of disrupting and co-creating understandings allows for the generation of data that moves as the process moves forward.

Finding out what really underpins personal and collective action and building together is a complex process. Participatory research can, with its relational approach to building spaces for collective learning, become a vehicle for enabling people to develop new ways of thinking and acting, to shift their cultural landscapes through creating safe spaces for instability and uncertainty. Working with culturally familiar practices to engage people in pushing their thinking whilst maintaining a safe space can be used to generate data. It is an important way to support engagement and reflections over time.

7.6 Power Issues

Participatory research, and other forms of research that facilitate communicative spaces as part of the research process, work from a horizontal, democratic, communicative approach to power. This has been a challenge to more conventional forms of research which, as Orlando Fals-Borda (1997) pointed out, as late as the 1970s was still seen as unconventional and contrary to accepted understandings of distance as a key foundation for research practices.

In the 1970s it was heretical to preach horizontal relationships in the research adventure, even in professional life. It became clear to me, however, that sociological investigation should not be autistic but a rite of communion between thinking and acting human beings, the researcher and the researched. The usual formality and prophylaxis of academic institutions had to be discarded and space given to some sort of down-to-earth collectivisation in the search for knowledge...For me it became like litmus paper in determining authentic participatory practices in research and action (Fals-Borda 1997, p. 108).

Participatory research and other forms of action research are critical of the traditional power asymmetries in which external researcher observations are viewed as objective and lived experience viewed as subjective, with the subjective considered less valuable. Distancing approaches are considered to be barriers to learning, leaving power for action in the hands of external bodies that may well have a competing set of needs and demands beyond the immediate needs of the communities where the research takes place.

In traditional forms of research the interaction between the researcher and participants is conceived as leading to “bias”, and something that needs to be prevented. In participatory research the interaction between and among researchers and the people involved is central, necessary and helpful for stimulating learning via the exchange of various perspectives. Such dialogue can lead to a deeper understanding of a situation and broaden the horizon of all.

7.7 Examples of Participatory Ways for Collection and Generating Data

In this section we present examples of participatory ways for collecting and generating data, both through qualitative and quantitative methods, and how to organize this process in a cyclical and iterative way.

7.7.1 *Gaining a Voice, Forming a Group and Co-laboring*

In participatory research, when people become researchers of their lives or work rather than objects of research, they typically start with sharing their experiences amongst each other, telling stories to understand their experiences, and to raise

questions about their lives and situations. They may also engage other people in gaining answers to their questions in order to improve and change their situation. Methods like interviews and focus groups or surveys can be used to structure this inquiry. Who will take the lead in this process is hard to predict. Usually over the course of the process a core group of people is formed who feel motivated and like to work together and take responsibility for leading the process. The formation of such a group often stems from an experience of being silenced, of having been unable to tell stories. As Rebecca Solnit (2017) rightly points out, silencing is a universal condition of oppression. This feels unjust and there is an urgency to break through the silence. The expression of stories comes as a liberation. Experiences that are shared, gain a voice.

Example: Unexpected Enthusiasm to Be Involved Led to a Voice-over Group

Until recently, health research agenda-setting was led by professional researchers and dominated by biomedical research. The Dutch Parkinson Association found, however, that many questions from their members were about coping with Parkinson's disease and its impact on daily life, including social contacts, work and education, family life etc. rather than purely biomedical. So, they wondered whether the research agenda was adequately reflecting people's preferences and needs, and asked one of us (Tineke) to develop a participatory research process to investigate the priorities of people with Parkinson's (See Chap. 6). In the Parkinson's agenda-setting project the research team, consisting of people with Parkinson's and academic researchers, formed a "Voice-over Group" of those who expressed the wish and dearly wanted to join the project. They felt silenced, unheard, repressed for a long time and saw the study as an opportunity to break through the silence. The name "Voice-over" was chosen to signify that the *voice* of people with Parkinson's was central to the whole project. The interpretations of the researchers were commented on by the voice of this group to keep an eye on the perspective of people with Parkinson's in the process of data collection and analysis. Together with the Voice-over group, the research team decided that, rather than the mixed research team leading the development of the rationale for involvement in the participatory research process, the Voice-over group itself would be responsible for this. The Voice-over group members met face-to-face with each other and later with the research team. Initially, a group of 15 people gave feedback to the data, analysis and reports. During the process a core group of eight people stayed actively involved. Through the Voice-over group, the research team was able to value and use the experiential knowledge of people with Parkinson's and to create a large social base within the Association. (Source: Abma 2018)

Here is an example from the “Towards Inclusive Living” project.

Example: Starting with a Listening Event to Build Strong Relationships

This study, Towards Inclusive Living, was designed to investigate what inclusion looks and feels like for people with long term neurological conditions (LTNCs) and the impact of inclusive practice. The starting point for the study was a Listening Event with people with LTNCs held when the current building that housed services was about to be replaced by a new build. Questions were being asked about what the new build might look like. In amongst the consultation process were questions about what kind of research people might want to carry out when they moved to the new building. The question about the impact of inclusive practices was one that was put forward on that day. A core group of researchers was then formed from the nucleus of people at the initial Listening Event. They were users of services, family carers, people who worked in or with third sector agencies (for instance Headway, a charity that helps and supports people affected by acquired brain injury) and a member of staff from neuro-rehabilitation/neuro-psychiatry services. One of us (Tina) became the facilitator for the research process. This group worked together for two years to learn about the nature of qualitative/participatory approaches and how to design a research study. Together they developed the research question, methodology and methods, ways of generating and analyzing data and approaches to dissemination. The group was successful in gaining funding (Department of Health Policy Research Program: LTNCs) and was part of a group of 11 studies looking into the impact of the National Service Framework for LTCs in the UK. http://www.ltnc.org.uk/research_files/impact_inclusive.html

In both examples there was a process of engagement that can be characterized as one of co-laboring, a process that involved

...toil, distress, trouble: exertions of the faculties of the...mind...an activity which is at times likely to be uncomfortable (Sumara and Luce-Kapler 1993: 393).

This process of co-laboring cemented a strong relationship between the people involved, a crucial part of enabling critical enquiry to be central to the practice of the research.

7.7.2 Working in a Cyclical and Iterative Way

As we have seen in the previous chapters, the process of engaging people ideally begins with the Framing, Getting Started and Shaping of the research questions and objectives and the co-designing of a research proposal (Chaps. 2, 3 and 4). When

there is shared agreement and commitment about the design of a study, the participatory research process continues with Organizing (Chap. 5) and thinking about and envisioning change (Chap. 6). Engaging people in the gathering and generation of data is the next step. This step usually goes through several phases in order to gather experiences from various people, to gain diverse perspectives on these experiences, to interpret and to analyze them (See also Chap. 8 Sense Making), to understand what issues/themes stand out, what kind of information is still lacking, to take actions in practice to improve a situation, to gather more data and revisit the “older” data.

Example: Phases for Setting Research Priorities in the Field of Parkinson’s

The design for this study followed several phases. During the *exploration phase* information about the project was disseminated to Dutch Parkinson’s Association members, health care professionals and professional researchers. Interviews were completed with (para)medical and nursing researchers, health care professionals, people with Parkinson’s and their family members to become familiar with their ideas on patient participation and research priorities. The *consultation phase* started with interviews about illness experiences among people with Parkinson’s. In addition, health care professionals and professional researchers were interviewed. Findings from the interviews formed the input for four focus-groups with people with Parkinson’s. During the *prioritization phase*, research topics identified in the focus groups were used to develop a survey with the research priorities. Research topics could be prioritized per domain (fundamental, medical, psychological, societal and care-related research) and between domains. In the *integration phase* two dialogue meetings were organized to reach consensus among all parties (people with Parkinson’s and their families, health care professionals, professional researchers and funding agencies) over the research agenda. In the *programming phase*, the research agenda was translated into a program for research by the board of the Parkinson’s Association. A meta-study was commissioned on one of the research priorities, namely minor psycho-cognitive problems. Finally, as part of the *implementation phase* a coordinator was appointed at the Parkinson’s Association to recruit and train a pool of co-researchers to foster patient involvement. The coordinator and co-researchers started visiting all the clinical research units across the country to disseminate the research agenda. (Source: Abma 2018)

The above example shows how information from earlier phases in the participatory research process fed into later phases and led to actions (implementing a

research agenda from the perspective of people with Parkinson’s). Below is another example of how participatory research works in a cyclical and iterative way.

Example: “Towards Inclusive Living”

In this study the process of data generation, designed by the core researchers (including Tina) was undertaken through distinct workstreams. Workstream one, where people came together with other people with whom they shared similar characteristics, and workstream two where people were mixed together (users of services, family carers, people who worked in or with third sector agencies). Both workstreams involved both data generation and analysis. Workstream three was designed as a space for collaborative data analysis and face validity. The workstreams were cumulative in nature allowing people to revisit the issues they were discussing. Each had data analysis built into the process to enable the subsequent workstream to build on understandings developed during the previous one, thus it was designed as a learning for change process (data generation) rather than purely data collection (See Fig. 7.1 below)

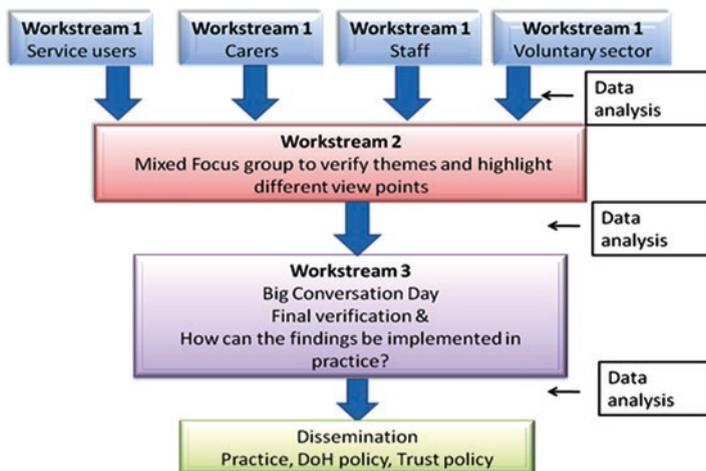


Fig. 7.1 Workstreams in the “Towards Inclusive Living” project

7.7.3 Interviews Used in a Participatory Way

Interviews can be a suitable way to gain an in-depth understanding of personal experiences and feelings, and the meaning endowed to these experiences. Interviews can engage people with open questions, where the researcher is mainly listening and probing. This approach is not only a way to gain insight into the experiences of the people involved, but can also enhance the personal understanding of the person being interviewed. Articulating your story in this way helps in sense making. It prompts that person to make their tacit knowledge (things they know but have neither recognized nor articulated as known) explicit, both to themselves and to the person hearing their story. In participatory research it is this aspect, the heightening of the personal understanding, that is considered particularly relevant. Stories are not just gathered for the purpose of description or external interpretation, but in the spirit of transformation and change for the participants themselves. Doing interviews in a participatory way means creating a situation wherein people can freely express their voice to gain a hearing, break through the silence they may have experienced, and to enable them to begin to understand their situation and experiences.

In participatory research it is quite common to work with peer or co-researchers who interview each other, or who form a duo with an academic researcher to conduct the interviews. Duo-interviewing can have several advantages such as: greater depth, more openness, emotional recognition and trust on the side of the participant (Nierse et al. 2012). It can also become a form of shared learning.

Example: Raising Personal Understanding Through Peer Interviewing

In the Parkinson's project three researchers with Parkinson's joined the research team. It was jointly decided to collect interview data in duos consisting of an academic researcher and a researcher with Parkinson's. Together the duos developed topic lists and then interviewed people with Parkinson's. The open character of the interviews in the safe environment of the participant's own home, and the connection felt with the researcher stimulated them to explore the meaning and impact of their illness on their lives. This can be illustrated with the following fragment:

Researcher with Parkinson's: *Can you give examples of social contacts.*

Person with Parkinson's: *Yes, they mean a lot. Lost my best friend. She couldn't deal with Parkinson's. We knew each other since we were young. But she was all well, never had had any trouble in her family, illnesses and so on. She didn't understand that I couldn't go shopping a whole day long.*

Researcher with Parkinson's: *Lost her.*

Person with Parkinson's: *Actually I also played a role in that. We talked a lot, but once I said I can't live up to your norms, so I give up. It made me sad for a long time. I didn't fit into her world anymore, so to say.*

This example shows that the person with Parkinson's developed an understanding of the impact of the illness on her social contacts, and loss of friendship, through the dialogue with the researcher. She became aware the loss of her friend was related to societal norms which she could not live up to. By acknowledging experiences as relevant, people with Parkinson's became more self-confident in articulating their voice and researching their lives. Moreover, the conversational style of the interviews, the openness of the peer researchers, and their encouragement, helped participants to go into greater depth and detail in inquiring into their lives.

This "duo" interviewing approach was also used in the Towards Inclusive Living project (workstream one, see Fig. 7.1). Service users interviewing service users were able to develop a greater empathy and reach deeper into the real and meaningful experiences of those they were interviewing. Staff interviewing staff also revealed how people with shared knowledge and experiences were able to discuss issues in greater depth. To meet people as a duo was, however, not always logistically possible. The impact of not adhering to that approach is clearly illuminated in the following extracts. The first is from an interview when an academic researcher (Tina) went alone to interview a service user in a residential home. They had been talking about taking photographs of the person might feel comfortable and included.

Example: Academic Interviewing a Service-User About Feeling Comfortable and Included

Academic researcher: *Where would you take a photograph of, what would you take a photograph of? Somewhere where you feel really comfortable.*

Service User: *Ermm*

Academic researcher: *It could be the armchair you're sitting in now or somewhere where you go out sometimes or*

Service User: *Ermm, I'm not very helpful here am I?*

Academic researcher: *It's a hard question.*

Service User: *Yes erm well it could be a nice view or something.....*

Academic researcher: *And for you is that countryside or is it a town or*

.....

Service User: *Oh not a town, countryside or coast*

Academic researcher: *And that's somewhere that you're happy and feel part of things*

Service User: *Uhh, uhhu.....*

The same question asked by a services user interviewing a service user in a residential home received a much more expansive answer. This included acknowledgements that the interviewer, despite not being in the very same situation, would have some understanding of the services user's experiences.

Example: Service User Interviewing a Service User About Feeling Comfortable and Included

Service User Interviewer: *Okay, so if you could take a photograph of being included, what would that photograph look like? What would it have in it?*

Service User: *Other disabled people. Together – us all being individuals but on some outing or trip. To say, “Hang on, we can do whatever.”*

Service User Interviewer: *And is that a picture of a group of disabled people?*

Service User: *Yeah. I mean, to give an example, when I moved here I was the first person here and they had us a champagne reception. All the tape was out and I cut the tape. You know, and of course I felt that was good, you know. I get on well with everyone here.*

Service User Interviewer: *Yeah, so that would be the picture that you’d have – a group of disabled people?*

Service User: *Yeah, well not only us really, that one up there [photograph on the wall] is the manager of here. She’s made me included in here.*

Service User Interviewer: *Okay. And how has she done that?*

Service User: *Just by, I mean... Friday morning, all the residents here are different. You know, people with Alzheimer’s and whatever, and it doesn’t make a difference. You know, I just get on with it and... – everyone goes, “Oh, are you alright?” Yeah. When they keep me in it, to be in it is very good you know.*



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*Participation is the essential element of **participatory research** enabling us to discuss what really matters to people.*

***Reflect** on what participation means for you in terms of engaging with people in your work. How can you create space for participation? What might hinder the establishment of participatory practice in your data collection/generation approaches?*

7.7.4 Focus-Groups Used in a Participatory Way

Focus groups are a collective and interactive way to talk and discuss an issue. Focus group interviewing is a research technique that collects data through group interaction on a topic determined by the researchers. Ideally, in participatory research, the researchers will include those whose lives and work are central to the research being undertaken. The moderator of the focus group stimulates deliberation and interaction among participants, which results in a diversity of perspectives and deepening of various arguments on the discussed topic. It is considered a relatively cheap, easy

and flexible way to invite participants to share their experiences and opinions on a certain topic. Focus group techniques are used in the various disciplines, including family therapy, psychotherapy and other fields of health research.

From a feminist perspective, focus groups enable storytelling and the expression of voices often not heard, enabling emancipation and liberation (Madriz 2000). We may compare focus groups with *consciousness-raising groups* that were popular in the 1970s, where women talked to each other about their experiences. It was felt that the accounts of oppressions that were not previously named or described, brought women out of isolation and into power. Focus groups are also known for having a pedagogic value (Kamberelis and Dimitriadis 2011) as they hold the potential to foster mutual learning among participants. From the perspective of participatory research, these aspects of the emancipatory and pedagogic nature of focus groups make them an attractive method if the deliberation, interaction and mutual learning among participants is stimulated.

Example: Focus Groups Leading to Critical Awareness

Focus groups were organized with people with Parkinson's disease to revisit and deepen the findings from the interviews, and to broaden the exchange of stories about Parkinson's and its impact on daily life. The atmosphere in these meetings was open and even topics usually surrounded with taboos were discussed freely. The freedom to speak up was important and fostered by the decision to compose the focus groups of the members of the Voice-over Group who had been engaged throughout the process. They already had a trustful relationship and dared to discuss intimate topics and taboos, like losing urine, shame, fear of loss of face and societal disapproval. Among peers these experiences could be shared without others withdrawing from the conversation or downplaying experiences. An excerpt of a focus group transcript:

Participant 1: I personally find it difficult to talk about incontinence. People don't know about losing urine. It feels like a loss.

Participant 2: Yes, it is a loss, and a taboo, and it is related to sexuality [...] For me, talking about, telling that I have Parkinson's disease is a taboo. Then I am very emotional. I do not want talk about anything related to Parkinson's with other people. Not at all.

Participant 1: This summer I lay on an inflatable bed. Then he [my husband] said: "You should think about going to the toilet." But that made no sense because I am incontinent! Then sometimes I noticed I didn't like to talk about it with him. That's just how the people respond.

This fragment shows the deliberative character of the conversations; people exploring issues in depth to gain a better understanding of their situation. In these conversations the understanding among patients grew that certain elements were central to their stories. A core issue appeared to be the daily basis on which people

experienced their limitations. They did not realize this before and felt this was a crucial insight. It was repeated many times, and people's insistence about this meant that it became a central theme. Those involved began to recognize that they were confronted with Parkinson's during the whole day, 24 h, every day of the week. Their quality of life was related to the sometimes very small everyday issues, which build up and thereby become large and important. Critical awareness of the influence of the environment also appeared an important insight that was developed in their open, inquiring and encouraging conversations. Participants started to realize how our contemporary culture sometimes makes it harder to deal with their limitations. An illustration:

The environment speeds up, always: hurry, hurry..., while I become slower, in movement, in thinking, in responding. As a result many daily activities become problematic, even minor things like shopping. Standing in line in a shopping mall is a very frustrating and very stressful event. It is hard to get money out of my pocket, and I feel bad if it takes longer.

7.7.5 Mixed Groups Used in a Participatory Way

While focus groups are generally understood as being composed of a relatively homogenous group of people with converging interests, in participatory research mixed groups are preferred as a way to generate data (for example see Towards Inclusive Living workstream two, see Fig. 7.1). The benefit of mixed groups is that various perspectives can come together. Here are some examples from our work:

Example: Dialogue About Research Priorities

In the Parkinson's project heterogeneous focus groups were composed of people with diverging interests to facilitate dialogue. These took place between the Voice-over group, professional researchers, health care professionals and funders. A variety of researchers, both medical and paramedical but also health care professionals such as nurses, were included. The meeting itself was carefully prepared by sharing information to all about the aim of the meeting and the program. The Voice-over group and the mixed research team discussed prior to the heterogeneous meeting who should introduce which priority on the research agenda, also bringing in some examples from their own lives or those of others they had heard during the process. The idea was that the other participants would then respond to the topic. Next, everyone would talk about the feasibility and implementation of that particular topic. They then agreed that a change was needed in the proportions of money going to fundamental and applied research. Also, they emphasised the importance of psychological, societal and care-related research to heighten the relevance and impact of research on the quality of lives of people with Parkinson's.

Another example of mixed groups that shows how we can work towards equal participation and open dialogues:

Example: Revisiting Data in the Towards Inclusive Living Project

One purpose of the segregated design of workstream one was to allow people to become comfortable within the research environment and build their confidence to talk about their experiences, thoughts and feelings. Data from workstream one were analyzed by the core research group. The interpretations (or emergent themes) were then fed, anonymized, into workstream two for further discussion and critique by everyone involved (this time without segregation by background/experience). Having the themes presented without attribution, not knowing who said what, was important for full and frank discussions. Providing opportunities for revisiting this anonymized information, both individually and collaboratively, offered spaces and impetus for critical reflection. The aim of this approach was to build a safe space where people felt confident to disturb their own current perceptions, and those of others, to allow new understandings to be shaped that reflected their experiences in a meaningful way. Revisiting data with people who had a range of perspectives led to agreement and disagreement, re-consideration and reshaping. It pulled apart rhetoric that can dominate single encounter approaches to data collection and enabled people to apply different ways of thinking to their own understandings, reaching back to their first thought but reshaping it in line with new ways of thinking. In this way people shaped their own communicative space, some telling more stories in relation to the themes, others applying the themes to data already presented. This recursive in depth exploration provided opportunities for further nuanced and understandings with collaborative learning embedded in the process.

A risk of focus groups is, of course, that power asymmetries can play a role. Participatory researchers need to be aware of these and seek to create conditions for equal participation. This is discussed further in Section 7.8 below.

7.7.6 *Creative Ways of Engaging*

In participatory research we also use creative ways of engaging together to learn about life and work experiences. As noted by Munn-Giddings and Cook (2016), engaging with more creative approaches to generating data has been demonstrated to provide a fertile context for change. Embedding creativity, creative methods and expression as a positive means of bringing about disruptions in thinking is critical to providing points in research that can prick our usual understandings and provide new insights. They go on to say “Creativity in process and method also enable an

important ingredient – having fun – which is powerful in creating conditions for enabling the hard work to happen en route to seeing things differently” (Munn-Giddings and Cook 2016). There are many creative ways to engage people in discussion (See the sections in Chap. 8, Sense Making). Important elements of these approaches are that they work in the context of the research and for the people who are engaging in the research process.

A number of creative methods were developed and used by the core research team for use in the Towards Inclusive Living project. Two examples of these are photography and mapping:

Examples of Creative Engagement from the Towards Inclusive Living Project

A photography project: during a one week period people took photographs of what they saw as examples of inclusive practice. They were then invited to discuss their photographs and the meaning they attached to them. The aim was to consider what made the subject of their photograph inclusive, what enables that inclusion to happen, whether there were any barriers to it happening, and the effect of inclusive practice on their lives.

Mapping: people were asked to map places where they felt included. These maps were then used to discuss what, for them, made these places inclusive and why.

Visual approaches are not only useful when working together with adults. Children can use cameras to great effect to enable them to communicate with adults about their own understandings of situations and ideas about those situations (See Chap. 9 for an example of school children working with cameras). When working in early years projects one of us (Tina) discovered that one of the biggest barriers to using creative approaches was our own adult interpretation of what makes an acceptable research approach. Sometimes adults think that creative approaches will not yield “good data” and are nervous about using them (Cook and Hess 2007). The examples below show, however, just how strong such approaches can be.

Example: Using Visuals

In the Parkinson’s project the engagement of co-researchers was especially high when using visual material like drawings and collages. Also in the focus groups creative methods were inspiring. An illustration of this is that people participating in the third focus group explained that it was not possible to differentiate between themes for research, because they were all interrelated. One person used the metaphor of a “radar wheel” (see Image 7.4) to illustrate this and other participants recognized it. Findings were then regrouped in line with the radar wheel metaphor resulting in a figure understood and embraced by all participants, and shared with the advisory group, health care professionals and research community (Image 7.4).

Image 7.4 Visual material generated by people with Parkinson's



One of us (Tina) regularly works alongside people with learning disability. Here the use of different ways of expressing yourself, of telling your story, is important to the process of enabling people to speak out. One of the companies Tina works with, The Lawnmowers Independent Theatre Company (Lawnmowers ITC), has particular expertise in the area of Forum Theatre. Forum Theatre is a theatre system born out of, and for, those who are seldom heard. It was created by the innovative and influential Brazilian Augusto Boal as a forum for working with people to change their world (Boal 2000). The Lawnmowers ITC have many years' experience using this format to engage people in addressing issues through shared critical exploration. This means we learn about shared and diverse issues together, rehearse change and plan for future change within the plays we produce. Below is an extract from a proposal for the use Forum Theatre as part of a research project looking at "Quality of Life" from the perspective of people with learning disabilities (Image 7.5).

Example: Forum Theater with the Lawnmowers

Lawnmowers company members (people with learning disabilities) will first research the issue of Quality of Life (QoL). Working alongside staff and academic researchers company members will use role work to explore and critique their understandings of QoL. They will also look at what other people, particularly people who provide care and policy makers, think of as QoL for them. These conversations will be collected as data but also anonymized and acted out for the film. The film will use forum techniques; this means that within the film there will be pauses at vital points. The purpose of this is to generate discussion about issues when the film is shown to audiences of other people with learning people with learning disabilities. This is the central element of accessible creative workshop sessions. Data collected through these creative workshops will be anonymized and analyzed into themes by all

(continued)

researchers, including those with learning disabilities. Everyone who has taken part in the research will then be invited to a Big Conversation Day to consider the findings, whether they make sense for them, whether anything is missing and to plan how they might themselves use what has been found. <http://www.lawnmowerstheatre.com/content/about-us>



Image 7.5 The Lawnmowers ITC using Forum Theatre with University Students, Newcastle upon Tyne, 2017

7.7.7 *Quantitative Methods in a Participatory Way*

To gain an understanding of the magnitude of a problem, it can be useful to organize a survey or use a standardized instrument. This can become a participatory step if the team decides together what survey or measurement is suitable, and if the data from the survey are interpreted and analyzed collaboratively. A survey can be attractive because it has the potential to engage a larger group people, although of course this means that the in-depth/learning work we have described previously is less likely during this phase, as can be seen here.

Example: A Survey Developed to Broaden the Social Base

In the Parkinson's agenda-setting project the aim was to prioritize research topics. In the phase of prioritization the social base for the research agenda was further enlarged via a survey among a large group of people with Parkinson's. This survey was developed by the mixed team because no existing instrument was available. In this phase the Voice-over group had again an

(continued)

important role. They commented on all data, and one of the most meaningful deliberations related to the survey. One of the findings of the survey was that fundamental biomedical research had gained the highest priority as the topic to be researched, followed by clinical, psychological, societal and care-related research. The research team was intrigued by this result, because in the former conversations other topics and types of research were equally appreciated among people with Parkinson's. Voice-over members helped to interpret these findings. They explained that the high priority given to fundamental biomedical research was related to the "hope" and "high expectations" of recovery and the wish of leading a "normal" life among many people with Parkinson's. Voice-over members believed that getting to grips with and finding a solution for an "uncontrollable" disease was also triggered by the medical and societal attention paid to chemical processes in the brain. Another explanation Voice-over group members gave was the association of scientific research with lab research. In the Voice-over group members emphasized how important dialogue is to discover what is important and needed, as illustrated by this comment from a member of the Voice-over group:

"What is important, that is something we all learned in this Voice-over group, is that the results of the survey do not always reflect what is really important to people with Parkinson's. For example, quite some people ticked the box stress and energy-levels as not important. When we talked about it within our Voice-over group, we discovered this is of utmost importance. These energy levels are really a core aspect, that is why it sometimes all blocks or stifles. That one needs a real dialogue to get to a deeper level." (person with Parkinson's: Voiceover group)

7.8 Facilitation and Roles of the Facilitator

As we can see from the above, the role of the facilitator is crucially important in the process of engaging in participatory research. Since the process should be fair, giving each person and group a say in the process, the collaboration between people requires an "independent" process facilitator who creates the conditions for successful participation and dialogue. Independent, as used here, means that the facilitator has no stake in the content of the outcome. This does not mean that the facilitator has no interest but that they are primarily motivated not to reach a specific solution. Their role is to build a space to help people involved in the research to feel comfortable enough to share things they have in common but also talk about areas where they might have a different view. The facilitator's purpose in creating this communicative space is to enable people to work together to recognize other ways of thinking and through this, ultimately to form a new and shared understanding for ways of taking action. The facilitator requires interpersonal skills (for example, sensitivity, person- centeredness, see Image 7.6) and knowledge of group dynamic processes and be able to develop multiple partiality; each stakeholder group should be

Image 7.6 If the facilitator was an animal what would he/she look like?



understood. The facilitator should not be considered an advocate of any set of people engaged in a dialogical process as this will prevent the engagement of other stakeholders (Image 7.6).

Since stakeholders may tend to re-establish their own perspectives, the facilitator should be able to act as a Socratic guide, a person who uses questioning as a guide to discovery, questioning certainties and taken for granted assumptions. The facilitator, in that way, helps people to disturb their long held beliefs. At the same time they can – when consensus is absent – act as a mediator and help to create mutual agreement when and where necessary. A process facilitator is not only responsible for the process, s/he will also keep an eye on the meaningfulness of the dialogues. Substantial thought and care is required to ask questions, probe, dig deeper and to value the quality of the dialogical process.

7.9 Stumbling Blocks in the Process of Engaging

Dialogue captures the essence of participatory research. Central features of such forms of dialogue are openness, respect, inclusion, engagement and critique. Conditions for dialogue are the willingness of people to participate, to share power, to be open to thinking and re-thinking and to change in the process (Abma 2001; Cook 2009; Pushor and Clandinin 2009). Dialogue may lead to consensus if personal

and mutual understanding has increased or if the understanding of differences is enhanced. This is seen as a trajectory to greater learning for change. Participatory research implies that the relationships among the range of people involved are respectful, open and symmetrical. It is important that people in a participatory research process do not dominate, ignore or condemn others and their perspectives, but listen carefully to the other as a conversation partner from whom one might learn. Participatory research requires open and equal relationships and a certain power balance to give all a fair chance in the process and to facilitate meaningful and genuine engagement. Key political challenges for engagement in participatory research are discussed below.

7.9.1 Conflict and Strategic Behavior

Strategic behavior of stakeholders, for example, acting on the authority of one's professional role may hinder honest responses and an open inquiry into value assumptions. For example, some academic researchers and people from funding agencies were not willing to engage in dialogue with people with Parkinson's because they felt superior and did not want to change their practice to include people with Parkinson's.

Strategic behavior occurs when the interests at stake are high. In a project at a school for Higher Performative Arts Conservatoire, teachers did not want to join in dialogues about injury prevention in the school, and were not cooperative, because they wanted to maintain the status quo (Abma 2005). Their professional pride was such that they did not expect much could be learned from the students. Teachers did not show openness to the experiences of students. This kind of behavior is counter-productive in the case of participatory research where, instead of a discussion where parties exchange standpoints and arguments, we look towards setting up conversations in which people with names and faces share experiences and inquire collaboratively into the nature of "the" topic that is the focus of the research. Strategic behavior prevents a genuine dialogue. Facilitators of PHR face the challenge of preventing and reducing this behavior on the part of stakeholders in order to obtain honest responses and create an open inquiry process.

7.9.2 Power Asymmetries in Communication

Asymmetrical power relationships between people involved, for example between medical doctors and their patients or between doctors and nurses can act as subtle mechanisms of exclusion. The effect of asymmetries being that groups who feel vulnerable, or superior, may not join in a genuine dialogue.

Having everyone around the table is not enough to have a good dialogue. Communication problems may occur when people use the same words but endow

them with different meanings (illusory consensus). For instance one person's understanding of what it means to be in a partnership can differ from another's. This can lead to very different expectations about how that partnership will function. Language is also laden with power asymmetries. Consider the patient with Parkinson's, who will present a problem in unique personal terms, while a researcher or professional might try to interpret a problem in general, abstract terms.

Linda McKie (2003) introduces the term "*rhetorical space*" in order to emphasize that patients' input will not automatically be heard and taken seriously. A rhetorical space structures and limits the kind of words and knowledge that people are allowed to express, as well as how, where and by whom that knowledge can be expressed. The rhetorical space implicitly puts forward certain normative expectations about the subjectivity of an authoritative knower. Stated differently, external researchers such as academics and professionals may expect a patient to talk in the language of their field and if they do not they dismiss what has been said by that patient.

In the context of research, the existing code is one of deference to those who are experts and whose knowledge is valued, such as academic researchers and sponsors. This makes it hard for patients to talk about their daily experiences if they want to be acknowledged as a credible speaker. These subtle processes can often become manifest through the language and terms belonging to research and the professions.

The most important issue in participatory research is not whether or not a patient will say something in a particular way, but whether or not the patient gains a hearing and is taken seriously.

7.9.3 Epistemic Injustice

Miranda Fricker (2007) introduces the concept of epistemic injustice to understand why someone might get a hearing or not. Clients in the domain of care and well-being are vulnerable to this if they have learning or cognitive impairments or present in an emotional way. This can mean they may not be listened to by the traditional experts. This is illustrated by the story told by this woman involved in the TIL project.

Example: Not Being Listened to

A mother/wife of a family where Huntington's disease was well known, explained how she felt that, because they were not listened to by medical professionals, her son had years of incorrect treatment. "*My little boy has been to hell and back with different diagnoses. Injections after injections. And blood-taking and operations and procedures he's had done on him. For nine years he was treated [for something he hadn't got]...instead of doing what I'd said in the first place – which my own husband who has got Huntington's kept saying... 'He's like me.' He used to say, 'He's like me.' These people, the medical profession, don't like being told. ...and they [the medical profession]*

(continued)

were so against it because it was very rare for juveniles to get it. He was just pushed aside and just treated for the symptoms. Chest infections and digestive problems. He was put on medication but he didn't need it because his pancreas was working alright...And they used to send me to different consultants to have, like, scans done on his bowels and things like that... Until I met a Professor at the [hospital]. She is absolutely wonderful. She listened and she said, 'I think you're right.' I nearly fell off my chair... And it was just a case of going and confirming it for the appointment....And I got confirmation. That's how he is diagnosed with that now. But he's been to hell and back. He's terrified of doctors. He's 13 and he still sits on my knee when he goes into Consultant's rooms." (Cook 2011: pp 80–81)

Fricker (2007) uses the terms “witnessing or testimonial injustice” to refer to not being heard in the way demonstrated in the example above. The mother knows and says to the medical doctors her son might have Huntington’s like her husband, but she gains no hearing for several years until she meets someone who does take her seriously.

7.9.4 Hermeneutic Injustice

“Hermeneutic injustice” refers to not having the opportunity to, or not being able to, interpret one’s situation. For example, people with Parkinson’s initially did not know what kind of research questions and priorities were important to them. They first needed to express themselves through stories and to hear the stories of others to be able to develop an understanding of their situation. The telling of stories enabled them to see the bigger picture, to understand that most research was biomedical and not about what mattered to them in the here-and-now. This can also be seen in the example of The Taste Buddies in Chap. 6; the older women needed each other to develop their voice.

7.9.5 Expecting the Unexpected

As participatory research is based on human engagement, not everything can be planned for. The dynamics of such research necessitate that the unexpected should be expected. What is meant by this?

As described above, one of the purposes of doing research in a participatory manner is to generate as well as collect data, to learn together and ultimately to develop a way forward that is forged by allowing ourselves to not know, to let go of our certainties and “get in a mess”. The process of meaning making may take us down an unexpected track, a route less travelled or even never travelled, but engag-

ing in participatory research involves being open to the unexpected, the new and the different.

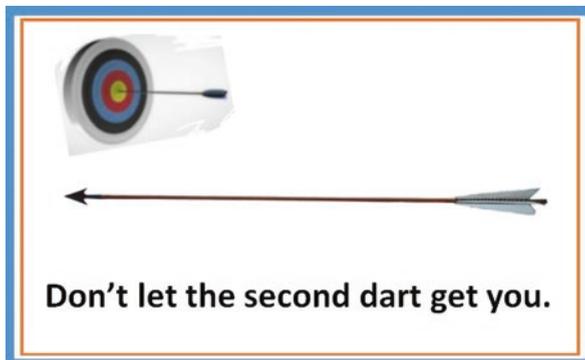
The unexpected may be found in what we learn, but also in the way we undertake that learning, the way we find the new path or address the complexities of organizational and/or political issues that may make situations tense and awkward. It is common for people to want to engage in research in a familiar way, to know what they are going to be involved in, to reach out for the comfort of the known. Frameworks for research where the distanced researcher is seen as the expert, the person who controls and leads the research, are expected because they are the known. These, combined with the use of conventionally recognized methods such as interviews, focus groups, questionnaires, provide comfortable frameworks for people to enter.

Beginning a participatory research project without a defined pathway leaves empty spaces to be filled. There is a temptation to fill them with pre-conceived ideas, ways and thoughts. It is these spaces, however, that provide the opportunities for more radical forms of engagement that enable in-depth processes. They hold the potential for developing practical solutions. We leave spaces for recognizing and embracing the unexpected, for finding new ways of thinking and acting together. A recent example from a project one of us (Tina) was involved in, where family carers have been both taking a course and engaged in researching and developing that course for future family carers, demonstrates this (for more about this project see Chap. 10).

Example: The Fridge Magnet

At the end of the final session of the first course, describing not only what had been useful but why it was useful was important for shaping the future courses. A discussion began about what might help future participants. One family carer suggested “a fridge magnet” to help people remember the important things to do at home. Picking this thread up I (Tina) asked, if we were to produce a fridge magnet, what would we have on that magnet? A discussion ensued about what was the key thing that would remind them to practice what they had learnt on the course. This involved discussions about the value of certain elements of the course and how they could be depicted. This discussion was invaluable for getting beneath phrases such as “I liked that best” or “that helped the most” to answering the question “why it is important” as it lead to statements such as “this has to be on the fridge magnet because...” The process of choosing a fridge magnet (or something similar) is likely to a one of the methods used with family carers on the next course to help us articulate the importance of the elements of the course to family carers and the reason why it was important. This new method, “collaborative decision making through a fridge magnet” was certainly unexpected, but was a valuable way of finding out together. And yes, we did have fridge magnets made for this group of family carers! (Image 7.7).

Image 7.7 The fridge magnet



7.10 Questions for Reflection and Discussion

This chapter considered the notion of “method”, what the purpose of method is, what it is for, ways through which we might collect and generate data in line with the values of a participatory approach and issues that might hinder such an approach. We’d like you to reflect and discuss the following questions:

1. Think about your own work, what the purpose of data collection/generation is and whether the way you engage with people aligns with your values and purposes for doing so?
2. Consider what types of skills you might need for the process of engaging people in participatory research to generate data that you might not have considered if using more distanced practices for collecting data?
3. How and where might forms of “professional pride” affect the quality of data?

Further Reading and Sources of Inspiration

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Chapter 8

Sense Making: The Process of Data Analysis and Interpretation



Chapter Summary

Abstract In this chapter you will be led step-by-step in how to analyze the data generated in the research process. The focus is on how to organize a group process to make sense out of the data, taking into account various data forms and the different competencies and skills of the various participants and community members. Principles to guide the quality of sense making are presented, with a focus on maintaining a critical stance and a high level of participation in the process.

Purpose To guide you in making sense of the data from a participatory research project together with the local research team.

Central Question How do we make sense of the generated data within a participatory process?

8.1 How Participation Enriches Sense Making

Once all the data have come together, it can be tempting for one member of the research team to withdraw from the others and make sense out of the data him/herself. Often the academic researcher takes on this role. The strength of participatory research lies, however, in the different perspectives which the various participants bring to the work. Different people with different backgrounds and life experiences often find different meanings in the same data. For example, a member of a research team who has experienced homelessness may look at an interview with someone who is homeless in terms of how authentic and true the experience of homelessness is depicted in what the person said. Whereas, a social worker may find in the interview unmet needs that could be addressed by homeless agencies. Through dialogue, these different perspectives can uncover the richness of the data that has been collected, allowing the research team to better answer the questions they have asked.

Health and social issues are often very complex to describe and to address effectively. By incorporating different perspectives from the key groups of people involved, many dimensions of the issue can be researched simultaneously. Several meaningful new alternatives to the present situation can arise, based on the many different forms of knowledge and engagement which the participants bring to the issue.

Many people who do participatory research are doing it for the first time. This includes not only service users and other community members, but also academics and service providers who may have experience doing other kinds of research, but not participatory research. Everyone involved needs to learn how best to work together in order to make sense out of the data. This chapter provides a framework for doing that. Every research team and every research project is different because it involves a different group of people who need to find a way to collaborate that works best for them. The data need to make sense to the specific group of people involved in the project.

Many participatory research projects include training on how to collect and analyze data. Such trainings build capacity for working together by giving all members of the research team the information they need to make decisions about what approach is most suitable (Wicks et al. 2013). The trainings can include information on common data collection methods, such as conducting and analyzing interviews. Academic researchers often have the expertise to do such trainings. It can also include information on how to interact with community members and background information on the structures and norms of communities. This information can best be provided by members from the communities involved in the research. Information on service systems and funding structures is often best provided by practitioners.

We begin by discussing general principles and then we provide a framework based on the following building blocks for making sense out of the data. As has been seen in Chap. 7, Engaging, some ways of collecting and generating data have data analysis embedded in the process. Nonetheless, the same underlying principles apply:

- Bringing together the data;
- Deciding on a strategy;
- Being critical;
- Checking the quality of the process;
- Answering the research questions based on the analysis;
- Challenges/stumbling blocks and possible solutions.

8.2 General Principles for Making Sense Out of the Data

The goal of data analysis in participatory research is to find meaning in the data for all the members of the research team and for those people outside of the team who are meant to benefit from, or be influenced by, the study. Given the different perspectives of the various people involved, this is not an easy task. There is no one “right” way of making sense of the data. Each research team needs to find a way that fits its context. The following points are meant to help research teams identify what is right for them.

8.2.1 *The Importance of Credibility and Meaningfulness*

Over time, academic researchers have developed increasingly elaborate methods for analyzing data. Unfortunately, the more elaborate the method, the more difficult it is for many people involved to understand what the researchers actually did. This, in turn, causes them to doubt the value of the research. Another source of doubt is the gap between the often narrow issues which are the focus of academic researchers and the interests of other stakeholders. In participatory research the focus is on developing projects that from start to finish are meaningful and credible for those involved. That often means less elaborate methods of data analysis and a broader focus so as to include more people in the process.

Example: Investigating Children's Health via Descriptive Statistics

A group of academics and parents wanted to find out what health problems children in a neighborhood have. They had a copy of a health monitoring report for the region, but there was no information about their specific neighborhood. The research team developed their own standardized questionnaires for parents and for different age groups of children which were distributed through the schools. They used existing questionnaires from other places as a starting point. The goal of the study was to find out which problems were most important and which groups of children had these problems. The research team (academics and parents) decided to use *descriptive statistics*, reported in the form of easily understood diagrams, to show the main findings of their study. They decided not to use more advanced statistics which wouldn't be understood by the people they were trying to reach.

Credibility and meaningfulness can only be reached when the sources and kinds of data are seen by the stakeholders as being trustworthy and useful. For some, official numbers and statistics are important; for others the personal stories of individuals play a central role. In many projects, a mix of data is necessary in order to meet the various needs. There can be a tension between the types of data and data analysis the academics want for a publication and the interest of non-academic stakeholders for types of data and analysis that can be applied directly to solution strategies.

8.2.2 Valuing the Different Skills of the Various Partners

A common misunderstanding in participatory research is that everyone who participates in the study needs to be involved in all aspects of the research. Even in participatory research there may be many people who will be asked to answer questions without having a say in how the research project is being done, as in the case of the group conversations in the example below. It is the research team which makes decisions about the project. Not all the members of the team have the same skills, interests, or amount of time available. It is important to find out early in the project who is interested in doing what and which skills the various partners bring to the process (see Chap. 5, Organizing). It is also important to find out who may be interested in learning new skills during the research. Often, not all team members are involved in the same way in making sense of the data. In the case of the group conversations, some members may be interested in finding out what was said in each conversation, so they will want to see all the details of the documentation. Others may want to wait until the main topics of all the conversations have been identified so they can talk about what these topics mean in terms of what the community can do.

Example: Various Contributions to Neighborhood Health Planning

Several conversations were held in a neighborhood about how public spaces should be re-designed to make them safer. The conversations were held in many different kinds of settings and were documented by community workers. The community workers were interested in finding out the main themes in the conversations, writing a card for each of the main topics in each conversation. These cards were brought to the whole team which worked together to find the themes which were in all or most conversations so as to name the main concerns of the neighborhood residents. One of the members of the team was a city planner. She took the list of concerns and translated them into the language that planners normally use. The research team worked together to develop a proposal for the city using professional language and to develop a plan in plain language to discuss further with the residents.

8.2.3 *The Usual Methods of Data Analysis in the Context of Participatory Research*

A tension can arise in participatory research projects between the academic researchers who want to use elaborate methods of data analysis, such as advanced statistics and in-depth qualitative methods of text analysis, and the other members of the research team who are not trained in such methods (as in the example just given). The participatory research process is threatened when the balance of power shifts to the academic researchers who then have the sole power to decide which method of analysis is “right” and how that method should be applied. There is much to learn from established methods of data analysis which can help a group of participatory researchers avoid some major mistakes, such as assuming that a very small group of people can represent a very large group. However, a strict application of pre-existing standards and norms can easily prevent a research team from discovering meaning in their data. For example, although it would be a mistake to assume that a small group of people can represent the situation of a very large group, the answers from a small survey sample may spark new ways of understanding the problem under study. The usual methods of data analysis can thus be a good basis for a participatory research team to make sense of its data while maintaining credibility in the eyes of those outside the group. If all members of the team have been involved in the decision-making and the administration of the data collection, they are more likely to be aware of the issues. However, flexibility needs to be applied so as to allow for new discoveries which may not follow conventional research logic.

Example: Starting with a Small Set of Chat Conversations to Outreach to a Group

An outreach project working in HIV prevention forms a partnership with an academic institution to find out what men in an immigrant community need in terms of prevention information and support. The immigrant men have sex with other men, but do not see themselves as homosexual or gay. The research team decides to conduct a study by using chat conversations on an internet site where many of these men meet. Several men refuse to chat with the social worker organizing the conversations and others break off the contact before the conversation is ended. After several hours of online time, a total of twenty chat conversations has been recorded. The conversations are very short and the information is sketchy. The academic partner questions the value of the data because there are so few conversations and there is such little content. The social worker sees the value in the fact that it was possible to reach a group of men with whom there had been no previous contact. The social worker sees himself as being in a better position than before to begin outreach to this group, based on the information the men provided.

It is also important to recognize that members of research teams have different backgrounds and competencies. This is too often seen as a barrier to data analysis, when it is actually a strength in terms of discovering new synergies and possibilities for knowledge and action. The differences among the members need to be acknowledged and respected so that each member of the team can have a meaningful role (see Chap. 5, Organizing). For example, members outside of academic institutions (e.g. health professionals or community members) can provide important insights for the focus of a statistical data analysis and the interpretation of the results, even if the actual calculations are done by the statistician on the team.

8.2.4 *The Importance of Adapting Conventional Methods*

Many participatory research teams find a middle way between conventional academic research methods of data analysis and more common ways of understanding information by adapting the conventional methods and the everyday ways of knowing to each other. For example, it is common research practice that interviews with study participants are conducted in a formal setting, recorded, transcribed, and then analyzed by academic researchers according to specific criteria for qualitative research. In a participatory research project such a procedure may not be possible or desirable. Community workers could have spontaneous conversations with groups of people at places where they normally meet: pubs, playgrounds, parks, etc. The conversations would not be recorded or neatly documented as in a usual interview.



In participatory research, methods are adapted in order to maximize the engagement of the people whose life or work is being studied. Sometimes it is not possible to use formal methods of interviewing, etc.

Reflect on how you would handle unrecorded conversations with people in order to make sense of these conversations. How can you engage others in constructing meaning out of these conversations?

The community worker may need to have several conversations with the same people over a period of time to get all the information needed. There is also the challenge of finding an unobtrusive and reliable way to record what people have said. The advantage of such informal conversations lies in reaching people in places where they are comfortable and where they can talk freely about what is important to them. The community workers can work together with the academics and other team members to find meaning in the conversations they have had by adapting the principles of qualitative analysis to the type of data they were able to collect, as illustrated below.

8.2.5 Round and Round We Go! (Iterative Process)

Participatory research happens in cycles, following a so-called *iterative process*. That means, a research team often has to repeat steps before they are satisfied with the answers to their questions. For example, after looking at their data, a research team may decide that they have not heard from certain people, or that they need more information. That would require them to collect more data and then to bring it into the analysis. This means that sense making cannot be a single, one-off process but needs to be developed in line with the iterative nature of a project. Or a team may have very complicated data, such as documents from public authorities with a large amount of numbers and text. The analysis may then have to proceed by going over the documents several times, perhaps with different members of the team taking on different parts of the reports. Or, using the urban planning example above, a group may come up with a solution (here a plan for re-designing public spaces) which needs to be changed, based on the feedback from various stakeholder groups, including neighborhood residents and planning authorities.

8.3 Bringing Together the Data

8.3.1 Identifying the Sources of Data

As described in Chap. 6, Acting for Change, there can be many kinds of data in a participatory research project. The first step in making sense out of the data is to identify all the sources of data which the research team has collected.

Example: Sources of Data in an Affordable Housing Project

A coalition of engaged citizens and social workers wants to find out how they can end homelessness in their community. The research question is: How can more affordable housing be made available in our district? The goal is to have influence on local government to create more housing. The group has the following sources of data: a story dialogue session with homeless people; information from the city on the rent structure in the district by street; photos from a photovoice project with renters who are having trouble paying their rent; interviews with developers; a Forum Theater project in a neighborhood center; and a written statement from the city urban planning office.

8.3.2 Ordering the Data by Type

The next step is to place the different sources of data into categories. The following categories cover most of the forms of data in participatory research projects:

Numbers In this category are actual numbers in the form of statistics that can be found on the internet or which are provided by local authorities. In the example above, the city has provided information on the rent structure, which will include the number of housing units within certain price ranges and how many of these units are on each street. Such information is easily available on many topics related to health and social welfare. In this category are also questionnaires in which the answers are *standardized*. That is, the possible answers are already on the form; the participants just need to fill out the questionnaire by marking the answers that are right for them. The answers will be turned into numbers through a process of *coding*, as described below.

Conversations In this category are conversations (interviews) with individuals or groups of people. The conversations can be recorded and then transcribed, or they can be documented with notes or through visual media during the conversation. In the example above, conversations took place in the form of interviews with developers.

Stories Stories are different than conversations because a person or a group of people tell what happened to them in a certain period of time. The people are not answering questions, as in an interview, but are rather recounting an event or a series of events. The stories can be recorded and transcribed, as with conversations, or they can be documented in other ways, as with a story board or using note cards, as recommended in using the *story dialogue method* (Labonte and Feather 1996; Labonte et al. 1999; Abma 2003; Abma and Widdershoven 2005; Widdershoven and Abma 2007). In the example of the Affordable Housing Project above, a story session was held with homeless people during which they recounted how they lost their places to live.

Pictures and Other Visualizations In many participatory research projects people have the opportunity to visualize their answers to the research questions. This can be in the form of photographs, videos, drawings, maps, three-dimensional models,

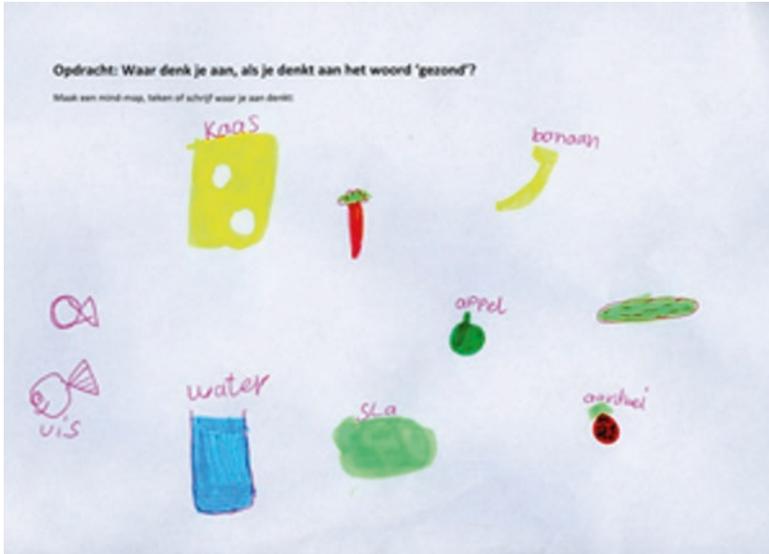


Image 8.1 Mind-map on healthy food



Image 8.2 Making smoothies of Wildflowers, KLIK Project

sculptures, or other visual forms. In the Affordable Housing Project, residents of the neighborhood created a series of photos to document their difficulty meeting the high rental costs using a method known as photovoice (Photovoice 2017; Brinton Lykes 2001). In a project known as KLIK, Children used photovoice to assess what is a healthy lifestyle (see Chap. 9, Telling and Showing) (Images 8.1 and 8.2).

Performances Another way of collecting data is by acting out a certain problem or a solution to a problem. The result is a performance which can be recorded by video. The reaction to the performance can also be recorded using note cards, observation notes, or another medium. In the Affordable Housing Project, a neighborhood center organized a *Forum Theater* project focused on the issue of affordable housing (Boal 1993, 2002). The performances were recorded and members of the team took notes on the reactions of the audience during the performance and in the discussion directly following.

Documents There are often many public documents which can help a research team answer its questions. These may be in the form of laws, policy statements, mission statements, annual reports, press releases, newspaper articles, or another written form that provides important information on the topic being studied. In the case of the example above, the municipal urban planning office wrote a letter in response to an inquiry from the research team.

8.4 Deciding on a Strategy

Once the data has been sorted into the above categories, a strategy can be identified for making sense of the data, based on data type, keeping in mind the original research question. An iterative approach (repeated cycles of analysis and reflection) ensures that all voices and perspectives are heard. It also strengthens the validity of the research. Below we present a range of strategies to make sense of various data.

8.4.1 *Making Sense out of Numbers*

Example: Promoting Sexual Health Among Sex Workers in Portugal

A group of academics, including one of the authors (Sónia), health professionals, representatives of non-governmental organizations, community-based organizations, and community members interested in and affected by HIV came together around the issue of the increased vulnerability of sex workers to HIV infection. They formed a partnership to generate information for new interventions aimed to promote sexual health, reduce the transmission of HIV infection, and improve access to health care among sex workers in Portugal. A participatory survey was conducted to examine HIV knowledge, attitudes, and practices; to understand the social and behavioral correlates of HIV infection; and to examine the issue of access to health services related to HIV/AIDS among sex workers (Dias et al. 2015). Based on this data, partners gathered in various meetings and workshops to analyze and discuss the findings.

Although participatory research builds on the active participation of all partners in the various steps of the research process, not everyone knows how to conduct certain research-related activities, such as the statistical analysis of quantitative data (Dias and Gama 2014) needed to analyze the data from the survey. Acknowledging that partners have different competencies and expertise, the research team in the Promoting Sexual Health example above decided that all team members would participate in deciding on the data analysis plan, including the identification of the variables for analysis. The academic members of the team were given the task of *coding the data*, that is, converting the answers on the questionnaire into numbers to be entered on a spreadsheet. For example, a question may ask how satisfied people are with a service on a four-point scale ranging from “very satisfied” to “very unsatisfied.” When coding the data, each of the answers receives a number which could be “4” for “very satisfied” and “0” for “very unsatisfied.” On yes-or-no questions, a yes may be coded as “1” and a no as “0.” Even questions where the answers have no order or ranking are coded, for example the gender of the participant can be coded as “0” for male, “1” for female, and “2” for “other identity.” Once all the answers have been coded and entered into the spreadsheet, they are analyzed statistically, using the appropriate software. In the Promoting Sexual Health example, the input from community partners on the data analysis was particularly important for exploring factors that determine different patterns of condom use within the relational context of sexual intercourse, particularly the influence of type of sexual partner (regular vs. occasional vs. concurrent) and the sex work setting (outdoor vs. indoor context). The academic members of the team would not have considered these factors if conducting the analysis alone.

The results obtained from the statistical descriptive analysis were distributed to all the partners of the project. They were encouraged to make their own notes on what they saw in the data and on what questions the community wanted answered. Then a series of workshops was conducted with all partners to receive feedback on the results for the purpose of interpreting and contextualizing the findings. Workshops were chosen as the most appropriate method for exploring these topics because they provided for group discussion. At the workshops, the results obtained from the statistical analysis were presented to the group in a PowerPoint presentation, followed by a round in which each participant posed questions and asked for clarification about the data. The next step was a dialogue around the questions: how should we interpret the results, what aspects from the context of the sex work can help us understand the findings, and what further analyses are needed to explore the data? This process of exchange between partners enriched the interpretation of the results by allowing for the integration of multiple perspectives.

8.4.2 *Making Sense Out of Conversations*

Example: World Café Sessions to Capture Change in Health Care Leadership

A group of health care managers had been involved in new practices to increase equity in health care delivery. They wanted to explore what they had learned and if their practices had changed anything in their leadership style. Since time was short, they collected their data on 1 day by partnering with a local university who facilitated a world café (World Café Community Foundation 2017) around three questions: what did we learn, what are we doing differently, and what has changed as a result? Three rounds of world café were undertaken, focusing on one of these questions in each session. Hosts wrote notes on the cumulative discussions while each table also had a non-participant observer who also took notes. The research team then analyzed the records of the conversations to identify the key themes. These included both the lessons the managers had learned and the changes they had observed in how they work with staff.

A participatory analysis of conversations builds on existing approaches to qualitative data analysis usually employed by academic researchers, but it adds a participatory and collective element. So, instead of one or two people analyzing the data on their own and presenting it to a group, all the members of the team are involved (Image 8.3 and 8.4). Sarah Flicker and Stephanie A. Nixon (2015) describe a process for analyzing interview transcripts which can be applied to any data set based on conversations, whether conversational interviews, group discussions, or world café conversations (as described in the example above). Called DEPICT, the process involves six stages. Each stage has a set of questions which the participants use to help them understand the data. Here is an overview of the stages:

1. **Dynamic Reading:** All the participants read the written records of the conversations, while making notes on important issues in relation to the original research question. They actively engage with the text through linking concepts and highlighting connections from their own expertise. In the example above, the members of the research team read the notes from the discussions and the notes of the observers, each participant writing down what stood out to him or her while reading.
2. **Engaged Codebook Development:** The team members develop a codebook together. This means that the members compare their notes and identify categories describing the major themes in the texts they read.
3. **Participatory Coding:** Each member then applies these categories to all of the records, or to a certain number of records where the volume of the material makes it impossible for everyone on the team to read everything. In the example above, the passages in the notes from the conversation and the notes of the observers were marked which correspond to each category. This process is also

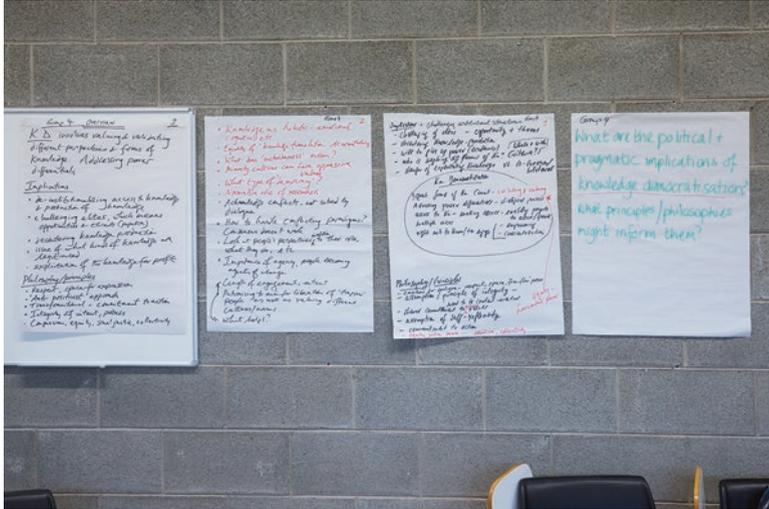


Image 8.3 Gathering material from discussions on “Knowledge ecologies” at the Annual Working Meeting of the International Collaboration for Participatory Health Research in Limerick 2017



Image 8.4 World café to make sense of leadership, Center for Client Experiences, Amsterdam

known as *coding*, but it differs from the coding presented above (see Sect. 8.4.1, Making Sense of Numbers).

4. Inclusive Reviewing and Summarizing of Categories: In pairs, the results of each person’s coding are reviewed. Passages in the texts are noted where the two team members disagree on the categorization or where they are unsure what is meant in the text.
5. Collaborative Analyzing: The team comes together to discuss their results and to decide on the most important themes of the conversations and what they mean in terms of the research question.

6. **Translating:** The team creates a plan for sharing their analysis with a wider group of stakeholders, *creating what is known as a knowledge translation and exchange plan.*

8.4.3 Making Sense Out of Stories

Example: Generating Themes from Stories on Discharge Planning from the Hospital

A group of nurses and their patients were concerned about the way discharge from hospital was working. They came together and each told a story of their experience. After each story, participants discussed what happened, why it happened, what they had learned, and what could be done about the issues raised. After a period of structured dialogue and reflection on each story, individuals thought about the key patterns that they could hear in the stories and put them down on pieces of paper. They then collected everyone's pieces of paper and grouped them together in categories. On the basis of the categories they formulated answers to their research question and also identified the actions that needed to be taken. Three themes emerged: (a) *Existential thoughts*. The group members agreed that over the course of discharge planning patients experience deep concerns about their health and well-being following the hospital stay. This implies that the patients need information about the purpose of the discharge planning in order to be prepared and able to express their needs and wishes. It is the practitioners' responsibility to create understanding by dialogue and feedback. Also, where the discharge planning is held is important. The environment needs to be positive, undisturbed, and inviting. (b) *Practitioners' feelings of competence* in discharge planning routines. It is important for the practitioners to listen to the patients' wishes and to other practitioners' opinions, rather than to think they themselves have all the solutions. This requires knowledge about the discharge planning process and routines in this planning process. It also requires practitioners to be flexible and to have the courage to suggest unconventional solutions. Practitioners need to feel confident in order to stand up for the patients and act as an advocate. (c) *Organizational support*. The organization needs to acknowledge that the discharge planning is an important activity. To build relationships between patients and practitioners, and between practitioners, requires time and continuity. The organization also needs to clarify issues about responsible authorities and economic issues.

The above example uses an approach to data collection and analysis called *story dialogue* based on the work of Ronald Labonte et al. (1999) (see also Labonte and Feather 1996; Abma 2003; Abma and Widdershoven 2005; Widdershoven and Abma 2007). The method is based on constructivist, feminist, and critical pedagogical theory, and has roots in qualitative methods. Story dialogue structures group dialogue around stories addressing particular themes. The method was developed as a means of recognizing and respecting the expertise that people have in their own lives in relation to health issues. The process is simple but empowering (see also the section on Telling Our Stories in Chap. 7, Engaging). It is structured so that valuable personal experiences are used to draw out important themes and issues affecting the community for the purpose of planning action based on these insights.

To start the process, those whose life experience is relevant to the chosen research topic generate a story from that experience. Each person tells his or her story to a small group of people who also have experience in that area. In that group is a story recorder who will make notes on the subsequent conversations that form part of the dialogue. This recorder can be a participant or an accepted outsider. However, all participants are also encouraged to make their own notes on what they are hearing and learning. After each person tells his or her story, there is a reflection circle in which each person individually reflects out loud on his or her reaction to the story in turn, without dialogue. After the reflection circle, the group moves to dialogue around four questions in relation to the story: what? (description), why? (explanation), so what? (synthesis), and now what? (action).

Open questions are asked of the storyteller by the other members of the group to generate dialogue with a particular objective in mind: to move from the personal experience to more generalizable knowledge (insights) and action. After the dialogue, people share their notes on the conversation and then together create a series of insight cards. The group creates 2–4 insight cards for each of the four types of question, or about 8–16 cards altogether. This is not a fixed number, and some questions will produce more insights than others. Each insight is written on a separate piece of card and includes enough detail so that it is understandable to people outside the group, particularly as a number of story groups are often run in parallel. The insight cards from each story group are posted together. All the participants start looking for common themes to group the cards, in the same way as is usually done when analyzing qualitative data; the difference here is that the data analysis is done together. A final stage involves crafting a theory based on the findings as one would do according to the principles of Grounded Theory (Heath and Cowley 2004) (Image 8.5).



Image 8.5 Making sense of stories at a work session, Center for Client Experiences, Amsterdam

8.4.4 Making Sense Out of Pictures and Other Visualizations

Example: Aboriginal School Youth in Manitoba Creating Videos

Cultural differences in the concept of health have led to distrust amongst First Nations in Canada regarding how the dominant population approaches health issues. Indigenous youth often get caught between the two worlds. A project among aboriginal school youth in Manitoba sought to understand their concepts of health by getting the youth to create videos showing what they considered to be healthy and what not. During the process of video making, the students selected stories and images that represented their perspective. The video was then shown to teachers and elders in the community which led to discussions on the different models of health presented by the youth.

The use of visual data collection and analysis methods has become widespread, particularly in participatory research. One participatory approach that is particularly commonplace is *photovoice* or *photo-novella* (Wang 2003; Photovoice 2017). The heart of photovoice is the intermingling of images and words. Photovoice is an empowering practice, as it offers an alternative way for individuals to come together to reveal and express their concerns in pictures, allowing different forms of knowing to surface. The participants take pictures as a response to the question being asked in the research project. Although photovoice is most often used to examine serious issues, as shown in the example above, the photovoice method incorporates fun, creativity, and collaboration in a way that encourages participation from community members (Blackman and Fairey 2007) (See also the section on photovoice with children in Chap. 9, Telling and Showing). Participatory analysis of the data can be conducted using the following steps (Wang and Burris 1997):

1. **Selecting Photographs:** Participants choose the photographs they feel are representative of their common strengths and struggles. This stage of analysis helps to open the door for dialogue.

2. **Contextualizing:** Participants contextualize the photographs by telling stories about what the photographs mean to them. They tell their stories through dialogue with group members and through journaling. It is during the dialogue and guided discussion that participants can voice their individual and group experiences.
3. **Coding:** This is a process of identifying and sorting data into categories of issues, themes, or theories (as described above under Sect. 8.4.2., Making Sense out of Conversations). Some photovoice projects use a specific set of questions to help the process be more fluid. In the less structured approach, the person who took the photograph explains why he or she chose the picture and tells of any stories shared by the person photographed (if a person is a subject of the photograph). In the second round of analysis, the small group chooses two to four photographs and organizes them into topic areas. Together, the group members cluster their ideas, identify similarities across photographs, and construct a holistic analysis of the clusters of photographs through open dialogue (Brinton Lykes 2001). Whether the group uses a more structured or less structured method of dialogue, it is likely that other group members will be able to relate to the stories and find similarities in their own experiences. This is an important step in seeing the links between personal and common experiences. For example, group members will begin to see that the public policies and practices that shape their own lives also influence the lives of their family, friends, and neighbors. During data analysis, participants will have selected photographs and prepared written statements to accompany the photographs.
4. The final task is to create a photo exhibition to showcase the work to key stakeholders. In this process, the participants make decisions about which of their photographs they would like included in the exhibit and they finalize the words attached to each photo.

8.4.5 *Making Sense Out of Performances*

Example: Theater to Identify Local issues in Texas

El Teatro Lucha grew out of a community outreach program on environmental toxicology at the University of Texas Environmental Health Department. It used theater to engage citizens, public policy makers, and academics across a several different ethnic groups to identify local issues and to develop solutions around asthma and lead poisoning. This led to organizing a range of environmental health improvement projects (Sullivan et al. 2008).

Since its inception as an art form, theater or dramatic representation has been used not only for the purposes of entertainment, but also as a means to inspire thought, critical reflection, emotional engagement, and personal transformation. Its unique

ability to draw on different ways of knowing provides an important approach to data collection and analysis. Theater can be used in a number of different ways (Rossiter et al. 2008). At its most basic, it involves the development of a drama piece based on research findings which have been generated through other, more conventional forms of data collection, such as interviews. During intense group sessions, the participants engage in dialogue and improvisation to produce the drama. Then, based on the ideals of Boal's *Forum Theater* (Boal 1993, 2002), the drama is performed to an audience whose members take on the role of *spect-actor*, that is, both the roles of spectator and actor. The audience is allowed to engage with scenes relevant to their own situation of oppression and marginalization, intervening in the form of comments or taking on a certain role. As such, audience members and actors alike may improvise multiple ways of understanding and reacting to a set of experiences in order to co-create knowledge. In this way the Forum Theater space can be a safe way for those who have not been given a voice to both critically reflect upon, and envision alternatives to, the social conditions creating their marginalization. The data analysis is a combination of the production of the drama and the subsequent interactive forum. The experiences of the actors, the audience, and the performance itself can be recorded in various ways and then subjected to a thematic analysis, as in the other examples above.

8.4.6 *Making Sense Out of Documents*

Example: Assessing Health Promotion Materials through Focus Groups

A group of academics, representatives of non-governmental and community-based organizations, and members of sex worker communities were concerned about developing more adequate information, education, and communication (IEC) materials for HIV prevention and sexual health promotion targeting sex workers. For this purpose, an assessment of existing IEC materials was conducted through focus groups.

The assessment of IEC materials was conducted in two stages. First, a search of existing IEC materials on HIV prevention and sexual health promotion was done. The complementary expertise found among the partners was useful from the start. Academics identified material on HIV programs, policy reports, and best practices guidelines. Community partners provided the materials available at non-governmental and community-based organizations; these included information on HIV transmission, HIV prevention, risk reduction measures, access to health services for HIV diagnosis and treatment, as well as organizational procedure manuals and fieldwork guidelines which gave a more comprehensive overview of the activities actually conducted in the field and the real needs encountered by outreach teams. After the collection of the IEC materials, an analysis of its content was conducted, in which all the partners were involved. In focus groups, participants dis-

cussed the IEC materials in terms of the quality of the contents, information gaps, and the appropriateness of information to the target population (sex workers) as compared to existing international and national guidelines on HIV prevention campaigns. The results of the focus groups were brought together in the form of recommendations. These were used to create new, more appropriate and targeted IEC materials on HIV prevention and sexual health promotion which were made available to NGOs and institutions working with sex workers for distribution within sex worker communities.



KNOT

*A central theme in this book is that **participatory research is not driven by adherence to method.***

Reflect on how the findings from a range of methods may come together to form a whole. Have a look at Chap. 7, Engaging where a Big Conversation Day was organized as part of the Towards Inclusive Living Project to make sense of all the data.

8.5 Being Critical

In doing research, we need to be open to results that may not be what we expected or hoped for. Maybe we have put a lot of time into a new way of counseling for immigrant families, but our research shows that this new way is not successful. Or we are convinced that we need to do an information campaign so that the children in our city will eat healthier, but we find out through our research that children are already well-informed about healthy eating. Or we believe that smoking is a big problem for the youth in our drop-in center, but we find out that the youth have other concerns which they see as more important.

The following tips can help the research team to be critical about their work and so to remain open to whatever results they find. It is this openness that will allow the team to discover new information and to increase the amount of knowledge produced.

8.5.1 Being Aware of Assumptions

As described in Chap. 4 (Shaping), it is important to name any assumptions that the research team has about the topic being studied. As just described, these assumptions often concern the cause of a problem or how it can be solved. By naming our assumptions we become aware of what we know or think we know. Our research project can help us to find out if we are right.

8.5.2 *Bringing in Different Perspectives*

Every issue is different, depending how we look at it. For example, when it comes to services for people with psychiatric problems, the service providers, the service users, and the families of the service users can have very different ideas about what is good care. If our research project has the goal of improving services, it will be important to involve these three different groups in the research process – if possible, as members of the research team – so that the different perspectives can be taken into account during all phases of the project. By involving people with different perspectives in the research, we avoid the “blind spots” that one group of people may have, based on their particular role or experiences.



Every issue is dependent on how we look at it. In participatory research, various perspectives are brought together in order to come to a richer, more informed understanding. Various strands of knowledge are knitted together to form one piece.

Reflect on how you would handle a conflict between service users, their families, nurses, psychiatrists, and clinic management concerning the quality of psychiatric care and support. What happens if the meaning constructed by service users is considered to be biased, while the meaning constructed by the practitioners is considered to be unbiased?

8.5.3 *Comparing to Outside Sources*

Very seldom do we come up with a research question that no one has ever thought about before. We should find out if others have done research on our topic so we can benefit from what they have found out. This means comparing our results with theirs to see if we might have missed something. By comparing our work with others we can see better where the strengths and weaknesses of our project are.

8.5.4 *Reflexivity*

In non-participatory forms of research, the academic researcher is expected to reflect critically on his or her work. In participatory research *collective reflexivity* – thinking together critically within the research team – is a key component in all stages of the research process, including data analysis. That means providing what Stephen Kemmis (2006) calls *communicative spaces* for dialogue and reflection during the analysis phase (see the section on Communicative Space in Chap. 7,

Engaging). Such joint reflection ensures a critical questioning of assumptions as the analysis takes place, taking into account the various perspectives of the research team members and others.

8.5.5 *Journaling*

Data analysis and interpretation can be greatly enhanced by using journaling throughout the research process. Journal entries help record preconceptions and values, but also record actions taken, observations made, responses of and to others, what could or would be done differently and why, and ideas for future plans. Participants should be encouraged to keep a journal. During the data analysis they can be engaged in an exercise of sharing their journal entries, including a round of commentary on the meaning of the entries. This promotes a meta-reflection process on the meaning of the data.

8.5.6 *Consulting with Critical Friends*

In participatory research we often talk of *critical friends* (cf. Kember et al. 1997). Those are people who understand our research project and who share our concerns, but who are also ready to give us honest feedback during all stages of our work. This includes feedback on what our data mean. Critical friends help us to see the strengths and weaknesses in our research. The critical friends who are most helpful are often those people we know personally and who share a similar situation to our own, for example, our colleagues, our neighbors, or people involved in clubs or other activities we find important. Sometimes people we know less well, for example people we meet at a conference, can also serve as critical friends, if a basis of trust and understanding can be established.

8.5.7 *Playing Devil's Advocate*

The term *devil's advocate* comes from a former role in the Roman Catholic Church. When someone was recommended to be made a saint, the devil's advocate tried to find all the reasons why the person shouldn't be canonized. In participatory research projects, it is important to have people who will take on this role, making a case against what we believe to be true based on our study. These can be people who are deeply involved in the project or others from the outside who know well the position of those who may call our work into question. Devil's advocates can help us find weaknesses in our work or in how we present it.

8.6 Checking the Quality of the Process

As with all forms of research, participatory research strives to reach a high quality. The quality of research is often discussed in terms of *validity*, which means to what extent we can judge the research to be meaningful, credible, and true. The following criteria can be used to help a research team reflect on the quality of their work in this sense. These are taken from the paper “Quality Criteria for Participatory Health Research” (ICPHR 2017).

- **Participatory Validity:** The extent to which stakeholders take an active part in the research process. Who took part and in what way? Were these roles meaningful to them?
- **Intersubjective Validity:** The extent to which the research is viewed as being credible and meaningful by the stakeholders from a variety of perspectives. Is the research seen as being credible and meaningful by the different stakeholders involved?
- **Contextual Validity:** The extent to which the research relates to the local situation. Does the research make sense for the people involved in terms of their lives or their work?
- **Catalytic Validity:** The extent to which the research is useful in presenting new possibilities for social action. Do we know what action can be taken to improve the situation on the basis of the research?
- **Ethical Validity:** The extent to which the research outcomes and the changes exerted on people by the research are sound and just. Do the people involved feel justly treated? Do they feel that the research reflects their values?
- **Empathic Validity:** The extent to which the research has increased empathy among the participants. Do the participants have a better understanding of how and why each other think and act?

8.7 Answering the Research Questions Based on the Sense Making

As remarked at the beginning of the chapter, the goal of sense making is to answer the research questions posed by the research team. Keeping these questions in mind throughout the sense making keeps the process focused. As the above examples show, in each case the team used the data they collected to answer their questions which are often connected to a goal of taking action to address the situation under study.

When giving an answer to a research question, it is important that the team recognize the limitations of their study. There is no such thing as a “definitive” study on any topic. And seldom can a study “prove” anything in an absolute way. By recognizing and naming the limitations in their work, a research team adds to their credibility. In the example above under Sect. 8.2 regarding the internet chats with immigrant men, the number of contacts with the men was relatively small and the information was poor in quality. Therefore, the research team still doesn’t know much about the situation of these men. However, the team did learn how to contact

a group of people which had not been previously reached by HIV prevention programs. The means of contact and the information provided can be a basis for an initial outreach project in which more information can be gained to better understand what the immigrant men may need and which services may be most appropriate.

8.8 Stumbling Blocks and Possible Solutions

In making sense of the data, there are several common challenges and stumbling blocks which are presented here with some possible solutions.

8.8.1 Reconciling Multiple Understandings

If different stakeholders are involved in the research process there will probably be different views on what the data mean. In the example above from the HIV prevention outreach team under Sect. 8.2, the academic partner and the social worker have different views on their study. There are several options to address different understandings. One option is to come to consensus on the value of the study, the members of the research team deciding on statements that all can agree to. Another option is to include the different views when reporting on the study, showing the importance of each of the perspectives. A further option is to have different presentations of the data for different audiences. In our example, the social worker could make a presentation for his colleagues in which his view is primary, thus reflecting the concerns of practitioners in the field. The academic partner could take the lead on a journal article in which she discusses the limitations of the study, based on certain standards for data quality.

8.8.2 Overly Complex Methods of Analysis

As mentioned above, a common point of conflict between academics and other partners is the issue of methods for collecting and analyzing data. In the neighborhood health monitoring study under Sect. 8.2, the research team decides for a less elaborate approach in the interest of having findings which are understandable and credible for the people they are trying to reach with their study. Sometimes a research team may decide in the other direction. There are many examples from participatory research projects on environmental justice in which highly technical and specialized methods are needed in order to show the presence of certain hazards. But even in these cases, the results need to be communicated in an understandable and credible way to those who are to act on the findings. One option is to have different kinds of analysis which are reported in different ways to different audiences by different members of the research team. Certain, more elaborate forms of data analysis may be important for specific groups of decision-makers or an academic audience; whereas, other forms of analysis may be appropriate for other

groups. In such cases, it is important that the more elaborate forms not dominate or somehow be seen as being the “real” analysis that only academics can understand. The research team needs to decide together which forms of analysis are appropriate for whom and how the different forms fit together.

8.8.3 *Not Being Critical*

Participatory research is done by groups of people acting on their values and in their self-interest to create positive social change. Critics can claim that the people involved are biased, that is, they are not open to finding out anything that they don’t like and that they are just using the research project as a way to say what they have always thought. By being transparent and critical, a research team can counter such a criticism.

It is important to avoid so-called *defensive routines* (Jacobs 2010). Practitioners can reject information which challenges their sense of identity and role. Oppressed groups of people can be challenged by information which calls into question how they deal with their difficult living situation. Both practitioners and those oppressed in society are reacting to persons and structures more powerful than themselves (Gramsci 1971). Paulo Freire’s (1970) concept of *conscientization* is a means to overcome this defensiveness. By gradually understanding the wider social forces affecting the issue being studied, participatory researchers can critically reflect on their actions and roles, developing new understandings so as to find ways of moving forward.

8.8.4 *Being Measured Against “The Standard”*

Academics and others who are accustomed to more conventional forms of research can criticize participatory research projects because they don’t follow the usual norms of data collection and analysis. In meeting such criticism, it is important to show that participatory research is its own form with its own quality criteria. These criteria are the basis for this chapter and for the textbook as a whole. There are several published guidelines outlining the criteria for participatory research (for example, ICPHR 2017, see the Appendix). Participatory research projects recognizing these criteria are increasingly accepted by peer reviewed journals. There is also an increasing number of journals focusing specifically on participatory research approaches, and funding agencies in several countries are now calling for participatory forms of research.

8.8.5 *Not Being Transparent*

All researchers, not just participatory researchers, should work in a transparent way, so that all those involved and all those learning about the study know what was done, how it was done, and why. It is important that the research team is thoughtful about its

decisions and that they can give reasons for the decisions taken over the course of the project, making these reasons known in their various publications and presentations.

8.8.6 Not Being Consistent and Systematic

Participatory research projects often change many times over the course of the study. The participatory process demands a high degree of creativity and flexibility. But that doesn't mean that the work is arbitrary! It is important to show how the project developed, to explain why things were done as they were done, and to show that care was taken to ensure the quality of the research.

8.9 Questions for Reflection and Discussion

This chapter aimed to guide the reader in making sense of the data from a participatory research project together with the local research team. We would like you to reflect on and discuss the following questions:

1. How would you engage the strengths of the participants in your research project to make sense out of the data?
2. What kind of training might be useful for people involved in your participatory research project to help them develop skills for data analysis?
3. Describe the data sources and ways to make sense of the type of data generated in your research project.

Further Reading and Sources of Inspiration

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Chapter 9

Telling and Showing: The Shared Decisions About Dissemination





Chapter Summary

Abstract In this chapter we will consider the collaborative steps that need to be taken to narrate the participatory research process and findings. Telling and showing, often called dissemination, is about sharing knowledge with others. This may include searching for useful “evidence” generated by the research, deciding what audience groups should be reached and which media and narrative forms are appropriate for promoting social change. Examples are presented to assist you in facilitating a group process for disseminating research findings. Stumbling blocks particular to this collaborative process will be discussed, and we offer some solutions.

Purpose To guide you in disseminating research findings for the promotion of social change.

Central Question How do we disseminate participatory research findings?

9.1 The Importance of Sharing Knowledge for Change

Sharing of knowledge and understandings is one of the key principles of participatory research; it helps foster social change, the ultimate aim of participatory research. In this chapter we will consider how a participatory researcher, or collaborative research team, find ways to share insights that come out of a participatory process and serve the purpose of social change. It is important to emphasize that in participatory research the dissemination of findings is not only a matter of describing what is currently understood as reality. It is also a means of engendering change, to

engage people in further critical reflection, dialogue, learning, imagination and action.

The findings should not only describe the status quo, but contribute to the growth of communicative spaces and reciprocal, equal and tolerant relationships by acknowledging various insights and realising possibilities for collective interpretation and sense making. A so-called *writerly* text does this (Sumara and Luce-Kapler 1993). A writerly text creates room for readers – inviting them to rewrite the text. Unlike a *readerly* text it does not communicate any precise meaning for a pre-defined target group. It is more open and does not seek closure through summaries, recommendations, or judgements. A writerly text is also more ambiguous and less predictable. Writerly texts demand active and reflexive readers.

We have seen in the previous chapters that emotions play a key role in the process of critical reflection and in touching and moving people to act for change. Gergen and Gergen (2012) point out that the emotional appeal of stories has a different way of engaging people than when we share reasons. Reasons stimulate *intellectual engagement*. Stories create an *affective engagement*. Listeners may begin to care about what is said or written. This implies that we have to consider how we can evoke the affective engagement of people, not only in the process of doing participatory research, but also afterwards, so that the process of learning and change continues after the project has finished.

9.2 Case Stories from the Field

Let's start off with three case stories to which we come back throughout this chapter to illustrate some issues that are critical in disseminating findings from participatory research.

Case Story: Photos Attracting the Attention of Journalists

One of us (Tineke) and Janine Schrijver (a professional documentary photographer) initiated a project with primary school children in the urban neighborhood where we live in the Netherlands. We felt it was unjust that our own children might lead a healthy life, while a few blocks away children were living in a way that was considered less healthy. We set up a participatory health research project called KLIK. KLIK refers to the click of the camera, and is an acronym for a Dutch name (Kinderen Leren Inventief Kracht) which translates into English as *Children Learn Inventive Power* (see: www.klikrotterdam.nl).

KLIK aimed to improve the health and resilience of children of families who have less access to what is considered a healthy lifestyle (healthy food and sport/exercise) in a non-normative way (that is, it did not prescribe what was best for them). Ideas and plans were developed to promote the health of children through partnerships and participation of children and other groups/individuals from the neighborhood. The role of university, where Tineke is embedded, was limited to engaging a junior researcher (Femke Boelsma) in KLIK to assist Janine with her

activities in the participating schools. The school children got engaged through playful activities in the classroom, such as walking trips in the neighborhood, photovoice workshops, making smoothies of edible plants, tasting various sorts of vegetables in a laboratory setting and investigating the way the food is digested in our body. Other people (mainly adults but also adolescents acting as “big brothers” on playgrounds) were engaged through gatherings and exhibitions of the photos made by the children. The project was funded as part of a larger program called *The Healthy Future More Nearby* (De Gezonde Toekomst Dichterbij) focusing on the reduction of health disparities among children by Fonds Nuts Ohra, a charity fund in The Netherlands.

The experiences of children were the base of the bottom-up health promotion process, and photography was the common thread throughout the process. Being raised in a visual society, we felt that photography was an appropriate, creative and positive way to engage children, and a powerful method for them to research their own lives and articulate their voices. Giving children a camera meant they had control over the process. No longer were they being watched (an object), rather they themselves watched and observed (becoming a subject).

Photography can be used in this way to find ways of hearing children’s voices and enabling them to represent their thoughts, understandings and constructs in ways that are not only accessible for them but also to adults. Once photographs have been taken they can act as a tangible representation of the children’s interests and in this way, they enable them to return to a topic at a future date for further discussion with the children as the photograph can be used as a reminder of what we are discussing (compare: Sarti et al. 2017). As Cook and Hess (2007) point out, “Photographs provide an opportunity to have group discussions around a visual prompt which makes it easier than trying to talk about something in the abstract” and “Given that a child will have taken the photograph, the stimulus for discussion starts from their interest.” (p. 4). In KLIK the children took photographs of their neighborhood, the meals at home and school and their playing activities during and after school. Also via other creative means, like an adventurous walking tour, they were engaged, and via their photos they engaged other citizens; findings were not communicated top-down, but shared in interaction with the neighborhood (see Images 9.1 and 9.2).

The findings were presented in a very colorful, handsome report – designed by a professional designer – full of stories, photos and statistics. Also several interviews were given with local (on-line) media to share findings as well as a master class for civil servants and students as part of the program run by the Local Democracy House in the city.

The funding agency also shared findings and hired a public relations officer to develop a communication plan. KLIK was recognized as a special project because it was a project *with* (not on) children, and some of pictures of meals were used in the funder’s public relations and communication. This material was picked up by a lot of journalists. The photos of the meals were found especially shocking and powerful, showing what some children whose families had less money to spend on food were actually eating at night. So, on a Friday evening one of the journalists interviewed



Image 9.1 Walking through the neighborhood. (Photo, The KLIK project)



Image 9.2 Making sense of pictures. (Photo, The KLIK project)

Tineke and Janine for the Monday morning national newspaper. We were, of course, happy that we had attracted his attention and anticipated that this was a way to put the issue of access to healthy food and lifestyles on the political agenda.

Yet, we also felt that it was problematic that the journalist only emphasized the negative side of the neighborhood. The frame of the newspaper article was that the people in the neighborhood did not live healthily and that children were the



Kinderen uit groep 6 en 7 van de openbare basisschool De Triangel fotografeerden vier weken lang hun avondmaaltijd.

GEZONDHEID EN ARMOEDE

Dit eten de kinderen in de Rotterdamse achterstandswijk Oud-Charlois

Van onze verslaggever

Geef basisschoolkinderen een camera en laat ze hun avonden fotograferen. En wat krijg je? Niet veel groente, kuddt het antwoord in de Rotterdamse achterstandswijk Oud-Charlois.

Met dit project wilden fotograaf Janine Schrijver en Tineke Abma, hoogleraar participatie en diversiteit aan het VUmc, hardnekkige problemen rond gezondheid en armoede in

hun wijk met zo'n 16.000 inwoners aanpakken - op een creatieve, niet betuttelende manier.

Zo'n twintig kinderen uit groep 6 en 7 van de openbare basisschool De Triangel beten het spits af. Gedurende vier weken maakten ze elke dag een foto. Dat de maaltijden in de wijk met meer snacks dan groentewinkels niet allemaal even gezond waren, verbaasde Schrijver niet.

"Maar dat sommige kinderen bijvoorbeeld pas om negen uur

's avonds alleen warm eten, dat vond ik zorgelijk. Ik trof één foto van een meisje dat om kwart over elf in haar eenje nog een snack zat te eten. In andere gevallen werden er nog laat tijden gegeten of energiedrankjes gedronken."

Na de vier weken werden de foto's aan de ouders getoond. Een beetje tot verrassing van Schrijver en Abma zeiden de ouders dat ze het er lekker vonden uitzien en wilden ze van elkaar weten hoe de maaltijden

bereid waren. Binnenkort start het project bij de tweede, openbare basisschool, daarna willen de initiatiefnemers alle ouders uitnodigen voor een kookworkshop, met aandacht voor gezond eten.

"Vanuit de traditionele gezondheidsbevordering wijst men altijd op de noodzaak van een andere leefstijl", zegt Abma, die net als Schrijver in Oud-Charlois woont. "Maar dat slaat in zo'n wijk, waar ouders vooral bezig zijn met overleven, niet

zo aan. Daarom wilden we spelenderwijs bewustwording creëren en kinderen en ouders stimuleren om gezonder te leven."

De aanpak maakt deel uit van KLIK, een project voor beweging en gezondheid dat onder meer bestaat uit wandelingen door de wijk, kunstlessen, voorlichting, sport en dans. Een gift van vier ton van vermogensfonds NutsObrva stelt partners in de wijk in staat om dat zo'n drie jaar te doen.

Image 9.3 Newspaper article

"victims" of this unhealthy lifestyle (see Chap. 2 Framing). Image 9.3 shows the Newspaper article, with the headline: "This is what children eat in the deprived neighborhood Oud-Charlois in Rotterdam" (Dit eten de kinderen in de Rotterdamse achterstandswijk Oud-Charlois).

The article stereotyped the children and families and did not acknowledge their creativity. There was a sense of voyeurism and the role of the wider environment that contributed to health disparities hardly received any attention. As a result of this frame the issue was blamed on the adults (parents and teachers) while health disparities are not only an individual but a social and political issue related to structural disadvantages. When we (Tineke and Janine) sensed that the parents, school and some teachers felt rightly they were being criticized, we decided to stop all the press to prevent relationships of trust being put under pressure. This story clearly reveals that the research had an impact, but also that sharing knowledge has aesthetic, political, ethical and relational dimensions.

Case Story: Whose Voice? Writing Together on Emergency Care in Psychiatry

Another case story comes from a project with people with a psychiatric vulnerability in The Netherlands (Groot et al. 2018). The project was embedded in the Centre for Client Experiences, a Community of Practice initiated by Ad Warner, the Director of a client advocacy organization in Amsterdam (Clientenbelang Amsterdam), and one of the authors of this book (Tineke Abma), in collaboration with Barbara Groot from the VU University medical center (see also: www.centrumvoorcliëntervaringen.com). Ad Warner was well embedded in the city and in one of the meetings in the mayor's office, attended by a group of key decision-makers in Amsterdam, there was a discussion about the emergency care provided for people with psychiatric vulnerabilities. The introduction of the Psycholance – an ambulance for people with psychiatric problems – was evaluated as good, and much better than how the care was organized before (people often ended up in the police station). When Ad asked: “*What do clients and families think and feel of the care given to them?*” a silence fell in the room. It appeared the evaluators had only asked professionals.

Subsequently, the two main psychiatric centers in Amsterdam commissioned an evaluation to gain an understanding of the experiences of clients and their families. A participatory research approach was taken by a mixed team consisting of six people (Barbara Groot, Mavi Vink, Annyk Haveman, Mia Huberts, Gert Schout and Tineke Abma), including academics, experiential experts and those who had a double identity as both academics and experiential experts. The report chronicles the experiences of people with psychiatric vulnerabilities when they end up in a crisis and the fragmented process leading to an admission to the emergency care unit. We also hear the experiences of families and health care professionals as well as other professionals involved such as police officers and ambulance staff. Eighteen people with psychiatric vulnerabilities and six family members participated; they were interviewed by the co-researchers with an experiential expertise. Seventeen professionals were interviewed. Later several focus groups were organized to make sense of the interviews and broaden the social base.

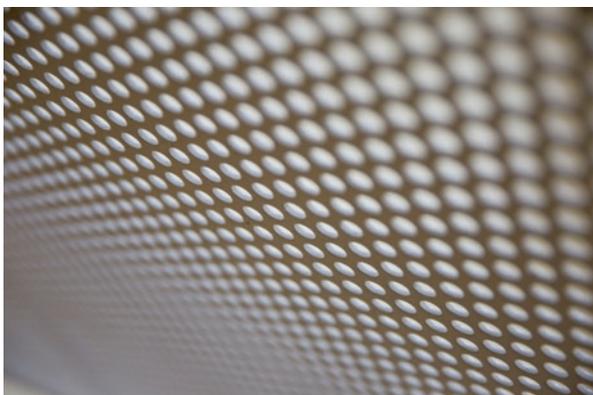
Together the researchers and the experiential experts decided to focus on how psychiatric vulnerability changed their lives, how it affected their family and social relationships, and how they made sense of their experience with this vulnerability. The focus was on how they experienced the care given to them during a crisis, and the admission to the emergency care unit. We intended to redress the traditional imbalance between researchers and participants through the inclusion and engagement of the experiential experts in all phases of the research. One of the things we struggled with was what we wanted to tell and share and for what purpose. Some of us wanted to focus on how fragmented the care chain was, and how this resulted in discontinuity. Others were more focused on the care at the emergency unit, and the use of coercion. Many discussions followed. Another tension arose when – partly due to a pressure of deadlines – one of the experiential experts felt that she could not keep up with the pace. She made us think about this, also asking attention for her dyslexia that prevented her from being an active co-writer. As she saw how all other

members were engaged in the writing process, she felt isolated. She made it very clear a power issue was at stake here; she felt excluded. We needed to take a step aside to reflect on this mechanism of exclusion before we could go on, and so we arranged for a conference call as a group to decide how to support the person who felt excluded.

The final report reflected the life-stories of psychiatric service-users in order to gain a voice otherwise not heard and to improve the lives of other people with psychiatric vulnerabilities. We also had our academic voices included in the book. We felt this solution honored all interests. The final report is a combination of the conversations and stories that are clustered around the crisis, relationships, making meaning, living with a psychiatric vulnerability, the fragmentation of the care chain, use of coercive power at the emergency unit and the role of the family to signal a crisis. The report also sketches the broader issues raised by the recent policy transitions in Dutch health care as well as snapshots from poetry and photography. The combination of the various texts takes readers on a journey that does not allow them to escape into an easy definition of what it means to live with a psychiatric vulnerability and to be admitted to the emergency department. There is a section in which the team legitimizes their way of working together, research methods, and theoretical frameworks and analysis. Finally, scattered around and throughout the pages are “factoid” boxes, which contain information about the number of people attending the emergency department annually and writings from some of the experiential experts in the form of poems, letters, speeches, and emails.

The emotional appeal of the report is precisely why we think it is so strong. Marian Barnes (2006) argues that emotions form the basis for social movements and change. In this respect, sharing personal experiences and allowing emotional expressions are important in developing social action and change. We see that political, ethical and relational aspects are part of the process of knowledge sharing which deserve careful attention (see Images 9.4, 9.5 and 9.6).

Image 9.4 The emergency care project: isolation. (Photo, The Emergency Care Project)



awareness of unethical practices of loan companies and to call for more legal regulation of their activities. Community organizers and volunteers from Thrive Teesside were involved in both the data collection and action elements of the project, alongside an academic researcher employed by the University. Various public assemblies, workshops and other events were held during the course of the project (see Images 9.7, and 9.8), and many different kinds of outputs were produced, written/created by



Image 9.7 Debt on Teesside: speaking at a public assembly. (Photo, Thrive Teesside)



Image 9.8 Debt on Teesside: the audience at a public assembly. (Photo, Thrive Teesside)

different people and designed to reach different audiences – ranging from academic book chapters and articles to reports, briefing papers, toolkits and a campaign film (see Banks, Brown et al. (2013); Banks, 2015; https://www.dur.ac.uk/socialjustice/researchprojects/debt_on_teesside/).

The public assemblies and film were the vehicles through which the voices of the participating households were heard most directly. These media presented similar risks to those experienced by the researchers in the KLIK project over the newspaper story. There was the potential for stereotyping of people in poverty as irresponsible in taking out loans for “luxury” items (large televisions, new sofas), as well as the personal risk of feeling shame and getting upset. The public assemblies involved people with experience of debt telling their stories in front of an audience of politicians, policy-makers, representatives from loan companies, debt advice agencies and other organizations and members of the public. On one occasion a woman became upset while talking about her predicament. This raised ethical issues in the research team about whether people were exposing themselves too much by giving testimony (Lipson 1997; see also Chap. 3 for ethical guidelines). In this case the woman said afterwards that she was happy to contribute and did not feel pressured. But it is nevertheless important for research teams to think hard about placing such responsibility on individuals and how they can be properly supported (see Images 9.7 and 9.8).

9.3 Formulating the Message

Central to the process of telling and showing is the shared and collaborative action to define what findings are key to the research group and important to get out to the outside world. Key findings are findings that are meaningful for the whole group of participants as well as for those who have an interest in the topic but were not part of the research. Often these meaningful findings are new or have not been heard before in the decision-making arenas, among the general public or in the academic world. Key findings may well counter the current thinking, common opinion or policy measures and intentions, and may thus stretch the horizons of practitioners, policymakers and the general public.

Often these key findings give in-depth insights into the lives of people who are isolated or marginalized in society. Think of the stories of the children and the type of meals they were having at night, the people with a psychiatric vulnerability in crisis and the families experiencing unmanageable levels of debt. The community partners in these projects were keen to share some of the stories of the injustices they faced in their lives. The KLIK partners wanted to show how difficult it is to raise children living in an environment that tends to cause obesity (obesogenic), with parents who are stressed because of their difficult financial situation, poor housing conditions and unemployment. People living with a psychiatric vulnerability wanted to tell and show that they missed personal attention and contact when

in a crisis, how traumatic coercion was at the emergency unit and how the fragmented care chain led to discontinuity. People taking part in the *Debt on Teesside* project found it difficult to tell their individual stories, as they knew society would be judgmental and sometimes they felt ashamed of their large debts. However, over time, through involvement in the research and meeting others in similar situations, they wanted to get across the collective message that living in poverty is hard and some money-lending companies are exploiting people with insufficient resources.

Telling and showing the lives of children, service-users or other people who may be living on the margins of society in their own terms, in a way that strengthens both the message and the ability of people to tell their stories, is an important goal of participatory research. These groups are often relatively invisible in professional discourses, and participatory research attempts to find a space where people who are seldom listened to can have their voices heard. Often participatory research also offers a critique of the way society responds to oppressed people and how they are approached in traditional medical and social science, health promotion or social care provision.

When a research team has a shared understanding about what findings are important to them, they have to decide what it is they want to communicate and share. In KLIK the research partners, including the children, jointly decided to show the resilience and creativity of the children, and take an appreciative approach (starting with positive features of people's lives). It struck the team how skilled the children were in seeing little details and how balanced they were in evaluating their neighborhood. They were able to see both the beautiful and ugly, the strengths and weaknesses, and played with humor. The team showed the enthusiasm of the children; how well they responded to being engaged, receiving positive feedback on their photos (big smiles in the classroom), having a meeting with adults (the children responding: "*Are we famous, or what?*") and above all how eager they were to learn, discover, experiment and taste more.

In the case of the people with psychiatric vulnerabilities the group decided that struggles for contact were very important for them: the right to be recognized as a human being, the right to be taken seriously and the right not to be left alone. In the *Debt on Teesside* project, people involved who became activists worked with the Thrive community organizers to run campaigns on key issues arising from the research, contributed to public assemblies where people would speak out, and made a film showing how an exploitative lending company preyed on people and encouraged them to take out unaffordable loans.

"Where is the 'evidence'?" is the next question to answer in order to share knowledge. The term "evidence" is in inverted commas, because we not only think of facts and numbers, but also of stories and experiences as evidence. In KLIK, the emergency care project and *Debt on Teesside*, evidence is found in the photovoices of the children, the voices of the service-users with a psychiatric vulnerability and the families in debt. The people speak for themselves. The children show us the circumstances of their life-world, also how adaptable they are, how proud they are of their neighborhood and their school. The service-users tell us about rejection and

social isolation, and their resilience. We come to understand that their well-being depends on the connection with other people. The sharing of their emotions makes the reader aware of the fact that the mask of control hides a set of complex feelings. These are people with many faces. In other words, they are complex and define their own identity depending on the situation they are in. The people involved in the *Debt on Teesside* project show how easy it is to fall into debt (with sickness, loss of work, bereavement or other life crises) and how difficult it is to get out of debt once they start to borrow from high-cost credit companies.

Once the key message has been constructed, the group discusses what the right medium is to share what has been shown to be key to that group. In this conversation it is important to consider the notion that “the medium is the message.” This means that what we want to convey, is also heavily influenced by the medium we choose. If content and form are congruent, the message is stronger. This can be illustrated again by all three projects. The KLIK report and emergency care report are set up as a sort of bricolage (a collection of diverse materials). They convey many voices, layers and perspectives, various types of knowledge, and thus communicate the notion of complexity when growing up in a family without the money to buy healthy food, living in a disadvantaged neighborhood and dealing with psychiatric vulnerability and situations of crisis. It is not only academics or professionals talking, the children and service-users are experts too.

The *Debt on Teesside* project produced several different types of outputs aimed at different audiences – including reports, briefings, toolkits, a film and academic chapters and articles. The film was the vehicle that involved local people most directly in depicting a scene from their own experiences about which there was a moral message. The film was made in one of the participants’ houses and depicts a representative of a loan company stuffing money down the throat of a householder. The message given at the end is that such loan companies need to be regulated by law, and that they should be required to check if their customers can afford repayments before they issue a loan. This powerful film was used by Church Action on Poverty as part of its “affordability” campaign and a wider national campaign to reform the way that short-term, high-cost credit (including “payday” loans) operated (<https://www.youtube.com/watch?v=txk4YbqDbvs>).

9.4 Whom Do We Want to Reach?

Participatory research is based on democratic values. Sharing of knowledge serves these democratic values, meaning that findings from a participatory research process or project should be equally accessible to all citizens and participants so that all are in the position to influence decision-making processes (Richardson 1990). We see this in our examples. The teams have deliberately attempted to reach an audience that is wider than academics alone. In KLIK we have tried to reach the families and parents, local authorities and the general public via the national media. In the

case of the emergency care project, the research team tried to reach service-users, their friends, families and loved ones, professionals, decision-makers as well as the general public. The *Debt on Teesside* project targeted a variety of people and organizations, including people in debt, local and national politicians, advice agencies, loan providers and community-based support organizations.

It is a good idea to think carefully in advance what type of organizations and individuals need to hear the messages from the research, in order that communication can be tailored to the right audiences. These might include the following:

- Decision-makers – politicians, civil servants, directors of organizations and businesses;
- Members of the public – people who vote, live locally, or might have an interest in the issues being researched;
- Journalists – working for TV, radio, newspapers, magazines, online news and blogs;
- Participants in the research project – people and organizations that have been involved in the research and may want to use the findings to make changes in their lives or work settings;
- Other people experiencing the same issues as have been covered in the research;
- Academics – staff and PhD students interested in the topic;
- Practitioners in specialist fields – clinicians, social workers, artists, etcetera who may work in areas related to the topic of the research.

Each of these groups may have different information needs. In the emergency care report, for instance, the authors chose various kinds of information to attend to these differing needs. People who know little about the psychiatric vulnerability and use of emergency care unit may value the “factoid boxes”. Policymakers and academics may find the texts and references to scholarly works on emergency care and sociological insights as well as care ethics interesting. The stories, photographs and conversations will have a broad appeal to various audience groups.

There are of course more ways than a report to share knowledge. So, we need to consider effective ways to communicate to various audience groups. One can imagine that the general public might prefer television, radio or newspapers, or social (online) media like Twitter or Facebook. Journalists can fulfil an important role in bringing the message to the general public, as we saw in the KLIK project (although as we also saw in the KLIK project, this has to be very carefully done as it is not always positive). Decision makers might want to join in a debate, and receive a set of practical recommendations, as happened in the *Debt on Teesside* project through the public assemblies, policy and practice round tables and research briefing papers.

Now you have these insights, you may come up with more ideas for communicating knowledge that fit your social and cultural context. For example, might you consider using hip hop or participatory theatre to communicate your findings?

9.5 What Types of Knowledge Do We Want to Share?

There are different types of knowledge which can be considered in the conversation on telling and showing the research findings.

Statistics and Evidence

Facts and figures can have a great impact, because people tend to see numbers as objective, and believe they convey “true” information. Numbers reveal the scale of a problem, and can therefore contribute to putting an important issue on the political agenda. Graphics are even more attractive than merely presenting figures, because of the visual impact. In an era of information overload, a simple graphic can display information in one overview. In KLIK, factual, statistical information was presented about the demographic character of the neighborhood: that it has a relatively young population and is home to a great variety of people with different cultural backgrounds (Moroccan, Turkish, Surinamese). It was noted that residents had a lower level of education and many struggled financially to make ends meet. Obesity was noticed as an important health risk. At the same time, many artists and creative entrepreneurs were attracted to this area because of cheap rentals, and they were willing to share their “cultural capital” with the local communities.

As pointed out, in the emergency care project we used so-called “factoid” boxes to present readers with facts and figures. The use of the term “factoid” indicates our belief that facts are constructions, but nevertheless we find it useful to present this information. The *Debt on Teesside* project undertook a literature review on the causes and prevalence of household debt and poverty, to show the extent of the problem nationally. A local demographic and social profile of the Teesside area was presented, along with profiles of the households participating in the research.

Stories and Counter-Stories

Through stories, people make sense of their world and are interconnected with each other. Storytelling is considered to be an ontological condition of human life (at the core of our existence), helping us to impose order on our experiences and emotions and make sense of actions in our lives (see Chap. 7 for a section on storytelling). Narratives and stories create meaning, emotion, memory and identity. Emotions and experiences can come to the fore through stories, which reveal a personal standpoint and morality. Therefore, storytelling and narratives can be used to illuminate issues, emotions and underlying values. A personal story can have an enormous impact, and can move people to action. Personal stories, whether they are based in the life experiences and memories of the co-researchers or other participants, enable readers to use them in their own lives, perhaps as reassurance that their experiences are not unique, or as a guide to understanding and action.

A “counter-story” critically questions dominant social norms and ideas. This therefore fits with the participatory research paradigm of surfacing unheard voices and challenging dominant orthodoxies. Some of the participating households in the

Debt on Teesside project were willing to give testimonials at public assemblies and allowed case studies to be used in the reports of the project to illustrate the struggles they faced. The following example was published in a research briefing from the project (Banks et al. 2013: 3):

Claire is a single parent with four children, one of whom is autistic. She is currently registered as a carer for her father who lives locally. She has a range of debts including: two rent-to-own debts, 25 doorstep loans with seven different companies, a logbook loan, catalogue debts and another sub-prime loan, all of which she thought totalled around £10,000 at the time of initial interview (although actual debts came to around £15,000). An example of excessive interest can be seen on her logbook loan, which was originally for £960.94. Total to repay came to £2827.50 ...

People may also want to write their own personal counter-stories, as in auto-ethnography (Ellis and Bocher 2000) or what Reason and McArdle (2004) call first-person participatory research, researching their lived experiences through a process of critical reflection, dialogue and writing. In the emergency care project we reflected on our collaboration in the research team via a collaborative auto-ethnography (Chang et al. 2016; Groot et al. 2018). In the following example, Truus Teunissen et al. (2015), we see how a woman living with multiple chronic diseases and disabilities, started her PhD with a study of her own illness experiences. She describes her 27-year struggle from the moment she became ill to the present. Her search and counter-story gave rise to further research into the voices and values of people with a chronic illness or disability. In her PhD she acknowledges how the writing of her counter-story increased her personal understanding and “*her grip on and perspective in her life*” (Teunissen 2013, p. 230). Grounded in this experience, she therefore recommends storytelling or other artistic expressions like poetry as a way for people with chronic diseases and disabilities to investigate their lives.

Personal stories, such as the ones above, can have an enormous impact, because they touch us emotionally. Emotions are embedded and evoked through the personal, and move us into action. How this works can be illustrated by the following example:

Example: Response from a CEO About the Report on Emergency Care

A main finding from the project was that service-users felt the care was fragmented and did not pay enough attention to their personal needs. They dearly missed personal contact and attention. The report was written with them and their voice was critical. This is how one of the commissioners and CEO responded in an email:

I have read the whole report and I have to say that it touches me. We have something to do in the emergency care chain. It is clear that besides the people working in the emergency care unit many people play a role during a crisis. The whole of all those people ultimately determines the lived experience of our clients. The recommendations are good and I like to see that our organizations jointly take action.

We can see how this CEO was emotionally touched by the stories of clients. This then led her to address her colleagues to take joint action.

Learning Experiences, Increased Understanding

The main aim of participatory research is to foster learning and bring about change. Learning and change happen in the process and need to be captured (see Chap. 10). Change may be tangible, like the reopening of the kitchen in the case story of The Taste Buddies (Chap. 6, Acting for Change), but may also be intangible such as the increased personal and mutual understanding, relational empowerment and mutual transformative power as also seen in Chap. 6. Participatory research reports therefore often narrate about these learning experiences and increased understandings. This includes the learning experiences and understandings of the researcher-facilitator. In her PhD, Miranda Snoeren writes about her learning experiences being engaged in work place learning in two nursing homes. This is a good example of how we as researchers can be reflexively alive in the texts we write:

Example: Learning Experiences of the Researcher-Facilitator

My somewhat rigid use of structure was demotivating for my co-researchers. They experienced the action research process as being passive, demotivating and bureaucratic. The somewhat slow process, in which thinking and doing, and planning and acting were separated and divided in diverse phases, did not fit the hands-on, embodied and responsive nature of learning and did not reflect the dynamic context. It hindered practitioners in taking action while the energy within the group decreased. Furthermore, the ward atmosphere and relationships with others were considered as more influential than the strategic planned actions, while unforeseen incidents, actions and interactions did encourage momentum, learning and change [...]. Based on these lived experiences, I attempted to respond more flexibly to events and tried to adapt and to affiliate with others' learning (preferences) to encourage learning and change. (Snoeren 2016, p. 172–173).

Thick Descriptions

“Thick description” is a term coined by the anthropologist Clifford Geertz (1973). This entails researchers giving detailed accounts of the contexts in which they undertake research, making explicit the patterns of cultural and social relationships, and offering their own interpretations (Van Maanen 1988). In participatory research it is important to consider carefully the details of the research context when reporting. Historical context is usually of interest, but so are cultural, physical, social, economic and political contexts. In KLIK, the context includes the material-physical aspects of the neighborhood, like inadequate housing conditions, lack of sport and play facilities, the large volume of cars and pollution due to the chemical industry. Social aspects include the high rates of unemployment, relatively low levels of educational attainment and higher levels of migrants living in the area. Regarding care for people with a psychiatric vulnerability, the context includes, for example, the

emergency care unit, the social community, and the declining health conditions. The context also may include the scarcity of health care professionals, policy transitions including retrenchments of services as well as the physical environment of an isolation cell, the family and social relationships. Furthermore, not to be forgotten, is public opinion and the stereotyped imagery of people with a psychiatric vulnerability. In *Debt on Teesside*, similar considerations apply, and thick descriptions might include the practices of loan companies driving around low-income neighborhoods looking for gardens containing toys in order to target families with children.

Multiple Realities

Participatory researchers often work with many different stakeholder groups, and should therefore consider including a variety of perspectives when communicating their findings. This decision to include multiple perspectives derives from the ontological notion that reality is constructed, and that experiences gain different meanings in the context of different biographies, disciplinary frameworks and positions (see Chap. 2). Although it is impossible to gain a full and fixed portrayal of reality, our assumption is that understanding reality becomes richer and more informed as we investigate multiple stakeholder perspectives.

Voice and Polyvocality

It is common for researchers to speak for others in their texts. This academic convention is grounded in the idea that an outside researcher is better able to report findings because the people experiencing the problems being studied are not objective. In *KLIK* we (Tineke and Janine) chose another style, one that fits the participatory research paradigm. We created room for the children to speak for themselves via photos, quotes, drawings and mind maps. In the emergency care project we also wanted to give pride of place to the service users' words. In the main text all service users speak via direct quotes to the reader. These are derived from conversations that have taken place. In the preface, we explain that we rearranged the conversations for the dramatic flow. So, we encounter a "carnival of voices", and the variety of languages, jargons, dialects, and discourses makes the text polyvocal. Another tactic to give voice to service-users was to include a song chosen by one of the experiential experts. The main avenues for the direct voices of households involved in the *Debt on Teesside* project were through public assemblies, a celebratory learning event and a film.

9.6 Creative Ways

There are more ways than just words to get a message across. In the emergency care report we included abstract photographs that express the feelings of service-users: the isolation, the impersonal, sterile cleanliness of the emergency care unit. Those visual images communicate things that cannot be easily expressed in words. Thus, the illustrations add value to the text, as does the song "How could anyone" chosen by one of the experiential experts. The condensed forms of writing and the

multiplicity of meanings embedded in the pictures and lyrics of the song stimulate readers to reflect upon the situation of these service-users. Also throughout the text readers can recognize the overwhelming feelings of pain, fear, anger about indifference and neglect, as well as sparkles of hope. Below is a fragment of the song presented in the report, and also played at one of our gatherings at the emergency care unit. This song exemplified the following: “If anyone starts from the assumption that people are whole and beautiful, a lot of misery could be avoided. No use of labels before you really get to know someone. Being curious, making contact.”

How could anyone
 How could anyone ever tell you
 you were anything less than beautiful...
 how could anyone ever tell you
 you were less than whole...
 how could anyone fail to notice
 that your loving is a miracle...
 how deeply you're connected to my soul...
<https://www.youtube.com/watch?v=aF7yFOIk9M>

The inclusion of the lyrics of a song is an acknowledgement that poetry is an appropriate form to illuminate the emotional domain. Poetry goes beyond the rational and can evoke strong physical and emotional responses (Richardson 1993). This form of representation acknowledges that knowing works not only through cognition, but also via our hearts. The selection of pictures and poems is such that they may appeal to various audiences.

Photographs can be a good way to communicate, because they are rich in information and have an emotional appeal. Many participatory researchers work with Photovoice (<https://photovoice.org/>; Wang and Burris 1997; Cook and Hess 2007) to include the voices of children and other groups that may be less comfortable with words. Reading a report on poverty and its impact on the health conditions of children is one thing, but it is much more powerful when readers encounter children's lives visually and become aware of the reality in which they live. Photos can reach further than a set of abstract ideas, numbers and meagre facts, illuminating matters that cannot be put into words. The style of clothing, the messages printed on T-shirts, the way people look into the lens – everything communicates. Photos invite us to interpret what we see. They offer that “writerly” text described by Sumara and Luce Kapler (1993) and offer us a “vicarious experience” of what it means to grow up in a family with limited access to resources. If we report research in a dry academic style, rather than engaging readers in the complex stories of the research, we keep our audiences at a distance.

If we look at the photos taken by the children and the photographer, Janine Schrijver, we are drawn into the picture, and hence into the children's worlds. Then we may raise questions like: “Why do these children sit there at night alone having fast food? What do they actually eat in the morning? Do they drink water or energy drinks? And what does this mean? Is it a lack of money? A consequence of their environment? Discipline? Health illiteracy?” We are emotionally touched by the photos, the distance disappears. This is not just about gathering knowledge of a

neighborhood. The photos appeal to us, and their affective dimension will also move and stimulate us to develop actions to improve a situation. Another advantage of working with photographs is that the findings are not limited to a relatively small elitist group of professionals who read reports, but can reach a far broader audience, including those who are less comfortable with words.

Film is an equally powerful medium and can stimulate similar questions to photos. It also brings to life people's circumstances and can be used to convey political messages, as with the *Debt on Teesside* film, called "Loadsadebt" in which some of the household members featured (<https://www.youtube.com/watch?v=txk4YbqDbvs>).

Theatre, especially Forum Theatre, is useful for interacting with audiences. Actors, or co-researchers themselves, may play out certain scenes based on research findings, asking members of the audience ("spect-actors") to stop the proceedings at key points and suggest alternative courses of action or to come on stage and intervene themselves (Boal 1979; Mienczakowski 1995; Tofteng and Husted 2011; Quinlan 2010). For example, at the celebratory learning event held towards the end of the *Debt on Teesside* project, a community-based theatre group called Shontal performed a short interactive scenario based around a family whose changing life circumstances caused them to take out high-cost loans. A good example of participatory theatre involving co-researchers as actors is the Lawnmowers Independent Theatre Company run by and for people with learning disabilities (for a short film featuring some of their work, see the third film, "Breaking Down Barriers", www.dur.ac.uk/socialjustice/ethics_consultation/films/; for details of the company, <http://thelawnmowers.co.uk/>).

9.7 In What Kind of Form Do We Want to Present Our Findings?

Accounts of the research may be presented in many different forms for a variety of audiences, for example:

- *Short documents in lay language*: flyers, brochures, summaries, practice briefings ...
- *Specialist documents*: articles in magazines/journals, books, chapters, reports ...
- *Coverage in popular print/broadcast media*: newspapers, radio, television ...
- *Web-based media*: webpages, blogs, Facebook, YouTube films ...
- *Other media*: postcards, stickers, shopping bags, T-shirts ...



KNOT

Communicating what has been learnt through participatory research is a further form of action and is not necessarily straightforward.

Reflect on how the types of knowledge being produced through a research project that you have been involved with or are planning can be communicated in a way that engages people beyond those who have been/will be part of its work. Who do you need to engage in the communication process? How do the forms of communication you plan to use meet the needs of both the project and people you want to make changes in policy or practice, based on the learning from the project?

9.8 Stumbling Blocks in the Process of Telling and Showing

How to Collaborate in Showing and Telling About the Research

Even in participatory research, we find it is often academics or other professional researchers who have taken a lead in communicating findings. There are, however, methodological and ethical difficulties surrounding the wish to speak for others. Ultimately the author/editor/designer remains in control. It is the author/editor/designer who selects, and perhaps also leaves out, certain voices, meaning the findings lean towards one particular perspective. This issue can be solved if a team works together to select the voices and stories included, giving everyone credit by name (if they wish), or they publish/disseminate under a collective name.

Resistance to “Thick” Description

An issue that often troubles participatory researchers is how “thick” the description in a report should be to further understanding of the issues studied. There is the problem of balancing description and interpretation in research designed to assist policy-making. Too little, “thin” description may leave out inconsistencies and odd cases. Too much, “thick” description may leave the reader overloaded and confused. Too little interpretation may widen the gap between research and policy-making, while too much may deal more with stereotypes than reality. Practical wisdom is required to find the right equilibrium. Another ethical issue related to thick descriptions is that detailed description of people’s experiences may threaten confidentiality and anonymity.

Expectation to Practice Traditional Writing Styles (Expert, Distanced, Linear)

The wish to reach a more heterogeneous audience than peers within the academic world challenges participatory researchers to produce different kinds of outputs than frozen technical reports. Their academic peers may have other expectations, and participatory researchers have to anticipate criticism about being overly descriptive and subjective. Academics have to unlearn the distanced voice and the presumption of overall expertise. If the research teams want to influence policy-makers, for example, then a certain kind of specialist language may be important. It is not about burying expertise, but contributing it at the appropriate time, in the appropriate place, and recognizing it for what it is, a part of the whole, not the whole.

Publish or Perish Culture in Academia

Participatory research aims to develop co-ownership within communities, so that knowledge generation is collaborative and transformation becomes a shared responsibility of all involved. This co-ownership and sharing of knowledge among a broad audience does not mean that writing for academic peers is irrelevant within participatory research. We find it relevant to share lessons with the broader academic community. The value of scientific publications and one-sided focus on international peer-reviewed journals needs, however, to be placed in perspective. Writing scientific papers can still be very useful for strategic purposes (offering legitimacy), but it is also important to realize that a typical journal article in the social sciences will be fully read by very few. When choosing scientific writing, the issue of authorship arises. Participatory research is typically a collaborative process, with knowledge owned by those involved. This shared ownership has repercussions for the authorship of papers and other products. Multiple authorship, including both professional and community researchers, has to be negotiated.

Appropriation and Framing of Messages by External Parties

In the KLIK example, the publicity material produced by the funding agency was so attractive that journalists spontaneously began to write about the findings in the national media. This created moral dilemmas. On the one hand the research team wanted to have impact, on the other hand they valued relationships and co-ownership. When we (Tineke and Janine) almost lost control over the media frame, we decided to stop the press, asking them to come back later so we had time to better prepare the community partners and children, and when we had more to share. Participatory researchers have a responsibility for the framing of their research findings. They may want to resist frames from outside that do no justice to the people involved in their inquiry.

No Budget or Expertise for Other Ways to Communicate

Although art and performance are strong means to communicate research findings, one should beware of the budget and expertise needed to achieve a good quality experience. Working with artists is certainly something to consider, and this should be included in the budget when applying for grants.

9.9 Concluding Comments

At the start of a research project, it can be hard to imagine how the process may unfold and what the findings might be, let alone how key issues raised by the project will be communicated to others. On the other hand, some thought needs to go into this in advance, to allow for time and money to communicate about the research appropriately, and to consider who might be involved and what roles they might play. As the research develops, then a more detailed plan for dissemination can be produced. It is important to think imaginatively about what forms of communication will best reach different audiences (ranging from photographs and films to policy briefings and academic books) and how to maximize the involvement of co-researchers, each playing to their own particular areas of interest, experience and expertise.

9.10 Questions for Further Reflection and Discussion

This chapter was designed to help you think about disseminating research findings for the promotion of social change. We would like you to consider the following questions for further reflection and discussion:

1. In this chapter we have presented ways to communicate knowledge to foster social change. Can you think of other ways than those presented here to promote the use of research findings for social change?
2. Imagine that you are an academic, and want to write an academic paper on a participatory research process in which you have been involved. What is needed genuinely to involve every participant in the writing process? When does the inclusion of community members become tokenistic?
3. Communicating the process and findings of a participatory research project to satisfy the needs of different audiences can be challenging, costly and time-consuming. Reflect on how you might prioritize target groups and decide on the media to be used if you were: a young person in the KLIK project; a user of psychiatric services; or a member of an indebted household in the *Debt on Teesside* research.

Further Reading and Sources of Inspiration

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Chapter 10

Capturing and Reflecting for Change: The Generation of Impact



Chapter Summary

Abstract The role of critical reflection as a key ongoing element of participatory research is explored with reference to previous chapters. The power of critical reflection to encourage learning and change is discussed alongside the formalization of reflection as evaluation: as a way of recognizing and capturing change. Participatory evaluation and its benefits are outlined, including the demonstration of the impact of the practice of participatory research itself.

Purpose To demonstrate the important and key role of critical reflection and evaluation in participatory research as a change mechanism, how change is recognized and ways of capturing change/impact.

Central Question What is the role of reflection in participatory research and how do we capture those reflections and the types of change that occur throughout the process?

10.1 Introduction

Reflection is interwoven into the participatory research process. It is fundamental to the learning and transformation (Kolb 1984) that influences change. Reflection is a process of sense making and through critical reflection we disrupt previously held understandings to develop new knowledge. This process of reflexivity takes place within the “doing” (Jacobs 2008) of the research. It is an integral component of dialogue because rather than entering into discussion in order to articulate what we already know, dialogue involves the critical examination of thinking and knowledge (Allman 2009). In reflecting, therefore we are also evaluating. Evaluation involves assessing something against a set of values which in turn means being explicit about the values of our work and where they are drawn from. When we are evaluating we are taking a systematic approach to that reflection based on those values. In a world where demonstrating research impact is becoming more important, the systematic recording and articulation of the changes that we co-create is essential. This chapter explores how we can create the space for reflection in many forms throughout the research process so everyone researching together can make meaning together. It examines ways of thinking about what constitutes change (or impact) and how to engage in participatory evaluation to capture the changes we have created.

10.2 Opening Up Communicative Spaces for Critical Reflection

As seen in Chap. 6 on Engaging, participatory research is a relationally driven process that has the intention of opening up communicative spaces (Habermas 1984). Communicative spaces enable people to come together in a spirit of shared learning

whereby they are exposed to different ways of viewing their experiences as they hear other people's perspectives on those experiences. In Chap. 6 we showed that a central feature of this process is that it "separates rhetoric from well-rehearsed notions of practice" (Cook 2006, p. 429). Hearing the views of others and following this up with a shared questioning of views, the key element of critique, can puncture current perceptions, assumptions and beliefs held amongst people involved in the research. It moves the conversations from being descriptive, to being reflective, then from reflection to critical self-reflection and then to joint critical reflection. This process supports people to move beyond their own familiar understandings to learn something new, to "go beyond the already 'expert' understandings which defined their starting points" (Winter 2002, p. 36).

The importance of this relational process is that it provides a forum for people to not only share, but reflect and critique their own knowledge in the light of that brought to the table by others. Co-laboring may disrupt the status quo and existing power structures and create tensions through the challenge of working with the perspective of others. Building robust relationships that enable people to stay together through more turbulent times within the research process, is vital. Good relationships are needed to keep people together through this turbulence. Being aware of the previous history of relationships is as important as building new relationships within the research context. Both are necessary for building robust communicative spaces as the key element in a change process, the process of critical, recursive reflection. From the dialectical processes at the heart of participatory research come discoveries and ways of knowing that have not been predicted and planned.

When new knowledge is created by those involved, rather than been delivered by external "experts", this creates an "insider imperative" for change (Cook 2006, p. 430). In this way change is a shared process of critical reflection on situations with the aim to change them. It is a pragmatic response to the new insights that grow from working and thinking together, and can occur at any stage of the project.

The example below is drawn from the "Towards Inclusive Living" project, described earlier in Chap. 6. Here a group of staff, who work together and know each other well, were discussing the notion of inclusion. The initial question was about where they felt included, not just in their work lives, but in their lives generally. One person had said they felt included when they went on a night out with friends, but as the conversation progressed the reflections became more critical, and new insights into both their own experiences and that of their patients, were surfaced (see Table 10.1).

10.3 Being Critical

In cycles of research action and reflection, the process of reflection involves critical questioning to make meaning, in other words *conscientization* (Freire 1972). "In a process of enlightenment there can be only participants" (Habermas 1984, p. 40).

Table 10.1 Towards living together, a group of staff discussing the notion of inclusion

Conversation	Process
<p><i>“A lot of them [friends] have kids and when we go on a night out, sometimes the conversation goes to children. In a way I can relate because I’ve got nieces and nephews of a similar age, but then I feel excluded when I make comments, you know, like it’s kind of dismissed... So I’m included in the social event but then when the conversation turns to something that I haven’t got as much of an experience with, or if I try to include myself and it’s kind of brushed off. Like, “Oh well, what would you know, you haven’t got children.” (Staff 8)</i></p>	<p><i>Recognizing that in the midst of inclusion there can be exclusion</i></p>
<p><i>I am sometimes in that exact same situation; I would say I deliberately include myself by staying. I sit and smile. But I exclude myself as in I don’t give an opinion in that situation anymore for that exact reason... I don’t have direct, first-hand experience of having children therefore my opinion isn’t valid or grounded on experience. (Staff 3)</i></p>	<p><i>Recognizing how her own behavior can maintain /exacerbate exclusion</i></p>
<p><i>So do you exclude yourself or do you feel excluded by the...? (Staff 4)</i></p>	<p><i>A colleague asks a probing question in line with the above</i></p>
<p><i>I probably feel excluded by past experience and allow that to influence how I behave the next time. I mean I smile and ask questions and listen, but I don’t offer opinions about how things are developing or what might be happening because...the odd times I do spark an idea I don’t express it.(Staff 3)</i></p>	<p><i>The critical conversation develops a deeper reflexivity on how past experience effects current behaviors – how exclusion can be covered up and not articulated, even with friends</i></p>
<p><i>Exclude yourself. Or assume that you will be excluded? (Staff 4)</i> <i>....feel that you are excluded because of past experiences, really. (Staff 3)</i> <i>You protect against it happening again. (Staff 4)</i></p>	<p><i>The above prompted musings by other staff that continued the enquiry into how presumptions affected actions and why that might occur</i></p>
<p><i>Do you think your friends notice that? (Facilitator)</i></p>	<p><i>Facilitator moves it round to what the friends with children might notice</i></p>
<p><i>I don’t know. Some people are very receptive and some aren’t (Staff 3)</i> <i>You’ve raised a very interesting issue there...what if somebody comes (a service user to an appointment) and they feel a bit excluded...but they’re politely looking okay about it, how would you ever know? (Facilitator)</i></p>	<p><i>Facilitator brings professional practice into the frame for discussion, the underlying question being “how would you know, in your clinic, that someone was excluding themselves in the same way you have just described?”</i></p>

(continued)

Table 10.1 (continued)

Conversation	Process
<i>That's where we all have to take responsibility for...I know I'm behaving in that way, so either I could address that directly with my friends or I could...You know, at what point does your own personal responsibility come in if you wish to participate in something? (Staff 3)</i>	<i>This member of staff started to think about this by relating it back to her own experience – but brought in a new concept: “responsibility”</i>
<i>I mean you're confident enough to say – to make a joke... But it's quite hard to be confident, isn't it? In that situation. And to take charge of it. (Staff 4)</i>	<i>And this member of staff brought in “confidence”</i>
<i>I think it can become quite upsetting...certainly after it happened to me I was quite reluctant to speak out but then...because it was actually my best friend who was carrying the conversation and stuff, I just carried on the way I was and obviously it upset me the way it went on... but I can see what you're saying about, you know, relating to a patient.” (Staff 8)</i>	<i>This member of staff made the connection between her personal experience and how difficult it is for service users to articulate their thoughts, even in a friendly space.</i>

Adapted from Cook et al. (2018: no page numbers)

That is, others cannot do the enlightening for participants; in the end, we are, or are not, enlightened in our own terms (Kemmis 2001). Anthony Giddens (2000) argues that we live in a reflexive society in which we are continually making our own interpretations, rather than engaging with and acting in the light of the purposes, beliefs, judgments, and feelings of others. Facilitating such understandings is the cardinal goal of critical reflection. The notion of criticality, however, can immediately conjure up something negative and confrontational. It has connotations of criticism or attack rather than the contemplative deliberation and reflective questioning of what is taken for granted. The use of critical questioning in participatory research denotes listening to other people's meaning makings and taking them seriously while at the same time digging deeper, with them, into their thinking and understanding alongside ours. This includes questioning the assumptions that underpin such meaning making.

As seen in Chap. 2 on Framing, critical theory can help us ask those important questions that support the development of the enquiry. Questions such as whose voice is being heard here? What is not being said or seen or acknowledged as relevant? helps us move towards critical reflexivity. It is such reflexivity that Paulo Freire (1972) talks about when he discusses the role of *conscientization* as a prerequisite for action and social agency. Reflection thus helps us to question and become critical in the way we make sense of the world in order to act for change. Dialogue is a transformative, democratic communication between people and fosters relationships in which people build learning communities:

they reflect on what they know, their lived experiences, and on how these impact the way they read their world...[and in doing so] they freely give voice to their thoughts, ideas, and perceptions about what they know and what they are attempting to understand, always within the context of a larger political project of emancipation. (Darder 2002, p. 103)

Reflection exposes the social contradictions that create injustices, and this new knowledge, in turn, leads to practice that is insightful, analytic and informed.

Only dialogue, which requires critical thinking, is also capable of generating critical thinking. Without dialogue there is no communication, and without communication there can be no true education. (Freire 1995, pp. 73–4)

10.4 Moving Through Resistance and Engaging with Emotion

For people to change their “meaning schemes” (frames, specific beliefs, attitudes, and emotional reactions) (See Chap. 2, Framing), they need to engage in a process of ongoing critical questioning, not just as an intellectual exercise but as an “*intuitive, creative, emotional process.*” (Grabov 1997, p. 90) The process of reflection involves three interrelated elements: receptivity, recognition, and grieving. Receptivity because a person has to be receptive or open to considering “alternative expressions of meaning” (Boyd and Myers 1998, p. 277) for any learning to take place. Recognition as this involves a realization that there is a need for change. Grieving because when someone takes on a new way of doing things or tries to integrate new ideas into their lives they then must come to terms with the fact that steps that they have taken before might no longer have relevance to what they are going to have to do in the future in the light of their new understandings.

This whole process of critical reflection is one of going inwards and outwards and back and forth between the rational and the intuitive/imaginative/subjective drawing on the “realm of interior experience, one constituent being the rational expressed through insights, judgments, and decision; the other being the extra-rational expressed through symbols, images, and feelings” (ibid., p. 275). What we mean by this is that people can use what is in their imagination, but also have that imagination nudged by seeing more visual, concrete representations of their imaginings and those of others. What is articulated and seen becomes more “real” for people and open for further reflection in the light of the reality of others. What is in the imagination can move endlessly and makes it harder for it to be recognized by self and others. This is why remembering, and making explicit those memories and thoughts, through creating a collage, painting a picture or creating a play can be powerful. They are also fun processes at the collective level (see for example the collage The Taste Buddies created in Chap. 6 or the radar wheel metaphor developed by people with Parkinson’s in Chap. 7). Since reflection with all its components is often an uncomfortable and challenging process, and so can be consciously and unconsciously resisted, having fun helps to build relationships, ease tensions and encourage people to continue to work together even when difficult issues are being teased out (see Image 10.1).

Both professionals and other participants can find this critically reflexive way of working particularly threatening as it can unsettle identities, expose insecurities and challenge the meanings attached to the ways in which we act. To see, in clear terms, another perspective that contradicts our own embedded way of understanding can



Image 10.1 Discursive activity to build shared understandings, ICPHR, Limerick, 2018

result in anger, upset and confusion, and in some cases, conflict. Whilst it is part of the mess previously described in Chap. 6 as necessary for learning, without careful attention it can lead to people excluding themselves from the research and losing the very perspectives that help us understand how and why people act in the way they do. The participatory researcher who understands this can then see the process for what it is. Rather than seeing conflict and anger as signs of problems, we see it as part of the process of reflection, re-thinking and learning different ways together. Participatory researchers need to consider how we facilitate the spaces for reflective activities so that we are inclusive, not just for those whose lives are the subject of the research, but for those whose work can be affected by the research. Holding the space while emotions are worked through is an essential skill just as understanding the technicalities of a particular survey approach (see Chap. 7, Sect. 7.8). Despite initial resistance, resentment, or confusion inherent in critical reflection, when new ideas come to the fore and new ways of acting are forged together, there is also joy, exhilaration and excitement leading to increased self-confidence and empowerment (Brookfield 1987).

Here are three examples of this from the project Tina was involved in with men with learning disability and forensic behavior living in a medium secure unit in the north east of England (Cook and Inglis 2009).

This man enjoyed the opportunity to hear multiple perspectives:

Being with everybody. Putting it together. Like, hearing it from what other people have to say on their points of views on it. Because there was different views from what everybody was saying. Not everybody was equally the same. So that was fun. (p. 96)

This man pointed out the importance of having your point of view valued:

The contributions made by all members of the group were valued. It was...important that support was something we all gave. It wasn't just supporters helping out researchers with learning difficulties, we all helped each other. It was a two-way thing. (p. 96)

And this man enjoyed the sheer fun of it:

The most fun was trying to put the pieces together to start off with.... I just love having information and coming up with new things for it. Just love it...I've got my little drug going where I've had all the discussion and everything going. And information going and flying all over the place. And it's just like, Yessss! Aye, I just love learning. (p. 98)

10.5 Evaluation and Evidence: Participatory Evaluation in Participatory Research

Case Study: The Power of Formative Collaboration as a Route to Impact and Impact Evaluation

Representatives of a Women's Mental Health Project met with university colleagues to discuss the evaluation of a new initiative they hoped to introduce. That they wanted to consider evaluation mechanisms at the beginning of the project suggested that their stance to evaluation was more formative than summative. Although they had not considered participatory evaluation as an approach, this provided an opening for the academics to discuss its merits. The Women's Project members were interested in taking this forward as the values of agency through participation matched the values of their organization.

The initiative to be evaluated was the proposed introduction of a web based chat room. The university researchers began the work of establishing a participatory evaluation by speaking with the women (users of the services, managers and administrators) about why they wanted to have a chat room and their expectations of what this might offer for women who used it.

The first conversations established that the women wanted a chat room for three main reasons:

1. women would be able to chat to each other at times beyond the opening hours of the project;
2. women who found it physically hard to get to the building would be able to chat from home;
3. women who could not cope with the intensity of person-to-person chat could be enabled by an online approach.

These three reasons could have become the framework for an evaluation of the project using the following measures:

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1. how many women are chatting with women beyond the opening hours of the project?
2. how many women who don't come to the building due to geographical or other physical barriers (carer issues etc) are using the chat line?
3. how many women who want to remain anonymous are using the chat line?

The mission of the organization was to improve mental health for women who use it. We began to discuss how what the women wanted the chat room to achieve fitted in with the overarching mission. Their initial thoughts were that they wanted to set up a chat room because they believed it would be good for women to chat to each other. Why this was good had not been identified. What would make it effective in terms of the espoused values of the whole organization that had women's mental health at its central driver needed to be considered. Asking what was good about a chat room in terms of the context of the overall project was initially hard. At first, the women could not see a connection. A number of meetings later however, they had developed their thinking through questioning the benefit of chat rooms in relation to mental health. Shared deliberations about what would make the chat room good within the framework for the whole organization prompted new thinking about the effective chatroom in line with the health benefits. Questions that were asked included "*What was 'healthy' about talking together?*" and "*How might we see whether the potential health benefits of chatting have been achieved?*" At this point the simple measures such as capturing if women were consistently using the chat room were seen to be flawed. Such measures did not account for women who might use the chat room briefly and find it helped them work out what they needed and so did not return to it. On the other hand, if women continued to use the chat room regularly, what might that say about their pathway to self-confidence and independence? Rather than consistent use being an indicator of the positive impact of the chatroom, was this really an indicator that it was not working in terms of meeting the organization goal of improved self-reliance and mental health? These very tricky questions were returned to many times to ensure that real indicators of success, based on the organizational aims and the lived experience of the women who use the project, could be established.

Through working together to elucidate the real purpose, meaning and usefulness of what they wanted to do, the shape of the project was amended. The women changed the design to an online forum, rather than a real-time chat room. Whilst they still wanted an online facility they came to wonder whether the chat room format was the most appropriate. They also liked the process of getting to this point, of evaluating what they intended to do as a change mechanism in itself, a process one woman termed "pitfall management." Without this formative approach to evaluation, this digging into what the project was really all about and how it fitted, one woman said she believed they would

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have fallen into the process of building something that did not really meet women's needs. The process of relational, dialogical, critical space for sharing knowledge and shaping new ways of seeing changed what they initially planned and how that might have been evaluated without a recognition of its true value. They were much happier about what they intended to do and could really see the benefits. This was not a brief encounter between the women and the university staff, it matched the process of building a participatory project, that is, time at the start of the project is lengthy. One off encounters with given ideas are not used as the basis for a project, they are the starting point for building and shaping a project.

Source: Unpublished project. Tyneside Women's Health: www.tyneside-womenshealth.org.uk/.

Participatory evaluation, like participatory research, is not just a matter of using participatory techniques within a conventional setting. It involves radically rethinking who initiates and undertakes the process, who learns or benefits from the process and how the causal consequences of a process are recognized: who decides what findings matter (Abma 2006; Greene 2006).

Historically evaluation has been conceptualized as “a quantitative procedure consisting of the ‘task’ of generating unbiased, precise estimates of the causal consequences of programmes” (Cook 1997, p. 32). The distinctive feature of participatory evaluation is not distanced precision but the immersion of all those engaged in a messy process of unearthing what is yet to be known. Participatory evaluation begins from the people involved and the position that all people are creative beings. They contribute to a:

...collective conception of learning about themselves, the organization in which they are involved and ultimately the essential features underlying the phenomena being evaluated. (Ratiu et al 2014, p. 141)

All forms of evaluation practices are drawn from a set of ontological and epistemological underpinnings that shape the way in which processes are designed and understood. To make sure we keep the “value” in participatory “e-**valu[e]**-ation”, we have to be sure that the evaluation reflects the values of the process being evaluated. What was it that the process set out to achieve and what values were the drivers for action. Those values are the bedrock for the integrity of that evaluation.



KNOT

Participatory Evaluation is not just a matter of using participatory techniques within a conventionally framed evaluation approach. What holds participatory evaluation, its knot, is the recognition of the same fundamental principles that underpin participatory research with agency, democracy and collaboration as central.

Reflect on the difference between a participatory approach to evaluation, and the application of participatory techniques. Try to identify where you find yourself. Are you using participatory techniques or do you follow a consistent, holistic participatory approach to evaluation?

When evaluating the impact of participatory research, to capture what enables participants to be aware of what drives their own thinking and acting; how their own thinking and the thinking within their setting has affected change; how changes in thinking to have translated into changes in practice, the process must be participatory, dialogical, embedded and dynamic with critical reflection at its heart. A challenge for participatory approaches is to demonstrate how, by embedding an evaluation within the dialogical research process, this ensures trustworthy evaluation rather than creating a particular pathway that favors one way of thinking. Participatory evaluation helps develop participatory research, and vice versa, they cannot be unpicked. This is the complexity of our weave. Without warp and weft, materials and knots, the whole cannot come together.



10.6 Participatory, Dialogical, Embedded and Dynamic

...the creation of a dialectical process in which the focus is not only on the consensus between different and often conflicting stakeholder perspectives, but also on the development of a set of ongoing practices based on mutual interaction, cooperation, dialogue and negotiation. (Suárez-Herrera et al. 2009, p. 322)

If externally derived, uncontested measures are used for describing what makes effective programs and program development, as Elliot Eisner (1998) points out, an error in judgement may already have been made in terms of what constitutes quality, good practice and worthwhile development. He goes on to say that a result of this error is that people meticulously monitor the process of pursuing a course of action with a great deal of exactitude but with little worth. Capturing externally derived and devised “objective” measures, is less likely to offer information about program quality, and less likely to be a sound basis for program development, than one that engages people in disturbing notions of what makes for program quality and how that can be articulated. Externally imposed systems and measures are not necessarily sufficiently finely tuned to enable us to get to the heart of what gives such a project or program meaning. As Tina Cook (2006) states,

Claims for accountability that use predetermined preconceptions and standardized external measures are not always helpful in making judgements or in capturing the fine threads that weave together the relative merits of program and practices. They can be a blunt tool that reduces the “knowing” to the measure of particular observable or reproducible variables. (p. 425)

In more traditional forms of evaluation we often see, at best, “before and after” spaces. These provide a framework for capturing what people knew before a program started, related to what is expected from that program by those who deliver it before any learning has taken place about that program of activity. These same frameworks are used to check again at the end to see whether what has been expected to be learnt, set against a set of preconceived indicators or measures, has been learnt.

The issue for participatory evaluation is that constructions of worthwhileness are shaped through an embedded syntheses of understandings made meaningful in context. A tight framework of predetermined measurable imperatives may not allow for the construction of concepts of quality that capture the changing and multiple perspectives of program development over time. Traditional notions of evaluation that assume programs or projects are static throughout a research and evaluation cycle, are not suitable for the dynamic processes of interwoven agencies we find in participatory research. Such evaluations need to be process driven and formative (aimed for development and learning versus control and accountability). Formative evaluations have the potential to affect the way in which the research progresses. A formative approach starts to analyze the worth of a project or program while the activities of that program are being formed. As a process it can be embedded as a blend of design process, building process and assessment of the worth and impact of that program. It can continue throughout all stages of the project. They are instrumental in not only capturing what has happened to date in a project, but in shaping what might happen next. This way of evaluating can be seen clearly in even the most basic action research cycle (see Image 10.2).

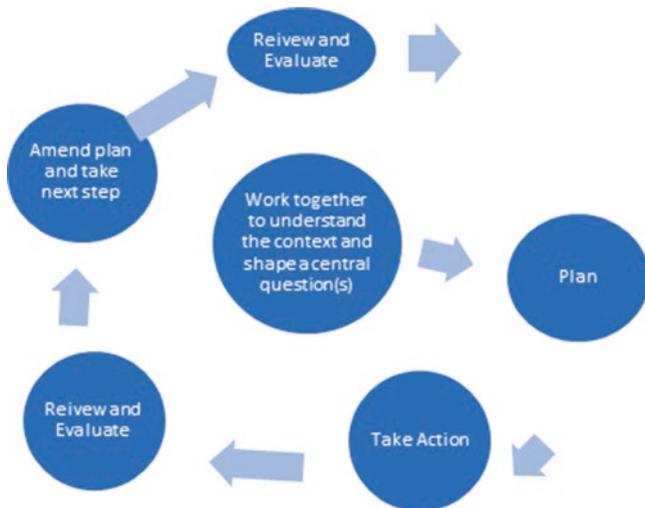
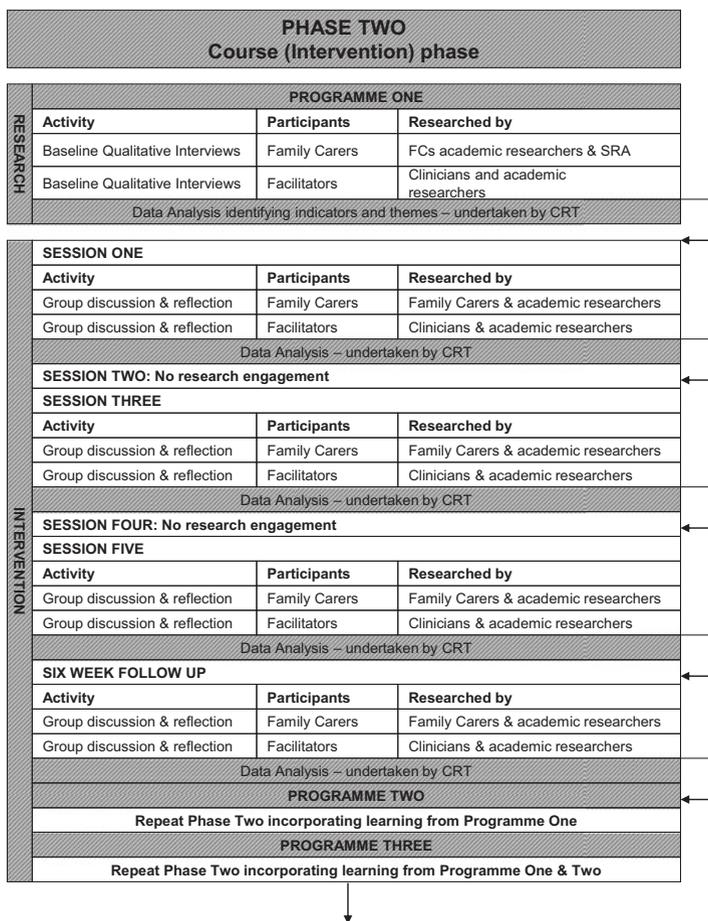


Image 10.2 Diagram of a basic action research cycle



Continued on next page

Image 10.3 Diagram of the formative evaluation process embedded within the FaBPos Project

It is important to recognize that changes that take place as a consequence of participatory research may occur at any stage of the process; at the beginning of the process when having discussions about the focus of the research (the design phase); from the data generation process (loosely called methods); through meaning making processes (analysis), or be taken up in the more traditional way, as change that comes as a consequence of the “findings” of the research.

Using the project Family Based Positive Support (FaBPos <https://fabpos.wordpress.com>) as an example, the diagram in Image 10.3 demonstrates the embedding of a formative participatory evaluation in a project intended to support the family carers of adults with learning disability and challenging behavior cope with stress (see Image 10.3).

Case Study: The FaBPos Project: Positive Behavior Support

The central element of the FaBPos project was a course on Positive Behavior Support, Mindfulness and Acceptance and Commitment Therapy. This was a new course and the family carers were fundamental to the process of deciding whether it worked for them and if so, what were the elements of the course that worked best and why did those elements work. Following extensive consultation with family carers about the nature of such a course, three courses were planned, each course being 5 sessions long. Embedded in the courses was the space for family carers, facilitators of the course and facilitators of the evaluation to come together in a dialogical evaluation process. Data analyzed from this dialogue informed the design of the ongoing courses. The first two courses not only provided information to develop the course iteratively but also provided indicators for success that would be used to evaluate the third course. These communicative spaces for evaluation provided opportunities for people to both understand more about the course itself and what they might want to achieve by either coming on the course (family carers) or delivering the course (facilitators). People learnt together. The shared expectations worked to identify how the course might be developed and changed and what might indicate the success of the course for those participating and those facilitating the course.

Ideas of what makes for success are likely to change over time as the lived experience of program delivery develops over time. As changes/impact are likely to occur and emerge gradually throughout the processes of the research, emerging through the activity of doing and being together, they are less likely to be recognized at the end of the research. So that changes can be recognized retrospectively it is important to consider how to build in ongoing spaces for “taking stock” together, for revisiting and questioning, spaces to make an assessment of where all people involved are in their understandings at certain points in time. Keeping a narrative account of what people considered important at various stages in the project helps track changing perceptions, assumptions and understandings for action. In this way participatory evaluation facilitates the development of a program alongside capturing both intentional and unintentional change. Embedded in the whole life cycle of the research, as well as forming the way in which we understand what is important about a project, formative, participatory evaluation is part of shaping that project to deliver meaningful change.

10.7 Process Driven Evaluation: The Challenge for Participatory Researchers

In participatory research evaluation is built into the process of research. We call this process driven evaluation. A rationale for doing this is that without ongoing spaces for reflection being present during a project, the unexpected and the unintended, the embedded learning, can easily be lost. As with participatory research a key issue for participatory evaluation is building time and space at the start, and throughout the life of the project, for evaluation. As can be seen from the FaBPos Case study/diagram, the evaluation began before the program, and was planned for on a continuum during and after the program, with the full range of people engaged in that process.

10.7.1 Outputs and Outcomes

The tangible service that a research project delivers, for example toolkits for practice, maps of support networks, as well as publications and presentations, are generally called “outputs.” The changes in behavior brought about at least in part through participation in the project, which may include, thinking skills, thinking differently, improved self-confidence, or practical skills, such as a better appreciation of the importance of self and a focus on self are generally termed “outcomes.” As can be seen from the Women’s Health Project case study, we need to beware of simply capturing outputs. It is however, likely to be much more difficult to define, observe or measure outcomes, even when they may represent the main impact of the project. The determination of meaningful outcomes arrives through that dialogical process of asking the questions about which changes are important to whom, and how were these changes achieved. Questions such as “why do we want to do this?”, “how does what we are doing fit with the values of our project or program?”, “how will we know if we have achieved this?” reveal what is meaningful and what might be the indicators of meaningful change.

....given the nonlinear chains of causation in the co-creation pathway, ways of demonstrating impact must reflect the dynamic nature and complex interdependencies of health research systems and address process as well as outcomes. (Greenhalgh 2016, p. 393)

10.7.2 Demonstrating Impact: Working in the Spaces Around and In Between

In recent years demonstrating research impact increasingly has been seen as crucial to substantiating research value for funding organizations, stakeholders and the research community. In its simplest form impact can be seen as the difference the

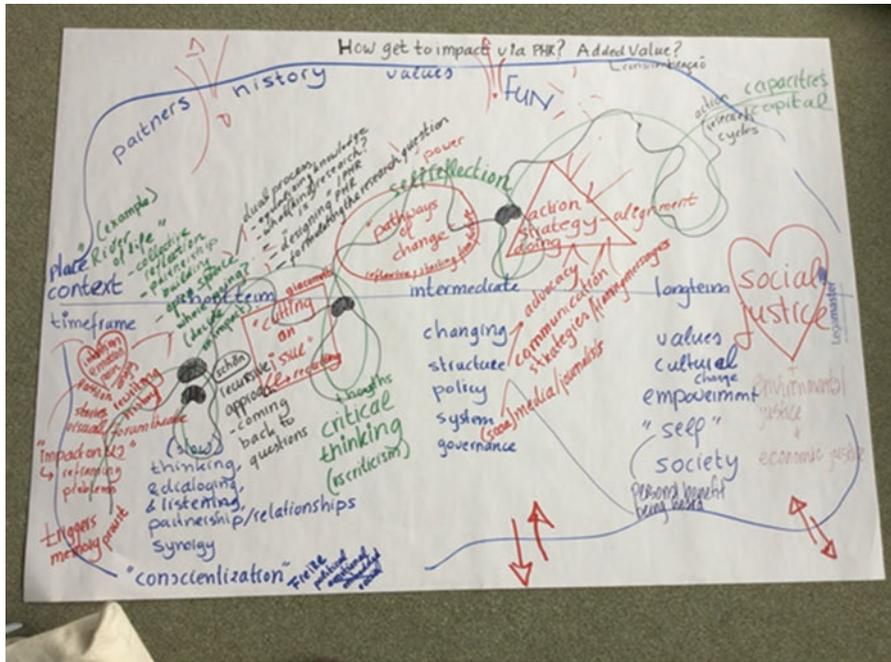


Image 10.4 Illustration of routes to impact by the ICPHR working group on impact, Bielefeld, 2015

research has made to the community of practice, the legacy it leaves behind. As we have highlighted previously in Chap. 6 and in this chapter as well, change and impact can occur throughout the process (see Image 10.4).

Impact has been characterized as observable changes to people, practices, organizations and mechanisms. As the intention to create change (to have an impact) is embedded in participatory research, we might therefore be forgiven for thinking that our “moment in the sun had finally arrived” (Thomson 2015, p. 309). This has not, however, been the “shoe-in” we might have hoped for.

How impact is characterized varies across disciplines and contexts. Differences in the meaning of impact, how it is developed and how it develops across the lifetime of research (and beyond) have led to issues for participatory researchers. The way in which impact is conceptualized and recognized has elevated a particular set of research approaches and evidence forms favored by positivist, linear research paradigms. This tends towards a narrow form of explicit, concrete notion of impact, a form of impact that can be pre-determined and measured (Stake 2004). Table 10.2 shows how the main differences between a standard-based approach to evaluation and participatory, responsive evaluation (Abma 2018).

This conceptualizing does not easily accommodate the diverse pathways to, and understandings of, impact that contextualized research, such as participatory research, utilize. As Rachel Pain and others (2015) suggest, the attempt to measure

Table 10.2 Comparison between standards-based approach and participatory evaluation

	Standards-based approach	Participatory evaluation
Evaluation criteria/ indicators	A priori set by one stakeholder group	Open to issues of concern of various stakeholders
	Externally derived	Developed from within
	Policy-centered	Pluralistic: the values and interests of all stakeholders
	Output	Outcomes, output and process of implementation
Evaluation process	Pre-ordained and fixed hypothetical-deductive design	Emergent design based on stakeholder issues
	Analytic and procedural	Judgement including critique, dialogue and interpretation
	Decision-makers are main stakeholders	Open to multiple stakeholders
	Evaluator as expert	Evaluator as interpreter
Learning	Didactic	Experiential
	Starts after the evaluation with the application of data	Begins during the evaluation process
	Enhanced knowledge “about” the program	Personal and mutual understanding
	Donor-recipient / knowledge transfer	Co-creation of knowledge

Source: Abma (2018)

impact has characterized it “as a concrete, visible phenomenon that is fixed in time and space, that one party does to another party” whereas “deep co-production is a process often involving a gradual, porous and diffuse series of changes undertaken collaboratively” (p. 4).

The use of the word “measure” is not always constructive in helping us to articulate the difference made through participatory research processes. Other terminologies can help us think in different ways. For instance, if we ask ourselves how we might “demonstrate” impact, rather than “measure” it, this offers broader scope for considering impacts beyond the measurable. One way of demonstrating changes that have occurred is through the use of indicators. These are signs of progress that we might see even if the actual event is hidden from us and are used to determine whether a project is having an impact in ways commensurate with program expectations. An indicator is something that signposts the presence, state or appearance of something else. For instance home ownership might be used as an indicator of affluence, it does not measure affluence nor is it a direct correlation, it just suggests that it is there. In the FaBPos project for example, an indicator of recognizing the importance of taking care of personal (family carer) mental health needs could be seen when one family carer, instead of rushing home to take over from the person looking after their son/daughter, used the unexpected hour afforded by an early end to a session to do something for themselves. This was not what they would have done before. It indicated a change in thinking and one that was both recognized and applauded by the group members.

It is of course, important to ensure that indicators are framed within the purposes and values of the project and that the values, logics and practices are reflected in determining how meaningful change is recognized.

Deciding on representations of quality without inquiring into the complex features of everyday practice can be seen as tantamount, in traditional scientific terms, to making decisions without knowing all the “facts.” (Cook 2006, p. 425)

As the facts in participatory evaluations may be far from tangible and observable but have equally important effects on the way organizations develop practice, program indicators are particularly useful in participatory research. They help us track changes in thinking that have emerged from the shared, critically reflexive dialogue that is at the heart of our research praxis. Identifying indicators is a participatory practice in itself.

10.7.3 Legacy and Attribution

We might also think of using the word “legacy” for helping us recognize the ways in which the research process has left its mark. The knowledge transfer/translation, or “donor-recipient” model of impact, where knowledge is produced by one set of people and taken to another, has little relevance in participatory research. The collaborative process at the heart of participatory research means there can be little or no distinction in ownership of the ideas, design or findings that lead to impact. Knowledge production and transfer are integrated.

Impact is a collaborative, transdisciplinary praxis, that involves collaborators from different backgrounds coming together to undertake research with a common purpose. (Pain et al. 2015, p. 12)

It is therefore important when starting out on a participatory research journey, that the implications of this are discussed and understood. This is particularly so when the project involves organizations who are used to making ownership claims for knowledge production, such as universities. It is also important for university academics engaged in participatory research. For many, claiming that it is their work that has produced the impact is vital to career progression or tenure. For academics in particular, alternative ways of understanding contributions to knowledge production and change mechanisms need to be overtly discussed and documented. This is not to deny that academic evaluators are an important part of the process. Indeed the converse issue is that many academics engaged in participatory research do indeed recognize the interconnectedness of their work but are reluctant to make claims in respect of their participation, claims that are needed to protect their reputations as academics. Academics do have an important part to play, and this needs to be recognized and articulated, but they, and other such external players, cannot lay claims for ownership.

The most pressing need, however, is for all those involved in the research to be thinking about demonstrating impact from the beginning so information on impact can be recorded from the start not thought about only at the end to the project.

10.8 Conclusion

Given that change is at the center of participatory research processes, participatory research has a high potential for generating societal impact. This potential is most likely to be realized if we are mindful of the ways in which the values of the participatory paradigm are enacted in all stages of the research and evaluation processes. In practice it is often hard to distinguish what is research, what is practice and what is evaluation as they are interwoven and produced in the same times, in the same spaces and by the same collaborators. All are woven together, giving due respect to various sizes, shapes and dynamic spaces for impact. With an eye to ensuring that the linear does not dominate, impact takes and makes its own pathway within the critical, reflective spaces formed through the practice of participatory research. Ways for recognizing impact and change are guided by the set of principles and values that are the hallmark of participatory practice. This produces new pieces, new practices and new ways of knowing for action, appropriately, but possibly temporarily secured by knots of our shared ways of making.

10.9 Questions for Reflection and Discussion

At its core this chapter aimed to demonstrate the important and key role of critical reflection and evaluation in participatory research in facilitating and capturing change. We would like you to reflect on the following questions:

1. What processes, inherent in the practice of your participatory research, are likely to stimulate change?
2. How is evaluation of change or impact conceptualized within your research plans?
3. Who has been involved in that conceptualization?

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Chapter 11

Continuing the Journey: The Quest for Sustainable Partnerships





Chapter Summary

Abstract Participatory research is dependent on a number of factors, but perhaps most important is the relationship that develops between the research partners. This chapter focuses on a number of factors that impact on the sustainability of research partnerships, including the challenges posed by undertaking time-limited research projects. These factors include: whether projects are regarded as discrete entities; funding; geographical distance; prior relationships; co-researcher boundaries; and evaluation of partnerships. These factors also open opportunities for research partners to develop as participatory researchers, either with the same partners or through developing partnerships with other co-researchers.

Purpose To explore the end-point of participatory research: why some partnerships finish when a single project ends; how and why partnerships continue on to become more sustainable across a number of projects; and as milestones for learning.

Central Question What do we mean by sustainable participatory research?

11.1 Introduction: Projects and Partners

This final chapter is structured around Wendy's experiences to illustrate some of the types of partnerships that develop in participatory research and the issues around sustainability raised by these. We also pick up a number of threads that have been woven throughout the book as we bring these together in finishing off this contribution to undertaking participatory research.

Case Story: Collaborating with a Rural Community in Australia

My (Wendy's) first experience of a participatory research project did not start out in a participatory way at all, but became so as it progressed. It involved an academic colleague and myself driving a 600 km round trip to a rural Australian community once a month for over a year in order to explore a community's understanding of resilience after a natural disaster. We worked with a loose group of general community members, although this group became more refined as we worked together on various phases over the next 2 years. The initial project was designed without the input of the community members because of funding and timing issues. Furthermore, we did not have any previous relationship with this community at the time of the funding bid. This meant that despite having funding and ethical clearance to undertake the project, the community had had no input into the development of the research questions or direction. We recognized at the time this was far from ideal, but comforted ourselves in the knowledge that many "participatory" research projects start this way and whilst some continue to function with limited participation and hence do not go on to be participatory in nature, some will blossom out from this. Luckily, in this project, Wendy was working with a very forgiving community, members of which came to accept and trust these two novice participatory researchers. Two small "rounds" of research were completed with the initial funding that included using Photovoice to explore the community's understanding of resilience after a natural disaster, followed by a survey that was community-led. We then gained funding for a third project that related to a community oral history, resulting in the publication of a small community book that raised funds for the local volunteer-led museum. Once this project was completed, we went our separate ways. I haven't been back since, although I often wonder about the people we had so much to do with for those couple of years. I learnt so much from these projects.

This case story identifies issues of sustainability around:

- projects as discernible or discrete entities;
- funding issues tied to projects;
- challenges to sustainability associated with proximity and developing and maintaining relationships across geographical distance;
- prior relationships;
- issues around co-researcher boundaries;
- evaluation of partnerships;
- partnerships and project outcomes;
- our own learning as participatory researchers.

It is these issues that we will explore in this chapter. While the case story does not outline a sustainable partnership, these experiences were fundamental in developing one researcher's (Wendy's) understanding of participatory research and how

participatory research partnerships may be developed that allow them to exist beyond the first project. We also want to make it clear that while long term participatory research partnerships are well placed as a vehicle for sustainable social change, not all participatory research partnerships will necessarily be sustainable. This does not, however, make them any less valuable in contributing to community change.

As this chapter focuses extensively on partnerships rather than participatory research projects, it is worthwhile to firstly explore what we mean by “partnership.” Like many concepts in participatory research, the term “partnership” is used in various ways. Jennie Fleming et al. (2014) define “partnership” as a more formal relationship whereby each member has specific rights and responsibilities, in contrast to a “collaboration” which they suggest is a more informal process of agreeing to work jointly. Similarly, Angela Scriven (2012) has outlined a whole raft of terms that are used in health promotion settings that relate to partnerships, specifying a “partnership” refers to a formally constituted group with representatives from various sectors. Scriven goes on to describe “coordination” also as a formal relationship, whereas “cooperation” and “collaboration” refer to more informal groups whose members share various goals, information, resources or processes. In contrast, in Australia, most health professionals use the definitions offered by the Victorian Government (VicHealth 2003, as cited in Baum 2008) around the different types of partnerships that have increasing levels of commitment and formality on the part of the members: networking; coordinating; cooperating; collaboration. Thus, “collaboration” in Australia refers to a highly formalized partnership.

While we touch on formal and informal relationships throughout this chapter, we use the term “partnership” to incorporate both, rather than get caught up in delineating between them and trying to describe the various relationships with labels that are not agreed upon internationally. Notions of partnership working do not have a ready framework or defined model to draw on. As Tina Cook (2016) suggests “Partnerships exist along a broad continuum of practice with different interpretations enabling them to mean different things to different people, even when those people are engaged in the same partnership” (p. 84). In this Chapter, to help with understandings, whenever it is necessary to distinguish, we will describe a formal partnership as one that involves the signing of a formal agreement, such as a Memorandum of Understanding as part of the ground rules for the relationship as described in Chaps. 3 and 5, whereas we will refer to informal partnerships as those that do not have signed written agreements in place, although the members are likely to have discussed and agreed upon group processes and goals. Importantly, as highlighted throughout this book, the process of working in partnership is one that is based on a relational way of thinking and understanding of how knowledge is generated (Kral 2014). Thus, while different forms of partnership and levels of engagement are likely to offer different opportunities, a broad understanding of partnership, useful for this chapter, is as an arrangement for joint working that provides a space where people:

... are both invited to engage in work which is important and meaningful for them, and also ... reflect on the manner in which they perform that task so that together they learn how to move towards a more genuine collaboration. (Reason 1998, p. 153)

11.2 Projects as Discrete Entities

In the case story provided by Wendy, we note the initial project was driven by academics. This was because of a narrow window of opportunity to apply for some funding. Unlike the recommended process of establishing a relationship before a piece of research starts, as outlined in Chap. 3, many “participatory” research projects are nevertheless instigated by academics (Fleming et al. 2014; Stoecker 2013). This is not ideal for the reasons explored in previous chapters, but in particular because this tends to reinforce the idea that projects are discrete or discernible entities; that the reason for the relationship to exist is purely project-based and therefore time bound. This can contribute to community organizations developing a mistrust in academic researchers as unreliable, or worse, as using community organizations to further their own careers. As pointed out in the story of Hilda in Liverpool in Chap. 1, some communities have had considerable knowledge extracted but little benefit from being involved in research experiences. The reality of starting out as an academic researcher is the need to undertake small projects in order to establish a research track record – of successful grants and publications – and this often leads to a number of short-term relationships with various community organizations. In an oral history project undertaken by Wendy Madsen that involved interviewing a number of international participatory health researchers, including some of this book’s co-authors, Michael Wright (oral history interview 2014) noted:

So I worked as a consultant and I did smaller research studies, getting money from different sources and then when I got to the research institute then I started to apply for more grants and I started to build up this area in participatory health research.

While Michael was able quite quickly to establish research relationships, including a number of long-term partnerships, this is not the path followed by all participatory researchers and it may take a number of discrete projects with a number of different community partners before the “right mix” of topic/stakeholders/opportunities/context is found. The same may happen from a community organization’s perspective and it may take a number of projects working with different academic researchers before there is a synergy that works between all partners. As such, in order to avoid creating negative expectations between community and academic researchers, it is important to be open and honest in outlining all intentions and constraints, including potential future commitments beyond the initial project.

In the absence of a participatory research equivalent to speed-dating, it is likely academic researchers and community organizations may need to “try each other out” through small discrete projects. As long as these are approached with the aim of mutual benefit and open communications, such projects can serve a number of purposes for all partners, even if they do not result in a long term partnership.

11.3 Funding Tied to Specific Projects

Many participatory research projects work largely or entirely from within the organizational and personal resources of the co-researchers, as discussed in Chap. 5. However, funding is often closely associated with discrete projects; projects that are bound in terms of time, space and activities. While many funding sources are regular and can be planned for, there are also often ad-hoc sources that are suitable but which do not allow for proper relationship building beforehand. In Wendy's example in rural Australia given at the start of the chapter, such an ad-hoc opportunity meant those involved needed to act quickly and it was only after funds were obtained that a relationship was built. This was probably a factor in the relationship not developing into a sustained partnership and ending when the money ran out. Indeed, Jayne Pivik and Hillel Goelman (2011) suggest one of the main systemic issues identified as a barrier to the sustainability of participatory research partnerships is that of discontinuation of restricted funding. If there is a lack of capacity within the community and the academic organizations for the partnership to continue without funding, then the relationship is likely to end. In an oral history interview, Nina Wallerstein (2014) commented on the importance of embedding sustainability into participatory research relationships:

... if we're going to improve health equity we have to look at what the terms are to do that, and how do we do it in a way that communities can own and sustain – because grant money ends and that's the problem with research grants. They always end, so the question is what are we leaving and how do we keep partnerships going even without funding; so we're talking a lot about sustainability and what that means.

Establishing research relationships that survive the fluctuations of funding is the ideal, but the partners within these relationships do need to be able to draw on internal resources to continue the relationship between funding rounds, or to find ways to secure on-going funding sources. The good news is that in many countries, research funding is increasingly being prioritized towards partnerships, including community-academic partnerships. Clearly those partnerships that have an established track record and have managed successfully to navigate the leaner times are more likely to be successful in gaining these types of larger grants. However, we do need to be wary that both academics and community partners may view these research grants as simply sources of money and see the ideals and principles that underpin participatory research as secondary. One of us, Sarah Banks (2015), reflected on this in an oral history interview:

So many of these organizations that we partner with for research are struggling. So they're keen to make links with outside organizations and to get money, and sometimes they can see it as a source of funding rather than a genuine research partnership. So I think that's a bit of a challenge when you're working in partnerships.

Again, this emphasizes the importance of having open and honest conversations between research partners around core issues such as values and expected outcomes from being involved in a participatory research project and what is needed to achieve those outcomes. This aspect has been highlighted a number of times throughout this book.

11.4 The Context for the Project

Jayne Pivik and Hillel Goelman (2011) note that while factors such as open communication, trust and respect have been well documented as important for the success of participatory research partnerships, context is also important, including issues around proximity and availability in regards to being able to meet. If we have funding and a defined time-limited project to work on, we may find the means to make the partnership work, for the sake of the project, but once the funds end, context can loom very large indeed as a barrier to sustaining the partnership. It can be the difference between partners being able to meet for a coffee and a catch-up to maintain the relationship while planning or waiting for the next round of funding, and the relationship deteriorating through lack of attention. Time and workload commitments and what may be required to make a research partnership work within a particular context have to be taken into account when discussing potential partnerships or projects. One of the key contextual factors in the research relationship outlined in the Wendy's case study story not being sustainable was that of geographical distance. The drive out to the rural community was always pleasant, but it took a good 4 h one way and necessitated staying overnight. This essentially took nearly 2 days out of Wendy's working week. The geographical distance between partners can be a barrier in being able to meet regularly face-to-face. Jennie Fleming et al. (2014) describe how a research consortium used a variety of avenues to ensure regular communication, including teleconferencing and emails; however, they ensured they met face-to-face for important decisions and found this to be an important crucial aspect to the success of their work. Of course, geographical distance may not be the issue in some contexts. Traffic congestion and lack of parking can be just as significant a barrier for face-to-face meetings in large cities.

This is not to say that successful long-distance participatory research partnerships, or partnerships that have other contextual challenges, cannot be sustained for many years. Rather, in these circumstances, the partners will need to work at negotiating these factors in their relationship building and maintenance.

11.5 Previous Relationships

Joan Velasquez et al. (2011) outline the process used by *Mano a Mano* (Spanish meaning "hand to hand"), a non-profit organization that works with Bolivian communities. A core part of their success relates to developing community partnerships that incorporate *Mano a Mano* personnel, community leaders, the municipal leader (normally the mayor) and lay community members. This group then extends out into the community using already established networks in order to gather the viewpoints of a broad section of residents. It builds on existing relationships and as such, the foundations of the partnership are firmly rooted in established social capital.

In Chap. 7 we introduced another example of using long-established social capital, that of the Lawnmowers Independent Theatre Company, a group in Newcastle, UK, that Tina has worked with over many years as a voluntary Board Member/Trustee. Through this long history, Tina has developed strong relationships with the company staff and the members (people with learning difficulties). The Company uses participatory theatre, developed by Augusto Boal (1993), to develop the shows it stages. Thus, participatory research is central to the Company's mission with staff and members equally engaged in this practice. The long-term relationship between Tina and the Company was fundamental in a bid for National Government funding for the Company to develop their work into the need for people with learning difficulties to have a better understanding of brain function. Tina, knowing the focus of the company's work, identified this call for funding. And in conjunction with company staff, wrote the bid. The success of the bid then enabled the Company to research and develop a play and associated cartoon booklet, and to carry out a participatory evaluation of the impact of touring the play to people with learning difficulties (see www.thelawnmowers.co.ukThe Big Brain Show). In this case then, the funding was an outcome of sustained partnership rather than partnership being an outcome of funded research.

In the Portuguese research project on HIV among sex workers introduced in Chaps. 4 and 8, the sex workers were not organized nor easily recognizable. Thus, Sonia's experience was quite different to that of Tina, in that great efforts were needed to reach and involve this community in the project. This required the community partner promoter of the project to take a central role in reaching and contacting network partners before the project could even commence. Furthermore, there was potential for considerable mistrust towards the research by some of the sex workers. The creation of a Community Advisory Board provided a space for regular meetings and constructive dialogue. This enabled each member to acknowledge others, share knowledge, expertise and resources, to debate on foundational perspectives and expand on further collective new ideas and aspirations for the project. In this case, it was the project that deepened the social relationships, mutual trust and paved the way for sharing resources and for a sustainable partnership to be formed.

Participatory research partnerships built on existing relationships can be successful and sustainable because the partners already know what to expect from each other and have already built trust (Pivik and Goelman 2011). Furthermore, in the throes of undertaking a project, there is often little time to focus on building relationships within the partnership, although neglect of this aspect can have significant consequences for the outcomes of the project. However, in the absence of previous constructive relationships, it is still possible to establish an effective participatory research partnership.

In their realist evaluation of community-based participatory research partnerships, Justin Jagosh et al. (2015) describe how trust needs to be established and maintained throughout participatory research partnerships in order to increase synergies over time, resulting in long-term outcomes and sustainability, as well as potential spin-off projects and the possibility of transforming systemic elements within the context itself. They also note that for many partnerships, there is a pre-context of mistrust, rather than trust, that needs to be overcome in the early stages of the partnership. This can come about when community or academic partners have

had less-than-ideal encounters and experiences of research that has resulted in misunderstandings, disappointments or worse, exploitation of some form.

In the community outlined in Wendy's case story, community members indicated they had been the subjects of multiple research projects and as such, were cautious of becoming involved in the project being proposed. The first phase of Photovoice introduced the community members to a style of research they had never encountered before. As they came to see they were gaining something out of being involved in the research, trust developed to the point where the academics were invited to be involved in other community based activities, including the final phase that consisted of a community oral history project. This is an example of the impact of the research unexpectedly spilling beyond the boundaries of the original project (as explored in Chap. 10).



***Ideally participatory research** starts from a relationship of trust between partners.*

***Reflect on** a situation where there is mistrust and conflict. How can you develop trust with and among your partners? How can you overcome conflict and impasses?*

In the absence of a previous relationship, consideration could be given to developing a more formalized relationship with a signed agreement or Memorandum of Understanding that outlines various roles and responsibilities, goals and objectives, communication strategies, decision-making strategies, modes of information dissemination, budgets and timelines (See Chap. 3; also Pivik and Goelman 2011). This is not necessarily because such formality is needed for trust to be established or for any guarantee of success in the partnership, but it does provide a framework around which to have important conversations that may be easier for partners who are unfamiliar with each other (see Chap. 3). Such formality may contribute to partners feeling more comfortable with each other and can lay a foundation upon which trust can be then established. Alternatively, partners who know each other well also need to have these conversations and ensure there are no unexplored assumptions around the expectations each has of the other, whether or not a formalized agreement is signed.

11.6 Boundaries Around a Co-researcher Group

Closely related to the issue around building trust within research partnerships is that of who the partners are and how fluid the boundaries may be around the partners. In Wendy's case story, the community partners consisted of quite a porous group. While there were three or four consistent members of the community who came to most meetings, there was a constant ebb and flow of others. These community members were always welcome to the meetings, but it was difficult to establish strong

relationships within the partnership and this is likely to have been another factor in the partnership not surviving beyond the end of the funded projects (Compare Chap. 7, Engaging, on the formation of a research group).

In an example of a different type of changing membership, Tineke Abma is involved in a participatory action research platform in the Netherlands called *Centrum voor Cliëntervaringen* (*Centre for client experiences*). This initiative involves service users, client representatives, academics, local government officers, professionals and directors of health care and welfare institutions as well as students, teachers and community artists. The mission of this platform is to enhance the quality of life of citizens and service-users regarded as “vulnerable” by conducting participatory research projects together. At the start of each project, a team of co-researchers whose lives are directly impacted by the topic is formed. Thus, while there is a different co-researcher group associated with each specific project, all exist within a broader whole of a stable partnership (see www.centrumvoorcliëntervaringen.com; Groot et al. 2018).

Some research partnerships will have quite clear boundaries as to who is in and who is out. Understanding what or who is in a “community” is not always straightforward, however, nor it is always helped by referring to the literature. For example, Jill Grant et al. (2008) talk about building relationships with community members through open and honest communication, regular meetings to check in on process and progress, and to keep dialogues open. Yet there is often an underlying assumption that the “community” is well defined when this is rarely the case. Without careful consideration of the boundaries around the partnership, many academic researchers will easily default to controlling the decision making and the research ceases to be participatory.



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In participatory research, building relationships with community members ideally flows through open and honest communication, and regular meetings to check in on process and progress.

Reflect on this advice above. How, for example, do you build relationships with a “community” of 300 people or more? Who is it that is coming to the meetings? Whom do they represent? How might changing membership alter the momentum of the research? How do you build relationships with changing membership? What are the power implications of this situation?

Even in partnerships that consist of quite fixed personnel, all partners bring with them a certain amount of “baggage” to any relationship: cultural expectations, ways of being and ways of knowing. We have been alerted to this issue in previous chapters. Negotiating a way through the pooling of everyone’s baggage is a key factor in establishing successful and sustainable research partnerships. It is a factor that needs to be regularly reviewed and we turn our attention to this now (Image 11.1).



Image 11.1 Building relationships, ICPHR, Limerick 2017

11.7 Evaluation and Celebration: Deepening the Relationship

All the research meetings outlined in Wendy's case story were held in the local pub. It was the only meeting venue in the rural town open after hours, but it did naturally facilitate a sense of celebration as key milestones within the projects were recognized. Such celebrations also provide an opportunity to evaluate the partnership; to check in on each other and how we are travelling as a partnership. It is good practice to include process evaluation in a research project (Harris 2010). Part of this should be evaluating the partnership, as discussed in the Chap. 10. Bradley Cousins and Jill Anne Chouinard (2012), in their review of participatory evaluation, note that evaluation is an essential process of mutual learning, a dialogic process of coming to know self and others, through the dynamic, emergent and ongoing co-creation of knowledge. Indeed, it is through periodically reviewing relationships in participatory research that learning and trust are maintained (Jagosh et al. 2015; Coco et al. 2007; Groot et al. 2018; Nitsch et al. 2013).

Margaret Ledwith and Jane Springett (2010) recognize that many partners are deterred from evaluating their relationships because of time pressures. They put forward a pragmatic way of creating a space to reflect and learn based on Learning, Evaluation and Planning (LEAP), developed by the Scottish Community Development Centre, that uses stories and dialogue. Like other research evaluations, partnership evaluation includes deciding what data should be collected, or generated, and by whom to allow for meaningful information on which to reflect and learn. However, this process does not have to be an onerous one, but can instead be one that is celebratory, not only of the project but of the partnership itself. Seeing evaluation and celebration of the partnership as an integral part of a participatory

research project is consistent with a whole systems approach being espoused in disciplines such as health promotion. Narratives are being increasingly recognized as offering significant insights into the complicated unfolding of events in complex systems (Hodgins and Griffiths 2012). Telling our stories to each other, outlining our perspectives of how things are going, whether that be over a glass of wine at the end of a day or over a cup of tea at the end of a meeting, allow us to check in with each other, to clarify any misconceptions, and to deepen our connections with each other. Of course, sometimes these conversations may not be easy to have, but they are important for the health of the partnership. Sometimes writing reflexively and collaboratively about the relationships can help to gain a heightened personal and mutual understanding of each other and the relationships (Groot et al. 2018). Leaving unspoken issues alone will result in festering that can undermine the partnership and thus its sustainability.

11.8 Developing as a Participatory Researcher: Learning About the Role of Being a Partner

At the same time as Wendy was involved in the research partnership outlined in the case story, she was involved in another partnership that did not go so well. The contrast between these two partnerships allowed her to reflect deeply on successful participatory research partnerships, especially around issues of unexamined assumptions and unexplored power relations (Madsen and O'Mullan 2017). Lai Fong Chui (2008, p. 546) outlines her learning over a number of participatory action research projects and the development of a participatory praxis, which she identifies as “the constant engagement of oneself in a process of negotiation with a myriad of obstacles as events unfold.” She indicates this occurs as we reflect on and become more aware of our structural relations with others and the system in which we work, so we are able to better uncover our assumptions and develop alternative frames. Indeed, she suggests it is through facing contradictions, predicaments and uncertainties that we come to better understand participatory research. We do this personally, but we can also learn and reflect in partnerships, and through reflexive, collaborative writing (Groot et al. 2018; Snoeren et al. 2012; See also the section on learning experiences in Chap. 9, Telling and Showing). Developing critical reflexivity has been emphasized throughout this book.

Peter Reason and Hilary Bradbury (2008) remind us of first, second and third person research and practice. First person research is an attitude of inquiry on the part of the individual as an individual. This is the reflection we make on our own thoughts and actions as well as how various processes have evolved. As indicated in Chap. 8, many of us find it useful to keep journals as part of undertaking projects in which we not only record details of the project, but reflect on personal and emotional reactions. It can be useful to have a separate journal for each project. Most who use journaling will be constantly amazed at how often the act of writing allows

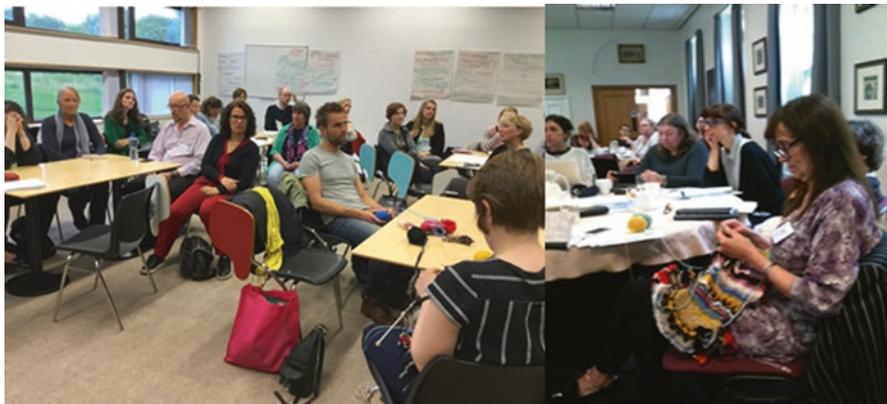


Image 11.2 Communities of Inquiry: ICPHR, Limerick, 2017; PAR course, Durham University, UK, 2017

them to clarify their thinking and deepen their understanding of what is going on, practically as well as theoretically.

Second person research is the ability of two or more people in a small group to reflect and learn together through interpersonal dialogue. This is primarily the sort of group reflection undertaken within most participatory research partnerships. As we explored in the previous section, narratives and dialogue can play a key part in evaluating not only the project but also the partnership as well. It is in these conversations that we pull apart, interrogate and come to know better the mechanics and structures that are influencing ourselves and our work (Image 11.2).

Finally, third person research extends beyond small scale projects to create a wider community of inquiry. This sort of reflection and learning may relate to networks such as the International Collaboration for Participatory Health Research. The forums created by such networks allow researchers to delve deeper into the philosophy and principles of participatory research, and open up spaces for supportive critique to occur. The need for this type of space is voiced by one of us (Tina Cook, oral history interview, 2015):

We don't have to explain ourselves [because of our shared interest in participatory research] and then we can be critical and unpick what we do together and learn from each other in a way that's been so enormously supportive... we can map together, be critical of what we do and understand better, and better articulate it.

Whether we are reflecting at an individual, group or network level, taking the time to stop and carefully consider what is happening in our practice, relationships and projects is essential in not only avoiding making the same mistakes twice, but also in nurturing our learning as researchers. There is a joy and deep sense of satisfaction in this learning. For many of us, this is what motivates us to continue as participatory researchers. It is what sustains us to reach out to others and to explore new grounds, new partnerships, new projects, and new stories.

11.9 Being Transformed

This chapter has explored a number of factors that can influence the experience of a sustainable research partnership, from issues around discrete projects, funding, proximity, previous relationships, boundaries, evaluation and celebration. Whether you are in a long-term research partnership, have just completed one participatory project or are about to start your one hundredth, all participatory research experiences provide you with opportunities to learn and enrich your practice as a researcher. That journey does not end when a particular piece of research is written up or when the funding is reconciled. You may continue the journey with the same partner on another adventure, or you may find some other companions. One thing that is assured, the adventure will be eventful and provided you are open to the experiences, you will not be the same researcher you were when you started. Key to participatory research is that all are being transformed in the process.

We have touched on a range of issues related to participatory research partnerships in this chapter. These issues are not stumbling blocks in and of themselves, but they do alert us to potential knots and tangles that are bound to occur during the course of participatory research.

11.10 Questions for Reflection and Discussion

In this book we have taken you on a journey through the experience of doing research with people, not on them, in order to help bring about social change for health and social well-being. We hope by now that you have a compass of the sort of questions you need to ask yourself at different stages of the process to help you deepen your knowledge and explore the practice of participatory research.

The focus of this chapter has been to explore the sustainability of participatory research relationships, including: how to build trusting and long-term research partnerships; why some partnerships finish when a single project ends; how and why partnerships continue on to become more sustainable across a number of projects; and how we can learn along the way. We would like you to reflect on the following questions:

1. What are your expectations around the sustainability of your research relationship continuing? What about the expectations of your research partners?
2. What is the reason for this research partnership existing? Can it continue in the absence of funding or close proximity? Have you talked about continuing this relationship?

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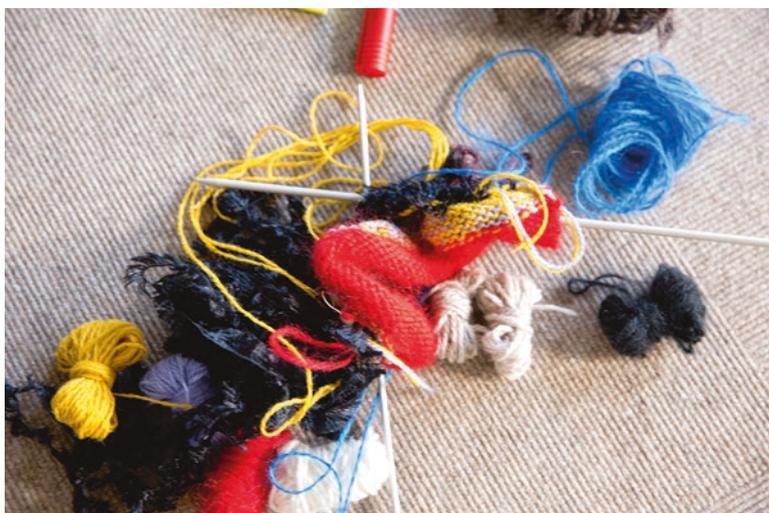
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Chapter 12

Epilogue: Bringing the Threads Together



Chapter Summary

Abstract This final Chapter sheds light on the reasons why participatory research is so worth all the effort. It comes back to the essence of participatory research: the communicative focus, the relational, the reflexivity, the co-labouring, the critical and the creative dimensions. Participatory research is also a research approach that addresses traditional power imbalances to reveal new ways of knowing and acting.

Purpose To come back to the essence of participatory research and why it is worth the effort and to illuminate what makes that effort worthwhile.

Central Question What is the essence of participatory research and why is it worth the effort?

At the beginning of this book we introduced you to the metaphor of knitting; of the intertwining of yarn to create patterns on one side and these patterns emerged from the messiness and knots of the reverse side. As we, the authors of the book, have been knitting together our knowledge and ideas to try and explain the creative process of participatory research, just as in a participatory research project our co-labouring has extended the sum of our individual knowing. This book was developed by us as a group together. It reflects our collective wisdom, born from the experience of thinking about, talking about, reading about, writing about and above all, carrying out, participatory research in our own contexts. In many ways, the writing of the book has almost become a participatory research project in itself. It has offered the creative and joyous learning processes that come from working out what we, together, might be thinking, but also the challenges that working in partnership necessarily brings. Working across geographical distances that span continents we have, however, challenged ourselves to construct, from our diverse circumstances and experiences, a book that realistically articulates the qualities and values of participatory research alongside an honest presentation of some of the elements of carrying out participatory research that challenge us.

Throughout this book we have explored the interdependence, interconnectedness and intertwining of participatory research, its researchers and various projects. We are clear that not all participatory research projects will look the same in terms of process, nor should they. They are contextually bound and driven, but we offer what we have generated in the form of what we hope will be useful guidelines for undertaking participatory research. We have highlighted the richness of diversity as we interweave people and ideas from diverse backgrounds and worldviews. We have articulated the importance of making space for the potential for new ideas and issues to arise as the research unfolds – expecting the unexpected (Chap. 7) but also of the importance of designing a pattern and plan from the beginning of the research to help organize and focus the necessary materials, people and ideas (Chaps. 3, 4 and 5). There are many creative and collaborative ways of building participatory

research. What follows is a summary of the key principles which we consider necessarily underpin this approach.

1. *Cultivating trusting relationships.* Openness and honesty in expectations of partnership is vital. Not all participatory research relationships will be sustainable in the long-term, but all partners need to have shared expectations as to the purpose and benefits of the partnership. If there is mistrust at the start of a partnership due to previous experiences of co-researchers, or mistrust that develops as a result of a lack of transparency in the partnership, this can be a major stumbling block.
2. *Good communication for successful partnership development.* Effective communication lies at the heart of sustainable partnerships wherever and whenever these are formed. This means that each partnership needs to be considered within its own context and effort needs to be directed towards overcoming real and potential communication obstacles.
3. *Facilitating sustainable transformation through human agency.* Based on the power of collective endeavor, participatory research supports locally driven transformational processes with the intention that, whilst fostered during the research, changes will be maintained and rippled out beyond the life time of a discrete project. Social learning (learning together and from each other) is a fundamental dimension of the participatory research process, and this continual cycle of “look, reflect, act” underpins the dynamics of developing a connected knowing with the potential for wider impact.
4. *Handling ever-changing membership in the co-researcher partnership.* There are many things we cannot control in participatory partnership, and one of these may be who is a part of the partnership itself. People and positions change and this can be disruptive for both time-limited as well as long-term partnerships. There is likely to be an ebb and flow in participatory engagements as not everyone will be involved in the same way, at the same time or in the same elements of the process. Having clear communication channels – both oral and documentary – can provide a useful way to navigate these changes.
5. *Making time to monitor and evaluate the partnership.* We all lead busy lives but when we allow this to detract from monitoring and nurturing our research relationships, we risk undermining the very research in which we are involved. Unlike other approaches to research, participatory research is totally dependent on a relational way of thinking, being and doing. We need to pay attention to our partnerships as much as our data.
6. *Taking time to reflect and learn personally and collectively.* Sustainable social change is about finding different ways of perceiving and acting in the world. This means we must take the time to reflect on our research and to learn from the process and findings. Otherwise there is little point in doing the research.
7. *Independence from funding.* It is important not to rely too much on funding. Money may not be the root of all evil, but it can become an obsessive feature for many researchers, and therefore inhibit exploring ways of working in partnership and achieving sustainable social change in the absence of funding.

8. *Expecting messiness.* Participatory researchers acknowledge the importance of not always knowing what we are doing as a means to creating space for the development of new knowledge for action. “The occurrence of messiness is a fundamental characteristic of participatory research” (ICPHR 2013: 20). Participatory research is relational, nonlinear and multi-focused and expects to generate outcomes that could not be characterized, framed and boxed prior to the study.

12.1 Reminding Ourselves of Why We Do Participatory Research

Through shaping communicative spaces for democratic participation, especially the active participation and agency of those who are seldom heard, we seek to create deep and meaningful understandings of situations with the aim of fostering social change. We recognize the practice of participatory research as:

- **Ethical:** to exclude the voices of those with lived experience in relation to the issue or practice being researched challenges our notions of equality and social justice.
- **Political:** if authentic voice is not afforded to the people who currently experience marginalization, issues relating to their lives are over-shadowed by the voices of others who may have different experiences, needs and interests. Being excluded from knowledge production reduces opportunities to inform, shape and transform practice for improving lives, and results in epistemic injustice. Who decides on the meaning drawn from research, and how it is disseminated, distributes power.
- **Methodological:** knowledge can only ever be partial if it is constructed without the authentic voice of those with lived experience. Co-labouring can disturb the current rhetoric, rhetoric which is usually shaped by those with the power to determine what knowledge counts. Working together in this way, integrating different and multiple voices, provides space for new, generative ways of seeing, understanding and acting.
- **Practical:** when the learning through engaging in a participatory research is experienced together with those for whom it makes a difference, impetus for change and developing sustainability of that change beyond a project life time is enhanced. Working together, in partnerships, and developing co-ownership provides strong routes for change.

Just like the garments we could knit, participatory research partnerships come in all shapes and sizes. Some of them will be more long-lasting than others. Some may possibly be more satisfying than others. However, if we continue to work on the relationships that form the basis of any project and partnership, we will ensure we get the best outcomes for all concerned, both in the short and long term (see Image 12.1).



Image 12.1 Knitting and yarns, ICPHR, Limerick, 2017

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