



*How to involve
lived expertise
in research,
policy and
campaigning*

a Changing Realities Toolkit



authors

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introduction

Recent years have seen an increased recognition of the need to involve people with lived expertise in campaigning, research and policymaking. While this work is important, it is certainly not easy. It needs to be pursued sensitively, and in a way that recognises the resources required to do it justice.

This toolkit aims to help readers embark upon or refine their work with people with lived experience (also referred to as taking a participatory or co-produced approach). It provides eight ‘top tips’ and practical examples about how to undertake participatory work.

This toolkit draws on our learnings from the project Changing Realities (formerly Covid Realities), a partnership between parents and carers living on a low income, academic researchers and a national charity. Changing Realities creates opportunities for parents and carers to document their everyday experiences of hardship and to work together with others to push for change. More information about the project and our approach is available at: **changingrealities.org**.

Participants' perspectives

We should start, as always, by considering participants' perspectives. The passage below was written by Victoria, a participant in both Covid Realities and Changing Realities. It demonstrates how participatory work can make a difference to individuals and society.

My confidence, especially in my ability to have a voice in a world I often feel unvalued in as a single mother with severe mental health issues, has grown as a direct result of being part of this project.

I have a book on my bookshelf that the team put together from the experiences of participants during lockdown, and parts of the research collected have been shared in parliamentary debates. With the support of [the team], I've been able to anonymously and safely share my experiences with newspapers.

I've felt connected to my wider national community, a part of living history and a valued voice for change in a world where the lived experiences of people like myself and my peers are seldom heard or respected.

All or nothing? Thinking of participatory work as a continuum

The involvement of lived experience is not a zero-sum game. As the academic Jo Aldridge reminds us (see further sources below), this work sits on a continuum of activities that can be more or less participatory. As an example, take a meeting between a parliamentarian and a small group of individuals with experience of using food banks, supported by a national charity. For the process to be fully participatory, those with lived experience should be involved in all the decisions that shape the meeting: the choice of parliamentarian, the format of the meeting, the content of the presentations, and the call to action.

But a meeting that is less participatory still has value – the charity could arrange the meeting and determine the discussion topics and then invite and support those using food banks to speak. Even though it is less participatory, it's a step in the right direction.

We encourage readers to consider working up and down the continuum of participation as resources allow. It can be a good idea to trial something which includes a small element of participation; learn from it; and then next time try and do something which includes a greater degree of participation.



Eight tips to advance your participatory work

Sweat the small stuff

When you are doing participatory work, it is the small stuff that makes a big difference. Is this venue fully accessible, is it intimidating in any way, is it easy to find? What about catering – do people have the food and drink they enjoy, are cultural and dietary needs accommodated in a way that doesn't make people feel marginalised or awkward? It's important to spend time making sure people are comfortable, they have what they need to take part, and their journey to the venue is as easy as possible (this can mean arranging and paying for taxis, meeting people at the station, and being on call in case anything goes wrong).

Making spaces comfortable and accessible is important in itself but it is also a small and meaningful way to challenge power differentials. In an online space, we can replicate this approach by taking time to ensure that people have the technology and the mobile data to access the meeting, by coaching people to use the technology required, and by sending out food and drink to enjoy during the meeting. It is this stuff, the 'small' stuff, that participants often remember and value most. So, before you think about your agenda and what you will be discussing, think about what participants will be eating and drinking while they talk.

1

Making the online space a nice place to be

In 2020 we began working on Covid Realities, a participatory project seeking to document everyday life during the pandemic for parents and carers experiencing poverty. The team leading the work had a history of participatory work, but had never conducted work online, or during a lockdown! We set up online meetings for parents and carers to get together, share experiences, and develop recommendations for change. We needed to make these spaces welcoming and demonstrate that we cared, but through the prism of a mobile phone or computer screen. We spent lots (and lots) of time thinking carefully about this, as we knew how important it is to get it right. Among other things, we decided to send each participant a ‘snack pack’ by post before a meeting with a hot drink sachet and a snack. In face-to-face meetings we always take time to get the catering right, and we saw that our role for an online meeting was no different. The act of sending out the packs was a statement of the care we took in these encounters. Participants valued the packs and felt valued by us.

We also included a section at the start of each meeting where people were invited to share their ‘covid realities’. This created a space for sharing and for peer support, and importantly everyone shared – participants, researchers, voluntary sector partners alike. Participants often reported experiencing peer support from this initial sharing, while it also made real our commitment to an ‘ethics of reciprocity’ (***see tip eight***).

Build in adequate time

The most precious and vital resource to this work is time; and making sure to build in adequate time for planning, conducting and reflecting on participatory work. This can be difficult set against fast moving policy contexts and high workloads. But very real risks come with not taking enough time to properly think through the activity being developed; while a great deal of time is needed to arrange the practicalities around supporting participants. There are multiple visible and invisible barriers for those with lived experiences of poverty, disability and structural racism (to take just three examples) being involved and listened to, and so time is required to identify and dismantle the barriers in each individual case.

Time is also needed to build relationships of trust between facilitators and participants; and to make sure there is a shared understanding of the work being conducted together, and where it starts and ends. Time is required to properly brief others involved in the activities; and to make sure that participants are kept informed of things that happen (and hopefully change) as a result of their involvement. So make time. Take time. And recognise that you will need time to do this.



3

Reimbursement

It is important that participants are recognised and compensated for the time and expertise that they give. We think that the most ethical approach to reimbursement is to pay participants no less than the Real Living Wage. For clarity, this is not something that Changing Realities (and Covid Realities) has done to date; participants are instead provided with vouchers and, in some instances, BACS transfers to thank them for their time as participants (see Box 2).

When working with people in receipt of social security it is important to check if being paid money could affect their entitlement to social security benefits (in which case vouchers could be an appropriate alternative). Paying participants recognises the expertise that comes from experience and begins to address the wider inequality in how we value educational or professional expertise over other forms. Paying an hourly rate can be more complex if you are asking participants to carry out a task which does not take a set amount of time (e.g. writing a series of diary entries). In this case, tell participants what they'll receive for their contribution and recommend a maximum amount of time to spend on the task. When deciding your approach consider how it affects who can participate and how it addresses any power differentials; and be open and honest with participants about what they are being offered for their time. Where possible it is also good to give people choices - e.g. some people may prefer to be paid by vouchers whereas others may want to be paid through a bank transfer.

Participants may also incur expenses when taking part in participatory work - e.g. the travel to attend a meeting; the purchase of smart clothes to feel comfortable in a new setting. It is essential that these expenses are funded by those supporting people to participate; and this should happen in advance of the expense being incurred. If a participant does pay upfront for something, it is vital that reimbursement is timely and the process is as straightforward as possible - provide support with this too, as is needed.

Zine page by Ruth



An example of payment structures

Through Covid Realities and Changing Realities we wanted to thank participants for the expertise they contribute to the project – as academic researchers we are financially recognised for our expertise so why shouldn't participants be recognised for theirs? We chose to reimburse participants for their involvement through vouchers to avoid affecting their entitlement to social security benefits. From March 2020 (the start of Covid Realities), participants received £10 worth of vouchers for each month of involvement in the project (which may involve writing a diary entry or responding to one of our 'Big Questions of the Week') and £20 for more intensive involvement, for instance, attending an online discussion group, writing a blog, or speaking to the media, and £5 for small tasks such as responding to a short feedback survey. In April 2023, these amounts were increased to £15 and £30 respectively in response to high rates of inflation; we are grateful to our funder – Ayr Financial Fairness Trust – for allowing this change to happen. These levels are set based on thinking through the expected amount of time each activity would take – e.g. the £30 payment is for involvement in activities generally taking one to two hours, and so is in line with Real Living Wage rates. Despite this we recognise that inequalities remain: members of the project team receive a salary while participants are compensated via vouchers of minimal amounts. We are open about these inequalities with participants and also aspire to develop better practices in the future.

Going beyond the case study

Sometimes, in work with people with lived experiences, a great deal of emphasis is placed on their 'story' – on the powerful account individuals can provide of their life, and what it illustrates about all that is wrong with the status quo. Policymakers, campaigners, the media, and academics all know there is power in the case study, but there is a danger that those with lived experiences are co-opted to tell their story; share their experiences; and then the work of developing proposals for change are left to other 'experts'. This happens a lot, and it is routine to hear a radio set piece introduced with a 'case study', before a 'professional expert' comes on to explain what this means for policy. This undermines and ignores the insight of the lived expert, and the role they can play in crafting solutions and being part of processes of policy change. Truly participatory work counters this. If you invite someone with lived experiences to speak, ask if they would like to share their ideas for change as well as their 'story'. If you are putting together an advisory group for a project; think about the diversity of expertise that you are including to capture lived experiences. And if you are supporting someone to speak to the media, encourage the media contact to involve them in change-based conversations as part of that piece.



5

Continually seek and learn from feedback

Participatory work is often experimental – to incorporate lived experiences into areas where it is often excluded requires us to try new approaches. In the absence of tried and tested methods, we need ways to assess if our approach is working. It is only by creating a space where we can recognise what hasn't worked and own up to our mistakes when things go wrong – which they do – that we can create a participatory project that accommodates a range of participants and that can change as situations shift.

One side of this is creating a team culture that encourages members to share when things go wrong and decide together how to move forward. The other side of this is gathering feedback from participants themselves. This could be through online surveys or group discussions. Whatever the format, it should invite critical feedback as well as advice from participants, take place at regular intervals, and inform participants how their earlier feedback has been acted upon. In doing this, your participatory work becomes a process of continuous learning and improvement.



Creating structures for feedback: Changing Realities participant advisory group

Throughout Covid Realities and Changing Realities we have sought participant feedback on their experience of the project, what works, what needs to change, and what we could do differently. Originally, we did this through online meetings of 20 to 40 participants (which we call 'Big Ideas' sessions) and through short online surveys. Their feedback has been immensely valuable in pushing us to continually change the project so that it better meets the needs of participants.

During the project we realised that our approach was ad hoc and restricted to certain elements of the project. To address this, we established the Participant Advisory Group (PAG), a panel of eight participants who meet monthly to provide constructive feedback on the project. This is a formal volunteer role which is paid at a rate of £60 per session; all Changing Realities participants had the opportunity to apply to be a member of the PAG by submitting a short written statement and the final members were chosen by a colleague independent from the project. Members provide frank, critical, and immensely useful feedback on all aspects of the project as well as acting as a conduit between the wider Changing Realities membership and the project team. As the project team, it is our obligation to make changes in light of the PAG's comments and to feed back to them on changes made.

Support those undertaking this work

Participatory work can be emotionally intensive and ethically complex. It is vital to recognise this complexity, and to create spaces for those supporting participants to debrief, to reflect and to share their experiences of working in this way. Meeting regularly as a team can be beneficial, but so too can creating more informal spaces to reflect, to share and to seek peer support. For example, on Changing Realities we have a shared journal (a Google doc), where we write out and think through difficult experiences. We also take time to talk and think through ethical challenges as and when they occur; for example, how we best support people to participate where they are struggling with mental health challenges; or how to address and resolve dissatisfaction from participants with elements of the project. Ethical challenges run through this work like a stick of rock; and this can be incredibly draining for all involved. Recent initiatives to support those doing this work that we are trialling include clinical group supervision for the project team; and wellbeing days for individual team members after especially intensive participant facing days. Doing participatory work is incredibly rewarding, but it is tough too, and this needs to be recognised.



7

Challenge power dynamics

It is important to keep in mind the power dynamics and imbalances that shape encounters between people coming together and sharing different forms of expertise. If you are working in the space as a 'professional' (perhaps as a campaigner, a researcher or an academic) it is likely that you will hold power, and you need to recognise this and try to soften the power differentials. Keep this at the forefront of your mind when working in participatory ways, and seek creative ways to push back against power differentials. This can be done in quite simple ways - for instance, try and stand back from making decisions without involving the participants that you are working with. Experiment with approaches that you are less confident with - for example, on the Changing Realities project we do a lot of collage and zine making. Many of the participants are incredibly creative, and much more so than the project team, some of whom feel nervous and awkward about sharing their art work. Working in a way that the 'professionals' are less comfortable with softens power dynamics, as does the act of having an external facilitator supporting the session, with the project team and participants working together.

8

Communicate clearly and honestly with participants

In the midst of busy workloads, balancing multiple projects and priorities, it can be hard to communicate well and to keep participants up-to-date about the activities they're working on with you. It's important though to make time to keep participants updated

and to prioritise frankness but also empathy in this communication. If you make a commitment to provide an update to an individual within a particular timeframe, do try and stick to it, and if you're not going to be able to, let them know as soon as possible. And be honest about problems or changes to a plan that has been developed as and when this happens. For example, if someone has agreed to speak to the media but the journalist then decides to go with another person, be upfront about what has happened and why. When communicating with people with lived experiences, don't assume which mode of communication works best for them. Ask them and work with their preferences wherever possible.

It is also important that communication with participants, and participatory work more broadly, is underpinned by the principles of care and reciprocity. When we ask people to share personal things about their own lives (for example in lived experiences work), we should be willing to share things about our own. When people undertake participatory and lived experiences work, they are giving something, and, along with financial remuneration for their time and expertise, they should be treated with care, with respect, and be kept up-to-date about the work as it progresses, even after their involvement ends.

Find out more about the participatory work of **Covid Realities**

<https://covidrealities.org>

and **Changing Realities**

<https://changingrealities.org>

considered; on strike;
extinguished; into the o
ned. * prep out of
h; outside. * adj
d. * n means of escape

adj strange; unco

CLASS



10K
ENGLISH
ONIONS

orthodox *adj* conforming with established behaviour or opinions; not

understanding

WELFARE

stigma

ow v to surpass in growth; to
too large for (clothes); to
ge one's ideas, habits, etc, as
velops.

outlook *n* a view; a prospect; a v
point.

Participatory zine making

Across this toolkit, you'll see several zine pages which have been made by participants and team members taking part in workshops with artist Jean McEwan. Zine making is a really effective way to create informal spaces to come together and create. Most recently, we have used it to reflect on the way we work together. You can find the zines we have made already on our website, where you can also find a guide to using zine making in participatory research. Keep an eye on the website for a new zine focused on the principles of good participatory research coming soon.

<https://changingrealities.org/zines>

want to find out more?

- The University of Durham and The Lune Rivers Trust have produced a toolkit guiding those wishing to conduct participatory research on the key questions to ask. <https://tinyurl.com/2rett2c8>
- Save the Children have created a toolkit for people looking to involve children in research into violence against children; with wider relevance to other work <https://tinyurl.com/3w9mvft4>

- A Guide to Ethical Principles and Practice by the International Collaboration for Participatory Health research provides more information on the ethical considerations when undertaking participatory research. <https://tinyurl.com/2tsr2wsr>

- Jo Aldridge's book (2016) is a really helpful introduction to participatory research - Participatory Research: Working with Vulnerable Groups in Research and Practice. Bristol. Policy Press.

- Sara Kindon, Rachel Pain and Mike Kesby's book (2007) provides a summary of approaches to participatory research: Participatory Action Research Approaches and Methods Connecting People, Participation and Place <https://tinyurl.com/k772rayp>

- The Centre for Future Health at the University of York has produced two guides to co-producing research, one is a reference guide aimed at academic researchers <https://tinyurl.com/rp8ea5p8> - the other is an introduction to some of the key principles and practicalities of co-production aimed at members of the public. <https://tinyurl.com/y3bzwrb>

- Mel Ainscow's seminar considers what participatory research is and discusses some of the possibilities and challenges. <https://tinyurl.com/ytn48v39>

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