



Zine image by Ella. Co-producing policy recommendations with people with lived experience can be more sensitive to what affected individuals actually need and want, picking up things routinely missed in narrower research studies and reports.

# Involving people with lived experiences: the Changing Realities toolkit

**RUTH PATRICK and MADDY POWER**

**When it comes to campaigning, academia, the media and government, whose voices count? Whose expertise do we engage with and listen to in policymaking debates and processes? And what responsibility do charities, think tanks and academics have to make sure that the voices of those they are campaigning for and/or researching are part of the broader conversation for change?**

In recent years, there has been increasing recognition that we need to do more to involve those with the expertise that comes with lived experiences in campaigning, research and policymaking. While this activity is important and valuable, it is certainly not easy. It is common to feel uncertain about it, and to find it difficult to know where to start.

That is why we produced a toolkit, *How to involve lived expertise in research, policy and campaigning*. It provides an overview of key principles to keep in mind when working directly with people with lived experiences; this is sometimes described as taking a participatory or co-produced approach.

## **Co-production = more meaningful, more impactful**

The toolkit draws on our programme work on first Covid Realities and now Changing Realities, a long-term partnership between parents and carers on a low income, researchers and CPAG. In this work, we create opportunities for parents and carers to document their everyday lives and experiences of hardship, but also to work together and with others to push for change. Change-making activities include developing policy recommendations; speaking to parliamentarians and policymakers; and appearing on broadcasts and in print media.

We have also used arts-based approaches (zine making, audio recording sessions, podcasting and writing workshops) to communicate the urgent messages from this work to key audiences. These creative activities are often more meaningful and impactful to the public and participants themselves. You can read a bit more about the work we do on these projects and reflections from a participant herself in Victoria's account of being involved.

## My experiences of participating in Covid Realities and Changing Realities

Hello everyone, my Changing Realities name is Victoria and I've had the good luck to have been a participant of Changing Realities all the way back to 2021 when it was the Covid Realities project. I'm so glad to have been part of these projects, Covid Realities and Changing Realities. Through them 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.

Changing Realities is a unique research project that collects the real lived experiences of low-income families through the unsettled and unsettling economy that we find ourselves in.

They provide me and other participants various ways to engage in the project, including:

- diary entries on the website/app
- answering 'big questions of the week' on the app/website
- regular 'big ideas' zoom meetings that for me often feel more like friends gathering to talk about common interests than stale tense talks or Q&As one might expect from research projects. There's a really relaxed vibe that encourages participation without making us feel self-conscious or unheard.

The project has also grown and developed over the time since it started to include providing workshops on anything from zine making, to animation, to music and audio recording for videos and clips that promote the project and its valuable collection of information. I even 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. So when I say being part of Changing Realities project feels like I'm a valid voice in living history, I do so very literally.

The Changing Realities team takes the time, often in big ideas zooms but we can also email them any time with questions or suggestions, to get feedback from participants and provide opportunities for them through the project. Examples being recently running a workshop on CV building and other workshops on how to talk to news outlets and media. 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.

Additionally, the project provides safe opportunities for participants who wish to talk to news outlets, from quotes for newspapers to being part of live news. With the support of Changing Realities, I've been able to anonymously and safely share my experiences with newspapers and can proudly tell my children that I'm doing what I can to try to make this country better for them. I can't overemphasise how important that feels, the sense of pride and validation I get through this project is worthy of note. And I'm just one voice of the many participants.

And it won't stop here, Changing Realities is a unique and modern take on research that combines quantitative and qualitative research with the human experience, using modern technology that allows for participants from every corner of the country to take part.

Through these programmes, the value of participation has been reinforced to us: it matters and it leads to work that is better and more likely to resonate and have impact with diverse audiences. But why is this?

Working with and valuing the expertise that comes with experience is important in its own right. It is also important because it can serve as a challenge to the misrecognition and disrespect that the individuals with whom we are working so routinely face. For example, parents in poverty are often stigmatised, derided by politicians and stereotyped by the tabloid press. Valuing people's lived experiences of poverty is a vital corrective to this, and those involved often report the advantages that

flow from it, to them as individuals as well as in terms of the broader social and economic impacts that can come about from the work.

Work that includes lived experiences is arguably better work because it can mobilise and lead with really powerful insight into how and why policy change is needed, rooted in experiences of the everyday. This can be vocalised directly by those affected, which can then engage support from diverse audiences including politicians, policymakers, campaigners and broader public audiences. Co-produced policy recommendations can also be more sensitive to what affected individuals actually need and want, picking up things routinely missed in narrower research studies and reports.



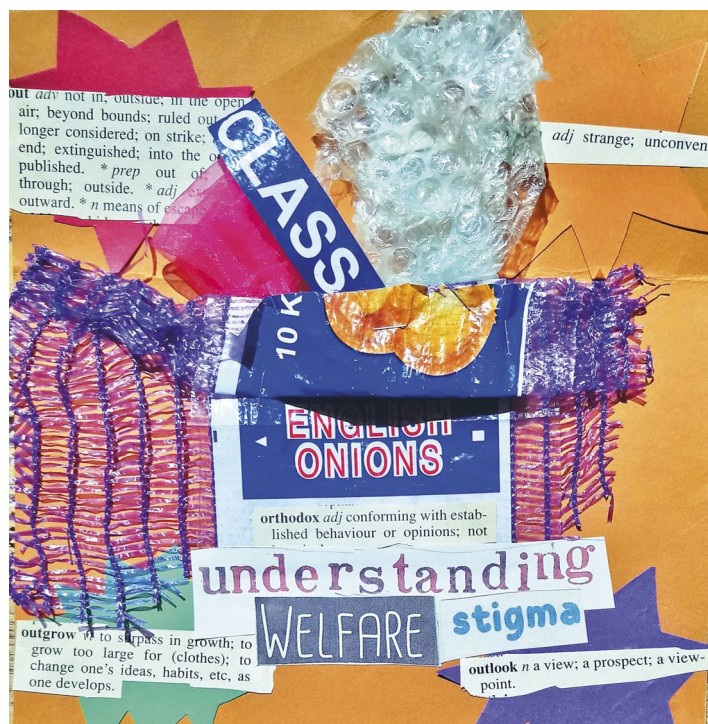
**Valuing people's lived experiences of poverty is a vital corrective to... the misrecognition and disrespect that they so routinely face... Those involved often report the advantages that flow from it, to them as individuals as well as in terms of the broader social and economic impacts that can come about from the work.**

## Recommendations from participants

Here are just a couple of examples from our own recent work. On Changing Realities, we have been working to develop proposals for change that improve employment support services so that these might finally become fit for purpose. Key recommendations from participants themselves included the importance of making sure that those accessing these services have a 'statement of rights', which sets out clearly what they are entitled to expect. This emphasis on rights, and on rebalancing the contract between state and citizen, is significant, but it would not necessarily emerge so strongly from engagement with a narrower range of expertise. Work on Changing Realities has also made abundantly clear how families are struggling with the short-term, temporary forms of support for the cost of living, which are often not very easy to access. By working directly with people in receipt of these types of support, we can better understand the shortcomings of the support – especially, for example, how they embed and entrench insecurity, perhaps by design.

We have witnessed growing recognition of the value and benefits of working in this way. It is undoubtedly heartening to see much greater interest in involving those with lived experiences across different sectors: in campaigning, think tanks, policymaking, academia. While this is a welcome development, it's important that this work is pursued sensitively, and in a way that recognises the resources of time and care that are needed to do it justice. We hope that this toolkit can help with that work.





Zine page by Faith. Creative activities such as zine making are often more meaningful and impactful to the public and participants themselves.

## Top tips

The toolkit includes eight top tips for how to most effectively involve people with lived experiences across a range of activities in policymaking, research and campaigning. We emphasise that we do not always get this right – we are always learning and making mistakes – but we are glad to share some of the key things we have learned from the past three years of working on first Covid Realities and then Changing Realities.

Tips include things like the importance of ‘sweating the small stuff’: recognising that it really matters to make sure that all expenses are covered, that

catering and venues are accessible and welcoming, and that the role of a facilitator should be to focus on these elements, freeing up those with lived experiences to engage with, discuss, explore and propose agendas for change. We also emphasise the importance of recognising the time that it takes to do this work properly. We call for more to be done to support those conducting this work, which can itself be incredibly emotionally intensive and fraught with ethical challenges. We explain how the work we do is underpinned by an ethics of care and of reciprocity, which are feminist principles that apply very strongly to the participatory space. These can provide a really strong guide to how to engage with participants and with colleagues.

Zine page by John W. Changing Realities has run workshops on zine making, animation, music and audio recording for videos.



Zine page by Ruth. Zine making is a really effective way to create informal spaces to come together and create.



## Opening up conversations

Do have a read of the toolkit and share any feedback with us. Are there things that you think are missing or that are wrong? We'd like this toolkit to open up more conversations about both the challenges and the possibilities of working in this way. You can contact us at [changing-realities-project@york.ac.uk](mailto:changing-realities-project@york.ac.uk)

Most of all, we are hopeful for a better, more inclusive future in which different forms of expertise are valued equally and in which those who have historically been marginalised in conversations about change and the future are protagonists in these debates. This toolkit is one of many stepping stones towards that future.

You can read *How to involve lived expertise in research, policy and campaigning: a Changing Realities toolkit* at [changingrealities.org/write-ups/toolkit](http://changingrealities.org/write-ups/toolkit)

A new zine focused on the principles of good participatory research will soon be published at [changingrealities.org/zines](http://changingrealities.org/zines)

The authors are grateful to *abrdn Financial Fairness Trust* for funding *Changing Realities*, and to *Nuffield Foundation* for their funding of *Covid Realities*. Thanks also go to the *ESRC* and the *University of York* for additional support that made the production and dissemination of the toolkit possible, and to *Wellcome Trust* who fund *Maddy Power's* fellowship on food, mental health and power.

Thanks too to all the parents and carers who take part in *Changing Realities*.

*Ruth Patrick* is professor in social policy at the *University of York* and leads the *Changing Realities* programme.

*Maddy Power* is a *Wellcome Trust* research fellow and assistant professor in the *Department of Health Sciences* at the *University of York* and methodological lead on the *Changing Realities* programme.