



The Embodied Everyday
**Ethical approaches to including lived experience in
policymaking**

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Executive summary

Engaging with lived experiences of people at the sharp end of inequalities has become a popular method for improving the analysis and development of policy. Lived experience has come to refer to the different kinds of expertise that a person can bring to research and policymaking based on their personal experience. In a policymaking context, embedding lived experience can ensure that decision making is inclusive and that people are at the heart of policies. However, there are also ethical concerns about the process and outcomes of this work, and reflecting on the ethical practices also needs to be driven by those sharing their experiences.

To explore this, I collaborated with communities in Glasgow and Greater Manchester on a qualitative project aimed at exploring people's everyday experiences of inequality. This involved a steering group of participants collaborating in the research design to decide the focus and the methods for the project. Over the following year and a half, we used online workshops, journals and art packs to write, draw, and collage, and to send voice recordings. Together, we created a visual output called [*Filled to the Brim*](#).

The research found a range of challenges associated with carrying out lived experience research, including:

- extracting information while leaving people and communities with no say over the findings or opportunity to correct where misunderstandings emerged;
- asking people to separate out their experiences into distinct categories which do not reflect the intersecting issues they face;
- failing to recognise the wins and agency of people and their communities, and the impact that 'small wins' may have for them;
- allowing stigma and bias to creep in, reducing people's willingness to share important information.

Including lived experience in policy development does not automatically mean that it is equitable. To ensure that the research process and its outputs are as equitable as possible, I outline several steps practitioners can take to address these challenges, including:

- developing plans for co-produced approaches that focus on people's everyday experiences of inequality that do not separate out or categorise their lives into different issues;

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- ensuring that accommodations are met throughout any work, including providing more time than you think will be required for meetings, and having breaks in the session;
- ensuring that people who have shared their experiences are involved in the interpretation of what they have shared, and where possible part of the fuller process of developing reports, policy recommendations, and outcomes.

Introduction

Engaging with lived experiences of people at the sharp end of inequalities has become a popular method in policymaking and advocacy. Lived experience has come to refer to the different kinds of expertise that a person can bring to research or policymaking based on their personal experience. In a policymaking context, embedding lived experience can ensure that decision-making is inclusive and that people are at the heart of policies.

In 2024, the [Policy Lab](#) launched a '[Lived Experience in Policymaking Guide](#)'. Importantly, this guide highlighted the risks of 'extractive approaches' and noted the need to suspend judgement and give people time to prepare their ideas.

At a regional level, the Greater Manchester Combined Authority engaged with people who have lived experience of gender-based violence as part of the development of their [Gender-Based Violence Strategy](#). They have since also established a Lived Experience Panel to influence policy design and delivery by integrating diverse lived experiences into decision-making processes.

However, there are challenges in working with lived experience, especially as the term has become so commonly used that the processes and expectations can be ambiguous or unclear. It is therefore important to be clear about what is expected in designing and undertaking a process that involves people sharing and listening to lived experiences.

It is important that the co-production which analysts, advocates, and policymakers undertake is equitable and valued *for its own sake*, as well as ensuring that the outputs of co-production provide truly insightful analysis. If the process of sharing lived experiences only focuses on a narrow concern, any subsequent policies could fail to consider how interrelated concerns could impact the effectiveness of that policy. Similarly, if people are not involved in designing how co-production takes place, then even practical details around availability and accessibility of meeting together might be missed out.

Co-production is not automatically equitable

Lived experience is frequently framed as a more 'direct' form of knowledge that lends validity and inclusion to processes of research or policymaking. However, engaging with people's lived experiences and processes of co-production do not automatically make policies and practices more fair or equitable. It can become a demand for people to provide useful and 'authentic' examples, and unequal power dynamics can be reinforced in these processes.

My research with communities experiencing poverty in Glasgow explored the ethics of engaging lived experience for social change. People highlighted how they can end up being stigmatised and shamed in what they are sharing, and that the complexity of their lives can be reduced to 'a good story'. This can play out in several different ways. The key messages they conveyed are listed below.

Life does not fit into neat boxes

- People felt that they were asked to speak to a specific issue, for example food poverty, disability, or racism. These issues often became categories separate to one another, such as discussing homelessness **or** mental health, rather than understanding that people's lives are not lived in such separate boxes. Often it was in open discussions over a cup of tea that important experiences were raised. These discussions started with 'How are you today? How has your week been?'

Risk of extraction

- There is the risk that policymakers and those in positions of power can treat such lived experiences as 'raw data' or evidence to extract and interpret at a distance. Instead, it is imperative to understand that people sharing their experiences are already engaging in the critical work of reflecting and interpreting their lives, including in how and what to share.

Not recognising wins and the agency of the community

- People also spoke about a lack of recognition for how long they had been living with and working to address particular issues of inequality. As such, there was often a lack of recognition for the agency of communities in surviving, caring for one another, and creating change because it might not fit prevailing narratives of inequality.
- Researchers and policymakers might also fail to recognise the 'small wins' in long-term struggles because they would not understand the difference that something small might make in people's lives. This also highlights

questions about who has the power to frame an issue, or to decide what a 'win' looks like.

Judgement creeps in

- In a culture where stigma is so strongly attached to disabled people, people in poverty, and people seeking refuge, they often encounter judgement and dismissal in sharing their experiences.
- For example, for people with chronic, fluctuating, and 'invisible' illnesses this can mean that those listening might dismiss their situation because they perceive them to be 'well enough' to sit and share their experiences.
- People might not be willing to speak about particular experiences if there is a risk that they might be branded a bad parent, not 'contributing' to society, or being bad with money. This means that people may find it difficult to talk about certain aspects of their lives. If there are risks of being re-stigmatised or judged, then being asked to share lived experiences can be something harmful.

Collaborating on everyday experiences of inequality

Recognising these challenges, I collaborated with communities in Glasgow and Greater Manchester on a qualitative project aimed at exploring people's **everyday** experiences of inequality. Focusing on the everyday was a way of understanding how different aspects of inequality overlap and starting from that connectedness of concerns. We reflected on how inequality plays out in people's daily living, but also the day-to-day ways that they are surviving, showing care, and addressing inequality in their lives.

This involved a steering group of participants collaborating in the design of the research to decide the focus and the methods for the project. Over the following year and a half, we used online creative reflection workshops alongside sending people journals and art packs where they could write, draw, collage, or send voice recordings in response to prompts.

At the end of the project, the group decided to showcase the experiences we had explored in the workshops and journals in a way that was anonymous, accessible, and showcased the creativity already expressed in the journals and workshops. We created a visual output: [*Filled to the Brim*](#).

In *Filled to the Brim*, there are a range of different experiences that emerge, from concerns around food, medication, caring for neighbours and family members, being part of community organisations, housing, seeking refuge, healthcare, policing, isolation, grief, making art, restraint in mental healthcare, experiencing racism, legal redress, pain and long-term health conditions, being in nature, money, and education. There's also a lot about what it means to express yourself, share your experiences, and what it means to be sharing and listening with others.

People felt that the process of working together showcased their creativity and the real life 'goings on' in navigating inequality that they have as human beings. This was what they wanted to showcase in *Filled to the Brim*, that inequality is not the defining feature of people's lives, but their care, creativity, and struggle for change - their humanity - is.

As the page below from *Filled to the Brim* states: 'Life is not a static thing'. There are five things that *Filled to the Brim* highlights that are important for engaging with lived experiences in policymaking:

Ethical approaches to including lived experience in policymaking

- Address assumptions about the process of co-production
- Understanding the bigger picture
- Creating inclusive spaces
- Recognising people's agency
- Creative approaches

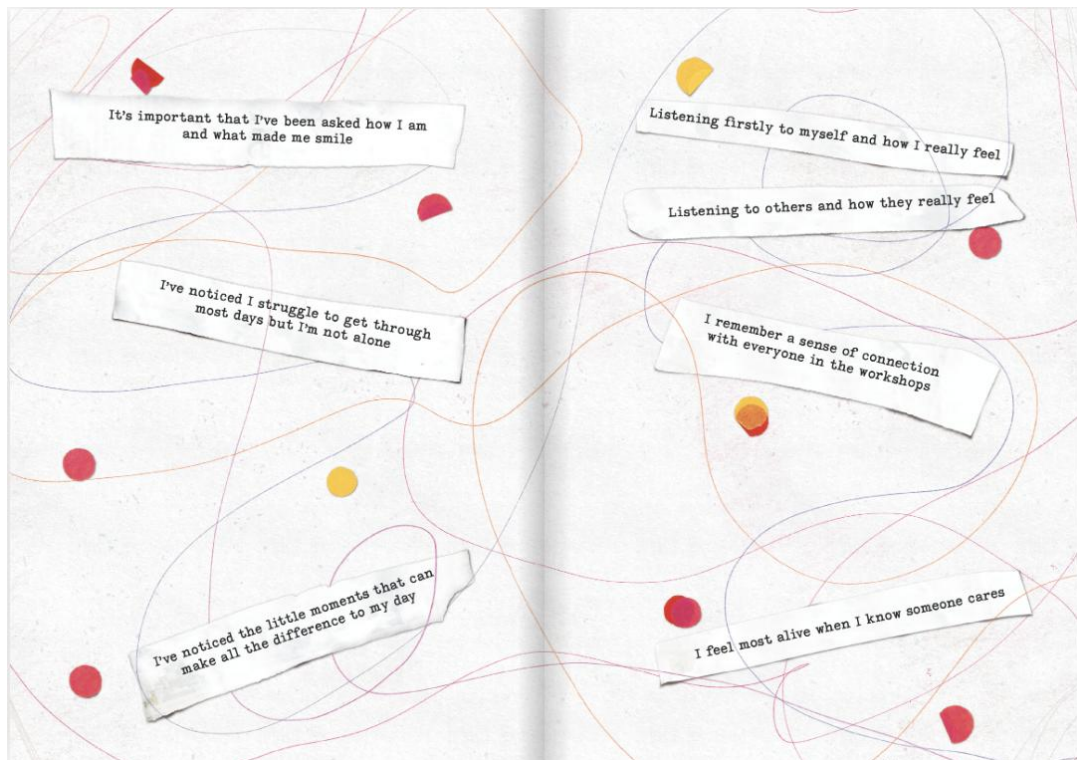
In this report, I discuss these and provide recommendations to embed them when collaborating with people in a policy setting based on their lived experience.



Address assumptions about the process of co-production

People reflected that it was important to have space to reflect and share their experiences without immediately turning their lives into quick action points. They shared their concerns about being misunderstood, judged, and stigmatised even if they explained themselves as clearly as possible.

This page from *Filled to the Brim* shows a person reflecting on the importance of being in process of both sharing and listening, and the importance of making connections. The person notes that being asked 'how I am' made a difference and knowing they are not alone in struggling to get through the day.



Recommendations

In the short-term, policymakers working with people who have lived experience of the policy issue they are discussing should allow time and space for them to reflect and share their experiences, rather than just asking them for solutions.

This might include:

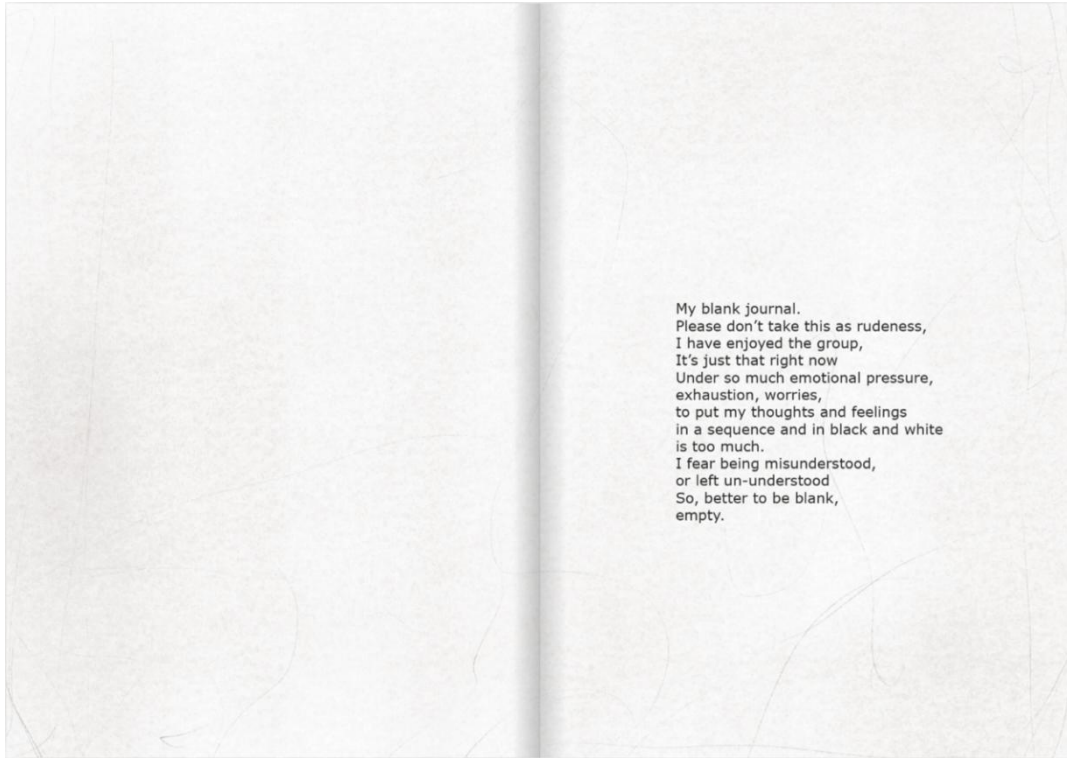
- having at least 20 minutes at the start of meetings to spend time hearing how people are that week;
- planning at least two to three sessions that focus solely on people sharing their experiences before moving to any kind of analysis;
- allowing people time to talk about their experiences; do not rush them or expect them to have (or not have) a particular emotional response.

Policymakers should also plan for people to be part of the full life cycle of research and policymaking.

- Involve people with lived experiences in the design of the co-production. What format will suit people's time and energy levels? How would they want to share their experiences? What does being listened to and respected as part of the process look and feel like for those participating?
- Involve people in the analysis of the issue, ensuring that there can be a shared understanding of how the group's experiences are being framed and interpreted.
- Be transparent about how people's experiences might be used and shared in the process and enabling people to retain control over this. If people might be quoted in a later report, explain this clearly and give them time to review the report and make a decision about the inclusion of their words.
- Where possible, develop alternative outputs designed by and belonging to those participating, alongside any reports of a research or policy nature. This can be something simple that gives more space for people to express what cannot be summarised in a report. Alternatively, partner with community organisations who might be doing this work already.
- Implement processes to follow up and check-in with people, and provide follow up one-to-one support.

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- Ask if what people share in the process of co-production will make a difference to what can be said, published, or acted on about the issue? If not, then reflect on what could be changed, and whether co-production is desired as part of the project.



Another person in the project sent back a blank journal. It was important to recognise this and listen to this too. Talking with the participant, we wrote some short phrases to include as part of 'blank' pages in *Filled to the Brim*, to remember that people can be exhausted and do not have to share their experiences publicly. As they said, and we included in the 'blank' pages: 'I fear being misunderstood or left un-understood'. It is crucial that this experience of being 'un-understood' is recognised as a very real experience for many people.

Understanding the bigger picture

Working with people's everyday experiences and their creativity enabled a way of seeing the connections across different aspects of their life.

One of the reasons that we created *Filled to the Brim* was to showcase the complexity of people's lives in the number of different circumstances they were facing both individually and as a group. This page highlights that for one person, on any given day, they can feel trapped. Yet, on good days the connectedness to others and involvement in taking action on various issues provides challenge and hope - from food poverty groups, to women's support services, to disability benefits consultations, to writing to elected representatives, to book club and connecting with friends.



Recommendations

In the short term, if it is not possible to focus on broader issues that come up within a policy topic, consider how this could be communicated to another project/team, or acknowledged as something to take forward in another process.

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In the longer term, develop plans for co-produced approaches that focus on people's everyday experiences of inequality that do not separate out or categorise their lives into different issues. This would improve understanding of how policies play out in practice in people's everyday lives, making for more effective policy in the longer term. This might involve:

- working with a group of people who have various experiences of inequality and using prompts around people's everyday experiences. This might then be used to enable people to identify key concerns that would set a programme for further discussion and action;
- ensuring that people are encouraged to listen to one another and build relationships so as to recognise differences in experience;
- working with a steering group to review the current processes of engaging with people's lived experiences;
- collaborating with different organisations and community groups to bring people with a range of different experiences together;
- integrating different ways that people can engage with the process, including creative forms where people can write, draw, collage, doodle.

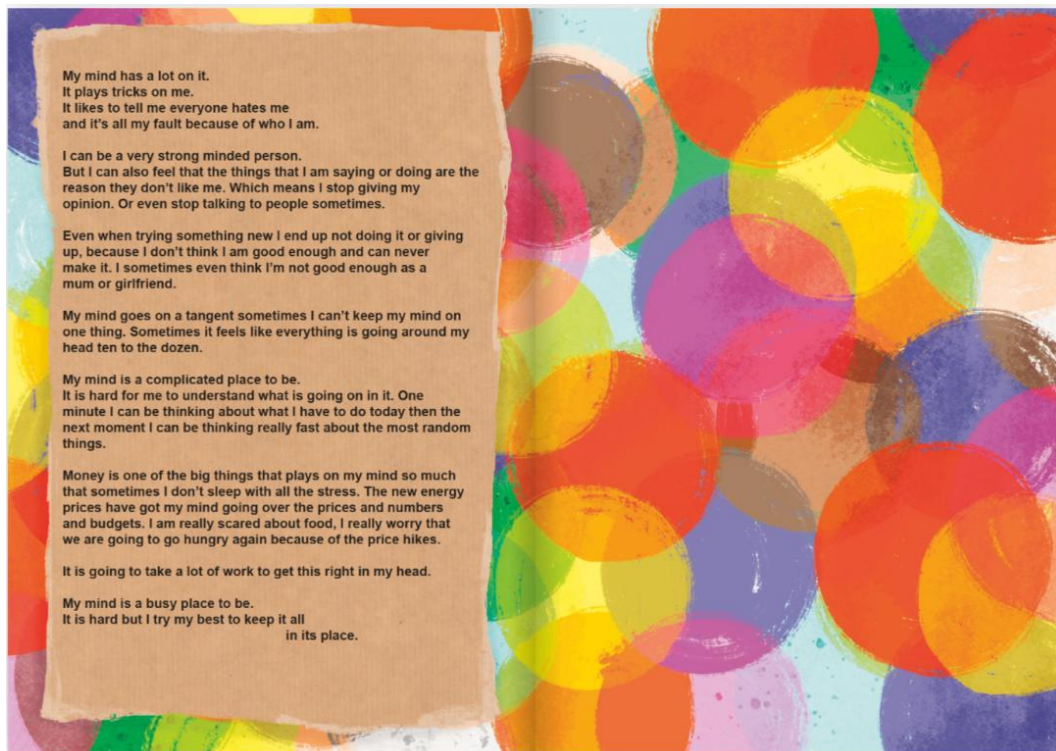
Acknowledging this complexity does not have to be overwhelming or negative, nor does it preclude taking action on specific concerns. This page from *Filled to the Brim* highlights how people feel that the complexity and chaos, like in nature, enables moments of beauty and peacefulness too.



Creating inclusive spaces

In addressing any concerns around inequalities, it is likely that these experiences will also interact with people's experiences of long-term health conditions, stress, disability, and mental health concerns. Even if the meetings are not focused on disability as a topic, it is important to acknowledge how this impacts people's ability to take part. Ahead of any collaborative work, it is important to ask people about any accessibility requirements, but also what would enable them to be comfortable and at ease in taking part.

In the workshops, people reflected on the impact of physical and mental health conditions on how they felt on a daily basis, and the challenges of explaining this and being understood. In their journal, and replicated in *Filled to the Brim*, one person drew images of overlapping circles to explore that their mind 'is a busy place to be', or shared images of clouds to explain how stress and health conditions create brain fog, or abstract shapes with symptoms of how their body feels every day. This highlights that the expectations of staying 'focused' in a meeting might be challenging for some people when they are experiencing a lot of stress and multiple concerns in their life. This also highlights the need to have spaces where people can speak about their everyday life and the different concerns they are facing.



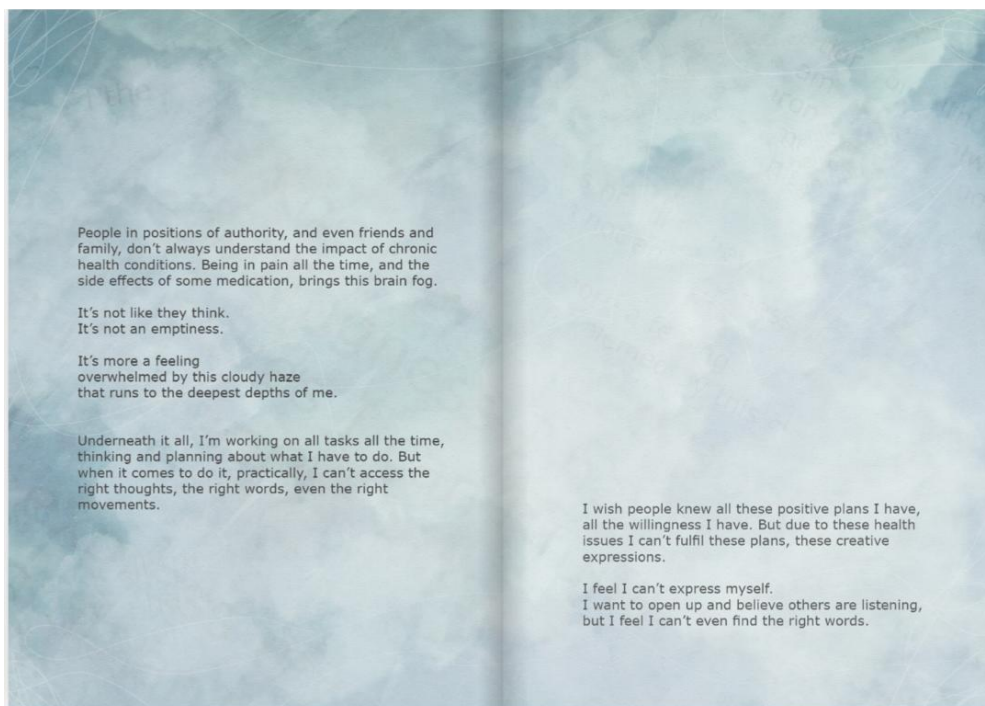
Recommendations

Ensure that accommodations are met throughout any work, including providing more time than you think might be required for meetings, and having plenty of breaks in the sessions. This includes asking people about what will enable them to take part in the best way possible, rather than asking them to disclose any disabilities or health conditions.

Enable people to be in control of how they might share their experiences. This can include providing various ways for people to share and listen, as not everyone feels comfortable responding on the spot or speaking in front of a group. This can include:

- having plenty of paired or smaller group discussions that provide feedback to the wider group;
- giving people time ahead of a meeting to prepare what you will be discussing, and providing a clear plan of the session so people know how to manage their time, energy, and focus;
- asking ahead of sessions how people feel most comfortable contributing and what will support them to feel that their contributions have been heard and valued.

Take time to plan how the process can include being receptive to experiences that are not immediately 'useful' in policymaking but might help deepen your understanding of people's lives.



Recognising people's agency

People created images of the things that make a difference to them and that they do to make a difference to other people. This includes listening and talking with others or taking part in community groups; making bread with their kids; keeping detailed records of their child's educational and medical reports and fighting for their inclusion in education; caring for community gardens and being in nature; taking time to rest; making art; being part of activist movements. Yet, people also shared their sense of exhaustion in trying to make a difference and create change.

This page from *Filled to the Brim* highlights the complexity of the circumstances that people can continue to face, and the impact this can have on their sense of self. It also shows that when people are valued as part of a community who are listening to and sharing with one another and contribute to making a difference it has a wider impact.



Recommendations

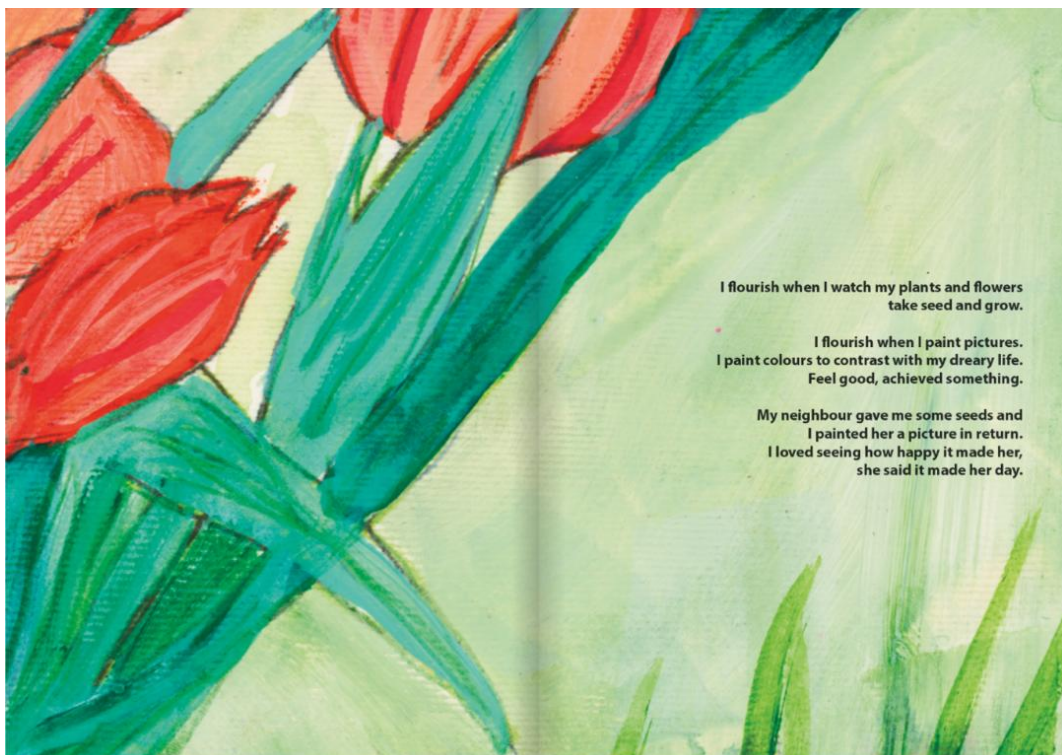
Methods of recognising and respecting people's agencies include:

- building in space to discuss and reflect on what makes a difference in the lives of those taking part;

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- recognising people's agency and the actions they are already taking to try and survive, care for themselves and others, and create change. This can look like:
 - asking people about what has made a difference in their week;
 - asking people about community groups or organisations that they might be involved with already;
 - acknowledging that people are giving up their time and energy to be there;
 - asking people what a positive outcome from these sessions would look like.
- ensuring that people who have shared their experiences are involved in the interpretation of what they have shared, and, where possible, part of the fuller process of developing reports, policy recommendations, and outcomes.

This page from *Filled to the Brim* highlights things like sharing with neighbours, painting and creativity, and gardening are important parts of someone's life, and how they reflect on what is meaningful and important to them in the midst of everything else. The image is taken from a digital scan of one of their paintings. Seeing people as having complex interests and passions enables policymaking to take into account the different ways that people might interact with the practical outcomes of that policy in daily life.



Creative approaches

Engaging with creative forms of expression can be a way for people to explore their experiences in different ways and are particularly relevant for engaging with a focus on everyday experiences. In this project, creative approaches are also important as part of emphasising the agency and interpretation that people are bringing to doing this work. Creativity and imagination are important parts of working for change; being able to imagine that the world could be different and asking, 'what if...?'



Central to this is emphasising that creativity is not about being able to paint something worthy of hanging in a gallery or writing a perfect poem. Creativity is about being attentive to the world and responding to it. Creativity can be the way that you play with your kids or grandkids; it can be making a meal with what's available; it can be taking photos on your phone of what you notice walking around; it can be how you listen to and support other people; it can be putting together an outfit.

Several pages in *Filled to the Brim* are taken from quotes from the workshops, noticing the way that people speak and talk about life has its own sense of creativity and depth. Creativity also involves being able to respond to what someone has shared and offering encouragement.

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Several pages in *Filled to the Brim* reflected the importance of creativity and expression in people's lives, from a page about the expansiveness felt when making art, to a page about making bread with family, to another about painting pictures, to the poem about feeling alive in a community garden that ended up providing the title for *Filled to the Brim*.



Having both the creative journals and the workshops was important – people had a sense of developing their own pieces within the journals, but the workshops provided an important touchpoint for responding to prompts, sharing with and hearing from other people, and being encouraged in what they were creating. In the journals, people could collage, draw, write, doodle, stick in photographs, or they could also send voice recordings. This was important for opening up lots of different ways for people to respond. In the end, all the journals were so different to each other because people had been able not only to provide their perspectives, but *how* they wanted to respond.

Recommendations

- Consider including a range of ways that people can respond in a setting that can suit what they feel most comfortable with.

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- Provide ways that people can work on their own creative pieces, giving time for people to think, play, and respond, rather than needing to know a response to something immediately.
- Collage and zine-making can be brilliant ways of getting started, where there are already images and colourful pieces to select from, arrange, and respond to.
- Setting small prompts can help give a way of focusing while remaining open enough to encourage a range of responses.

Conclusion

Sharing and engaging with people's lived experiences can be powerful and impactful, but it can also reinforce the issues of unequal power and exclusion. It can also be a way of making participation a tokenistic gesture by claiming to know what people's experiences are without addressing the wider structures that maintain inequality.

As this report has addressed, considering the ethical implications of working with lived experiences must be central to the process. Thinking about *how* people are involved in the wider issues of interpreting key issues and imagining change, and how they are valued as part of an ongoing process is an important step. Considerations of time, accessibility, and creative methods working with lived experience can be crucial to addressing these ethical concerns.

About the author

Dr Wren Radford is a Lecturer in Liberal Arts. Their research focuses on engaging in research that addresses the relationship between theology and contemporary socio-economic inequalities. Within the broad field of practical theology, Wren focuses particularly on feminist, disability, queer, and postcolonial approaches that enable a questioning of how power and politics shape theological knowledge.

Wren is interested in collaborative research with marginalised communities and activist groups, exploring their lived experiences and their practices for transforming inequality. In this, methodology and methods questions are particularly vital for Wren, and they enjoy engaging in and reflecting on creative, collaborative, and qualitative approaches.

[View Filled to the Brim here.](#)