

Exploring “community” & the mental health lived experience landscape

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Terminology

This report uses words and phrases that are often used in mental health lived experience work. These terms are evolving and sometimes contested; their definitions are not fixed, and should never be imposed on somebody who chooses different language.

Lived experience

Direct, first hand experience of any particular issue (in contrast to theoretical knowledge about it). In this report, I use the term lived experience to mean those who have direct, first hand experience of mental ill-health, distress, and trauma.

While “lived experience” is a broad and inclusive term, sometimes it can be vague; making it harder to identify differing needs or analyse how power operates among those with “lived experience” and/or intersecting marginalisations.

Lived experience leader(ship)

Lived experience leader refers to people who have lived experience and use this to make change in the world, this could be through their work or activism.

Co-production refers to initiatives or efforts to ensure that people likely to be affected by decisions are involved in making them. The term co-production is often used interchangeably with other terms such as (service) user involvement, or patient and public involvement.

Mental ill-health, distress, and trauma

This phrase is often used by NSUN as opposed to talking about “mental illness”, in recognition of the different ways people may understand or describe their experiences and identities in relation to mental health. Throughout this report, I use the term ‘mental ill-health’ as a shorthand to encompass mental ill-health, distress, and trauma.

Mad/madness

The terms 'mad', 'madness', and 'mad people' are often used by those in the psychiatric survivor movement. The purpose of this is to reclaim the term 'madness' which has historically been weaponised against those experiencing mental/emotional distress.

User-led group

A user-led group is one that is led by and for people with lived experience of the issues they work around. For example, a group working for the rights of sex workers led by sex workers, or a group for people who self-harm led by those with experience of it.



Artwork by **Hat Porter**. You can [find Hat on Twitter at @hat_tea](#)

Image description: Photograph of quilted artwork, hanging on a cream wall. The quilt is square and made from cream coloured hospital gowns with "for hospital use only" printed in small blue and yellow text . The quilt is bordered in light yellow fabric. Embroidered onto the quilt are the words "nothing about us without us" in dark blue, all caps; the fabric for this text is made from hospital scrubs.

Introduction

“Community” is a big word. It is often used, but also very hard to define. The same is true for the term “lived experience”. The aim of this research is to explore what each of these words mean in relation to each other, including some of the complexities of talking about “community” when thinking about “lived experience”.

There have been many attempts over the years to bring people with experience of mental ill-health, distress, or trauma together into a unified or collective movement. Despite this work, **there is no single “community” of people with lived experience;** instead there are many of us identifying and using our experience to make the world a better place, often with different visions and tactics for what needs to be done.

Still, there is an appetite and a need — perhaps more than ever — for community-building and collective action led by people with lived experience. **We must be able to think seriously about what it means to claim or build community; including how people can be harmed, who is being left behind, and how the term can be co-opted for interests other than our own.**

About the project

This report is built on the outcomes of a survey, interviews, and focus groups with people who identify as having lived experience of mental-ill health, distress, or trauma (conducted August–November 2023).

The aim of this research was to learn more about how people understand or use the term “community” in different places or parts of their lives, including its limits and its possibilities as a term.

Key questions explored as part of this project include:

- **What does it mean to try and build solidarity and collective action among those with lived experience of mental ill-health, distress, or trauma?**
- **How is community assumed, implied, or forced upon us?**

Please note: to open hyperlinks within this report when viewing it in a browser, please right-click on the hyperlinked text (bold, underlined) and select “open in new tab”.

Who is this report for?

This report is intended for a wide audience, in the context of rising interest in talking about, engaging and co-producing with, representing, researching, and funding communities who have shared lived experiences of mental ill-health, distress or trauma.

While the report has a focus on a mental health context, it also considers related and adjacent conceptualisations of community based in other shared identities and experiences of marginalisation.

It may be of interest to **anyone keen to explore some of the benefits, complexities and challenges of talking about and building “community”** and broaden their understanding of what the term might mean to people. It is ultimately intended to inform and challenge work focussed on engaging communities and lived experience.

It may be of particular interest to the following groups:

- **People with lived experience** of mental ill-health, distress, and trauma who are interested in the concept of what gets called the survivor/service user “community”, whether they have or have not felt part of it, or work to represent it.
- **People involved in wider, community-based work, activism or campaigning** who are interested in the complexities of uniting people in or of representing communities with a collective voice.
- **Mental health charities**, especially those carrying out projects, campaigns and research that seeks to represent, build, or engage communities, particularly a/the “lived experience community”.
- **Mental health researchers/research institutions**, especially those who seek to engage, draw from, and represent the views and experiences of particular communities with shared lived experiences.
- **People with peer, lived experience, and/or professional roles** in mental health services/the NHS.
- **Funders of community groups**, initiatives and projects relating to mental health and lived experience.
- **Policy-makers** interested in engaging communities and people with lived experience in mental health related policy.

Key findings

Defining community

“Community” is hard to define. When asked, it became clear that participants in this project meant different things by the term. Community could mean a group you feel aligned with, those who support you, a group you’ve been told you’re part of, or a space that felt painful to be in. Some people valued community, others felt ambivalent. Some people had negative experiences or felt harmed by community.

People valued being able to be part of lots of different communities, allowing them to be different people in different spaces. More importantly, people valued being able to self-define what communities they were in (rather than being told they were part of a group they didn’t feel or want to be part of). **Categorising people as part of broad communities they do not identify with can be painful and alienating.**

A focus on “community” can sometimes take a single-issue approach, invisibilising intersectional experiences of multiple marginalisation. There may be value in exploring smaller communities, which are sometimes viewed as most valuable by people within them.

Lived experience

Lived experience is a broad term. Its breadth allows lots of different people to feel part of something. However, **the breadth can also make it difficult to identify differing needs among those with lived experience.** It can also individualise and sanitise conversations around mental health; stripping us of the ability to engage with the politics of mental ill-health, distress, or trauma. As one participant put it: *“the pursuit of inclusivity can inadvertently erode solidarity”*.

Lived experience is also a vague term. It allows people to identify their experiences without having to make specific disclosures. However, the vagueness can also mean that those with power can claim to have involved “lived experience voices” without specifying how or what experiences those people had. **The vagueness of the term “lived experience” can be used to rubber stamp interests that are not our own.**

Despite hearing more from people with “lived experience”, **there are still voices we do not hear much from**, particularly those with so-called “severe mental illness”, or people who are incarcerated (whether in prison or psychiatric facilities). The breadth and vagueness of the term “lived experience” may contribute to this. While inclusive, using “lived experience” as a catch-all category can make it harder to identify differing needs or analyse how power operates among those with “lived experience”. **Failing to engage with the politics of lived experience can keep power in place.**

The lived experience “community”

Lived experience can refer to a shared *experience* or shared *politics*. It is not clear that those with shared experiences are a “community”, whereas those with shared politics might be.

Not everyone is willing or able to describe themselves as “someone with lived experience”. **Many people are excluded from identifying as having lived experience — particularly those whose experiences are criminalised, or for whom making a disclosure would be dangerous.**

It can be difficult to stay part of the lived experience “community”. This includes the toll of witnessing others’ pain, or having to be/stay in a particular relationship to our distress. **It is important that we have or are given space to be something other than someone with lived experience.**

It is also hard to keep faith in doing lived experience work, particularly as it is undervalued and underfunded, and we often work hard for marginal gains.

Tensions can arise between different individuals/groups doing “lived experience” work; often this comes from differing views on what needs to be done (reformist versus abolitionist approaches), and a lack of resources which can lead us to fight over scraps. **Tensions within the movement are exacerbated by funding criteria which miss the specificity of our work, and are most likely to under resource groups doing liberatory organising, or facing multiple minoritisations.**

Uses of the term “community”: specificity, co-option, and co-production

Community can be a powerful term in grassroots work, particularly when trying to create a collective voice or highlight issues that face most of us. However, we must be careful not to lose specificity.

Community could include those we feel aligned with, accountable to, or those whom we hope our work would benefit. **In order to evaluate the efficacy of our organising, it is important to get clear on what we mean when we use the term “community”.**

In mental health, **the term “community” is often used as a synonym for “not in hospital”.** While this paints a rosy vision of life not-in-hospital, it can also be used to reject responsibility for care, and assumes that people have either a home or support to return to.

The term “community” can be co-opted for interests other than our own. “Community” can be used by the powers that be to make minoritised groups responsible for keeping each other well, including celebrating communities of necessity. **While this work can be life affirming; many of us would rather not have to be doing it all.**

Those running co-production initiatives can capitalise on the breadth of the term “lived experience”; cherry-picking people they involve to tick a box of having involved “the community”.

This can also include extractive approaches to “storytelling”: asking people to share vulnerable stories from their lives without payment, promise of change, or consideration of how this may impact people.

Too little attention is paid to the ways in which “co-production” or “telling your story” can be harmful to people with lived experience.

What next?

There are important nuances with the language of “community” and “lived experience” that are often overlooked.

At the end of the report we offer suggestions for what might happen next; these are not straightforward. While there are some practical changes that could be made (like changing language or practice), there are no simple catch-all fixes.

This is complex and ongoing work. Because of this, our suggestions largely offer opportunities for reflection.

Some things we would like to see are:

- **Less glamorising of “community”.** More consideration and specificity is required when using the term “community”; particularly how it can be used to homogenise groups, or to make them responsible for rectifying structural issues.
- **More space for those with so-called “severe mental illness”,** ongoing/current (rather than historical) distress, and multiple minoritisations to participate in lived experience spaces. This includes looking seriously at how and why people are currently excluded, and whose interests this serves.
- **More engagement with the politics of claiming “lived experience”.** While the breadth and vagueness can be inclusive and anonymising, it can also erode solidarity and make it difficult to identify or prioritise differing needs.
- **Increased recognition of the toll lived experience work takes** on people, including experiences of being in community with one another, the emotional labour it takes to stay a part of, and how easy it is to become disillusioned.

Background

What is “community”?

Despite widespread use of the term, there is no single definition of the term “community”, nor is there work engaging with the complexities of claiming or using it as a term.

Research on “community” tends to point to some sense of sharedness; this might include where people live, their values, their interests, or the work they do. Research suggests that people in stable housing or employment are more likely to say they feel part of a community than those who live more precarious lives ([Centre for Social Justice, 2021](#)). Whereas the idea of “strengthening communities” sounds good on paper, it is often used to serve interests other than our own e.g. government policy discussing the value of communities as “fundamental to our nation’s wellbeing and prosperity” in creating “more efficient labour markets” ([Ministry of Housing, Communities, and Government, 2019](#)).

While many in the third sector and/or grassroots groups use the term “community”, there is little discussion as to what this means, nor the complexities of what it means to claim community or act on behalf of one. I have found many instances of people using the term community, and none that explain what they mean by one. This is not unique to the mental health context: we often see terms such as the “LGBTQ+ community”, “BIPOC community”, or “migrant community”. **What does “community” mean in these contexts? Are there things that are worth (re)considering?**

Community and mental health

Mental health is entangled with “community” in complex ways. The systems and structures that produce and maintain madness and distress — such as capitalism, white supremacy, and patriarchy — serve to split us off from our communities, leaving us isolated and alone. Isolation can lead us to suffer, which can both induce and exacerbate experiences of mental ill-health, distress, or trauma.

While it is often claimed that communities are good for wellbeing, madness *itself* can cut us off from our communities. The “community” is not always a safe or welcoming place for the so-called “mentally ill”. **The limits of community, including how it can be harmful or isolating, are scarcely recognised.**

While much effort in recent years has been put toward mental health awareness raising, this can present a picture that all people with a particular diagnosis or experience think or feel the same. This can create a false sense of “community”, or an assumption that those of us with lived experience should or could feel like a “community”. It can also suggest that distress could be solved if we were better at having conversations, and that what we need is to bust stigma.

An analysis of mental health without an analysis of politics strips us of our ability to see different needs, and to understand how distress and “care” are experienced differently in different lives. For example, why Black people are four times more likely to be detained under the Mental Health Act, while those with so-called “mental illness” receive on average £8,400 less annual income and live 15–20 years less than those without. Mental health is clearly political.

Without engaging with issues surrounding power, uses of the term “community” can work to individualise issues surrounding mental ill-health; it can make minoritised groups responsible for their own/each other’s wellbeing, and it can be a way of avoiding having conversations about the systematic issues that produce and maintain distress.

Lived experience

In the context of mental health, lived experience refers to anyone with direct, personal, first-hand experience of mental ill-health, distress, or trauma. For a long time people with lived experience have been resisting oppressive practices taken in the name of “healthcare”, including fighting punitive forms of “care”, or building alternative ways of supporting each other. A helpful history of the ex-patient/survivor movement can be found in Jan Wallcraft’s 2003 report, *On Our Own Terms*.

“From the acts of resistance in early asylums to the radical ex-patient/survivor groups of the 70s – activism, peer support and community organising are some of the key threads woven throughout our history”.

Rai Waddingham, 2021. Mapping the Lived Experience Landscape in Mental Health.

In some senses, those with lived experience have worked and acted as a community by taking care of one other and raising a collective voice. At the same time, it is essential to interrogate lived experience work, and particularly to ask which voices are sounding the loudest, and why. The mental health lived experience landscape is dominated by the voices of white, middle-class, cis-het-passing, articulate, university educated folk. This may be less true within radical survivor/mad activist spaces, but is still the case. **In claiming “community”, who is left behind?**

In recent years there has been an increase in the use of the term “lived experience” among organisations that hold power: within policy, NHS services, or large mental health charities/not-for-profits. Part of this has involved increased “co-production”

initiatives in which people with lived experience are involved in designing and delivering mental health services and research. It is also, in some part, inspired by a belief that “the community” should have a say on things that affect their lives. This is, of course, a welcome step.

Despite wins, co-production initiatives are widely critiqued. “Co-production” is often tokenistic and harmful (e.g. [Wells, 2023](#); [Hart, 2022](#)), exclusionary of those already monitored (e.g. Deaf and disabled people, see: [Batty, Humphrey, and Meakin, 2022](#)), and run by those in power with no promise or potential for change. We are invited to be a critical friend, but nothing changes. **While we have asserted our right to be in the room, we must now ask: on what terms?** What is the value of a seat at someone else's table?

Those who do use their lived experience to advocate for change face many barriers. We are also often tokenised, under-resourced, and underpaid. We can also be promised the world, and see little by way of change. **“Failure” in this work takes a double toll: in our work we are not only advocating for others, we are also advocating for ourselves.** The complexities of what it means to be a lived experience leader in mental health are outlined in detail by [a piece of research by Rai Waddingham \(2021\)](#).

“The critical friend often has the burden of representation thrust upon them, of the marginalised identity or community they are deemed to embody at the table [. . .]. The reality is that positioning me or my organisation in this way only reinforces existing hierarchies and dynamics. My ‘telling truth to power’ does not change anything. The power in the room ‘welcomes the challenge’ and continues doing what it was doing before.”

Akiko Hart, 2022. [I am not your critical friend.](#)

While we may share some experiences, not all people with lived experience agree on what needs to be done. Some focus on reforming the current system, others want to tear it down entirely. This could broadly be defined as a tension between reformist (changing the current system) and abolitionist (build alternatives) approaches.

This can and has caused tension between different groups within mental health and broader health justice organising (a helpful analysis of the Health Justice Movement can be found in [this \(2021\) research led by the New Economy Organisers Network](#)). At the same time, **friction can be productive as we embark on the collective project of**

working for mental health justice, taking seriously how issues of power and coercion also arise within our social movements.

Tensions within the lived experience “movement” can be made worse by **funding criteria and agendas, which set us in competition with each other**. The funding that does exist is almost always outcome-driven and focuses on funding project costs rather than the work it takes to keep a group going (see: [Ruairi White, Amy Wells, and Haneen Hammou \(2022\) on the challenges of funding grassroots mental health work](#)). But it is hard to quantify outcomes when we are trying to imagine a new world, meaning that those most likely to get funding are groups who are working on easy to understand and readily-quantifiable projects.

Methods

The purpose of this research is to:

- Explore how people with lived experience of mental ill-health, distress, and trauma understand and experience “community”.
- Understand some of the complexities of using the term “community”.

I explored these aims in various ways: through research, a survey, interviews, and a focus group. I ran the “data collection” part of the research from August–November 2023. In total this project had 81 participants. As well as more formal “research”, this work is informed by a set of informal conversations with people working across the mental health and health justice movements. It also rests on my experience of working within the survivor movement.

Data

Research: I began by reading a collection of relevant reports, research, and blog posts surrounding community and health justice work. They are quoted throughout the report. The purpose of this was to learn about what was already known.

Survey (73 respondents): When I had finished reading, I hosted a survey on Google Forms which was advertised on NSUN’s Twitter and within their members’ bulletin. The survey asked questions in three parts: one about participants’ lives and identities, another about their definitions of “community”, and finally about whether they felt there was a mental health lived experience “movement”. All questions were open-ended and optional. The purpose of this was to get a broad sense of how people understood the term “community”.

Focus groups (3 participants): The focus group acted like an advisory or working group for the project. These were people I had worked with before, and invited to take part in the group. We met twice across the project: once at the beginning, and once toward the end. This was a space for group discussion around the aims and insights of the research. Each of these participants could be described as “lived experience leaders” (though, we agreed that we weren’t keen on that term).

Interviews (5 participants): Finally, I held 5 interviews with people working across the mental health lived experience world, whether in community organising, research, or policy. These were acquaintances I had met through lived experience work, or were recommended to me by other participants. These conversations focussed on how people saw the term “community” used in their contexts.

Analysis: Once I’d completed an interview/focus group, I spent time reflecting on the key points: what I felt was important, what I’d learned, and how it connected to the reading I had done. I did the same with the survey, as an entire data set. The second focus group was an opportunity for me to discuss and think about these insights. From there, I developed them into themes, asking myself what it felt important to say, and what I hadn’t seen written about elsewhere.

Research ethics

- Interview and focus group participants were paid for their time.
- All participants were anonymous by default (unless they chose otherwise). Participants were also offered the option to be included in the list of contributors.
- All participants were given clear information about what the project involved, and what would happen with the insights they shared.
- Many people shared vulnerably about their experiences of mental ill-health, distress, or trauma. While they make for “good quotes”, I have omitted them from the research report.
- All interview and focus group participants were sent a draft of the report to check they were happy with how they had been quoted, and to offer their feedback. To the best of my ability I have integrated these comments.

Participant demographics

All participants were invited to fill out a form involving demographic data such as age, disability status, religious and/or spiritual practice, class, gender identity, and location. Not all participants filled out these questions. Some filled out none, some left only a few blank.

- Lived experience: 99% of participants had lived experience of mental ill-health, distress, or trauma.

- **Disability status:** 89% identified as having a disability. 19% had a combination of mental health problems, physical disabilities, and were neurodivergent. 18% listed a single cause of their disability. 14% were neurodivergent.
- **Age:** 66% of participants were over 40 years old. 18% were 31–40. 16% were aged 18–30.
- **Race/ethnicity:** 87% of survey respondents were white. Of those who were not white, 8% were “other” (including British, English and ‘human being’), 4% dual heritage/mixed (including mixed white/Asian and mixed European), and 1% were Black British.
- **Religious/spiritual practice:** 61% did not have a religious or spiritual practice. Of those who did have a spiritual practice: 11% were Christian, 8% Catholic, 5% Pagan, 3% Buddhist, 3% Muslim.
- **Gender identity:** 70% identified as female. 13% were male, 3% transmasculine, 8% non-binary, 3% said ‘none’/they did not believe in gender.
- **Sexuality:** 48% were heterosexual. 21% bisexual, 11% queer, 7% asexual, 3% lesbian, 3% gay. 7% answered something else (including ‘none’, ‘irrelevant’, and ‘prefer not to answer’).
- **Geography/region:** 90% lived in England. 44% lived in South England (including 11% London, 14% South East/East Anglia, and 14% South West). 22% lived in the Midlands, 15% lived in the North of England. 6% lived in Scotland, 1% lived in Wales, 2% lived in Ireland (both Northern and Republic of).
- **Class:** 43% of respondents were middle class. 6% described themselves as under/lower class, 26% working class, 12% something different including ‘collateral damage class’, ‘professional’, or ‘unemployed’.

Participant quotes

I have quoted participants throughout the findings sections. Longer quotes from participants are included in text boxes and are, where possible, quoted verbatim. Shorter quotes are in-text, in single speech marks and in coloured text.

In some instances I have used an ellipsis (“[. . .]”) to indicate that I have cut out a portion of the text for the purpose of brevity. Elsewhere I have used square brackets ([]) to add information to help the quote make sense in a written context, or to redact and replace a specific information to ensure a participant remains anonymous (e.g. NSUN could be replaced with [mental health charity], or Courtney replaced with [my colleague]).

Findings

Part 1: Defining & experiencing “community”: Who? What? Where?

This section focuses on people’s experiences of community: both what a definition of “community” might be, which they feel a part of (or not) and why.

Learnings

- Despite being used a lot, the term “community” is difficult to define; people often mean lots of different things by it.
- People are part of lots of different overlapping communities in various different places. There is value to being able to switch between different communities, and bring different parts of ourselves out in different places.
- While communities can be a source of support, they can also be harmful.
- People are often told they are part of a community in ways that feel disempowering and harmful.
- We must be careful about the way we use the term “community”, particularly when we are assuming that people feel like they belong to a particular group or should be responsible for supporting one another.

1.1 Defining Community

There was no single definition of “community” communicated by respondents. Actually, people found it quite hard to define. Overall, there was a sense of something shared. Some felt they were part of no community at all, some felt parts of lots, others wanted to be in community but found it harmful.

“Community is something which excludes me.”

Survey respondent

Most people defined a community as a group of people who have something in common such as shared experiences, interests, and identities.

Some people focussed less on shared attributes and instead shared purposes, such as achieving a political goal, being part of an activist group, or being part of the same religion.

A popular definition of community went beyond shared attributes or goals but instead what it feels like to be a part of one: **a group in which there is a sense of belonging or safety, where you do not have to explain yourself.** By this definition, a community could also be any group of people that support each other.

“Community to me means having a sense of belonging, feeling safe, non-judged, accepted and included. Having mutual interests and support for one another.”

Survey respondent

Some people went a little further than simply feeling safe or supported, and instead spoke about a community as a group of people to whom they felt accountable or responsible to, in some way.

“The way I'm using it [the term community], what I'm trying to describe to people often is accountability. I'm not trying to talk about population groups, and try to talk about like, who do I personally feel accountable to? And like, who do I imagine as being the people to whom my work has to stand up?”

Interview participant

There were **different types of community.** Those you felt part of, and those you trusted. Both could be considered a “community”, but each may be easier (or more difficult) to be a part of, and serve different purposes in people’s lives.

“I can have an obligation to a wide range of people. And I can feel a commitment to them. And I can feel like we're working towards shared aims, and have shared beliefs. And I can wish them well, and want to do a good job for and on behalf. And that's one sense of community. The other sense of community is people I trust, that's very small, that's quite different”.

Interview participant

What communities do people feel part of?

Part of the survey involved asking people what communities they felt part of, if at all. Those who did feel part of a community felt a part of lots of different types of “community”. For example, some people felt that they were a part of identity-based communities (e.g. ‘working class community’, ‘domestic abuse survivors’, ‘autistic people’, ‘mental health community’, ‘migrant community’, ‘neurodivergent’, ‘Muslim community’, ‘fat’, ‘single moms’, ‘Pagan’, ‘disabled’).

Others felt they were part of communities that came together around a shared purpose, interest, or activity (e.g., *'the running community', 'parish council', 'musicians', 'church', 'work colleagues', 'the team i work with at my local food bank', 'tech worker community', 'international student[s]', 'writers', 'red squirrel conservation group'*). One person felt part of the community *'cats'*.

Some felt part of non-specific communities of **people who share their values**. For example, *'a network of people who share similar values and interests relating to environmental issues', 'compassionate activists', 'left wing political community', 'political activists'*.

Many people felt part of **mental health specific communities**. Some of these communities were based on support (e.g., weekly online meet ups *'with other people who have experienced psychosis', 'a private and confidential peer to peer support group', 'an art studio who support people with their mental health'*).

Others identified more broadly with **other people who had experience of mental ill-health, distress, and trauma** (e.g., *'families bereaved by suicide', 'mental health service user community', 'lived experience workers', 'survivor researchers', 'mental health sufferers', 'mental health survivor community'*).

Some people did not feel part of broad communities, and instead spoke about **smaller groups**, usually made up of friends and/or family. One participant referred to these as *'micro communities'*.

While there is a tendency to use the term “community” to refer to broad collectives, **in some instances it is the smallness of a community that makes it valuable.**

“And I think that's where, for me over the years, community, just as a concept is much more meaningful, because community can be something so small, it can just be you and your five friends, that's your community.”

Focus group participant

Where do communities happen?

Despite a focus within policy and funding criteria on local communities, locality was one of the least important factors in people's sense of community. Instead, communities could be built online, or in groups that come together in certain spaces but live in lots of different places.

Many spoke about communities they felt part of online. In some ways, online communities were easier to access: you can be anonymous, they are “open” 24/7, and are easier to join if you have difficulty getting out or being in in-person social spaces. There was also some sense that online communities are easier to leave.

“Well 500 years ago, community really was, it was space, it was the people you knew, and knew the people who lived next door. I mean, that's an exaggeration and a simplification of a complex historical moment, but you know what I mean. And now that's not true at all. And so it's much easier for people to pull out of community. But it's also much easier to have meaningful community, with the people you really want to be in community with, but not stuck being in community”.

Interview participant

1.2 What matters most: Ownership, multiplicity, and acknowledging harm.

Learnings

- Being in “community” is not always a positive experience; many people are excluded from or may feel harmed by community.
- People do not value being told they are part of a community.
- There is value to being part of multiple, overlapping communities that allow you to be different versions of yourself in different spaces.

Ownership and self-definition

There are many ways in which gatekeeping plays out in “communities”, particularly boundaries that allow some people to be included and others excluded. Many people spoke about gatekeeping; the way that they are viewed as not part of a community or excluded from it. For example, one participant spoke to me about the “LGBTQIA+” community and how, as an asexual person, they feel on the fringes or excluded from the broader queer movement.

At the same time, many explained to me the discomfort with being told they are part of a community, and the ways in which ‘it becomes quite easy for people to conflate “community” with a homogenous group’.

“I am queer, and do feel in community with my queer friends, but I don't necessarily think it's helpful to group all queer/LGBTQ+ people together in one community, as we all have different experiences of how our queerness relates to our identity, and how we experience marginalisation and discrimination. I use the word Mad to describe myself, and do feel in community with some others online with lived experience of mental distress, but it does not feel like one community of all people with lived experience, because within that there are people with very different experiences and wants”.

Survey respondent

“So kind of, yeah, I, we can often get kind of, because of others, and their kind of judgments and assumptions can be assumed to be part of maybe communities that we don't necessarily identify with, or, or whatever else, and that people can often like, kind of just put us in that “community” box”.

Focus group participant

Another participant reflected on how top-down definitions of community may come about, linking it to trends in using data to design/evaluate services.

“I think, especially when we're thinking about mainstream organisations and services and statutory services [. . .] I think, from their perspective, they feel it is sort of like evidence led, as well. So just because data shows, I don't know, sort of using demographic or socioeconomic data to decide what communities are in a way, if that sort of makes sense. And those characteristics may be important for people but it doesn't mean that defines community for them”.

Interview participant

Kaleidoscopic selves: multiple, overlapping communities

One participant told me that while they were someone with lived experience, they were also someone who loved video gaming. It was important to them to be able to not simply be seen as someone with “lived experience”. Sometimes they didn't want to disclose, discuss, or be in relation to their lived experience; they just wanted to be a gamer. It was helpful then, to have the space to foreground certain bits of themselves in different spaces.

“It's a really nice thing to know that you can have a different sense of community, and they all have each meaning and you have different identities, right? And you can be different people in one given day”.

Focus group participant

Inclusion and acknowledging harm

While “community” is often used as a positive term, many highlighted to me the harm that can be done by or within communities. In part, this was linked to exclusion; that many people had experiences of feeling excluded from “community”, or like parts of their identities/experiences were not welcome or understood in “community” spaces.

For example, when asked about what gets in the way of feeling part of a community, survey responses included ‘transphobic attitudes or trans-hostile organising arrangements (e.g. venues where I can't comfortably use a bathroom)’, and ‘formal Covid protections being taken away’.

Others noted that it can be emotionally taxing to try access “community”. can be painful. For example, participants spoke about being ‘*overwhelmed by humans*’, ‘*agoraphobia*’, and ‘*lacking trust*’.

“Sometimes it's hard to be near lots of other people with the same problems as me, as I pick up their emotions and it can trigger my panic, depression or worry”.

Survey respondent

Interestingly, many participants also noted **financial barriers to being part of a community**, for example having to pay to attend or get to events. Future research may explore how financial issues, particularly the impact of austerity and the cost of living crisis, impact people’s experiences of/access to community.

Part 2: The lived experience “community”: Inclusivity, politics, and power.

This section explores the definition of “lived experience”, including what it is good for, and the ways that it can be used to keep power in place.

2.1 Defining lived experience

Learnings

- Lived experience is a broad term that is hard to define. This can be inclusive but also make it difficult to identify and prioritise differing needs.
- There is no one lived experience “community”; we have many overlapping experiences and needs. One of us cannot speak for all of us.
- Lived experience can refer to a shared experience, or shared politics. Sometimes the two are in tension with each other.
- Despite hearing more from people with “lived experience”, there are still voices we do not hear much from; particularly those with so-called “severe mental illness”, or people who are incarcerated (whether in prison or psychiatric facilities).

One of the difficulties when thinking about whether there is a “lived experience community” is that lived experience as a term is also very broad. Despite widespread use across ‘social purpose work’, there is no universal cross-sector understanding of what we mean by the term “lived experience”.

'Everyone has lived, and everyone has experience' ([Baljeet Sandhu, 2019; Page 12](#)).

When does a life experience turn into "lived experience"?

"Lots of people I've seen say "you have lived experience of everything", and if it isn't lived, it's dead. So what would a non-lived experience be?

So you have to kind of qualify it as "lived experience of mental distress". You have to qualify it in order to make it mean something".

Interview participant

Despite the difficulty of defining it, **prioritising and advocating for people's lived experience is important to disrupt power (im)balances** and to challenge dominant understanding of whose voice matters and what forms of knowledge are seen as "legitimate". Similarly, as one participant explained, the term lived experience is a helpful way of **differentiating between theoretical and experiential knowledge**.

"[The term "lived experience"] kind of feels like it comes from a sense of emphasising like, it is as a personal narrative and the importance of it relating to your own experiences. So like, if somebody said they are a lived experience researcher it's kind of lived experience, as opposed to theoretical knowledge because they have studied a certain group of people. I think in that sense it's actually quite useful, to emphasise the distinction".

Interview participant

Another difficulty of the term "lived experience" is its breadth as a term. It can mean many different things. On the one hand, its breadth can be inclusive and allow many different types of people to feel part of something. However, its vagueness can also be anonymising; **"lived experience" allows people to acknowledge that they live with mental ill-health without disclosing exactly what it is they have experienced**.

"I definitely feel that kind of like, there's a bit of safety and kind of being able to use like, pretty broad terms so you don't need to, you don't need to disclose too much. Possibly also, kind of similar to the way that I kind of like to identify with the word queer because it's so vague that I don't know actually telling anyone anything by it. So it's like not a lot so I don't need to go into the specifics".

Interview participant

Power and lived experience

Despite largely advocating for the value of lived experience, many people acknowledged that there were difficulties with the term. **“Lived experience” as a broad term can make it hard to differentiate between different types of experience.** While it is good that more people can self-identify into the category, people with less power are often left behind. For example, those with so-called “severe mental illness”, people with “unfavourable” diagnoses, and/or people who are incarcerated (whether in psychiatric institutions or prison).

“I think now you have more people coming to the fore, who identify as having lived experience, and that is a much vaguer term, often often used in a broader vaguer way to refer to a great many different things. But it quite often isn't people with more “severe” or more “unpopular” diagnoses [. . .]. But yeah, it feels like things have broadened in a good way and in a bad way. So in a good way, inclusivity; people are more able to come out and say that they've been, you know, that they've had periods of depression, that they've, had to give up work, they've had treatment, and they've hopefully managed to get back to work. You know, you've got more people who are able to talk about that, which I think in the past was really not the case [. . .] But on the other hand, those voices are also louder than the ones who are, you know, incarcerated on a more regular basis, and, or are disabled by the medication that they're taking in the long term. And you're not necessarily hearing from those voices so much”.

Interview participant

“I think in the mainstream, it [the term “lived experience”] gets - I don't know how to say this without sounding a bit wrong - but it kind of gets co-opted by people who may have less severe, mild to moderate mental health needs. And then because of the privilege of slightly better health and power and influence, they are the voices that get heard the most”.

Interview participant

Similarly, the term “lived experience” can also make it hard to identify and prioritise the needs of different sub-groups within the lived experience banner, meaning that *‘the pursuit of inclusivity can end up inadvertently eroding solidarity’*.

Intentions aside, **failing to engage with the politics of lived experience can keep power in place.** This was not limited to the mental health context, but was something that could be seen across sectors/social movements.

“[Broad definitions can] become a challenge because it makes it harder to identify specific sets of needs to prioritise service delivery in a limited service delivery environment [. . .] Because not only do you have a net cast very, very wide, but you also end up with people who have shared experiences, but radically different needs”.

Interview participant

People who were doing “lived experience” mental health work were reflective about claiming lived experience positioning, and were wary about being asked to speak on behalf of others/on topics they did not have experience of. For example, they acknowledged that **it could (but might not always) be inappropriate for a person without a particular diagnosis to speak on behalf of those who do** e.g. to engage in co-production initiatives on inpatient care if they hadn’t experienced being on a mental health ward. At the same time, **others expressed caution about requiring disclosures of specific experiences and/or precluding people from speaking to experiences they have not had.**

Another complexity of defining lived experience (and thus, who is in the lived experience “community”) related not only to severity but also to chronology: whether a person’s experience was in the past or present. Participants were reflective and cautious about claiming lived experience status; they wondered who could or should speak on behalf of who, and the trade-offs involved in whether or not to decline a particular opportunity.

Multiple lived experiences

Almost all people who participated in this research identified as having lived experience of mental ill-health, distress, or trauma. However, **people’s life experiences were not limited to one “category” of lived experience; they lived intersecting, overlapping lives.** While this seemed to bring richness and multiple insights to people’s lives, it was also painful.

For example, of those survey respondents who identified as disabled, very few “only” had experiences of mental ill-health, distress, or trauma. For the most part, people also lived with physical disabilities and/or were neurodiverse. On top of this people lived in precarious financial or social situations, without adequate resources or struggling to make their basic needs met. **Each of these experiences: distress, disability, neurodiversity, and lack of resources served to exacerbate each other.**

Intersecting identities aside, there was huge variation within the category of “lived experience of mental ill-health, distress, or trauma”. There was variation in how people understood and described their experiences: some used diagnostic categories, others spoke of iatrogenic harm, some listed in vulnerable detail the personal traumas they had faced, while others spoke about their social/economic conditions, such as lack of housing.

There was a similar variation in the “care” people had received. Some had been inpatients, some had accessed private therapy, others medication, community groups, or NHS outpatient services.

What this reiterates is that **those with “lived experience” are not a homogenous group**; we have vastly different experiences, backgrounds, understandings, and visions of the future. This is often missed by those who seek “lived experience” perspectives, assuming that one, two, or even ten of us may speak on behalf of an imagined “community”.

Community of experience, or politics?

As well as difficulty defining what “lived experience” is, there are also tensions about what the idea of a lived experience community “means”. **Are we a community of experience, or politics?** On the one hand, identifying as someone with “lived experience” may simply describe a set of experiences. On the other hand, mobilising our lived experience may denote a particular politics or approach to mental health care.

“We use lived experience to mean two things simultaneously. And one of them is about structural positioning and like people's right to speak and have their voices heard. And one of them is like, the systemic disregard of certain political stances, and the ways in which those stances do and don't become associated with a set of experiences, right?”

And in that sense, actually, perhaps that community [of experience] is served pretty well by [large apolitical mental health charities/awareness raising campaigns]. There's a really wide range of people who are having this experience, and most of them maybe go straight to [a large charity's] website, to their GP, to 6-12 weeks of CBT [Cognitive Behavioural Therapy] and they are okay [. .]

And then there's a community of people who are trying to do user-led work and are interested in peer support, who have a sense of themselves as related to different forms of activism around mental health. That's a pretty different community”.

Interview participant

The tension between a community of experience or politics was also teased out in the focus groups I held. We discussed, for example, how those of us doing “lived experience leadership” work (even though we did not relate to that term) tended to hold left-wing politics rooted in anti-oppressive and/or abolitionist practice. We wondered whether someone with right-wing politics would be welcome in our “community”.

In relation to the idea of “community”, it seems that lived experience means two things. Firstly, a descriptive catch-all term that describes people’s experiences; this was a broad grouping of people who, generally, would not be considered a community. However, **the smaller community of “politics” tended to have more shared values and visions for the future; this was more likely to be considered and feel like a “community”.**

2.2 Being part of the lived experience “community”

This section outlines what it means to join the lived experience “community”, including who gets to be considered as someone with “lived experience”, and why some people may or may not feel welcome in these spaces.

Learnings

- Not everyone is willing or able to describe themselves as “someone with lived experience”.
- Many people are excluded, particularly those whose experiences are criminalised, or for whom making a disclosure would be dangerous.

Power and vulnerability

To become someone with “lived experience” you must understand yourself/be understood as one. But fragility and distress are not evenly distributed. There is a privilege in being seen as someone who is vulnerable.

Many people who experience distress are not treated as people in need of care, but as troublemakers and potential criminals. This was notably highlighted by the [StopSIM coalition](#), who worked to expose police involvement in mental health and the ways that police and punitive approaches were/are mobilised within the NHS to dissuade people from seeking care.

Many have also exposed the ways in which racism plays out in the attribution of vulnerability. For example, [a recent \(2023\) report chapter by NSUN in partnership with human rights organisation, Liberty](#), discussed how emotions are often criminalised in Black and brown communities. **Simply put, the further you are from power, the less likely you are to be considered “vulnerable”.**

Survival

Often, those who are part of the lived experience community enter this work/organising through their experiences of accessing mainstream mental health care. These people, who have accessed (or tried to access) mental healthcare, are often referred to as “service users”.

But **it is more difficult than ever to become a service user**. This may be due to inaccessibility or exclusion, or it may be by choice: due to the harm people can experience within the mental health system, many people may choose not to engage with services.

Equally, **in order to become a psychiatric “survivor”, you must have in fact survived**. That includes both the physical act of survival (still being alive), and also the willingness/ability to politicise and mobilise your experiences for the purpose of making change. This is not available to many.

“And then it's interesting, because there's people then who face different forms of oppression who are trapped in those settings. So for example, like, especially with young Black men, and I can even say with my own younger [family member], it's been like, 12 years of being in that system. He's not a survivor of it, or recognised as such, or would describe himself as one. And he can't even escape the system, because it's been set up to keep people like that, you know, constrained from society. And then again, I think to myself, like how do people like him have their voices heard? And who are they in community with and that sort of thing, it's very hard. But if he was maybe a middle aged white man, he might have survived the system and, you know, be seen as recovered sooner than he is being a young Black man who's like, has the label of being aggressive and everything constantly pointing him you know, so it's very hard”.

Interview participant

Ability to disclose

While the term “lived experience” is vague enough that people do not have to make specific disclosures, using it is still some kind of disclosure. While I may not have to say “I have self-harmed”, calling myself someone with “lived experience” lets you know that I have experience of mental ill-health, distress, or trauma.

Not everyone is either willing or able to make these disclosures. For some, this may be due to emotional capacity; we simply do not want to be asked about our experiences. It may also be about power, setting ourselves up as someone with lived experience creates uncomfortable power dynamics in which we lose authority and the ability to challenge the status-quo (see [Bajleet Sandhu, 2019; Pages 38-39](#)). We might lose our jobs; particularly if we are in roles that require us to have a particular mental/emotional state.

For others, **it may be dangerous to disclose our lived experience status**, or to seek mental health care. For example, [Medact's “Patients Not Passports” campaign](#) highlights how the UK's Hostile Environment plays out within the NHS.

Particularly, highlighting how data sharing practices between the NHS and the Home Office can deter or make it dangerous for migrants to access care (including mental health care) through the NHS.

Our ability to claim madness in public is therefore impacted by our other identity positionings and the power we hold in the world.

2.3 Staying part of the lived experience “community”

While being part of the lived experience “community” can be valuable, it is also hard to stay a part of.

Learnings

- It can be painful to stay part of the lived experience community. This includes the toll of witnessing others’ pain, or having to be/stay in a particular relationship to our distress.
- It is hard to maintain faith in lived experience work; we have to keep calm, perform our sanity, and work hard for marginal gains.
- Tensions can arise between different individuals/groups doing “lived experience” work; often this comes from a lack of resources and having to fight over scraps.

Pain and emotional capacity

It is painful to be part of the mental health lived experience community. We watch over and over as people suffer for lack of mental health care. **While our work can be life-affirming and humbling, it requires us to stay open to having our hearts break over and over.** It takes a lot. Of course, all mental health work is difficult, but it is especially hard when it touches on our own experiences.

“Actively trying to be part of the community is in and of itself, almost dangerous, because you are putting yourself in and around so much terribleness [. . .] It is the nature of being in this community that we see very closely terrible things happen all the time. And that a lot of people are people to whom terrible things are happening, or have happened. And I don't even know what I want to say about it. Because obviously, it makes it more important. But it makes it so hard. Like every part of doing every part of the work. It's such a weight on everybody. And there is no space for the weight”

Interview participant

During the course of this research, yet another fellow survivor activist died by suicide. This person was active on Twitter; many of us followed her and felt invested in her life. Her account was anonymous, and many of us only knew her first name. Still, her death was painful and confusing. She is not the first of us to die for lack of adequate care, nor will she be the last.

This is something that came up in an interview with another participant, who spoke about the sheer difficulty of being part of the “community”, especially online. A few participants bought up the pain of this death, and many others we have experienced over the years. **We mourn each death.**

“I'm pissed off. And I'm sad. And I'm annoyed and I feel terrible. And I can't even explain to people what it means. And I'm bringing this anger into my frustration [at work] with their glibness and their like self satisfaction, and the smallness and the stupidity of what they're doing. When I know, I know, in a way that feels really close to what is happening. And I can't, and I'm not even part of it, I hadn't met them”.

Interview participant

Equally, for many, a sense of community is the only way we can carry on doing this work.

“I feel like sometimes you can just get lost in your head around this work. So yeah, it's like I find that [community] really valuable. I don't have a concrete structure around it. Right. So I don't have like monthly meetups I go to, it just happens organically. But the people you end up making friends with and you call “community” is like, so invaluable once you like, get to know them and like, learn about them and stuff like that. Yeah, it's the joyful part. And it's, it's actually the fire that keeps you going because I feel like the day to day grind. If you get stuck in it for too long, you're gonna burn up just like it's, it's too much. It's too much to carry for yourself and other people”.

Focus group participant

(Over) identification?

Identifying as someone with “lived experience” requires a very particular relationship to our own distress, identities, histories, and/or trauma. We are constantly having to invoke and remember things that are painful. A few participants noted this, that while the work was life-affirming, they also needed to take steps back to take care of themselves.

“For me, like my lived experience, role, or work is so much defined by pain and is defined by that sense of struggle against structural inequality, and yada, yada, yada, yada. I can't be that all the time, I really can't”.

Focus group participant

Participants felt that this over-identification was another reason for burnout, that it is simply **unsustainable to constantly have to invoke and relate to our pain.**

In all honesty, I like what I do. I love what I do. But I don't think I really want to do more of it. Like, if there's an event after work, I don't want to go to it, I'd much rather be at home and play some games. Like it's because, there's different parts of my being that want to exist [. . .] Because you feel like you have so much responsibility when you do this kind of work, you don't want to let anyone down [. . .] But it's like, I need to take a step back now in a way that works for me”.

Focus group participant

Disillusionment

It can be hard to maintain faith in taking mainstream “lived experience” roles/opportunities. It is easy to become disillusioned. This comes from the pressures of having to be or act a certain way, and feeling like only certain parts of us are welcome (for example, [Taimour Ahmed's \(2023\) reflections on class and doing lived experience mental health work](#)).

“I think I've definitely had to like up my vocabulary games since becoming more involved in this work. And becoming more kind of, I guess, trying to kind of, yeah, go to uni, and all that kind of stuff, I kind of really, again, worked hard on trying to basically swallow a thesaurus so that I could kind of like, use those kind of jargon terms and stuff. But I think sometimes that can feel quite exclusionary as well.

And I know that sometimes, when I'm in certain spaces, I actually get exhausted by all the words that get used. I often when I speak at conferences and stuff I get, like, complimented on how I make complex topics accessible [. . .] But sometimes, yeah, I feel like I have to work quite hard to feel part of some aspects of these communities. And I imagine, yeah, for some people, that puts them off entirely”.

Focus group participant

Another element of disillusionment is the **weight of having to perform sanity**; to be “together”, remain professional, and only present neatly polished parts of our madness/distress. One participant spoke in detail about this, wondering whether they are welcome in the “movement” when they are not doing well.

“There's not much room for the messiness of lived experience a lot of the time. And I think, yeah, it's tricky, because then the people who then are part of the lived experience world tend to be kind of quite articulate and quite, you know, kind of educated to a certain degree or whatever else. And then for all the people, I mean, even me on days, when I'm like nonverbal, or I'm just like a heap in the corner of the room, and I don't really feel able to share those stories in like, even within a lot of my communities, because a lot of it relies on me being kind of a certain degree of functional. So I guess, yeah, for me, there's also an element of kind of, how much am I able to be part of some of these communities when I'm less functional? Although I'm not a fan of like, the whole, like, “high functioning, low functioning” terminology, there is something there about how I'm doing and at what point I'm still welcomed in those communities”.

Focus group participant

Differing visions and fighting for scraps

As I highlighted in the introduction, not all who have “lived experience” see the world in the same way. While we often agree on what is bad, we do not often agree on what needs to happen next. Often, **we see a tension between reformist and abolitionist approaches, or apolitical and political analyses of mental health**. This can and has created friction among those who identify as having lived experience. **While friction can be productive, it is important to recognise how power plays out to weaken the movement.**

For example, tensions about different strategies are made worse by the **funding landscape which often sees us having to fight for scraps**. This is not limited to the mental health context. Overall, research shows that grantmakers are rarely interested in radical organising. For example, [a 2023 investigation by the Civic Power Fund](#) found that only 5.7% of grants in the UK are given to groups working on social justice, and that the largest portion of grants were made to those doing “inside game” work such as changing policy or improving existing services.

Not only are funding initiatives less likely to fund “outsider” work, but they are also seeped with institutional racism in the way in which they distribute funding, meaning that historically under-resourced initiatives face additional barriers (see; [Equally Ours, 2020](#) and [The Ubele Initiative, 2021](#)).

“Sometimes we're trying to do too much with limited resources, and under the risk of maybe being a little critical, we exist in communities that have a highly refined language of social justice, and can sometimes without meaning to strive for perfection, before having achieved a foundation”.

Interview participant

Those whose work focuses on disrupting the status quo may therefore feel dominated, side-lined, or even betrayed by those who do “insider” work. They may see others who already have power gaining prominence, fighting for things that will benefit dominant groups while leaving others behind. **We must balance the need to call out those who hoard or fail to see their own power, with an ability to see how “the system” sets us against each other.** This is not an easy task.

Being a “good” activist

Multiple participants spoke to me about the pressures of claiming lived experience and feeling like they needed to be a “good” activist. They wondered whether they could consider themselves “an activist” at all, and felt like there was pressure to always be “doing more”.

“But I kind of feel like a lot of activist kind of communities are kind of characterised by this, almost, it feels, almost inevitable burnouts. Like, it kind of feels like it's become an acknowledged kind of part of doing that work and being part of those spaces. And sometimes I've kind of felt like I'm not doing enough, because I'm not, I don't do that activist stuff like 24/7.

And I'm not always on it”.

Focus group participant

Some people linked this to the rise of online spaces as a place where community happens. They felt **pressure to constantly take public stances, and to comment on things that they didn't know much about.** They feared that if they weren't seen to have done the “right” thing, they would face consequences within the community.

“Sometimes as well, I feel like I'm not speaking about an issue enough. But there might be constraints to what I can or can't do, and sometimes I just don't have the mental energy to, and I feel like I'm letting my community down. Or sometimes I might just want to work out what I think about an issue first. And I don't know, it might be something I'm putting on myself, but it's almost because I just don't always have the emotional energy to engage with that online, I'm like, “Oh, am I not part of it enough”, or something like that?”

Focus group participant

Part 3: Using the term community: Who benefits?

This section brings together a final thread of the findings, outlining the different ways people use the term “community”.

3.1 Community on our own terms

“Community” is a powerful term in activist and organising spaces, not just among those with lived experience. It is often used to signal that an action or initiative is developed with people in mind rather than profit or power. Within the term “community” however, there appears to be a few different meanings.

Learnings

- “Community” can be a powerful term in grassroots work, particularly when trying to create a collective voice or highlight issues that face most of us. We must be careful not to lose specificity.
- Community could include those we feel aligned with, accountable to, or those who we hope our work would benefit. It is important to get clear on what we mean when we use the term.

Firstly, the term “community” can be used to signal **those we aim for our work to benefit**; whose lives we are working to better. While it is important to know who we are working for, there can be complexities drawing the line between advocacy and representation. Particularly, we must pay attention to the power we hold when speaking for and on behalf of others even if we share identities or experiences with those people.

Similarly, the term “**community**” was also used by some to talk about **accountability**; those people who we hope our work stands up to. While we may feel accountable to people in the community, it is not always clear how mechanisms of accountability actually occur. If someone in our community dislikes what we are doing, how do they tell us? Who gets to make decisions about what we do with that feedback?

We may also talk about a “**community**” for the purpose of **political organising**. While we know that there are many differences within a group (who may not feel like a group at all), we may want to refer to collectives to insist on change about the issues that many of us face. One participant spoke to me about the term “the transgender community”:

“We're often talking about the “the trans community” as a political entity, rather than a philosophical entity [. . .] [my organisation] works around the political existence of trans people in terms of things like service denial, loss of opportunity, pathologisation, barriers to health care, barriers to education and things like that, that emerge whether or not someone experiences membership in the trans community or not.

But these people are united by the way in which that regulation or legislation, or like societal factors affect them, in one way or another”.

Interview Participant

This approach was described by academic **Professor Gayatri C. Spivak** as **“strategic essentialism”**, in which minority groups may present a collective voice in the struggle for rights, even though there are many differences within/among them. For example, it can be helpful to talk about people who have lived experience of mental ill-health as a community to raise concerns about the criminalisation of distress, or the unavailability of mental health care provided by the NHS. This approach can be helpful when building power in a campaign. However, we must be careful about straying too far and losing sight of the ways in which issues affect different groups in different ways.

3.2 Co-opting community and the powers that be

Many participants spoke to me about the ways the “powers that be” use the term “community” when talking about people with lived experience. Overall, participants showed a **wariness about how those with power such as funders, NHS trusts, or policymakers use the term “community”** when talking about mental health.

Learnings

- Health services often refer to “care in the community”; this felt like an empty term that could better be replaced with “not in hospital”.
- Those with power often celebrate communities of necessity; we are made responsible to resolve the problems of failing public sector services, without adequate resources to do so.
- Those running co-production initiatives can capitalise on the breadth of the term “lived experience”, cherry-picking people they involve to keep power in place.
- Efforts directed at “hearing from the community” often involve extractive approaches to storytelling, asking people with lived experience to share personal and vulnerable narratives without payment or promise of change.
- Too little attention is paid to the ways in which “co-production” or “telling your story” can be harmful to people with lived experience.

Care in “the community”

In the mental health context, “the community” is often referred to as anywhere other than the hospital setting. When you are not an inpatient, you are in “the community”. This is reflected in many names of NHS services: Community Mental Health Teams, or Community Treatment Orders.

This use of the term “community” was raised by multiple participants, who largely felt that the term didn’t really mean much in this context. The term “community” in health services also implied that not being in a hospital was better or safer for people, and assumed that people had support “back home” (if indeed, they had a home at all).

“Its like jargon isn't, I don't ever say in real life my friends like "I'm just gonna pop into the community like, going to the community see you later", it's not really like language that anyone uses outside of health services [. . .] it's like hospital health service jargon and I genuinely don't think I think like because it's used so much it kind of becomes diluted and it loses its meaning [. . .] It kind of implies some sort of like support and connection and like togetherness, which is interesting because actually being in the community as opposed to being in hospital can actually be more lonely and more isolating. Because I don't know, we live in a very individualistic society anyway [. . .] I think I just see the word know how it's used, the word community, how it's used, in the health services, it's kind of lost any actual meaning [. . .] I think it [“care in the community”] could just be replaced with "as opposed to hospital”

Interview Participant

Celebrating communities of necessity

Many participants spoke to me about the way that the term “community” is used to shift responsibility for good mental health away from public services and on to fellow citizens or those working in the third sector. I discussed this finding with another person working in mental health lived experience work and they talked to me about how it felt like there was a ‘*devolution of responsibility without a devolution of power*’.

“Communities” are often asked to mop up the failings of public services, without adequate resources to do so. All the while, we are expected to be grateful for the opportunity.

Another difficulty people faced was watching the way in which these “communities of necessity” are celebrated by those with power. **While we were proud of our work, many of us would rather not have to do it in the first place.**

“And you know, like, that's just my strong view on awards [for lived experience work], I really struggle with that concept, because I'm like, “Yes, we should celebrate the work that we do. But we shouldn't be having to do it in the first place”. So I don't want to normalise it to the point where it's like, because ultimately, we've all been through something that shouldn't have happened in the first place. So to a degree, it has taken potential from our lives. Let's just be realistic, right? So while I celebrate what I do, and the people I do it with, I really don't see it as something that I would be doing in another life”.

Focus group participant



This piece was created by Bekah Harris for an exhibition called “A Sophisticated Insult”. It was made in response to Bekah not being permitted to show her work in another project as it was deemed “too controversial”, despite the original piece having used direct quotes from mental health professionals and policy makers.

You can find [Bekah on Twitter @100beks](#).

Image description: Photograph of cross-stitched artwork, in front of a white wall. The artwork hangs in an exhibition space from two black bulldog clips attached at the top corners. The artwork includes cross stitched text written across a white background, bordered by frayed black, red, and beige cloth. Text reads: “stop sanitising our experiences for your tickbox co-production”.

Hearing from “the community”

Participants noted extractive approaches toward involving or hearing from members of “the community”. This included **tokenism in co-production and extracting traumatic stories from people with “lived experience”**.

“People are looking for like a neatly packaged version of your lived experience, that they're not really ready to accept the messy parts of it. And I feel like then it almost creates like a funnelling process of like, the person who can eloquently convey the story in a way that is, like, digestible, doesn't make you feel too uncomfortable. It's almost created that kind of funnel where like, the more polished you are, the more you get those opportunities and stuff like that. And like as someone who was recently diagnosed as neurodivergent, as well, like so for me, it's like it just doesn't work for me anymore”.

Focus group participant

It was noted that **those with power can capitalise on the breadth and vagueness of the term lived-experience**, noting that they had “involved” people with lived experience without specifying exactly who, and what the nature of their involvement was. Instead, co-production was a way to tick a box rather than reimagine the status quo.

The vagueness of the term “lived experience” is helpful for those in power. For example, one participant spoke to me about how a particular (and highly controversial) mental health “innovation” had used “lived experience” on their website as a way of rubber stamping their work and creating the illusion that they had consulted “the community”. The same participant likened this to pinkwashing or greenwashing.

“Thinking about these types of conversations within the policy context, I think we are, as organisations and as facilitators in policymaking processes, extremely lazy. Like, I think we're just draw on the same types of voices and people. And that ticks the box of “liaising with the community”, or “co-designing with the community”.

Interview participant

Participants were also wary about the breadth of the term “lived experience” and claims to have involved “the community”. People felt that those in power were likely to involve people who can articulate themselves concisely and calmly; who could bring just the right amount of challenge without being disruptive. Issues relating to power, privilege, and keeping your cool can be found in **Nev Jones and Emily Cutler’s (2018) article on “The Angry Consumer”** and **Akiko Hart’s (2022) reflections on being called to be a “critical friend”**.

“If we are to truly listen to the perspectives of those who have been historically excluded and marginalized, then we need to listen to their emotional reactions as well as their words”.

Nev Jones and Emily Cutler, 2018. “The Angry Consumer”: Embracing Difficult Conversations.

Another issue relates to chronology and insisting that people’s lived experience is in the past. People felt that **those in power would rather people who had lived, rather than living experience**. For example, one participant told me about a job advert for an NHS Lived Experience role, in which an essential criteria was to have lived experience “of recovery”. In essence, their distress must be in the past. In my own work around self-harm, I am frequently asked to advertise research studies that require participants to have been “self-harm free for at least 12 months” (I decline, each time).

Some participants suggested that emphasis on distress in the past could stem from safeguarding concerns and risk culture. While those who are “stable” may appear less “risky”, this assumption forgets the fact that co-production initiatives themselves can also be harmful.

“And because the system is very risk averse in that sense, right? It's so silly, because that even if somebody is in recovery doesn't mean that the whole process of engaging with co-production, or like a media interview, or whatever it is, can't then re-traumatise or re-distress somebody”.

Interview participant

Another issue that came up a lot related to storytelling. Particularly, how organisations with power draw on individuals to “tell their stories” in the spirit of “hearing from the community”. A focus on storytelling often **forces those with “lived experience” to tell vulnerable stories about their lives without adequate pay or control over how those stories get used.**

Storytelling can not only put people in a vulnerable position, but can also impact their lives in ways that are hard to anticipate at the time.

"I take quite big issue with these kinds of "champions" at various charities and stuff. So that kind of encouraged people to kind of, you know, tell their stories in the name of helping people. And that was, yeah, something that I was kind of sold on when I was when, again, when I was quite young. [At a time when I was quite unwell]. And I was kind of allured by this sense of "you know, you can make a difference in other people's lives by sharing what you've been through", and all this kind of stuff. It's all shiny and stuff.

And there was no one who kind of sat me down and kind of was like, "you know, what might the implications be of like sharing your story, and like, you know, later down the line". If I wanted to become a clinical psychologist, would I be able to? like, you know, an internet search shows all these things about that I kind of was promoting when I was a teenager. And also, you know, being in the local newspaper about stuff and having people contact me, look me up on social media, and, you know, the kind of consequences of that. Luckily I didn't have any trolls reach out to me, but I could well have done. And I was super, super vulnerable".

Focus group participant

At first being able to "tell your story" feels good. But after a while, when you see no change, the magic wears off. **It can make us feel like the only thing that matters about us is our trauma.**

"I can tell them a story 100 times, like, but after 99, and I see no structural change. It's a bit like, "okay, yeah, like, how much more can I like, ring the doorbell?" [. . .] It's always corporations or charities being like, "it's time to talk" and "come in tell us" and like there's no policy change or anything like that".

Focus group participant

At the same time, some participants were wary about saying that all forms of storytelling were bad. Stories are important for our lives. Some people may benefit from telling them.

What was important then, is not limiting co-production or storytelling, but instead making sure people had all of the information they needed to make the choices that feel right for their lives. People felt that being part of a people with lived experience helped them to identify harmful approaches to storytelling and co-production.

"There was a period where it was just like, okay, just putting on like a clown makeup and just getting out and telling, like, the worst things I've been through, and like, not getting paid. So that's why [the lived experience] community has been quite helpful, because they have been like, "No, you charge for this"."

Focus group participant

Conclusion

While “community” is a word that is commonly used; there is little by way of definition or attention to the nuances it contains. This research has shown that community means different things to many people. Far beyond just a group we share an attribute with, community can be where we feel safe or supported. **Community can be a place where we do not have to explain ourselves. Communities can be any size, and exist in many different places.**

Within the mental health context and beyond, the term “community” is a buzzword, often used by those with power to refer to groups of people that share a single identity, characteristic, or a local area. What this research shows is that feeling a *part* of a community is actually far more complex; it is often the smaller groups, between which we chop and change, where we feel like we can truly belong. **We must ask what these broad and non-specific uses of the term “community” do, including paying attention to how minoritised groups are being made responsible for each others’ wellbeing.**

Those with lived experience of mental ill-health, distress, or trauma, hold deep insights about what is needed to live well and what is getting in the way. In some ways, those with lived experience could be considered a “community”, but not always. There are differences between a “community” that shares a particular experience, and one that has a shared politics around what leads people to suffer, and what needs to be done next. **While it is easy to refer to those with lived experience as a “community”, there are important nuances that we must not overlook.**

While much work has been gained by the lived experience movement, we must also be careful about whose voices are becoming loudest, and who is still being left behind. We must be careful of vague or broad terms that lose sight of specificity, that are readily co-opted by those who would rather tinker with the system than reimagine it entirely. **How do we build collective voice without losing specificity and attention to power?**

It is also important to take good care of ourselves and others while invoking our lived experience. This includes tending to the resources and resilience of the lived experience “community”, while also recognising its limits. Not all can, want, or desire to be part of this work and nor should they have to. Instead, it may be more fruitful to think about building solidarity across groups, finding the overlaps and synergies between our experiences, and identifying opportunities to work together.

No matter how welcoming, safe, or encouraging a lived experience “community” is, we

cannot be in it full time. We need spaces to foreground other parts of our lives, and to be different people at different times. **How then, do we assert our lived experience without reducing ourselves to it?**

At the same time, as groups with power are called to account, there is increasing appetite to “involve” people with lived experience in decision-making processes. While this is an encouraging step, too often this is done with **little resource, care, or consideration for the people who are asked to do the labour of lived experience work.** These efforts — sometimes called “co-production” — are often done in the name of hearing from or involving “the community”.

While talking about “communities” (hearing from them, funding them, consulting them) sounds good on paper, we must be wary. Often, the term “community” is used by the powers that be to virtue signal without adequate redistribution of resource or power. **Where are we being homogenised, or made responsible for rectifying failings that are not our own?**

Overall, it may be helpful to get a little more specific when we are using the term “community”. While it can call for unification or denote connection, it can also obscure what we really mean. When it comes to talking about communities, there is often something more specific, and more difficult that we are trying to articulate. **It may be easier to speak in broader terms, but it is specificity that will get us free.**

What would we like to see?

The following points are **aimed at those working in spaces and organisations seeking to engage or co-produce with, represent, research, or fund “communities”** (most specifically those with lived experience of mental ill-health, distress, and trauma), such as **mental health charities, campaigners, researchers, funders, and policy-makers**. We hope that they may inform and challenge work focussed on community and lived experience.

Using the term “community”

- More specificity when using the terms “community” and/or “lived experience”.
- Critical analysis of how calling broad groups of people who have a shared identity or characteristic “the community”, for example, “the mental health lived experience community” or “the LGBTQ community”, can homogenise groups of people who may have very different experiences and viewpoints.
- An awareness that community is not inherently beneficial: people have mixed experiences of community, or may not feel part of one.
- Recognition that communities can cause harm. They can be sites of exclusion, tension, and in the context of experience of mental ill-health, they can be places of both solidarity and of pain or loss. Failing to engage with the difficult or uncomfortable elements of “community” can exacerbate the harm they cause.
- Affording people greater autonomy in naming the communities they are a part of; avoid assuming or telling people that they belong to a “community”.

Resourcing communities

- Adequate recognition and resourcing of small and specific communities, rather than a focus on broad groups.
- An analysis of how resourcing a “community”/communities, such as through funding, can make groups, particularly those facing marginalisation, responsible for taking care of one another. We must resource marginalised groups while also tackling the systemic factors which create marginalisation in the first place.

Using the term “lived experience”

- Recognition that the term “lived experience” involves a wide range of experiences and perspectives. Attention must be paid to whose perspectives are not/are less likely to be represented within this umbrella term, such as those with so-called “severe mental illness”, ongoing/current distress, and multiple marginalisations.

Efforts to “involve” lived experience communities

- Ensuring that efforts to “hear from the community” or co-produce with people with lived experience are not extractive, tokenistic, or harmful.
- Resourcing and remuneration for lived experience work; not only paying people for their time, but taking care around the emotional labour it takes, often extending well beyond a specific opportunity/piece of work.
- Giving people with lived experience more power over how their lived experience is used, particularly when sharing their stories/testimonies.
- More clearly setting expectations of what it is possible to influence or change within the bounds of an involvement opportunity. A lack of clarity or over-promising undermines consent and can be harmful to those who engage in co-production initiatives.
- Meaningfully involving enough people, with enough variation in experience and viewpoints, to more confidently say that lived experience communities have been engaged with, heard, and represented.

Reflection questions for readers

1. When using the term community, what do you mean? Examples could include: those you are trying to benefit, a group you have tried to involve, those you feel accountable to? What mechanisms are in place to ensure you are achieving these goals?
2. Are you categorising people as being part of particular communities based on their explicit identification with those communities, or your own assumptions?
3. How might you identify, “represent”, and resource communities without homogenising people, and their wants and needs, in ways they do not identify or align with?

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