Engaging with people with lived experience

Evidence review March 2023

See Me
End mental health discrimination

MENTAL HEALTH FOUNDATION

See Me

See Me is the national programme to end mental health stigma and discrimination in Scotland. Guided and supported by people with experience of mental health problems, See Me challenges mental health stigma and discrimination. The programme aims to influence changes in attitudes, behaviours, cultures and systems so that people with experience of mental health problems are respected, valued and empowered to achieve outcomes important to them. A priority for the programme is to better understand and address the mental health stigma that is disproportionately experienced by particular groups of people in Scotland.

Mental Health Foundation

The Mental Health Foundation is the UK's leading charity for everyone's mental health. We are home to Mental Health Awareness Week and, with prevention at the heart of what we do, we aim to find and address the sources of mental health problems so that people and communities can thrive. Alongside its role as managing partner, the Mental Health Foundation (MHF) works in partnership with See Me to deliver its research, learning and evaluation functions. This includes the delivery of primary research, evaluation, evidence reviews and knowledge exchange to inform programme development.

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Clarification of definitions

See Me recognises that terminology and labels used to refer to groups marginalised by society is ethically and politically complex, can be harmful and is subject to debate and update. Throughout this report we have mirrored the terminology used within the literature we have reviewed. Wherever possible, we have also tried to use the terminology partners themselves have used to refer to the communities they are led by and work with. We are committed to continually engaging with this critical debate to understand and mitigate harm.

Lived Experience: There are many different definitions of lived and living experience, but within this document the term Lived Experience (or People With Lived Experience: PWLE) refers to people who draw on their direct personal experience (previous and/or current) of living with a mental health condition (or of supporting someone with a mental health condition) within a voluntary or paid role.

Intersectional Stigma: This term describes how social identities and structural inequities shape and influence each other (Sievwright et al., 2022). This means we cannot understand any one stigma (more often discussed in terms of prejudice when related to other protected characteristics) in isolation from another, which might simultaneously be at play, compounding negative experiences, e.g. of services as well as health outcomes.

Executive Summary

This review seeks to provide a comprehensive foundation for organisations aiming to authentically involve people with lived experience in mental health and anti-stigma work, ensuring their voices are central, respected, and supported throughout all stages of engagement.

Ten core principles for building meaningful engagement with people with lived experience (PWLE) are identified within this review:

Reciprocal relationships: Meaningful engagement depends on mutual trust, empathy, respect, and equality. People with lived experience should feel listened to, included, and supported. Power imbalances should be addressed; using simple language, informal discussions, and removing labels can help. Inclusion of peers and support networks is vital to avoid isolation.

Wrap-around support: People with lived experience should feel supported when engaging with organisations or projects. Support should be ongoing, flexible, and individually tailored, including both peer support and support from staff. This includes mentoring, supervision, and preparation for specific events to empower people with lived experience without harming wellbeing.

Meaningful opportunities: People with lived experience should be presented with a range of options for involvement, from staying informed to leading projects. Engagement should avoid tokenism and recognize the full skills and strengths of PWLE. Development opportunities and co-learning are encouraged. Accessibility considerations, including reasonable adjustments and support for participation, are crucial. Opportunities should be flexible, allowing people to make informed and dynamic decisions about their level of involvement.

Clear communication: Communication must be clear, timely, accessible, and use plain language throughout all stages of involvement. People with lived experience should receive comprehensive information before participation, regular updates during, and feedback and outcome information afterward.

Equality, equity and diversity: Treat everyone as equals while recognising and embracing diversity, intersectionality and individual needs. Recruitment for lived experience roles should be fair and transparent, aiming to expand the diversity of experience represented. Attention must be paid to removing barriers to participation for genuine involvement of people from marginalised or minoritised groups.

Valued: People with lived experience should feel that their contributions are valued and that they matter. Their opinions and ideas should be encouraged and seen as equally valuable as those of other contributors. Remuneration for lived experience roles is debated; many argue for equal pay to avoid economic exclusion, while acknowledging barriers and individual preferences. Financial compensation is

recommended for panels. Transparency and discussion about payment options are essential.

Commitment and accountability: Organisations should show a strong commitment to authentic, consistent, and meaningful engagement with people with lived experience. Engagement strategies should be embedded in all projects from the beginning, with appropriate time and resources allocated. Accountability structures should welcome all feedback and ensure consistent policies for lived experience.

Supportive culture: A positive team culture is crucial for engaging people with lived experience. This includes strong leadership, transparent decision-making, adaptability, and a welcoming environment where everyone feels included. Principles of inclusion, collaboration, and co-production are central, treating people in lived experience roles as full team members regardless of employment status.

Evaluation, monitoring and research: People with lived experience should have a central role in ongoing research, evaluation, and monitoring. Their involvement helps maintain a focus on key issues and improves the relevance of research

Safety: Safety is a core principle, particularly in relation to the vulnerability that comes from sharing personal stories. A trauma-informed approach and the creation of safe spaces are essential for effective engagement

The review recommends using a model defining different levels of engagement to guide planning and communication around lived experience opportunities for involvement. Engagement level models should be used flexibly, with the understanding that people's involvement may fluctuate across the duration of a project.

Introduction

There is widespread recognition of the value of lived experience in anti-stigma work. Internationally, engagement and empowerment of people with lived experience within anti-stigma work has been steadily growing – moving from describing the reality of stigma experienced due to mental ill health, through stories and personal narratives, to becoming central to the design, delivery and evaluation of anti-stigma approaches (Sunkel & Sartor, 2022). Global (lived experience) peer networks have been established including the Global Mental Health Peer Network, restating the value of engagement of people with lived experience. Recently a Lancet Review gathered evidence from many national level anti-stigma programmes across the world (Thornicroft, et al., 2022). The Review Committee concluded that lived experience engagement is critical to the success of anti-stigma activity. Within Scotland, lived experience involvement is becoming increasingly central to emerging mental health and social care policy, as evidenced in the new suicide prevention strategy, mental health law review and national care service consultation. Groups and panels involving experts by experience exist for many national policy and guidance developments.

Whilst the evidence for why lived experience engagement is necessary continues to expand, clear and consistent guidelines to support meaningful engagement are lacking. This review explores existing guidance into how to engage people with lived experience of mental ill health meaningfully within anti-stigma work.

Lived experience and See Me

See Me has a long history of engaging people with lived experience. From inception of the Fairer Future campaign in 2007, founding partners recognised the essential nature of lived experience contribution. The Rights for life agenda progressed by See Me (alongside partners) encouraged adoption of human rights based approaches and application of Panel Principles to ensure engagement of both rights holders and duty bearers. Panel Principles included: Participation, Accountability, Non-Discrimination, Empowerment and Legality.

See Me has continued to facilitate lived experience contribution as core to the programme's work. Social movement, another pillar of anti-stigma practice, works best when lived experience is central to it. See Me's 2020 report describes a journey of social movement; See Us is the most recent engagement campaign. In 2021, See Me introduced a volunteering strategy, setting out core principles and priorities to ensure lived experience volunteers plays a central role in the programme.

See Me is encouraged by the growth in, and widespread appreciation of, the need to effectively engage people with lived experience, and has been advocating for this more generally for many years. See Me has recognised that empowerment is increasing the ability of individuals and groups to influence issues that affect them and their communities through individual and/or collective action and have been trying and testing ways to achieve this. See Me has learned that part of this is ensuring people with lived experience have access to information, tools and opportunities that support empowerment and that conditions, structures, culture and

practice need to be considered to ensure effective engagement for people with lived experiences. See Me have been supporting partners to develop and test approaches to engaging people with lived experience based on our learning and experiences

See Me recognises the programme has not reached all communities across Scotland and that we have work to do to address systemic barriers to inclusion and representation, particularly of those marginalised by society. Our current strategy and delivery framework prioritises work to support us to take an anti-racist, anti-discriminatory and intersectional approach in areas from research to commissioning to community engagement. See Me has developed a range of tools, checklists, processes and ways of working for effectively involving volunteers with lived experience, the team is working to embed this across all aspects of the programme and to support partners to apply emerging learning from best practice. The team at See Me also wants to ensure that whilst engaging with people with lived experience, safeguarding and risk management and the complexities involved in this are carefully considered to make sure that people working with See Me are fully, respectfully and individually supported.

See Me appreciates stigma will be a factor in preventing people from engaging. If stigma or discrimination occurs and is not addressed in the process of engagement this will most likely lead to the person with experience withdrawing. Recent learning from the team's recent research The Scottish Mental Illness Study (SMISS) (Ewens, et al., 2022) highlights the importance of creating the best conditions and safeguards for engagement of people with mental illness: as part of all aspects of the engagement process from pre planning to evaluation.

See Me has a long history of engaging people with lived experience. Since the Fairer Future campaign in 2007, founding partners recognised the vital role of lived experience. The Rights for Life agenda promoted human rights-based approaches and Panel Principles—Participation, Accountability, Non-Discrimination, Empowerment, and Legality—which See Me integrated at the core of its work. Social movements, another pillar of anti-stigma practice, are most effective with lived experience at the centre. The See Us campaign and the 2021 volunteering strategy underscored this, outlining principles to ensure volunteers with lived experience remain central.

See Me recognises that empowerment means increasing the capacity of individuals and groups to influence issues affecting them, and has explored ways to support this, ensuring people have access to information, tools, and supportive structures. The programme has supported partners to develop approaches to meaningful engagement based on evolving best practice.

While See Me has not yet reached all communities in Scotland, the current strategy prioritises anti-racist, anti-discriminatory, and intersectional practices across research, commissioning, and engagement. The team works to embed effective involvement of lived experience volunteers, supporting partners to apply emerging best practice. Safeguarding and risk management remain key, ensuring all involved are individually supported.

See Me acknowledges stigma can deter engagement, and if not addressed, can lead to withdrawal. Learning from the SMISS study (Ewens, et al., 2022) reinforces the importance of creating supportive conditions and safeguards at every stage of engagement for people with mental illness.

Aim

The aim of this review is to collate and review guidance already available to support authentic, effective and safe engagement of people with lived or living experience of mental ill health, and to help ascertain if additional guidance is required – with particular emphasis on stigma, intersectionality and safeguarding.

Methods

Between 11th January and 16th February 2023, the Mental Health Foundation (MHF) conducted several searches of Google, Google Scholar and the Knowledge Network library. MHF also contacted colleagues with expertise in the field of lived experience within See Me and the Mental Health Foundation, and asked them for references.

Search terms included the following:

- Engaging people with lived experience of mental illness/ mental health problems
- Engaging people with lived experience of mental illness /mental health problems stigma & discrimination
- Lived experience + mental illness + engagement + stigma
- Lived experience + mental illness + engagement + discrimination
- Lived experience + mental illness + intersectional + engagement + stigma

Findings

A total of 52 resources and documents were identified, stemming from 11 different countries (see table 1). In total, 26 documents were retrieved from within the UK including 14 from Scotland.

The search identified a wide range of resource-types including academic journal articles, guidance and policy documents, reports and online toolkits. Most resources have been published very recently; all Scottish resources have a publication date of 2020 or later, and only nine resources reviewed were published prior to 2019.

UK (total)	**26**
England	6
England & Wales	4
Scotland	14
UK (unspecified/whole)	2
International (total)	**34**
Australia	7
Canada	6
India	1
International/ South Africa	4
Nepal	1
Netherlands	1
South Africa	2
USA	2

Table 1: Breakdown of documents reviewed by country.

Framework for engagement

Resources and documents (52) were searched for principles, frameworks or key themes for successful engagement with people with lived experience. A basic

thematic analysis of these identified ten overarching themes arising from the literature:

- Reciprocal relationships
- Wrap-around support
- Meaningful opportunities
- Clear communication
- Equality & diversity
- Valued involvement
- Commitment/accountability
- Supportive culture
- Evaluation & research
- Safety

Each theme is addressed in turn below.

Theme 1. Reciprocal Relationships

Across the documents, there was an emphasis on the importance of strong, meaningful two-way relationships (Rethink, 2016) built on a foundation of mutual trust, empathy, respect and equality (Global Mental Health Peer Network, 2022). VOX members highlighted the key role played by trust in making people with lived experience feel safe (VOX, 2022). People with lived experience want to feel listened to, supported, included and involved (Scottish Recovery Network, 2022).

1.1. Building connections

The literature emphasised the importance of not isolating people with lived experience (Byrne, 2016), providing examples of ways to promote holistic inclusion within the workplace:

- Welcoming people with lived experience wholly into the group, project or workplace team
- Involving as many people with lived experience as possible on any project - not singling out one person in isolation
- Promoting and supporting the development of connections between peers (for a guide, please see Let's do peer group facilitation (Scottish Recovery Network, 2022))
- Recognising and building ways to engage with all of a person's connections, including their family and/or support network. (Faulkner, et al., 2015)

1.2. Balance of power

One key point made in almost all documents reviewed was around the balance of power. People with lived experience of mental illness and related stigma will likely have experienced many situations within health and social care interactions as well as their lives more broadly, in which they feel they hold little power. Recognising and challenging power dynamics, unconscious bias and privilege is crucial to establishing strong working relationships between people with lived experience and other members of any team or group (Faulkner, 2015, Sesula, 2014, Victoria State Government, 2019). Strategies suggested within the reviewed literature included:

- Use simple language (avoid jargon and acronyms) (VOX, 2022)
- Create informal spaces for discussion (SRN's conversation café provides one model for this (Scottish Recovery Network, 2021))
- Remove labels – come as people, not roles.

Theme 2. Wrap-around Support

Another theme arising from the literature was that people with lived experience want to feel supported when engaging with organisations/projects (Richmond, et al., 2023) (Alliance, 2022). Support should be ongoing and may include both peer support and support from others involved in the group or project (e.g., staff) (National Mental Health Commission, Australia, 2019). Support should be flexible and individually tailored, allowing for both regular connection (e.g., supervision, mentoring (Centre for Addiction and Mental Health (CAMH), 2019)) and input at specific points within a project (e.g., event/meeting preparation, pre and post-event check-ins) (Johnson, et al., 2022).

Staff, peers and other networks providing support need to be appropriate and well trained. The aim of support should be to help people to actively reflect on their engagement, and to empower people to make decisions about their involvement, in order for them to be as involved as they wish to be for as long as they want without any detrimental impact on their wellbeing.

Theme 3. Meaningful Opportunities

The literature outlined a range of different types of work, groups or projects that people with lived experience may be involved or choose to become involved in. Whilst some may wish to just stay informed or be consulted regarding ongoing work, others will be looking for deeper levels of involvement including opportunities to influence, inform, participate in and lead projects/programmes (Faulkner, et al., 2015) (Centre for Addiction and Mental Health (CAMH), 2019). Different levels of engagement are discussed further below, but the key thing underpinning this topic within the literature is choice – people should be presented with a flexible range of options, and given all the information and support they need to make an informed decision about the level of role they wish to take and what is involved. This is demonstrated within Mind's work, of which their involvement policy (Mind, 2017) might prove particularly useful.

3.1. Meaningful contribution

Documents highlighted the importance of involvement not being tokenistic (Global Mental Health Peer Network, 2022) (Shaping Our Lives National User Network Community Interest Company, 2022). Throughout the literature, people with lived experience spoke of their desire to contribute, and to make a difference. Some seek emancipatory involvement in mental health services; for others, engagement offers a chance to gain 'socially valued roles and resources' (Landy, 2018). To enable people with lived experienced to engage in meaningful, impactful and action-focused involvement, opportunities should be well thought through with a clear purpose and planned as early as possible within a project. To help people feel that their contribution is purposeful, the objectives and potential impact of engagement should be made clear from the start. Some in the literature discussed how engagements should go beyond storytelling to recognise the whole person, their skills and strengths beyond their experience of mental illness. It is recommended that opportunities for influencing and leading pieces of work are developed, so that people with lived experience feel that they are contributing, influencing and are part of the change.

3.2. Transparency

Literature emphasised the importance of being realistic and transparent about any constraints on involvement (e.g., time, money, other resources) to ensure that people getting involved have a clear idea of what is expected of the role. It is recommended that flexible options for involvement are provided, and that people with lived experience are actively involved in discussions around what meaningful engagement looks like to them. The Matrix guide from researchers in Utrecht (Smits, et al., 2019) may prove a useful tool for thinking this through. Another resource is Mind's Influence and Participation Toolkit (Mind, 2020) which goes into a lot of detail on the subject of planning and provides a range of tools that may be helpful.

3.3. Development opportunities

Involvement of people with lived experience should offer benefits for both the organisation and the person involved. The literature recommends taking a skills or strengths-based approach and offering a range of development opportunities to enhance the skills, knowledge, experience and confidence and competence of both people with lived experience and others on the team. Co-learning opportunities involving both people with lived experience and staff/others involved in the project are widely encouraged; to fully embrace the knowledge, expertise and experience of people with lived experience, it is important to explore ways in which the rest of the team or group can learn from people with lived experience.

3.4. Accessibility

> *"If you do it wrong [engagement], and it often is done wrong, then you're only gonna have people with... less disabilities, less barriers, participating"* (quote from a person with lived experience; (Landy, 2018)).

To enable people with lived experience to get involved to the level that they wish to, projects/organisations should offer flexible options for involvement (this may include finding ways to allow people to participate anonymously), ensuring that each individual is consulted regarding accessibility issues to identify and address potential barriers to involvement. It is recommended that conversations about accessibility and needs happen early on when engaging with someone with lived experience. A report from Shaping Our Lives outlined several recommendations:

- Ask about and record access requirements in advance
    - Make sure you have an understanding of other support needs
- Plan ahead to make necessary adjustments
- To facilitate attendance, think about:
    - Accessible venues
    - Remote options
    - Arranging and paying for transport and other expenses (in advance if needed)
- Reasonable adjustments, think about:
    - Timing of meetings and breaks
    - Encouraging people to bring along someone for support
    - Format of information provided
    - Overcoming language barriers

- Room layout

Theme 4. Clear Communication

Communication featured strongly within all documents reviewed within this scoping exercise and was a key feature throughout all stages of people with lived experience's involvement. It was widely recommended that clear, comprehensive information should be provided to people with lived experience throughout their engagement, and that people with lived experience are provided with opportunities for informal conversations with team members before, during and after their involvement. All communications whether written or verbal should:

- Use plain language (no acronyms or jargon)
- Be accessible (ask person about their preferred methods of communication)
- Be timely (provided in advance)

4.1. Before becoming involved

People with lived experience should be provided with clear and comprehensive information about the project and involvement opportunity, what is involved and what the expected outcomes will be, to help them make an informed decision about getting involved. This should help people to manage expectations and determine their level of involvement. Further, to address the power dynamic referred to above, the process of determining what involvement looks like and what the expected outcomes are, should be done in collaboration with people with lived experience.

4.2. During involvement

People with lived experience should be provided with regular and timely updates to help them stay engaged in the group or project and continue to make informed decisions about their involvement. Any decisions made about the work should be clearly and transparently communicated to everyone involved, including details of the decision-making process.

Ahead of any meeting or event, information and materials needed should be provided well in advance. People with lived experience should be provided with opportunities to table agenda items or otherwise influence the running of the event, and supported to prepare for their contribution.

After an event/meeting, minutes/discussion summaries, action points or other outcomes should be widely shared to ensure transparency.

Feedback should be provided to people with lived experience whenever they make a contribution, not saved until the end of a project. Feedback should be reciprocal, so that people lived experience get the opportunity to reflect on their experiences and make suggestions for improvement. This could be done one to one or in groups depending on the group, or project and sensitivity of the feedback. may be helpful to reinforce the importance of the balance between supporting inclusion and involvement against treating PWLE as different – isolating them and ostracising them through the process. that's it good practice for all members of the project including those with lived experience.

4.3. After involvement

People with lived experience should be kept up to date with any outcomes resulting from work that they have contributed to. It is important to truly appreciate anyone who dedicates their time and energy to a project, yet one of the most common pieces of feedback from people with lived experience within the literature was that often, when their direct involvement in a project was over, communication stopped and they never heard whether their work had made a difference. Examples of how to keep people informed include:

- Provide updates of progress by email/ phone/ text
- Send out completed reports
- Run accessible events to let people see the outcomes of the project – invite anyone who worked on it, no matter how small their role.
- Stay connected on social media
- Invite people for informal chats (e.g. meet for a coffee)

Theme 5. Equality, equity, and diversity

Throughout all documents reviewed in this scoping exercise was a clear message regarding the importance of treating everyone as equals, whilst recognising, embracing and supporting diversity and individual needs. Some documents highlighted particular differences that should be embraced, e.g., generational differences (National Mental Health Commission, Australia, 2019), race equality (National Survivor User Network & National Involvement Partnership, 2015), whilst others recognised the importance of taking an intersectional approach (Roche et al, 2020; Faulkner & Thompson, 2021, Landy, 2018). People with lived experience spoke of wanting to be treated fairly, as individuals and equals within any team, including over issues such as payment (see 'valued' below). There was however little discussion within the reviewed documents about how the mental health of staff or volunteers who are not in a lived experience role should be addressed (e.g. are people not in lived experience roles still encouraged and supported to talk about / draw on their experiences of mental health problems and related stigma?)

5.1. Recruitment

Recruitment for people with lived experience roles, like other staff roles, should be fair and transparent, and seek to expand the diversity of experience represented on any project. Whether or not new people are recruited, the Alliance recommend teams try not to go to the same people for similar projects time and time again (Alliance, 2022). Organisations should seek to ask 'what is meaningful and to whom' when thinking about engaging people with lived experience.

Theme 6. Valued

Lived experience should be seen as equally valuable to other forms of expertise, and should play a central role throughout mental health organisations. People want to feel that they matter, they want to feel heard, validated, believed and understood. Votilja and colleagues (2021) name this principle 'active voice' in which staff encourage people with lived experience to voice their opinions and ideas, reinforcing the message that their opinions are equally as valuable as any other contributor (Vojtila et al, 2021).

6.1. Whole person approach

People with lived experience want to be allowed to be themselves - treated as autonomous individuals with full lives and networks of loved ones. Literature recommended taking a whole person approach (see Scottish Recovery Network, 2022), in which everyone is accepted for who they are (more than a diagnosis/experience), and it is recognised that mental health fluctuates for everyone. Another key point raised by Landy (2018) was that people with lived experience want to feel free and safe (supported and encouraged) to be critical – to share their lived experience without feeling the need to 'whitewash' it or hold back.

6.2. Remuneration

There was much debate within the literature regarding the issue of remuneration. Within many documents, particularly those written by people with lived experience, an argument was made for the value of equality to stretch to remuneration (Richmond, et al., 2023; Shaping Our Lives National User Network Community Interest Company, 2022). The Global Mental Health Peer Network for example, spoke of how people with lived experience are of equal value to other members of any team, and their expertise should be reflected in their payment. They further argued that "by expecting individuals with lived experience to participate as volunteers disproportionately excludes those that have previously been or continue to be economically marginalized and reinforces inequality" (Global Mental Health Network, n.d., p. 2). Some organisations are now adopting different remuneration models through which people with lived experience receive payment for their input. For example, the Homelessness Network Scotland pay people with lived experience as Associates (sessional workers), offering £13.74 per hour for approximately 8 hours of work per month.

Others did not advocate as strongly for equal pay, recognising that there are many barriers to providing such remuneration including funding, short/fluctuating involvement, and individual preferences from people with lived experience who may not feel comfortable accepting payment for a variety of reasons (National Survivor User Network & National Involvement Partnership, 2015). Reasons for not accepting payment are very varied, but can be positive (for example they feel that they want to give something back and payment would detract from this feeling of benevolence) or negative (e.g. they are worried about the impact of payment on any benefits they receive, or they don't believe themselves worthy/valuable enough to receive payment). Common across all documents though was a call for transparent payment and reward processes, discussions with people with lived experience about what was on offer and why, and commitment to explore all options. There are some good examples of payment policies that address this (e.g. Co-Production Collective; Mind, 2017).

Theme 7. Commitment & accountability

The literature clearly stated the need for mental health organisations and staff to show a strong commitment to authentic, consistent and meaningful engagement with people with lived experience.

7.1. Planning for engagement

To engage people with lived experience as early and as fully as possible, engagement strategies should be embedded within all projects from the beginning (Global Mental Health Peer Network, 2021). Planning for lived experience engagement should become a standard part of any project plan, and where possible, people with lived experience should be involved in the planning process itself (identifying project need, setting the questions, etc.). Mind's Influence and Participation toolkit includes a selection of tools that may be useful, including an Annual influence and participation planning tool Timescales should account for relationship and capacity building, seeking to embed lived experience all the way through the life a project (Roche, et al., 2020; Johnson, et al., 2022).

7.2. Resourcing engagement

Wherever possible, it is important to build in good amounts of time and resources (including skilled staff) to support lived experience engagement (Suomi, et al., 2018), and appropriate compensation (whether full payment, expenses reimbursement or something in between) should be built into funding proposals (Centre for Addiction and Mental Health (CAMH), 2019).

7.3. Accountability

Organisations and teams should welcome all feedback (including negative, (Batty, et al., 2022)) on their current engagement strategy and practice, with the accountability and governance structure clearly defined (National Survivor User Network & National Involvement Partnership, 2015). Appropriate policies and hiring practices need to be established and used consistently for lived experience roles across the organisation.

Theme 8. Supportive Culture

Organisational and team culture was a strong theme within the literature when considering what helps engage people with lived experience (National Mental Health Commission, Australia, 2019). Many fundamental elements of a positive team culture described in the literature arguably apply whether or not an organisation/team is looking to engage with people with lived experience. For example, strong leadership, transparent decision making, adaptability and openness to change, digital innovation and continuous quality improvement. The Canadian Mental Health Association (CMHA) suggest using appreciative enquiry as a tool to help foster a culture that embraces a strengths-based approach (Sesula, 2014). Another common element of positive workforce culture, several documents described the importance of creating an informal, welcoming environment in which people have a positive attitude, help others to feel included and that they belong (Scottish Recovery Network, 2022). It is worth noting that whilst this section refers to workplace culture, and some authors did specifically discuss this theme in relation to people with lived experience in paid employment roles (e.g. peer researcher/peer worker roles), most documents had a broader focus on paid and unpaid lived experience roles. This highlights the position of many authors, that people with lived experience should be treated as members of the team – no matter what their employment status – for any project that they are significantly contributing to (Byrne, et al., 2016).

8.1. Stigma & discrimination

In their 2022 report on stigma, the Alliance recognised coproduction and lived experience engagement as crucial to reduction of stigma and discrimination (Alliance, 2022). Supporting this perspective, mental health stigma and discrimination were frequently discussed within the lived experience engagement literature as a key priority (e.g. Kaur et al, 2021, Hawke et al., 2022, Mburu & Sartor, 2022, Richmond et al, 2023, Scottish Recovery Network, 2022).

Social contact is widely acknowledged as a key mechanism for reducing stigma and discrimination (Thornicroft, et al., 2022); engagement of people with lived experience can potentially help tackle stigma by eroding perceived social distance (us/them social groups) and, 'normalising' experiences of mental health conditions. Involvement of people with lived experience can help bring to the fore the reality of stigma and discrimination and how it's experienced, and help challenge myths, prejudice and misunderstanding. In their 2022 article, Hawke and colleagues discuss the potential for lived experience researchers to reduce stigma within research institutions. They acknowledge that if people with lived experience are meaningfully engaged by a research institution with a supportive culture, then they have the potential to reduce stigma by: "acknowledging the universality of lived experience and breaking down the 'us versus them' dichotomy that epitomizes stigma" (Hawke, et al., 2022, p. 2301). Hawke et al also identify key roles for people with lived experience in critiquing the status quo and providing new perspectives. The authors discuss challenges to each of these roles however, highlighting the potential for colleagues to respond negatively to what they perceive as challenges or slights to their conventional ways of working/ assumptions. The role of people with lived experience as stigma disruptors therefore needs to be carefully considered.

Whilst embedding lived experience roles can play a key part in overcoming stigma and discrimination within many settings, people have disclosed experiences of being subjected to stigma and discrimination whilst undertaking lived experience work. Stigma and discrimination were recognised as a particular challenge affecting lived experience roles within clinical healthcare (e.g. Kohrt et al., 2021) and research settings (e.g. Johnson et al, 2022), but acknowledged as a prevalent issue across all settings. Byrne and colleagues (2016) conducted qualitative interviews with people with lived experience working in healthcare settings in Australia. The researchers identified stigma and discrimination as a central theme; interviewees reported prevalent experiences of stigma and discrimination that negatively impacted their ability to function and grow within lived experience roles. Within these roles, stigma and discrimination were experienced so frequently as to have become 'normal'; Participants described colleagues holding low expectations of them and reacting with surprise when they produced good quality work. This resulted in participants feeling a need to overcompensate or remain hyper-sensitive to how they looked and behaved at work. One participant said,

> "*I do think I've had to overcompensate. I'm aware of how I dress, of how I move, of how I engage, that there is always the potential that I will be misread as being inappropriate, and that being due to my lived experience rather than just a personality thing." (Byrne at al, 2016, p6).*

Participants also reported colleagues asking intrusive or inappropriate questions about their personal life, and failing to distinguish between them and service users (being belittling or demeaning in the process). Byrne and colleagues reported that their participants fought hard to be respected and treated equally, but found themselves professionally isolated, and often exhausted by their efforts.

It was clear across all documents that an anti-stigma, anti-discriminatory culture is fundamental to working with anyone with a lived experience of mental illness – whether working in a role that acknowledges this, or not. Richmond et al (2023) discussed the importance of creating a culture in which all team members (paid and unpaid) feel that they can challenge established narratives, including power structures and stigma.

One final point within this theme; Mburu and Sartor (2022) argue for the central role of lived experience within anti-stigma campaigns, arguing that "there is a need to move from a "we need to help them" attitude to an inclusive attitude devoid of tokenism. Ultimately, the aim should be to meaningfully engage with lived experience in anti-stigma initiatives and policies and to empower and develop leadership by the lived experience community in these efforts" (Mburu & Sartor, 2022, p. 1390).

8.2. Shared values

Most documents listed fundamental shared values that underpin a workforce culture in which people with lived experience will feel comfortable and accepted. Commonly stated values included: equity (Centre for Addiction and Mental Health (CAMH), 2019), kindness (National Mental Health Commission, Australia, 2019), respect (Richmond, et al., 2023), understanding (Roche, et al., 2020), and respect of human rights (CAMH, 2019). Wellbeing of all involved was also highlighted; a blog relating to participatory research methods (Johnson et al, 2022) argued that wellbeing needs to be clearly seen to be more important than work.

8.3. Ways of working

Principles of inclusion, collaboration and co-production were emphasised within many documents as core components of a lived experience-supportive culture. Organisations should aim for lived experience involvement to be the norm within all their work (Wallcraft & Bryant, 2003, referenced in (National Survivor User Network & National Involvement Partnership, 2015)), and engagement and participation should be accepted as everyone's responsibility (National Mental Health Commission, Australia, 2019). Fundamental to any work involving people with lived experience is the principle of synergy, which VOX describe as "people coming together in a positive way to produce or create something. It is the interaction involved in this process which ultimately makes it work" (VOX, 2022)

Theme 9. Evaluation, monitoring & research

Some documents highlighted the importance of involving people with lived experience within ongoing research, evaluation and monitoring. It was argued that people with lived experience should have a central and leading role in determining the focus, scope and outcomes for mental health work. Engaging people with lived experience in evaluation and monitoring of projects can help maintain a focus on the key issues, and the same is true of research: "when the lived experience of

academic researchers is applied to academic work, there is the potential to improve the relevance of the research, while destigmatizing mental illness within academia. (Hawke, et al., 2022, p. 2299)" Several academic articles (Roche et al., 2020; Votilja et al., 2021) and blogs (Johnson et al., 2022; Gatera & Singh, 2021; Williams, 2022) demonstrated ways in which people with lived experience could be involved in research in a variety of roles such as sitting on Participant Patient Involvement (PPI) panels, taking on paid peer-researcher roles (e.g. Votilja et al, 2021; Johnson et al., 2022), through to designing and leading research projects and programmes. Authors generally advocated for a participatory approach, outlining clear frameworks for involvement (e.g. Roche et al., 2020), however several also identified challenges within peer researcher roles. A particularly helpful exploration of how lived experience can be embedded within research is provided by Hawke and colleagues (Hawke et al., 2022) who highlight the value of peer-led research, but identify several key issues including challenges relating to power, stigma and identity. For example:

- Unbiased representation of mental health conditions - who is missing from peer-led research? For a variety of reasons including intersectional characteristics, differences in level of disability and average age of onset, some mental health conditions (e.g anxiety, depression) are common whilst others (e.g. schizophrenia, personality disorders) are under-represented within peer-led research, challenging equality and diversity efforts. This is also a key point when considering PWLE more broadly.
- Peer researcher role requirements: Hawke et al point out that "a definition [of peer researcher] that does not require traditional academic qualifications would open the research space to new voices, while acknowledging that lived experience prevents some from entering the academy. Yet, this approach could also fuel stigma by reinforcing differences and denying the universality of lived experience."

The challenges of lived experience research roles are further explored in an article by Faulkner and Thompson (2021), who focus on the emotional labour of involvement and co-production in mental health research. They discuss the challenges of bringing a 'mental illness' identity to an unprepared workplace on a daily basis, and highlight additional intersectional nature of challenges faced by researchers from minority and/or marginalised communities.

Theme 10. Safety

Finally, safety was identified as a core principle within some documents, particularly in relation to the vulnerability that comes from sharing your story. Literature that discussed safety closely linked it to several other themes that have already been addressed, including power (relationships), culture and support. Whilst some literature focused on safeguarding practices, wider safety discussions additionally highlighted the importance of taking a personalised, trauma-informed approach (Scottish Recovery Network, 2022). The Scottish Recovery Network advocated for the role of trauma-informed practice in tackling stigma and discrimination related to mental illness.

10.1. Safe spaces

The importance of safe spaces – whether virtual or physical – was recognised in several documents (e.g. (Global Mental Health Peer Network, 2022), (Victoria State Government, 2019)). The Alliance identified 'safe spaces for conversations' as a key recommendation in relation to lived experience engagement in anti-stigma work (Alliance, 2022), for people to feel comfortable sharing their own experiences. A sensitive, person-centred approach is needed to create safe spaces for conversations in which people feel comfortable with those present (e.g. women-only spaces for those with lived experience of male-perpetrated abuse). Votilja and colleagues discussed the importance of safe online environments. A peer-researcher within their research project was able to guide development of an online peer space that paid careful attention to language (e.g. avoiding stigmatising words') (Votilja, et al., 2021)). The lived experience framework outlined by the Victoria State Government includes a particularly useful table highlighting key engagement concerns, as replicated below.?

10.2. Informed consent

Although not commonly discussed in these terms, most documents referred to informed consent indirectly, by highlighting the need for clear communication

between all parties regarding the nature, expectations and constraints of lived experience roles. This has been discussed within many of the other themes outlined above, in relation to establishing relationships, managing expectations, clear communication and fair recruitment strategies. Mind's Influence and Participation Toolkit includes tools to create a group agreement, and their guidance document includes a template role description, however there isn't an example of a consent form or partnership agreement that could be used with an individual.

10.3. Story telling

Story telling was acknowledged to be an important way in which many people with lived experience get involved in mental health work, but the sharing your story can be emotionally intense (Faulkner & Thompson, 2021) "some described the experience as intrusive and were left feeling invaded" (Shaping Our Lives National User Network Community Interest Company, 2022). It is therefore recommended that when story telling is used, it should be voluntary and supported, and other methods of involvement should be offered to reduce the pressure to participate in this way. Richmond and colleagues (Richmond, et al., 2023) discussed the importance of 'restorying', an approach in which people with lived experience are supported to re-frame painful memories before they engage in telling their story. Landy (2018) highlighted the possibility of 'exploration as empowerment' – that engaging in lived experience work can help people take ownership and gain a deeper sense of meaning from their own experiences, through sharing and exploring their own story within a new context.

10.4. Safeguarding and risks of involvement

Some of the literature argued the importance of accounting for the potential risks of engaging people with lived experience (Alliance, 2022), particularly within certain groups of people, for example involving people with lived experience under the age

of 18 was identified as requiring “another level of ethical complications in terms of consent and safeguarding the mental health and wellbeing of children who participate in projects” (Global Mental Health Peer Network, 2022). Mind have included a discussion and tools related to risk in their Influence and Participation Toolkit. Safeguarding and risk were not explicitly discussed within many documents however, and this statement from the National Mental Health Commission in Australia may go some way to explaining this: “any steps taken to improve, strengthen or introduce engagement and participation should avoid creating new behavioural or risk management approaches that single out people who declare they have a lived experience. That would be discriminatory and would take the engagement and participation process backwards. Risk management should apply equally to everyone, not only those who identify as having a lived experience” (National Mental Health Commission, Australia, 2019). It is therefore important that any risk protocol and procedures that are implemented are done so in a transparent, inclusive manner that is scrutinised through an anti-stigma lens. The Victoria State Government (Victoria State Government, 2019) have produced a helpful table of barriers and enablers to lived experience engagement, which address several of the points raised in this review relating to safety, power, support, communication, and the emotional load that this work can bring.

Types or levels of engagement

Most documents included in the scoping review referred to different levels at which a person with lived experience can become involved in a project or organisation. Levels of engagement identified in models within the lived experience engagement literature are summarised within Table 2.

Whilst there were several different models mentioned, each tended to range from passive involvement (informing) to active participation and leadership, most frequently employing a five-stage model. Commonly referenced models included Arnstein’s ladder of participation (Arnstein, 1969), which formed the basis for several models including the Ladder of Coproduction referenced by VOX and the IAP2 public participation spectrum, as described in Victoria State Government’s Lived experience framework. The participation matrix developed by researchers in the Netherlands (Smits, Klem & Ketelaar, 2019) also drew upon Arnstein’s ladder, developing a sequence of roles that they describe as less ‘hierarchical’. These are combined with the project stage (preparation, execution, implementation) in a useful matrix to help project leads determine when and how people with lived experience could be involved. There is a guide to how to have conversations about involvement which accompanies the matrix, which may also be of use.

Actively leading							
Empower	Leading	Co-production (empower)	Co-production	Assume control	Leadership	Leading	Decision-maker
Collaborate	Deciding together Doing together	Co-design (collaborate)	Co-design	Delegated responsibility Plan jointly	Active partnership	Collaborating	Partner
Involve	Working together	Involve	Engaging	Advise		Working and doing together	Advisor
Consult	Consultation	Consult	Consultation	Consulted & provide information		Consulting	Co-thinker
Inform		Inform	Informing Educating Coercion	Receive information	Passive involvement	Informing	Listener
Passive involvement							
Canadian Mental Health Association (CMHA), 2014	Mind, 2020	Victoria State Government, 2019	VOX, 2022 (ladder of coproduction)	Black dog institute, 2018	Centre for Addiction and Mental Health, 2019	Alliance, 2022	Smits, Klem & Ketelaar, 2019

Table 2: Comparing levels of engagement identified in models within the lived experience engagement literature

How to use engagement level models

Engagement levels can be usefully applied to the categorisation of lived experience engagement opportunities, to help inform planning, information sharing, recruitment and support. For example, the way that an opportunity for lived experience volunteering is categorised can inform how the opportunity is communicated; it might be categorised for example as consultancy (e.g. 'we're seeking your views on our new webpage'), co-design (e.g. 'we want your help designing a new page for our website'), or co-production (e.g. 'we're seeking people with lived experience to partner with us to shape the ways in which we communicate with our stakeholders').

Models of engagement can also be used as tools to guide conversations with people with lived experience, to understand the depth of involvement they are seeking, and their expectations around this.

Helpful resources

There are a range of resources that look specifically at the higher levels of engagement. For example, several resources focus on co-production, in particular the Think Local Act Personal website, UCL's Coproduction Collective website, and VOX's 2022 report 'Making Coproduction work'. VOX argue that coproduction needs specific attention because:

"In mental health there are already significant power dynamics which exist between those who provide services and those who use them…Co-production…helps build stronger communities, develops citizenship, and is linked with better outcomes both for people who access services and for their carers." (Vox Scotland, 2022)

There is also a selection of tools that focus on or may be particularly useful for other specific levels of involvement. For example SRN's Conversations Café may be particularly useful for consultations, and they have a range of tools focusing on peer group facilitation.

Flexible levels of engagement

Whilst tiered models of engagement such as those described above can be a helpful tool in identifying and maintaining opportunities for involvement, flexibility in their application is crucial to their success. The level to which a person with lived experience may wish to be involved can fluctuate however, as can capacity and resource within the organisation. It is therefore important that engagement remains flexible, and regular conversations are had within the organisation and with people with lived experience to recognise and understand any shifts as they occur. A flexible model of involvement is provided by NHS Research Scotland (see Figure 1). Although designed specifically for lived experience involvement in research (through Patient and Public Involvement groups), this model has clear applicability to broader lived experience engagement.

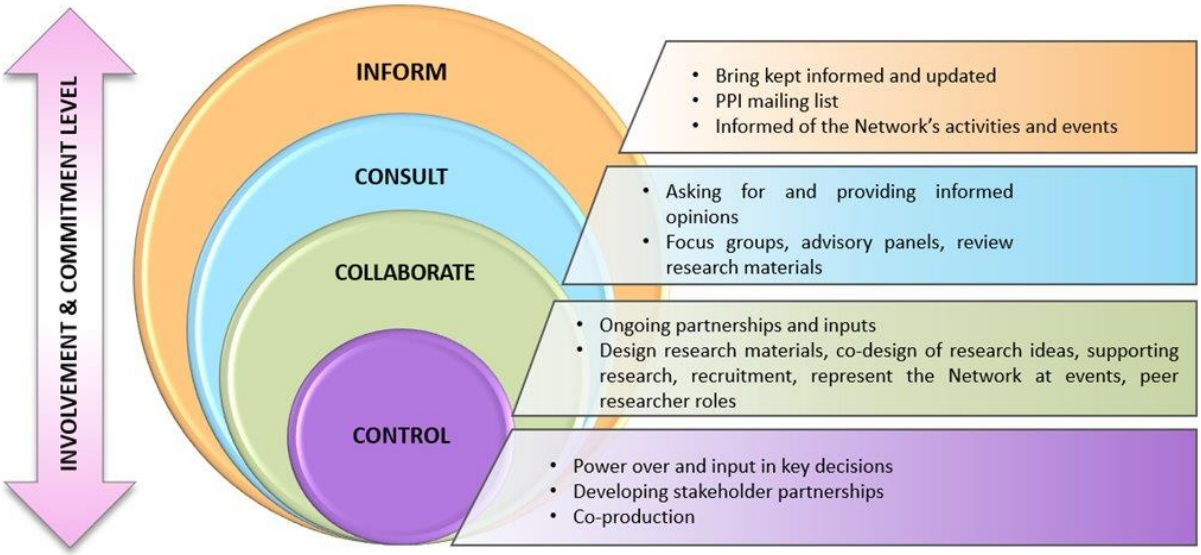

Figure 1: Developing a flexible approach to Involvement. NHS Research Scotland

Conclusions

This rapid desktop review explores how to build meaningful engagement with people with lived or living experience of mental health stigma into anti-stigma work.

Thematic analysis of the literature included within this review identified ten core principles for creating an inclusive and supportive environment for people with lived experience, ensuring their meaningful involvement in anti-stigma work. The review highlights the importance of establishing strong relationships, creating safe spaces, addressing power dynamics, stigma and discrimination, and ensuring transparent communication for effective engagement. Meaningful engagement requires a commitment at all levels of an organisation to embed lived experience and value and support both people with lived experience as equals, alongside all others involved in the work. Providing wrap-around support alongside well planned and genuine involvement opportunities will help ensure people with lived experience can contribute meaningfully to anti-stigma work. The report emphasizes the importance of adopting an intersectional approach to ensure that the diverse experiences of people with lived experience are represented and addressed. Organisations are encouraged to focus on the removal of barriers to participation to ensure representation of marginalised groups. The framework for engagement is summarised in full overleaf.

Lived experience engagement guidance documents commonly employ frameworks based on a linear model of engagement, ranging from passive involvement (informing) to active participation and leadership. This review recommends using such models to inform planning and communication regarding lived experience opportunities for involvement, but highlights the importance of enabling people with lived experience to retain choice and flexibility over their level of involvement.

The review also sought to identify key tools to guide engagement with people with lived experience at See Me. Whilst no single document was uncovered that neatly describes all of the key themes identified within this scoping review, several come close. Nine resources were identified merit a closer look by organisations seeking to work with people with lived experience (see Appendix 2), however none of these make specific reference to stigma within their frameworks. It is therefore recommended that further work is undertaken with people with lived experience of mental health-related stigma and discrimination to further review the key themes and resources identified here and determine whether any further guidance is required.

Framework for engagement

1. **Reciprocal Relationships**: Seek to develop strong, meaningful two-way relationships built on mutual trust, empathy, respect, and equality. Trust plays a key role in making people with lived experience feel safe and included.
2. **Wrap-around Support**: Provide ongoing, flexible, and individually tailored support for people with lived experience. This includes both peer support and support from staff.
3. **Meaningful Opportunities**: Provide a range of options for involvement, from staying informed to leading projects. The key is to offer flexible opportunities that allow people with lived experience to make informed decisions about their level of involvement.
4. **Clear Communication**: Communication should be clear, comprehensive and accessible. Information should be provided in plain language, with timely updates and opportunities for informal conversations.
5. **Equality, Equity, and Diversity**: Treat everyone as equals while recognising and supporting diversity and individual needs. Recruitment for lived experience roles should be fair and transparent, aiming to expand the diversity of experience represented.
6. **Valued Involvement**: People with lived experience should feel that their contributions are valued and that they matter. Their opinions and ideas should be encouraged and seen as equally valuable as those of other contributors.
7. **Commitment and Accountability**: Organisations should show a strong commitment to authentic, consistent, and meaningful engagement with people with lived experience. Engagement strategies should be embedded in all projects from the beginning, with appropriate time and resources allocated.
8. **Supportive Culture**: A positive team culture is crucial for engaging people with lived experience. This includes strong leadership, transparent decision-making, adaptability, and a welcoming environment where everyone feels included.
9. **Evaluation, Monitoring, and Research**: People with lived experience should have a central role in ongoing research, evaluation, and monitoring. Their involvement helps maintain a focus on key issues and improves the relevance of research.
10. **Safety**: Safety is a core principle, particularly in relation to the vulnerability that comes from sharing personal stories. A trauma-informed approach and the creation of safe spaces are essential for effective engagement.

Appendices

Appendix 1: Table of barriers and enablers from Victoria State Government's Lived Experience Framework, 2019

Barrier	Enablers and solutions
Feeling unsafe	**Creating a safe space** Ensure any potential issues have been identified and options are in place to offset these well ahead of commencing engagement (see examples below). This is particularly important in a mental health context where re-exposure to past experiences of disempowerment, negative treatment, attitudes and outcomes can cause harm.
Feeling intimidated	**Re-balancing power** Power imbalances can play out between policymakers, sector stakeholders and participants during engagement activities, especially in traditional committee settings where there may be many clinicians and service providers present but only one consumer and one carer. Co-production principles focus on rebalancing power to transfer decision making back to those using the services in question. The culture of government (such as physical environment, language and processes) can feel intimidating to people who are not used to these aspects of working with government. There are many simple ways in which a government agency and its staff can mindfully support people from the community to feel more welcome and able to participate fully.
Lack of support	**Connect consumers and carers with peer support** Consumers and carers may require support either during or after an engagement activity has occurred. This is to ensure people who may have been emotionally distressed over content, or who may feel overly burdened by the pressure to effectively represent the lived experience, are able to debrief.
Using overly complex language	**Using plain English** Any committee with a range of representatives will require common and plain English to be used. This is also true when engaging consumers and carers. To support common understanding, limit the use of overly clinical language, acronyms or terms only understood by one group or interest. If complex language cannot be avoided, a briefing note of terms should be provided as part of pre-reading, and opportunities for clarification that are respectful should be taken throughout the engagement process.
Consultation fatigue	**Develop clear objectives and process** There is a high level of consultation of people with lived experience, with outcomes often not reflecting feedback provided. This can mean that engaging people can be challenging. Ways to mitigate this include setting clear expectations around process and possible outcomes and recognising that unless there are commitments to incorporating feedback in line with co-production methodologies, engagement may be difficult. It is also important to provide a feedback loop that includes reasons why something may not have been taken on board.

Emotionally triggering content	**Provide trigger warners before meetings** For people with lived experience, engagement can mean reliving traumatic and painful experiences. This can include compulsory treatment, experiencing restraint and seclusion while in treatment, or the separation or death of a family member or loved one. To minimise the impact of emotionally triggering content, pre and post briefings should be established by anyone leading a project. If an individual is being engaged through the participation registers, this can be organised through either VMIAC or Tandem. In preparing for meetings, it is important to consider words and concepts that will be discussed and to acknowledge that certain topics can be challenging. Discrete processes should be established should anyone need support. If advice on managing emotionally triggering content is required, contact the Lived Experience Engagement team or the Office of the Chief Psychiatrist/Office of the Chief Mental Health Nurse. VMIAC and Tandem can also provide general advice.
Poorly defined issues	It is important to ensure that aims and scope are clearly defined and communicated, that roles and responsibilities are clearly articulated and that reporting and feedback are built in.

Appendix 2: List of key resources

Authors	Year	Title	Document type	Lived experience of…	Notes	References stigma?	# key themes covered
Alliance	2022	Engaging people with lived experience: best practice, challenges and opportunities	Guidance	Health & social care	This is very helpful. Includes lots of examples/case studies as well as clear recommendations with examples.	Yes, it provides a clear recommendation around improving knowledge and reducing stigma	10
Centre for Addiction and Mental Health (CAMH).	2019	Fostering Meaningful Engagement of Persons with Lived Experience at the System-level	Report	Mental health problems/ addiction	Helpful document - includes a good figure on culture & process barriers to meaningful engagement	Yes, there are several references to stigma including in relation to culture and barriers to engagement	9 – doesn't discuss risk/ safety
Mind	2017	Lived Experience Influence and Participation Policy: Ensuring that people with mental health problems drive all that we do	Policy	Mental health problems	Good example of a lived experience engagement policy which builds on clear framework for engagement.	There is one reference to stigma in relation to inclusion and diversity	8
Mind	2020	Influence & Participation Toolkit	Toolkit	Mental health problems	Really comprehensive, mixture of tools and guides. Extensive consultation process; recently reviewed & updated. Based on the 4P1 principles.	No	10
National Survivor User Network & National Involvement Partnership	2015	Involvement for influence	Report	Mental health services	This is a useful review of other reports/guidance documents, frameworks and legislation. Sets out it's own framework (4Pi) which is not as inclusive as it could be, but the report as a whole is helpful.	Yes, there are several references to stigma including within the purpose, literature review findings and barriers to engagement.	10

Authors	Year	Title	Document type	Lived experience of…	Notes	References stigma?	# key themes covered
Victoria State Government	2019	Mental health lived experience engagement framework	Framework	Mental illness/ mental health services	This is great - really easy to follow, sets out a clear framework for engagement alongside a toolkit (not open access).	Yes, within the preface.	10
VoX	2022	Making Coproduction Work	Guidance	Mental health problems	Short, straightforward and coproduced.	No	6
Landy	2018	Community engagement through the lense of intersectionality	Master's thesis	Mental health problems	This is an in-depth exploration of what community engagement means to people with mental health problems – taking an intersectional perspective. Well worth a read.	Yes, both in relation to mental health directly and the intersection between mental health and other stigmatised characteristics.	10

Additional resources

Since this report was written, new resources have been made available. These are not contained in the main body of the paper, as they have not been fully evaluated however they may include further valuable insights, and so links are included below:

SAMH: Evaluation of the NSPLG's Lived Experience Panel

SRN: Sharing experiences of suicide

Appendix 3: Documents included in scoping review

	AUTHORS	YEAR OF PUBLICATION	TITLE	DOCUMENT TYPE	RATING *(relevance & usefulness)*
1	Roche et al	2020	Valuing All Voices: refining a trauma informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach	Academic article	3
2	Votilja et al	2021	Engaging a person with lived experience of mental illness in a collaborative care model feasibility study	Academic article	3
3	Suicide Prevention Resource Center	Unclear. After 2015	Engaging people with lived experience: a toolkit for organizations	Online guidance	3
4	Wellcome Trust	2021	Let's talk about lived experience	Blog	1
5	SMIAdvisor	2022	Engaging People with Lived Experience in Mental Health Services and Research	Bibliography	2
6	Canadian Mental Health Association (CMHA)	2014	Engage People with Lived Experience of Mental Health Conditions and Addictive Behaviours Workbook	Toolkit	3
7	Mind	Unclear	Involving people with lived experience of mental health problems in the design and delivery of your work	Guidance	3
8	Rethink	Unclear. Maybe 2016/17	Progress through Partnership: Involvement of people with lived experience of mental illness in CCG commissioning	Report	3
9	Mind	2017	Lived Experience Influence and Participation Policy: Ensuring that people with mental health problems drive all that we do	Policy	4
10	University of Birmingham	2022	Reflection and learnings on engaging people with lived experience	Blog	2
11	Kaur et al	2021	Directly engaging with People with lived experiences of mental illness from the communities in India	Academic article	1
12	Kohrt et al	2021	Collaboration With People With Lived Experience of Mental Illness to Reduce Stigma and Improve Primary Care Services: A Pilot Cluster Randomized Clinical Trial	Academic article	1

	AUTHORS	YEAR OF PUBLICATION	TITLE	DOCUMENT TYPE	RATING *(relevance & usefulness)*
13	Global mental health peer network	2022	What is our value: Competing for Equality in Funding and Remuneration: Lived Experience Collaboration, Engagement and Consultation	Report	2
14	Community Drug and Alcohol Strategy (CDAS)	Unclear. Maybe 2019/20	Bibliography: Best Practices for Engaging People with Lived Experience of Mental Illness of Addiction.	Bibliography	2
15	Hawke et al	2022	Embedding lived experience into mental health academic research organizations: Critical reflections	Academic article	2
16	Victoria State Government	2019	Mental health lived experience engagement framework	Framework	4
17	Davis et al	2022	Engaging People With Lived Experience in Mental Health Services and Research	Academic article	Unknown (can't access)
18	VOX	2022	Making Coproduction Work	Guidance	4
19	SRN	2022	Making engagement more meaningful	Infographic	3
20	SRN	2022	Moving from consultation to codesign	Report	3
21	SRN	2022	Findings from engagement: one page summary	Summary	3
22	SRN	2022	Findings from co-design sessions	Summary	1
23	Sunkel & Sartor	2022	Perspectives: involving persons with lived experience of mental health conditions in service delivery, development and leadership	Academic article	2
24	Black dog Institute	2018	LifeSpan Lived Experience Framework	Framework	3
25	Black dog Institute	2018	Lived Experience Framework	Report	3
26	Black dog Institute	2020	LE Paid participation policy	Policy	3
27	Alliance	2022	Reducing Stimga, Emphasising Humanity	Report	2
28	Byrne	2016	The stigma of identifying as having a lived experience runs before me: challenges for lived experience roles	Academic article	2
29	Mburu & Sartor	2022	Centring lived experience in anti-stigma programmes	Academic article	2
30	Queensland MH Commission (Byrne)	2016	Promoting lived experience perspective	Discussion paper	2

	AUTHORS	YEAR OF PUBLICATION	TITLE	DOCUMENT TYPE	RATING *(relevance & usefulness)*
31	National Mental Health Commission, Australia	Unclear. Maybe 2019/20	Sit beside me, not above me	Guidance	3
32	Rebecca Johnson, Jess, Kirsty & Rhi	2022	Blog: 'We are a research team!' - Including young people as co-researchers	Blog	2
33	Centre for Addiction and Mental Health (CAMH).	2019	Fostering Meaningful Engagement of Persons with Lived Experience at the System-level	Report	4
34	Faulkner & Thompson	2021	Uncovering the emotional labour of involvement and co-production in mental health research	Academic article	2
35	Landy	2018	Community engagement through the lense of intersectionality	Masters thesis	4
36	NHS	2005	Experience based design using patient and staff experience to design better healthcare services; guide and tools	Guidance	1
37	Richmond et al	2023	Creating positive experiences of involvement in mental health research	Academic article	3
38	Mind	2020	Influence & Participation Toolkit	Toolkit	4
39	SRN	2021	Recovery Conversations Café Toolkit	Toolkit	3
40	Authentic Voice	2022	Discovery Report	Report	2
41	Global mental health peer network	Unclear	Considerations when working and engaging with lived experience with mental health conditions	Summary	3
42	Global mental health peer network	Unclear	Considerations when working and engaging with lived experience with mental health conditions	Report	3
43	Co-Production Collective (UCL)	2022	Our Co-producer Payment Policy	Policy	3
44	Scottish Government	2022	Suicide Prevention Action Plan - Action 7: Experiences of adversely racialised people in Scotland related to suicide ideation		1
45	SRN	2022	Let's do peer group facilitation	Guidance	2

	AUTHORS	YEAR OF PUBLICATION	TITLE	DOCUMENT TYPE	RATING *(relevance & usefulness)*
46	Alliance	2022	Engaging people with lived experience: best practice, challenges and opportunities	Guidance	4
47	Global mental health peer network	Unclear	Policy document for lived experience compensation for work/consultation requests	Policy	3
48	Mental welfare commission for Scotland	2021	Racial inequality and mental health in Scotland: a call to action	Report	1
49	Trevena, Gawlewicz & Wright	2022	Addressing the needs of Scotland's migrant and minority ethnic populations under Covid-19: lessons for the future	Report	1
50	Shaping Our Lives National User Network Community Interest Company	2022	Tickboxes and Tokenism? Service User Involvement Report 2022	Report	3
51	National Survivor User Network & National Involvement Partnership	2015	Involvement for influence	Report	4
52	Smits, Klem & Ketelaar	2019	The Involvement Matrix: Involvement of patients in projects and research - practical guide	Guidance	3

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