

# Regional Mental Health Service

Person with Lived/Living Experience Guidance

## Regional Mental Health Service NI – Person with Lived/Living Experience Guidance

The Mental Health Strategy (MHS) 2021-2031 sets out 35 actions to improve mental health services over the next 10 years. Action 31 of the MHS commits to the development of a Regional Mental Health Service (RMHS), which provides people across Northern Ireland with equitable access to high quality, regionally consistent but locally based mental health services, working across primary and secondary mental healthcare and with the full integration of the community and voluntary sector including the commissioners of services across the region.

This Guidance cannot be read or used in isolation and must be seen in context of, the wider body of strategies, frameworks, and statutory duties that inform practice. Only when considered together with these interrelated frameworks can the principles set out be fully realised in practice. For example, Protect Life 2 and the Substance Use Strategy to reference but two. This applies to the whole HSC system and department of health and not just mental health.

Central to the development of the MHS and the RMHS is ensuring that service users, carers and people with Lived/Living experience are involved in the strategic planning, delivery, and ongoing evaluation of services. Lived and living experience in mental health refers to the personal and first-hand insight gained through experiencing mental-ill health or distress – past or present- and the distinct but equally valid insight gained by carers who support someone through these experiences, creating an evidence base that informs recovery, service improvement, and system change. People with Lived/Living experience bring unique insights that can transform services, making them more person-centred, accessible, and effective. Their involvement ensures that mental health and addiction services are designed and delivered in a way that reflects the needs and priorities of those who use them.

### 1.0 Purpose & Scope

The purpose of this document is to provide guidance and direction to staff and HSC leadership to ensure that those with Lived/ Living experience voices are properly heard and respected in a safe, appropriate and empowering way. This guidance has been co-produced by those with Lived and Living experience, the Mental Health Engagement Platform, the Regional Service User Consultant, Service User Consultants, RMHS, Service User Improvement Managers, SPPG/PHA/DOH. It reflects the collective insight, experience, and commitment of all concerned to improve how mental health services engage with and support individuals in service user involvement. This document is based on best practice from the Mental Health strategy, Department of Health (NI) Co-production Guide, Regional Mental Health Care Pathways (Northern Ireland), Quality Network for Community Mental Health Teams (Royal College of Psychiatrists), and Trauma-Informed Care Principles. By outlining clear standards and values, this guide supports a culture of mutual respect, coproduction, and continuous improvement across mental health and addiction services.

The focus is both on long term and short-term engagement with lived and living experience. Long term engagement requires creating sustained, relational, and reliable structures that extend beyond one-off consultations or events. This can include, for example, establishing standing lived experience panels and maintaining co-production forums that are integrated into processes. To support continuity, participation must be underpinned by consistent communication, clear role expectations, accessible briefing materials, and predictable meeting schedules. Long-term involvement requires ongoing capacity building -such as training and well-being supports – to ensure individuals can contribute safely and confidently. Mechanisms for feedback loops, and impact reporting should be maintained so contributors can see how their involvement shapes change.

Mechanisms for securing the meaningful participation of people with lived experience within the RMHS are currently delivered through the RHMS Regional Service User Consultant and the Patient Client Council (PCC) Mental Health Engagement Platform. These established routes ensure participation is appropriately supported, co-ordinated, and embedded within recognised governance structures. Engagement is undertaken through trauma informed approach, prioritising psychological safety, informed choice, and appropriate support, thereby reducing the risk of harm and enabling authentic, sustained involvement.

Those with Lived and Living experience involvement does not need to be rigid and is often a flexible model of involvement, adopting different approaches depending on the scope and scale of the work, allowing for the most effective input. However, whilst the use of surveys, consultations and focus groups for example have a valuable place in the design of services, this guidance focuses particularly on partnership/shared leadership approaches to engagement.

Within this context, those with Lived and Living experience is to:

- To share experience, knowledge, insight, expertise
- To review and comment on papers, proposals, plans
- To bring issues / concerns from those with Lived and Living experience to the group
- To represent those with Lived and Living experience
- To provide a Lived and Living experience perspective
- To feedback to a Lived and Living experience constituency

## 2.0 Principles

At its core, the purpose of any involvement activity should be to empower service users, ensuring that decision-making is shared, and developing models of healthcare that are co-designed and co-produced between all stakeholders. (NICE Shared Decision-Making pg. 197 2021.)

The following principles should therefore be adopted:

### **Valuing People:**

People with Lived/Living experience bring unique insights — they are experts by experience. They should be treated as individuals, respecting their privacy and dignity.

### **Diverse Expertise:**

People with Lived/Living experience often bring additional skills and knowledge in areas such as community development, education, business, or advocacy. It is important that a wide range of

views and experiences are sought and included, ensuring the co-production process is enriched by this diverse expertise.

**Collective Leadership:**

Leadership is often understood as something hierarchical that meets the managerial needs of an organisation. In an engagement and involvement context, leadership is a collaborative process that shares expertise and life experiences to produce a collectively agreed way forward. It relies on the individual skills and commitment of participants to drive initiatives forward based on shared values and productive communication as part of the planning with each individual piece of work or event.

**Reciprocal Recognition:**

Effective involvement should be based on mutual respect, where the contributions of persons with Lived and Living experience and professionals are equally valued. This principle emphasises the importance of acknowledging the time, effort, and knowledge that individuals with Lived experience bring to the process.

**Cross Boundary Working:**

Meaningful co-production requires collaboration across organisational, professional, and community boundaries. This principle encourages the breaking down of silos to create partnerships between statutory services, voluntary and community groups, and individuals with Lived/ Living experience.

**Enabling and Facilitating:**

Involvement activities should be designed in a way that actively enables participation by addressing barriers such as accessibility, language, digital exclusion, or lack of confidence. Providing appropriate training, support, and flexible engagement methods helps to empower individuals with Lived and Living experience contribute meaningfully.

**Enhanced Accountability and Transparency:**

Transparency in decision-making processes is vital to building trust and confidence in involvement activities. Clear communication about how feedback will be used, what decisions are being made, and how individuals with Lived and Living experience have influenced outcomes is essential. Regular feedback loops should be established to ensure people feel listened to and understand the impact of their contributions.

**Capacity Building:**

Effective involvement requires investment in the development of knowledge, skills, and confidence for both those with Lived and Living experience and professionals. Capacity building includes co-designing and providing training, peer support networks, and mentoring opportunities that enable those with Lived and Living experience to participate on an equal footing.

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### 3.0 Recruitment of those with Lived and Living experience

Multiple factors affect the willingness and ability of people with Lived and Living experience to engage, including beliefs about their role, health literacy, education, access, organisational policies, practices and culture, society and social norms.

The recruitment process outlined in the HSC Personal and Public Involvement (PPI) Recruitment Guide provides direction including outlining background planning, where the purpose of the involvement opportunity, expected commitments, and necessary support systems are defined. Next, a role description and skill set are developed, detailing the responsibilities and desirable qualities of participants.

The guidance provides recommended recruitment methods, including local outreach, through social media, newsletters, and community groups, as well as regional promotion via stakeholder networks and the Engage website. It is important that the Recruitment and Selection process is open and transparent, including any criteria used to recruit e.g. 'first come, first served' or random selection. Recruitment messages need to be clear, jargon-free, and highlight the benefits of participation.

Any personal or sensitive information shared by individuals with lived and living experience during events, engagement activities, or subsequent recruitment into activities, or subsequent recruitment will be handled in accordance with the UK GDPR, the Data Protection Act 2018, the HSC Code of Practice on Confidentiality, and relevant safeguarding frameworks. Personal data will only be collected for a clearly defined purpose, with informed consent where required, stored securely on HSC-approved systems, accessed only by authorized staff, and retained in line with statutory retention schedules. Individuals have full rights to access, correct, or withdraw their data, and any safeguarding disclosures will be managed through established safeguarding procedures in line with regional Adult and Children Safeguarding Policies.

#### 4.0 Support Framework

Managing expectations is crucial, with ongoing communication and support provided throughout the involvement journey. A structured approach ensures the process is transparent, inclusive, and aligned with statutory duties. Key considerations within any support framework should include:

##### **Practical Support:**

- **Access:** How participants actively participate - if online, do they have access to appropriate technology. If in person, is the venue accessible? Ensure appropriate notice is given and consider the length and timing of any meetings. It is important that documentation is provided in a timely fashion and that reasonable adjustments are made if required. This may include alternative formats or easy read versions. The person with Lived/Living experience may be asked open ended questions such as, "Do you have any specific preferences or needs that will help you engage better?" Or the service user may request reasonable adjustments.
- **Costs:** Reimbursement of travel and expenses should, if possible, be provided.
- **Meeting Chairs:** Meeting chairs should ensure all voices are heard and valued. Where possible, it may be appropriate to rotate the position of chair or facilitate co-chairs to insure inclusion and active participation. Where possible this should be expected as a standard that those with Lived and Living experience will cochair meetings. This approach ensures shared ownership, strengthens accountability, and embeds coproduction at the heart of meetings.

- **Communication:** Ensure there are clearly defined mechanisms for communication and provide a key contact person where appropriate. If the person with Lived/Living experience is asked to present at the event the request should outline what area the presentation covers and the duration of the input should be communicated at the earliest opportunity.
- **Training:** RMHS will ensure that participants are fully supported and will have development opportunities so they can build on their skills and knowledge in relation to involvement work. Responsibility for the training will sit with RMHS and Patient Client Council Mental Health Engagement Platform and any training will be agreed with people with lived experience to ensure relevance and authenticity and it meets their needs.

#### **Psychological Support:**

- Where possible access to support for the person with Lived/ Living experience should be provided by a mental health professional or another peer as appropriate, with clear safeguarding procedures in place – including protocols for responding to distress, immediate risk, or safeguarding disclosures in line with HSC Trust policies and regional Adult and Children Safeguarding frameworks. To secure the necessary psychological support – HSC bodies should agree advance protocols such as, for example, referral to Lifeline 08088088000. These arrangements should be written into terms of reference and coproduction guidelines so that every engagement activity has named personnel responsible for wellbeing, clear escalation routes, and timely mechanisms for follow-up support. This ensures that involvement is not only meaningful and valued, but also safely delivered within the safeguarding, governance and duty-of-care obligations. Pre- and Post-meeting debriefing sessions, if appropriate, might also be provided.

Useful questions/ reflections might include:

- Describe the event that led to debriefing.
- What were your initial thoughts and feelings about the situation
- What went well?
- What could have went even better?
- Has this impacted you in any way?
- Do you feel you need additional support? E.g. further debrief.
- What coping strategies or other strategies have been helpful in the past?
- Any other reflections?

#### **Crisis support:**

- Professionals/ Peers should be trained to notice distress signals (withdrawal, shaking, tearfulness, dissociation etc.) If the presentation has impacted or triggered the person with Lived/ Living experience then:  
Move to quieter, calmer and private space with a trained person. The guiding principles are; listen, validate, give choices and ensure follow-up.

## 5.0 Risks

As with any project it is important to acknowledge and provide mitigation for potential risks. A number of potential risks identified in Lived/Living engagement are summarised, adapted and discussed below:

**1. The risk of misunderstanding:** Those with Lived and Living experience and professionals may not understand what their role is and/or commit to something unexpected. Communication challenges including hearing, capacity and language barriers could potentially compound this issue. It is important to ask about needs early and be clear on the role. Provide opportunities for questions and clarification in a non-pressured way. Offering accessible materials and explaining roles can also help.

**2. The risk of predisposed selection:** You are likely to ask the people you think will be good at engaging or have previously participated. These are probably the people who are well educated, articulate, and 'on the same page' as you. This is not necessarily a problem, they have experience and often the confidence to participate in discussions however it is important not to exclude people who you pre-judge to be 'inappropriate' contributors. Recruitment strategies should be adopted to ensure wide inclusivity. An example might be engagement with mental health peer support groups, advocacy organisations, and community networks. Also advertising on social media and traditional print with plain language and visuals may also be of assistance. The posts of Regional Service User consultant and service user consultants may also help spread the word in their networks.

**3. The risk of conflict of interest:** There is a potential that those with Lived/ Living experience and professionals may know each other in a clinical context. In this instance they may be less critical about the issues, over concerns about ongoing or future care. The person with Lived/Living experience should be assured that anything shared is not an invitation for support and is educative and not therapeutic. This is protected under confidentiality. If this risk is identified then an open discussion can be had to assess whether the person with Lived/ Living experience is most appropriate person to deliver.

**4. The risk that those with Lived/ Living experience is too early in their recovery journey or had a relapse.** Informing a service of this requires privacy, empathy and respect. It is important to validate their experiences while ensuring their wellbeing and the quality of the presentation. Ideally the person informing them, such as the person who made the invitation, should highlight their concerns in a supportive way, acknowledging their efforts and commitment. If possible, a later opportunity might be suggested. Reassuring the person with Lived/Living experience and supporting them in processing this decision is paramount. Where appropriate signposting to further sources of support could take place. This risk should be seen in context and not used to exclude those who might be able to present such as those who are still early in their journey but are ready, willing and able or those who might still be actively using substances.

**5. The risk of the person with Lived/ Living experience being no longer required to present due to unforeseen circumstances e.g. event cancellation.** The person with Lived/ Living experience should be given as much reasonable notice as possible. If the event has been reduced in time and the person with Lived/Living experience cannot present, other ways such as delivering the presentation in writing should be sought. A reasonable explanation to the service user should be provided at the earliest opportunity. If the person with Lived/Living requires more explanation, then the concern can be raised at a more senior management level. The role of those with Lived/ Living experience should be kept as central as possible if the event is scaled down or reduced in time.

## 6.0 Monitoring progress and providing feedback

Evaluating the effectiveness of involvement activities ensures continuous improvement and accountability. An evaluation framework might:

- **Set Clear Metrics:** “What success looks like” will be defined for each involvement activity.
- **Collect Feedback:** Input from participants will be gathered to assess the quality and impact of their involvement.
- **Report Outcomes:** Findings will be shared with stakeholders and insights used to inform future practices.

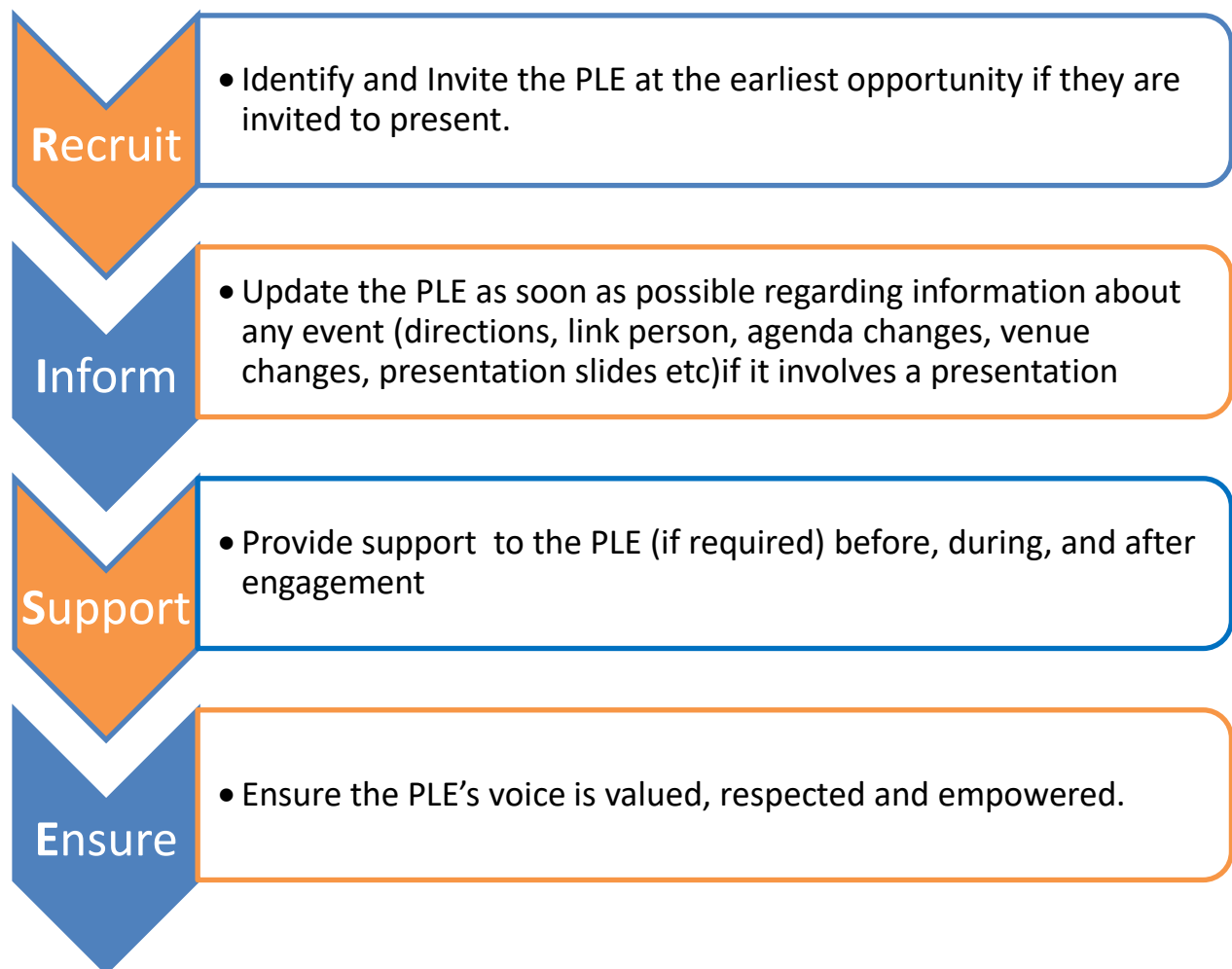
**Key questions might include:**

- What we intended to achieve?
- What participants said?
- What they thought we did well?
- What we can do better?
- What we will do differently next time?

# Appendix - Flow Chart

## RISE

Standards to Apply When engaging with a person of Lived/Living experience (PLE) e.g. in delivery of a presentation



**References**

Mental Health Strategy 2021–2031 (Department of Health NI): <https://www.health-ni.gov.uk/publications/mental-health-strategy-2021-2031>

Co-production Guide (Department of Health NI): [126493 H&SCB - Co-Production Guide.indd](#)

NICE Shared Decision making 2021. <https://www.nice.org.uk/guidance/ng197>

Regional Mental Health Care Pathways (NI): <https://www.health-ni.gov.uk/topics/mental-health-and-substance-misuse-services>

Quality Network for Community Mental Health Teams (Royal College of Psychiatrists): <https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/community-mental-health-teams-cmht>

Trauma-Informed Care: Principles and Practice (NHS Education for Scotland): <https://www.nes.scot.nhs.uk/our-work/trauma-informed-care/>

HSC Personal and Public Involvement (PPI) Recruitment Guide: <https://online.hscni.net/wp-content/uploads/2022/01/PPI-Recruitment-Guide.pdf>

Engage Website (HSCNI): <https://engage.hscni.net/>