NCISH

NCISH Patient and public involvement and engagement strategy (2024-2026)

February 2025

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NCISH PPIE Strategy (February 2025).

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1. PURPOSE

This strategy describes the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) approach to involving, engaging, and informing patients, and their family members, friends or carers who have been involved with mental health care throughout our work.

The experience and views of patients, their family members, friends or carers are important to the work of NCISH. They help inform our recommendations, develop new areas of work, and provide guidance on dissemination. This helps us gain a more rounded and broader perspective of how our research can be developed and utilised to make care safer.

This strategy has been developed by NCISH in consultation with the National Institute for Health Research (NIHR) Greater Manchester Patient Safety Translational Research Centre (PSTRC, the Greater Manchester Patient Safety Research Collaboration (PSRC) from April 2023), including the PPI lead and non-executive lay member of the PSTRC, the Director of the Patient and Public Involvement, Engagement and Experience at the Oxford Academic Health Science Network, and with experts by experience from the NCISH Independent Advisory Group. It has also been reviewed by the NCISH Project Board. The independently-chaired project board includes service user representatives who advise on the direction of the NCISH programme. The first version of the strategy was published in May 2022, and updated in May 2023. This is the second version of the strategy. The strategy is reviewed every two years. Much of this strategy feeds into a shared learning toolkit on patient and public involvement in self-harm and suicide prevention research, created by people with lived experience and researchers from the NIHR GM PSRC and the Centre for Mental Health and Safety at the University of Manchester.

The NCISH patient and public involvement and engagement (PPIE) strategy has the following priority areas:

- Ensuring that patient and public involvement is incorporated across all NCISH work programmes and projects from governance to dissemination;
- Engaging our PPIE group in focused NCISH projects and working with members to promote NCISH, specifically acting as advocates for NCISH's findings and recommendations for patient safety;
- Ensuring the member profile of our PPIE group is regularly reviewed and new member call outs are made to ensure broad representation;
- Exploring strengthening links with the University of Manchester Centre on Dynamics of ethnicity (CoDE) to support PPIE group membership.

2. BACKGROUND AND CONTEXT

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) delivers the Mental Health Clinical Outcome Review Programme (MH-CORP), one of 5 Clinical Outcome Review Programmes managed by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England (NHSE), the Welsh Government, and other devolved nations. NCISH, based within the Centre for Mental Health and Safety at the University of Manchester, is the UK's leading research programme into suicide prevention in clinical services. NCISH is an internationally unique project collecting in-depth information on all suicides in the UK, conducting major studies of suicide on groups such as children and young people, middle-aged men, and veterans of the UK Armed Forces, and providing real-time surveillance data of suspected suicides under mental health care as they occur. We provide crucial evidence and recommendations to support service and training improvements and, ultimately, to contribute to a reduction in patient suicide rates and an overall decrease in the national suicide rate. This evidence is cited in national policies and clinical guidance and regulation in all UK countries.

The NCISH aims to: (i) examine the circumstances leading up to and surrounding the deaths by suicide of people under the recent care of, or recently discharged from, specialist mental health services; (ii) identify factors in the management and care of patients which may be related to suicide and (iii) recommend measures to reduce the number of suicides by people receiving specialist mental health care.

We also undertake studies into suicide prevention in the general population, and report on the incidence of homicide by people in contact with mental health services.

The Centre for Mental Health and Safety also hosts the Manchester Self-Harm Project (MaSH), part of the Multicentre Study of Self-Harm in England, a long-running collaboration with two similar high-quality self-harm monitoring projects (based in Oxford and Derby) and recognised as the most reliable source of data on self-harm in England; the NIHR Greater Manchester Patient Safety Research Collaboration (PSRC), a ground breaking patient safety research collaboration aiming to make health and care systems safer, especially for those with the greatest need for improvement; and the Health and Justice Research Network (HJRN), a multi-disciplinary research network focusing on the health and social care needs of people in contact with the criminal justice system. This puts us in a position to work together to ensure patient and public voices are at the centre of our self-harm and suicide prevention-related research.

3. OUR DEFINITIONS

3.1 Involvement

For us this means we actively involve patients, families, friends, carers, and their representatives involved with mental health services in our research, from the development of research ideas and questions, membership of NCISH governance structures, the development of study design and resources, and the interpretation and dissemination of findings. It does not mean the undertaking of research itself.

Involvement in our research can mean those patients (and their representatives) directly involved with specific aspects of patient care and service provision (e.g. middle-aged men, people given a diagnosis of personality disorder) or input from a more general level with regard to how care can be safer.

3.2 Engagement

This describes the multiple ways in which our findings and recommendations, and the resources we produce based on these, can be shared with a range of professional and non-professional audiences in order to achieve maximum impact. Examples of engagement NCISH have used are shown in Box 1.

3.3 Information

We will continue to improve our provision of information in a range of formats. Information from NCISH will be available on easily accessible platforms and through our social media, we will also continue to work with our partner organisations to dissemination this information as widely as possible.

4. NCISH PPIE APPROACH

We are committed to reflecting the patient experience in our studies at every stage, including study design and methodology, interviews, review of output, dissemination, and governance. We involve, engage with and inform patients, families, and carers throughout our work in the following ways.

4.1 Mutual Support for Mental Health Research (MS4MH-R) PPIE Group

The Centre for Mental Health and Safety has a dedicated PPIE group – Mutual Support for Mental Health Research (MS4MH-R). Established in October 2018, the MS4MH-R includes 18 members with personal experience of self-harm, suicidal behaviour, or of caring for people with such experiences.

Members come from a range of socio-economic backgrounds and diverse communities. Members were recruited in a variety of ways, including public engagement events, social media and through existing local charity and healthcare networks. The member profile is regularly reviewed and regular calls for new members are made to ensure broad representation. Potential new members are asked to complete a simple application form where their skills and experiences are recorded.

The group was set up and developed by the GM PSTRC research team who ensure members can contribute safely through co-designed well-being plans and fluctuations in wellness. Research training and opportunities for further development are provided (e.g. quantitative/qualitative data analysis, reflexivity, public speaking). Several members have spoken at conferences and public engagement events about MS4MH-R's approach to PPIE, including at NCISH's annual conference, and have been involved in research publications. The group have also been awarded "Outstanding contribution to patient and public involvement and engagement" at the University of Manchester Making a Difference awards (2019) and were selected for recognition in the NIHR Clinical Research Network (CRN) Greater Manchester Evening of Excellence awards for "Inspiring Inclusive Involvement" (2021).

Meetings

The group contributes to meetings and individual project tasks. Meetings may be online or in person, the frequency changing in-line with research needs. Meetings are usually attended by two researchers from the GM PSRC research team and 3-10 PPIE members. Guest researchers (such as NCISH project leads) may also attend meetings to hear PPIE views on studies they are responsible for. An agenda is set and circulated ahead of the meeting, with any relevant documentation pertaining to PPIE involvement in individual research projects within the Centre. The Terms of Reference for MS4MH-R meetings are shown in the Appendix. These were co-designed by members of MS4MH-R and GM PSRC researchers Drs Donna Littlewood, Louise Gorman and Leah Quinlivan.

PPIE involvement in NCISH research

Each NCISH project includes PPIE input, which is considered at study conception. When involvement or engagement with a NCISH research project from the PPIE group is needed, MS4MH-R members will be contacted by email, via the GM PSRC PPI Lead. Members will be informed of the subject of the individual project – this may require the involvement of members with specific experience or from a specific demographic group – and what they can expect from the work, including the amount and complexity of the work, fees payable, the expected time commitment, and any deadlines for completion. Members will then respond indicating their interest and their availability. Should there be more members willing to do the activity than funding permits, then this will be resolved based on firstly, members who can demonstrate they relevant experience in the study field and secondly, through random allocation to the activity.

Examples of PPIE contributions to the NCISH work programme, include:

- Reviewing research funding bids;
- Providing advice and feedback on research design, data collection and recruitment plans;
- Reviewing and providing feedback on research documents (e.g. data extraction pro-formas, participant information sheets, lay summaries, revision of questionnaires, survey design);
- Providing feedback on our Healthcare Improvement Plan;
- Taking part in study-specific reference groups (see below);
- Providing feedback on patient safety issues we think need to be reflected in our work;
- Commenting on the interpretation of findings, and advice on how to share this with a range of audiences (e.g. infographics, easy read reports);
- Translating previous study findings into training for professionals working in mental health services (e.g. Safer care for people given a diagnosis of personality disorder: a learning resource).

Payment

To recognise the meaningful contribution to the research process, NCISH offer payment for time, skills, opinions, and out of pocket expenses where this contributes to their work. All members are paid the same. Payment is based on payment benchmarks set out by NIHR of £25 per one hour or less (£12.50 for less than 30 minutes, for tasks such as reading brief summaries or abstracts). Where meetings are held, we pay £25 per hour plus any additional expenses for travel (up to £15) and an additional £5 to cover internet connection costs that may occur when working remotely. We usually allow a minimum of one hour for tasks to widen inclusion. If lunch and refreshments are provided, this will be from University of Manchester caterers at £7.90 per person. The cost of PPIE involvement is considered at the very beginning of study design so it can be factored into the budget management of a study. Payment details are given to PPIE members before they agree to an activity. The GM PSRC PPI Lead and NCISH PPI Lead closely monitor and track payments to ensure contributors are paid as promptly as possible.

Wellbeing

Ensuring the wellbeing and safety of group members is a priority. Most people will have positive experiences from being part of research. However, talking about suicidal behaviour is sensitive and emotive and could trigger painful past experiences. Every member is therefore encouraged to complete a co-designed wellbeing plan when they feel they are well and able to think about what they might find helpful. The GM PSRC PPI Lead and research task lead ensures there are regular wellbeing check-ins and debriefs during and following tasks. Each member involved in completing a task is contacted in the following few days after involvement (either by phone or email, depending on member preference) to check-in on wellbeing. We have a flexible approach and will work around wellbeing. Group members are welcome to take time off from involvement activities and will be welcomed back once recovered. Tasks can be dropped if found to be too distressing without any consequences. The public contributor wellbeing plan, co-designed by members of MS4MH-R and GM PSRC researchers Drs Donna Littlewood and Leah Quinlivan, is shown in the Appendix.

Feedback and engagement

Follow-up emails are sent to members who contribute to our work thanking them for their time and contribution. NCISH researchers also regularly feedback to the PPIE group following involvement tasks, with an overview of the impact their contributions had and the suggestions adopted (e.g. changes made to documents). The PPIE group also receive quarterly updates in relation to the progress of all research projects within the Centre. Feedback and engagement with the PPI group is managed via the GM PSRC PPI Lead.

4.2 Governance

Lay members

An Independent Advisory Group (IAG) provides independent external oversight of the work of NCISH. The IAG includes representatives from key stakeholder groups, and lay members who are involved in key decisions including topic selection for NCISH time-limited studies and quality assurance for reports. The IAG is appointed by our funders, the Healthcare Quality Improvement Partnership (HQIP).

Project Board

Two experts by experience have been recruited to the independently chaired NCISH Project Board for a term of 3 years. The purpose of the Board, which meets biannually, is to oversee the overall direction of the NCISH programme, ensure we continue to address areas of importance to patients and families, and provide guidance on appropriate dissemination. The experts by experience must feel comfortable sitting on a high-level board with the NCISH senior management team, our funders, and representatives from clinical services, research, and big data.

Topic-specific steering groups

For each new time-limited NCISH spotlight study, we convene a topic-specific steering group compromising 10-12 members. This group includes people from organisations which represent the specific topic of interest, academics in the field, and people with lived experience of the field of study (including from the Centre's PPIE Group). Members are invited to join by the NCISH research team, following discussion, on a study by study basis. These focussed groups provide advice on aspects of study design, interpretation of key messages, including the language and tone of draft reports, and dissemination.

4.3 Dissemination

We are dedicated to translating our research findings and recommendations into formats that are most likely to reach services, and the people who use them, and improve their safety (see Box 1). All NCISH findings and recommendations are therefore presented in a range of formats, including lay summaries of findings, infographics, animated videos, slide sets and dedicated webpages for each report we publish, which are suitable for multiple audiences and easily available on the NCISH website. Our findings and resources are regularly publicised through social media (@NCISH_UK) to reach as wide an audience as possible. All NCISH annual and topic-specific reports are written in plain English with all specialist vocabulary explained to ensure they can be read by professional and non-professional audiences. Jargon and acronyms are avoided or (where necessary) explained.

Box 1: Examples of NCISH engagement and dissemination

NCISH website

The NCISH website is continually updated and developed to raise awareness of our research and our findings and recommendations for safer care (including lay summaries). It includes dedicated report pages for every report we publish.

NCISH annual conference

Findings and recommendations from our annual report (and topic-specific reports, if applicable) are presented at our annual conference (currently virtual), which attracts both UK and international registrants, including ~100 service users and representatives from third sector organisations.

Infographics

Our infographics, designed for both clinicians and service users with input from our PPIE group, accompany our annual reports and the majority of our topic-specific reports. They are intended to promote and share onward learning from our research in a quick and simple way.

Animated videos
We produce short (~2/3minutes), animated videos of the key findings and recommendations from each of our reports. We have also produced longer videos (including transcripts) of our senior clinical academics discussing our report findings.
Easy read report
To accompany our annual report, we also produce an “easy read” version of the report with input from our PPIE group. The easy read report uses easy words and pictures to tell people about our work and what our findings may mean for their care.
Web-based learning resources
We produce a number of resources available for teaching and local dissemination, including data slides and toolkits intended to be used as a basis for self-assessment by mental health care providers.
Safer care for patients given a diagnosis of personality disorder: a learning resource
This online resource was designed to help staff working in mental health services understand more about what it means to have been given a diagnosis of personality disorder and how to help people who present to services with this diagnosis. It comprises four videos examining different aspects of safer care for people given a diagnosis of personality disorder and includes the personal testimonies of people who have been given this diagnosis and the expertise of clinical academics.
Speaking invitations
Our senior clinical academics and researchers present our work to a range of audiences, including the NHS, local authorities, and schools.
Social media
We regularly tweet about our research from our @NCISH_UK Twitter account, reaching ~9,250 followers.
Science festivals
Our researchers attend science festivals open to the public with debates and discussions on our research.
Exhibition stands
We hosting exhibition stands at national conferences offering delegates the opportunity to find out more about our research.
Public events
We attend public events dedicated to bringing researchers closer to the public closer to showcase research and highlight its impact on day to day lives.

Alongside our reports we produce dedicated resources for patients, their families and carers, including infographics of key messages and videos of key findings and clinical messages, with transcripts. We plan to develop a living web resource of relevant outputs alongside quality-assured reports that are relevant to the field of suicide prevention research. Patients, carers and members of the public are a key audience for this planned resource, which will include accessible summarises of relevant reports, guidance and policies alongside NCISH evidence.

We continue to invite a speaker with lived experience to our annual NCISH conference, to provide essential context to our findings. To ensure this lived experience is valued meaningfully we offer to pay our speaker a fee commiserate with our NCISH senior clinical academic speaking fees, along with covering travel and expenses.

4.4 Priority consultation

We continue to consult with service users about priorities for safer care and how we can develop our work via social media, our service user feedback form and stakeholder survey (these are available via our website). Feedback provided via these forums is regularly reviewed and feeds into the development of our questionnaires, and topic selection for key areas to investigate in the NCISH annual report and for individual studies.

4.5 Opinions on specific aspects of care

We are committed to listening to patient views. Each of our topic studies includes a plan for PPIE input. This is worked out as early as possible in the design of the study and is decided by the project research lead and in collaboration with NCISH's PPIE Lead. We have recruited patients (and their families, carers) to tell us about their experiences and opinions on specific aspects of patient care and service provision. For example, the expert reference group for our study on suicide by people under the care of alcohol and drug services, included people with experience of drug and/or alcohol misuse/dependence. Previously, we have asked about experiences of risk and safety assessment and views on personality disorder and psychiatric in-patient services. Future work seeking the experiences and views of patients and their families on specific aspects of care will be published on our website and via social media.

5. EVALUATION AND IMPACT

The impact of NCISH PPIE is measured by:

(1) Monitoring the level of involvement, particularly within our established PPIE group. Members are offered regular check-ins to discuss what they are gaining from their involvement, including negative issues. Panel meetings are used to allow reflection on research experiences and offer opportunity for panel members to share projects they have worked on and what they thought did (or did not) work well;

(2) Monitoring our inclusion of comments and suggestions as provided by members of the PPIE group, and the effects of these suggestions, i.e., what changes we have to make to studies in response to this involvement;

(3) Monitoring stakeholder and service user opinion about our work quality, relevance and PPIE inclusion via the NCISH stakeholder survey, service user feedback and via social media.

6. OUR RESOURCES

Dr Cathryn Rodway, NCISH Programme Manager and Research Fellow, oversees PPIE involvement on behalf of NCISH. This includes co-ordinating NCISH involvement in face-to-face events with MS4MH-R, overseeing all PPIE paid tasks and overall responsibility for developing and improving PPIE across the NCISH work programme. We ensure that payments to contributors for PPIE-related work are consistent with NIHR guidance and are applied consistently across all NCISH work programmes. The MS4MH-R PPIE group was established by GM PSRC Researchers Drs Leah Quinlivan and Donna Littlewood with significant and ongoing support from Dr Sarah Steeg. Leah Quinlivan is the GM PSRC PPIE Lead. She continues to monitor and manage PPI Involvement and wellbeing across the Centre for Mental Health and Safety.

7. APPENDIX

7.1 The MS4MH-R Group Terms of Reference

Revising the terms of reference
Terms of reference will be subject to an annual review (or as required).

Aims of lived experience panel
The aims of the group are to:
• Provide views, opinions and insights informed by lived or carers experience of self-harm and/or suicidal thoughts and mental health services to inform research in this area;
• Help to interpret research findings;
• Provide ideas on how we can share research findings with the wider public;
• Promote and publicise research conducted by the Centre for Mental Health and Safety and the role of lived experience involvement in research;
• Members to have an active role in questioning research and research processes.

Membership
• Membership is open to any member of the public who meets the experience requirements specified, is aged 18 and above, and is not currently practising as a healthcare professional.

7.1.1 Working together agreement

All members are expected to observe and abide by the points below:

Confidentiality
• As members of the research team, panel members have a duty to treat anything said in meetings as confidential (unless written permission has been granted);
• Members have a duty of confidentiality concerning knowledge about the research being undertaken in line with University of Manchester Intellectual Property guidance (available on request);
• Confidentiality extends to information shared by other members of the group, including people's personal experiences of accessing health services;
• Safeguarding concerns: confidentiality should be broken if someone discloses information about risk to self or others.

Meetings
• It is anticipated that meetings will be held approximately three times per year;
• A meeting agenda will be sent to all members prior to the meeting, which will include details of the meeting, including specific venue (for in-person meetings) and information regarding any guest speakers who will be attending the meeting;
• Action points from the meetings will be taken by a representative from the Centre for Mental

Health and Safety;

- The fee for attendance at meetings, or in relation to remote reviewing activities, will be outlined prior to the activity taking place;
- Expenses to cover travel to and from meetings will be reimbursed in line with relevant Centre policy. This will be clarified by the researcher organising the meeting;
- Start/end our meetings on time and follow an agenda;
- Keep to the task; no side conversations;
- Mobiles on silent;
- Everyone will read materials ahead of the meeting and will be prepared to provide input at meetings;
- All work together as a team and seek to reach general agreements all can “live with”.

Online/remote meeting (Zoom/Teams etc.)

- Maintain privacy and confidentiality throughout the meeting. Be mindful about your location and who else could hear what is being discussed;

Communication

- Listen to others, speak one at a time and don’t interrupt or talk over people;
- Be able to speak freely and openly, without any judgement (no right/wrong answers);
- Speak clearly as some people may find it difficult to hear or understand;
- Ask questions and seek clarification where matters are not clearly explained;
- Use non-technical language or jargon, and provide clarification of terms as requested;
- Everyone’s opinion and experiences are of equal value and all must be equally respected;
- Members will be given the option to provide input in writing as well as verbally in meetings;
- People will have the opportunity to state their preferred communication method for commenting on documents (e.g. via email, post, telephone call);
- Researchers will provide regular updates in relation to progress of the project.

General ways of working

- Following meetings members will be given time to reflect on topics and discussions raised and have the option to provide additional input within a specified time period post-meeting.
- Researchers will aim to provide activities and tasks which are manageable and not overwhelming. Members will commit to providing feedback to researchers if they fail to do this;
- Only work on projects when you feel well enough to do so;
- Members can opt-in and opt out of work. Please let the researchers know which projects/ documents you have time to review;
- Researchers will provide an overview of specific reviewing/involvement activities to the group. Should there be more members willing to do the activity than funding permits, then this will be resolved based on drawing member’s names from a hat/using a randomiser to allocate the activity;

- Researchers will feedback to group following involvement tasks, to include overview of impact resulting from group's involvement (e.g., changes made to documents).

Source: NIHR. MS4MH-R PPIE Group. Version 5 (16.05.2024)

7.2 Wellbeing plan for public contributors: self-harm and suicide prevention research

As a member of the lived experience research advisory panel you will be asked to give your thoughts and input into the development and communication of self-harm and suicide research. Therefore, this will involve discussing topics such as suicide, self-harm and mental illness. Group members' wellbeing and safety is our priority. As such we wish to remind members that we would like them to prioritise their own wellbeing first, and only contribute in ways that they feel are safe and do not negatively impact their personal wellbeing.

In discussion with the group, we agreed that we would all complete a wellbeing plan – as a way of helping us to safely manage our involvement in the group.

Members will be asked to complete the below plan at a time when they feel they are well and able to think clearly about what they may find helpful. We will store a copy of the plan in a locked cabinet in a secure office. Members will be given the option to share a copy of the plan with a trusted friend, family member or healthcare professional.

Name	
Date of birth	
Address	
Postcode	
Phone number	
Email	

Early warning signs that I am becoming unwell may include:

When I notice any of these signs, I will do the following things that have helped in the past:

(For example, some people find it helpful to talk to trusted friends, family or support services? Some also find that doing things to distract themselves is useful – can you list things here?)

If I have suicidal feelings, or thoughts of harming myself, I will do the following things that have helped in the past:

Where will I go to help me feel safe?

What I would like others to do if they notice these signs or if I become unwell:
If I feel like my involvement in MS4MH-R is having a negative impact on my wellbeing, I will take the following steps:

To be discussed in a meeting – so we can agree how the research team can link in here

Please complete the below section(s) if you would be happy for us to share your wellbeing plan with trusted friend(s), family member(s) or healthcare professional(s).

Their name	
Their relationship to me	
Address	
Postcode	
Phone number	
Email	

Their name	
Their relationship to me	
Address	
Postcode	
Phone number	
Email	

I agree that the researchers may retain this wellbeing plan in a secure cabinet and share the plan with the trusted individuals whose details I have provided above.

Name of member: Signature: Date:

Name of researcher: Signature: Date:

Source: Littlewood DLL, Quinlivan L, Gorman L, Webb RT, Kapur N, & the members of the Mutual Support 4 Mental Health Research (MS4MH-R). *Wellbeing plan for public contributors: self-harm and suicide prevention research*. NIHR PSRC – Mental Health, 2024.