Patient and public involvement in self-harm and suicide prevention research: shared learning toolkit

Toolkit created by people with lived experience and researchers from National Institute for Health and Care Research Greater Manchester Patient Safety Research Collaboration (NIHR GM PSRC) and the Centre for Mental Health and Safety at the University of Manchester

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The University of Manchester

NIHR | Greater Manchester Patient Safety Research Collaboration

This toolkit is a working document and will be updated according to feedback received and as new resources become available. This toolkit is freely available to use for planning patient and public involvement and engagement (PPIE) activities. We'd love to know how you have learnt from the toolkit. If you'd like to use any of the freely available templates, please do acknowledge the team using the citation below.

Citation:

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Thanks to Dr Donna Littlewood, who was a co-founder of MS4MH-R and an integral part of establishing the PPIE processes at the Centre for Mental Health and Safety.

About the team

The team includes researchers and public contributors (patients and carers) with personal experience of self-harm, suicidal behaviour, suicide bereavement and attending mental health services. The team is based in the Centre for Mental Health and Safety at the University of Manchester. They have extensive experience in self-harm and suicide prevention research and co-production.

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Summary

Suicide and self-harm are key public health and clinical concerns internationally. For over 20 years, the team at the Centre for Mental Health and Safety has conducted research to reduce suicide and improve patient safety for people who attend healthcare services for self-harm or mental health conditions. Experts-by-experience are involved throughout all stages of our research. We developed this toolkit to share experiences, tips, and strategies for patient and public involvement that developed from our self-harm and suicide prevention research.

Some researchers and public contributors may be apprehensive about involvement work in sensitive research topics, such as self-harm and suicide. However, research demonstrates that involvement in self-harm and suicide prevention research can be beneficial for people and does not increase people's risk of further self-harm or suicidal behaviour.

In this toolkit, we provide a brief overview of patient and public involvement, and describe co-designed processes that facilitated good practice in our work. We summarise issues to consider when planning and conducting meaningful involvement activities including: diversity and inclusion, accessibility and flexibility, training and development, payment, wellbeing (researcher and public contributor) and online safety. Practical issues like recruitment, developing involvement plans and activities, and a range of tips/strategies to facilitate meaningful involvement and engagement are also overviewed. Throughout our work, we developed a range of co-designed documents (e.g., wellbeing plans, researcher PPIE development plans, and ground rules). These resources, in addition, to wide range of open-access links and templates are also included in the toolkit.

The purpose of this toolkit

We hope to share learning from our patient and public involvement work in self-harm and suicide prevention. We hope that sharing our experiences will help involvement practices in research and particularly in self-harm and suicide prevention.

How to use this toolkit

You can read each section, or focus on the parts that are relevant to you. You can download a copy, take notes, and highlight parts that mean something for your work. It may be helpful to think about the processes and how they may apply for your work. Use the toolkit to open discussions, share content with others and develop knowledge according to your needs. Make it your own.

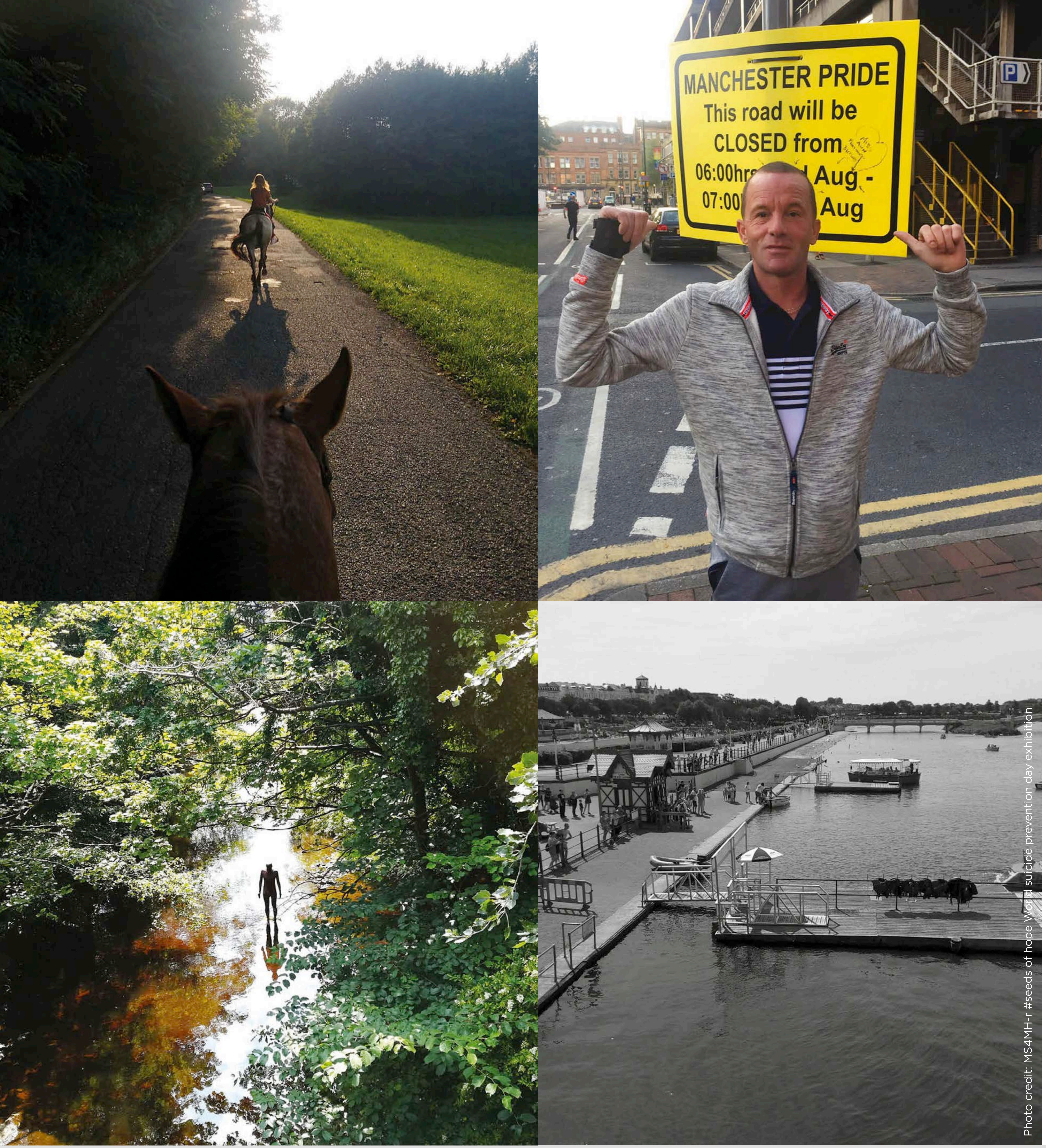

Photo credit: MS4MH-r #seeds of hope World suicide prevention day exhibition

Who will find this toolkit useful?

Anyone (e.g., researchers, public contributors, and clinicians) who is planning self-harm and suicide prevention research or quality improvement studies may find this toolkit helpful. This toolkit is designed as an introductory guide and should be read alongside existing resources for conducting patient and public involvement. We've listed some helpful references to existing sources throughout the guide.

Help in a crisis

This toolkit does not provide treatment or advice about care for people in crisis. If you are in crisis or feel suicidal or like hurting yourself, please seek help from your general practitioner, local hospital emergency department, helpline service, or by discussing your problems with a trusted friend, family member, or colleague. Some UK support services are available on page 56

Terms used in this document

Patient and public involvement terms

Terms for patient and public involvement vary and change over time. The term ‘public’ includes any communities, patients, carers, and any people that use health and social care services. NIHR has recently started to use the term ‘Patient and Community Involvement and Engagement’. Both terms refer to an active partnership between patients, the public, and researchers throughout the research process.

Public contributor term

We use the term public contributor in this document for anyone with personal experience of self-harm, suicidal behaviour, and using healthcare services (e.g., emergency departments, primary care and/or mental health services). Public contributors can be current or previous patients in healthcare services, or carers of people with such experiences.

Lived experience

We also use the term ‘lived experience’, or ‘personal experience’ of self-harm/ suicidal behaviour. We recognise that people may be currently ‘living their experience’ on a daily basis. Mental health and psychological distress fluctuate. People decide for themselves if they are ready to contribute to research studies.

About us

Our areas of research

Our research is focussed on improving patient safety for people who have self-harmed and/or attend healthcare services for mental health conditions. We also try to understand patterns in self-harm, health service use, deaths by suicide and other events (e.g., repeat self-harm, death by any cause). This shared learning resource developed from our extensive programme of work across the Centre for Mental Health and Safety at the University of Manchester.

Self-harm and suicide prevention context

Suicide is a major public health and clinical concern, with more than 700,000 people taking their own lives each year globally. [1] The loss of life has devastating effects on families, friends and the person's wider network. In England, the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) report that around a third of people who die by suicide are in contact with mental health services and people often reach out to healthcare services prior to their death. Self-harm is an important clinical issue and strongly associated with future non-fatal and fatal self-harm. Healthcare services have an important role in suicide prevention, by providing good quality care.

Typical research methods

We use a range of research methods including those based on numerical (quantitative) approaches and analysing what people say about their experiences (qualitative). Some of our research papers and projects with patient and public involvement are included on page 53

Quality improvement in healthcare

We work closely with healthcare services to translate and implement research on self-harm and suicide prevention to clinical practice. Healthcare services often use quality improvement methods to improve patient care. Quality improvement approaches use quantitative and qualitative methods to improve healthcare systems, whilst working closely with staff, patients and carers/families.

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[1] World Health Organization key facts

Our patient and public involvement activities

Our involvement activities are based on the UK Standards for Public Involvement. These UK-wide standards provide guidance on conducting good quality and meaningful public involvement.

For example:

- Providing inclusive opportunities
- Working together and valuing all contributions
- Building relationships
- Support and learning opportunities
- Involving the public in governance
- Using clear communication, and sharing the difference that involvement makes to research

If you are thinking of any involvement activities, the NIHR resources and UK Standards for Public Involvement are a great way to start your learning. We also recommend also referring to the University of Manchester, Faculty of Biology, Medicine and Health information and toolkit on patient and public engagement (open access).

Public contributors who want to be involved in research at the Centre for Mental Health and Safety

Public contributors are welcome to be involved in our self-harm and suicide prevention research if they have personal experience of self-harm, suicidal behaviour or attending mental health services. Public contributors are experts by lived/living experiences. No research experience is required or assumed. We have a flexible approach to patient and public involvement and are happy to work around individual needs.

The Faculty of Biology, Medicine and Health has a freely available induction guide on Being a Public Contributor, for people who are involved in research at the University of Manchester. They also have a great PPIE blog and an email 'public engagement' digest with training and other opportunities. The Faculty of Biology, Medicine and Health has also created an excellent toolkit for patient and public involvement and engagement. Training is often provided by the research team and via the University of Manchester (links below).

Patient and public involvement and engagement resources at the University of Manchester

Website: University of Manchester PPIE website

Public contributor introductory guide: Being a public contributor

Community and engagement groups at the University of Manchester:

Patient and public involvement | Social responsibility | The University of Manchester

Social responsibility and community digest:

Contact social responsibility | Biology, Medicine and Health | The University of Manchester

Faculty of Biology, Medicine, and Health PPIE resources:

Website of resources: Resources | Public and patients | Biology, Medicine and Health | The University of Manchester

PPIE toolkit: PPIE toolkit | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester

NIHR Involve:

Starting out: essential information for members of the public who are thinking about getting involved in research

What is patient and public involvement and engagement?

Patient and public involvement and engagement (PPIE) is an active partnership between public contributors and researchers. Public contributors in our research include patients, carers, and people with personal experience of self-harm, suicidality, and accessing health and social care services. For example, those people attending emergency departments, accessing mental health services, or their GP for self-harm/suicidal behaviour. Patient and carer public contributors use their experiences to inform and enrich how research is designed, carried out and shared more widely.

Participation

NIHR also discusses participation in research. Involvement is not the same as participation in research studies. Involvement includes people with lived experience contributing to research (e.g., developing research questions, reviewing documents, analyses). 'Participation' is focussed on recruitment and taking part in research studies, for example techniques used to recruit participants, or patients being interviewed about their experiences or undergoing a trial treatment.

	Patient and public involvement, engagement, and participation includes:
1	**Involvement:** guidance on research from a lived experience perspective (e.g., co-applicants on grants, advising on research questions, methods, recruitment strategies, defining priorities, reviewing research materials, acting as co-researchers for interviews, conducting analyses, contributing to papers, presentations)
2	**Engagement:** the translation of research and involvement activities to the public (including patients and healthcare services) (e.g., engagement events or arts led events to talk accessibly about research or patient involvement)
3	**Participation:** increasing uptake and awareness of research studies (techniques to improve recruitment, or recruitment into research studies, such as trials or survey research).

Involvement

"Each member brings their own different views, insights, experience, and knowledge, which as a group allows us to review and consider"

- JS (Public contributor)

Photo credit: MS4MH-r public contributor #seeds of hope World suicide prevention day exhibition

Why is patient and public involvement important?

Self-harm and suicide prevention are emotive and sensitive topics. Decades of research have been conducted in self-harm and suicide prevention, but patient and public involvement in this area has only occurred relatively recently. Similar to the concerns of ethics committees, some individuals may be concerned about discussing sensitive topics with people who may be feeling unwell, or experiencing psychological distress. However, we've found that researchers and public contributors can thrive, professionally and personally, via their involvement activities in research.

Patient and public involvement ensures that research is done collaboratively, with or by people rather than about them. Involving public contributors ensures that research is accessible, meaningful, and relevant. Patient and public involvement also strengthens research, dissemination, and implementation practices.

We hope this toolkit will help both researchers and public contributors feel more confident when planning involvement and engagement work in self-harm and suicide prevention research.

Equality, diversity, and inclusion

Equality, diversity and inclusion (EDI) in patient and public involvement and research is essential to ensure research is meaningful and accessible to all people. NIHR INCLUDE use the term ‘under-served’ for people who may experience barriers to inclusion through no fault of their own. NIHR INCLUDE provide a roadmap for building inclusion into all aspects of research (e.g., setting research priorities, research questions, through to impact, dissemination, and engagement). NIHR state that the term ‘under-served’ is context and study specific. Please read the information on [Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project | NIHR]

Protected characteristics and other imbalances

Protected characteristics according to the Equality Act 2010, include: age, disability (includes for example, mental health conditions, autism, attention deficit hyperactivity disorder), gender reassignment, marriage or civil partnership, pregnancy and maternity, race, sex, sexual orientation. Other imbalances and inequalities to consider include: socio-economic status, geographic location, and access to health and care.

Intersectionality

Some people may have overlapping characteristics and social identities which may exacerbate experiences of inequalities.

Race Equality

The NIHR Race Equality Framework tool is designed to address inequities people from Black African, Asian, and Caribbean heritage communities. People from these communities are under-represented in patient involvement and research. The NIHR has collaborated with the Centre for Ethnic Health Research at the University of Leicester to develop guidance on designing and conducting research that is sensitive and inclusive of Black African, Asian, and Caribbean-heritage people. NIHR have also published the INCLUDE Ethnicity Framework to create greater awareness of the diversity of health and cultural needs of potential participants. NIHR developed the Patient-Public Partnership Model to include patient-public voices: their model is:

LISTEN + RELATE + RECOGNISE + INCLUDE
NIHR Race Equality Framework tool

NIHR Patient-public partnership model: LISTEN + RELATE + RECOGNISE + INCLUDE (from the NIHR Race Equality Framework)

1. Listen to people from Black African-, Asian-and Caribbean- heritage communities. Acknowledge lack of trust in healthcare and research;
2. Engage in open and honest conversations to relate more deeply and strongly with these communities;
3. Recognise what you are doing in your organisation/group that is not inclusive and causes harm;
4. Include members of the public from these communities by inviting them to be part of this work, giving them credit for their opionions and compensation for their time.

Helpful links and guidance on Equality, Diversity, and Inclusion

NIHR Equality, Diversity, and Inclusion strategy 2022-2027

NIHR Equality, diversity and inclusion

NIHR Improving inclusion of under-served groups in clinical research: Guidance from the INCLUDE project

NIHR INCLUDE

The INCLUDE Ethnicity Framework

NIHR Race Quality Framework

UK Standards for Public Involvement

Race equality in public involvement

The Centre for Ethnic Health Research: Increasing diversity in research

The Centre for Ethnic Health Research: Increasing participation of Black Asian and Minority Ethnic groups in health and social care research toolkit

Being human delivering inclusive activities

Being human planning for inclusion

NIHR Learn course

Photo credit: Thomás the Greek in Ireland and Dr Katerina Kavalidou

Accessibility and disability

Around 1 in 5 people have a disability*, which may or may not be visible. Disabilities may include physical disabilities, long-term mental or physical health conditions, or neurodivergence. People may have overlapping conditions (e.g., neurodivergent with a physical disability, and long-term health condition). These conditions may also overlap with other social identities and systems of oppression or discrimination.

True equality, diversity and inclusion can only happen when involvement and engagement activities are accessible for all research staff and public contributors. Unfortunately, many locations continue to be inaccessible for people with disabilities. Some helpful links for further reading about accessibility on page 19.

*Disability Action Plan, UK 2024

Tips for inclusive meetings/events

- Ensure your event is fully accessible for people with physical disabilities and reduced mobility
- Consider hybrid meetings as standard for increased inclusion
- Avoid early morning starts, and rush hour/school pick-up times (e.g., 9am, 5pm)
- Provide visual maps with directions to any venues
- Provide poster/oral presentation with a universal design regarding fonts e.g., Trebuchet MS font, and colours through accessible colour palette web sources. Such as Adobe colour contrast analzer
- Provide clear accessibility information ahead of any meetings, including a contact person in case any issue arises. Have a list of disabled people attending in case of evacuation due to a fire and provide this to the emergency services when they arrive
- **Once people have registered for an event/conference:** Enquire about any adjustments necessary to allow full inclusion for people (e.g., step-free accessibility for wheelchair users, accessible toilets, step-free and accessible podiums for disabled presenters, headset wireless microphones instead of typical microphones, reduced lighting, consideration of background noise, alternatives to clapping, communication needs, access to a quiet space, water bowls and space for assistance animals)
- During any warm-up sessions/icebreakers, or activities: Avoid ableist language and physical sensation techniques (i.e. body movements, physical grounding), and consider individual sensitivities for activities.

Helpful links and guidance on accessibility and disability

- University of Manchester Disability Advisory and Support Service
- University of Manchester Accessibility: campus information
- DisabledGo: AccessAble. This website is also available as an app on the App Store or Google Play
- Goblin tools formalizer
- Creating Neuro-inclusive events
- Neurodivergent enabler
- ADHD Foundation
- Equality and Human Rights Commission (2018). Engaging with disabled people: An event planning guide
- University of Manchester (2023). Make your event accessible. University of Manchester
- University of Manchester: Equality, Diversity, and Inclusion website and resources

Developing involvement plans for research studies

Thinking about your research

When planning research, it is helpful to develop detailed involvement plans. For example, it may be helpful to detail research questions, potential patient groups, diversity and inclusion strategies, methodology and outcomes, and how involvement activities can help you reach your research goals. It is good practice to complete an Equality Impact Assessment for any research activities to ensure under-represented groups are considered in research. We also use the NIHR Equality Impact Assessment (EqIA) Toolkit.

What to consider for research studies

- What is your research question?
- What patient groups are involved in your study?
- What are the research outcomes?
- What is involved for participants?
- Which aspects of your research would you like patients and/or the public to be involved in?

Equality impact Assessment

- How will your research affect people differently or impact upon equality?
- How will you address potential inequalities and include underserved communities?

Photo credit: MS4MH-r public contributor #seeds of hope World suicide prevention day exhibition

Thinking about your involvement plans

Your involvement plan can detail which members of the public you would like to engage in your research, how often you will involve them, and any funding and payment procedures.

Things to think about in your involvement plan

- Have you considered equality, diversity, and inclusion as part of your involvement strategy?
- What types of lived/living experience, skills, and experience would be most helpful to your research?
- What roles will public contributors have throughout your project? For example, advising on the research topic, questions, recruitment or methods, reviewing documents such as funding bids, analyses, dissemination.
- How often would you like to involve public contributors? What are the time commitments? For example, preparation, reading, travel, meetings.
- What is your funding and payment process for involvement and engagement activities? Map involvement activities and estimate the cost for each activity.
- Have you any training or development plans for public contributors? Consider asking your PPI group what training might be useful for them. to develop their roles as public contributors.

Templates from the Faculty of Biology, Medicine, and Health:

[Guidance documents and templates | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester]()

Recruiting patients and the public for your involvement group

When recruiting public contributors:

- Think about contexts: **Reach out to people in their own contexts** (community groups, voluntary sector organisations). One of our members recommends having an initial visit to a new group to understand group dynamics and any interpreter needs
- Recognise that different cultures have different health beliefs and understandings
- **Be flexible and have a wide reach**: Public contributors at the University of Manchester PPIE group, MS4MH-R recommend chatting to people at community events, university public engagement events, and working with local services. You could also reach people through social media and patient-led organisations
- **Clear communication**: Design recruitment materials to be accessible, and use clear wording and visual images. We include photos of our researchers on flyers. You can share these at events, community groups, and online
- Be **culturally aware, mindful of language, and ensure relevance and sensitivity** when designing/writing recruitment materials
- **Be transparent around what's involved in terms of time commitment**, travel, types of tasks, participation, and payment.
- **Connect with other patient and public involvement groups** to offer people the chance to contribute other areas of personal experience. For example, public contributors may have physical and mental health experiences
- **Consider how different identities overlap** (e.g., intersectionality of social class, disability, gender, ethnicity)
- **Build meaningful relationships with community leaders** from the groups you identify for your research focus. They can help form 'bridges' into communities who may have never engaged with research before or who may mistrust research
- **Treat people with kindness, encourage feedback, and adopt a learning mindset.**

University of Manchester, Faculty of Biology, Medicine, and Health links:

PPIE toolkit | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester

Template PPIE Information Sheet.docx

Template Appointment Letter Public Contributor

Working together agreements

During our initial meetings, we co-developed a ‘working together agreement’, which allowed us all to understand expectations from researchers and public contributors. We found it helpful to discuss different ways of working and any flexibility needed when contributing to tasks. Examples of areas to discuss when setting up a ‘working together agreement’ include:

- Overview of the flexibility in tasks - including when or if people need more time when providing input into tasks
- Agreeing how to allocate tasks when more contributors wish to be involved than funding permits
- Agreeing on what tasks will typically involve and expected timelines
- Outlining the payment processes
- Agreeing a process for managing wellbeing (see wellbeing section for template wellbeing plans)
- Agreeing a process for feeding back following involvement tasks and how to reach consensus of opinion
- Define the remit of confidentiality in terms of both personal experience and intellectual property
- Reassure people about their right to anonymity and be explicit about where this may be compromised.

We also provided information on contact details and the excellent document ‘Being a public contributor’ developed by the Faculty of Biology, Medicine, and Health at the University of Manchester

Templates:

Please also see the University of Manchester, Faculty of Biology, Medicine, and Health’s templates for examples of ‘terms of reference’ and examples of ‘ground rules’ documents: Guidance documents and templates | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester

Photo credit: MS4MH-r public contributor #seeds of hope World suicide prevention day exbition

Flexibility and ways of working

Flexibility is an important cornerstone of our work and enables people to continue working even when they become unwell. Wellbeing is always the top priority. We always have an open door for people to contribute to research whenever they feel well enough again. We always emphasise the importance of wellbeing, taking breaks and/or stopping any activity that makes public contributors feel upset or distressed.

Tips for building strong relationships

- Establishing trust takes time, commitment, loyalty, honesty, generosity, acceptance and acknowledgment
- Strong relationships enable people to feel confident enough to contribute and feel their voice is heard
- Recognise that everyone brings their own skills and experiences and create opportunities for individual personal development
- Consider chatting with members and seeking feedback and reflection – this will benefit the researcher and the public contributors.

Photo: Elizabeth Monaghan MS4MHr public contributor speaking at NSRF PPIE event

Training and development

Training and development opportunities for public contributors strengthen skill sets and learning and can provide valuable experience for further employment or educational opportunities.

We've provided in-house training on:

- Reviewing research
- Providing feedback
- Public speaking
- Dissemination
- Quantitative and qualitative analysis

We also provide top-up training before tasks (e.g., top-up qualitative training). Members have also attended conferences as participants and keynote speakers, and external training. The University of Manchester has an excellent 'Social Responsibility and Public Engagement Bulletin' for patient and public involvement, that outlines opportunities, events, and training in patient and public involvement. Check it out and look around for any opportunities local to you and your organisation.

Faculty of Biology, medicine, and Health: Working together: patients, staff, and the public website and resources

Payment*

All involvement work should be paid. We pay for any involvement tasks using the detailed guidance and payment benchmarks set out by NIHR. Please do read their detailed guidance Payment guidance for researchers and professionals | NIHR when planning any involvement work.

Consider how much time an involvement activity task will take (example activities are on page 30), and any additional expenses for travel and internet connection costs that may occur when working remotely. Please do consider that reading/focusing may take longer for some public contributors due to medications or feeling unwell. We usually allow an hour as minimum for tasks to widen inclusion in our feedback processes.

NIHR payment benchmarks (adapted from their website: Payment guidance for researchers and professionals | NIHR)

Time	Cost	Examples
Less than 30 minutes	£12.50	Reading brief summaries, abstracts, or research alerts
One hour or less	£25.00	Participating in a one-hour meeting, reviewing study document, or proposal
Two hours approximately	£50.00	Might require some preparation, or more intense work, or participation in a two-hour meeting.
Half day activities	£75.00	Around a half-day activities, for example delivering training, or tasks that require preparation.
All day meetings	£150.00	Involvement in all-day meetings.
All-day meetings with substantial preparation	£300.00	Involvement in all-day meetings that require substantial preparation, like co-chairing

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* Payment standards are set by NIHR and subject to change. Please check with NIHR for any updates.

Payment continued...

Payment processes in organisations

It is helpful to work closely with administrators, budget authorisers and the finance team to systematically track and audit payments. Public contributors may prefer cash payments. We also offer vouchers as they are often processed more quickly. The University of Manchester, Faculty of Biology, Medicine, and Health have developed guidance on payment methods for patient and public involvement and research participation, which may be helpful. Payment processes differ across organisations. Get to know the system where you work.

Transparency in payment processes

NIHR recommends developing a payment policy giving full details on the process, including for example, how much people will be paid, what is paid (e.g., expenses) responsibilities, and contact details. Be transparent about payment processes and the time frames involved. Public contributors should be informed that some payments can take six weeks or longer. Payment details should be given before a public contributor agrees to be involved in any activities.

Unfortunately, sometimes payments go missing or are delayed due to system errors. We developed an audit-based system for payments, whereby we include a person who tracks payments in emails, the relevant budget authorisers, the person leading the task, and the public contributor. We also keep a spreadsheet of all tasks, dates, payments submitted and confirmation of payments received.

Self-employed public contributors

Some public contributors may be self-employed and have needs for remittance. Try to establish which of your public contributors are self-employed and arrange with your finance department to provide proof of remittance for their audit and tax purposes. It can create challenges when tasks are not individually identified in payment processes. Work with your finance department to see if and how public contributor payments can be identified.

Relevant links and templates:

- Public and patient engagement Toolkit
- NIHR Fees and payment guidance for researcher and professionals
- University of Manchester FBMH Guidance on payment methods for Patient and Public Involvement (PPI) and Research Participation
- Template Public Contributor fees and payment record log
- NIHR Budgeting for involvement

Additional templates available here:

Guidance documents and templates | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester

Payment and welfare benefits

Payment and welfare benefits

Receipt of payment for involvement activities can affect welfare benefits. NIHR has detailed advice on payments and procedures for the recruitment of public contributors who are in receipt of state benefits. We have included helpful links detailing payment guidance on page 27.

Public contributors in receipt of benefits are required to notify Job Centre Plus or the department for work and pensions (DWP) of any paid or voluntary involvement. Before undertaking any involvement task, public contributors may need permission to be involved. As benefit conditions are highly personal, complex, and changeable, potential public contributors should seek specialised advice that is personal to their particular circumstances. They can contact the Citizens Advice Bureau benefits service for more information on how involvement may affect them.

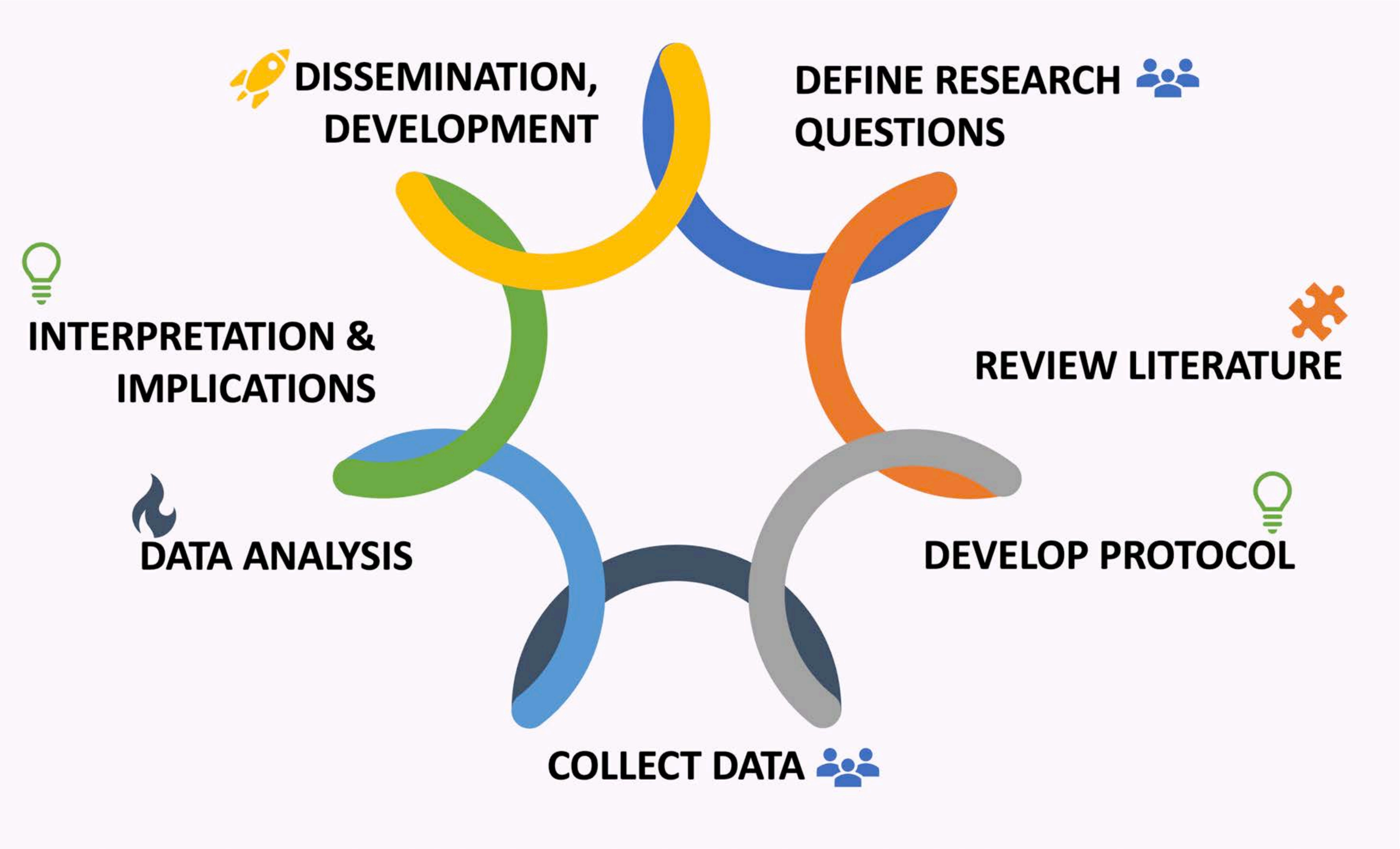
Researchers should inform all potential public contributors of the impact of paid involvement on benefits, and support them in finding out more information. The University or organisation may need to provide a statement regarding involvement and researchers should allow extra time for individual approvals for involvement activities.

More information can be found at:

- Citizens advice: benefits advice
- Citizens advice: how volunteering affects your benefits
- NIHR Payment guidance for researchers and professionals
- Gov.uk guidance on benefits

Types of involvement and engagement activities

Public contributors can be involved in different ways throughout the research cycle. For example, working together to define research questions, developing funding applications, reviewing and interpreting literature, reviewing study protocols and documents, conducting research/ recruitment, contributing to analyses, interpretation, implications, dissemination, and developing strategies for implementation.



Involvement activities throughout the research cycle

Example involvement activities

Meetings

Some research tasks are better suited to meetings and group discussion. For example, meetings can be valuable for workshops, delivering training, discussing sensitive topics, shaping research topics, questions, design, recruitment strategies, analysis, and providing updates. We find it helpful to schedule time in meetings for member updates and debriefs.

In-person meetings

In person meetings are helpful for building initial rapport and developing strong relationships. They are helpful for nuanced discussions or workshops, enabling individual and group interpersonal dynamics to flourish over tea and biscuits!

We print any materials, have pens/stationary and sticky notes available and use PowerPoint facilities. Between 2-3 staff facilitate the meeting, and we often have guest presenters speak about their projects. Cost: £25.00 per hour; travel expenses up to £15.00, (we try to pay cash on the day); £10-15 per head for food and refreshments.

Remote tasks

Remote tasks are useful when there is a need for direct and detailed comments, such as feedback on lay summaries, infographics, study documents, research papers and grants. These allow public contributors to work individually on research tasks.

Costs vary depending on the task. We use the NIHR guidelines for costing tasks, which usually ranges from £12.50 for less than 30 mins work to £50.00 for reviewing/contributing to full publications.

Expert reference panels

These are panels that are set up to guide specific projects, and include public contributors.

Costs: usually £25.00 per hour, plus £5.00 internet costs.

Personal/ lived experience speakers

We frequently invite people with lived experience to talk at our engagement events. Speaking about personal lived experience can be exhausting and emotive.

It is essential to work according to the speaker's preferences for all aspects of the meeting (e.g., privacy, introductions, contributions to panels). We greatly value all our invited speakers, and frequently check-in before, during, and after events.

Usually, we pay between £50.00 to £150.00 depending on the meeting requirements. Public contributors may also wish to receive training in public speaking.

Engagement

Engagement is the translation of research and involvement to the public. This can be through more traditional research talks in public spaces, or through creative endeavours such as photography and art exhibitions, and poetry or music events which connect research to the general public.

Costs vary depending on the task. Engagement events usually require a range of involvement activities, such as in meetings, document review, and often co-delivering events.

Tips and strategies for meetings

Meeting times

We only hold meetings between Monday and Thursday due to challenges in accessing mental health support at the weekend (some people may need access to mental health support after taking part). We hold meetings between 11.00 and 14.30 to allow for any difficulties with medications and early morning waking, caring responsibilities, or travel.

Before **During** **After**

Before meetings

- Send out a meeting agenda with details about the topic for discussion
- Provide any relevant directions
- Provide contact phone numbers
- Send calendar invites with meeting details
- Arrange refreshments
- Inform people of the length of the meeting
- Have travel payments in cash ready to reimburse contributors
- Have payment procedures and documents in place
- Be prepared to provide any review documents ahead of the meeting if requested.

During meetings

- Meet and greet public contributors
- Have two facilitators, one to chair the meeting and one to monitor wellbeing and administration
- Give topic warnings for tasks or talks
- Build in time for member updates
- Build in flexibility for discussion, wellbeing, and comfort breaks
- Let people know how to respond in meetings and provide different options (written and verbal)
- Reassure there are no wrong answers
- Maintain an open-door policy allowing contributors to leave and return.

After meetings

- Debrief at the end of meetings to create transition space
- Follow-up and check-in on members for wellbeing.

Considerations for virtual meetings

We learned how valuable virtual meetings are during the COVID-19 pandemic. We published a paper that looked at PPIE during Covid-19 - Challenges and adaptations to public involvement with marginalised groups during the COVID-19 pandemic. After a challenging start to learning different video messaging software, we found that virtual meetings increased accessibility for many members. They enabled us to widen our diversity and include people from more distant geographic locations. Video messaging enabled our research and involvement activities to continue through challenging times.

Cost: £25.00 per hour, plus £5.00 for internet costs.

Before — **During** — **After**

Before online meetings:

- Include time for introductions, updates, and an overview of the topic to be discussed
- Consider the impact of online meetings on wellbeing (e.g., lack of transition between often intense discussions and the home environment)
- Provide options for participation (e.g., voice only, video, chat functions, or dial in options)
- Don’t assume people know how to engage with people online (or in any meetings). Let people know how to engage in the meeting (speaking freely, hands up, facilitated chat).

During online meetings:

- Flexible and open-door policy. Public contributors can exit and re-join meetings if they find discussions upsetting
- Have two facilitators. One to chair the meeting and the other who checks in on public contributors using the chat function
- Have check-ins with public contributors who may seem distressed.

After online meetings:

- Debrief at the end of the meeting
- Follow-up group members for well-being (we use various communication channels including text, phone, email, social media).

Photo credit: Thomas the Greek in Ireland

Digital divide and inclusion

To maximise inclusion, we offer a range of potential ways to be involved in research projects. Having a range of opportunities (in-person, remote, video, phone), ensures that more people have the chance to share their views.

Digital divide

Researchers need to consider access to digital technology and the provision of opportunities for including all public contributors. Some public contributors may not have access to laptops with word processing software, cameras or audio capability. Where preferable to public contributors, we provide documents in pdf format, overview tasks/ documents and receive feedback by telephone. Public contributors can also send feedback via emails rather than using track changes.

Travel to meetings

We found online meetings beneficial for some public contributors that struggled with social anxiety, navigating travel, mobility issues, or who lived further from the University.

Time to respond to emails

Following feedback from one our members, we provide adequate time for public contributors to respond to tasks. First-come-first serve type approaches can exclude those people who are unable to frequently check or respond to emails. We now try to provide a week for confirming interest in tasks.

Selecting people for tasks and activities

We have developed a list-serve of all public contributors in our Public and Community Involvement and Engagement group.

Emails are sent out to the email list using BCC (blind carbon copy). We provide a brief lay summary of the work and adapt our template for each task.

Task template example text and box:

“The task details are below. Please do confirm your interest in attending. We will provide further information closer to the time (e.g., travel directions, agenda, room number).”

Selecting members for tasks:

We use a random number generation to select public contributors for tasks, based on skills, lived experience, and the topic.

Task request box (included in emails)

Activity:	Workshop to discuss and review a toolkit/guide for PPIE in self-harm and suicide prevention research
Deadlines:	Deadline to respond: 21st Feb; the workshop is on the 6thMarch: 11.30-13.3
Payment:	£50.00 (£25 per hour), plus travel expenses up to £15.00, refreshments will be provided on the day
Involvement:	We will overview and discuss the toolkit/guidebook
Who are we looking for?	Our PPIE members who are interested in developing the toolkit/sharing tips/strategies

Wellbeing is always our top priority. Please only do this if you feel up for it. We have lots of tasks coming up over the next few months.

Case study: PPIE with young people

Drs Jessica Leather and Ioannnis Angelakis

Co-designing a smartphone-based app to reduce self-harm among adolescents

We formed a Young Persons' Advisory Group (YPAG) comprising five adolescents with lived experience of self-harm with the support of a local youth mental health charity in Manchester. Our core objective was to co-adapt an existing self-harm intervention into a smartphone-based app. To achieve it, we liaised with the charity organisation during the planning stages of the project. The charity helped us identify potential YPAG members and recruited a mental health practitioner (MHP) to support the young contributors, and facilitate in-person meetings onsite at the charity premises.

First, YPAG members were asked to remotely review essential documents for the ethics application, including participant information sheets, consent forms, and study flyers. Then, a series of six weekly in-person meetings followed, chaired by two university staff and one mental health professional. During the initial meeting, we used ice-breaker activities and provided snacks to build a working relationship between group members and facilitators. The following five meetings were spent co-designing the content and outlook of the app and questionnaire materials.

To evaluate involvement, we used materials from the Participation Works Toolkit. Overall, YPAG members enjoyed the work but wanted more frequent study updates outside of the in-person meetings. They highly valued the opportunity to receive practical training and work experience to add to their CVs.

Tips and strategies for PPIE with young people

Practical considerations

- In UK law, restriction on child employment, there are several restrictions regarding young people's working opportunities and hours when they are being paid for their time. Restrictions due to full-time education, term times, part-time work, and exam seasons should be considered.
- As per the NIHR guidelines involving children and young people as advisors in research, young people can be paid for involvement work; however, the option of other forms of remuneration, such as vouchers, should be given. Some universities will not authorise payments to under 18s via bank transfer. Charity organisations may process payments directly to young people.

Rapport and trust

- Co-operative and competitive games are great ice-breakers. Acknowledging refreshment preferences is a small but effective way of building trust.
- Young people are particularly concerned about confidentiality and data protection. By using the 'working together agreement', a bespoke confidentiality agreement can be created that has a clear outline for safeguarding processes (e.g., confidential information may be shared with a guardian, if the individual is believed to be a risk to themselves or others).
- Summary documents under the heading 'You said, we did' can help illustrate the changes made based on involvement work and explain the reasons why other suggestions cannot be implemented.

Safeguarding and wellbeing

- Parental/guardian consent and contact details should be obtained before involvement as an important safeguard, especially for young people under 16.
- A mental health professional specialising in youth mental health is recommended to facilitate meetings and debrief individuals to protect their wellbeing.
- Safety and cost implications of transport solutions should be considered. Public transport may be inappropriate for young people. Parents/guardians may be unavailable to chaperone during working hours. Reliable taxi firms can be significantly more expensive than standard petrol/public transport allowances in PPIE budgets.

Remuneration and recognition

- As per the NIHR guidelines involving children and young people as advisors in research, young people can be paid for involvement work; however, the option of other forms of remuneration, such as vouchers, should be given. Some universities will not authorise payments to under 18s via bank transfer. Charity organisations may process payments directly to young people.
- Many young people have no prior work experience. Offering a character reference, a written summary certificate of work completed and skills obtained that young people can incorporate into their CV/ personal statements can be an important contribution to their career and educational opportunities.

Case study: interpretation of research findings and co-designing a blog and infographic

Dr Sarah Steeg

Two members of our Public and Community Involvement and Engagement group worked on a series of studies using health data to examine contact with primary and secondary care for self-harm following the pandemic.

The lived experience researchers worked on these studies for around a year, attending several online meetings to help design and interpret the research. Once research findings were available, the panel members worked on interpreting the findings and communicating them [in a blog and infographic: Self-harm and COVID-19: the first year of the pandemic and beyond.]

The work was done remotely due to COVID-19 restrictions. One member worked with the lead researcher to co-write a blog post, after taking part in an online Future learn course on ‘Making sense of data in the media’. Another co-designed an infographic which summarised the research findings. Remote access to the infographic software was provided to the panel member involved and we held an online meeting to develop the infographic.

MANCHESTER 1824
The University of Manchester

COVID-19 and use of health services for self-harm

Our research into how the COVID-19 pandemic has affected people's use of health services following self-harm.

Why we did this research

30-50% drop in health problems diagnosed

People were much less likely to seek help for **common physical and mental health** needs during the first wave of COVID-19 in the UK

The pandemic also negatively affected some people's mental health.

We wanted to understand how the pandemic affected likelihood of contact with health services for self-harm.

What did we do?

We used anonymised information from health records to look at:

- **Changes** over time in the numbers of people seen by health services
- The **care** received in primary care by people who were seen by health services

Case study continued...

The panel members involved had previously worked on studies using healthcare data. The additional training helped develop their expertise in this topic further. The involvement of lived experience panel members positively influenced the interpretation, presentation and planned dissemination of the study.

There were some limitations to the work. The research used health records which meant the available data could not be adapted; therefore, not all of the suggestions made by members were possible. While the involvement of lived experience panel members was limited to specific stages of the research, it contributed to important developments of the presentation of results, ensuring accessible forms of dissemination were prioritised.

[Self-harm and COVID-19: the first year of the pandemic and beyond | GM PSTRC (wordpress.com)]

Shared learning: Tips/strategies

- If it is feasible and is favoured by all individuals, working with public contributors on a series of projects allows them to develop specific skills around that particular methodology. This can be beneficial to personal and career development of contributors
- Offer training to complement the specific task; but also consider the longer-term training and development preferences of contributors
- Be aware of, and discuss, the stages of the research project that have the most potential to be shaped by the PPIE work. Be realistic about which aspects of the study can be influence.

> *"Contributing to the blog to share research findings in a less formal more accessible way was a great opportunity to develop my writing skills to reach a different (and, hopefully, wider) audience."*
>
> *(LM, public contributor)*

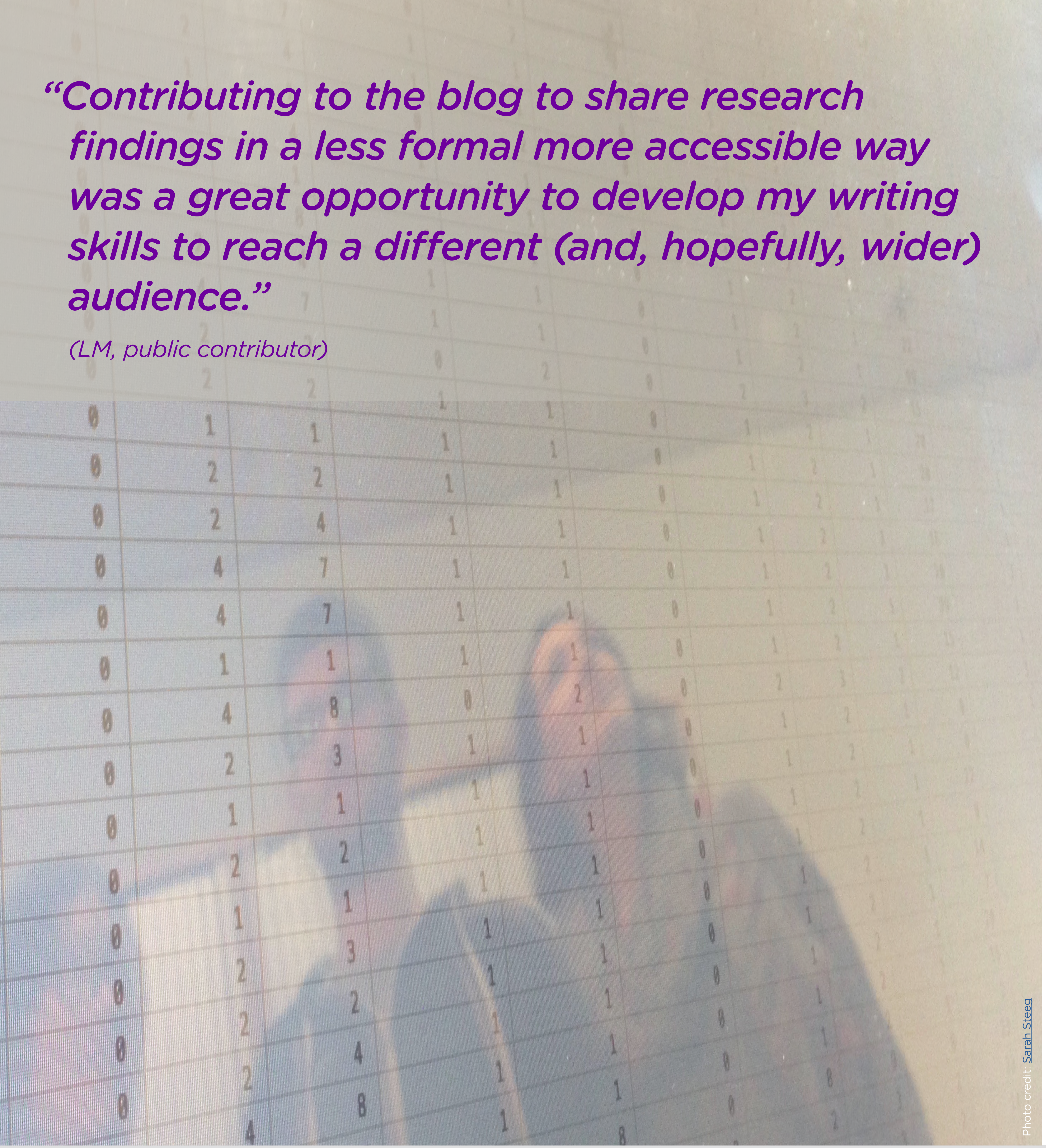


Photo credit: Sarah Steeg

Case study: PPI with older adults: Don’t brush it under the carpet

Dr Alison Baird

The Greater Manchester Suicide Prevention Programme’s Don’t Brush It Under the Carpet Campaign was co-produced by a working group comprised of representatives from the award-winning Shining a Light on Suicide Campaign, Greater Manchester Older People’s Network, GM Ageing Hub, health professionals, researchers and focus groups of older Greater Manchester residents. There are, unknowingly, assumptions and myths around self-harm and older people. The campaign aimed to start a conversation about self-harm with older people, to encourage them to seek support if needed and to raise awareness with those around them, including professionals.

The Greater Manchester Older People’s Network invited a group of people (aged 55-82) from across Manchester, including representatives from ethnic minority and LGBTQ+ communities, to take part in focus groups. An experienced graphic minute taker captured the focus group conversations in an accessible way using images that are diverse and age positive. The images formed posters which are themed around common sayings in order to capture people’s attention and encourage them to talk to someone e.g. “a problem shared is a problem halved”. As the campaign was co-produced with older people, they felt more engaged and provided support for the distribution of the posters.

Project links:

Older People - Shining a Light on Suicide

New campaign launched to shine a light on the issue of self-harm in older people - Shining a Light on Suicide

Psychology and mental health seminar series | Self-Harm and Older People: A Greater Manchester Campaign

NHS Greater Manchester Integrated Care Partnership and the Greater Manchester Older People’s Network: Reducing self-harm in older people | Local Government Association

Potential challenges in patient and public involvement

Delayed payments

Timely remuneration is a key factor in maintaining meaningful relationships with public contributors. This is particularly important when working with people from marginalised groups who may have low income or are in receipt of welfare benefits.

Unfortunately, payments can sometimes be delayed within larger organisations and this can create frustration and distress for both public contributors and researchers. Encourage public contributors to inform you as soon as possible if they have not received a payment. The sooner a delayed payment is identified, the easier it is to deal with.

What to do in the case of a delayed payment:

- Prompt action is important to resolve the issue quickly to minimise distress.
- Contact the public contributor by telephone or email to apologise for the delay.
- Reassure them that you will look into this, and that you will keep them updated.
- Ask the researcher who submitted the payment request to raise the query with budget authorisers and the finance team. Copy in the PPI lead for audit purposes.
- The finance team should be able to provide proof of receipt of the payment request and any notification of payment.
- While this can take time, keep the public contributor informed of developments and outcomes regarding the payment on a regular basis (preferably within one working week).
- Confirm with the public contributor when payment has been made.

Potential challenges: Conflict resolution

Drs Jessica Leather and Ioannis Angelakis

Conflicts can arise when working together. It is important to be prepared for potential disagreements by having:

1. Boundaries
2. A safeguarding, and conflict resolution strategy to preserve trust and protect the safe space in which people are working.

We suggest:

- Consider enrolling on conflict resolution training, where available
- Prepare a 'complaints and grievances' procedure for researchers and public contributors to follow.

This procedure should specify:

- Who a complaint or grievance should be reported to, and how it will be recorded
- The timescale for resolving a complaint or grievance
- What will happen if this procedure is violated (e.g., if an individual raises their complaint with other group members before raising their complaint with staff
- Include this procedure in the 'working together agreement', and ensure it is understood by all group members
- Invite group members to review, or add, details to the agreement in the initial meeting.
- Avoid chastising or ostracising group members who raise or cause a disagreement in front of the wider group
- When a conflict is raised, address any individuals involved separately to identify and resolve the problem
- Agree any proposed changes to resolve the conflict with the involved parties and group facilitators
- Feedback these changes to the wider group at the start of the next meeting and agree the next steps. Avoid singling out any member who raised or caused the disagreement
- Amend necessary documentation (e.g., 'working together agreement').
- Record the grievance and the steps agreed to resolve it.

Prioritise conflict resolution to resolve issues quickly. Groups are unlikely to work well together if issues go unresolved.

Safety and wellbeing

Does talking about self-harm and suicide lead to further self-harm?

We're often asked if talking about self-harm and suicide will lead to further psychological harms or distress. Thankfully, there is extensive research indicating that people are not harmed by speaking about self-harm or suicidal behaviour*. In fact, speaking of self-harm or suicidal behaviour might reduce suicidal behaviour and lead to improved mental health. However, self-harm, service use, and suicide prevention are sensitive, emotive, and challenging topics. Experiences of accessing mental health services can also be painful, upsetting and triggering.

Some public contributors may seek to be involved in research because of their negative experiences when accessing healthcare services. Public contributors may be under mental health services, or become unwell during the course of any involvement activities. Life can be hectic and distressing, and that's without the added pressure of any global pandemics or economic crises. Therefore, wellbeing and safety are always a core and intertwining part of involvement activities in self-harm and suicide prevention research.

Wellbeing as the number 1 priority

Above all, we emphasise the importance of wellbeing as our number one priority. We ask that people only contribute to tasks when they feel okay. We emphasise that it's completely fine to drop a task, if they find the content distressing, or if they feel exhausted or unwell. The door is always open, and people are welcome back at any stage. Flexibility and having a larger group of public contributors, enables everyone to work around fluctuations in mental health and wellbeing.

Disclosing personal information

Our involvement activities have a relaxed structure and format. Researchers and public contributors are free to disclose or not disclose personal information. Public contributors are eligible to join the group if they have personal experience of self-harm, suicidal behaviour and mental health services, or of caring for people with such experiences, but they don't have to talk about those experiences. We don't ask people to share any personal information about access to mental health services or their self-harm. However, people do reflect on their experiences, and often talk about when they were/are unwell, and/or have used services. If anyone does speak about their personal experiences, we have strict guidelines on confidentiality as part of our co-developed ways of working plans.

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* References on page 44

Safety and wellbeing continued...

Public contributor wellbeing

We openly discussed wellbeing and safety during initial meetings with our public contributors and what to do if people do become distressed or unwell during involvement activities. Our public contributors felt that co-developing safety plans was best way to manage safety and wellbeing. From that discussion, we co-developed a safety and wellbeing plan for involvement in self-harm and suicide prevention research. One of our members has called this the 'Just in Case Plan'. You are welcome to use and adapt this plan for your own involvement activities. Please do cite our toolkit, so we can track any impact from the work.

Preparation and debriefs before involvement activities

The importance of preparation and debriefs before involvement activities cannot be underestimated for researchers and public contributors. We include time before meetings to prepare psychologically for discussing sensitive topics. We also build time into agendas to prepare public contributors, discuss the nature of the topic, and what to do if anyone becomes upset. Debriefs are also essential to close meetings and provide transition from intense conversations. In-person meetings provide physical transition (e.g., people walk away from the meeting), but online meetings can be a bit trickier. We find it helpful to always schedule de-brief time in agendas to check-in on people, wrap things up, and start the transition then and there.

Follow-ups and check-ins after involvement activities

Most people have positive experiences from contributing to research. However, discussing sensitive topics can bring up painful experiences, and be exhausting. Check-ins by phone, email, text, social media the following day, can help ensure people are okay after any involvement activities. Co-developed wellbeing plan for self-harm and suicide prevention research

Links that may be helpful from the University of Manchester Faculty of Biology, Medicine, and Health

- Template risk assessment: PPIE template Risk Assessment Form
- Template distress protocol: Template PPIE distress protocol
- Distress help services (public contributors): Help Services for Everyone
- Distress help services: staff and students: Distress Protocol Help Services for Staff Members.

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Researcher wellbeing

Researcher wellbeing is also important and often under-discussed. There is some literature on researcher wellbeing in sensitive topics, but not enough. Discussions can become emotive, intense, and many researchers have their own lived experience in self-harm and suicide prevention. The International Network of Early Career Researchers in Suicide and Self-harm (netECR) has a netECR Collective Care peer-support space for researchers. We highly recommend linking in with this supportive group of researchers and close colleagues where you work.

Further reading on researcher wellbeing

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Research ethics and PPIE

Participation versus involvement

Participation and involvement activities are sometimes confused. During involvement activities, we do not use any personal information for research purposes. For example: a focus group for research might have a set of semi-structured or open questions asking about service use following an episode of self-harm, or ask about information to develop an intervention/tool. This study would require ethics approval and other typical research processes (e.g., participant information sheets and informed consent), because the data may be stored, analysed, and published.

For public involvement, we might have a group activity, but the focus is on reviewing/revising study documents, developing research questions, contributing to analyses, interpretation and dissemination strategies. Public contributors in involvement activities use their personal experience to inform the research. However, no personal history from involvement activities is documented and used as part of the research.

If the involvement activity does require data to be collected, recorded and stored to use as part of a research project, it is likely you will need to obtain approval from a research ethics committee. If you are unsure you should discuss this with the ethics committee at your institution.

Media engagement

Publishing research places the study and team in the public domain. Even if a media team isn't actively promoting a paper, just a tweet can generate media interest.

It is important that public contributors are aware that by being named on a paper they are linked publicly to that work. Public contributors should always be guided through the pros and cons of being named on a paper and given the opportunity to remain anonymous.

Potential pitfalls

Social media

It is common for research papers to be discussed on social media. Researchers and public contributors can become targets for negative comments. A plan needs to be in place so public contributors know what to do if any posts they've been tagged in receive negative comments.

Quotes used in press releases

It is common for public contributors to be asked to provide a quote for inclusion in a press release.

It is important to:

- Ensure it is clear in the press release that this is a public contributor, and not a participant in research
- Avoid making any reference to personal experiences
- Ensure the quote focuses on the research and the difference it could make

How to prepare for involvement in the media (public contributors and researchers):

- Be clear that the quote will remain in the public domain once it is published – it isn't easy to remove it
- There is always a risk of harassment and trolling via social media.

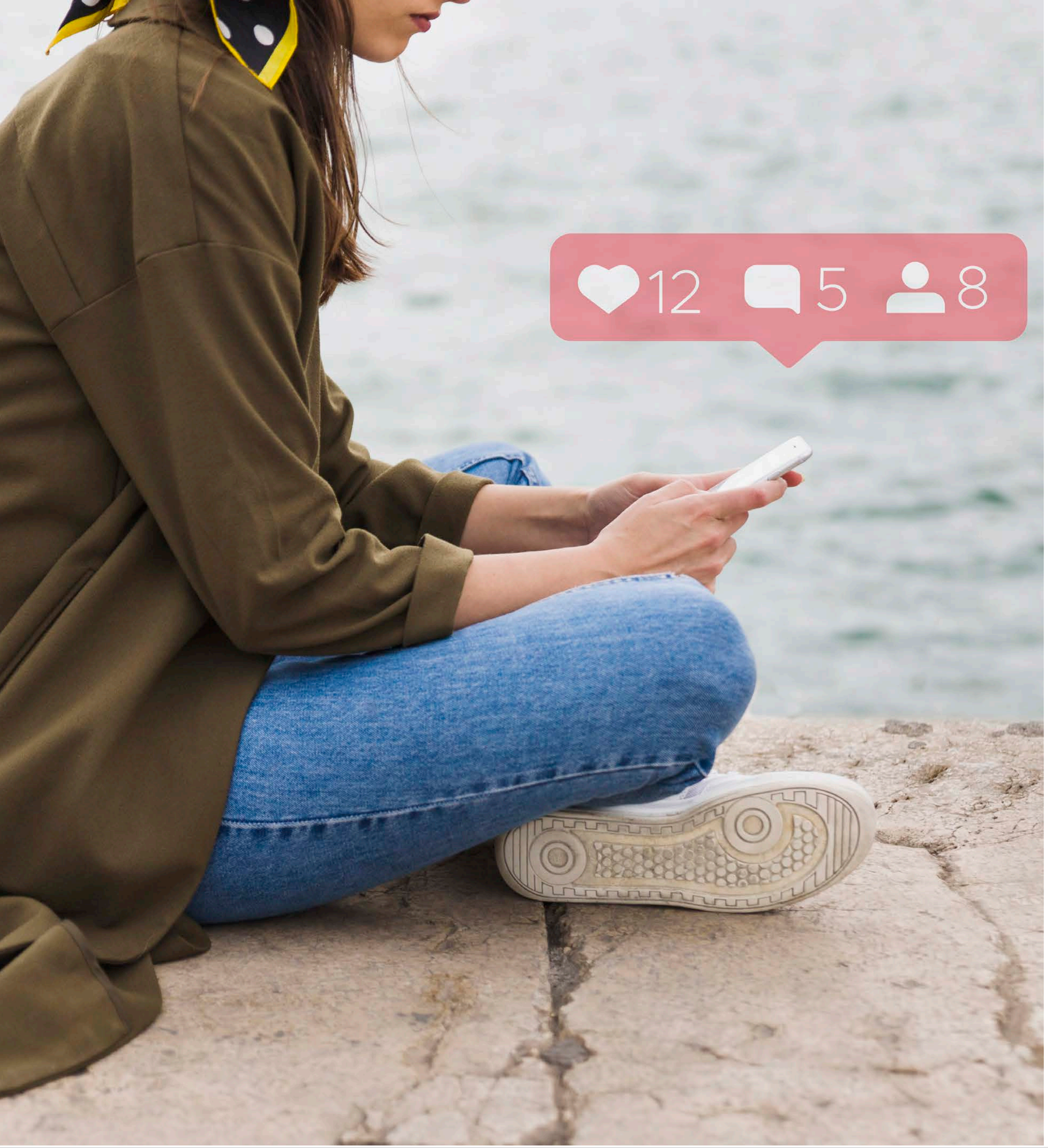
Social media engagement

Always ask permission to tag public contributors on social media and talk through the above before going ahead with social media engagement.

Create a social media protocol for public contributors

A protocol should be created to ensure a plan is in place should a research paper become the target of negativity online or via social media. Before any research is published the researcher should ensure everyone has a copy of the protocol should it be needed and there should be a system in place for how to flag any negativity. The protocol should include the following advice:

- Do not reply to negative comments. Think of it like a fire. Every time you reply to a negative comment you're providing oxygen. If you don't reply the comments are likely to burn out.
- If you spot a negative comment flag it to a researcher and they will monitor it and flag it to the communications team if relevant. Once you've done that stop looking at the thread and change your security settings where necessary.



How public contributors can stay safe online

Whether a public contributor already has social media accounts or is setting a new one up, it's important that they're aware of the information about them that's in the public domain.

There are 3 key things to check:

[1] Bio

Remember that if you plan to post about the research you're involved with as a public contributor mention this, and be honest.

- Don't include anything you wouldn't want to end up elsewhere.
- Avoid including anything that could give an indication of your location
- Add a short disclaimer: "Views expressed are my own".

[2] Security settings – check these regularly

- If you want to keep your posts private you can by only allowing the people who follow you to see them.
- You can also change your settings so that you can control which posts you' tagged in.

[3] Picture

- Having a picture is good but consider carefully what's in the picture and ask advice from the media contact in the research team if you're unsure

General guidance for social media

- **Remember that whatever you say online** may be traced back to you personally so check your security settings regularly
- **Express opinions** while being aware that you're in a public domain, and ensure you're accurate, honest and informed
- Try to avoid saying anything that you wouldn't say out loud in a public ensure you're accurate, honest and informed
- **Be careful around spelling and grammar** as this is something that can attract negative attention
- **Avoid guessing** if you're not sure about a question you've been asked.
- Either check with someone who would know like a researcher or tag them to allow them to answer the question
- **Consider who you follow** and the posts you engage with. Avoid engaging with a post unless you've checked out the person who has posted it. Just because you've engaged with a post could imply you endorse the person
- **Never comment on** anything that appears to have legal implications. If you're not sure then avoid engaging
- **Avoid commenting if there's a reputational issue or a 'storm'**, as although your intentions may be good it is best to let official channels handle communications. If you're at all unsure speak to the media lead
- **You can share content** but always credit the original source and if you're not sure of the source, avoid sharing it
- **Avoid deleting content** if you make a mistake. Instead, as soon as you can, acknowledge the mistake and apologise for it
- **Remember it's better not to post** at all rather than post something that could reflect negatively on your or the research you're involved in
- **Ensure you know how to block and report**– check the help section of the social media platform if you're unsure if any guidelines have been breached
- **If you spot a negative comment** related to you or the research you're i involved in flag this to a researcher immediately and follow the agreed social media protocol that's in place for these situations.

Helpful links from the University of Manchester, Faculty of Biology, Medicine, and Health

Email guidelines for public contributors

Social Media Guidelines for public contributors

Guidance on the use of social media to actively involve people in research

National Co-ordinating Centre for Public Engagement: Social media

NIHR Social media for public involvement: for Primary Care Research

Online glossaries for research and patient/public involvement

NIHR Glossary for research and involvement

NIHR Research Support Service

University of Oxford Medical Science Division: Patient and public involvement, engagement and participation definitions

Helpful websites/resources

Being a Public Contributor. Faculty of Biology, Medicine, and Health

University of Manchester PPIE toolkit and guidance

University of Manchester: Patient and public involvement and engagement (PPIE):
Patient and public involvement | Social responsibility | The University of Manchester

Bee, P., Brooks, H., Callaghan, P., & Lovell, K. (2018). A research handbook for patient and public involvement researchers. Manchester University Press.

Researchers experiences of patient and public involvement: Healthtalk

Project specific references and links:

NIHR Greater Manchester Patient Safety Research Collaboration

NIRH GM PSRC Public and community involvement and engagement (PCIE)

National Confidential Inquiry into Suicide and Safety in Mental Health NCISH

The Manchester Self-Harm Project | Support for improving community-based care for self-harm

Mutual Support for Mental Health Research (MS4MH-R)

Mental health assessments and psychological therapies following self-harm. MhAPT

UoM Blogposts (co-produced)

New research reveals why some people do not receive NICE recommended care following self-harm | GM PSTRC

New PSTRC research: Mental health assessments and psychological therapies following self-harm | GM PSTRC

Mental health is critical in the recovery from COVID-19 leading experts agree at virtual conference hosted by patient safety centre GM PSTRC

What hopes means during the COVID-19 pandemic – a virtual exhibition to mark World Suicide Prevention Day - Health Innovation Manchester

UoM Public engagement links:

Older People - Shining a Light on Suicide

Sowing #SeedsOfHope on World Suicide Prevention Day

Exhibition of hope to raise awareness for World Suicide Prevention day and launch #seedsofhope campaign

artsteps | Hope during the COVID-19 pandemic: perspectives from people with personal experience of self-harm, suicide and mental health

Some of our recent publications with patient and public involvement

- Mughal, F., Bojanic, L., Rodway, C., Graney, J., Ibrahim, S., Quinlivan, L., Steeg, S., Tham, S.G., Appleby, L., Webb, R.T., & Kapur, N. (2023). Final recent GP consultation before death by suicide in middle-aged men: a national consecutive case series. *BJ General Practice*, BJGP.2022.0589. DOI: https://doi org/10.3399/ BJGP.2022.0589
- Turner, L., Berry, K., Quinlivan, L., Shiers, D., Aggarwal, V., Palmier-Claus, J. (2023), Understanding the relationship between oral health and psychosis: A qualitative analysis. *BJ Psych Open*, 9, 23, E59.
- Quinlivan. L., Gorman, L., Monaghan, E., Asmal, S, Webb, R.T., & Kapur, N. (2023). Accessing psychological therapies following self-harm: Qualitative survey of patient experiences and views on improving practice. *BJ Psych Open*, 9, 3, E62.
- Quinlivan. L., Gorman, L., Monaghan, E., Asmal, S, Webb, R.T., & Kapur, N. (2023). Liaison psychiatry practitioner views on accessing aftercare and psychological therapies for patients who present to hospital following self-harm: multisite interview study. *BJ Psych Open*, E34. doi:10.1192/bjo.2023.2
- Gorman, L., Littlewood, D., Quinlivan, L., Monaghan, E., Smith, J., Barlow, S., Webb, R.T., & Kapur, N. (2023). “Feeling left in the dark”. Family involvement, patient safety, and suicide prevention in mental health care: ethnographic study. *BJ Psych Open*, 9,2, E54.
- Keyworth, C., Quinlivan, L., Leather, Z, J., & Armitage, J.C. (2022). Exploring the acceptability of a brief online theory-based intervention to prevent and reduce self-harm: a theoretically-framed qualitative study. *BJ Psych Open*, 8, e184, 1-8.
- Adeyemi, I., Sanders, C., Ong, B.N., Quinlivan, L., Gorman, L., Giles, S., et al. (2022). Challenges and adaptations to public involvement with marginalized groups during the COVID-19 pandemic: commentary with illustrative case studies in the context of patient safety. *Research Involvement and Engagement*, 8, 13.
- Keyworth, C., Quinlivan, L., Leather, J.Z., O’Connor, R.C., & Armitage, C.J. (2022). The association between COVID-19 related fear and reported self-harm in a national survey of people with a lifetime history of self-harm. *BMC Psychiatry,* 22, 68.
- Keyworth, C., O’Connor, C., Quinlivan, L., & Armitage, C. (2021). Mixed methods evaluation of the acceptability of a brief online theory-based intervention to prevent and reduce self-harm. Journal of Medical Internet Research, *Journal of Medical Internet Research*, 23(9):e28349.
- Tyler, N., Daker-White, G., Grundy, A., Quinlivan, L., Armitage, C., Stephen, C., & Panagoiti, M. (2021). ‘Goodbye and Goodluck’ The effects of the Covid-19 lockdown on quality and safety in mental health care transitions in England, *BJ Psych Open*,7, 5, E156.
- Quinlivan, L., Gorman, L., Littlewood, D., Monaghan, E., Barlow, S., Campbell, S., Webb, R.T., & Kapur, N. (2021). “Wasn’t offered one, too poorly to ask for one” – Reasons why some patients do not receive a psychosocial assessment following self-harm: Qualitative patient and carer survey. *Australian and New Zealand Journal of Psychiatry*, 1-10.
- Quinlivan, L., Gorman, L., Littlewood, D., Monaghan, E., Barlow, S., Campbell, S., Webb, R.T., & Kapur, N. (2021). “Relieved to be seen” - patient and carer experiences of psychosocial assessment in the emergency department following self-harm: qualitative analysis of 102 free-text survey responses. B*MJ Open*;11:e044434. doi:10.1136/ bmjopen-2020-044434.
- Littlewood, D.L.L., Quinlivan, L., Steeg, S., Bickley, H., Rodway, C., Bennett, C., Webb, R. T., Kapur, N. (2019). Evaluating the impact of patient and carer involvement in suicide and self-harm research: A mixed-methods, longitudinal study protocol. *Health Expectations*, 00: 1-7.
- Carr, M. J., Steeg, S., Webb, R. T., Kapur, N., Chew-Graham, C. A., Abel, K. M., et al. (2021). Effects of the COVID-19 pandemic on primary care-recorded mental illness and self-harm episodes in the UK: a population-based cohort study. *Lancet Public Health*, 6(2), e124-e135. doi:10.1016s2468-2667(20)30288
- Steeg, S., Bojanic, L., Tilston, G., Williams, R., Jenkins, D. A., Carr, M. J., et al. (2021). Temporal trends in primary are-recorded self-harm during and beyond the first year of the COVID-19 pandemic: Time series analysis of electronic healthcare records for 2.8 million patients in the Greater Manchester Care Record. *eClinicalMedicine*, 41, 101175. doi:https://dx.doi.org/10.1016/j.eclinm.2021.101175.

Photo credit: Liz, Dawn, and Dan at the University of Manchester PPIE Awards

MS4MH-R co-designed documents*

[Working together agreement/ terms of reference:]

The ‘terms-of-reference’ document was co-designed with the MS4MH-r PPIE group. The document sets out the roles and responsibilities for public contributors and research staff.

[PPI planning form for researchers:]

This document helps researchers think about and plan PPI for their research studies.

[Public contributor wellbeing plan:]

The wellbeing plan was co-designed with MS4MH-R during discussions on managing safety and wellbeing during involvement activities. One member calls the wellbeing plan the ‘Just in case plan’.

* free to use and adapt, but please do cite us in your documents

Contact:

If you would like to find out more information about patient and public involvement and engagement or would like to join the group, please contact Leah using the details below:

Email: leah.quinlivan@manchester.ac.uk

Website: Mutual Support for Mental Health-Research (MS4MH-R)

Help in a crisis and support groups

Below is a list of useful contacts and organisations that can provide help or support in a crisis. This list is not exhaustive and is specific to the UK.

Samaritans	Call 116 123 24 hours a day, 365 days a year
SANEline:	0300 304 7000 4.30pm-10.30pm, 365 days a year
Campaign Against Living Miserably (CALM)	Call 0800 58 58 58 5pm-midnight, 365 days a year
Women's Aid – national domestic violence helpline	Call 0808 2000 247 24 hours a day, 7 days a week
PapyrusHOPELineUK	For people under 35: Call 0800 068 41 41 – 10am Childline – for children and young people under 19: Call 0800 1111 10am-10pm weekdays, 2pm-10pm weekends, 2pm-5pm bank holidays
The Silver Line	For older people: 0800 4 70 80 90 24 hours a day, 365 days a year
NHS 111	Call 111 – 24 hours a day, 365 days a year
LGBT Foundation's Helpline	Call 0345 3 30 30 30 – 9am-9pm weekdays, 10am-6pm Saturday

No Panic	For people who suffer from panic attacks, phobias, obsessive compulsive disorders and other related anxiety disorders: Call 0844 967 4848 – 10am-10pm, 365 days a year
BEAT	Support and information about eating disorders: 0808 801 0677 3pm-10pm, 365 days a year
Alcoholics Anonymous	0800 9177 650
Harmless	Harmless resource hub
Battlescars	Survivor led charity for people who self-harm: https://www.battle-scars-self-harm.org.uk/services.html; Email: info@battle-scars-self-harm.org.uk Phone: 0741 0380747
Self-Injury Support	Helpline: 0808 800 8088; Email: tessmail@selfinjurysupport.org.uk; Text support: 07537 4324
GMMH 27/7 Mental health crisis helpline	For all ages: 0200 953 0285
42nd Street	(young people aged 11-25 years). 42ndstreet.org.uk

Helpful links on self-harm:
An organisation working to address and overcome issues related to self-harm and suicide. Harmless
Mind Manchester
Resource Hub - Harmless
Health Talk
Manchester Self-Harm Project

Notes page

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