Patient and public involvement in self-harm and suicide prevention research: public contributor guide

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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NIHR | Greater Manchester Patient Safety Research Collaboration

This guide will be updated as new resources become available. This guide 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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Contents

About this guide

This guide is designed to provide information about being a public contributor in self-harm and suicide prevention research. The guide can be read alongside existing resources, including ‘Being a Public Contributor’ from the Faculty of Biology, Medicine, and Health and the more detailed ‘Patient and public involvement in self-harm and suicide prevention research shared learning toolkit’.

This toolkit may be adapted for public contributors interested in self-harm and suicide prevention research in other areas. All the information and links are open access and freely available, but are based on our work in the University of Manchester. Please contact the patient involvement leads in your local area for what is happening there.

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 feel 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 28

The document and resources are freely available, but please do cite us in any work.

Quinlivan, L., Graney, J., Steeg, S., Gorman, L., Monaghan, L., Stears, D., Asmal, S., & Webb, R., Kapur, N., & the MS4MH-R PPIE Group. (2024). Patient and public involvement for self-harm and suicide prevention research: public contributor guide. NIHR Greater Manchester Patient Safety Research Collaboration, University of Manchester.

Further information:
Contact: leah.quinlivan@manchester.ac.uk
Website: Mutual Support for Mental Health-Research (MS4MH-R)

Terms and definitions

There are many different terms and acronyms for patient and public involvement, which vary and change over time. Some of the terms we use for involvement are below. We've also included glossaries for further reading and information.

Public

Includes any communities, potential patients, patients, carers, and any people that use health and social care services.

Patient and Community Involvement and Engagement

Refers to an active partnership between patients, the public, and researchers throughout the research process.

Public contributor

In this guide we use the term public contributor to describe 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.

Involvement

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

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.

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.

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.

Acronyms and glossaries

Acronyms

NIHR: National Institute for Health and Care Research
NIHR GM PSRC: National Institute for Health and Care Research, Greater Manchester, Patient Safety Research Collaboration
NCISH: National Confidential Inquiry into Suicide and Safety in Mental Health
MaSH: Manchester Self-harm project
MS4MH-R: Mutual Support for Mental Health - Research'
CMHS: Centre for Mental health and safety
EDI: Equality, diversity and inclusion
PPIE: Public and patient involvement and engagement

Online glossaries for research and 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

The Centre for Mental Health and Safety

What do you research at the Centre for Mental Health and Safety?

In the Centre for Mental Health and Safety, our research is aimed at improving healthcare services for people who have self-harmed or experienced mental health conditions. Your personal experiences of self-harm, suicidal behaviour and attending mental health services can help to ensure our research is meaningful and relevant for patients, carers, and healthcare staff.

Self-harm and suicide prevention context

Self-harm and suicide important concerns for healthcare services and all communities. In England, around a third of people who die by suicide are in contact with mental health services (NCISH). Health care services have an important role in suicide prevention, by providing good quality care.

Is there an involvement group in the Centre for Mental health and Safety?

The Centre for Mental Health and Safety has a dedicated patient and public involvement group. See the 'Mutual Support for Mental Health -Research' (MS4MH-R) group website for more information.

What is research?

The National Institute for Health and Social Care Research (NIHR) define research as a way of finding out new information that can lead to changes in treatments, polices and care. Research addresses clear questions, using rigorous and systematic methods.

What methods to researchers use to answer questions?

Research studies can be quantitative – (collecting and exploring numbers), qualitive (exploring what people say about their experiences), or a combination of both.

Further information and glossaries on research terms

- National Institute for Health and Care Research Glossary:
- NIHR Be Part of Research: glossary of research terms:
- NIHR Imperial Clinical Research Facility Patient and Public Involvement Panel:

What is patient and public involvement and engagement?

Patient and public involvement and engagement (PPIE) is a partnership between you, as a public contributor, and the research team. Your lived/living experiences can help make research more accessible, meaningful and relevant for patients and carers.

Is involvement the same as participating in research?

No, patient and public involvement is different from participating in a research study. You might do similar activities like group or individual meetings, but what happens your data is different. In research, you formally provide written or verbal consent for your personal data to be recorded, analysed, and stored for research purposes. In patient and public involvement, you use your lived experience to inform and develop research as part of the research team. None of these conversations are recorded or used for research purposes (e.g., analysed and published).

oto credit: Leah Quinlivan, Photo taken in UCC

Wellbeing

Will talking about self-harm and suicide research be upsetting?

Wellbeing is the number one priority for any involvement activities in self-harm and suicide prevention research. Most people have positive experiences from being part of research. However, suicide and self-harm are sensitive and emotive topics. Talking about healthcare services may be upsetting and triggering of negative past experiences. It is important to only contribute to studies when you feel well enough. Researchers are always happy to work around your needs.

Wellbeing plans

We co-developed a freely available wellbeing plan for public contributors in self-harm and suicide prevention research. One of our members called the wellbeing plan, the "just in case plan". So, you complete the wellbeing plan with helpful support information just in case you become unwell or upset during involvement activities. The wellbeing plan can be completed here.

Do I have to share my experiences?

No, public contributors are not asked to share their personal experiences during involvement activities. Discussions are focused on making research better, but sometimes people discuss their personal experiences during meetings. All group members recognise the importance of feeling safe and respecting boundaries.

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

Wellbeing continued...

Who can I talk to if I get upset?

Please tell researchers if topics or discussions become too much or upsetting. It's important that you feel comfortable enough to say how you feel and to always ensure that your wellbeing is priority.

What if I become unwell?

People may become unwell during involvement in research. Researchers in the Centre for Mental Health and Safety have a flexible, open-door policy and are always willing to work around your wellbeing. People are always welcome back to involvement activities if they need time off to recover from challenging times.

Trigger warnings: Will I know what the topic is before contributing to research?

Yes, the research team will let you know about the topic and you can think about taking part or not. You are always free to take breaks, or drop a task if it is too distressing without any consequence. Your wellbeing is always the priority in any project.

Confidentiality

Will group discussions and my involvement be confidential?

We request that all discussions, both about the research and any personal information are kept strictly confidential.

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

How will I know what to expect from research?

Researchers and public contributors often develop a set of ground rules or ways of working together agreements. These often include things like:

- Roles and expectations
- Needs for thriving and equity
- Preferred ways of working (e.g., online, by phone, in-person)
- Time to complete tasks and deadlines
- Payment processes
- Managing wellbeing
- Maintaining confidentiality for any discussion (personal and research)
- Being tolerant of each other and respecting everyone's opinions
- Listening to all views, even if they are different to yours
- Feedback processes
- Openness, compassion, and kindness.

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

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

Experience and training

Do I need research experience or skills?

You do not need to have any research experience. Public contributors are experts-by-experience and use this knowledge to guide and support research.

Will I receive any training?

Research teams may provide training and development opportunities for public contributors to help strengthen skill sets. The team at the University of Manchester have provided training on:

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

Public contributors can also attend conferences, 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.

Will I be paid?

Public contributors are paid for any activities using NIHR rates.* In the University of Manchester, public contributors can complete a form to be paid into their bank accounts, or receive vouchers. Payment processes vary across institutions, but can take up to six weeks.

Will travel expenses be paid?

Yes, travel expenses are paid by the research team up to £15.00. Mileage rates are 45 pence for the first 150 miles of a journey and 22.5 pence for any further miles. Researchers will usually either book your travel, pay the expenses on the day, or if these processes are not possible, add the cost to the payment.

Table 1. NIHR payment benchmarks, adapted from their website subject to change by 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

*Payment information is specific to the University of Manchester and the rates set by NIHR. Please check with the research team and NIHR as information is subject to change

Welfare benefits

What about my benefits?

Payment can affect welfare benefits. If you are receiving benefits, you may need to notify Job Centre Plus or the department for work and pensions (DWP) of any paid or voluntary involvement. Before doing any task, you may need permission to be involved. As benefit conditions are personal, complex, and changeable, you should seek specialised advice that is personal to your particular circumstances. As a public contributor, it is your responsibility to declare your income.

You can talk to researchers if you need to decline or reduce payments for benefit purposes.

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

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

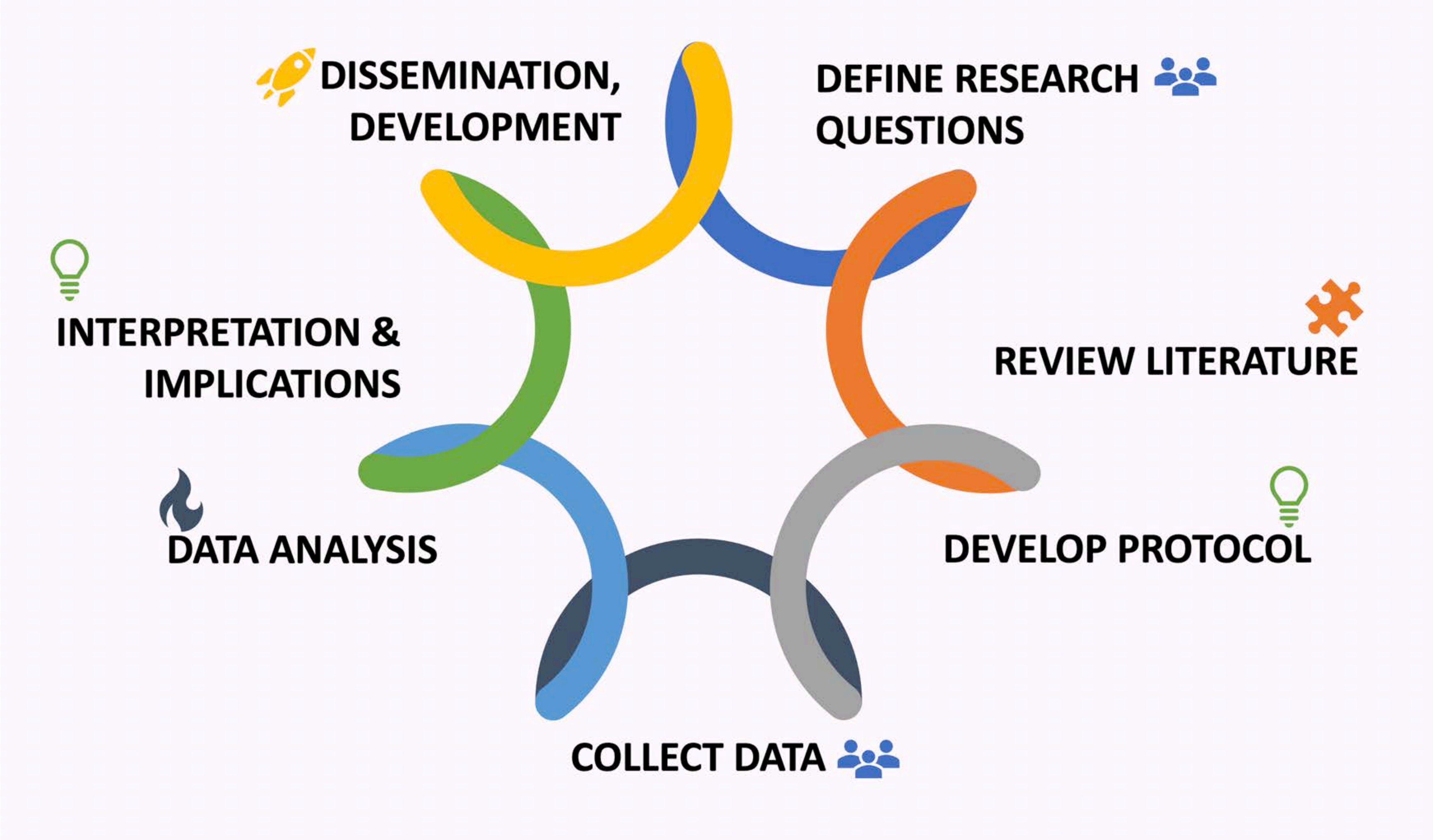
Guidance documents and templates | Faculty of Biology, Medicine and Health | StaffNet | The University of Manchester

How will I be involved in research?

You will have opportunities to be involved throughout the research cycle as an equal partner, expert-by-experience, and co-researcher. You can be involved throughout every stage of research, from developing research questions, through to making sense of findings and sharing results. For example, MS4MH-R members have developed research plans, analysed data, co-authored grant applications, publications, and talked about their work at conferences.

Activities can be online, in-person, or by telephone. Example activities include things like:

- identifying areas for research and developing research questions
- providing feedback on documents (e.g., infographics, consent forms)
- reviewing current research findings
- deciding how to carry out the research
- deciding who the research should be done with
- collecting data
- processing, coding, analysing and interpreting data
- reporting research and sharing results



Involvement activities throughout the research cycle

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

- JS (Public contributor)

Events and panels

What is an expert reference panel?

Expert reference panels provide feedback on overall projects. Members of the group usually have experience of the research area (professionally or personally). Public contributors typically get paid £25 per hour for attending these meetings.

Will I be asked to speak at events?

You may be invited to talk about your experiences at events and conferences. Speaking about personal experience can be exhausting and emotive. It is important to take care of yourself as a priority and only speak at events when you feel adequately supported. Payment varies from £50-£150 depending on the task and length of the meeting.

Is there a chance to be involved in other types of events?

Many researchers engage with the public over research via open events and creative practices (e.g., photography or poetry). This is called ‘public engagement’. For example, MS4MH-R members at the University co-designed photo exhibitions for World Suicide Prevention Day. Involvement and payment rates depend on activities (e.g., preparation, attending/co-facilitating events).

Can you give more information about meetings?

Meetings are friendly, informal, and flexible. Usually, two researchers and 3 to 10 public contributors attend meetings. Sometimes meetings are smaller or larger depending on the type of task. Guest researchers may also attend meetings to hear your views on studies. Researchers will share information about meetings (e.g., topic, agenda, location, times, pay), a few weeks beforehand. Payment is £25.00 per hour.

How long do meetings last?

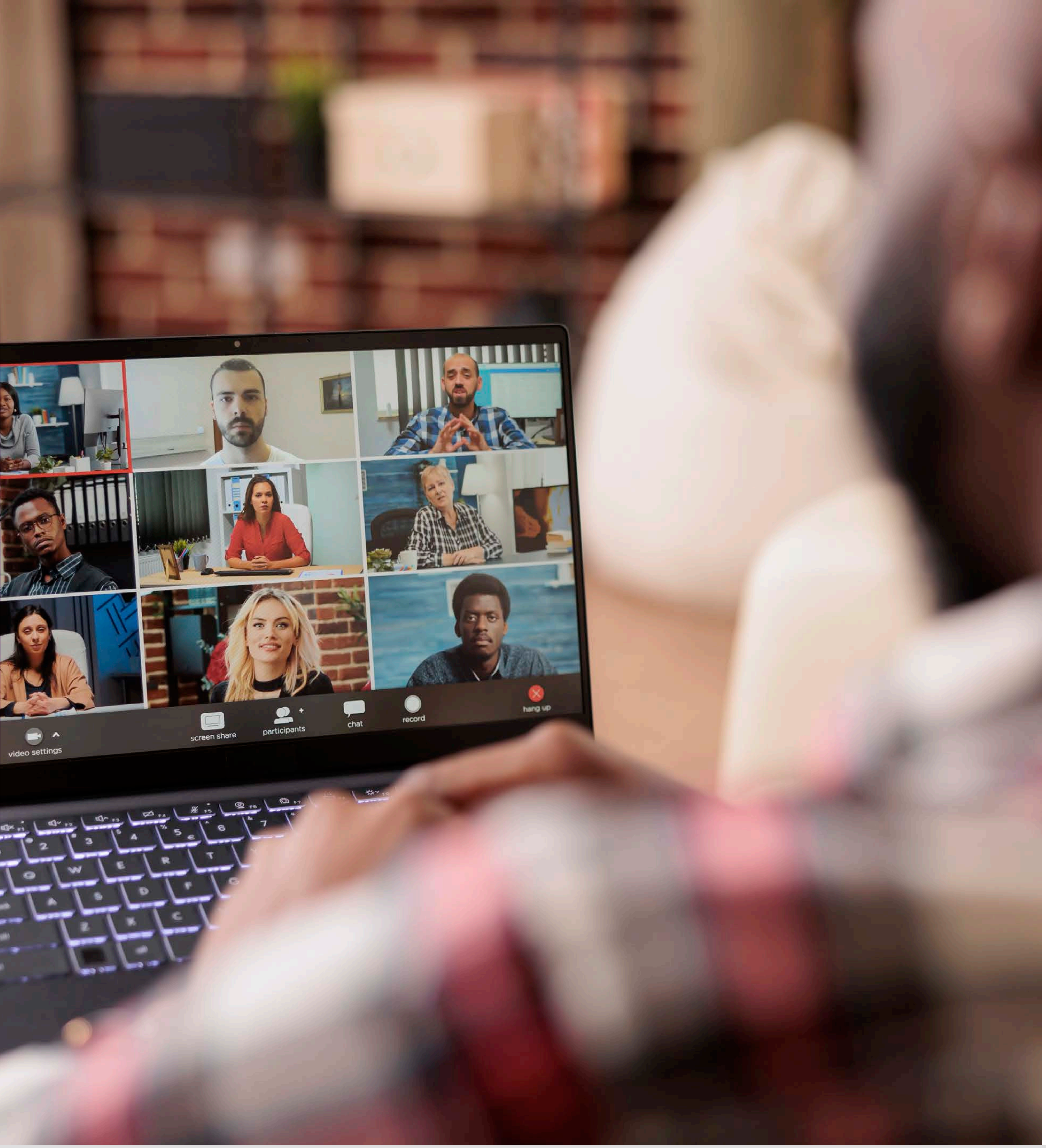
Meetings last from 30 minutes to three hours (with breaks) and you can come and go as you need.

What happens during meetings?

We catch up with each other at the start of meetings and have topic warnings before discussions. Researchers and public contributors discuss how to make research studies better. Members contribute to meetings in different ways (talking, writing). We end meetings by seeing how people are doing and what they got out of the meeting.

What happens after meetings?

Researchers check-in with people in the following few days to see if everyone is doing okay. You are always welcome to feedback any of your thoughts to researchers after the meeting.



Can you give more information about meetings?

What about in-person meetings?

The research team will provide travel and accessibility information before the meeting. Paper, pens/stationary will be available on the day. The research team will provide refreshments and cover travel expenses up to £15.00.

What about online meetings?

Online meetings take place over Zoom or Microsoft Teams. Like in-person meetings, they are relaxed and informal. You can leave your camera off and communicate by talking or in the chat section. Members receive an additional £5.00 to their typical payment to cover internet costs.

Photo credit: Thomas the Greek in Ireland

What about access to technology and the internet?

Involvement activities can take place in-person (e.g., workshops). However, most involvement activities require internet access and access to a computer, laptop, or phone.

The Greater Manchester Combined Authority website provides information on how to get online, nationally, locally, and provides digital support for disabled people. Please do have a read through their resources if you need help to get online. The research team will also work around your preferences for contributing to research (e.g., if you prefer phone calls or printed documents).

Greater Manchester Combined Authority: Get Online Greater Manchester: Support for disabled people:

Greater Manchester Combined Authority: Get Online Greater Manchester:

Greater Manchester Combined Authority: National support to get online:

What about equality, diversity, and inclusion?

Equality, diversity, and inclusion (EDI) in patient and public involvement are important to ensure that research is meaningful and accessible to everyone.

People from all backgrounds are welcome to contribute to research and involvement activities should be culturally sensitive. Please let the research team know if there is anything they can do to ensure you feel comfortable when attending meetings or other involvement activities (e.g., food preferences, timing around celebration events).

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

What if I have a disability or access needs?

Around 1 in 5 people have a disability,* that may include physical disabilities, long-term mental or physical health conditions, or neurodivergence. We also understand that not all disabilities are visible.

People may have several conditions (e.g., neurodivergent with a physical disability, and long-term health condition). Please let the research team know about anything you need to help you be involved in research in person (quiet space, water bowl for support pets, sensory specific needs, physical access needs) or online (camera off, communication needs).

Recommended links for further information:

University of Manchester Disability Advisory and Support Service:

University of Manchester Accessibility: campus information.

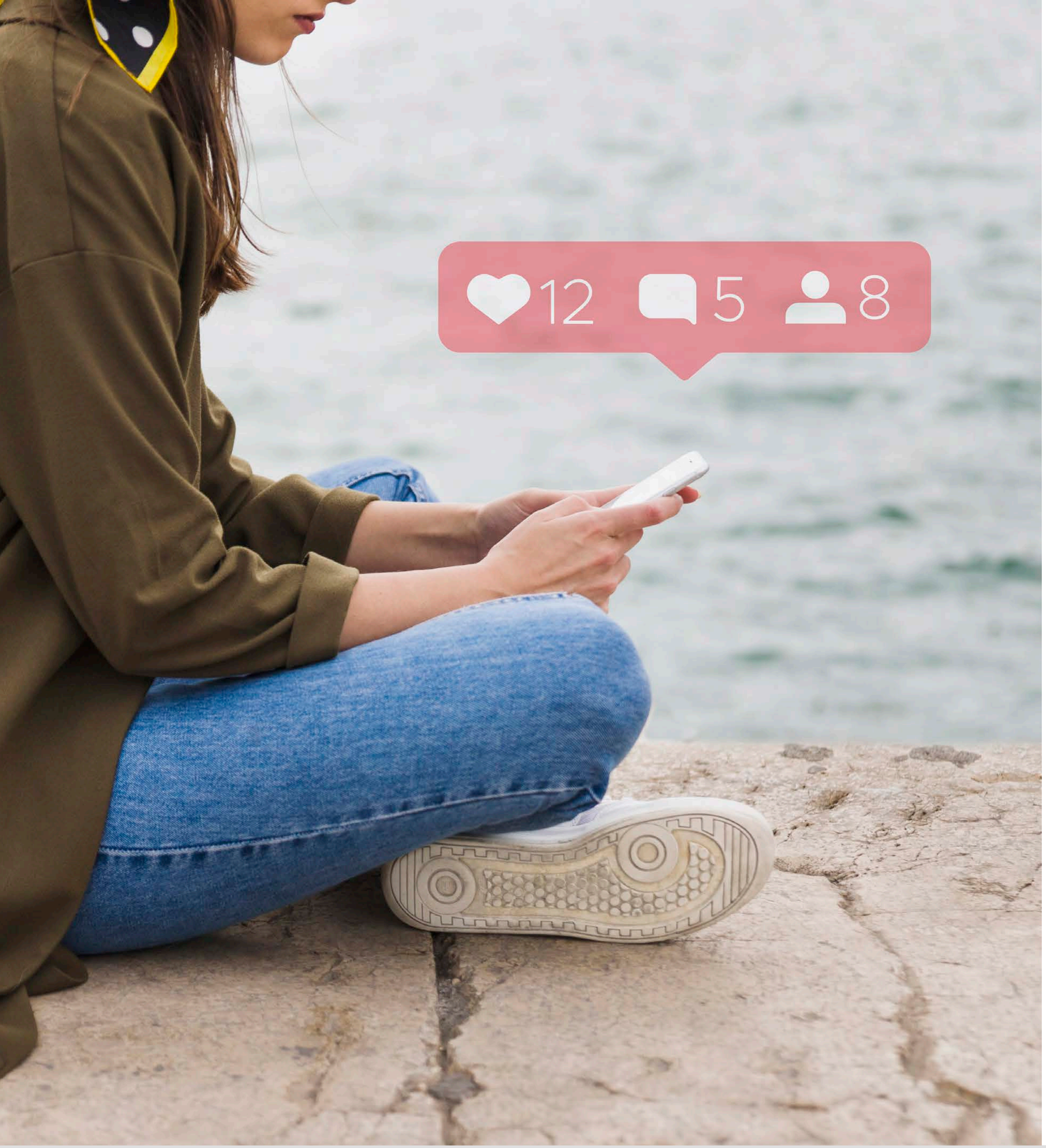
DisabledGo: AccessAble. This website is also available as an app on the App Store or Google Play.

Goblin tools formalizer:

Neurodivergent enabler:

ADHD Foundation:

*Disability Action Plan, UK 2024



Will I have to engage with the media (online/news)?

Publishing research places the study and team in the public domain. Research is often discussed on social media and can generate media interest. If you are named on a journal paper or other dissemination materials, this means that your identity is also in the public domain. However, you always have the option to remain anonymous (not identified), if you prefer.

Will I be mentioned on social media?

It is worth thinking carefully about whether or not you wish to be tagged on social media posts. Researchers and public contributors may recieve positive, but also negative comments. Research teams, often have a media engagement lead who can advise on any dissemination and engagement with the public over research. The media team at the NIHR GM PSRC suggest that researchers and public contributors:

- Avoid responding 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.
- Flag negative comments to the lead research and communications team. Once you've done that, stop looking at the thread and change your security settings where necessary.

Have you any guidance for social media?

Yes, our communications staff suggested the following recommendations for using 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 busy place
- **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 a researcher
- **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 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

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)

Research team at the Centre for Mental Health and Safety

Leah Quinlivan: Research profile
Sarah Steeg: Research profile
Roger Webb: Research profile
Nav Kapur: Research profile
NCISH: About our people
MaSH: Staff
NIHR: Our people

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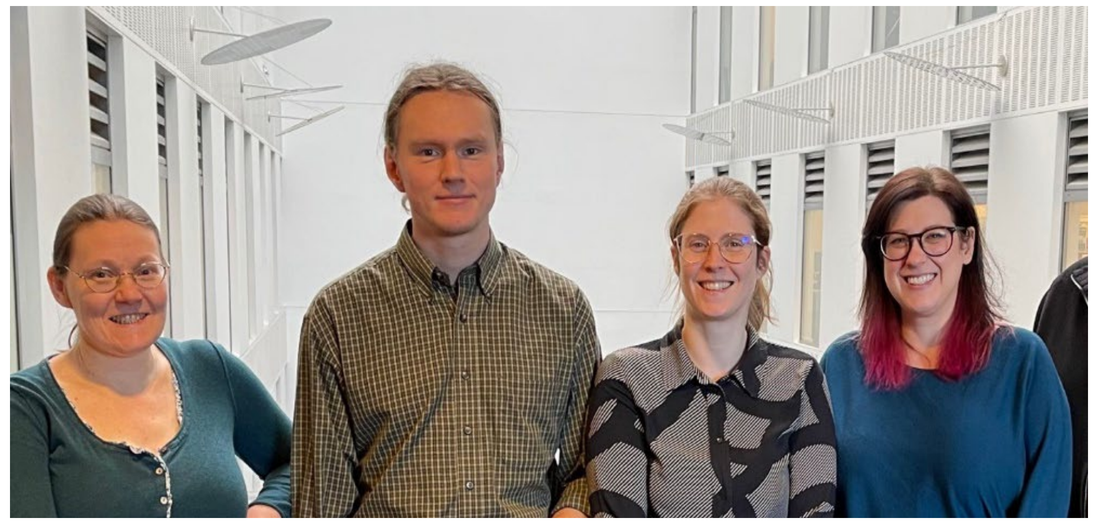
HQIP
Healthcare Quality Improvement Partnership



NCISH

The Manchester Self-Harm Project

NIHR | Greater Manchester Patient Safety Research Collaboration

@NCISH_UK

@mashproject

@GM_PSRC

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

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