

Bath Mental Health Research Group

Patient and Public Involvement and Engagement (PPIE) Strategy

About Bath Mental Health Research Group (MHRG)

We know that most mental health difficulties start in childhood, usually before the age of 14. Children and young people often wait a long time to get help when problems first start or are not offered the right help at the right time. This means that problems can get much worse, which can have a long-lasting effect on a young person's personal life, friendships, and family relationships. It can make it harder for them to do as well at school, reach their full potential, or to get and keep a job. We also know that some groups of young people need more help than others. This could be because of having additional learning needs, being neurodivergent (e.g. autism) or having had a difficult start in life.

The Bath Mental Health Research Group (MHRG) will carry out research with the aim of contributing to improving mental health and wellbeing in young people aged between 12 and 25 in Bath, North-East Somerset, Swindon and Wiltshire. We are focusing on this age range as we know youth-specific services are very important for supporting people through the transition into young adulthood, to prevent young people falling into the gap between child and adult services at age 18.

We are funded by the National Institute for Health Research (NIHR) which will run for 5 years from 2025-2029. The Bath MHRG is based at the University of Bath, and we work closely with our partners at the Universities of Exeter and Bristol. The Bath MHRG aims to bring together researchers, health care professionals, and people with lived experience to plan and carry out meaningful research which addresses the problems local people are most concerned about. To develop our research priorities, we have worked together with key partners who are involved with supporting children and young people in the region. This includes people who work in local health services, but also people who work in schools, universities, charities, and local authorities.

This has led us to develop our four main themes: -

- 1) Creating and testing simple and widely available support for common mental health issues such as anxiety and depression. This includes using digital treatments.
- 2) Improving understanding, awareness, and treatment for mental health difficulties in young people with co-occurring conditions such as autism, ADHD and behavioural difficulties.
- 3) Understanding how many of our young people in the region have issues with smoking, drinking, and drug use, and developing new ways to help reduce the harm this may cause their mental health.
- 4) Finding ways to help young people who have had difficult early experiences, to stop this leading to poor mental health when they get older

The overarching aims of the Bath MHRG group are:

- **Preventing** mental health difficulties from developing in the first place
- **Early intervention** for when problems first start
- **Increasing access** to good care when children and young people need it

Why do we want to do patient and public involvement and engagement?

We want to make sure all our research is developed and delivered in partnership with the people it aims to help. We recognise and value different kinds of expertise, including the lived experience of children and young people, and their families. We recognise there has been a historical power imbalance between health service researchers and the users of those services, with research sometimes being done ‘to’ people and not ‘with’ people. We want to share power more equally. This means people with lived experience being meaningfully involved with setting our research priorities, as well as working with us to carry out the research. We also recognise the benefits of involvement to the people with lived experience themselves. This can include increased confidence, learning new skills such as leadership and public speaking, and satisfaction from making a difference in improving services for children and young people in the region.

How will we do patient and public involvement and engagement?

We will be guided by the UK Standards for Public Involvement in health and social care research.



Image source: <https://sites.google.com/nihr.ac.uk/pi-standards/home>

1) Communication

We will aim to use plain language in all communications to make sure everyone can understand and contribute to the best of their ability. We will be flexible in the ways we communicate (e.g. email, social media, text/WhatsApp and in person) and will explore

with our advisory groups, the use of accessible and appealing forms of visual and verbal communication. This could include videos, cartoons, and podcasts for dissemination of research findings to the public. We will communicate clearly the actions taken because of PPIE input, through feedback loops such as 'you said, we did'. We will make PPIE meetings as accessible as possible to meet different people's needs, for example, in accommodating sensory needs or communication preferences.

2) Working Together

We will ensure our public involvement partnerships include a range of people and groups as informed by community and research needs. We will develop cross-sector partnerships with schools, mental health services, local authority and third sector organisations. We will build upon existing partnerships and relationships to ensure multiple voices, sectors, and perspectives are heard and represented in our PPIE work. We will ensure we work together in a way that values everyone's contributions, ideas and opinions and that builds and maintains mutually respectful, productive, meaningful relationships. We will jointly define and record the purpose of public involvement and ensure there is a shared understanding of the roles, responsibilities and expectations we each have and that PPIE is embedded and integrated throughout each work package and is part of the research from beginning to end. We will ensure there are formal and informal ways for PPIE members to get to know the professional research team and vice versa to ensure they feel comfortable talking to and working with, professionals. We will ensure people feel invested in the research, excited by common goals and share a feeling that the research is co-owned and co-produced by everyone.

3) Inclusive Opportunities

We recognise that our target region of Bath and North-East Somerset, Swindon, and Wiltshire (BSW) is a large geographical area including both rural and urban areas. The BSW region is also an area with high levels of inequality, with some people living in very deprived areas. In addition, young people with lived experience of mental health conditions, trauma, substance misuse and ADHD or autism, are likely to face further barriers to participation in PPIE activities. All these factors, and some in combination, could create inequity in accessing PPIE activities.

We will work to create inclusive opportunities by:

- Offering hybrid and/or online alternatives to meetings
- Addressing 'digital exclusion' by loaning people internet-enabled devices
- Going out to visit existing groups where this is more appropriate
- Paying people for their time, and paying up front for people's travel costs
- Supporting people with carer's costs where this is needed to enable involvement in an activity
- Considering the sensory environment for in person meetings are neuro-affirming e.g. keeping lights low, offering stim toys

- Asking PPIE members about their access/SEND needs on an ongoing basis and how we can best support them to participate
- Offering a range of ways in which people can contribute to the development of research

Payment for involvement will be a fixed rate of £25/hour, in line with NIHR involvement rates. This can be paid via a bank transfer, or voucher depending on the person's preference. Involvement will be informed of the potential impact of payment on tax and benefits, and can be signposted to sources of further information and support if needed.

4) Impact

We want to make sure co-production with people with lived experience translates into action and impact. It is important that we identify and share the difference PPIE has made to our research. We will draw on existing tool kits such as the PIRIT toolkit to evaluate our work. This record of impact will be kept by each of the work packages and the PPIE steering group. On an ongoing basis, we will use the PIRIT tool to track the difference the PPIE input has on projects and this will be fed back to the PPIE group at our regular meetings, so they are continuously informed of the difference their involvement is making to the project.

We also acknowledge the personal impact of doing PPIE work, and the benefits and challenges it can bring for people. We will have guidelines in place to help support people's wellbeing when they are involved in PPIE work. This includes a list of sign posting documents and opportunities to check-in and de-brief after sessions and young people can contact PPIE coordinators via email or phone if needed between meetings. We will co-create group agreements with young people about how the group operates and the boundaries including safeguarding and confidentiality. We will follow good practice in how and when people might want to share their own personal experiences, whilst also acknowledging a person's right to choose what they want to share, when, and with whom. We recognise people might need to step back or take a break from their PPIE roles at times. We will aim to form secure relationships with all lived experience contributors to help navigate challenges and ups and downs along the way.

5) Governance

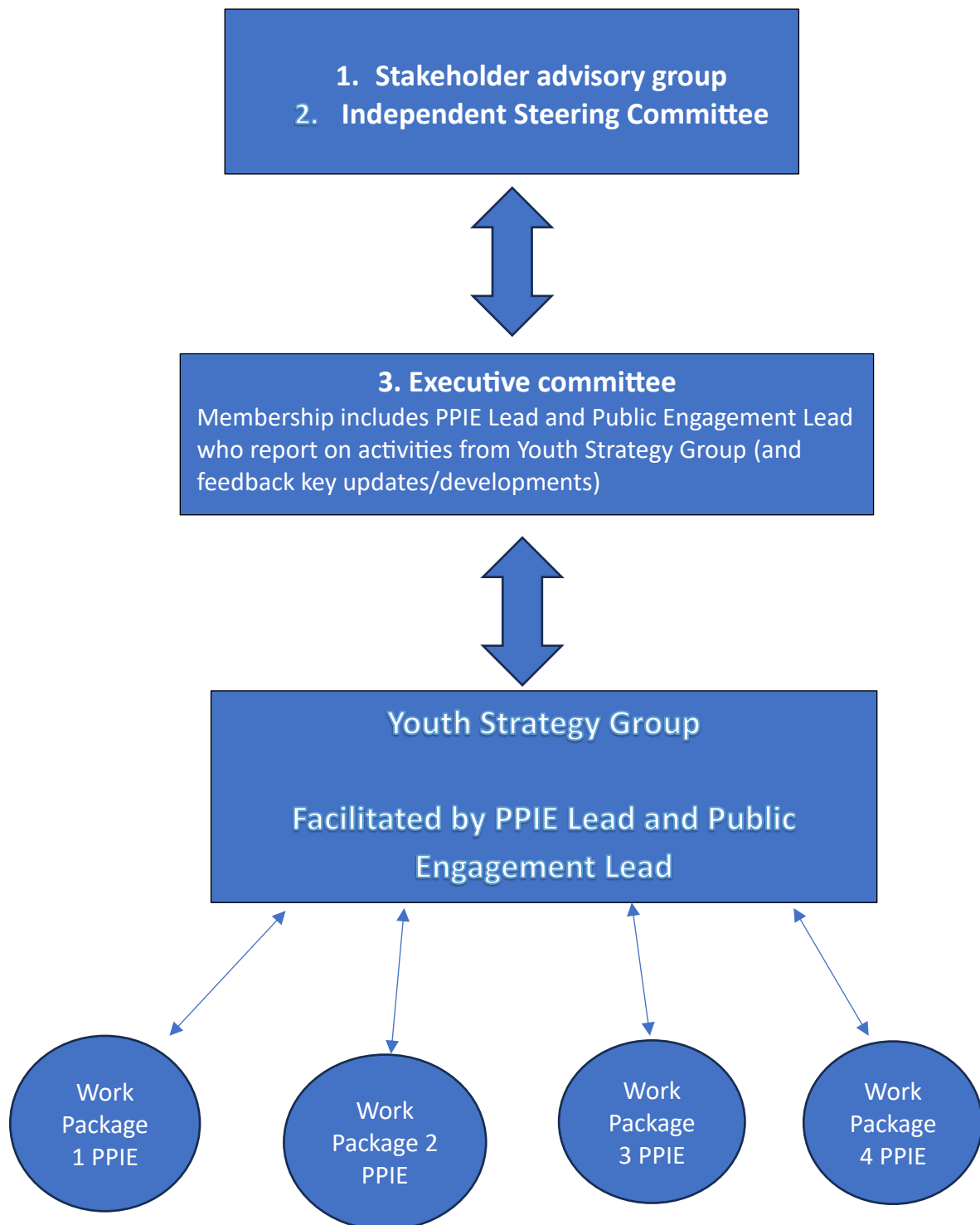
We will have an overarching Youth Strategy Group, made up of 12–25-year-olds living in the region, who will meet monthly. This group will sit across all workstreams and will be involved in strategic aims and decision making regarding the MHRG. They will help steer the overall direction of the work of the MHRG and provide high-level support and oversight to PPIE work going on within the four work packages. We recognise that each work package will need bespoke PPIE activities to support different studies within the work package, and at different times. The Youth Strategy Group will help

co-ordinate the range of PPIE activities across the different work packages, and make sure all PPIE work is being done in line with our overall strategy e.g. paying people fairly, providing accessible options for engagement, and feed into the other advisory groups where needed.

6) Support and Learning

It is important that people are given the opportunity to learn and practice new skills when doing PPIE work. Facilitating supportive, interesting, creative learning opportunities for PPIE members is important for both contributors and researchers. It can also help improve PPIE recruitment, retention, and enjoyment of PPIE involvement. Learning goals and opportunities should be co-produced by the group based on their interests and skills. This can be especially beneficial for young people for whom these opportunities are not always available or easily accessible, such as care experienced young people or those with special educational needs or disabilities (SEND). We will provide both formal (e.g. short training courses) and informal training opportunities (e.g. chairing a meeting). We will draw on resources such as <https://yparhub.berkeley.edu/home> to co-create learning and development goals, to help young people build confidence which can help them succeed in other areas of their life which are important to them, including education and employment.

Figure 1 – Governance Structure for PPIE within the MHRG



Delivering Patient and Public Involvement:

The team responsible for the oversight of patient and public involvement are named below and work in partnership with research team to have oversight of PPIE for the overall group.

Lucy Clarkson (PPIE Lead) - PPIE lead for the MHRG, with overall responsibility for PPIE across the work packages and overall work of the group. This includes developing and implementing PPIE strategy, using a lived experience perspective to inform the work of the MHRG, supporting and guiding researchers in the group in working with people with lived experience, and monitoring the impact of PPIE across the work of the MHRG.

Harriet Rose (Public Engagement lead) – Stakeholder engagement including liaising with stakeholders working in youth mental health locally, e.g. charities, local authority health partners, ICB leads. Leading digital engagement and communications. Supporting academics to engage with stakeholders and PPIE. Supporting youth involvement and community outreach and partnerships.

Partnerships and collaborations:

Since launching Bath MHRG have built on some already established partnerships and developed new partnerships. To date, this includes presence and support for several community-based events and partnerships with relevant local organisations:

- Research partnership established with Bath City Farm to deliver and evaluate nature-based interventions for work package 4
- Trowbridge Future community organisation is supporting the delivery of the Youth Advisory Group through promoting it to their users and renting us a youth friendly space in Wiltshire
- SMASH and Way UK in Swindon support in recruiting young people to lived experience groups.
- Youth Connect Southwest to support young people's voice in work package 2 development for young people out of education, join the stakeholder
- B&NES parent carer forum working in partnership with work package 2 to engage parents in shaping interview schedules and research protocol.
- Swindon and Wiltshire Community Foundation invitation to share research at youth work networks and reach out to young people in the region for input into advisory groups and connections across the region.
- Mind Swindon and Gloucestershire
- Bath Mind
- B&NES local authority- suicide prevention, public health connection, education

- Wiltshire Council – public health – substance and children and young people’s mental health
- Swindon Council – public health – substance
- NHS integrated care board for the area – including creating a lead link person and attending diversity in research networks and linking with leads for children and young people, mental health and research.
- AWP clinicians, involvement and research involvement for mental health
- Off the Record BANES- youth charity providing mental health services
- University of Bath Student Services

We have a planned program of activities for both the overall MHRG and work package specific activities. Below is a plan of the basic outline of PPIE involvement for the group and work package areas which will be updated as the project continues.

MHRG Wide PPIE Activities:

- Central Youth Strategy Group runs monthly, supported by PPIE lead and public engagement lead, including visiting research staff and input on strategic operations such as MHRG website and communications.
- Quarterly Stakeholder advisory group – made up of representatives from local authority health and social care, education, NHS, charity providers, parent/carer and young people.
- Annual stakeholder events / round tables for input, engagement and sharing updates, creating two- way communication with relevant stakeholders and policy makers

Work Package Specific Activities

These are some examples of PPIE activities specifically relating to Work Package projects. This is not an exhaustive list and work will develop over time.

- **Work Package 1: Digital Mental Health**
 - Young Adult Consultants (YAC)– 12 members working on the design and delivery of the single session interventions (SSIs) focused on targeting common mental health problems such as anxiety and depression, website design and trial recruitment.
- **Work Package 2: Neurodiversity**
 - Work with parent/carer groups to understand how to best conduct interviews with the target group of parents
 - Collaboration with local organisations supporting young people to develop question guides for young people with ADHD

- **Work Package 3: Substance misuse**

- Collaboration with lived experience young people engaged through public engagement around the topic of vaping to co-design
- Recruit lived experience group to co-design treatments and interventions
- Work with local authority leads for public health in substance misuse to understand local need and priorities

- **Work Package 4: Adverse Childhood experiences**

- Work with youth strategy group to interpret scoping review findings
- Develop research partnerships with up to three partner organisations delivering low stigma interventions.
- Develop a youth advisory group(s) to co-design interventions with the research team