National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) in Addictions

Patient and Public Involvement and Engagement (PPIE)

Welcome to our Network

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1. Purpose of this Document

This document welcomes you to the National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) in Addictions. It also provides some important information about our Patient and Public Involvement and Engagement (PPIE) network. This includes who we are, our purpose, our roles and responsibilities, the kinds of time commitment involved in our activities, payment and expenses, guidelines for meetings, raising issues or concerns, confidentiality, conflicts of interest, and a few other topics. We can think of this document as our Terms of Reference (TOR).

2. The NIHR PRU in Addictions

The National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) in Addictions is a group of researchers, other stakeholders, and people with living and lived experience of substance use and addictive behaviours, who undertake research to inform government policies. The PRU supports the identification, analysis, implementation, evaluation, and adaptation of policies across prevention, treatment, harm reduction, and recovery. There are five interconnected themes:

1. Tobacco/ Nicotine
2. Alcohol
3. Illicit/ Misuse of prescription drugs
4. Gambling, and
5. Patient and Public Involvement and Engagement (PPIE)

3. Name of our PPIE Network

Like many patient and public groups and panels, we wanted to give our PPIE network a friendly name. Following consultation and voting of our membership in early June 2024, we have adopted the informal term APPIE (Addictions Patient and Public Involvement and Engagement). This makes us the APPIE Network.

4. Purpose of the APPIE Network

The APPIE network aims to:

- Promote diversity and generate a wide, inclusive pool of people with living and lived experience of substance use and addictive behaviours to contribute to the PRU's work.

- Build PPIE capacity across addictions and create a national database of people with living or lived experience who want to improve research into substance use and addictive behaviours.

- Provide support and mentorship to PPIE network members and research staff through training, research experience, and networking.

- Support PRU projects by establishing bespoke PPIE groups, each consisting of between 6-10 people.

5. Network Membership

The APPIE network is made up of three groups.

1. At the centre is a _Hub_ comprising four people. These are the PPIE Lead (Professor Jo Neale), the PPIE Research Assistant (Abigail [Abby] Severn), and two living/lived experience Co-Applicants (Mel Getty and Paul Lennon).

2. Surrounding the hub is the _Strategy Group_. This comprises representatives of twelve existing specialist PPIE groups and panels covering alcohol, tobacco/nicotine, illicit and other drugs, and gambling. There will be up to 20 strategy group members at any one time and this group will be closed to new members except when spaces need to be filled because members have left.

3. Surrounding both the hub and the strategy group are the wider _PPIE Network Members_. Members of the APPIE network may include people with living/lived experience of substance use or addictive behaviours, as well as carers, friends or family members connected to someone with living/lived experience. They might also be members of the public or professionals who have a general interest in the work of the PRU in Addictions. There is no fixed number of network members, so this group will always be open to new members.

6. Roles and Responsibilities

i. *Hub Members*

Hub members are responsible for organising PPIE activities associated with the PRU's research. This includes making sure that any activities carried out by the APPIE network are ethical, free from outside influence, free from harm or offence, and follow UK law.

- <u>Jo Neale</u> is responsible for overseeing and delivering the strategic aims of the APPIE network, ensuring equality and diversity in the network's activities, and acting as key contact and safeguarding lead.
- <u>Abigail Severn</u> is responsible for setting up and running network meetings, taking minutes, organising payments to network members for their contributions, assisting with writing reports and other network outputs, managing our PPIE database, and acting as a key contact between PPIE network members and PRU researchers.
- <u>Mel Getty and Paul Lennon</u> are responsible for contributing to PPIE strategic documents and project-specific PPIE groups, co-ordinating input from PPIE network members and acting as contact points for researchers, assisting with training, and supporting and mentoring PPIE network members.

ii. *Strategy Group Members*

Members of the PPIE strategy group will advise on, and assist with, core PPIE activities. This includes advising on PPIE strategy (and ensuring that this is consistent with the ['UK Standards for Public Involvement'](#)), contributing to capacity building and promoting PPIE opportunities, preparing core PPIE documents, identifying potential research topics, building links with people from marginalized communities, and participating in training activities. Members of the PPIE strategy group may also join project specific PPIE groups.

iii. *Network Members*

Network members may be invited to perform the following activities:

- Join project specific PPIE groups and contribute to the design, conduct, writing up, or dissemination of research studies.
- Contribute by sharing their unique, personal, cultural, expert by experience perspective on research projects.
- Evaluate whether research projects hosted by the PRU are inclusive and accessible and suggest ways of promoting inclusivity and diversity.
- Provide feedback on patient and public facing documents produced by the PRU in Addictions team.
- Attend and contribute to training provided by and for the PPIE team.
- Participate in evaluations or feedback surveys of the APPIE network so that we can get a better idea of our impact and how to improve.

7. Time Commitment

There is no minimum time commitment to taking part in PPIE activities. However, we ask members of the network to read their communications from the PPIE team and respond if they are able.

Members of the strategy group are also encouraged to attend a 1-hour online quarterly meeting with hub members and any in-person or hybrid training or networking events.

Although membership of both the strategy group and the network may last for up to five years, people can leave at any time. Personal details can also be deleted by contacting the PPIE lead.

i.   Typical length of PPIE activities

Where online consultancy occurs (e.g., getting feedback on an information sheet), the time required to read and feedback on a document should not normally exceed 1 hour.

Where online meetings occur, the time commitment required will normally be 60-90 minutes (to prevent meeting fatigue)

Where in-person meetings, networking, or events occur, the time commitment required will normally be a maximum of 4 hours (with breaks). However, attendance at one-day events may also be offered.

8. Payment and Expenses

Network members will be compensated for the time and effort they contribute to PPIE activities. Below are the rates for the types of activities members might undertake. These are informed by NIHR guidance.

- Individual projects - £25 per hour (up to a max of 10 hours for any individual member)
- Other group meetings - £25 per meeting (up to 3 meetings for any group in any year)
- Any activity that lasts for half a day will be re-imbursed at £75 and activities lasting a full day will be reimbursed at £150
- Travel, carer expenses, subsistence, technology, and training will be assessed on a case-by-case basis. Please discuss with the PRU core team _before_ you commit to any spending as universities have additional guidance and receipts are always required.

In most cases, payment and expenses will be paid via bank transfer from King's College London. The PPIE team will need to ask you for your bank details to process these payments. Please note that it can take up to two weeks to receive payment from King's College London.

Network members should be aware that any payment they receive for PPIE work may affect state benefits, pension credits, tax credits, and other means adjusted benefits. It is up to network members to disclose any income from PPIE activities to either benefit providers or to HMRC where applicable. If you are unsure whether you need to do this, more information can be found on the NIHR website: Payment guidance for members of the public considering involvement in research | NIHR. In addition, it may be possible to reimburse you for APPIE activities in other ways, e.g., by vouchers or donations to charity. Please speak to the PPIE hub members about this if you would like to know more.

9. Meeting Guidelines

Everyone taking part in PPIE is there because they care about making a difference and helping others. Below are some general guidelines we will all agree to follow so that discussions remain respectful, rewarding, and constructive for everyone:

- Confidentiality – We will not share personal stories or information outside of the network and no personal stories will be included in any meeting minutes. If joining online, everyone will also try their best to be in a private space and to use head/earphones. No screenshots or photos will be taken by anyone during the meetings to protect everyone's privacy.
- Communication – Members will let others know if they are running late for a meeting or must leave early. We will keep our microphones on mute while others are speaking or if there is a lot of background noise so that people who are talking can be heard. It is nice to put our camera on so we can see who we are talking to and read their reactions better. We will use online functions such as 'raising a hand' and chat whenever we can, so that the person chairing the meeting can more easily identify anyone who wants to speak.
- Contribution – Nobody should be afraid of raising their hand to ask a question or to make a comment. Chances are another person in the group is thinking or feeling the same. The chair will do their best to keep the meeting to time so that group members can discuss each item on the agenda. The chair will also try to ensure that all group members participate in the discussion by checking if anyone who is being quiet has anything they want to say.
- Consideration – Recognising, respecting, and appreciating difference and other opinions during meetings are important. If we think about the numbers '6' and '9', both are correct from different standpoints. Whilst we recognise people use different terms, we want to avoid language that could blame, shame, or

stigmatise people. Network members will try to adopt a person-first approach when they talk about addiction-related issues. More information can be found here: Words Matter

10. Raising Issues or Concerns

We don't expect our PPIE activities to cause any harm to anyone. However, we need to be prepared just in case any difficult situations arise while we are working together. Below are some examples of difficult situations that could arise with recommendations on how to respond in a constructive way:

- Disagreement or being challenged by others – Other people may disagree with our views and thoughts. It is okay to offer alternative views on a topic. In fact, this can lead to helpful discussions so long as it is done respectfully. Should a disagreement arise, that cannot be resolved in the meeting, the chair will ask everyone involved to set aside the discussion until a de-briefing session. This de-briefing will be organised as soon as possible during a break or after the meeting has ended.

- Not getting paid for your contribution or not having your expenses refunded to you – Everyone who contributes to PPIE should be reimbursed for their work. If you think you have not been paid, please let us know. We can check the dates with you and, if the payment still isn't found, we will talk to our colleagues in the University Finance team. Sometimes there is a deadline associated with payments, so please let know about missing payments sooner rather than later (no more than 2 months).

- Not having any reasonable adjustments or support to get involved in PPIE activities despite sharing this information with the PPIE team – Inclusivity and diversity are vital to the strategic aims of the PPIE network, and we are always trying to improve access to PPIE activities. Please get in touch with us to discuss any issues or ideas you may have.

- Feeling that someone is struggling – We all care about the welfare of other people and will want to help if someone seems to be struggling or at risk of harm. Please reach out the core team (Abby, Jo, Paul, or Mel) if you hear or see something that is concerning you and you are not sure what to do. If the PPIE team feel unable to manage the issue between themselves, they will discuss with the PRU senior management team, many of whom have experience of working in healthcare.

- Witness to, or perpetrator of, racist, homophobic, or sexist language or behaviour – Everyone who works on PPIE activities should be able to do so without feeling like they are being judged or treated differently. We all know that

it is never acceptable to use language or behave in any way that is discriminatory towards others. In the unlikely event that you observe or experience any discrimination, you might consider responding as an active bystander. Please also contact the safeguarding and PPIE lead, Joanne Neale (joanne.neale@kcl.ac.uk) to discuss further.

- Other inappropriate behaviour, including bullying or harassment – When working with others, we will always avoid teasing or pressuring of others, name calling, or other inappropriate behaviours such as being intoxicated. Our meetings will be friendly and informal, so that nobody feels uncomfortable.

11. Confidentiality

Hub members will keep personal and sensitive discussions with members of the network confidential. The only time when confidentiality cannot be maintained is when the law requires us to act on issues that have been seen or heard. Hub members will not record personal information or experiences in meeting minutes.

Strategy group and other network members are asked not to share research materials (e.g. protocols, plain language summaries, information sheets etc) outside the PPIE group without permission from the lead researcher. Please also keep personal information about other group members confidential.

12. Sharing Contact Details

With your permission we may share your contact details with PRU researchers and other researchers who are doing similar research. This is so they can get in contact with you to let you know more about the research and to get your thoughts on it. If you would prefer to not to share your contact details, please contact abigail.severn@kcl.ac.uk.

13. Conflicts of Interest

Conflicts of interest arise when we take on commitments or activities which can work against each other. Please be mindful of the following:

Being a participant in a study you are contributing to as a PPIE member – having insight into how a study works can introduce bias into the results of that study if you were also a participant in it. This makes the research less robust and reliable.

Receiving support or funding from individuals or organisations connected with tobacco, alcohol, legal cannabis, gambling, or pharmaceutical industries – this is more common in some areas of research than others. It can create a conflict of interest as

the person contributing to the PPIE activity may not be completely impartial. Please note, though, that receiving funding and support for treatment and care is not considered a conflict of interest.

Knowing when a conflict of interest applies can be difficult. The PRU has detailed policies on what to do if there is a conflict of interest or if you are unsure. This may mean not being able to take part in some PPIE activities until that conflict is cleared. If you have any questions or concerns, please contact PPIE lead Joanne Neale (joanne.neale@kcl.ac.uk).

14. Glossary

To avoid using too much jargon, we have written out the terms and titles in full before using acronyms. Below is a list of acronyms we have used:

NIHR – National Institute of Health Research

PRU – Policy Research Unit

PPIE – Patient and Public Involvement and Engagement

APPIE – Addictions Patient and Public Involvement and Engagement

ToR – Terms of Reference

15. Key Email Addresses

- Joanne Neale (PPIE Lead): joanne.neale@kcl.ac.uk
- Abigail Severn (PPIE Research Assistant): abigail.severn@kcl.ac.uk
- APPIE Network: PPIEPruAddictions@kcl.ac.uk

16. Authorship and Review

This document has been written by the PPIE research assistant, Abigail Severn, with assistance of PPIE lead Joanne Neale and PPIE co-applicants Mel Getty and Paul Lennon. It has had additional input from the wider PRU in addictions PPIE network. The document will be reviewed every two years, to ensure that it confirms to current standards outlined by the NIHR. A plain language summary is also available.