

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

**Patient and Public Involvement and Engagement
(PPIE) Strategy 2024 – 2028**

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

Patient and Public Involvement and Engagement (PPIE) Strategy 2024 – 2028

1. Introduction to the NIHR Policy Research Unit in Addictions

NIHR Policy Research Units (PRUs) undertake research to inform government and arms-length bodies that make policy decisions about health and social care. The units create a critical mass of experts for research in priority areas of health and social care policy.

The NIHR PRU in Addictions (award number: NIHR 206123) is one of 20 new PRUs across England which were awarded over £100 million in total. They commenced on 1st January 2024 and are funded for five years initially.

The NIHR PRU in Addictions will work with the Department of Health & Social Care (DHSC) and other stakeholders, including professionals and people with living and lived experience of addictive products, behaviours and systems. It will support the identification, analysis, implementation, evaluation, and adaptation of policies across the spectrum of prevention, treatment, harm reduction, and recovery. There are five interrelated themes (i. Tobacco/nicotine; ii. Alcohol; iii. Illicit/misuse of prescription drugs; iv. Gambling; v. PPIE) and the links between substances and addictive behaviours will also be addressed.

1.1. *PRU in Addictions Objectives*

The objectives of the NIHR PRU in Addictions are to:

- 1) Monitor, improve and communicate current and emerging understanding of addiction risk factors across the life course, over time and in key population subgroups, including the role of legal and illicit industries, marketing, social media and wider social determinants
- 2) Analyse the physical, psychological, inequality and wider societal (including social care) impacts of individual and co-occurring addictive behaviours

- 3) Identify effective and cost-effective approaches to improving the design and integration of services for addictions treatment in mental, physical and social healthcare settings
- 4) Identify, appraise, and evaluate proposed or implemented addictions policy interventions using diverse and innovative techniques, (e.g. evidence synthesis, experimental, natural experiment, complex intervention, qualitative and model-based methods)
- 5) Increase the diversity of the addictions workforce and grow its capacity and capability in evidence-based policy

1.2. Patient and Public Involvement and Engagement (PPIE)

The work of the PRU in Addictions will benefit from the experience and expertise of people with diverse living and lived experiences of tobacco/nicotine, alcohol, illicit/misuse of prescription drugs, and/or gambling at all stages. The model underpinning our PPIE is shown in Appendix 1.

At the centre is a *hub* comprising four people: the PPIE Lead, the PPIE Research Assistant, and two living/lived experience Co-Applicants.

- The four hub members will be responsible for promoting involvement in PPIE activities, ensuring inclusivity and diversity, building PPIE capacity, providing relevant PPIE support and training to researchers/academics and patient/public members, organising specific PPIE groups for individual research projects, facilitating networking opportunities and an annual PPIE event, and monitoring the impact of PPIE activities. In addition, they will undertake general administration of PPIE meetings, ensuring compliance with data protection, GDPR, and safeguarding.

External to the hub is our *PPIE strategy group*. This comprises representatives of twelve existing specialist PPIE groups and panels covering alcohol, tobacco/nicotine, illicit and other drugs, and gambling.

- 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 aligns 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 (see below). There will be up to 20 PPIE 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.

Surrounding both the hub and the PPIE strategy group are our wider *PPIE network members*. These are experts by experience in the field of addictions recruited through various approaches to ensure diversity and inclusivity¹.

- PPIE network members will join project specific PPIE groups, each comprising 6-10 people. In this capacity, they may advise on study design, assist with the preparation of plain language summaries, become involved in conducting, analysing, and writing-up of data, and/or assist with dissemination. PPIE network members will also be invited to participate in training activities and networking opportunities. There is no cap on the number of network members and this group will be open to new members.

¹ Recruitment strategies for network members include, but are not limited to, i. strategy group members identifying and approaching other people in their networks who might be interested and ii. PRU team members, collaborators, and partners disseminating information about the PRU's PPIE activities to relevant services, groups and individuals (including via social media, handing out leaflets at services, and talking at conferences).

2. Patient and Public Involvement and Engagement (PPIE) Strategic Objectives

PPIE in the PRU in Addictions has four strategic objectives.

2.1. Objective 1: Promote Diversity and Inclusion

We will 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. This will strengthen the PRU in Addictions by ensuring that all PRU activities and each PRU project can be supported by people with relevant lived and living experience. This may be through their own personal experience or because they have been negatively affected by someone else's use of substances or addictive behaviours.

Our focus will be on people across all the protected characteristics. For example, people from racialized minorities have often been absent from addictions research, so we will include PPIE representation from different racial and ethnic groups. We will proactively recruit people of different ages and genders, people living in a range of geographical locations, members of marginalized communities (e.g. people experiencing homelessness or asylum seekers), and people caring for others living with addiction. Involving a wide network of people with living and lived experience will also ensure that prevention, harm reduction, treatment and recovery perspectives are all included.

To optimise inclusivity, we recognise that PPIE needs to be conducted in a way that is accessible and flexible. Our PPIE strategy group has already advised on the importance of adopting a range of communication channels (in person, telephone calls, emails, instant messaging, and using subtitles during online meetings), minimizing technical and academic language, checking the accessibility of slides and any other written materials prior to meetings, encouraging questions during meetings, and asking for feedback after meetings. We will also adopt the use of symbols representing marginalised communities where appropriate (e.g. rainbow flag during Pride month) to promote inclusivity and to make people feel more welcome.

2.2. Objective 2: Build PPIE Capacity

In using the term capacity, we refer to the absolute number of people with living and lived experience taking part in PPIE activities as well as their skills, training,

experience and confidence in fully participating. To build PPIE capacity across addictions, we will create a national database of people with living or lived experience who want to improve research on substance use and addictive behaviours. Both our strategy group and network members will be included in this database.

Within the Addictions field to-date, PPIE activity has historically comprised substance or behaviour specific groups (often connected to individual universities or projects). There has been no national PPIE database and few PPIE groups with experience and expertise across addictive products, behaviours and systems. Establishing a national database will allow people to participate in PPIE activities regardless of where they live, what substance/s or behaviour/s interest them, and irrespective of whether they have prior experience of PPIE. Since the database is likely to be useful to researchers and studies not directly connected to the PRU, we will also explore funding opportunities to expand the use of the database beyond the PRU.

Information about the NIHR PRU in Addictions and its PPIE theme are hosted on the [PRU in Addiction's website](#). A Terms of Reference document has been co-produced with our strategic group to help people understand what they can expect if they participate in a PPIE meeting. With support of our PPIE Strategy group, we have also created, piloted and launched an Expression of Interest (EOI) Form that allows people to notify us of their interest in joining the database and network. The form includes core demographic characteristics to facilitate monitoring of diversity and inclusion alongside space for people to enter any declarations of interests, such as industry connections. Information entered in the EOI form links directly to the database so that PRU researchers can search this when looking for people with specific experiences and interests. The database is GDPR compliant, securely stored by King's College London, and has a Privacy Notice.

Members of our PPIE strategy group have endorsed the need for more involvement of people with living and lived experience in addiction-related research; particularly young people, people leaving inpatient detoxification facilities, people who continue to use substances or addictive products, people who are receiving stable medication, and people who are homeless. Responding to this, they have agreed to talk to others within their own networks and to tell them about the database and how to join. Members of the PPIE strategy group have also identified a need for training to underpin increased capacity; for example, training on participating in online meetings (so that people feel fully able to engage), training on non-stigmatizing language (so that nobody is inadvertently made to feel excluded), and training on public speaking (so that people can take advantage of opportunities to attend and present at external events which will in turn build their confidence).

2.3. Objective 3: Provide Support and Mentorship

We will provide support and mentorship both to PPIE network members and to PRU researchers through various means. For example, we recognise that people with living and lived experience may need practical support to become involved in the research process. This may include financial support (to compensate for time, carers, travel, internet access); someone taking time to brief them in advance of, or debrief them after, a meeting; or formal or informal training etc. Equally, we recognise that researchers may need support in understanding what PPIE can and cannot offer, how to prepare for PPIE sessions, and how to run PPIE groups.

We will assess support and mentorship needs and opportunities on an ongoing basis. Sometimes, this may result in researchers supporting or mentoring people with living or lived experiences. On other occasions, it may involve people with living or lived experience supporting or mentoring researchers. Where desired, we will match members of our strategy group with researchers for mentorship. Additionally, we will facilitate opportunities for informal networking so that PPIE members and PRU researchers are able to meet in person, build trust and respect, and find new collaborations more organically. Through these measures, we will establish a strong network of researchers and people with living and lived experience who are confident and skilled in PPIE.

2.4 Objective 4: Support PRU Projects with Bespoke PPIE Groups

We will support each PRU project by establishing its own bespoke PPIE group consisting of between 6-10 people². To this end, we will be able to search our PPIE database for people with direct experience of, or interest in, the topic being researched. Each project specific group will be facilitated by at least two members of the PPIE hub and the PRU researcher leading the study. Members of the PPIE hub will schedule meetings, invite participants from the network, circulate an agenda, chair meetings, organise payments, and take a record of who attended and key issues discussed, decisions taken, and actions going forwards. In addition, they will assess any project-specific safeguarding issues or training and support needs. The PRU researcher leading the study will feedback on how the project changed because of PPIE input.

² The exact number of projects to be completed by the PRU in Addictions is currently unknown.

It is anticipated that each project-specific PPIE group will meet approximately three times a year throughout the life cycle of the project, encompassing all research stages from conceptualization and design through to dissemination. By establishing and facilitating project specific PPIE groups that comprise members with relevant lived and living experience who are supported and mentored as needed, we will ensure that all PRU projects have meaningful PPIE input. This will facilitate learning and collaboration for all involved parties whilst also benefitting the research and increasing its quality, relevance and impact.

3. Programme of Activities – How are we getting patients and the public involved in our work?

We have identified a programme of activities to support our PPIE objectives and to meet the wider objectives of the PRU in Addictions.

Activity	PPIE Objective/s	Time Frame (Months)
Develop and pilot a database of people with living and lived experience of addiction who are interested in PPIE	1, 2 & 4	1-6
Embed data protection, data sharing, and GDPR regulations into the database	2	1-6
Create a webpage on the work of the PPIE team with information on participating in PPIE activities	1, 2, & 4	1-6
Co-produce a Terms of Reference document, FAQs, and Safeguarding procedures for PPIE activities	1 & 3	1-6
Hold weekly hub meetings to discuss, <i>inter alia</i> , PPIE strategy, increasing involvement and day-to-day operational procedures	2 & 3	1-60
Organise quarterly meetings with the PPIE Strategy group	2	1-60
Share the EOI form nationally to individuals and organisations, and promote the database and network	1, 2 & 4	6-60
Identify webinars, lectures, seminars and other online resources and materials that might support the work of the PPIE team	2, 3 & 4	7-60
Organise bespoke training for PPIE members and researchers	2, 3 & 4	7-60
Offer mentorship opportunities for PPIE Strategy group members by pairing them with a PRU researcher	1,2 & 3	7-60
Organise PPIE meetings (6-10 people) for specific projects (each project will have up to 3 meetings per year)	4	7-60

Activity	PPIE Objective/s	Time Frame (Months)
Liaise with organisations - such as Society for the Study of Addiction (SSA), The Mental Elf, and Science Media Centre, as well as other PPIE groups across the country - to promote PPIE activities and opportunities	1, 2, & 4	7-60
Produce and circulate a biannual newsletter for PPIE network members detailing opportunities to get involved and providing feedback on activities and impact	3 & 4	9-60
Organise and deliver an annual in-person or hybrid event for all PPIE network members to meet each other, provide feedback and hear about the impact their contribution has made	2 & 3	10-60
Conduct a short annual survey with database members to assess training attended, further training needs, and general feedback	2 & 3	12, 24, 36, 48, 60

4. Resources – How are we facilitating PPIE?

The PRU in Addictions allocates a proportion of its funding to employ an Early Career Researcher to administer, manage and monitor all PPIE activities under the direction of a Lead Researcher with substantial experience of PPIE. It has also budgeted for two lived/living experience Co-Applicants to support the delivery of our PPIE objectives.

All PPIE activities are reimbursed at the rates recommended within the [NIHR payment guidance for researchers and professionals](#). Payment can be made in a variety of ways (bank transfers, vouchers, gifts or donations) to accommodate personal preferences. We have worked closely with King's finance team to ensure that the system for payments is timely and reliable. Additional funding is available to support initiatives to improve diversity and access to PPIE activities (for example, costs associated with carers, technology, translation, and training opportunities).

Other resources are more practical and include having the capacity to provide safe and inclusive physical spaces for people to engage in PPIE activities. Our lived and living experience co-applicants and strategy group members have strong relationships with community services and patient-led organisations where the PPIE team can host in-person meetings or talk to people about becoming involved with the PRU. Our budget also permits us to provide reimbursement to these organisations for this assistance.

We additionally recognise that there are existing webinars, lectures, seminars and online resources and materials produced by researchers, addiction services, patient and public involvement organisations, and NIHR that can be used to support the objectives of the PPIE team. These will be researched and documented for future use.

5. Partners and Collaborators – Who do we work with?

The PPIE team will work closely with researchers and academics involved in the PRU, including the PRU's wide list of collaborators across the United Kingdom. The PRU in Addictions also has an independent International Advisory Board which includes Dr Annie Maddon, who is a leading figure in both the International Network of People who Use Drugs (INPUD) and Harm Reduction Australia. We will additionally work with representatives from DHSC and NIHR, where appropriate, and report to them on our PPIE-related activities and impact.

Importantly, we will continue to collaborate with the twelve specialist PPIE groups, to which members of our PPIE strategy group also belong (a list of these can be found in Appendix 2). This will include sharing ideas and best practice on PPIE, advertising opportunities and events, and updating on the PRU's work. It has also been possible to partner with the SURE Recovery App to promote involvement from people in recovery from alcohol and other drugs nationally and internationally. The SURE Recovery App has been co-designed with people who have experience of alcohol and other drugs to help them track their recovery journeys and achieve their personal goals. It is free to use and has a resources section to which information on the PPIE database and a link to the EoI form has been added.

Other partners involved in promoting our PPIE activities will include NHS treatment services, addiction charities, public health organisations (such as The Mental Elf and The Society for the Study of Addiction [SSA]), the NIHR ARC South London, and the NIHR Maudsley Biomedical Research Centre.

6. Monitoring and review - How do we measure success?

It is important to assess whether our PPIE objectives have been achieved and whether our work has benefitted the research we conduct. However, success in PPIE is not solely about making research more rigorous or impactful. Success can also involve building long-lasting and stable working relationships with people and organisations that could either contribute to, or benefit from, research. In addition, as members of our strategy group have emphasised, success in PPIE is about creating a feeling of community between those involved, removing power differentials between researchers and the public, working in ways that are transparent and respectful but also challenging, valuing difference, and truly embedding lived experience into decision making across the life course of research.

6.1. How will we know if we have met our objectives?

Objective 1: Promoting Diversity and Inclusion

To assess our objective of increasing diversity and inclusion, we will utilise information from our national database of people with living or lived experience. By reviewing the protected characteristics and patterns of substance use of people who have joined the database (either as strategy group members or network members), we will be able to check that we have achieved a diverse membership and identify where we may be missing representation so that this can be rectified. We will also log who takes part in PPIE activities and what opportunities they are offered. We will know we are successful if we have included people across protected characteristics, geographic areas of the UK, and major patterns of substance use or addictive behaviours; and they have been able to participate in a range of PPIE activities.

Objective 2: Building PPIE Capacity

Building capacity will be assessed by the size and sustainability of the PPIE database. Our target is 80 active members, and the database will be monitored to see if people are requesting to leave or pause their involvement. We will additionally monitor the number of requests from outside institutions and organisations for access to the database for research projects from outside the PRU in Addictions as well as look at whether and how any revenue generated from being costed into external research to provide this service can prolong the life of the database beyond the current funding for the PRU. Success in capacity building equally means strengthening the skills and knowledge of our PPIE members and researchers. We will measure this through the volume of training we offer, the number of people completing training, and feedback forms. In addition, we will conduct an annual survey of database members to solicit their views on the training they have received and any ongoing needs.

Objective 3: Providing Support and Mentorship

Support and mentorship opportunities will be captured and assessed using an activity log, feedback forms, and our annual PPIE survey. We will monitor our systems for payment/reimbursement to ensure that these are operating efficiently and without undue delays or unnecessary bureaucracy. In addition, we will record any visits to services and meetings held in community settings to enable participation by people who may not be comfortable using online platforms. Success will include having good uptake of mentorship and networking opportunities, and positive feedback on these activities. This should in turn translate into PRU researchers undertaking more PPIE work with decreasing need for support from the PRU PPIE hub, and members of the PPIE network proactively supporting each other and feeling confident in undertaking a range of PPIE activities, including contributing to projects external to the PRU.

Objective 4: Support PRU Projects with Bespoke PPIE Groups

Each PRU project will have its own specific PPIE group. Success will be measured by our ability to match people with relevant living and lived experience to each project and those project-specific PPIE groups being well-attended through the life course of the project. Researchers will also record how PPIE activities have changed what they are doing (for example, modifications to the focus of a study or its design, recruitment or data collection methods), the number and nature of co-produced outputs, and joint dissemination activities. Each research team will work with its project specific PPIE group to complete a GRIPP2-SF report. The GRIPP2-SF offers an evidence-based evaluation of what has worked in a particular context and can help improve the quality of PPIE activities and outcomes. This is particularly important as little research has been done on PPIE within the addictions field.

6.2. How will we know that our work made a difference?

Uptake of research findings in policy and practice and citations to the work of the PRU are important ways of demonstrating that our work has made a difference. However, it is also important to capture impact qualitatively and through feedback and personal testimonies of our PPIE members. We will use quarterly meetings with strategic group members, our annual PPIE event, and our annual survey to encourage discussion and critical reflections on what has worked well, what could be done better, and what needs to happen next.

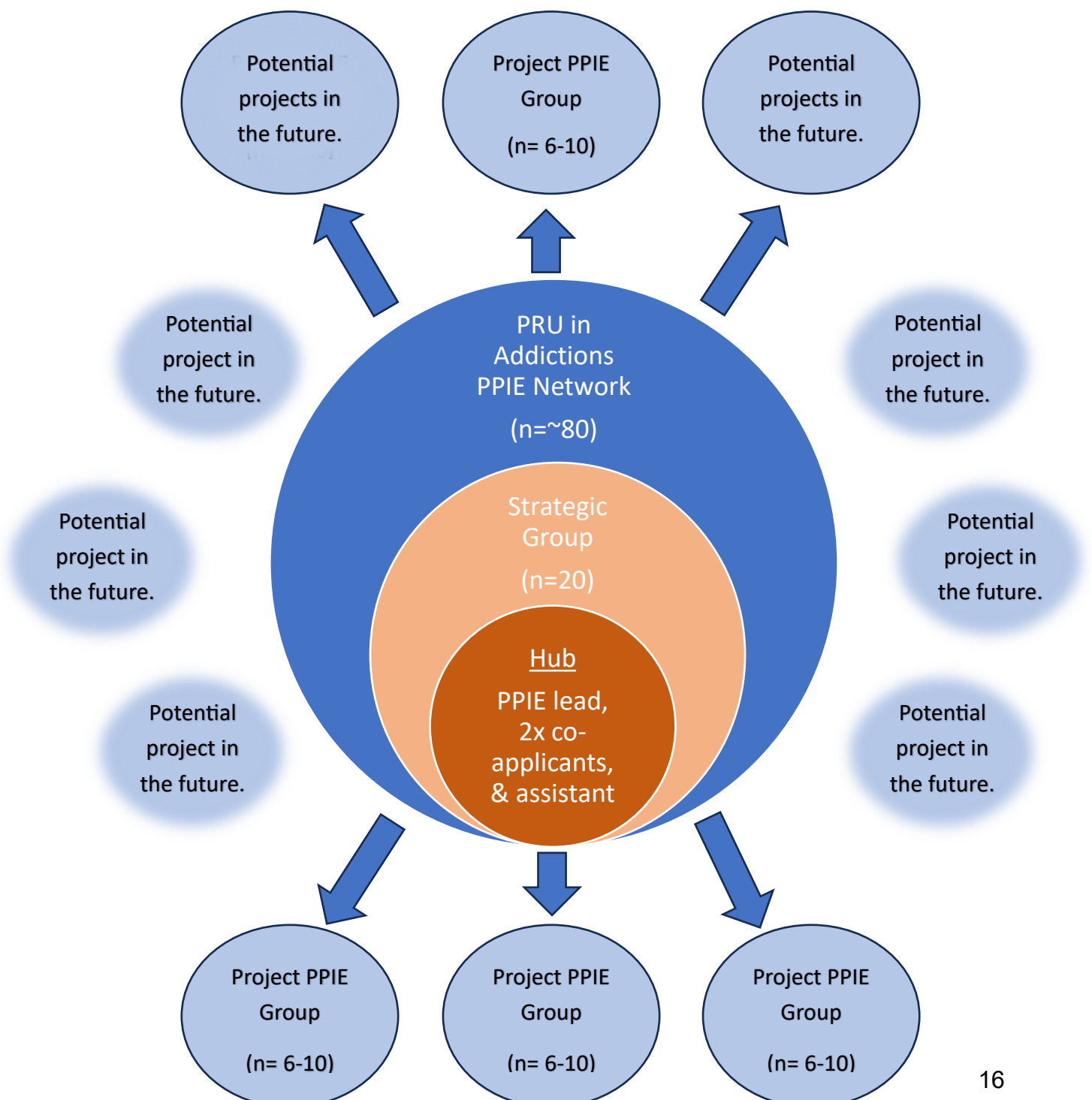
7. Authorship

Writing of this document has been led by the PRU PPIE team (hub), with input from our strategic group, and the PRU's Co-Leads, Deputy Lead and Project Manager. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Dated: June 2024

8. Appendices

Appendix 1: Diagram of PPIE Structure



Appendix 2: Key PPIE Groups, Panels and Collaborators

UK:

- GamFam
- GamLearn
- KCL Addiction Service User Research Group (SURG)
- KCL Young People's Vaping Panel
- KCL Nicotine and Mental Health Group
- Nottingham Tobacco and Nicotine Discussion Group (TANG)
- Sheffield Addiction Recovery Research Panel (ShARRP)
- Stirling Alcohol and Food Discussion Group
- SURE Recovery Network and App
- UCL Tobacco and Alcohol Research PPI Group
- University of Bath Cannabis Database
- Northern Gambling Clinic

International:

- Dr Annie Maddon - International Network of People who Use Drugs (INPUD) and Harm Reduction Australia