



## **Information sheet for community members of the Patient and Public Involvement (PPI) Group v0.2**

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### **Background information**

We are undertaking a 5 year programme of research (NICHE) which aims to Improve mental and physical wellbeing in people living with HIV (PLWH). As we know, HIV is now a treatable long-term condition with near-normal life expectancy. But we also know that for many PLWH that poorer mental health, lack of support, socioeconomic disadvantage and experiences of stigma remain a real problem. We want to assess the benefit of providing a more person-centred approach to care. This could involve one-to-one sessions with a health and wellbeing coach in which a PLWH can discuss their needs, be supported in making positive changes, and get additional help.

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The most important part of any research project is that the community are fully involved in all aspects of the research. As it would be impossible to speak to everybody with a specific condition about every piece of research, instead we work with people from those communities. They are often called Patient and Public Involvement members, or PPI for short, and are interested in supporting clinical research. They are able to provide valuable input from the point of view of someone who may benefit from the research.

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### **We are inviting you to join the NICHE PPI Advisory Group**

- Please take time to read the following information carefully. Take time to decide whether or not you wish to get involved.
- If you do decide to join the PPI Group, you can resign from it at any time, though we would like you to tell us you are leaving, and if possible, why.
- Ask us if there is anything that is not clear or if you would like more information.
- Thank you for reading this information.

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## Important things that you need to know

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- We are committed to meaningful PPI as we believe that it improves the quality of our research.
- Community members and patients have a valuable role in bringing their perspective to the work of NICHE and will work in partnership with researchers, academics and clinicians.
- The NICHE PPI Group meets virtually every three to six months to discuss and provide oversight into the developing programme of research and reviewing documents that require PPI oversight. Meetings usually last 1-2 hours. This appointment is for two years in the first instance.
- Training and support will be given as needed.
- A small fee is given for participating, and reasonable expenses will be covered.

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How to contact us:

If you have any questions about being a member of the NICHE PPI Group, please contact Alex Sparrowhawk, PPI Group chair.

Email: [alex.sparrowhawk@tth.org.uk](mailto:alex.sparrowhawk@tth.org.uk)

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## 1 What is patient and public involvement (PPI) in research?

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The term 'patients and public' includes current, former and potential patients, carers, people who use health and social care services, and people from organisations that represent people who use these services. The perspectives of members of the community are important and different from those who have a professional role in these services.

PPI ensures that research is carried out 'with' or 'by' patients and or members of the public rather than 'to', 'about' or 'for' them. This includes, for example:

- Ensuring all research aspects are ethical, relevant and acceptable from a public point of view
- Commenting on and developing research materials
- Providing oversight and advice on the implementation of research studies
- Developing a communication plan to promote the sharing of research results
- Disseminating research results among community networks

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## 2 What is NICHE?

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NICHE is a 5-year research programme that aims to design a new, patient-centred model of care to improve mental health and wellbeing for people living with HIV. It is funded by the National Institute for Health Research. The programme is run by Professor Alison Rodger and Dr Fiona Lampe at University College London. Alex Sparrowhawk is the community lead on the research programme, and Dr Janey Sewell is the programme manager.

Firstly, we want to identify the most important unmet psychosocial and health needs for people living with HIV, and investigate the causes of poor mental health and wellbeing. To do this we will talk in depth to people living with HIV and clinic staff and use data from the *Positive Voices 2022* national survey to better understand their needs.

Then, together with people living with HIV we will develop an intervention that uses health coaching to improve mental health and wellbeing for those living with HIV who need it. As well as one-to-one sessions, the health coach could connect the person to other sources of

support. This might include community groups, HIV support groups, organisations such as Citizens Advice as well as online or other support and advice.

Following that we will carry out a study called a randomized clinical trial to measure if the intervention improves health & wellbeing and reduces depressive symptoms for PLWH. We will also assess if the intervention is value for money for the NHS and will also work with policy makers to translate the research into health policy and practice,

Finally, because mental health and support issues are also very relevant to people with other long-term health conditions, we will assess if this approach can be adapted for other people receiving hospital care.

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## 3 What do I need to know about PPI and NICHE?

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Discussion with people in the HIV community drives the NICHE research programme. We aim to actively involve members of the HIV community in all of our studies and at an organisational level. Alex Sparrowhawk (Terrence Higgins Trust [THT] and UK Community Advisory Board [UK-CAB, the HIV treatment advocates network]) leads on PPI for NICHE and is a co-applicant on the grant.

### What is the PPI Group responsible for?

The PPI Group will be responsible for:

- Attending PPI Group meetings and carrying out activities as necessary between meetings
- PPI input into the development of protocols for NICHE studies, including the approach to participants, the ethics application and the supporting materials such as information sheets and posters.
- PPI input into Focus Group design and topics, and a Theory of Change workshop in year 1. Input into the NICHE trial design, acceptability, participant information, implementation and monitoring in years 2 and 3.
- Sharing and publicising of results throughout the programme of research.
- Developing a detailed plan to share research findings with community members, study participants and collaborators.

- Acting as ambassadors for NICHE in the wider research and patient communities.

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## 4 What will I need to do if I get involved?

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### What is the role of PPI Contributors?

PPI contributors share the general roles of all PPI Group members outlined in section 3 above. They also have a specific role to bring a patient/community perspective to the work of the Group. This might include:

- Providing a link to patient or community organisations and groups
- Talking with other patients or community members about the work of the PPI Group and seeking their views or input where appropriate

### How often does the group meet?

The Group will meet every three – six months either virtually or at University College London, Royal Free Hospital, depending on group preferences. Meetings usually last 1-2 hours.

### How long would I be a member of the Group?

This appointment is ideally for two years in the first instance but can continue for up to 5 years.

### What training or support will I be offered?

The PPI Group chair, or another experienced member of the PPI Group, will talk with you before you first attend a PPI Group meeting to give you a background to the work of the PPI Group and to address any questions you may have. They will also be available to discuss any concerns or questions at any time during your involvement. You may also be able to access any appropriate training you identify, or that is identified by other PPI Group members.

### Is there any payment for being on the Group?

Community members of the group will be able to claim a fee for taking part in meetings and related activities. Typically the NICHE meetings will not require more than 1-2 hours with some preparation time. The NIHR recommends £50 for involvement in a task or activity likely to

require some preparation and which equates to approximately two hours of activity (For example, a teleconference with related papers to read or review a few short documents.)

### Will I get back any travel costs?

Community members are entitled to claim travel and related expenses for attending meetings. Wherever possible and appropriate, travel bookings should be made by the NICHE team to ensure individuals are not out of pocket whilst expense claims are being processed by UCL. Further information about what can be claimed and how to claim it will be given if you join the PPI Group.

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## 5 What sort of experience or background should I have?

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You should have:

- a) An ability to offer a patient/community perspective from a lived experience with HIV, whilst at the same time valuing other perspectives.
- b) An ability to work effectively within a committee setting – this includes listening skills as well as an ability to make points clearly and succinctly.
- c) A commitment to attend PPI Group meetings for the duration of the term of office.

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## 6 Can I resign after I have joined the PPI group?

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We hope that you will remain an active member of the PPI Group for the duration of your term of office. However, if your circumstances change, or you have concerns about your involvement, you can resign from the PPI Group. We ask that you talk to the PPI Group Chair (or any other member of the PPI Group if you feel that is not appropriate) first. They might be able to advise you about any concerns you may have. If you still decide to resign from the PPI Group, we ask that you speak with the Chair, so that a replacement can be recruited.

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## 7 More information

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If you want further information about the PPI Group, please contact the Chair, Alex Sparrowhawk – contact details are on page 2.

More information is also available on our website [www.niche.ac](http://www.niche.ac)

Thank you for taking the time to consider taking part in the PPI Group.