

# UKRI Mental Health Platform PPIE Network Webinar-20260602\_100153UTC-Meeting Recording

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1h 2m 35s



**Susannah Strong** 0:04

I think people are still arriving, but I'll just start the meeting. So we're starting at one minute past 11. Just to welcome everyone who has joined and people who are joining to our very first mental health platform, PPIE Network webinar. Thank you very much for signing up and coming along. And without further ado, we'll get on with the first slide, please.

So just before we get going, I thought I'd just say something about how this webinar will run. So first of all, just to say that I'm Susannah Strong and I'm the PPIE coordinator for the Mental Health Platform and everybody else will introduce themselves as they go. This presentation or the presentations that you're going to see will be recorded and we're going to share the recording and the slides that go with this meeting.



**Sophie Quick** 0:26

Okay.



**Susannah Strong** 0:46

after the meeting so that you all have a chance to listen to the recording and watch the slides in case you know that you want to watch it a second time. So that will go around later on this week after the webinar is over. During our presentations, you won't be able to raise your hand or ask questions in person, but you will be able to put questions into the chat.

as we go. So if anything strikes you or you're curious about something or want to know more, please do use the chat function to put in your questions. If you have any technical problems, please don't worry. We might not be able to solve them, but we will be sending around the recording and the slides afterwards so you won't miss anything. And then when we finish the presentations, there'll be a Q&A at the end of the webinar through the last

I'm not quite sure how many minutes, but what we've got left after the presentations, that will be recorded, but we, I'm not sure that we actually will actually share it with

everybody afterwards. We will have a record of all the questions that are asked, however, so, and they'll all go into the chat and one of our team will actually read out the questions

and we will answer them. So rather than you putting your hand up and asking the questions in person, we will take them from the chat. So I hope that all makes sense and we'll send around the recording and the slides later on this week. Next slide, please.

So the agenda is very straightforward. In a minute, I'm going to introduce Andrew McIntosh, who is director of the Mental Health Platform. And other than that, we have Sophie Quick, who is a communications manager, talking about the platform as a whole. And then we have John Gibson, who is a senior service user researcher and a member of our PPI steering group and also a member of MCPIN.

And he's going to be talking about lived experience at the heart, how the work, you know, how he is involved in the work that we're doing and how, and some of the projects that he's been involved in with his own particular hub. Then I'm going to say a little bit about some upcoming opportunities for involvement for the network. We have a few paid opportunities.

coming up that we hope you'll be interested in. And then after that, for around about half an hour, depending on the length of the presentations, there will be a chance for you to put your questions in the chat and we'll answer them as best as we can. And that's it. I'm going to hand over now to Andrew McIntosh, our director, just to say a few words.



**Andrew McIntosh** 3:06

Hi everyone. Hi, I'm Andrew McIntosh, a psychiatrist in Edinburgh and director of the UKRI Mental Health Platform. I'm not going to say very much other than I'm thrilled to be here for our first PPIE Network webinar and really looking forward to see how this develops. I hope it's obvious to everybody how important, just how important, PPIE involvement

is in the network. We try and weave it throughout everything that we do so that the work stays relevant, also so that we maintain trust and for a host of other reasons besides those two. So thank you very much for coming today. I hope you have a, I hope you enjoy our first webinar and I think it's just for me to get out of the way now and hand over to Sophie so that you can get to the contents of the meeting. Thank you.



**Sophie Quick** 3:54

Thanks Andrew, and thanks Susannah as well. So yeah, just to reiterate that, thank you everyone for coming. My name is Sophie and I'm the communications manager here at the Mental Health Platform. So I'm just going to give a sort of brief overview, firstly of the Mental Health Platform for those who aren't so familiar with it, a little bit about sort of the type of research that goes on across the platform.

And then I'll introduce the PPIE steering group and sort of how we involve the PPIE steering group across all of our work. And then I'll hand on to John, who is, as I say, a member of our PPIE steering group. And he can give, more importantly than what I have to say, his perspective.

So firstly, the Mental Health Platform or MHP, sometimes abbreviated to, this is a, we have six different hubs of research that are based across the UK. You can see here on this map here, we've got these six different locations all across and this is a network of researchers.

all investigating different aspects of severe mental illness. So each of these hubs is a location and basically a university, and they're investigating something different about severe mental illness. There's also each hub kind of has these collaborating sites. So beyond these six locations, there are more locations. And this means that there's a huge amount of researchers are all kind of coming together.

as part of the Mental Health Platform. We also have the coordinating centre, which is our team. So myself and Susannah, Andrew, he just met and we have other members as well, our project manager, Indrani and Vaughn, who's also on the call. And we are, the purpose of us is to bring these six hubs together in various ways, some of those ways being through PPIE.

So this is a little overview of the different types of research that go on across the hub. And just as a reminder, these slides will be shared afterwards. So if you want to have a look at this a bit more in depth, there's also a lot of information about this on our website. So I'll just do a really just brief overview of this. We have these six hubs across the UK.

Brain and genomics, that's based in Cardiff, and they are focusing on the genetic, environmental and developmental factors of SMI, severe mental illness. Complex emotions, this is based in Sheffield. And this is quite, this is interesting. This is an approach which is not focused on a particular diagnosis. This is what we call transdiagnostic.

So things about guidance for better care and support for people with experiences of SMI and complex emotions. We have Data Mind, and this is based in Swansea. And this is a hub of all different types of data pertaining to mental health and the use of this for public benefit. Next, we have Immuno Mind, and this is based in Cambridge. And the focus of this is around the immune system, so immune and metabolic targets. Next, we have metabolic psychiatry, and that's based in Edinburgh. And that's really looking at the metabolism and the way that things like metabolic disorders like diabetes or obesity can be linked to SMI. And finally, social health hub, and that's based in London. And this is really thinking about non-medical factors that are influencing

SMI. So all the environmental factors, including how people are born, grow, work, live and age. So you can see there's a huge variety of different types of research that's going on across the platform. And what the platform we're hoping to do is get these hubs linked and talking to each other so even more novel research can be happening.

This is really just to show faces to put to those hubs, just to show these are real people doing this research. So each of these are a different hub lead. This is a person who is leading the research at that hub. And then within each hub, there are many, many researchers who are doing their own individual projects.

So I'll move on now to talk about the PPIE steering group, how we came to set it up, and kind of what we have been doing since we started the platform about two years ago.

So at the beginning, as Andrew said, we've always wanted to make sure that PPIE is threaded through all of the work that we do and putting lived experience at the heart. And when the platform was began, each individual hub, the six hubs that I mentioned, all have their own PPIE group that they lead in the way that they see as suitable for their hub.

So some of them are called LEAP, so that's a Lived Experience Advisory Panel or Lived Experience Advisory Group, that's a league or a co-production council. They kind of all operate individually. So there's lots of different PPIE going on across these individual hubs. But bringing these hubs together, we thought one of the important ways of doing this was through PPIE.

And so we were really lucky to have a lot of support and guidance from the McPin Foundation, which I think John will mention a bit later. And they really, they're a fantastic charity who help us to set up our own PPIE work that links these six hubs

together.

So this is what we did. We brought together the MHP steering group and this group is coordinated by Susannah, who was mentioned, who, sorry, who introduced today. So Susannah is our PPA coordinator and we brought together 2 representatives from each hub.

and they come together to form the PPIE steering group. So this can be PPIE hub leads or people with lived experience representatives from each hub. At the first proper meeting in January 2026, there's been going for over a year now and it's been a really fantastic group who've worked together on lots of different projects, which I'll talk about in a moment.

So this is just briefly meet the group. This photo is some of our group when they got together late last year, and they would like to describe themselves as united by lived experience, but diverse by life experience. As usual, lots of different backgrounds. And this is fantastic because it means we have lots of different voices in the room. and this means that we can really make good decisions together. This group, they put a lot of work into like the strategic, they do a lot of strategic input into various parts across the Mental Health Platform, but they also contribute to specific individual projects. So sometimes a small number of this larger steering group, which is 12 people,

And we'll come together to focus on a specific project and we can kind of drill down into the nitty gritty of it. So I'm going to give a couple of examples of those projects before I hand over to John to talk about his experience.

So these are just my example projects. I'm just going to give you 2 examples.

The first one is about industry alliance forums. So at the Mental Health Platform, we are interested in finding ways to link industry researchers and people with lived experience and starting a kind of conversation that means that everyone can be kind of working together in equity.

we can make sure that the research and the industry are working to make decisions that are the best ones for people with lived experience, who, of course, these treatments and therapies are for. And so as part of this, we've had a couple of in-person meetings that bring together these three different communities.

And the steering group members have helped to shape how these meetings should look. And they've been presenting at those and they've been involved in the conversations on the day. And these have been really interesting. And if you are interested in learning a bit more about this, there's a couple of blogs on our website

from the lived experience perspective, where you can read a bit more about how those forums worked.

And the second example that I'll give is about awards review committee. So researchers who are part of the platform, they can apply to us for a little bit more funding to do a new project. And as part of this, as part of this application, they do need to put

together their PPIE plans. So we want to make sure that they are, they have planned what, how they're going to involve people with lived experience throughout the project. And so when reviewing these applications for the funding, we had people from the steering group who review that part and just make sure that it makes sense and it is going to be, it is the right level.

of involvement. So this means that we have the scientific experts who are reviewing the scientific part of their application and we have people who are experts by lived experience who are reviewing the PPIE parts. So that's just a second example of some of the things the steering group have done. So that's an overview and I will now hand over

to John, who is going to talk about his experience.

**JG** **John Gibson** 12:50

That's great. Thank you, Sophie. Yeah, I'm John Gibson. I'm a senior service user researcher based at the McPin Foundation, which is a mental health research charity that prioritises lived experience and works at putting people with lived experience on an equal footing with academia and clinical settings as well.

Next slide, please, Sophie.

I work on a range of studies like RCTs, which are randomised controlled trials. I also work on qualitative studies as a peer researcher. In this context, I'm the PPI coordinator for the Social Health Hub, which Sophie has just mentioned. It's based at Queen Mary in London. I also work with several leaps. We have one for the social health hub and we have others. And that's how I kind of started my journey as a lived experience person. I became a leap member and then became a service user researcher. I'm one of two PPI representatives on the main steering group for the Platform, together with another leap member. And Yeah, next slide, please.

I think.

One of the things that really matter about...

people with lived experience and what they can bring are listed here. And I particularly like this image, which is actually hanging on our McPinn office wall. It's kind of the head and the heart working together. So as my colleague, Vanessa, who is the pin of McPinn,

said, you know, we want, we deliver high standards, but we do it with compassion. And I think that some of the things that people with lived experience bring are the motivation. They bring commitment, as you'll know, that if you've been through an experience of

severe mental illness, which I can see in the chat, is it like, what does that mean? To me, the studies that I work on, it would mean schizophrenia, bipolar, major depression, complex emotions, other psychosis. You know, it's finding a way and a space of what do you do with that?

experience because so much and certainly in my past has been, well, don't talk about it. And it's like I can't not talk about it because it's so important.

There's empathy that people on the steering group and the leaps bring, empathy with the participants in the different hubs and the different studies. And there's also being a critical friend. You know, we have quite open and

Not I wouldn't say disagreements, but we have quite open and ask difficult questions, but we do it in quite a good-natured and respectful way.

And I act kind of as a bridge between the people with lived experience in the hub and the wider team of the social health hub. So

It's a kind of balancing act and being quite diplomatic, which I'm told I am quite good at. Next slide, please, Sophie.

I think this slide is almost, you know, to answer the question, why, why get involved?

And I kind of just touched on that. It's like you learn about setting boundaries, you learn about managing disclosure of how, of what to say. You know, you could, you know, you disclose what you feel is

You're comfortable with?

and you learn how to respect other people, the impact it may have on other people with lived experience, but also the impact it may have on you when you reflect on it.

I think you also build resilience and because you realise that you're not alone and you're working with a group of people who are all very committed. And I think what is great about this kind of platform and steering group is that

People have diverse views and come at it from diverse experiences, but they all have the same aim of wanting to improve things for people who are living with severe

mental illness. Next slide, please, Sophie.

Social Health Hub, which I've just mentioned, this is something that...

is looking at the social aspects as opposed to the bio-psychosocial models, which to me, it always, it often feels that the bio and the psycho are addressed and then the social bit is kind of tacked on at the end.

But this is looking at different things. It's got three different work streams. We're recruiting research participants, looking at their social networks, which is that little diagram at the top right that you probably can't read. But there's also data science, big data sets of looking at evidence of deprivation and also quite an interesting nested small study within the cohort study, which is based on like neighbourhood tours, because it's something that you don't, you're not just sitting with someone in a room and saying, you know, what's your

your social context. It's actually going out with them and it will kind of pointing things out and making things, it almost come alive to a much greater extent. There's also an element of biomarking taking place, you know, with blood and saliva samples. Next slide, please.

We had our launch at the end of April and, you know, we've had so many opportunities from the study team that we've had to almost ration them to our elite members because they've been coming thick and fast. You know, we've kind of looked at measurement tools. People have been testing mobile phone data processing, looking at the draught website, which is now live. We had a subgroup of the leap that co-created the launch event itself. and we had a walking tour with a co-delivered by with elite member and also an icebreaker session where the same elite member co-delivered that as well. So it's been

very much a level playing field where there's been a great deal of involvement opportunities. Next slide, please, Sophie. Now, this complicated, wonderful image derived from our first in-person

Platform steering group meeting last October. And it's kind of it's a ripple mapping image which was actually suggested by one of the steering group members. And it kind of looks at all the different aspects from the beginning to what

next of what happens when the group was set up, how it was set up, having smaller subgroups, looking at, say, impact and evaluation. Another smaller subgroup is actually here at the moment with looking at planning the next summit.

and the next steering group meeting and the recruitment of a PPIE coordinator,

which is Susannah. And you can see all the way through what's next, what's next, what's next. So it's a live document and it will be added to and refreshed. And next slide, please, Sophie.

And where next, as opposed to what next? We'll be recruiting some more leap members for the Social Health Hub in the next year. Sometimes people drop out for different reasons and we're particularly looking for men, people from diverse backgrounds, people who may or may not have had experience of working in research, because it sounds a bit intimidating at times, but it isn't actually. And you can still bring a real wealth of experience, which is what I'm trying to emphasise here. If you're interested in my pin, you can sign up to receive our involvement bulletin. and there'll be more opportunities coming up through the platform. And with that in mind, this is an image on the right, which is was done by a member of one of the leaps and a member of the steering group. And it's basically, you know, the firm foundations growth. Where next? What's next? What are the opportunities for you? And on that note, I'll hand over to Susannah. Thank you.



**Susannah Strong** 22:44

Thank you very much, John. And I think John's just given an absolutely fantastic presentation and shown exactly why lived experience is at the core of everything that we do. And as John said, you know, the whole point of all of it is ultimately to make, you know, create better outcomes and better opportunities for people with lived experience of severe mental illness. So thank you so much, John. That was really brilliant. And I think that final illustration, I think the artist of that illustration may actually be on the call. You know who you are. So thank you very much indeed. And it's beautiful and we use it all the time. So just moving on then, We do have, I mean, as you know, as network members, there are over 100 of you and obviously we can't remunerate everybody. So for example, it's so brilliant you've come along to this webinar, but obviously we can't pay for the time and we're really just pleased that you were interested enough to come along. But we do have a few opportunities coming up that will be remunerated. And the rates that we pay out, just to get it out of the way, is we pay the NIHR, that's the National Institute of Health Research rates of 27 pounds 50 per hour of work. So that's what everybody with lived experience can claim for each hour that they work.

And all payments come through me. So just so that you know from the off what the rates are.

Next slide, please, Sophie.

So we've got 3 up and coming opportunities and I've got a little bit more information about all of them. One of them is a survey, which I'll say a little bit more about in a minute. The other one is a blog writing opportunity for a post that will actually go on our main website, obviously, which you could share and would be, you know, hopefully a really fun thing to do and also

provide a learning experience for other people who read it. And the third opportunity is about our award review committees, where we always include people with lived experience as part of the award review committee. So next slide, please, Sophie, and I'll say a bit more about the survey. So the survey that we're running is called the Interest Survey.

And we're doing a new piece of work, which is very much looking at developing relationships between people with lived experience and industry and research. And so we know that there's a really wide spectrum of views, opinions, curiosity, and possibly some suspicions about getting involved with industry. And we're interested in all of that.

So this survey is a means for all of you to have a look at it and to answer the questions that you would like to. Just to say very quickly, it's quite a big survey. It'll take about 15 minutes to fill in and there is some supporting information that comes with it, which includes some frequently asked questions where hopefully all questions you have, you can answer. So everyone can participate. You only need to answer the questions that you want to answer because it's

quite broad brush because the same survey is going to industry people and to researchers. So some of the questions are quite sort of catch all and we can't pay for the time. But what I would say is that this survey will lead, is leading to more work that's industry focused and there will be more opportunities to get involved with that.

I'm going to share the link to that survey and the supporting information a bit later this week so that all of you, actually everybody in the network, not just the people who are attending today, will get a chance to fill it in. Of course, it's completely up to you. You can ignore it completely if you'd rather. But we really hope it'll capture your interest and obviously the more responses we get, the more that we can do. So that survey, I'll share it later this week and it will be open until the 19th of June.

June. Next slide, please, Sophie.

So the next opportunity is a writing opportunity. And as Sophie mentioned, we already have a number of blogs on our website, quite a few of which have been written by people with lived experience and are about the whole range of activities that we do. Also to say that all of the hubs, as John has just said, also have their own websites and they also

have a representation of lived experience on those sites as well. So the opportunity is to interview one of our platform researchers about the work that they're doing, and then to write a short blog from your perspective about what you think about what you've heard. Now, up to three people will be able to participate in this round of it. We think there may be

more opportunities further down the line and we can pay for one hour for the interview time and for two hours writing time as well. I can't do the maths, but that's three times 27 pounds 50. What I would say is that we will, for those who are interested, please do let us know that we will be sending out an expression of interest form after the meeting. It may take us a little while to actually set up you know, how you do that, how you meet with the researcher, because we'll have to matchmake a little bit the researcher with, you know, whichever person with lived experience, you know, with what your interests are. So we hope that this might be the start of quite a few of these and this round will be 3. So I really hope that's something that captures your interest and we'd love to hear from you if you are interested. Next slide, please, Sophie.

And the last opportunity, and we can't give you a date for this as yet, is we've already, as Sophie said, run a few rounds of different sorts of awards. We've had early career researcher awards, we've had what we've called collaboration and innovation awards, which are quite big ticket awards. And we've also had PPIE awards for people with lived experience to enter as well.

With all of those awards, we always make sure that people with lived experience are absolutely part of the award, the review committee, and we ask in particular to have a look at the lived experience, how their applicants are going to involve people with lived experience in their research. So that's usually the bit we ask people with lived experience to focus on, although obviously you're very welcome to read the whole application as well.

and that work is remunerated and it means usually reviewing an application, sending in your comments and then attending a meeting, which is the actual review

committee meeting. So there are future rounds of awards scheduled for this and for next year and we'll be releasing the dates for those and those opportunities a bit later on this year. So I hope that also might be something for people on the network are interested in and a couple of you have actually have already been involved with one of them. So next slide please, Sophie.

Oh, and it's thank you. So thank you very much for listening to all of that. There's quite a lot and I imagine you might have quite a lot of questions. So thank you so much for your time. Just to repeat, we will be sending around the recording and the slides so you can have a further look at them. And we'd also really welcome you to have a look at our website, particularly the sort of lived experience aspects of it. and we'll start the Q&A now. You'll be able to ask questions in the Q&A chat and then Vaughn, our colleague on the coordinating team, will ask the questions. So thank you very much and thank you all the presenters.