Further information on the Lived Experience Network

Are you interested in our Lived Experience Network but unsure whether it's for you? Or do you have some questions and want to know more about it? We've pulled together a handy guide to help find out more.

About the Lived Experience Network

What is the Lived Experience Network?

The Lived Experience Network is made up of patients, carers and community contributors from North Central and North East London, who are interested in shaping the future of health and care in their area.

Members are given opportunities to share their experiences, views and knowledge, and work with projects to actively inform and shape the outcomes of health and care innovation. Ensuring read experiences shape tailored solutions that address need.

What do you mean by 'lived experience'?

By 'lived experience' we mean all the knowledge and understanding people have gained through direct, first-hand experiences that they've had rather than the understanding we get from things we are taught.

As health and care is something that touches on everyone's lives, we all have lived experiences of it. That could be as a person who has a health condition, as a person who has used some health services, as a person who cares or supports someone else with a condition, or as a person who might need to use health and care services in the future.

Why have you set up a Lived Experience Network?

As an organisation, our vision is a world where innovation creates better health for all. To do this, we work to develop and prove healthcare innovations and drive their adoption at scale. It is important for us to work hand-in-hand people whose lives our work affects throughout this process: and that's patients, carers and communities.

The Lived Experience Network is one of the routes we use to support our work together. The Network acts as a space where we can connect communities and opportunities together, making sure that patient, carer and community knowledge, experiences and views inform and shape the process of inventing, building, testing and scaling innovations.

Who manages the Lived Experience Network?

The Lived Experience Network is run by UCLPartners and managed by our Patient and Public Involvement and Engagement (PPIE) Team. These are the people who are responsible for supporting you through Network sign up, making sure any opportunities to get involved that we share with you are clear and contain all the information needed, and putting together the quarterly Newsletter.

Opportunities come from members across our partnership and beyond: so, this could be from UCLPartners teams, healthcare professionals, researchers, industry and innovators. We'll always make it clear which organisations you'd be working with.

Signing up to the Network

Am I able to join the Network?

The Network is for anyone who is a patient, carer or member of the public with an interest in shaping the future of health and care. As our organisation works across a specific geographical area the Network primarily features opportunities open to those who are living in, or receiving care in North Central London or North East London.

- North Central London: Barnet, Camden, Enfield, Islington, Haringey
- North East London: Barking and Dagenham, City of London, Hackney, Havering, Newham, Redbridge, Tower Hamlets, Waltham Forest

You do not need to have any specific experiences or skills to join the Network: we want to hear from, and work with, everyone in our region!

We do sometimes advertise opportunities that are open nationwide: so you can join if you do live outside these areas of London. However, you may find that we have less opportunities for you compared to those living in our region.

If I sign up to the Network, what will my role be?

There are no formal roles within the Lived Experience Network itself: it is an informal online group made up of patient, carer and community contributors.

Through the Network, you'll receive email updates which will contain opportunities that you can get involved in. You are then able to put yourself forward to take on opportunities, meaning you can take on roles that suit you best or that you find most interesting.

What is the time commitment needed for the Network?

There is no formal time commitment required to be part of the Network. You'll just receive email updates containing news and opportunities that you can read when it suits you.

You are then able to put yourself forward to take on opportunities, meaning you can choose the ones that match the level of time you have available.

Once I sign up to the Network, what happens?

Once you join the Lived Experience Network by **filling in the form here**, you will be added to our mailing list.

You'll then receive email updates from us which will contain a list of opportunities that you can put yourself forward to get involved in. There is also a quarterly newsletter which contains some stories/updates on opportunities we've previously shared with the Network, so you can find out how the Network is shaping and influencing work across our region.

Why do you ask questions about me and my location when signing up?

We want to make sure that everyone in our communities has an opportunity to shape health innovation: not just a few. That's why it is very important to us to create a network that represents diverse perspectives across our entire area.

To help make sure we are achieving that, we ask you to provide some optional information about yourself and where you live.

We ask about the **location** to ensure that all the boroughs within the UCLPartners area are represented and have equal opportunities to get involved. If we see there are boroughs with fewer representatives, we then know to do some more work in these areas to get people on board.

We ask about your **age, gender, ethnicity and education level** to ensure the Network is supporting people from all walks of life to get involved. If we see that there are certain groups that are less represented, we know that we need to do work with these communities to understand how to change the Network to be more accessible to all.

These questions are optional, and if you choose not to provide the information it won't impact your ability to be part of the Network and take part in opportunities.

Opportunities from the Network

What sorts of opportunities will come through the Network?

Because there are lots of different ways that we can work together, the opportunities that come through the Network are in a variety of shapes and sizes.

There will be opportunities that will explore certain health challenge areas (i.e. vision or mental health); some opportunities will look at certain services (i.e. GP services or community health); and some opportunities will be related to specific locations (i.e. Newham or Islington).

Some opportunities will come as small, one-off activities that could take as little as 30 minutes to do. Other opportunities might be larger, or involve working together over longer periods of time, for example over months or even a few years.

To give you a flavour of the sorts of things that might come through the Network, here are some examples of opportunities we've seen over the past year:

- Reviewing elements of a funding application form for a pilot project developing a new cardiac support service
- Being part of an 'Lived Experience' group shaping the design and development of a new screening and chatbot tool for families while they're awaiting neurodiversity assessments
- Taking part in a survey to share experiences of drug-based cancer treatments and thoughts about accessing care closer to home
- Becoming a Lived Experience Evaluation Partner to support the design and delivery of a real-world evaluation programme for a new womb cancer test.
- Participating in a roundtable discussion about the future of health and health innovation.

How often will there be opportunities to get involved?

The number of opportunities that come through the Network varies month-to-month: it really depends on what work is happening in the area. Some months you may find there are lots of opportunities popping up, but other months may only have a few.

What skills/experiences will I need to be able to be involved?

Because there are lots of different types of things coming through the Network, there will be opportunities to fit all sorts of skills and experiences. That's why we say the only thing you really need to have is an interest in health and care and a willingness to share your experiences, perspectives and skills when working on opportunities!

Some opportunities may need certain experiences (e.g. experiences of using a pharmacy) or people who represent specific communities (e.g. LGBTQ+); where this is the case, we'll make it clear in the information we share about the opportunity.

Are opportunities paid?

We know that patients, carers and public contributors may face barriers to getting involved in opportunities. That is why we are actively taking steps to make sure payment is made available to you where possible.

We will make clear the reimbursement you'd receive for all opportunities.

I've seen an opportunity that I'm interested in, what happens next?

Because opportunities that we share through the Lived Experience Network come from a variety of different organisations, we always provide the contact information for who you should be reaching out to to find out more about the opportunity.

You should contact the listed person to express your interest directly. They'll then let you know about the next steps.

Managing the Network

How is the information I provide stored and used?

All the information you provide via the Lived Experience Network sign-up form is stored safely and securely by UCLPartners in our internal systems, and only our Patient and Public Involvement and Engagement team have access to this. We will store this information until you unsubscribe from the list.

We use the contact information you provide to add you to the Network mailing list. From this list you'll receive email updates which contain a list of opportunities and some stories/updates on opportunities we've previously shared with you. We'll never use your contact information for any other purpose.

We use the demographic data you provide to monitor the representation of the Network, helping us to make sure we are creating a group that has diverse perspectives and experiences from across our region. When we do this monitoring, we make sure all the data is anonymous and that it is done across the whole group, not on an individual basis. We will never use this information for any other purpose.

You can find out more about this in our Privacy Policy

I want to unsubscribe from the Network, how do I do this?

If you want to unsubscribe from the Network at any time, you're free to do so. You can unsubscribe either by:

1. Clicking on the 'unsubscribe from this list' link which appears in the bottom of all emails from the Network. You then need to follow the instructions to be removed. We'll then delete all the demographic data you've given us.
2. Email the Patient and Public Involvement and Engagement Team at **PPIE@uclpartners.com** and we'll remove all your information from our records.

I have another question you haven't answered?

If you have any questions that haven't been covered above, we'd be happy to help. Just email us: **PPIE@uclpartners.com**