


Introducing the Lupus UK Research Network

 Explores the Lupus UK Research Network, the benefits of getting involved and answers common questions

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Research into lupus has made great progress, helping us understand more than ever before. But there's more to do – the next step is making sure studies reflect what life with lupus is really like. At Lupus UK, we're working to make that happen, by ensuring people affected by lupus are at the heart of what comes next.

We've heard from our community that people want to:

Have a stronger influence on lupus research decisions

Take part in and hear about studies that matter to them

See research represent the full diversity of people living with lupus, including those whose voices haven't been heard enough



That's why we're developing the Lupus UK Research Network, and we'd love you to shape it from the very start.

[Click here](#)



[Shape the research network!](#)

What is the Research Network?

It will bring together people living with lupus, those who support them, and researchers. Our starting aims are to:



Share opportunities to take part in lupus research



Connect people with researchers



Present research updates and stories clearly

The network will grow around what matters to you. Your feedback will guide what it offers and how it works.



These opportunities are important as it gives us back the power that the disease can take away. By participating we are fighting back, using it to grow, learn, gain confidence and more significantly, help our community.

– Maryann Coker, Research Contributor (Living with Lupus)

Why get involved?

By registering you will:

- ✓ Be the **first to hear** when the network launches
- ✓ Help **influence** what it offers and how it works
- ✓ Receive **updates** on upcoming research opportunities

Your lived experience of lupus makes you an expert in ways that only living with the condition can teach.



When your perspectives guide research, studies become **more relevant, better designed, and more likely to improve care and quality of life.**

[Click here](#)



[Keep updated on the research network](#)



Collaborating with lupus researchers and seeing their extraordinary dedication showed me a different side of lupus, helping me in this emotional journey and contributing to a better future for people living with lupus. I'm immensely grateful and hope everyone can experience the positive impact of collaborating with research.

— Dalila Tremarias, Research Contributor (Living with Lupus)

Your voice matters

To truly improve care for everyone, research needs to include the full diversity of the lupus community. Lupus affects people in many different ways – across all ages, genders, financial situations, in every nation of the UK. It also disproportionately impacts people from Black, African, Caribbean, and Asian communities, whose voices have too often been missing in research. We hope the Research Network will be a step towards changing that.

The more voices we include, the stronger lupus research will be for everyone.



[Click here](#)



[Make your voice heard](#)

What happens next?

When you complete the form, we'll follow the preferences you choose. We'll either keep in touch with updates about the Research Network, use your feedback to help shape it, or both. However you take part, your contribution will help make the network stronger.



Hearing from people with lupus was incredibly helpful and has given us plenty of food for thought!

— Dr Chris Wincup, Consultant Rheumatologist and Researcher

Frequently asked questions



Do I have to take part in a study if I sign up?

No. Joining simply means you'll hear about opportunities. You choose what's right for you, and there's never any pressure to take part.

Does it cost anything?

No. It's completely free to join.

How long does the form take?

About 10–15 minutes.

Do I need research experience?

No. Your lived experience of lupus, or supporting someone with it, gives insights that researchers can't get anywhere else.

What if I only want to give feedback, not be contacted?

That's absolutely fine. You can choose to only give feedback (without giving your name), or only share your details so we can stay in touch, or both. It's completely up to you.

Why is diversity important?

Lupus affects people of every age, gender, background, and nation of the UK. But some voices, such as people from Black, African, Caribbean and Asian communities, have often been missing in research. By including everyone, research becomes more relevant and leads to better care for all.

Who can join?

Anyone with a connection to lupus. You can join if you live with lupus yourself, care for or support someone with it, or simply want to see research improve for the community.

Can I opt out of the Research Network?

Yes. You can opt out of the Research Network at any time – just let us know and we'll remove you from the list.

What kinds of opportunities might I hear about?

You might be invited to take part in surveys, focus groups, advisory panels, or clinical studies. You could also be asked to review study materials or help shape research questions. Each opportunity will be clearly explained so you can decide if it's right for you.

How will my information be used?

Your information will be used to build and run the Research Network. It will be stored securely and only used in line with your preferences. Demographic answers from the 'About You' section are stored separately and anonymously. For full details about how we look after your information, please read our Privacy Policy [here](#).

Can people under 18 join the Research Network?

Yes, but a parent or guardian must complete the form on their behalf. Some opportunities may also need to be completed by an adult on behalf of the young person. This way, young people's experiences can still be included safely and appropriately.

I have a question – who do I contact?

You can reach out to the team by email at research@lupusuk.org.uk

Tell us what you think. If anything in this article wasn't clear, or if you have ideas for how we can improve PPIE, please share them in the form [here](#).