


What is PPIE?

 Explains PPIE and why it matters

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PPIE stands for Patient and Public Involvement and Engagement.

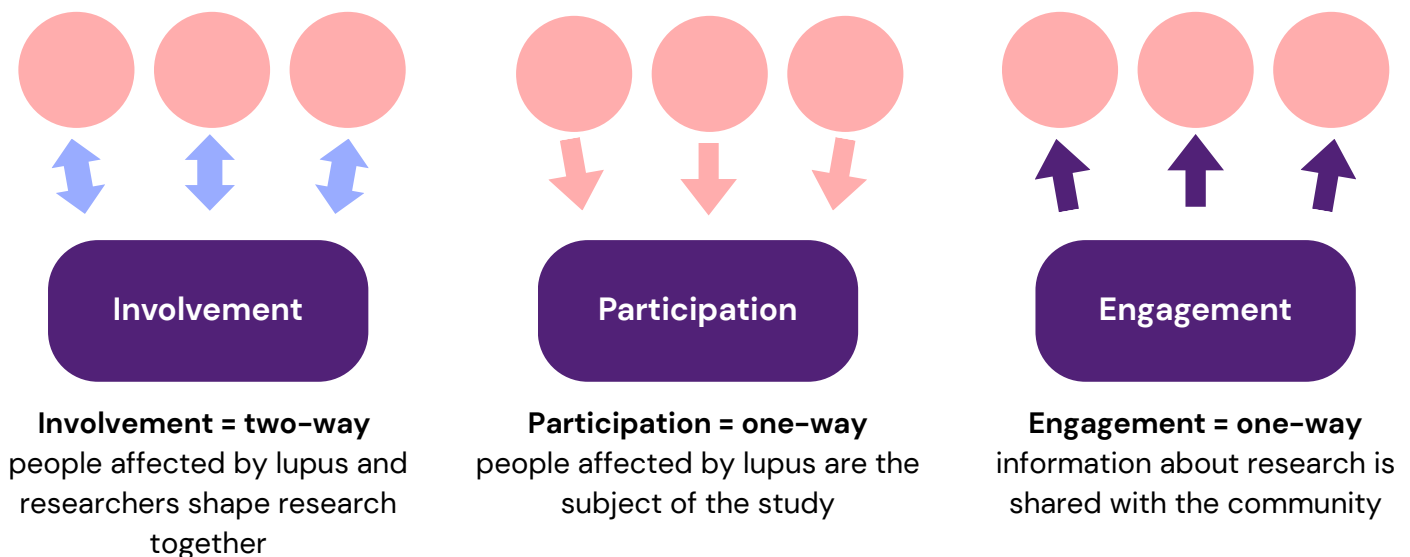
It means people affected by lupus and researchers working together, so research focuses on the questions that really matter, reflects everyone's experience, and leads to better care and treatment.

You don't need any research background to get involved, and it's not just for people with lupus – carers, family members, and others in the community all have valuable perspectives to share.



Strictly speaking, PPIE refers to involvement and engagement. But because our research network covers all three ways people connect with research, we explain them together here.

Involvement vs Participation vs Engagement



What does PPIE look like in practice?

People with lived experience can play a role at every stage of research. Some examples are:



Inclusion is essential.

PPIE works best when it reflects the diversity of the lupus community – people of different ages, ethnicities, genders, and those living in rural or under-served areas. Everyone's voice matters.



Why does PPIE matter?

Your time and experience are valued – you bring insights researchers can't get anywhere else. When your perspectives guide research, studies become **more relevant, better designed, and more likely to improve care.**



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Let's make a difference together

Want to help shape lupus research? Join Lupus UK's research network.

To find out more about the network, read our article [here](#).

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](#).