

NPaDD 2025: Championing public voices in data research

At DARE UK (Data and Analytics Research Environments UK), we believe that public data should serve the public good, and that this cannot happen without the public being involved every step of the way.

That's why we're a proud sponsor of the inaugural use MY data [National Patient Data Day Conference \(NPaDD\) 2025](#) – a first-of-its-kind event that is patient-designed, patient-driven, and dedicated to changing how we talk about and work with patient data in the UK.

Join us in Leeds on 24 June 2025 for what promises to be a bold step forward in ensuring that patient and public voices don't just inform data research but also shape it in ways that benefit them and all of society.

Putting public voices at the heart of our vision

At DARE UK, Public Involvement and Engagement (PIE) isn't a box to tick – it's built into the very foundations of our programme. We're working to create a more joined-up, trustworthy data research infrastructure for the UK, and to achieve this, we need to start where it matters most: with the public.

From our earliest activities in DARE UK Phase 1, including a [UK-wide public dialogue](#) on what people want from sensitive data research, to our ongoing plans in Phase 2 for a nationwide deliberative workshop series, we've prioritised listening to people's lived experiences, expectations and concerns.

We do this by:

- **Involving the public in decision-making** – with members of the public sitting on our [decision-making boards](#), along with plans for a broader public contributor network to take part in our programme activities and shape our delivery strategy.
- **Mandating public member co-chairs in the [communities](#) we support**, ensuring that public interest is present and powerful in every conversation.
- **Funding and co-leading sector-wide PIE partnerships** like the [Public Engagement in Data Research Initiative \(PEDRI\)](#), which promotes [Good Practice Standards](#) in PIE across the UK data research landscape and beyond.
- **Working closely with trusted patient and public champions**, such as use MY data, whose members contribute directly to our programme activities, such as the [TRevolution](#) collaboration cafes.

Our commitment is clear: research involving sensitive public data must be trustworthy, and public trust must be earned through transparency and shared purpose.

Why NPaDD 2025 matters

NPaDD 2025 brings together 250 patients, carers, health professionals, researchers, policymakers, and media in one room, all united by one goal: to make sure patient data is used ethically, effectively, and with patient voices front and centre.

What makes this conference unique is not just the agenda, but who sets it. It's a timely reminder that the future of health data in the UK depends not only on infrastructure, technology, and governance, but also on public trust, openness and collaboration.

Sessions will tackle big questions like:

- How can we build a National Health Data Service that works for everyone?
- What role does AI play in our health data future?
- How can young people be empowered to understand and shape their data choices?

And, of course, the Patient Data Soapbox provides a platform for patients to speak freely, passionately, and directly to decision-makers about what matters most to them.

We believe this event will be crucial in reshaping the UK data research landscape, and we are proud to stand alongside patients and the public as co-creators of this future.

Join the conversation

DARE UK is proud to support NPaDD 2025 because it aligns with everything we stand for: a transparent, inclusive, and public and patient-led data research ecosystem that delivers genuine public benefit.

Whether you're a patient, a carer, a researcher, or someone curious about how health data is used, you belong in this conversation. Join us in Leeds on **24 June 2025** from **09:00 – 17:00**.

[\[Register Now\]](#)

Follow DARE UK on [LinkedIn](#) and [X \(formerly Twitter\)](#) to stay informed, and join the conversation online using the hashtag **#NPaDD2025**.

See you there!