

Championing Patient Voices: [HDR UK](#) Backs the UK's First National Patient Data Conference

Public involvement is central to our work and guided by best practice, including the Public Engagement in Data Research Initiative's (PEDRI) [Good Practice Standards](#). These principles help data scientists across all sectors engage meaningfully with the public. In this blog, we'll use PEDRI's seven Standards to give you a quick look at how the public shapes our work at HDR UK.

1. Equity, diversity and inclusion (EDI)

Equity, diversity, and inclusion (EDI) are essential if health data research is to benefit everyone. We're working to better understand who engages with our programmes—and who we may be missing. Building on this, we plan to grow our public engagement beyond our [Public Advisory Board](#) (PAB), [HDR UK Voices network](#) and [community events](#), reaching even more people across the UK. We're also proud to welcome a new intern this summer through HDR UK's [Black Internship Programme](#) this summer.

2. Data literacy and training

Whenever we involve the public in our work, we do our best to provide as much support and guidance as possible for them to feel fully able to contribute. This includes induction sessions for members of our PAB when they first enrol, explanatory materials included in pre-reading materials ahead of meetings, and signposting to relevant resources and training opportunities through our bi-weekly bulletin.

3. Two-way communication

We believe in learning from each other through genuine two-way conversations. By involving both the public and researchers, we've created hands-on, [family-friendly activities](#) that spark dialogue about health data at community events. This shared approach helps tailor our work to real needs.

A recent [collaboration between our Public Advisory Board and early career researchers](#) opened up honest discussions about the challenges of public involvement in early-stage research. Together, they co-produced a project, shared insights, and built stronger, lasting connections.



Transparency

Transparency refers to making information freely available and easily accessible while encouraging a safe space for open and honest conversations with the public. Our PAB played a central role in developing a set of [Transparency Standards](#) to improve how data access processes are communicated by organisations across the UK. This collaborative work led to clear, practical recommendations that help ensure the public can understand how decisions are made, what data is being used, and how they can be meaningfully involved.

5. Mutual benefit

We value the public's input and want to make sure they feel valued too. Any time a member of the public is involved in our work, they are offered an honorarium for their time, as per our [policy](#). This can be in the form of a bank transfer or gift voucher, depending on what's most appropriate for the situation. We also aim to share with our public contributors how their input has had an impact on our work and invite them to share their experiences via [blogs available on this HDR UK webpage](#). Members of our PAB and HDR UK Voices regularly contribute to conferences and events we attend, sharing their experiences and having the opportunity to learn from others too.

6. Effective involvement and engagement

We are committed to ensuring that our public involvement and engagement work is genuinely meaningful. A great example of this was our recent [Patient and Public Involvement and Engagement Celebration Event](#). This was a truly collaborative effort, as reflected in the words of our HDR UK Voice member, [Tony](#). Over the course of a year, the Event Planning Group, made up of both HDR UK staff and public contributors, met nine times to co-design an agenda that celebrated our achievements and looked ahead to future goals. The event was met with overwhelmingly [positive feedback](#), and we're excited to build on this collaborative approach in future activities.



7. Creating a culture of involvement and engagement

Public involvement and engagement are deeply embedded across HDR UK's work. In addition to our Public Advisory Board (PAB), which plays a key role in HDR UK's governance, many of our funded [research programmes](#) and [regional networks](#) have their own dedicated involvement and engagement leads and strategies. This growing community regularly connects to share learning and coordinate efforts, and we recently had the opportunity to [meet in person](#) for the very first time.

Public voice is also championed at the highest levels of HDR UK. Our Director, [Andrew Morris](#), was instrumental in the creation of PEDRI, a [growing partnership](#) across the data science community that advocates for meaningful public engagement, which HDR UK proudly coordinates.

Get involved or get in touch!

Keep up-to-date with our public engagement work and find out about involvement opportunities by signing up to our [HDR UK Voices mailing list](#).

If you'd like to find out more about anything in this blog, get in touch with us at involvement@hdruk.ac.uk