

A trusted voice in patient data



OUR HEALTH, OUR DATA, OUR VOICE: USE MY DATA & THE HDRS

The UK government wants the new Health Data Research Service (HDRS) to “turbo-charge medical research” - use MY data provides the booster thrust of patient involvement

Independent | Patient-led | Data-focussed | Influential | Respected

use MY data is the only independent UK movement of patients and carers campaigning for the USE of patient data to save lives and improve outcomes. We are uniquely placed to help ensure the success of the Health Data Research Service.

POSITIVE ENGAGEMENT

We have long called for such an initiative. Now we are offering our services to make sure that **patients** are involved in the design of the HDRS from the outset. It is our data, our health, and our voice.

TRANSPARENCY & TRUST

To retain public trust in the HDRS, **patients** must be able to take a lead in planning, describing & promoting the potential benefits, processes and safeguards and in developing a robust, comprehensible, clear and open transparency framework.

POTENTIAL BENEFITS

Improved access to patient data, for researchers, removing current barriers & delays to bring benefits to **patients** and to our healthcare services.

DIVERSE PERSPECTIVES

Collectively, Members encompass a diverse range of knowledge, expertise and perspectives. Some Members have reservations about sharing their data in current conditions.

TRAILBLAZING

Our Members created the **Patient Data Citation**, widely adopted by researchers, to communicate the message that research and analyses are underpinned by patient data.



In 2025 we launched the UK's first **NATIONAL PATIENT DATA DAY**, an inclusive event for patients and stakeholders to celebrate the use of patient data across the UK. Uniquely the agenda was designed by and for patients.

INFLUENCE

We bring the patient voice to data debates, influencing data decisions nationally and locally. Members sit on steering groups, advisory boards, data access committees, research groups. We are respected as critical friends.

MAKE RESEARCH VISIBLE...

We need to be 'braver' in engaging journalists and shouting about the success stories that come from health data research.

...AND OPEN

Patients are not just data subjects — they are partners in research and progress.



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