

Bigger picture - the changing landscape of patient involvement in data

Version_23.04.24

Purpose of document

To describe the various organisations which Executive Group Members may have heard of who are working on the area of 'patients and data'. To briefly describe their position and role, and to ensure we are clear where use MY data fits and where we add uniqueness.

To help use MY data ensure that our priorities reflect our position and purpose and that we do not overlap unnecessarily with other organisations.

Organisations

use MY data



The only independent movement of patients, relatives and carers in the UK focused on the use of patient data to save lives and improve outcomes.

Entirely Member-led, we bring the patient voice to discussions about patient data, campaigning and influencing on a range of issues around using patient data. We have a clear set of data-principles which we encourage others to follow, and we act as critical friends to organisations which hold patient data.

Understanding Patient Data



“We work with patient groups, charities, NHS organisations and policymakers to bring transparency, accountability and public involvement to the way patient data is used”

“Understanding Patient Data aims to make the way patient data is used more visible, understandable and trustworthy, for patients, the public and health professionals”

Focus is purely patient data, with a remit that includes all countries of the UK and international collaborations.

Is now in its second generation and is a “hosted organisation of the NHS Confederation. It is funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research and NHS England. Our views and outputs are independent of Government and the other funders”.

PEDRI

PEDRI

Stands for ‘Public Engagement in Data Research Initiative’, a “new, sector-wide partnership bringing together organisations who work with data and statistics to generate insights that can inform policy and practice”.

“The goal is to collaborate on establishing and driving forward best practice for public involvement and engagement with data research, to bring the views of the public to policymakers and data holders in a more meaningful way.”

Not just health data. Ambition is public dialogue rather than patient dialogue.

The Patients Association



The Patients Association is an independent patient charity campaigning for improvements in health and social care for patients.

Their purpose is “to ensure that everybody can access and benefit from the health and care they need to live well, by ensuring that services are designed and delivered through equal partnership with patients”.

Has a limited focus on patient data, though has recently taken commissions from NHS England to undertake some survey & workshop work, which it partnered with an academic partner.

MedConfidential



The highest profile patient data privacy campaign group, with the strapline - “medConfidential defends the confidentiality you desire for your medical records”.

“Founded in January 2013 by a number of existing organisations...medConfidential began as a direct response to the imminent and serious threat posed by radical changes...in the way two new arms-length bodies, the NHS Commissioning Board (‘NHS England’) and the Health and Social Care Information Centre (HSCIC), planned to extract and pass on patients’ medical information from NHS health record systems in England...”

Health Data Research UK (HDR-UK)



“We’re the UK’s national institute for health data science. It’s vital we learn about the needs and experiences of the UK’s patients and the public, by involving them in how health data is collected, shared, and used for research. Their thoughts and opinions matter.”

“Our mission is to unite the UK’s health data to enable discoveries that improve people’s lives.”

Has adopted the principle of patient and public involvement since its outset 5 years ago. Has its own well-supported Public Advisory Board, which is where it takes most of its public steer from.

DARE-UK



“DARE UK aims to design and deliver a coordinated and trustworthy national data research infrastructure to support cross-domain research for public good”

“We are committed to meaningful public involvement and engagement”

Well-funded by UK Research & Innovation (UKRI), led by Health Data Research UK (HDR UK) and Administrative Data Research UK (ADR UK).

Not a patient organisation but has committed to patient involvement and engagement in its work.

Connected by data



“We want communities to have a powerful say in decisions about data so that it is used to create a just, equitable and sustainable world”

“We campaign to put community at the centre of data narratives, practices and policies by advocating for collective and open data governance”

Not just health data.