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

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use MY data's position on the Health Data Research Service (HDRS)

The Health Data Research Service (HDRS) was announced in April by the Prime Minister as a partnership between Wellcome and the UK Government "to turbocharge medical research".

As a movement of patients, relatives, carers and the wider public who want to realise the benefits of using our health data for research, use MY data welcomes the significant initial investment; £100 million from Wellcome and up to £500 million from the UK Government.

We have been calling for such an initiative for several years, so we thank the UK Government and Wellcome.

We want the HDRS to succeed, and we want to help it to do so. Giving approved researchers a single secure route to health data where personally identifiable information has been removed, and reducing unnecessary barriers that researchers face, will bring significant benefits to patients and our families and to our healthcare systems. We are especially pleased to note that the HDRS is to be a "service", one that is not only for approved researchers but in the longer term will benefit all of us.

Access to fully representative health data from across the four UK nations will be a globally unique resource to drive forward world health and health care, to improve the effectiveness and efficiency of the NHS across the four nations and to help catalyse the success of the UK's biotech and other Life Science industries, as well as harnessing the skills and enhancing the status of our academic researchers and institutions.

However some previous initiatives in this area such as Care.data and the General Practice Data for Planning and Research (GPDPR) have failed, largely because of their inability to win public and clinician support. We want the HDRS to learn lessons from the execution and communication of those previous large-scale data initiatives, which, if repeated, could undermine the whole venture and prevent an initiative of this type for some years.

use MY data is a multi-layered movement. We have Members who have been involved in trying to salvage similar ventures that have gone wrong in the past, so we bring practical experience. Uniquely, we have Members with considerable knowledge and understanding of data, health data and AI but we also have Members who have little knowledge/experience but who bring lay viewpoints. Our Members come from across the four nations, so we bring a truly UK perspective and an appreciation of the different concerns in each of the nations. Our Members span all disease types and include members of the general public who have not experienced major health episodes, but whose data will be vital to support the increasing focus on prevention and early diagnosis and on improving our health care systems.

For all these reasons we welcome the recognition that consultation with patient groups, academic, clinical and commercial researchers is essential to ensure a world-class health data research service, which benefits patients.

It is essential that the service builds in patient representation at every level. From governance and strategy through to operations, with potential roles on Steering Groups, Public Advisory Boards, Data Access and Review Boards and in co-producing public communications and materials, as well as the overall strategy for engaging the public and retaining their confidence and trust.

For our part, use MY data provides a tried, tested and trusted independent critical-friend role, using the voices of informed members of the public alongside those who may be less-informed but who are prepared to give their time to act as a confidential test bed for ideas, to ensure the success of this new service.

It is our data and our health, so we are offering our own services to the HDRS, to Wellcome and to the Government, to make sure that patients are involved at the outset in planning, describing and promoting the potential benefits, the processes and the safeguards, and in developing a robust, comprehensible, clear and open transparency framework to retain public trust.

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Our Vision

Every patient in the UK willingly giving their data to support medical research and their own care.

Our Mission

To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare.

Our Aims

- To promote the responsible and accountable use of our data to improve health and health research, and to help to remove barriers to preventing this.
- To highlight the benefits of using patient data for our individual health and for our communities.
- To help ensure patient data is used to create and support an NHS that is better for all.
- To advocate robust and transparent safeguarding of data, which is clearly communicated to patients and the public.
- To provide balance as a trusted voice in patient data, highlighting aspirations and concerns about the use of patient data.
- To act as a critical friend and sounding board to organisations who want to collect, store and use patient data to benefit society.
- To build knowledge and expertise for patients, family and carers to help them play a more active and informed role in discussions and decisions about patient data.

"use MY data to help others and help me"

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