Consultation Paper: Research matters: our plan for improving health and care research in Wales, December 2022

Summary response from use MY data

We note and support the need for a plan which sets out how Health and Care Research Wales intends to build on the legacy of the COVID-19 pandemic to improve all health and social care research, to drive improvements in health and social care services and to lay the foundations for better outcomes for patients, people and communities across Wales.

We appreciate the opportunity to comment on the draft. Our responses are focused on the areas related to the use of patient data.

Background to our response

To respond to the Health and Care Research Wales draft **Research matters: our plan for improving health and care research in Wales**, we have used use MY data's position statements and principles and existing views from our Members (some of these views have been used in responses to other consultations, across the UK).

As a movement concerned with the benefits of using patient data to save lives improve outcomes, the focus of feedback from use MY data is largely around the contents of sections 7.4 and section 9. The summary is presented here.

Key points from use MY data Members

"We will set out our industry engagement plans to provide a coherent and high-quality service to industry, increasing the profile of Wales globally as a site that delivers excellence in parallel to growing collaborative NHS, academic and industry research partnerships" (7.2)

Plans need to be clear, and communicated transparently, about how industry is going to be able to use a Trusted Research Environment (TRE). Primarily the tensions about the access rules by which industry users gain approvals for access, and secondarily, about the ways that industry users can operate in an environment where code and algorithms are shared. It is unclear whether industry users will have an exemption from code-sharing, and if so, how that will be undertaken in a transparent manner, and audited. This will be an essential element of operating in a trustworthy manner and being transparent.

We can understand concerns from industry about protecting their commercial interests, but this cannot be at the expense of transparency and trust.

We think it is important that the draft plan is clear how it will address difficulties faced with a rare disease, especially as 55% of UK cancer deaths are from rare and less common cancers (Cancer52). We can't accept a universal approach when tackling this issue as resources need to focus for the 'benefit' to be worthwhile.

"We will build on the strengths of SAIL as a Trusted Research Environment" (7.4)

TREs offer a unique opportunity to address the data requirements of rare diseases, which need national and international data, though TRE links to international data are unclear. Patient registries do not exist for every disease type, and there is no national approach to collecting this data. If we were to identify the research that should be prioritised for each disease area, TREs could be the place to collate this data for researchers to work with. Crucially, this needs a national approach, and we could argue that the SAIL Databank has led the UK in this area.

"An opportunity to take a more deliberative approach to public and stakeholder engagement" (7.4)

As a movement of patients, relatives and carers, we strongly support this point, but the summary lacked clarity of what is planned.

"Our plan is to build on this legacy with a One-Wales approach to communications for all health and social care research that is funded or part-funded by Health and Care Research Wales, which will underpin the three-year plan." (9.1)

We were unclear when reading this section how this plan involved communications to the public.

"Ensure Wales's contribution to research is acknowledged and promoted" (9.1)

We agree that this recognition is important but would equally point out that all research relies on data supplied by patients, and they should be recognised equally. We strongly propose the routine adoption of the Patient Data Citation, developed by our Members, to recognise that the research is only possible because of the data provided by the Welsh public.

"We will support new and existing researchers, academics and the NHS research community to communicate the impact of their work and involve the public in their research. This will include raising the profile of their research on Health and Care Research Wales communication channels, providing a bespoke media training programme, and developing our Ambassador programme for senior research leaders so they can be more effective brand Ambassadors for Health and Care Research Wales" (9.1)

Could this also include patients and citizens as equals, and have the same programme support the development of a stronger patient voice?

"Health and Care Research Wales is committed to improving the extent and quality of public involvement across health and social care research in Wales so that it is consistently excellent" (9.2)

We support this commitment, but would ask about wider public communications, to the vast majority of the public who are not engaged in research.

"The task of undertaking meaningful public involvement is one of continuous improvement, and there is always more we can do" (9,2).

As members of the public and patients we should all be able to access our own health data, whether this is held in primary or secondary care organisations, or indeed held centrally.

use MY data's position is outlined in the Call to Action, written by our Members "My Access to My Health Records", published in July 2021.

Whilst access to (and patient understanding of) GP records has improved in recent years, there has been limited progress in gaining similar access to hospital records. We see this as a key point that needs to be addressed not least because data quality issues, a significant barrier to research efficiency, can be helped when patients can spot errors or omissions in their own records, which can then be corrected.

use MY data supports a move to ensure all parts of your health and social care record are available and accessible to you and your health professionals across the UK when you need treatment or advice.

We would draw your attention to our Position Statement [Realising the benefits of a truly National Health Record](#) , which we would like to submit to the consultation.

"We will create tools and resources to support researchers to incorporate meaningful public involvement in their work, drawing on the UK Standards as the framework for good practice" (Key actions)

Can we not similarly provide resources that patients and the public can also use?

The following pages contain wider points related to positions set by use MY data Members

Gaining the trust of citizens in Wales will be helped by gaining the trust of health professionals in Wales

We are aware of surveys that have been undertaken to quantify the levels of trust in the way the NHS manages our health data. One survey, albeit done in England, about a person's likelihood to opt-out of their data being used for research, suggests a [lower degree of trust in NHS staff](#)than in the general public:

"After being told about the opt-out, 25% said they were likely to opt-out……. Among those working in health and care, likelihood to opt-out remains much higher – it was 46% in July 2020."

If this is similarly the case across Wales, do we need to think about doing something about why the NHS staff trust the NHS less than the public trust it?

A key element of improving trust in the use of health data is the need for a significant investment in communications and involvement skills.

Demonstrating the value of data

The conversation about the 'value of data' needs to develop, to ensure good intentions in the draft plan are realised and that patients' expectations are met.

A value sharing framework could help the health system to deliver good data partnerships. However, this framework needs to be developed alongside patients, and clearly communicated, if it is to provide the anticipated assurances.

We have seen several large national patient data policies across parts of the UK fail because of poor communication and involvement. We believe that large data programmes require a significant financial investment in communication, which

should be designed, costed and built into any programme of work, with a clear delivery plan.

Embedding Transparency

To ensure openness and transparency about how patient data is used, and to build trust in the uses of patient data, use MY data expects any organisation that uses patient data to explain their data uses, including how they use data to deliver benefits for patients: **Say what you do, do what you say and how you will do it**.

use MY data's Transparency Principles, developed by our Members are available here.

We expect organisations to be clear and open about how they respect any choices which patients have made about their data use.

As one part of transparency, data release and usage registers should be mandated. Whilst the SAIL Databank has already led work to do this, data release and usage registers are an essential element of increased transparency about the uses of health data. They are also an important starting point to be able to demonstrate the benefits that data can bring. There should also be consistency of style and content.

To build understanding of the benefits of using patient data, we would also highly recommend the wholesale adoption of the Patient Data Citation, written by use MY data Members. This is now rapidly becoming a standard across users of health data and we propose that it could be formally adopted as part of the draft plan.

Principles which we would expect organisations to publicly adopt (when communicating via website, press releases, reports, contacts, etc.):

Societal benefit
1. Be explicit that the primary focus must always be on benefit to patients, relatives and carers
2. Demonstrate the benefits of what you do, and what you have done, and publish this openly

Patient Voice
3. Embed patient voices in all parts of the organisation and be responsive and accountable to them
4. Recognise the use of patent data by adopting the Patient Data Citation
5. Be open to questions, and answer these questions openly, clearly and fully

Transparency

6. Be clear about how you are delivering fair value to the NHS in what you do with patient data, and how you do it, and publish your assessment of fair value

7. Be proactive - say what you do, how you do it, and publish this for transparency in plain language suitable for its intended audience - see our Transparency principles

Individual Choice

8. Describe clearly how you have respected the wishes and preferences of patients regarding use of their data

9. Respect the wishes of patients who choose to opt out

This information is also contained in use MY data's Position Statement: Our expectations of organisations which use our patient data.

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

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

· **use MY data** is a movement of patients, carers and relatives.

· **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

· **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

· **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

What we do

· We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.

· We work to bring a patient voice to all conversations about patient data.

· We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available here.

· We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

❖ We provide learning resources for patient advocates on patient data issues, including:
  - Hosting events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.

❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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