Consultation by the Department of Health & Social Care: NHS Constitution: 10-year review

24 June 2024

This is a summary response from use MY data, produced for the Department of Health & Social Care in response to the consultation “NHS Constitution: 10-year review”, published on 30 April 2024.

use MY data is the only independent UK movement of patients, relatives and carers focused on the use of patient data to save lives and improve outcomes. Our vision is of every patient in the UK willingly giving their data to support medical research and their own care.

Our Mission is 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.

Background to our response

The consultation asked for views on wording changes in specific sections. Of particular interest to our Members was the suggested changes to the section on Research, to strengthen the existing pledge (‘to inform you of research studies in which you may be eligible to participate”), adding an additional sentence to the pledge to say, “Health research and the offer to be part of research should be integrated into health and care across the NHS”.

Our response comprises the individual views of use MY data Members, which have been collated by the Secretariat, into this single summary response.

As with all use MY data responses, Members’ words reflect a range of views and these views can sometimes be conflicting. The Secretariat views the ability of use MY data Members to present/represent different patient voices on the use of their patient data, as a strength.

We hope this submission is helpful and would welcome following up further, as needed.

This summary response will be shared with our Members and published on the use MY data website, for transparency.

Summary of our Member’s responses

Firstly, it is important to note that every single response from Members was positive about the proposed change to the wording in the Research section. Our Members have a spectrum of views about the use of patient data. It is highly unusual to have such a strong singular view across all responses to a consultation.

The Secretariat has collated Members’ responses into themes, and included a selection of the quotations from Members, to illustrate the key feedback expressed by several responses.

Responses regularly highlighted the importance of involvement in research. These were summarised well by one respondent which noted “**opportunities to participate in research should not be considered as a last resort only, if people want to take part in research at any stage during their treatment**”.

Several comments suggested that the wording should actually be strengthened further. One particular comment was: “**I agree with the proposed additional sentence to the NHS Constitution about research participation (I have been arguing for it since 2012's ‘*Action On Access’* report from the old NCRN-NCRI Consumer Liaison Group), but it still doesn't go far enough - ‘should be’ is not the same as ‘will be’ and there is no duty or obligation on anyone in the NHS to deliver on this pledge - it is simply ‘the NHS’**".

Another respondent demonstrated this common view, stating “**I agree that this sentence should be added… if I'd disagreed, it would have been because I believe it could be even stronger - viz. not saying that something should be done but that it is being done! But I suppose we have to start somewhere....**”.

Another theme mentioned by some Members in their responses was about how this commitment will be monitored, if agreed. One Member usefully summed this up saying “**there is also no proposed metric to assess whether or not the system is delivering this pledge (what gets measured gets done). It's fine-sounding words and although welcome, there is nothing at all to support turning the words into deeds**”.

Related to the topic of implementation, some other general themes emerged, which included the roles of NHS staff in this. One comment, as an example of several, was
“**shouldn't something about this also be added to the section on Staff Responsibilities so that they have some basic training in research and can keep up with projects in order to help patients appropriately?**”

On a slightly wider perspective, a comment from a Member which relates to the scope of the consultation noted “**I am disappointed that there is no mention about improving access to data for research anywhere**”.

We would also like to highlight previous work by use MY data, which examined how the NHS Constitution could be rebalanced.

The full report. available here, noted that patients and the public have thirty-five legal rights and only nine responsibilities, within the NHS Constitution. This is an imbalance, particularly when the relative strength of the wording of the rights is much more forceful than the wording used to describe the responsibilities.

Specifically about the use of data for research, one of our Members quoted in the report, said **“I believe that as a patient I have a responsibility to the rest of society in permitting my data to be used, but I also have the right to ask clinicians and researchers, or perhaps rather demand, that my data is used, remove the barriers, use for purposes of audit, comparison, research, ask questions and find answers for me and all the other patients like me.”**

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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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