Consultation on MRC draft strategy for public partnerships

29 January 2024

This is a summary response from use MY data, produced for UK Research and Innovation on the contents of the document 'DRAFT MRC Strategy for Public Partnerships: 2024-2027'.

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.

This response will be shared with use MY data Members and published on our website, alongside all our consultation responses.

Background to our response

use MY data received in mid-January 2024 details about the public consultation by the UKRI on its draft 'DRAFT MRC Strategy for Public Partnerships: 2024-2027'.

As we received the notification so late, we were unable to issue our usual call out by the Secretariat to use MY data Members, asking Members to submit their individual responses to the Secretariat, for collation into a single summary response. As a result, this response is built from comments by our Executive Group, together with relevant comments received on previous related consultations from Members.

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 note that the draft strategy for public partnerships has been produced to support the existing UKRI public engagement strategy and was produced in consultation with an External Advisory Group, which included use MY data Member Emily Lam.

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

Question 1. Overall, do you agree with MRC's draft strategy for public partnerships??

Yes.

But we would highlight that the document is very high level and so hard to disagree with it as written.

Question 2. Is the strategy written in clear language??

Yes

The language is ok for this top-level strategy but hopefully at the next level down there will be longer, clearer explanations.

Question 3. What do you like about the strategy?

There are some specific statements in the draft that we have highlighted here in quotations, followed by our response.

"Across UKRI, we are developing a clear payment policy for public partners, building on existing good practice in the sector" (section 1)

We are pleased to see this statement. This is an important point to include. Currently there are significant problems in being able to make payments to patients and the public who have given their time and experience to research, analytics and policy development. We would be happy to follow this up with the team at the MRC and explain this point in more detail.

"Support public partners in leadership roles" (section 2)

Again, this is a positive statement, but needs to be followed up with practical actions. For instance, use MY data runs monthly education sessions for Members on topics related to patient data and research. These sessions, the topics for which are all suggested by Members, are designed to equip them with increased skills, knowledge and experience, allowing them to play an even more active role in research activities.

We think this is a model which works well and would be pleased to discuss with the MRC how we have implemented this.

"Publishing case studies" (section 3)

It was positive to see this highlighted in the strategy and it is something that we support. However, we think that there is a communications gap and that case studies are not getting out to patients and the public. There needs to be a significant improvement in the way that we collectively get positive stories out to the public, particularly through the mainstream media.

"We are co-developing, with public partners, a funding opportunity for research to innovate public involvement methods in non-clinical research" (section 3)

We were pleased to see this, but will this also innovate in the types of organisations that might be eligible to respond to this funding opportunity? As a movement of patients, relatives and carers, use MY data is often ineligible as many funding calls are only open to academic institutions. We would like to see this addressed and would be happy to discuss this point with the MRC.

Overall, we hope that the strategy represents a real commitment to getting the public involved meaningfully at all levels.

Question 4. What could be improved?

We think the strategy should make clear that where members of the public are involved at any level, such as funding boards, advisory groups or project groups, that the members of the public will be involved at an equal level to the professionals, researchers etc who are involved and that the public will have an equal say in decision making on these groups.

We would like to see a general move from patients and the public being in advisory roles, to decision making roles.

Where the MRC facilitates investment in programmes or projects it should mandate that members of the public should be involved at all levels of governance of the programmes or projects.

Question 5. Is there anything you want to add?

We strongly recommend an explicit commitment to transparency by MRC so that if members of the public or other members of decision/advisory groups have recommended a different approach rather than the final decision, that this is covered in published minutes.

Our Members (patients, relatives and carers) have developed a set of Transparency Principles which we think should be adopted by the MRC.

Similarly, our Members developed a Patient Data Citation; ‘This work uses data provided by patients and collected by the NHS as part of their care and support’. The citation is being used increasingly across research organisations.

Adopting the citation is one important and simple way to communicate the message that patient data underpins research, care and epidemic/pandemic response and we recommend that the MRC formally adopts this

Question 6. What difference do you think this strategy will make to you?

We hope that this strategy, when implemented, will result in better focussed and better implemented medical research.

Diversity monitoring

We note that the online submission form requests details to allow UKRI to undertake their diversity monitoring as regards responses for this draft.

As we are submitting on behalf of our Members, we thought it would be useful to share some of the most recent breakdown of our membership:

- 91% classify themselves as patients, 43% classify themselves as carers and 24% as relatives (an individual may be in multiple classifications)
- Our members are 60% female, 38% male and 2% other
- The profile of ethnicity in our members is close to the profile of ethnicity of the “patient” population
- 88% of our members are from England (the population of England is 84% of the UK population)
- We have limited representation in the younger age groups. At our last census, no members reported being in the 15-25 age group

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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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