Input to NHS Digital Strategy Meeting – Trusted Research Environments

Presented at meeting on 7 October 2020

Response from use MY data

28 August 2020

Introductory Note

This response has been coordinated by the Secretariat of **use MY data**, on behalf of members.

As with all the responses we collate on behalf of **use MY data**, these may contain contrasting views from members. It is inevitable that we receive a range of views from members, and all of these views are included in our response. We believe that there is strength in presenting a complete range of views.

It contains responses to questions we were asked by NHS Digital about the development of Trusted Research Environments (TREs):

Questions we were asked:

- *As a patient and member of the public, what should the future look like for a TRE Service in your opinion?*

- *What aspects of service are particularly important to you e.g. top 3 or 4 from our boxes*

We were also asked to group our responses into three areas:

- what are the **basic features and attributes** of the TRE Service that you want?
- what are the **satisfying features and attributes** of the TRE Service that you want?
- what are the **delighting features and attributes** of the TRE Service that you want?

Contact details and follow-up

Our members are happy for use MY data's response to be used or shared without restriction.

If you would like to follow-up with **use MY data**, or ask any questions about our response, please contact the Coordinator, Alison Stone - alison@useMYdata.org.uk

Our collated comments are shown below and include general points of feedback.

General Feedback

Some specific statements which we fed back by members were:

- *"I think it's the single biggest prize in moving forward UK data-driven health research"*

- *"What we've all dreamt about" – "an urgent need"*

- *"This should become a world-beating repository of research-ready data"*

- *"Representation by patients needs to be hard-baked into the Service"*

- *"We must be working now to plan for a future beyond COPI. There's no point in all this effort if it will be switched off or need total re-development once an effective vaccine is developed"*

Question 1: From a patient perspective, what are the **basic features and attributes** of the TRE Service that you want?

- Ensuring the patient agenda & representation (by patients!) is hard-baked and integrated into the Service

- Use of the TRE should be accessibly priced

- Charities and the researchers they fund tend to operate pan UK and they will be key customers so we must think about the possibility of opening it up wider

- Secure, robust, properly managed. Not a side-line interest

- Patients being an integral part of developing governance processes

- Data must be accurate, comprehensive and timely

- Balanced access process which is lean, understandable to researchers & patients but proportionate to the complexity of the data request

- Purpose of data usage is clearly defined and publicly available

- Published metadata regarding Data Quality of each dataset (using the Data Utility Framework)

- Scope and purpose of data linkages are clear

- Data should be used to identify inequality in diagnosis, treatment and outcomes

- Comms plan to ensure two-way communication & other consultation activities so the TRE grows public support from the very start

Question 2: From a patient perspective, what are the **satisfying features and attributes** of the TRE Service that you want?

- Avoid vested interests. Cross TRE collaboration agreements regarding access & data sharing

- Operational involvement of patients, training provided and honoraria given

- Avoiding a landscape littered with TRE's

- Comms plan to ensure patient and public awareness

- A common access process across TREs

- Update the release/access register with the research outcome and the benefits realised. Monthly. "say what you've done"

- Ensuring that the public (in general) are seen as a stakeholder.

- Individual report on the results of how your data has been used (n.b. is this even possible with de-deidentified data?)

Question 3: From a patient perspective, what are the **delighting features and attributes** of the TRE Service that you want?

- Think ambitiously both at UK level and potentially setting wider standards for global cooperation/comparison (Denmark?).

- Generic agreements on standards regarding (auditable) access timelines, data governance, data linkage, user access approach, publication of approved data applications (in a lay language) including any associated high level commercial information

- Switch off other, narrower data repositories

- Become a world-beating repository of research-ready data

- We must move towards one to facilitate cross disease research and minimise cost and incompatibilities at both technology and process level (approval process, GP and hospital data submission process, data use process)

- Provide a public face to committees by publishing the names of those on any committee and the skillsets that they bring to that committee

- Online access to your own records

About use MY data

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

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.

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.

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.

What we do

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

❖ 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 workshops for patients and the public, focussing on topics related to patient data
  - a library of resources of data security, consent
  - narratives from individuals about how collecting, storing and using data can help patients.

❖ 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.

www.useMYdata.org.uk
join@useMYdata.org.uk
@useMYdata