

Agenda and Action Notes

Meeting: Editorial Review Panel

Date: Thursday, 22nd July 2021

Time: 09:30 to 11:00

Location: MS Teams dial in

Time	Agenda Item	Owner
09:30	Welcomes and Introductions	Chair
09:35	GP Data for planning and research campaign research update (presentation attached)	Head of Marketing, NHS E/I
10:05	GP Data for planning and research update	MC
10:35	Discussion	All
10:55	Next steps / actions	Chair

Attendee name:	Organisation
Lay member 1	Independent member
Eileen Phillips	Office of the National Data Guardian
Representative	Healthwatch
Project Manager	NHS Digital
Michael Chapman - Director of research and clinical trials	NHS Digital
Senior Business Support Officer	NHS Digital
Head of Marketing	NHS England/I
Lay member 2	Independent member
Lay member 3	Independent member
Lay member 4	Independent member
Comms Business Partner	NHS Digital
Senior Comms Manager – Data *	NHS Digital

* Meeting Chair

Apologies	Organisation / Department
Programme Head GP Data	NHS Digital
Lay member 5	Independent member
Lay member 6	Independent member

User Researcher	NHS Digital
Natalie Banner	Understanding Patient Data
Nicola Perrin	Association of Medical Research Charities
Head of Communications	NHS Digital

Agenda Item	Notes <i>(record summary of discussions and decisions)</i>
1	<p><u>Welcome and introductions:</u></p> <p>Members were welcomed and informed that the next two meetings have been cancelled due to availability. Meetings will start again on 12th August 2021.</p> <p>Members' attention was drawn to the recent press release relating to the GP Data and they were directed to the link that was shared via email prior to the meeting.</p>
2	<p><u>GP Data for Planning and Research - campaign research update</u></p> <p>Members were given an update around campaign research.</p> <p>Building on previous campaign research seen by the panel (8 July) qualitative research, consisting of ten in-depth discussions held in pairs, was carried out to look at three creative proposition options. Members were asked to comment on the findings from the focus groups, including the use of specific words.</p> <p>Feedback and questions were welcomed from members which included:</p> <ul style="list-style-type: none"> ● Technical terms such as Trusted Research Environment (TRE) were not understood ● Opt out explanation and process should be simple. Concern it could be considered misleading if an individual cannot be fully opted out. ● The question was raised why research was undertaken as the campaign has been put on pause. It was explained research had been planned and would still be useful for future work. ● Need to get the wording right around insurance and whether data is being sold. Concern that money is made out of data being shared. ● Honesty comes through as a key requirement from the research. ● A requirement to talk about benefits of data sharing whilst also being clear on what makes an organisation trusted. ● There's a balance between explaining everything and being compelling. ● We need adapt information for different audiences including relevant formats and languages.
3	<p><u>GP Data for Planning and Research update</u></p> <p>Members were updated about the recent press release that was shared in an announcement on Monday 19th July 2021, following a letter sent from Jo Churchill MP, Permanent Under Secretary of State for Health and Social Care, to GPs and Primary Care.</p> <p>The letter articulated that data collection would not begin on 1st September, but when specific criteria had been met. There are three big commitments in there:</p>

- First is Opts Outs. We are going to remove the deadline by which individuals need to opt out.
- Second is about how data is used. Access to GP Data will only be in a trusted research environment. It won't be copied outside the NHS unless people have given their consent for that to happen.
- Third is communication and engagement. This is where this panel fits in. It is vital to get this right and get the trust element right.

We must now implement what has been agreed by the minister. We need to continue with pace and energy, ensuring policy and operation work is informed by communications and engagement.

Members were advised that this work can take months to get it right (not years). It is perceived that the panel's input may expand to align with the new direction.

A discussion was held about Trusted Research Environments (TREs).

- Outline of what a TRE was given and the benefits of agreement from Ministers that data can only be accessed from a TRE
- Discussion held about what makes a good TRE
- Discussion was held about criteria for when a commercial organisation could access data, with concerns about privacy and commercial uses raised and perception of NHS data being sold
- Discussion held about how TREs provide more protection
- In some cases, there are TREs where the user does not get to see the data but can only run queries which returns results
- Questions raised about how many TREs there should be
- Unclear if arms length bodies (ALBs) are classified as NHS with regards to being able to host a TRE
- Discussion held about how data for the TRE could link/flow with other data. Members updated that use cases would be explored as part of the development process looking at concepts such as encrypting and ringfencing data
- Members asked about existing TREs and some examples were shared.
- Clear and simple communication around the TRE was felt to be important, including through analogies.
- Concerns raised that many members of the public are unaware what data is already known about them which may cause anxiety.

Update from Project Manager, NHS Digital

Members were provided an update relating to research from those from underrepresented backgrounds. Key findings include

- Low levels of trust towards NHS
- Desire for data to be used responsibly
- Requirement for greater transparency
- Community benefit needs to be articulated

It was highlighted that if there is a skew of minorities opting out that may have an inversely negative impact on the quality of the data, more greatly impacting the communities that have opted out.

- End -