Agenda and Action Notes

Meeting: GP Data Editorial Review Panel

Date: Thursday, 9th September 2021

Time: 09:30 to 11:00

Location: MS Teams dial in

Time	Agenda Item	Owner
09:30	Welcomes and research advisory group update	**Chair**
09:40	Update following ministerial meeting - discussion	**Programme Head GP Data / All**
10:10	Communications and engagement update and proposed approach - discussion	**Comms Lead /All**
10:25	Publishing our work	**Chair/All**
10:40	Actions / AOB	**Chair**

NOTE – apologies there will be no panel meeting on 16 September

Attendee name:	**Organisation**
Communications Lead	NHS Digital
Eileen Phillips	Office of the National Data Guardian
Programme Head GP Data	NHS Digital
Lay member 1	Independent member
Natalie Banner	Understanding Patient Data
Comms Business Partner	NHS Digital
Senior Comms Manager – Data *	NHS Digital

* Meeting Chair

Apologies	**Organisation**
Lay member 2	Independent member
Lay member 3	Independent member
Nicola Perrin	Association of Medical Research Charities
Senior Business Support Officer	NHS Digital
Lay member 4	Independent member
Senior Project Manager	NHS Digital

Agenda Item	**Notes** *(record summary of discussions and decisions)*
1	***Welcomes and Research Advisory Group update*** An update on the programme was given, including how the communications and engagement workstream is one of three workstreams. The other two are opt-out improvements and data management, access and governance which covers work around trusted research environments (TREs). Members advised about the broad plans for the comms and engagement workstream that will engage with patients, public and other stakeholders in order to ensure the commitments set out in the letter to GPs have been met. The feedback from these groups will help to shape both the communications activity and the delivery of the programme. Members were given an update on the research advisory group meeting and the GPDPR programme. Feedback from the panel on these updates included: ● Questions and clarification around the trusted research environment (TRE) were asked. These were around policy, work of NHS Digital and NHS X, as well as understanding how TREs work with cohorts of patients who have consented for their data to be used for research (e.g. members of UK BioBank). ○ It was highlighted that there is a published blog written by Cathie Sudlow, scoped by UPD, about what TREs are, what they mean and what the benefits are and where the limitations are - The what & why of trusted research environments | Understanding patient data ○ It was highlighted that many questions around the use of TRE for GPDPR are still in development and are likely to be informed by communications and engagement activities. ● Clarification was sought around the definition of each of the phases of the communications and engagement plan (including listening vs consultation), as well as understanding how these activities would inform policy, not just communications activity. It was agreed that it is important that it is very clear what is in scope, what is negotiable and what is not. It was also highlighted that listening is not just about listening, but about taking action off the back of that. ● Questions asked around how the themes from the Literature Review (discussed in previous meetings) are being used in programme. ○ Members advised this panel is part of the communications and engagement area of work. The panel is the channel which will help us get the approach right and give feedback. ● Acknowledgement that the data space is very complex and complicated (and is much bigger than GPDPR) and it is difficult to understand. It would be good to be able to show the data, where it comes from, where it goes and what you can/can't opt out of. ● It was felt that role of patient panel is to help make sure that complex information is easy to understand for lay people, and that is where the panel can add additional value to the programme.
2	***Update following ministerial meeting – discussion*** An update was shared with the panel.

	Members were informed that weekly meetings with ministers are taking place while we progress this work. An update was that ministers are happy with the approach and are providing ongoing support. There is recognition that the engagement and communications have to work and that there is a requirement for longer term engagement with a range of different audiences.
3	***Communications and engagement update and proposed approach – discussion*** Member of the communications and engagement team gave an update on listening phase research plans, drumbeat of communications to update on programme progress, as well as explaining the role of other groups such as the Check and Challenge group. Team also highlighted that need to be careful of scope of GPDPR vs other data programmes - alignment is being sought where possible. Team member agreed to come to each session to provide relevant updates. Questions and feedback from the panel: ● Approach to focus on GP practices seems sensible but members raised questions about feasibility due to burden on general practice at this time. Team updated that it was working with colleagues, including Practice Manager Network, to identify how to best to do this. Questions also raised whether patient reps who were on general practice boards would be part of process. This will be explored as part of development of research plan. ● Clarification sought on use of some words such as ‘campaign’ - the team to look at this. ● Questions raised about whether there will be patient/public representation as part of check and challenge group? Members were informed that this is being discussed with the SRO (Senior Responsible Officer). ● Members spoke about the need for a bigger conversation about data sharing, difference between data for direct care and planning and research - bigger educational piece needed. ● The need for transparency highlighted by group - and members keen that this work forms part of that. Team agreed and are working to ensure systems and processes are in place for this to happen.
4	***Publishing our work*** Panel members were given an update on the Terms of Reference (ToR). Members were informed that the updated document will be shared with them for review and comments. It was noted that the ToR should be written in plain English. The panel discussed the option for redacting their names from any FOI requests about the work of the panel. Members questioned whether redacting names was in line with transparency. Members were informed that the NHS Digital policy is that executive directors only are named in FOIs to protect members of staff being contacted about the work. Discussions included whether we should consider giving support/guidance to members on how to handle any attacks from other groups. Members were happy in principle but would not want to be targeted by individuals due to involvement in the panel. Members were informed that it would be good to publish names of the panel if members were happy and also to include a few quotes about the involvement.
5	Actions / next steps

	No panel next week, the next panel meeting to include an update on the work about public benefit which was presented at the RAG this week.

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