

Action notes

Meeting: GP Data Patient and Public Engagement and Communications Advisory Panel

Date: Thursday 12 May 2022

Time: 09:30am to 11:00am

Location: MS Teams dial in

Time	Agenda Item	Owner
9.30am	Introductions	Eileen Phillips
9.32am	Formal noting of previous meeting's action notes	Eileen Phillips
9.35am	Programme update: Trusted Research Environment	Andrew Thorne-Marsh
10.10am	Presentation of public research findings	Andrew Kliman
10.45am	Recruitment	Eileen Phillips & Lucinda Jackson
10.55am	AOB	Eileen Phillips

Attendees	Organisation
Grace Melvin	AMRC
Lay member 1	Independent
Lay member 2	Independent
Eileen Phillips (CHAIR)	National Data Guardian
Information Governance Lead	NHS Digital
Communications and Stakeholder Engagement Manager	NHS Digital
Deputy Head of Communications	NHS Digital
Business Admin Support	NHS Digital
Programme Workstream Lead	NHS Digital
David Snelson	Use My Data

Apologies	Organisation
Lay member 3	Independent

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Agenda item	Notes
1	<p>Introductions The chair introduced the meeting. Apologies were noted.</p>
2	<p>Review of previous meeting's action notes</p> <p>The notes were agreed for publication with an agreement that any acronyms would be expanded.</p> <p>Grace Melvin thanked Panel members who had submitted views about the Panel and confirmed that she had drawn inspiration from them and reflected the sentiment in the blog she is writing about the work of the Panel. Once published, a link to the blog will be circulated to Panel members.</p> <p>Further to discussions in previous meetings, and the suggestion that the tenure of the chair be extended, the rotating chairs have settled on undertaking the role in periods of four months. This was welcomed by the Panel.</p>
3	<p>Programme update: Trusted Research Environment (TRE)</p> <p>The programme lead for the Data Management Access and Governance workstream gave an update on the development of the TRE.</p> <p>The update was welcomed by the Panel, however regret was expressed that working documents relating to the development of the TRE were restricted from publication at this early stage in planning.</p> <p>The Panel acknowledged the challenge in communicating information about the TRE in a way that can be easily understood and in turn offer reassurance.</p> <p>The layering of information, to cater for a range of needs and levels of interest, was discussed, as was the need to use a variety of communications methods including videos/animations. It was suggested that a helpful analogy to explain how a TRE works is to liken it to a research library (where the publications don't leave the building), as opposed to a lending library (where people borrow the books). It was agreed that communications materials would come to the Panel to seek views as part of the development.</p>
4.	<p>Presentation of public research findings</p> <p>The Panel received a presentation from the Assistant Head of Communications who provided an overview of the findings from the recently undertaken public research.</p> <p>The research had been undertaken with a representative sample of 2000 people including those who were not digitally engaged, as part of the programme's listening phase.</p> <p>The Panel noted the confusion between public understanding of what a type one</p>

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	<p>opt-out does compared to a national data opt-out. It was suggested that a more meaningful term for a type one opt-out was a 'local opt-out'. The Panel questioned whether any work was underway to review opt-outs, and if so sought reassurance that engagement with patients and the public would be part of the process. It was agreed that this question be escalated to national policy teams, via the programme leadership.</p> <p>There was a good initial discussion about the findings but owing to time constraints, and to allow for a full discussion, it was agreed that a discussion about the findings take place at the next meeting.</p> <p>The Panel were informed that the learnings from the survey, and other activity which has taken place during the 'listening phase' are being consolidated and will be published in a listening phase report. This was welcomed by the Panel.</p>
<p>5</p>	<p>Recruitment</p> <p>Further to agreement at the last meeting that the Panel be expanded, the Communications and Stakeholder Engagement Manager talked through the proposed approach to the recruitment campaign and sought feedback from the Panel ahead of progressing the work. It was noted that the recruitment seeks to strengthen the representation of a diverse range of demographics, attitudes and behaviours. The approach outlined sought to use a variety of channels and networks to reach diverse audiences and encourage people who don't have a voice in other ways to get involved.</p> <p>The approach was agreed, and the Panel will be involved along the development of the campaign.</p> <p>Given the desire to engage a wide range of individuals, the Panel raised that the current time of the meeting may preclude some people from getting involved. It was agreed that alternative times be explored as part of the recruitment process and also with existing Panel members.</p>
<p>6.</p>	<p>AOB</p> <p>The GDPR programme was discussed in the wider context of the pressing capacity challenges facing the General Practice Extraction Service (GPES) system. It was confirmed that several options are being considered to resolve this issue, with the intention being to progress with GDPR whilst addressing these other challenges in parallel.</p>

ENDS