

Action notes

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

Date: Thursday 21.07.22 09:30am to 11:00am

Location: MS Teams dial in [Click here to join the meeting](#)

Agenda Item	Owner
Introductions	Chair
Formal noting of previous meeting's action notes	Chair
GDPR programme Update	GDPR Programme Lead
Secure Data Environments – public engagement update	Health Data Policy Lead
Type one opt-out digital service – user testing feedback	Service Designer
Drumbeat amplification campaign update	Communications and Stakeholder Engagement Manager
Engagement phase plan update	Assistant Head of Communications
AOB	Chair

Attendees	Organisation
Eileen Phillips (CHAIR)	National Data Guardian
Grace Melvin	AMRC
John Marsh	Use MY data
Rebecca Moore	Healthwatch
Lay member 1	Patient representative
Health data policy lead	Department of Health and Social Care / NHS England – Transformation Directorate
Health data policy - engagement	Department of Health and Social Care / NHS England – Transformation Directorate

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Attendees	Organisation
GDPR Programme Lead	NHS Digital
Business Support	NHS Digital
Service Designer	NHS Digital
Service Designer	NHS Digital
Business support	NHS Digital
IG Lead	NHS Digital
Communications and Stakeholder Engagement Manager	NHS Digital
Assistant Head of Communications	NHS Digital
Head of Communications and Workstream Lead	NHS Digital

Apologies	Organisation
Lay member 2	Patient representative
Lay member 3	Patient representative

Agenda item	Notes
1	<p>Introductions</p> <p>The chair introduced the meeting, welcomed Panel members, and ran through the agenda and planned discussion points.</p> <p>Thanks were noted to John Marsh who, further to the publication of the public research findings, flagged that the title on slide 33 was misleading. This was promptly reviewed, and it was recognised that the title had been used in error as it was out of context. The slide deck has since been updated.</p> <p>Apologies were noted.</p>
2	<p>Review of previous meeting's action notes</p> <p>The action notes from the 7 July 2022 meeting were agreed as an accurate reflection of the meeting and approved for publication.</p>
3.	<p>GDPR programme Update</p> <p>The Programme lead for GP Data for Planning and Research (GDPR) gave an update on programme overall. He reminded the panel that his previous update was focused on the GP Extraction Service (GPES) changes and that GDPR was referred to as an end goal, with the GPES replacement scheduled to arrive first. He then updated the panel that the GDPR programme will make use of</p>

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the new GP data platform, which will also serve other purposes such as direct care, consented cohorts and payments – purposes which are currently served by the GPES system.

It was queried how this programme fits with the Federated Data Platform which has been in the news recently. The Panel were updated that broader alignment may be required in the future, and that high-level consideration was taking place about the strategy that sits around NHS data programmes.

The use MY data representative asked for clarity on the timescales for the delivery of the four stages of the GDPR programme. It was confirmed that the budget to cover the delivery of the ministerial commitments has been approved and the current expected delivery dates are as follows:

- 1) TRE delivery - planned for November 2022.
- 2) Retrospective deletions - This functionality will be ‘switched on’ when GDPR is delivered, but the capability will likely be delivered by the end of 2022.
- 3) Type 1 opt-out burden reduction for GPs – the delivery of a digital solution will be carried over to quarter one of the 2023/24 financial year, to help manage a reduction in this year’s budget.

Concern was voiced about whether a digital Type 1 opt-out service would be needed, given the delay of the introduction to 2023/24, and the pending review into opt-outs as part of the national data strategy. The Panel were informed that the policy position around opt-outs will be monitored, and the build will be adjusted if necessary to ensure that public funds are not wasted.

- 4) The comms campaign will be delivered prior to the data flowing for the purposes of planning and research. This is currently anticipated to take place in quarter one of the new financial year (2023/24).

The Panel acknowledged that given the uncertainties, due to impacting factors, it is currently challenging to provide accurate target dates and must be viewed as current, expected timescales, and are subject to change.

4.	<p>Secure Data Environments – public engagement update</p> <p>The Senior Health Data Policy Lead at NHS England presented an overview of the policy development around Secure Data Environments (SDEs).</p> <p>It was confirmed that in June 2022, the Steering Group for the Secure Data Environment programme, agreed to adopt the term ‘Secure Data Environment’ to describe all secure data access environments such as Trusted Research Environments and Operational Data Environments. The term was adopted because of:</p> <ul style="list-style-type: none"> ● GDPR public polling in 2022 found the term “Secure” is much more positively received than the term “Trusted”. ● Ongoing debate that the “trusted” term in TRE is an unhelpful use of
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language, public view that trust is earned.

- Expanding beyond the term “Research” to “Data” would accurately capture wider use.

The Panel passed comment on the use of the term ‘data’ and whether this would be understood.

They also queried whether it is beneficial to continue with the term ‘Trusted Research Environment’ in relation to the GDPR programme, rather than adopting the new terminology, given that the ministerial commitment around a TRE being in place, and previous communications referencing this. This was noted for consideration as part of developing future communications.

It was confirmed that:

- Secure Data Environments will be the default way that NHS data will be accessed and analysed, data sharing will be a highly limited exception.
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- SDE principles will be based on the “5 safes framework” (Safe people; Safe projects; Safe settings; Safe outputs; Safe data) developed by ONS.
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- Secure Data Environments that hold NHS data will need to be accredited on an agreed basis.
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- Researchers/analysts and their host organisation will need to be accredited in order to use a Secure Data Environment.
- We will co-design our policy through public and patient engagement.

An update was provided on the engagement being undertaken to develop communications for the public. The Panel noted the importance of ensuring the language is accessible and easily understood.

Future plans for engagement were outlined as:

- Continued development of a public explainer which would be hosted on the NHS website. A copy of this will be circulated to the Panel for them to comment upon.
- Development of an animation to support
- An animated video is planned to provide further explanations.
- Alignment of SDE communications and engagement activity with the evolving plans for the data saves lives strategy communications and engagement work.

It was reported that the draft policy principles are scheduled to be published in late summer 200, with the publication of the technical capabilities and accreditation framework, along with the implementation roadmap is expected to be delivered in Autumn/Winter 2022.

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	<p>Feedback from the Panel was welcomed by the SDE policy and engagement representatives. There was an ask to support the development of a public animation which the Panel confirmed it was happy to do.</p>
<p>5.</p>	<p>Type one opt-out digital service – user testing feedback</p> <p>The lead user tester for the Type 1 Opt-out service presented an overview of the ongoing process, the plan, overarching insights, the user journey, and the next steps for user testing. Initially two prototypes were built and then shown to a panel of 10 test users (each with different backgrounds – age, race, geographic region, and device type) to assess the factors that would make the app and website the most suitable to all users. The design will be iterated from the outcomes and responses of the public then validated in a second round with a fully-built prototype (beginning next week) to further improve the digital solution and make sure it meets the needs of users.</p> <p>Findings from the first round of user testing this week were:</p> <ul style="list-style-type: none"> ➤ 80% of users involved in the testing did not want to opt out having read the explanatory text. ➤ The word “data” was found to be unclear, and testers did not have a good understanding of information this might be. Alternative language will be explored in further testing. ➤ Users requested clear explanation and some examples of the data and what it would be used for to make an informed decision ➤ To reduce the number of clicks and need to scroll through information to improve the user journey (submitting a tax form was sighted as a good user experience and will be researched). ➤ The language needs simplifying, making consistent and more focused on choice rather than opting-out. A desire to see the inclusion of more diagrams to help explain the content. ➤ There was a lack of understanding about the different types of opt-out – type one opt-out and national data opt out. <p>In response to a query, it was confirmed that the user research has, and continues to, be done with a range of people to capture views from a variety of people from different backgrounds, and different levels of knowledge about data and the GDPR programme.</p>
<p>6.</p>	<p>Drumbeat amplification campaign update</p> <p>A short verbal update was provided to the Panel by the Communications and Stakeholder Engagement Manager. The Panel was informed that the concepts have continued to be socialised amongst key stakeholders. Ministerial approval was granted to progress to testing. Work is progressing with the creative agency to ensure the testing is comprehensive and provides the evidence needed to iterate the campaign and proceed with confidence. Work will continue whilst the Panel is on summer leave and a further update will be given in September.</p>
<p>7.</p>	<p>Engagement phase plan update</p>

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	<p>Due to time constraints a short verbal update was given by the Assistant Head of Communications. The engagement phase plan development is ongoing with much progress made. The strategy is nearly finalised and will be circulated to the panel with a request for feedback. The suggestions will be incorporated in the engagement phase plan with an aim to improve effectiveness.</p>
<p>8.</p>	<p>AOB</p> <p>It was confirmed that this is the final meeting ahead of the summer break. The recruitment of new members will take place over the summer break with a view to the new members joining the first meeting back after the summer break on 15 September.</p> <p>Thanks, from the panel, were expressed to Eileen Phillips, for her stint as Chair of the Panel. As previously agreed, the role of Chair rotates on a 4-month cycle and best wishes were sent to Grace Melvin who will take over as chair in September.</p> <p>A number of items were identified during the meeting, to schedule for September onwards. These were:</p> <ul style="list-style-type: none"> ➤ An update on the National Data Strategy communications and engagement plans. ➤ Feedback from the drumbeat amplification campaign testing. ➤ SDE animation development and progress update. ➤ Welcome and introduction to the new Panel members. <p>Panel members were asked to submit any other suggestions via email.</p>

ENDS