

Agenda and Action Notes

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

Date: Thursday, 11th November 2021

Time: 09:30 to 10:55

Location: MS Teams dial in

Time	Agenda Item	Owner
9.30	Welcomes and Introductions	NHS Digital (Chair)
9:35	Review roadmap (verbal) and attached in email	NHS Digital
9:45	Communications and Engagement update <ul style="list-style-type: none">User research updates (verbal)Drumbeat communications (verbal) and discussion	NHS Digital
10:15	Opt-out <ul style="list-style-type: none">Intro to opt-out (verbal)	NHSX
10:30	Patient principles <ul style="list-style-type: none">Response from NHS X and GP Data Programme and NDG feedback (verbal)	NHS Digital
10:50	Next meeting date and focus	NHS Digital (Chair)
10:55	Close meeting to allow for 2 minutes silence for those who would like to observe it.	NHS Digital (Chair)

Attendee name:	Organisation
Strategic Communications	NHS Digital
Information Governance Lead	NHS Digital
Programme Director - GDPR Opt-out working Group	NHS Digital
Representative	Use My Data
Eileen Phillips	Office of the National Data Guardian
Lay member 1	Independent member

Grace Melvin	Association of Medical Research Charities
Lay member 2	Independent member
Delivery Lead - GDPR Opt-out Service Discovery Team	NHS Digital
Senior Business Support Officer	NHS Digital
Lay member 3	Independent member
Head of Data Strategy	NHSX
Patient and Public Involvement and Engagement Lead *	NHS Digital (Chair)
Strategic Communications	NHS Digital

* Meeting Chair

Apologies	Organisation / Department
Lay member 4	Independent member
Lay member 5	Independent member

Agenda Item	Notes (record summary of discussions and decisions)
1	<p><u>Welcome</u></p> <p>New members of the group were welcomed.</p>
2	<p><u>Review Roadmap</u></p> <p>Members were presented with a document review roadmap of items that will come to this group for feedback and comment. The is to ensure the same items are seen at each of the different groups that form part of the programme. It was highlighted that this approach would also ensure we are delivering the objectives in line with the letter from Jo Churchill MP. The roadmap gave an overview of anticipated dates and expected items/documents for future meetings. The roadmap may change slightly depending on whether things move or shift.</p> <p>The roadmap covered the document description, the review purpose and summary of output.</p> <p>The various documents that will be covered in future meetings were briefly highlighted. Members were asked to highlight any topics that are not on the list but would like to see or cover, which can be factored in.</p> <p><i>Feedback from the panel:</i></p> <ul style="list-style-type: none"> • It would be useful to publish the review roadmap on the website and would help transparency and build trust.
3	<p><u>Communications and Engagement update</u></p> <p>Members were advised that we are looking to fill the gaps in our knowledge to ensure we are engaging properly with the public. It was highlighted that some desk research is going on and hope to have the analysis from this in the next</p>

	<p>few days. This will set out what we know from the public already. A survey is planned to a limited number of general practice staff and engaging with the Integrated Care Systems (ICS) and was explained to members.</p> <p>Members were informed that a plan is being produced which will enable us to go out to agencies to pitch the survey, this will come back to the group for feedback in due course.</p> <p>Drumbeat communication activity was presented, and it was highlighted that it is about telling our story to build confidence, inspire and raise awareness among the audience to help them understand.</p> <p><i>Feedback from the panel:</i></p> <ul style="list-style-type: none"> • Activity must reach hard to engage groups including those who don't speak English as the first language and those who have already opted out. • Communication needs to be accessible and reach different communities, without using acronyms and jargon and tell a story. • Communication should be balanced and show benefits and risks, and highlight security of data. <p>The strategic approach using themes and topics was shared with the panel and briefly outlined. The different communication channels and formats were highlighted.</p> <p><i>Feedback from the panel:</i></p> <ul style="list-style-type: none"> • Consider the effects of misinformation and how to manage it. • Consider whether patients and public be considered two different groups. • Consider how to share good positive stories of the benefits. <p>The panel were invited to share ideas of topics we may want to cover and what format would be most appropriate.</p>
4	<p><u>Opt-out</u></p> <p>Members were informed that as part of the commitments made by the health minister is to ensure we are reducing the burden on GP practice staff and support patients to register type 1 opt-outs. It is about being clear about what data is included in type 1 opt-outs. A lot of work has been done to speak to practices and several themes and challenges have emerged from this.</p> <p><i>Feedback from the panel:</i></p> <ul style="list-style-type: none"> • There is a lot of confusion around the different types of opt-outs. • It is important to explain what the Summary Care Record (SCR) is and what other data is used for in research and planning. How do we make the differences clear? • Consideration should be given to whether we can change the name of some things we refer to like SCR, type 2 opt outs and etc.
5	<p><u>Patient principles update</u></p>

	<p>Members were informed that NHS X have been working on the Data Strategy for health and social care the draft of which was published in June 2021. It was highlighted that a lot of feedback was received and will be taken into consideration when the final version is produced.</p> <p>Members were informed that the feedback was broadly in line with the patient principles/ recommendations and an overview was given on how the feedback will be reflected into the Data Strategy, which will be published in early 2022.</p> <p>Members of the GDPR programme gave verbal feedback on the principles, which are being considered as recommendations as part of the Listening Phase and will be included in the formal Listening Phase report that will be delivered in early 2022.</p> <p>NHSX will come back to a future meeting with the revised updated Data Strategy and talk in more detail about the commitments and invite the panel for feedback on that. Members were asked to note the work incorporates and builds on feedback from different groups and that one of the future meetings will be to share the boarder engagement plan.</p> <p>Members were informed that the principles/recommendations were shared with the National Data Guardian (NDG). Feedback on behalf of the NDG was:</p> <ul style="list-style-type: none"> • The NDG generally supported the approach to transparency. • NDG raised the question about how these principles would be used and how feedback on them was captured. NHS D colleagues confirmed they are viewed as recommendations as part of Listening Phase and will be formally addressed as part of Listening Phase report. • It is important to see people are being engaged as opposed to just presenting campaigning information at them. • GP support is very important and should be reflected in the recommendations. • The public needs to be given a sense of choice and making sure they are not misled. <p>ACTION: Chair to speak to Healthwatch to check who the intended audience is and inform NDG.</p>
6	<p><u>Next Meeting and focus</u></p> <p>Members were receptive to the idea of a new patient representative joining the panel from British Medical Association (BMA) patient liaison group.</p> <p>Previous meeting action notes dated 1st November 2021 were approved.</p> <p>The next meeting is in 2 weeks, the focus will be shared in due course. The action notes from this meeting will be shared with the panel along with the roadmap.</p>