

Agenda and Action Notes

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

Date: Thursday, 25th 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	Assurance paper	NHS Digital
9:50	Open discuss on use of language to consider alternatives and more accessible wording specifically around: User research updates (verbal) <ul style="list-style-type: none">• Opt-out• Trusted Research Environment (TRE)• Pseudonymised vs de-identified• Selling Data	NHS Digital
10:20	Type 1 recommendations	NHS Digital
10:45	Panel Membership	NHS Digital (Chair)
10:50	Next meeting date and focus	NHS Digital (Chair)
10:55	AOB	NHS Digital (Chair)

Attendee name:	Organisation
Communications and Engagement Workstream Lead	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
Lay member 4	Independent member
Patient and Public Involvement and Engagement Lead *	NHS Digital (Chair)
Strategic Communications	NHS Digital
Representative	Healthwatch
Clinical Trials Head of Business Operations	NHS Digital *meeting chair

* Meeting Chair

Apologies	Organisation / Department
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> <p>The news on the merger of NHS E, NHSX and NHS Digital was shared.</p>
2	<p><u>Use of Language</u></p> <p>Discussions took place around the sometimes difficult to understand language and wording used relating to certain terms like opt-out, trusted research environment and etc.</p> <p>Feedback highlighted that there is a lack of knowledge and understanding especially about data opt-outs. Explain what the differences are and what people are opting in or out of in a simplified manner. Language should be clear and using everyday terms and should be translatable for different communities. Consider using diagrams to explain the concepts. Consider using a checklist approach to enable people to opt-out easily. Consider educating people on what their data has been used for.</p>
3	<p><u>Type 1 Opt out service</u></p> <p>An overview of the various options available to improve the opt-out service was shared with members. Members were informed that the options are based on looking to put digital solutions into place. Concerns highlighted around the communities and people who don't/are unable to engage digitally. The solution would ensure that those groups are not excluded. The benefits should be</p>

	highlighted which discourage people from opting out especially those who have a distrust with the system.
4	<p><u>Assurance and next steps</u></p> <p>The assurance paper was talked through, explaining how feedback was captured and responded to.</p> <p>Members were advised that the engagement plan is in development and will be shared in due course. Members stressed the importance of community engagement and working with a wide variety of groups and organisations.</p> <p>Concerns were shared about the length of time it is taking to move things forward.</p>
5	<p><u>Recruitment to the panel</u></p> <p>Members were invited to share thoughts on how we might go about recruiting more diverse people to the panel. Suggestions from members included identifying which diverse groups we wish to recruit from. Consider looking at charities and patient support groups for particular conditions, particular faiths and potentially groups of people who are from the opt-out group.</p>
6	<p><u>Next Meeting and focus</u></p> <p>Previous action notes approved for publication. Next meeting is on 9th December 2021. And will be the last one before 2022.</p>

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