

Agenda and Action Notes

Meeting: GP Data Editorial Review Panel

Date: Thursday, 2nd September 2021 Time: 09:30 to 11:00

Location: MS Teams dial in

Time	Agenda Item	Owner
09:30	Welcomes and update on actions from last week	Chair
09:40	Opt-out update and discussion	Senior Project Manager
10:00	Public perceptions of NHS data sharing: Rapid literature review – further discussion	Chair/ Healthwatch/ All
10:25	Actions / AOB	Chair

Attendee name:	Organisation
Lay member 1	Independent member
Eileen Phillips	Office of the National Data Guardian
Lay member 2	Independent member
Lay member 3	Independent member
Natalie Banner	Understanding Patient Data
Nicola Perrin	Association of Medical Research Charities
Lay member 4	Independent member
Comms Business Partner (Manager)	NHS Digital
Senior Project Manager	NHS Digital
Senior Comms Manager – Data *	NHS Digital
Representative	Healthwatch

* Meeting Chair

Apologies	Organisation / Department
Programme Head GP Data	NHS Digital
Project Manager	NHS UK
Representative	Patient Experience Library
Senior Business Support Officer	NHS Digital
Head of Marketing	NHS England/I

Lay member 5	Independent member
Lay member 6	Independent member

Agenda Item	Notes <i>(record summary of discussions and decisions)</i>
1	<p><u>Welcome and update on actions from last week</u></p> <p>The panel members were welcomed and updated on outstanding actions.</p>
2	<p><u>Opt-outs update and discussions</u></p> <p>Members were given an update and information on the different types of opt-out, including the introduction of NDOP (National Data Opt-Out), its purpose and the proposed retirement of Type 1s. It was explained that Covid-19 had delayed this proposed retirement, with a commitment made by Jo Churchill MP that this would not happen for at least 12 months. It was agreed that the different kinds of opt-outs are confusing and many people do not understand the differences.</p> <p>Members were updated about the ongoing work to alleviate pressure and reduce burden on GPs. Discussions were underway in NHSD about managing the Type 1 opt-out centrally, whilst NDOP should improve the user journey for those wanting to opt out.</p> <p>Member discussion included the feedback below:</p> <ul style="list-style-type: none"> ● A member highlighted that their GP practice is a training practice. They asked questions about opt outs and the GP hadn't heard about it. How is the information getting to these junior/student (and other practice staff) and GPs so they can then provide the right messages to their patients? ● What will it mean for GP practices to apply NDOP? Does that then mean if someone completes NDOP it will stop their data flowing? NDOP has a lot of exemptions, GP system suppliers will have functionality in their systems. ● The spotlight on opt outs is now and lots of people are looking into opting out now. Clearer examples needed on the websites, e.g., want to do a Type 1 opt out but only says 'identifiable data' - why not all data? ● People didn't know their data was being shared, suddenly finding out and that's why so many people are opting out now. Examples of data sharing to show people, so they understand what this means. ● Another member was positive about opt out - conversation with someone who recently opted out, she went back and looked at what it involved and didn't think what was happening was that bad. Improvements are going to be made to explaining things, to creating TREs, improving controls.

	<ul style="list-style-type: none"> ● Backlash was around broader trust issues with government, lack of transparency - bigger contextual issues than just the GDPR programme. Without wider focus you'll miss the fact that people's trust is going to be impacted.
3	<p><u>Public perceptions of NHS data sharing: rapid literature review further discussion</u></p> <p>Members were updated about the literature review into public attitudes towards data sharing over the last 10 years, which was briefly discussed at the meeting on 26 August.</p> <p>Healthwatch gave a brief overview of the patient principles that have been developed off the back of the Literature Review which the panel would like the programme to consider. The main areas of focus include a public information campaign highlighting what people need to be aware of, that is co-designed with members of the public, addressing misunderstandings and concerns; third party sharing; and differences between the opt outs.</p> <p>The panel discussion on the principles can be grouped in the following themes:</p> <ul style="list-style-type: none"> ● They should be integrated with existing principles. ● Continued concern from the public about NHS selling data which needs to be addressed. Need to be clear who data is shared with and associated costs. ● Requirement for an ongoing conversation through engagement activities. them with principles that already exist. There is a need to dispel idea about the NHS selling data. There is currently no public conversation about sharing data for good. ● Need to bring the conversation back to impact on individuals ● Wary of the idea of a public info campaign, this has to be an ongoing conversation. There was a massive public information campaign around NDOP, no one remembers it. No one remembers they opted out of sharing their data. People will forget they've had that conversation. ● Smaller, more grass roots and local engagement opportunities will be more sustainable than a big bang campaign that people will quickly forget.
4	<p><u>Actions / next steps</u></p> <p>No actions or next steps.</p>

- End -