

Agenda and Action Notes

Meeting: GP Data Editorial Review Panel

Date: Thursday, 26th August 2021

Time: 09:30 to 11:00

Location: MS Teams dial in

Time	Agenda Item	Owner
09:30	Welcome Updates on GP Data for Planning and Research	Chair /Programme Head
09:40	Public perceptions of NHS data sharing: Rapid Literature review	Patient Experience Library
10:10	Emerging themes from the review	Healthwatch
10:30	Panel discussion	All
10:55	Actions / next steps	Chair

Attendee name:	Organisation
Lay member 1	Independent member
Eileen Phillips	Office of the National Data Guardian
Programme Head GP Data	NHS Digital
Lay member 2	Independent member
Lay member 3	Independent member
Representative	Patient Experience Library
Natalie Banner	Understanding Patient Data
Nicola Perrin	Association of Medical Research Charities
Clinical Lead	NHS Digital
Lay member 4	Independent member
Lay member 5	Independent member
Lay member 6	Independent member
Senior Comms Manager – Data *	NHS Digital
Representative	Healthwatch

* Meeting Chair

Apologies	Organisation / Department
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Senior Business Support Officer	NHS Digital
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Agenda Item	Notes <i>(record summary of discussions and decisions)</i>
1	<p><u>Welcome and update on GP Data for Planning and Research:</u></p> <p>The chair requested support for taking high level minutes in the absence of the secretariat.</p>
2	<p><u>Public perceptions of NHS data sharing: rapid literature review</u></p> <p>Members discussed the Literature Review, undertaken by the Patient Experience Library. The Literature Review took place over four weeks to understand what we already know in the UK about public attitudes to data sharing. It looked at over 100 reports and documents, all open access materials including 'grey literature' from charities and covered lessons learned from care.data. It identified barriers and enablers for data collection but did not provide comment on the relative or perceived merits of these.</p> <p>In summary, the Literature Review highlighted:</p> <ul style="list-style-type: none"> ● Data collected needs to be in the trusted research environment (TRE) ● Public understanding is poor and has not improved since care.data. Little understanding about the gathering process, anonymity/pseudonymisation, legal side, fair processing, informed consent, how data is used, ethics, difference between privacy and security ● Widespread mis and dis information e.g. SERCO running covid app ● Wide awareness of ransomware attack ● Regulators struggle to keep pace with IT developments. ● Not much evidence of demographic differences in attitudes. <p>It was agreed that data needs to be safe and secure technically but also in the eyes of the public. Opt outs need to be as simple as possible to understand including all comms material. The burden on GPs needs to be reduced.</p> <p>GPs need support and to indicate required resources. Front line GP receptionists are not necessarily capable of explaining 'opt out'. Working with GP managers there is a need to avoid burden on GPs especially in busy months.</p>
3	<p><u>Emerging themes from the review</u></p> <p>Members were informed that Healthwatch have been working with communities and organisations around trust building and awareness. We need to be open and honest showing both the positives and negatives - it is important to acknowledge concerns and allay fears.</p> <p>Members discussed the need for a call line or at least somewhere to raise concerns. These could be batched into themes and answered as 'you said / we</p>

	did / we couldn't do because'. This would be more practical than responding individually.
4	<p><u>Panel discussion</u></p> <p>Members were informed that there is no timeline for action around the programme at present as it is the listening phase, but they will be updated as plans develop. Members highlighted that the 'opt outs' were difficult to understand and that people opt out because they don't understand.</p> <p>There was also a discussion around the data grab headline – agreement that the programme needs a catchy strapline too, to win hearts and minds.</p> <p>There is value in communications even when nothing much is happening e.g. Elizabeth Line newsletter. Silence leaves room for suspicion.</p> <p>A discussion was held around who best to deliver the message, especially when trust in government was low. Discussion was held whether a national voices exercise would be beneficial.</p>

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