

# Action notes

**GP Data Patient and Public Engagement and Communications Advisory Panel**

**Date: Thursday 2<sup>nd</sup> March 2023**

**Time: 11am-3pm**

**Location: In person meeting, London**

	Agenda Item	Owner
	Introductions	Eileen Phillips
	PPECAP GP Data Access Models	Programme Manager

Attendees	Organisation / Department
Matt Howard-Murray	Association of Medical Research Charities/ Cancer Research UK
Eileen Phillips	National Data Guardian
Deb Smith	Lay member
Tanya Almeida	Lay member
Nicola Metcalfe	Lay member
Hayley Hall	Lay member
John Marsh	useMYdata
David Snelson	useMYdata
John Roberts	useMYdata
Manoj Mistry	Lay member
Rosie Hill	Lay member
Research and Insights Manager	NHS England
Head of Communication and Engagement	NHS England
Communication Manager	NHS England
Delivery Manager	NHS England
Programme Manager	NHS England

Agenda item	Notes
1.	<b>Introductions</b> Panel members were welcomed to the meeting by the Chair, who also ran through the agenda.
3.	<b>PPECAP GP Data Access Models</b> To support the programme in considering how different approaches to data access affect public understanding and support, the General Practice Data for Planning and Research (GPDPR) team undertook deliberative discussions with the Patient and Public Engagement and

	<p>Communications Advisory Panel (PPECAP) to better understand how patients might feel about different potential options for data access, including benefits and trade-offs of each approach.</p> <p>In addition to covering off the different options, the team wanted to delve deeper into expectations around applications of opt outs, particularly when discussing models where patient data doesn't leave the GP boundary but is able to be analysed remotely.</p> <p>The panel were presented with three approaches (The existing model, where queries are analysed and processed by the GP system suppliers and results are sent back to NHS England, a federated model using regional level data and a bulk extraction model) and discussed the proposed principles for accessing GP Data.</p> <p><b>Key feedback</b></p> <p><b>Future-proofed design</b></p> <p>The panel concluded that as the use of GP patient data is complicated and regularly changing due to the introduction of new technology to better process data, it was imperative to design and deliver a futureproof platform.</p> <p>The panel felt strongly that this would need to be simple, easy to explain to the public, “value for money”, flexible to changing strategy and leadership aims and provide the patient data protections the NHS promises patients.</p> <p><b>Clarity, communication and public trust</b></p> <ul style="list-style-type: none"><li>• There was a shared view that patients need to be clear about the purpose for which data is being shared, and there was a belief that currently, that is too often ambiguous, leading to mistrust and concern</li><li>• Panellists reflected implications on public trust and stated the need for greater clarity and improved communications about why data is shared, and the positive benefits that are derived from its use, and the safeguards that are in place to protect privacy and avoid misuse</li><li>• They also highlighted a risk that certain approaches could undermine public trust. There were some concerns data may be going out of the country, shared with pharmaceutical companies who are profiteering from NHS data or used by insurance companies to push up the price of insurance premiums. It was explained to the group that it is not legal to share data for marketing or insurance</li></ul>
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	<p>purposes and that there are strict rules about where and how data is stored.</p> <ul style="list-style-type: none"><li>• Panellists felt the ‘governance’ arrangements were better described as control measures to aid understanding.</li></ul> <p><b>Consistency and safety through a single, national approach</b></p> <ul style="list-style-type: none"><li>• The panel felt concerned that there could be inconsistency in how local solutions could be designed, implemented and operated. Because of this, the panel were more supportive of a national access model</li><li>• The panel felt there was greater risk of a data breach or cyber-attack if there are more data collection points, compared to a single model delivered nationally</li><li>• The panel were very uncomfortable with the suggestion that more NHS data be placed with private GP system suppliers</li><li>• The panel again reflected their view that a single, national, data model had greater safeguards, was more efficient and in sum was more beneficial. The panel referenced that value for money would be a key consideration to win over public support</li></ul> <p>The group concluded that of the approaches discussed, the design principles set out by the GDPR programme would support the creation of a solution they feel the public would be supportive of.</p> <p>The discussion with the GP Data Patient and Public Engagement and Communications Advisory Group was a useful first step in exploring, and starting to understand, public opinion about the different ways in which GP data could be accessed and used for public good. The team will take on board all feedback and will embed it into any future solution design, which would also be tested again with PPECAP members.</p>
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ENDS