

# Action notes

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

**Date: Thursday 12<sup>th</sup> October 2023**

**Time: 09:30am to 11:00am**

**Location: MS Teams dial in**

<b>Time</b>	<b>Agenda Item</b>	<b>Owner</b>
09:30	Introductions	Matt Howard-Murray (CHAIR)
09:35	Formal review of last minutes	Matt Howard-Murray (CHAIR)
09:40	SDE data access policy update	Senior Policy Lead & Policy Advisor – Data Access and Linking Policy
10:00	Break	All
10:15	Powered by NHS Data case study review	Research and Insight Manager
10:35	FDP portal feedback	Head of Communication and Engagement (FDP)
10:55	Any other business	Matt Howard-Murray

<b>Attendees</b>	<b>Organisation / Department</b>
Eileen Phillips	National Data Guardian
Matt Howard-Murray (CHAIR)	Association of Medical Research Charities / Cancer Research UK
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Understanding Patient Data
Lay member	Independent member
Research and Insight Manager	NHS England
Head of Communication and Engagement (FDP)	NHS England

Lead Analyst for Data Access and Platform Development	NHSE / DHSC Digital Policy Unit
Health data policy advisor	NHSE / DHSC Digital Policy Unit
Senior Policy Lead – Data Access and Linking Policy	NHSE / DHSC Digital Policy Unit
Policy Advisor - Data Access and Linking Policy	NHSE / DHSC Digital Policy Unit

Agenda item	Notes
1.	<p><b>Introductions</b></p> <p>Panel members were welcomed to the meeting by the Chair, who also ran through the agenda.</p>
2.	<p><b>Formal noting of previous meeting's action notes</b></p> <p>The action notes from the 28<sup>th</sup> September 2023 meeting were discussed and approved for publication.</p> <p>The action notes from the 2<sup>nd</sup> March 2023 away day were discussed and approved for publication.</p>
3.	<p><b>SDE data access policy update</b></p> <p>The panel were provided an update by the SDE data access policy team. The team provided the panel with an overview of past engagement of the panel, reflecting how feedback has been taken on board in the development of policy statements alongside broader stakeholder engagement. Colleagues also provided an update on the key messages on the policy development, and what the policies mean for researchers and patients.</p> <p>Panel members queried the integration of social care data within the NHS Research SDE Network. Colleagues informed panel members that teams are working towards including social care data within the SDE Network but this will take time to achieve, adding that the policy team has been engaging with the adult social care team within DHSC to work towards improving access to adult social care data.</p> <p>Panel members asked whether there will be an easy read version of the policy for the public. Colleagues recognised that the policy is technical and agreed in ensuring it is communicated effectively. Colleagues informed the panel</p>

	<p>that there is a public explainer which sets out what SDEs are and why the policy changes are happening. In addition to providing an update on the SDE data access policy, colleagues provided the panel with an update regarding how DHSC is accessing the NHSE SDE and examples of what data has previously been analysed by DHSC.</p> <p>The panel reflected on the development of case studies to communicate how DHSC has used the NHSE SDE, adding case studies should be in plain English and easy to ready for lay people. Panel members also queried the choice in case studies, questioning whether existing case studies are the most effective in communicating to patients and the public. Colleagues took this feedback onboard.</p> <p>The panel also asked why the forward look timelines didn't include when stakeholder and public engagement was planned, and what these plans were. The policy team will use this feedback to improve future updates.</p>
4.	<p><b>Powered by NHS Data case study review</b></p> <p>The Research and Insights Manager presented the draft case study script to the panel.</p> <p>The panel were invited to provide feedback on the script. Overall, the panel felt the script was well written and liked the overall approach.</p> <p>Panel members suggested terminology amendments could be made to put it in plain English, as well as suggesting the use of “scientists” in place of “experts”. The panel also felt that the shorter version of the script needed to have a smoother transition between the problem and the solution.</p>
5.	<p><b>FDP portal feedback</b></p> <p>The Head of Communication and Engagement for FDP sought the feedback of the panel for an engagement portal in development for the FDP. Panel members were taken through the prototype portal to comment on the user journey at each stage, providing feedback along the process.</p> <p>Panel members discussed why it was necessary to capture equality monitoring information to register interest in engagement and to provide feedback. It was explained that completion of the information was optional, and the public could choose to complete some or no questions. It was further explained that the information would help to identify</p>

	<p>trends in views which would inform future communications and engagement activity, as well as ensure future engagement activity was representative.</p> <p>A suggestion was made to sequence the collection of the equalities information after people left feedback or registered interest.</p> <p>The views of the panel were captured and were to be used to refine the development of the portal. The panel were thanked for their valuable input.</p>
5.	<p><b>AOB</b></p> <p>The current rotating chair announced to the panel that Understanding Patient Data will be taking on chairing responsibilities from November.</p> <p>No other points were raised.</p>

ENDS