

OneLondon response to Discover-NOW report

26 March 2021

OneLondon welcomes publication of Discover-NOW report following Citizens Advisory Group deliberation

Discover-NOW, the Health Data Research Hub for Real World Evidence, has published the findings from its first deliberation with a newly formed Citizens Advisory Group. This deliberation, involving 40 participants from north west London, focused on public expectations around the conditions in place for non-NHS partners accessing health and care data in a trusted research environment (TRE).

The recommendations and conditions formed by Discover-NOW's Citizens Advisory Group, build on the outputs of the OneLondon Citizens' Summit on the uses of health and care data, held in 2020.

Importantly, this includes the establishment of the Citizens Advisory Group. This is a direct response to recommendations formed through the OneLondon Citizens' Summit for how the public should be involved in ongoing oversight and development of policy relating to the use of health and care data.

We are pleased to see these recommendations being taken forward so positively and proactively, and in line with what Londoners expect. This reflects the commitment made by London's health and care system to shape policy around data use in a way that is trustworthy and builds public confidence.

It also includes the use of data for research and development, with the Citizens Advisory Group deliberating the conditions in place for non-NHS partners - including universities, commercial organisations, and charities - accessing health and care data in a TRE. Participants set out their expectations in relation to the controls and governance for accessing this data for research, alongside linking de-personalised (non-identifiable) data with other TREs, and ensuring safe outputs.

Luke Readman, Chief Officer for OneLondon and Director of Digital Transformation for London, said:

“Public trust and legitimacy are arguably the most important things when working with health and care data. I am therefore delighted to see the expectations set out by Londoners at the Citizens' Summit being fulfilled through the establishment of a Citizens Advisory Group for Discover-NOW. This is fundamental for building public confidence in this space.”

“This deliberation, focussed on public expectations around the conditions in place for non-NHS partners accessing health and care data in a trusted research environment, offers

important, meaningful insight for Discover-NOW as a Health Data Research Hub. It will also help to inform the implementation of a wider health data strategy for London.”

Link to Discover-NOW Citizens Advisory Group deliberation report:

https://imperialcollegehealthpartners.com/wp-content/uploads/2021/03/Discover-NOW-Citizens-Advisory-Group_Deliberation-1_Report_Feb2021.pdf

Link to more information about Discover-NOW:

<https://imperialcollegehealthpartners.com/discover-now/>