

Agenda and Action Notes

Meeting: GP Data Editorial Review Panel

Date: Thursday, 23rd September 2021

Time: 09:30 to 11:00

Location: MS Teams dial in

Time	Agenda Item	Owner
9.30	Welcomes New focus and name change for the panel.	Chair/ All
9.45	Draft Public Benefit Guidance and panel discussion	Office of the NDG / All
10.15	New web content for GP Data for Planning and Research and panel review	Comms NHS D / All
10.55	AOB/Actions	Chair
11:00	Close	Chair

Attendee name:	Organisation
Communications Lead	NHS Digital
Associate Content Designer	NHS Digital
Lead Technical Architect	NHS Digital
Eileen Phillips	Office of the National Data Guardian
Programme Head GP Data	NHS Digital
Lay member 1	Independent member
Lay member 2	Independent member
Natalie Banner	Understanding Patient Data
Nicola Perrin	Association of Medical Research Charities
Senior Business Support Officer	NHS Digital
Lay member 3	Independent member
Lay member 4	Independent member
Comms Business Partner	NHS Digital
Senior Comms Manager Data *	NHS Digital
Victoria Chico	Office of the National Data Guardian

* Meeting Chair

Minutes

Apologies	Organisation / Department
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 new focus and name change of panel:</u></p> <p>New members and presenters were welcomed and introduced to the group.</p> <p>Members reminded about the Check and Challenge group (reference meeting 9 September). A request has been made asking that someone from this panel should be part of that group so that there is a link between the two.</p> <p>This panel will be commissioned to do work by the engagement and communications workstream and feedback on recommendations and comments will be provided.</p> <p>The amended terms of reference will be shared with panel members in due course.</p> <p>Members were happy with the direction of travel for the panel and were content that input is effective and beneficial.</p>
2	<p><u>Draft Public Benefit Guidance and panel discussion</u></p> <p>Members were given an outline of the process that sat behind the development of public benefit guidance <i>Putting Good into Practice: evaluating public benefit when health and adult social care data is used for purposes beyond direct care</i>. The process to date has included workshops and future consultation is planned. This is outside GDPR but is an example of other programmes that both impact on our work and where we can learn from their activity.</p> <p>It was highlighted that the substance of the guidance falls under three main headings which are proportionality; transparency; and balancing risks and benefits.</p> <p>Discussion held on the guidance included:</p> <ul style="list-style-type: none">• It is difficult to define public benefit, the concept is complicated and hard for the public to understand. It is felt that this guidance will help individuals to understand more about the balance between risk and benefits.• The guidance is good, and it would be very beneficial to see an 'easy read' or have a more accessible version.

- How will you translate it into other languages? Some of the wording could be lost in translation. This is within the plans and the launch of the guidance.
- Transparency obligations are easy to state but can be hard to deliver. It is important to make sure that we not only talk about transparency but also deliver on that and check that it has been received in that way too.
- The guidance is helpful and very timely as it will help to communicate and help people understand more about GP data.
- It is good to see that it is not just a case of promoting benefits only but also highlight where there are commercial interests and benefits and really communicate and reflect on the safety of data.

Feedback received by emails will be sent on to Office of the National Data Guardian.

The draft principles (the work which Healthwatch did pulling findings and recommendations from the Patient Experience Library public attitudes literature review) is currently with NDG and is being looked at and the panel will be updated again on this.

New web content for GP Data for Planning and Research and panel review

Members were informed about the process of updating web copy and how NHS Digital traditionally was aimed at professionals, not the public. Members were updated that the website is a channel where amends can be regularly made.

Comments included:

- Agreed by all the web copy needs to be accessible, in plain English and easy to understand with minimal medical or legal jargon.
 - Members were asked to highlight any areas of the content which could be simplified to help people understand the context better.
- Members expressed their view that the web copy should clearly state that NHS Digital's approach to GDPR had not been successful and that a new approach, with engagement at its heart, aimed to shift the programme considerably.
 - Members were advised that the team have certain parameters that they need to work with and there are certain challenges in the environment we work in.
- It was queried whether there is an option to allow people from the public to add comments or raise questions?
 - Members were advised that it can be considered but at present there is a resource issue which would mean that we would not be able to answer each question raised.
- A member raised whether explanation of the NHSDDataGrab would be a good place to start
 - Mixed reaction from members, with some feeling this would cause further confusion

Minutes

	The NHS website's look and feel was briefly discussed.
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