

# Agenda and Action Notes

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

**Date: Thursday, 28<sup>th</sup> October 2021**

**Time: 09:30 to 10:40**

**Location: MS Teams dial in**

Time	Agenda Item	Owner
9.30	Welcomes	Chair/ All
9:35	Purpose of the group, alignment to other groups and ways of working <ul style="list-style-type: none"><li>• Terms of Reference</li><li>• Action notes</li><li>• Approach and roadmap for future meetings</li></ul>	NHS Digital
10.10	Communications and Engagement update <ul style="list-style-type: none"><li>• Patient principles/recommendations</li><li>• Web copy</li></ul>	Comms Team NHS D
10:35	AOB & Thanks	Chair / All

Attendee name:	Organisation
Comms Lead	NHS Digital
Lay member 1	Independent member
Eileen Phillips	Office of the National Data Guardian
Programme Head GP Data*	NHS Digital (Chair)
Lay member 2	Independent member
Lay member 3	Independent member
Natalie Banner	Understanding Patient Data
Grace Melvin	Association of Medical Research Charities
Senior Business Support Officer	NHS Digital
Communications Team Member	NHS Digital
Research Manager	NHS Digital
Representative	Use My Data

Representative	Use My Data
Representative	Healthwatch

\* Meeting Chair

Apologies	Organisation / Department
Lay member 4	Independent member
Lay member 5	Independent member

Agenda Item	Notes (record summary of discussions and decisions)
1	<p><b><u>Welcome</u></b></p> <p>New members joining the panel were introduced to the group.</p>
2	<p><b><u>Purpose of the group, alignment to other groups and ways of working</u></b></p> <p>Members were informed about how the four different advisory groups will fit together and their purpose. The four groups are:</p> <p>4 different groups are:</p> <ul style="list-style-type: none"> <li>• Check and challenge advisory group (fortnightly meeting). The group provides advice and guidance from the perspective of GP profession and data usage communities.</li> <li>• Patient and public engagement and communications advisory group (fortnightly meeting). The group provides guidance and advise from the perspective of patients and public.</li> <li>• Information governance expert liaison group (fortnightly meeting). This group provides specialist IG advice.</li> <li>• Research advisory group (bi-monthly). This is a broader group that provides advice and guidance from the perspective of the research community.</li> </ul> <p>An overview of how this group will work going forward was highlighted, this included the frequency of meetings and action notes being published to aid transparency and visibility.</p> <p>Members were advised that future meetings will be targeted on specific topics to support the programme deliverables and clearer dates will be shared with the group in due course. It was highlighted that a detailed roadmap will be produced and shared.</p> <p>Members were informed that the advisory groups are being aligned to maintain openness and transparency. Members were also advised that the terms of reference document will be updated with this information. The alignment will also ensure that each group works in tandem and any differences in feedback are picked up. The minutes will become summary and action notes which will make it easier to feed back into the different groups. The previous minutes will be updated to be action notes before they are published.</p>

**ACTION:** Communications Team to update the previous meeting minutes to action notes for publication.

It was queried how the groups feed into each other and connect? Are there common members between groups in terms of lay members?

Members were informed that different groups bring different perspectives and are fed into the Programme Board. Groups have been kept separate to enable open and detailed conversations. Any tensions and/or differences in groups will be addressed using a roundtable approach. Members were reassured that the groups are linked and not operating separately.

Feedback from members included:

- The level of transparency in action notes was very good. It is good to see specific questions being raised and addresses without attaching them to individuals. It shows that the group is picking up and discussing issues and is reassuring.
- It is good to see that changes were adapted in the terms and references when members' expressed opinions. This is very important to the group.
- It is important to capture the feedback loop and is the approach we would like to maintain going forward.

**ACTION:** The terms of reference and example action notes document to be shared with the new group members.

It was highlighted that action notes will be published as soon as they are ready following meetings. Members emphasised that there is a critical need for the previous minutes/action notes to be published as soon as possible which will aid transparency.

It was questioned if there is a patient representative at Board level for the patient voice? Who the group representatives at Board are? Members were advised that this is not the approach that has been taken on this occasion but can be taken back and picked up with the SIRO.

**ACTION:** Programme Lead to pick up with the SIRO whether representatives from each group should be represented at the programme board.

Members were informed that the approach taken is that the programme board brings together the NHS leaders to check that the different groups are coming together to achieve the deliverables and looks at the risks and issues.

Brief discussions took place around how the patient voice is often excluded and that it is important to include that otherwise it can lead to an immediate disconnect.

**ACTION:** Programme Lead to see what options are available for the patient voice to be included and represented at board level.

AMRC queried how confidential the content shared within the group is and whether it would be allowed to be shared more widely for comments? It was emphasised that content shared with the group is in confidence and should not be shared further. However, where it is considered more beneficial for content to be shared further for comments from partners, it will be made clear. It was also highlighted that this group falls under Chatham House rules therefore anything said in this group is confidential.

It was reiterated that it is important that action notes are kept in plain English and that the right language is used to enable a better understanding.

**Communications and Engagement update**

Members were provided an update on the patient principles which have previously been discussed in group. The patient principles have been brought into the programme as they apply to GP data but also apply to data in general, therefore, have been passed onto NHSX as the policy arm. NHS X have been asked to look at the principles and to feedback more widely. NHSX have been requested to join a future meeting to feedback on this more formally.

It was queried whether the principles will form part of the data strategy? It was highlighted that it is too early to say at present, but it is the principle on which they were shared with NHS X. A short background summary was given to new members highlighting how the principles came about.

**ACTION:** Healthwatch representative to share the patient principles document with new members who have joined the group.

It was highlighted that the web copy has been through several iterations and a lot has been learnt from this and has received a lot of feedback. Members were informed that the document was no longer fit for purpose once all comments were incorporated from other groups. A new web copy was produced which used the same language and was in line with all feedback received. Member were asked for further comments rather than re-writing the content.

Comment from members included:

- The tone of the content is very good and relatively clear.
- Concerns around patient security and how it will be protected from third parties?
- Need to get the message across about why it is important to share data and get the public to understand what a patient feels.
- Content flows well, links are useful and is understandable.
- It would be useful to include the word 'choice' to reassure people that they have options available them.

Member briefly discussed whether a public representative was needed in the group. Discussions indicated that it would be difficult to find someone who has not been a patient or knows a patient, therefore brings a public voice only.

Members asked how the web copy was being shared and advertised to others? It was highlighted that the web copy is being shared with GP and research

	<p>communities through newsletters and bulletins. Members recommended that the web copy is shared with trade and national journalists to attract some coverage. It is important that more of the public know about it for transparency. Members were advised that the website will be regularly updated with information and content.</p> <p>We should encourage people to disseminate it through their own channels to different communities to make people aware of it.</p>
	<p><b><u>AOB &amp; Thanks</u></b></p> <p>The meeting was drawn to a close following thanks to a member who was leaving the panel for pastures new.</p>

- End -