

Action notes

GP Data Patient and Public Engagement and Communications Advisory Panel

Date: Thursday 27th of October 2022

Time: 09:30am to 11:00am

Location: MS Teams dial in

Time	Agenda Item	Owner
9:30	Introductions	Grace Melvin
9:40	Formal noting of previous meeting's action notes	Grace Melvin
09:50	Programme update	NHS Digital
10:00	General Practice Extraction Service (GPES) process feedback	NHS Digital
10:10	Drumbeat amplification campaign	NHS Digital
10:50	AOB	Grace Melvin

Attendees	Organisation
Grace Melvin (CHAIR)	Association of Medical Research Charities (AMRC)
Eileen Phillips	National Data Guardian
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Lay member	Independent member
Dave Chuter	use MY data
Rebecca Moore	Healthwatch
Communications and Stakeholder Engagement Manager	NHS Digital
Head of Communications and Engagement	NHS Digital
Project Manager	NHS Digital
Assistant Head of Communications	NHS Digital

Apologies	Organisation
Business support	NHS Digital
Lay member	Independent member
Lay member	Independent member

Action notes

Agenda item	Notes
1.	<p>Introductions</p> <p>The Chair led a round of introductions for the new members to the Panel.</p> <p>Panel members were welcomed to the meeting by the Chair, who ran through the agenda and planned discussion points.</p> <p>Apologies were noted.</p> <p>The Chair summarised the updates to the terms of reference for the Panel, discussed in the previous meeting:</p> <ul style="list-style-type: none"> • Apologies are to be noted 48 hours before the meeting • Lay members to be assigned a buddy • A new addition to the terms of reference has been added since the last meeting: A threshold for the number of consecutive missed panel meetings will be introduced (however it will be taken into consideration that extenuating circumstances will be reviewed on a case-by-case basis) <p>The updates were noted and agreed by the Panel.</p>
2.	<p>Formal noting of previous meeting's action notes</p> <p>The action notes from the 13 October 2022 meeting were agreed as an accurate reflection of the meeting and approved for publication.</p>
3.	<p>Programme update inc. Q&As</p> <p>The Head of Communications, for GP Data for Planning and Research confirmed that a new Secretary of State for Health and Social Care, Steve Barclay, has been appointed (he previously served as Minister of State for the Department of Health and Social Care from January - November 2018, and again from 5 July 2022 – 6 September 2022) and will be briefed in due course. A briefing paper will be presented at the NHS private board next week for agreement on the direction of travel of the Direct Care work.</p> <p>The following questions were raised by the panel and responded to by the Head of Communications, for GP Data for Planning and Research:</p> <ul style="list-style-type: none"> • <i>Once the Ministerial meeting has happened, will there be clarity for the programme?</i> The briefings are to ensure that the relevant Ministers are aware of our agreed approach and direction of travel and to reconfirm the programme's position.

Action notes

- *Do we know if Steve Barclay will be focused on data or will data be more of a focus area for junior ministers?* Steve Barclay is expected to have an interest in data (and has previously shown interest when in other roles), however, historically data has been a responsibility of a junior minister with some engagement from the Secretary of State for Health and Social Care. NB: Since this meeting was held, Lord Markham has been confirmed as the minister with responsibility for this area.
- *Would it be possible to get some feedback post the briefing on the impact and effectiveness of the PPECAP?* Yes, the panel will be updated at a future meeting.
- *Are the [Ministerial commitments](#) for GDPR being considered and delivered as part of the Direct Care work?*
The commitments were specifically made in relation to the GDPR programme, but where they apply to the Direct Care work we will still follow the same principles.. Like GDPR, we are committed to working closely with our key stakeholders and programme assurance groups to assure our approach, both in terms of programme design and to help us shape our communications approach.
- *Will there be further links between Direct Care and GDPR in the future?*
 The technical solution for direct care, is an adapted version of the technology that could be used to flow data for planning and research purposes. However, the focus currently is on using it for Direct Care only. No data will flow for planning and research purposes until the Ministerial Commitments for this work have been met.
- *How does GPES provide data for research?* GPES provides mostly aggregate data, which is analysed and produced for a single purpose. It also produces some identifiable data for Direct Care purposes, such as for Covid vaccinations. There are limitations around the data it can process and access. . The only data that GPES accesses for research is data to support, Cardio Vascular Disease (CVD), Physical Health Checks SMI (PHSMI), Learning Disabilities Data (LDD) and research into Covid.

The Head of Communications, for GP Data for Planning and Research continued with the update and provided an overview of the [GDPR communications strategy](#), which is based on building trust through transparency.

Phase 1 – Assurance - Define the scope of the communication and engagement approach

Phase 2 – Listening - Listen to people’s views and concerns

Phase 3 – Engagement - Engage and involve the public, patients and health professionals in shaping the approach

Phase 4 – Delivery - Demonstrate how we have responded to what we have heard

Phase 5 – Demonstration - Ensure the public is well informed about the improvements.

Action notes

	<p>She confirmed that the research findings and end of phase reports for phases one and two have been published on NHS Digital's website.</p> <p>It was confirmed that the programme is currently in the engagement phase.</p> <p>The Chair commented that with the expansion of the PPECAP, to include more lay members, there is a better representation of the voice of patients and the public.</p> <p>Further questions were raised by the Panel and responded to by the Head of Communications, for GP Data for Planning and Research:</p> <ul style="list-style-type: none"> • <i>Is the report for the listening phase generating engagement with the public?</i> The programme blogs are performing well and regularly receiving over 1000 views per blog. In terms of web content, the web stats weren't readily available, but the Communications and Stakeholder Engagement Manager offered to bring these back to the Panel and shared that the PPECAP webpage is one of the most viewed of the GDPR webpages. • <i>Does the information about opting out, also contain details of how people can opt back in?</i> The Communications and Stakeholder Engagement Manager confirmed that the pages providing information about opting out also provided information about how to opt back in. In terms of the opt-out report, that was recently published as part of the GDPR programme, an action was taken away to check that that it included links to information on how to opt-back in.
<p>4.</p>	<p>General Practice Extraction Service (GPES) process feedback</p> <p>The Assistant Head of Communications thanked the Panel for the feedback received, lots of useful input was provided. He clarified that the web content about the GPES process, that was shared with the Panel, is the existing web content, only the diagram has been newly developed. The input of the Panel will help to improve the information around GPES.</p> <p>The Assistant Head of Communications then gave a quick overview of GPES for new members.</p> <p>The Panel had some questions following the update, which were answered by the Head of Communications for the GDPR programme:</p> <ul style="list-style-type: none"> • <i>Is it possible to opt-out of GPES extracts?</i> A type 1 opt-out is held at the GP practice. It is applied to stop data from leaving the GP practice for purposes beyond your direct care, however, it is not possible to opt out of Direct Care. Patients can opt-out of the sharing of identifiable data for all other purposes. In terms of the Direct Care data, a patient can request to not be contacted for screening appointments (for example), but that will not stop the data flowing. Opting out of receiving these communications

Action notes

	<p>would mean that the patient does not receive the Direct Care from which they would benefit.</p> <ul style="list-style-type: none"> ➤ <i>Is there any public involvement in the GPES process?</i> Input on the GPES processes comes largely from the GP profession (represented by the BMA, and RCGP). The GPs perspective, and agreement to work with the GPES system is key to its operation. It was noted that when GPES was created, over 10 years ago, public communications and engagement was not embedded as best practice, particularly as the system then collected aggregate data, meaning data privacy is ensured. However, time has moved on and communications and engagement is now recognised as a key element of any changes related to the collection and use of patient data. <p>The Assistant Head of Communications shared that the structure of how patient data is held in IT systems run by GP System Suppliers (GPSS) was met by some surprise when the diagram was initially presented.</p> <p>There was a request to receive an update, and have a conversation, about the commercial arrangements around GP data and some of the wider flows of GP data beyond the NHS. It was agreed this would be covered at a future meeting.</p> <p>The Head of Communications made it clear that any commercial arrangements or wider GP data flows, that are not managed by NHS Digital are out of the scope of the GDPR programme or the direct care project but confirmed that the topic would be revisited at another session for information and to build the group's understanding.</p>
<p>5.</p>	<p>Ambient campaign</p> <p>The Communications and Stakeholder Engagement Manager delivered a presentation to update the Panel on progress with the 'Ambient data campaign' – a digital campaign to inform the public about how data is used, and the benefits derived from its use. The panel were given a re-cap of the purpose of the campaign and the work done to date, and the findings from the recent public testing of the three concepts was shared.</p> <p>The testing took place with members of the public, a representative sample of 600 individuals, and was completed via a 15-minute online survey. Respondents were asked a series of questions about the campaign, were able to mark up the elements of the creative and language that they liked and disliked.</p> <p>The findings have been used to develop a single concept, which was shared with the group.</p> <p>The campaign was well received, and it was commented that the explanation of how data is used, and the benefits covered in the campaign is very powerful.</p> <p>The panel had the following questions and comments which the Communications and Stakeholder Engagement Manager responded to:</p>

Action notes

- *Will Facebook reach older audiences?* No channel will reach 100% of every audience, however over 60% of those aged 60 or over use Facebook, with over 70% of 50-54 year olds active on the platform. It was confirmed that whilst the campaign would be predominantly digital, it would be supported by posters and videos being displayed in clinical settings and there is scope to extend the campaign onto additional channels if budget is available.
- *Can partners leverage the campaign?* Yes, it has been designed so that the campaign mark can be used by incorporated into the communications of other organisations to create a connection to the campaign and show the many positive ways that NHS data is used.

The panel advised that it would be sensible to engage with charities early on. It was confirmed that the initial concepts have already been shared with some partners and further engagement was planned.

- *Will there be a variety of faces to include more diverse patients and how will this accommodate members of the public with learning difficulties?* Yes, at least three initial case studies will be developed to appeal to key audiences.

One member of the Panel reflected that the black and white campaign imagery could be seen as monotone.

It was suggested that Snapchat and Twitter are good platforms to engage with younger generations. It was confirmed that there would be organic posts on Twitter but no paid adverts, unless additional budget become available. If that is the case, other channels would also be considered, such as YouTube which has good reach for the key audiences.

Next steps were outlined as:

1. Gain executive approval at NHS Digital
2. Develop the additional case studies
3. Aim for a pre-Christmas launch
4. Socialise it with other NHS teams to gain support and have them collaborate with GDPR
5. Gain support and engage with partners and charities so that the campaign mark can be used in relevant materials.

The chair requested that the campaign materials be re-visited with the Panel before launch. It was agreed this would happen.

6.	<p>AOB</p> <p>The Chair asked that members contact the Communications and Stakeholder Engagement Manager to suggest new agenda items.</p> <p>No further points were raised.</p>
----	--