

# Action notes

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

**Date: Thursday 13<sup>th</sup> of October 2022**

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

**Location: MS Teams dial in**

Time	Agenda Item	Owner
9:30am	Welcome and introductions	Eileen Phillips
9:35am	Formal noting of previous meeting's action notes	Eileen Phillips
9:40am	Programme update inc. Q&As	Programme Manager
10:00am	Improving how we talk about the General Practice Extraction Service	Head of Information and Analytics and Assistant Head of Communications
10:30am	PPECAP Terms of Reference	Communications and Stakeholder Engagement Manager
10:40am	AOB	Eileen Phillips

Attendees	Organisation
Eileen Phillips	National Data Guardian (Chair in absence of Grace Melvin)
Lay member 1	Independent member
Lay member 2	Independent member
Dave Chuter	use MY data
Rebecca Moore	Healthwatch
Communications and Stakeholder Engagement Manager	NHS Digital
Project Manager	NHS Digital
Programme Manager	NHS Digital
Assistant Head of Communications	NHS Digital
Head of Information and Analytics	NHS Digital

Apologies	Organisation
Grace Melvin	Association of Medical Research Charities (AMRC)
Business Support	NHS Digital

# Action notes

Apologies	Organisation
Lay member 3	Independent member

Agenda item	Notes
1.	<p><b>Introductions</b></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 for Grace Melvin, the Business Support Officer and Lay member 3</p> <p>Panel members, who had not already done so, were encouraged to complete the survey, which had been circulated to gather their views about a possible face-to-face meeting.</p>
2.	<p><b>Formal noting of previous meeting's action notes</b></p> <p>The action notes from the 29 September 2022 meeting were agreed as an accurate reflection of the meeting and approved for publication.</p>
3.	<p><b>Programme update inc. Q&amp;As</b></p> <p>The Programme Manager for GDPR opened the floor for questions following the information presented in the last meeting around GP data for planning and research (GDPR) and the proposed direct care work.</p> <p>No questions were asked.</p> <p>The Programme Manager for GDPR reiterated the position set out at the previous meeting regarding the progression of the GDPR programme, stating that whilst work will continue towards the ministerial commitments for the GDPR programme, the priority this financial year is focused on resolving the issues for direct care data.</p> <p>He further updated that a formal mandate to progress the direct care solution is being pursued in parallel with engaging key stakeholders. A Strategic Delivery Board has been established, to develop the proposal, and will meet for the first-time w/c 17 October to support driving the project forward, whilst a briefing for Ministers is also developed. To date this is a proposal until we have formal sign off.</p> <p>A more detailed explanation of the technology and process for data collection was given by the Programme Manager. He noted that focusing on direct care, compared to GP data for planning and research has a significant impact on the</p>

# Action notes

volume of data to be collected. The GDPR programme would collect over 1 million data codes, the collection for direct care is very targeted and therefore significantly smaller – only 32,000 codes would be collected for direct care.

He provided a more detailed overview of the direct care work confirming that:

- The project is focused on upgrading the technology used to collect data to support patient's direct care. Coded data is already collected and used to identify patients and to invite them for screening, tests and treatments which will benefit them personally, for example vaccines.
- There are currently six specific use cases for which we collect data for patient care, however our process is not as efficient as it could be and the current model of collection is expensive. For those six purposes we might collect the same code and identifiable data six times, because GPES works on the basis that you collect the data again, every time you have a new purpose.
- The proposed approach will move away from individual data collections, and replace them with a consolidated single data collection, which will collect and store the data in a pseudonymised form, only re-identifying it when it needs to be used for one of the agreed purposes.
- The data dissemination will be the same data, in the same format, to the same recipients, for the same purposes as are shared now. The protections around these disseminations will remain the same.
- The data collected, processed, and shared, will always be for a specific purpose and shared with a specific recipient, for the purpose outlined in the Direction and Data Provision Notice and for nothing else – as is the case now.

The Panel queried the timeline for the work, and it was noted that a solution for direct care is needed as soon as possible, however in reality the delivery will take some time and is dependent on the GP system suppliers committing to doing the work. These conversations are currently taking place. Additionally, Ministerial approval is required before the work can proceed.

The Panel also asked how this technology change would impact patients who are diagnosed with new conditions, i.e. would new codes be added to the collection so that they received the right care. The Programme Manager responded that, the SNOMED codes collected vary slightly over time based on the definition of the data cohort. If a new condition becomes a factor influencing a patient being included in a specific cohort, then the collection would be amended. This is decided by NHS England. The Panel were informed that details of all the data collected via GPES, and the process for doing so, are published on the NHS Digital website here: [General Practice \(GP\) Collections - NHS Digital](#)

The Panel, reflecting on the update, noted that clear and simple public information was needed, and that this would be challenging. The Communications and Stakeholder Engagement Manager shared that initial work on the messaging was underway and noted that the communications and

# Action notes

	<p>engagement workstream would be drawing on the support of the Panel to help shape the public communications.</p> <p>The availability of data for research purposes was noted by the Panel and the impact of this queried. It was confirmed that conversations are taking place with the research community to explain the need to focus on direct care as a priority.</p> <p>The use MY data representative shared their view that the research community are eager for good, detailed data, and shared their concern that any restriction at scale may hamper research.</p> <p>The Programme Manager offered some assurance that there are some existing data flows already available for research purposes. Owing to limited time being available to explore this further within the meeting, it was agreed that the Programme Manager would arrange to meet with the use MY data representative to discuss it further.</p> <p>The final update was to inform the Panel that a report, summarising the findings from user testing of a prototype Type 1 Opt-out digital service (which has previously been presented to this panel) has been published, supported by a corresponding blog. Both have been published on NHS Digital's website here:</p> <p>Link to report: <a href="https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/gpdpr-programme-reports-and-publications/type-1-online-service-report">https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/gpdpr-programme-reports-and-publications/type-1-online-service-report</a></p> <p>Link to blog post: <a href="https://digital.nhs.uk/blog/data-points-blog/2022/what-we-discovered-when-designing-an-opt-out-service">https://digital.nhs.uk/blog/data-points-blog/2022/what-we-discovered-when-designing-an-opt-out-service</a></p> <p>The panel enquired how many views these two publications have had. It was confirmed that both were published in the past 24hrs, so reach was in its infancy, however both are being shared proactively across social media channels and engagement is being monitored. The Communications and Stakeholder Engagement Manager for GDPR updated the Panel that on average, to-date, the series of blogs related to the GDPR programme, are achieving around 1000 views each, which was news welcomed by the Panel.</p>
<p>4.</p>	<p><b>Improving how we talk about the General Practice Extraction Service</b></p> <p>An overview of the General Practice Extraction Service was provided by the Head of Information and Analytics before the Assistant Head of Communications briefed the Panel on work that's taking place to improve the information about the service on NHS Digital's website.</p> <p>He shared a flowchart that had been designed to help support the written explanation of the process on the website. The aim is to make the website information clearer and more understandable, and he sought feedback from the Panel on the flowchart.</p> <p><b>Summary of feedback</b></p>

# Action notes

	<p>One panel member commented that the diagram alone could be difficult to understand for some individuals who are neurodiverse, and that it would be preferable to have the process written out alongside the diagram. It was confirmed that this information is already available on the website, and the flowchart was being developed to sit alongside that.</p> <p>In relation to ‘independent panel’ referred to in the checkpoint step, there was an ask for this to be clarified, in terms of its memberships and function.</p> <p>Some concern was raised about some of the language being used in the flow chat, and it was felt that if left as shown, it would be a distraction to the other information. It was agreed that the terminology would be reviewed.</p> <p>There was a query about the relationship between GPES and the GP records being made available to patients. Clarification was given that these are completely separate pieces of work.</p> <p>It was agreed that the flow diagram would be shared with the Panel to review further and provide feedback by 26 October, ahead of the next meeting. It was agreed that it would be circulated along with the website copy so that Panel members could see the context in which it would be used.</p>
<p>5.</p>	<p><b>PPECAP Terms of Reference</b></p> <p>A version of the amendments was shared with Panel members prior to the meeting. The Communications and Stakeholder Engagement Manager for GDPR presented the proposed updates.</p> <p>The following changes were highlighted:</p> <ul style="list-style-type: none"> <li>• All references to GDPR have been updated to include the scope of the proposed Vaccines, Treatments and Screenings (VTS) project</li> <li>• The background section has been expanded to include the VTS project</li> <li>• In section 4, the method of operation now includes the rotating chair every 4 months.</li> <li>• The quorum has been increased to the chair and 5 public or patient members, including the use MY data representative (due to the expansion of the number of patient and public members on the panel) to strengthen the voice of patients and the public.</li> <li>• Wording has been updated around acceptable conduct and behaviours.</li> <li>• A new section, 4.5, has been added to reflect that a declaration of interest will be asked at the start of each meeting. This is to be aware of the conflicts of interest as some people sit on more than one panel and aligns with all other stakeholder assurance groups.</li> <li>• The confidentiality section now references the responsibility of Panel members to review the notes and, where appropriate, to give feedback in the meeting (or via email if they are not in attendance for the next meeting), so that the meeting notes can be published.</li> <li>• There will be a programme board for the new VTS project which will be referenced in section 4.7 when the terms of reference have been agreed.</li> </ul>

# Action notes

	<p>The panel were supportive of the changes proposed, and they were agreed. In support of the change in quorum, it was suggested that a minimum notice period of apologies to be sent should be added, so that any issues with reaching quorum was known ahead of the meeting and could be proactively managed. It was agreed this would be added.</p> <p>It was also suggested that new Panel members be offered a 'buddy' from the existing membership, to support and welcome new members to the Panel. This suggestion was warmly welcomed, and Communications and Stakeholder Engagement Manager thanked members for the suggestion. It was agreed this would be reflected in the document.</p>
<p>6.</p>	<p><b>AOB</b></p> <p>It was noted that further to the discussion about the Secure Data Environment (SDE) in the last meeting, the SDE team have been invited to attend a future meeting and will give a presentation on their progress.</p> <p>No further new suggestions for future agenda items were put forward and no further points were raised.</p>

ENDS