

# Action notes

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

**Date: Thursday 19 January 2022**

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

**Location: MS Teams dial in**

| Time  | Agenda Item  | Owner        |
|-------|--|--------------|
| 9:30  | Introductions  | Grace Melvin |
| 9:35  | Formal noting of previous meeting's action notes                         | Grace Melvin |
| 09:40 | Programme update   | NHS Digital  |
| 10:15 | Comfort break  |              |
| 10:20 | Findings from the audit of information about patient data on GP websites | NHS Digital  |
| 10:45 | Ambient campaign update  | NHS Digital  |
| 10:50 | Any other business   | Grace Melvin |

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

# Action notes

| Apologies  | Organisation       |
|------------|--------------------|
| Lay member | Independent member |
| Lay member | Independent member |
| Lay member | Independent member |
| Lay member | Independent member |
| Lay member | Independent member |

| 12 | Notes   |
|----|---|
| 1. | <p><b>Introductions</b></p> <p>Panel members were welcomed to the meeting by the Chair, who also ran through the agenda.</p> <p>Apologies were noted.</p>   |
| 2. | <p><b>Formal noting of previous meeting's action notes</b></p> <p>The action notes from the 8 December 2022 meeting were agreed and approved for publication.</p>   |
| 3. | <p><b>Programme update</b></p> <p>The Head of the GDPR Programme gave an update on the status of the programme, the challenges with direct care and challenges related to GP data more broadly.</p> <p>She started by welcoming the new members to the panel, emphasised the important work that the PPECAP supports, and expressed her thanks for the commitment and contribution of the panel.</p> <p>She reflected on the substantial progress made against the ministerial commitments, which were made in July 2021. She explained that we are working with the Check and Challenge Group to confirm progress to date and the appropriateness of designs, which we will publish. Key points to note are:</p> <ol style="list-style-type: none"> <li><b>Design of a digital type 1 opt-out service</b> which, if implemented, would make it quicker and easier for patients to apply that choice, by providing a self-serve option. This in turn, would also reduce the burden on GPs.</li> </ol> <p><b>Q) Will there be a review of opt-outs? Does that need a Ministerial decision?</b></p> |

# Action notes

*A) This question will be referred to the NHS policy team who are responsible for decisions regarding opt-out policy, but a review of opt-outs was committed to in the Data Saves Lives strategy.*

*Response from the Policy Team – provided 23.2.23:*

*A commitment to review opt-outs was made in the Data Saves Lives Strategy.*

*We will work with the public, the expert advisory group, the National Data Guardian (NDG) and other stakeholders to ensure that we have a simple opt-out system in place that provides clarity and choice, giving patients confidence, and ensuring data continues to support the functioning of the health and care system.*

2. **Retrospective deletion** - Technical design developed, to enable data to be deleted from the Secure Data Environment from the TRE when a patient applies a Type 1 opt-out, including when that data has been collected prior to the opt-out being submitted.
3. **Trusted Research Environment** (now known as Secure Data Environments) – NHS Digital’s Secure Data Environment is now in private BETA phase. A [blog](#) by Michael Chapman (NHS Digital’s Director for Research and Clinical Trials) about TREs (SDEs) was shared with the panel.
4. **The opt-out backlog has been cleared.** A report confirming this is being prepared for publication.

**Q) Does the clearing of the backlog of opt-outs from 2021 mean that a large number of the public are now opted-out?**

*A) The clearing of the backlog means that all requested opt-outs have been applied. A total of 2,099,991 type 1 opt-outs have been applied, which is 3.5% of people registered at a GP practice. The number of applied national data opt-outs is 3,343,294, which is 5.4% of the population.*

5. **Comms and engagement strategy** - The [Listening phase](#) and [Assurance phase](#) are complete, and reports summarising the learning from each phase have been published. The Engagement phase has not yet started. It was confirmed that the PPECAP would be engaged in the development of plans for future comms and engagement phases, and in the development of communications for the public.

**Q) When will there be a campaign to reassure and build trust with the public about the programme?**

*A) Future phases of the communications and engagement strategy will focus on understanding stakeholder needs, campaign development, and the cocreation of materials with the PPECAP and other stakeholders. This will culminate in the delivery of a public campaign aimed at ensuring the public are aware, informed, and understand their options regarding how their data is used.*

**General questions raised:**

# Action notes

**Q) Can data be shared with insurance companies?**

A) No. Data is not shared with insurance companies unless an individual has given consent for their data to be shared. Patient data can only be collected where there is a legal basis to do so, and used for the stated purposes as outlined in the [Direction](#).

**Q) What is the cost of data sharing?**

A) The NHS operates a cost recovery model regarding data sharing, data is never sold for profit. This means that NHS funding, derived from taxpayers, isn't being used to facilitate the use of data for research and planning purposes. There are strict controls in place that govern access to data which is managed by the [Data Access Request Service \(DARS\)](#). Details of data sharing agreements, and charges are published on NHS Digital's [website](#).

**Ambient communications**

Progress to date was noted. It was confirmed that a spokesperson is being sought to support this work.

**Consideration of NHS structural changes**

The panel were informed that since the GDPR programme was designed and launched, the NHS has embarked on a significant programme of change in terms of its operating model. In June 2021 42 [integrated care boards](#) were established to empower local areas to more closely integrate health and social care.

The head of the GDPR programme shared that that this change needs to be reflected in our thinking about how we design a solution to facilitate the use of GP data for planning and research purposes.

Regardless of how realising the use of GP data for planning and research purposes is brought to fruition, NHS England is committed to working openly and transparently, supported by effective communications, to inspire public trust in how patient data is used. However the technical challenge is solved, there is no intention to move away from the Ministerial commitments for GP data.

**Q) Will the GDPR programme address the inconsistencies in how GP data is currently shared?**

A) Yes, *GDPR seeks to provide consistency and standardisation, reducing the flows of data around the system, so that one data flow is in place which then transparently shows how it is used.*

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| <p>4.</p> | <p><b>Findings from the audit of information about patient data on GP websites</b></p> <p>An overview of the findings from a recent audit of 55 GP websites, which looked at the information provided to patients about how their data is stored and used, was shared. It was noted that there were similar findings from an audit of NHS trust websites undertaken by a team outside of the GDPR programme. The</p> |
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# Action notes

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|           | <p>report of findings will be published on NHS Digital's website (the report is now live <a href="#">here</a>).</p> <p>It was confirmed that the findings would be used to inform further research. The panel recommend that clear guidance needs to be provided to GP practices. This recommendation will be shared with the relevant team.</p> <p>It was agreed that a further update would be provided to the panel on this area of work.</p> <p>The discussion led to a query about how patients would know if they have full access to their patient record (as part of the accelerating citizen GP data initiative). A response to this will be sought from the team working on this and shared with the panel.</p> |
| <p>4.</p> | <p><b>Update on the ambient campaign</b></p> <p>This item was covered under the programme updated. Link to notes <a href="#">here</a>.</p>  |
| <p>5.</p> | <p><b>AOB</b></p> <p>The Communications and Stakeholder Engagement Manager for GDPR thanked the Chair, Grace Melvin, for her contributions to the Panel and wished her good luck in her new role!</p> <p>The Panel thanked Grace for her commitment and hard work and wished her all the best for the future.</p> <p>Rebecca Moore from Healthwatch will take over as Chair from the next meeting, for a four-month rotation.</p> <p>No further points were raised.</p>   |

ENDS