

GP Data for Planning and Research
Check and Challenge Group
Minutes of the meeting held 24th November 2021
Final – Approved for publication

Attendees

Name	Organisation	Name	Organisation
Anu Rao	British Medical Association	Ian Diamond	Office for National Statistics
David Parkin	British Medical Association	Alison Pritchard	Office for National Statistics
Ruth Ellenby	Royal College of General Practitioners	Ben Goldacre	Nuffield Department for Primary Care Health Sciences
Nicola Byrne	National Data Guardian	Nicola Perrin	Association of Medical Research Charities
Tim Donohoe Chair	NHSX (Programme SRO)		
NHS Digital Programme Team Representatives			
Further representatives from: <ul style="list-style-type: none"> • Office of the National Data Guardian (1 attendee) • NHSX (1 attendee) • Information Commissioners Office (1 attendee) 			

Actions & Decisions Recorded

Action ID	Description	Owner	Target Date
CAC-A002	Roadmap document reviewed, with members encouraged to add and suggest additional items or to request information at different time to support their active involvement	All Members	Ongoing
CAC-A004	Action updated Provide feedback on comms and engagement topics discussed at meeting, as required	All Members	8/12/2021
CAC-A005	Programme to update and circulate roadmap document monthly	Programme	Ongoing
CAC-A007	Consider and review draft Programme Objectives document, and provide feedback, enabling the programme to shape objectives around stakeholder views throughout programme delivery	All Members	Ongoing

Meeting Notes

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Introductions

- Meeting opened and members welcomed
- Review of previous session and agenda outlined

Comms & Engagement Assurance Report

- Group discussion held on initial work undertaken to develop the programme communications and engagement approach, and interviews held to provide input and assurance against this approach
- It was noted and acknowledged that the initial work has been very much driven by the programme, and going forward real opportunity for stakeholder input needs to be provided to allow this to influence the overall direction and progress
- There was a follow-on discussion about how it can be ensured that all types of stakeholder groups are represented, and that discussions are fully captured and made visible to all stakeholders. There was broad agreement for this approach, and member feedback would be welcomed on how this should be undertaken, or which groups are currently not fully represented. The programme confirmed that they are capturing the changes they make as a result of feedback and that they are developing the engagement strategy, which will provide more detail and will come to this group.
- Appreciation was noted that a thorough presentation by the Programme SRO was given to a wider ONS audience regarding data sharing. Further close working is expected in this area

Opt-outs Programme Objectives Overview

- Spotlight discussion on the items in the Letter to GPs which relate to opt-outs and some key discussion points raised:
 - Understanding the overall quality and usability of the data collected depends on gaining further understanding into the numbers and demographics of those who have registered an opt-out. This may determine how much the data can be used to benefit the country, and should be built into the programme planning
 - The timeframe regarding the delivery of the programme and the retirement of the Type 1 opt-out is extremely important. It was noted that the letter to GPs deferred the retirement of Type 1s by at least 12 months from July 2021, therefore more understanding regarding this is needed to ensure that timeline and stakeholder opinions are carefully considered

- It was noted that patients should be specifically advised on the implications and what would be involved if they were to reverse their opt-out decision and opt back in. It is vital that clarity is provided to patients as this could be a complex area
- It was noted that the current number of Type 1 opt-outs is not known due to the nature of the opt-out solution, which means that the data on numbers does not flow centrally.
- It was acknowledged that retrospective deletion of patient data (where opt-outs are registered after data collection has started) would only be possible if data fully resides within a TRE. As per the commitments in the ministerial letter, it is expected that all data will be stored in a TRE unless part of a consented cohort for a specific project
- A full discussion on retrospective deletion is planned for this group in early 2022 and was welcomed
- As per existing action CAC-A007, stakeholders are invited to provide any feedback regarding the content, focus or question areas associated with this topic or on the wider list of programme objectives distributed

Opt-out Type 1 Service Spotlight

- Spotlight presentation and discussion held on the discovery work for potential Type 1 service solutions as per the statement in the ministerial letter. Some key discussion points were raised:
 - It was noted that the initial overview was helpful in framing the different options, however providing example user journeys would allow a more thorough review. This will be considered as the options analysis progresses
 - It was acknowledged that the introduction of a digital service would most likely go against the current Type 1 policy, as it would require NHS Digital to be aware of who has registered a type 1 opt-out so that they can apply it. The discovery work has been focussed on exploring all potential solutions whilst noting the challenges and opportunities associated with each. Amendments to current policy may be required to provide patients with the best service
 - Given the above statement, it was acknowledged that any policy clarification or amendments for either Type 1 or National Data Opt-outs (NDOPs) should be considered ahead of planning for technical solutions due to the onward implications
 - There is no current preferred option recommended as we seek stakeholder feedback so that all options can be considered objectively. All feedback is

welcomed, and future check & challenge or ad-hoc sessions can be arranged to further discuss any challenges raised through these recommendations

AOB

- It was noted that the announcement on NHS mergers will have implications for the delivery of GP Data for Planning and Research although full understanding is yet to be reached. Stakeholders will be kept up to date as this understanding progresses
- It was raised by the programme that the check & challenge group may be more effective in holding the programme to account with a single or rotating group of independent chairs. The programme SRO will write to members for input on this suggestion and to ask members to flag their interest in chairing the group
- There is a commitment to working in the open and the programme fully intends to do this. The programme team is actively working to use the NHS Digital website to provide information about the programme reset and approach and will provide frequent updates on progress and what we are hearing from stakeholders. Approvals to launch the website refresh are underway.
- The next meeting will focus on the Trusted Research Environment and related data objectives, and the spotlight discussion will cover the technical functionality needed for the GDPR TRE
- Next meeting will be held 8th December 2021