

GP Data for Planning and Research
Check and Challenge Group
Minutes of the meeting held 16th March 2022
Final – Approved for publication

Attendees

Name	Organisation	Name	Organisation
Helen Stokes-Lampard Chair	Academy of Medical Royal Colleges	Ben Goldacre	Nuffield Department for Primary Care Health Sciences
Michael Lewis	National Institute for Health Research	Nicola Byrne	National Data Guardian
Ruth Ellenby	Royal College of General Practitioners	Nicola Perrin	Association of Medical Research Charities
Mark Coley	British Medical Association	Tim Donohoe	NHS Transformation Directorate
Alison Pritchard	Office for National Statistics		
NHS Digital Programme Team Representatives			
Further representatives from: <ul style="list-style-type: none"> • Office of the National Data Guardian (1 attendee) • Information Commissioners Office (1 attendee) • Office for National Statistics (1 attendee) • NHS Transformation Directorate (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	Provide feedback on comms and engagement topics discussed at meeting, as required	All Members	Ongoing
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 and update on previous actions

- Chair welcomed members to the call and introduced meeting agenda
- It was noted that introductory conversations have been held with the Research Advisory Group as agreed in previous meeting. Further discussions need to be held to provide full clarity on current programme position, and work with research community to effectively plan and manage the transition to the new data collection and access mechanisms

Ratification of previous action notes ahead of publication

- Minor amendments were requested to the notes from 2nd March meeting to include further context regarding the discussion point on wider operational challenges and the potential impact GDPR. The programme team will update and recirculate to members for ratification ahead of publication
- The programme team will also take this feedback on board for future notes

Opt-outs – Type 1 Digital Service Planning

- The programme team gave a brief overview of the Type 1 opt-out history, current process for patients to register their preference, and the key challenges that the programme needs to address to meet the ministerial commitments for GDPR
- Based on a discovery process and a large amount of feedback from stakeholders and advisory groups (including previous presentations to Check & Challenge), the current proposed approach is to provide a digital service to allow patients to register their Type 1 preference in a similar manner to the National Data Opt-out process. It is proposed that this digital service will be established in addition to the current paper-based process for patients to manage their opt-out preference through their General Practice.
- This would be supported by information to ensure all patients and General Practices can access consistent and accurate information if required, regarding what a Type 1 opt-out is, how it impacts patient data-sharing, and how to change their status to opt-out or opt-in as they choose
- The underlying principles for this approach are:
 - to improve the user experience for those wishing to opt-out, whilst ensuring full accessibility is retained for those who cannot, or do not, want to use a digital route
 - to reduce the burden placed on General Practice of processing Type 1 opt-outs, and to ensure a backlog of requests could not build up again

- meeting the commitments in the letter to simplify and centralise Type 1 opt-outs
- The focus for the discussion was whether the proposed solution meets these commitments. Comments and guidance were as follows:
 - The supporting comms will be key to ensuring all patients can access appropriate information to make them aware what their opt-out means for them, and how to register an opt-out if they wish
 - The approach has similarities to the organ donation preference process. The programme should review lessons and successes for that process and apply them here
 - It was confirmed this would apply to patients registered with GPs in England only as the Type 1 opt-out only applies in England and not in the other UK countries
 - The commitment to accessibility was welcomed as it is essential that any patient who wants to update their preference can do

It was agreed that ensuring General Practice staff are fully informed is just as critical to providing patients with information directly.

- It was noted that at present, the programme believes this approach provides the best way to balance the competing challenges whilst meeting the ministerial commitments for the Type 1 service
- The programme team confirmed they will take all feedback into account and build into the current planning as this approach is progressed.

TRE – Phased Release Approach

- The programme team gave an overview of the current approach to creating the GDPR TRE. The proposal is to build the TRE and expand its functionality through four incremental releases
- There will be an ongoing comparison against research accreditation systems to ensure close alignment with industry standards as well as NHS policy and independent, external accreditation
- Comments and guidance were as follows:
 - It was welcomed that the proposal prioritises security through the technology, but it needs to be clear how this is managed through each phased release
 - It would be beneficial to further review and discuss some of the design decisions for the TRE, and how security risks are being mitigated

- There is a need to ensure the new TRE is accompanied by transparent and appropriate governance processes, and it is built with future developments in mind to ensure it can remain fit-for-purpose
- Given this is a very technical area, the delivery and required documentation should be accompanied by accessible material to allow all interested parties the ability to understand what is being built and how it ensures secure data storage and access
- The discussion was paused to allow time for planned AOB, but it was agreed that further discussion on the TRE and associated data access safeguards will be needed to complete this discussion. The programme team will ensure this is brought back to an upcoming meeting

AOB

- It was noted that the initiative to allow patients wider access to their GP records is due to go live in the coming months. Although this is firmly outside of the scope of GDPR, the group noted the potential for this to impact GDPR if there is a negative impact on public trust because of any delivery challenges that may arise
- It was agreed that the group will continue to meet every two weeks given the volume of content under review, however the group are open to individual meetings being cancelled if they are not required based on the stage of the programme. This will be kept under review.
- The programme team provided an update on the comms and engagement activity. Research surveys have been issued to General Practice, and a representative patient sample, and will be supplemented with telephone interviews for patients who are not online. Feedback from these surveys is expected within April and this will inform the next stage of comms and engagement activity
- The programme team committed to review the topics for the upcoming sessions in March and April as a result of today's discussion and will confirm with members ahead of the next meeting on 30th March.
- Members were thanked for their time and input during the session, and the meeting was closed by the Chair