

GP Data for Planning and Research
Check and Challenge Group
Minutes of the meeting held 18th January 2023
Final – Approved for publication

Attendees

Name	Organisation	Name	Organisation
Nicola Byrne Chair	National Data Guardian	Paul Atkinson	Royal College of General Practitioners
Alison Pritchard	Office for National Statistics	Mark Coley	British Medical Association
Ian Hulme	Information Commissioners Office	David Parkin	British Medical Association
Ben Goldacre	Nuffield Department for Primary Care Health Sciences	Nicola Perrin	Association of Medical Research Charities
NHS Digital Programme Team Representatives			

Actions & Decisions Recorded

Action ID	Description	Owner	Target Date
CAC-A012	Review the TRE readiness proposal based on member feedback and iterate as required. - Action planned for completion during March Check & Challenge sessions	Programme Team	29/03/2023
CAC-A014	Ensure discussion on TRE governance, security, and access oversight is included on an upcoming Check & Challenge meeting agenda. - Action planned for completion during March Check & Challenge sessions	Programme Team	29/03/2023
CAC-A020	Understand how Data Strategy team are addressing Goldacre recommendation on mapping system wide data flows - Action planned for completion during March Check & Challenge sessions	Programme Team	29/03/2023
CAC-A021	Share Commitment Overview papers with members following meetings where they were discussed	Programme Team	01/03/2023
CAC-A022	Review Commitment Overview papers within their organisations and provide feedback to programme team within 4 weeks of paper issuance - Comms & Opt-out papers issued 20/01/23, therefore feedback due 17/02/23	Members	29/03/2023

CAC-A023	Where appropriate, confirm approach for gaining formal approval for papers with key stakeholders named in ministerial letter	Programme	01/03/2023
CAC-A024	Re-share associated design documentation regarding opt-out deliverables to refresh member understanding	Programme Team	COMPLETE
CAC-A025	Provide further information on data sharing approach with respect to retrospective deletion across multiple NHS TREs and for data disseminations	Programme Team	01/03/2023
CAC-A026	Understand process and comms associated with Type 1 aggregate numbers in Network Contract DES collection, and share with members	Programme Team	01/03/2023

Meeting Notes

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<p>Introductions and update on previous actions</p> <ul style="list-style-type: none"> • Chair welcomed members to the call following the winter break • Apologies noted from members due to prior commitments and/or annual leave • No new conflicts of interests noted, or changes to existing declarations made • Open and closed actions noted with members, and programme team outlined approach to address all actions carried over from 2023 during the upcoming sessions in February
<p>Ministerial Commitments progress overview approach</p> <ul style="list-style-type: none"> • Chair introduced agenda for this session and next session <ul style="list-style-type: none"> ○ Programme will present progress made to date towards meeting the ministerial commitments made in the Letter to GPs issued July 2021 ○ This was a continuation of the approach first presented to Check & Challenge members in November 2021 and discussed again in May 2022 ○ Papers will be shared with members following the session for review and feedback within their respective organisations (CAC-A021). Approach will be to provide members 4 weeks with each paper before bringing back to Check & Challenge for discussion and finalisation (CAC-A022) ○ Key stakeholder groups named in the ministerial letter will be contacted directly by the programme to organise approach to record formal feedback and approval from each organisation to be published on NHS website alongside finalised papers and Check & Challenge meeting notes (CAC-A023) • Chair introduced GDPR Programme Director to provide further context for members

- Noted that the programme has not yet met all commitments and we are not using this session to gain approval to start data collection imminently. As yet, there remains no confirmed timeline until further progress towards the commitments has been made and this will be discussed in this session
- This session is about noting our progress and confirming that the direction of travel is aligned with members' views
- Also noted that no decisions have been made regarding the tactical challenges presented to Check & Challenge members in September 2022. The programme team are still working with leadership to confirm how we meet the urgent system needs in line with the ministerial commitments and stakeholder concerns. We will ensure members are kept up to date on any further developments
- Focus for this session is to maintain momentum in the face of wider conflicting priorities impacting GDPR progress

Communications & Engagement Commitments progress overview

- Programme Comms Lead gave members an overview of the Comms & Engagement commitments paper and current position against the programme comms strategy
 - Noted that programme is not yet in a position to finalise the detail and required metrics for the GDPR comms campaign
 - Out of the original 5 stages in the comms strategy, we have completed the Assurance and Listening phases, and the reports and research discovered during these phases have been published on the NHS Digital website
 - The programme was due to start the Engagement phase of the strategy, but through the earlier research, we have learnt that having a specific conversation on the GDPR data collection will be challenging due to the lack of a broad foundation of public knowledge around data usage in the NHS
 - As a result, the programme has been prioritising the creation of the Ambient Comms activity, in alignment with the Data Saves Lives strategy team, to begin to provide the public with information about current data uses in the NHS. This has been presented to Check & Challenge members at numerous points throughout 2022. The pilot for the Ambient Comms activity has been approved by Tim Ferris to delivered through 3 case studies during February and March 2023, with further activity to be planned for next financial year
 - The Engagement Phase will be influenced by areas of interest raised during the ambient activity, by the specifics in the other workstreams and also by the wider data strategy work. The plan for this phase will be brought to Check and Challenge for consideration before it is implemented.

- It was made clear that the case study-based work is not a replacement for a programme of communications about GDPR specifically, it is to build understanding and awareness to support that more specific conversation with the public at a later date
- Programme Comms Lead invited questions from members. Key discussion points were:
 - It was noted that the ONS is about to launch a public consultation regarding the national census to understand public acceptability of using administrative data to supplement/support the completion of the census. ONS and Programme Comms team committing to remaining aligned as the two activities progress and to work together and share learnings as appropriate
 - Noted that it was important to ensure that wider information is updated alongside Ambient Comms activity to allow the public to gain further objective and balanced information based on their wants and needs.
 - Programme confirmed that work is underway to ensure that members of the public who want to gain more information will be able to do so
 - It was noted that the NHS team should be ready to swiftly address any challenges or misinformation. The programme team acknowledged this and noted it is looking into this alongside the pilot
 - It was agreed that the use of case studies to provide historic and factual information on real uses of data can help to support understanding of the ways that data can be used for the public good.
 - The use of case studies will also align with what the system is doing as a whole, and will support the public to consider this topic and their views on it more generally, without also considering any specific data project
 - ONS noted they are taking a similar generic approach and looking to not use binary questions, but to gain insight into broader attitudes using more open questions
 - Question as to whether the programme is looking to research whether the Ambient Comms activity will minimise opt-outs or drive people to opt back into data sharing
 - Programme noted that at present opt-outs are stable, therefore it may be challenging to measure any positive impact on opt-outs as a result of any comms activity, although a negative impact will be seen as an uptick in opt-outs
 - Current approach for the pilot is to measure how web traffic across the NHS website is impacted, however we can build the findings into the GDPR Engagement phase to better understand specific concerns regarding opt-outs and what would drive people to opt out or opt back in
 - It was also noted there is a specific challenge regarding contacting patients who have opted out of data sharing as we would not be respecting the terms of the opt-out by doing so

- Members noted the other key challenge is the different opt-outs can be very confusing for patients and healthcare professionals. It was agreed this is a challenge and is being reviewed as part of the Data Strategy work, but not within the direct remit of the GDPR programme
- Further question on whether the programme has an acceptable level of opt-outs recorded before planning and research use cases might be impacted
 - The programme noted that the campaign success metrics have not yet been confirmed for GDPR as these will be detailed following the Engagement phase
 - The current position is that this varies greatly depending on the use case and who you are talking to, therefore we will need to do further research on this. The programme is also looking to align with wider research from NHS E on opt-outs and patient sentiments to gain further insight
 - It was raised that just knowing the demographics of people who have opted out is not enough, as better understanding of opt-outs could be extremely important to understand other drivers of patient behaviour. It was stated that the Bennett Institute team would be happy to meet to discuss how various approaches to research on opt outs might be explored.
 - It was noted that this is a challenging area, and any research would need careful review with a variety of stakeholders to ensure that it falls in line with the current opt-out principle and does not result in unintended challenge and negative impact
 - One option proposed by members would be to insert a voluntary question to ask patients as part of the opt-out process. This will be explored by the programme team
- Chair thanked members for their input and moved the discussion on to the next topic area

Opt-out Commitments progress overview

- Programme Manager gave members an overview of the opt-out commitments paper and current position against meeting those commitments. It was noted that all elements for discussion had been presented to members throughout 2022 and this was a consolidation.
 - The programme has completed the design for a digital service that (alongside the current paper form process) would address the letter wording to provide a simplified and centralised service to reduce the burden placed on GPs for actioning Type 1 opt-out requests. Build and implementation of the service would begin dependent on alignment with Data Policy and Ministers
 - An overview of the design to address the ministerial commitment for retrospective deletion was provided, and it was noted that the technical design

was complete and would progress to build and implementation once a confirmed date was established for data collection to start

- As confirmed in September 2022, it was confirmed that the opt-out backlog has been addressed and a full paper is currently being finalised ahead of sharing with members, for review and ratification
- Programme Manager invited questions from members. Key discussion points were:
 - Members requested that any previous design documentation is also shared alongside the opt-out commitments paper to help their review. Programme team took an action to provide all relevant information **(CAC-A024)**
 - Question from members about how patients will get confirmation that their opt-out has been actioned and that their data has been deleted. Programme confirmed that visibility would be via the NHS App and within GP Practice - the process for this is not yet finalised to ensure that there is a consistent approach for patients across all information sources
 - Question from members on whether retrospective deletion would apply to disseminated data or just data in the NHS Digital TRE. Programme confirmed that retrospective deletion would only apply within the TRE, but that data would only be disseminated for purposes of consented research as per the letter
 - There was a further question on whether this would apply across TREs if the NHS had more than one TRE. Programme took action to provide further information on data sharing approach with respect to retrospective deletion **(CAC-A025)**

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- Next session will focus on TRE and the IG & legal commitments. Programme team working to confirm date for next session due to upcoming merger and mid-February school holidays. POST MEETING NOTE: Next meeting confirmed as 1st March. Actions updated appropriately
- Question raised by members on whether the programme was aware that Type 1 information is now being collected and whether the programme was aware of how this was communicated to the GP Profession. Programme was aware that Type 1s were now being collected through the Network Contract DES, but this was instigated through NHS England. Programme team took action to understand if the GP Profession were informed of the addition of this metric to the existing Network Contract DES collection **(CAC-A026)**
- Members were thanked for their time and the call was ended by the chair