

Communications and Engagement Commitments Update

GP Data for Planning and Research

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data and technology**

Purpose of this report

To outline the progress made by the GP Data for Planning and Research Programme against the ministerial commitments (*issued in July 2021*) and ratify the designs and forward approach with key external stakeholders to fully meet these commitments. As noted in the ministerial letter, these commitments have to be met before data collection can begin.

This report will specifically cover the commitments relating to the Communications and Engagement elements of the programme (*as confirmed with the Check & Challenge Advisory Group on 10th November 2021*).

Expected outcomes of this report

The expected outcomes from the dissemination and review of this report with key stakeholder groups are:

- Check & Challenge members are provided with a written overview of all progress made to date in relation to the Communications and Engagement ministerial commitments
- Check & Challenge members ratify that the forward approach defined will support the ministerial commitments, and when they are delivered as defined, alongside both an approved communications programme for GDPR, which has been co-created with the public and stakeholders, and all of the other key commitments, then approval will be provided to commence data collection
- Key stakeholder groups named in the letter provide formal confirmation of above ratification (BMA, RCGP, NDG)

Report publication and transparency

Following ratification with Check & Challenge members, the report will be finalised and published on the NHS Digital website alongside the relevant meeting minutes noting member ratification and documents noting formal confirmation from the three key stakeholder groups.

Communications and Engagement

Ministerial Commitment(s)

The below commitment wording has been transposed directly from the letter signed by Jo Churchill MP and issued on 19th July 2021.

Key Ministerial Commitments *(required prior to data collection commencing)*:

- Patients have been made more aware of the scheme through a campaign of engagement and communication

Further Communications and Engagement ministerial letter wording:

- We will ensure that the BMA, RCGP and the National Data Guardian have oversight of the proposed arrangements and are satisfied with them before data upload begins
- This is intended to give both GPs and patients a very high degree of confidence that their data will be safe, and their privacy protected

Programme Interpretation:

- We will continuously engage with key stakeholders, namely the RCGP, BMA and NDG and work with them to ensure the campaign will meet our commitments and our legal transparency obligations
- We will listen and engage with a range of stakeholders (e.g., the public, patients, GP staff) to help co-create a campaign that informs patients about how their data is safely collected, stored, and intended to be used, and allows people to make an informed choice about how their GP data is used
- We will run a national awareness raising campaign around the proposed collection and the ability to opt out, whilst looking to minimise the rate of opt-outs

Delivery Approach

The following delivery approach has been confirmed with key stakeholder groups as part of the initial Assurance phase in 2021.

- **Assurance phase:** Engage with key stakeholders to define the communications and engagement approach
- **Listening phase:** Undertake new research through surveys and focus groups, to better understand how to engage stakeholders
- **Engagement phase:** Involve the public, patients, GPs, and others, to co-produce campaign approaches, materials, and messaging
- **Demonstration phase:** Explain the impact of stakeholder contributions through previous phases
- **Delivery phase:** Deliver a public awareness campaign that builds on the previous phases to assure understanding and increased awareness

However, during the research and feedback gained throughout the Listening phase, it became apparent that patients and the public would benefit from a broader information

campaign to build a foundation of knowledge about how the NHS currently uses data. This would allow patients to better understand what will change when GDPR commences.

This foundation knowledge campaign will be planned and delivered in tandem with the new NHS ‘Data Saves Lives’ strategy and has been incorporated into the GDPR Comms delivery approach ahead of the Engagement phase but will run throughout to support knowledge building.

- Ambient Data Campaign:** Build broad patient and public knowledge in current usages and benefits of NHS data through a series of cases studies and information campaigns, delivered mostly online and in partnership with organisations currently using NHS data

Progress against Delivery Approach

The below table details the outputs and success measures for each delivery phase, and the progress made to date against each one.

Deliverable	Outputs and Success measure(s)	Progress to date
Assurance Phase	<p>Series of meetings with a wide range of stakeholders to gather feedback and improve the communications and engagement plan</p> <p>Publication of the Assurance Phase report online</p>	<p>Assurance phase complete and the end of phase report shared with the programme Assurance Groups.</p> <p>Report published on the NHS Digital website: Assurance phase report - General Practice Data for Planning and Research (GDPR) - NHS Digital</p>
Listening Phase	<p>Undertake research with the general public and GP staff and publish the findings and insights</p> <p>Publish a drumbeat of communications to support publication</p> <p>Online publication of the Listening Phase report</p>	<p>Listening phase complete and the end of phase report shared with the programme Assurance Groups.</p> <p>Report published on the NHS Digital website: Listening phase report - General Practice Data for Planning and Research (GDPR) - NHS Digital</p> <p>Findings from the GP and public research published: GDPR Programme reports and publications - NHS Digital</p> <p>Drumbeat comms - six blogs published: GDPR Programme blogs - NHS Digital</p>
Ambient Data Campaign Launch and	Development of campaign concept and strategy.	Campaign concept and strategy developed – informed by public

<p>ongoing delivery</p>	<p>Exec approval and stakeholder support to proceed to delivery</p> <p>Delivery of campaign burst 1 as a pilot.</p> <p>Evaluation of burst 1.</p> <p>Other data users start to use the campaign materials as part of their materials and assets</p> <p>Delivery of further bursts and transition into BAU data communications.</p>	<p>and stakeholder engagement feedback and public testing.</p> <p>Ongoing stakeholder engagement.</p> <p>Exec approval gained.</p> <p>Procurement of campaign delivery underway.</p> <p>Expected start date = late March 2023.</p> <p>Evaluation showing increased knowledge about and awareness of NHS data use as a result of seeing the campaign.</p>
<p>Engagement Phase</p>	<p>Publish further research findings addressing our knowledge gaps</p> <p>Identify particular communities at risk of disproportionate opt out or with particular concerns</p> <p>Ensure that we use the learning from the data strategy engagement work in our development, including testing the findings and insight with the Check and Challenge group</p> <p>Agree and ratify approach with Check and Challenge group and outline how we will use information from the wider data strategy work to support our engagement</p> <p>Publish engagement phase research findings, which, alongside ambient campaign evaluation, will shape and inform the development of the campaign work, both in terms of creative development and strategic delivery.</p> <p>Hold a series of events with stakeholders to develop campaign materials, test, iterate and assure them for different audiences.</p>	<p>Phase not yet started.</p> <p>Engagement phase to be progressed once budget for delivery is agreed</p>

	<p>Production of a campaign plan and materials that are agreed by programme Assurance Groups and that have been developed and iterated with public feedback</p> <p>Continued drumbeat of communications.</p> <p>Development of campaign materials for use in GP training and for GP staff to share with the public</p> <p>Online publication of the Engagement Phase report</p>	
Demonstration Phase	<p>Online publication of our, 'You said, we did' report outlining how listening, and feedback has shaped the GDPR programme and reports, as well as our high levels of transparency</p>	Phase not yet started.
Public awareness campaign	<p>Delivery of campaign and plan, as defined and agreed by Check and Challenge Group</p> <p>Increase in awareness of the GDPR programme against the baseline</p> <p>Reduced spike in opt outs at collection compared to Summer 2021</p> <p>Increase in baseline visitors to GDPR online hub</p> <p>Higher levels of reported understanding of GP data and opt outs against baseline</p> <p>Demonstrate that the campaign has met the objectives agreed in the plan</p>	Phase not yet started.

Risks and Considerations

The below table summarises the key risks and considerations affecting the completion of the Comms and Engagement delivery approach and gaining formal sign-off that all associated ministerial commitments have been met to allow data collection to commence.

Risks and Considerations	Mitigations
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<p>BMA, RCGP or NDG don't sign off that the comms and engagement commitment has been met</p>	<p>Ongoing involvement of the Check and Challenge Group to ensure programme workstream is meeting the requirements as agreed by the group.</p> <p>Sign off of the communications campaign plan with all groups before launch.</p> <p>Regular evaluation of effectiveness, to provide evidence of reach and increased engagement.</p>
<p>Opt-outs spike at launch</p>	<p>Continue to be fully transparent around opt outs and engage broadly to build trust.</p> <p>Set out the new security measures in place around the collection (TRE/SDE) and ensure people have a positive association between patient data, planning and research.</p>
<p>GP staff do not support the programme and data collection</p>	<p>Ensure the burden on GP staff is reduced through delivery of an online type 1 opt out solution and by reducing the number of requests for data extracts.</p> <p>Engage with the GP professional groups to seek their active support for the project.</p> <p>Engage and communicate with GPs before and during the public campaign to seek their support and to raise their awareness, confidence and understanding from the baseline identified through existing research.</p> <p>Seek and use GP views to help develop public facing materials.</p>
<p>Data privacy campaigners don't think the awareness campaign is as broad as it could be</p>	<p>Continue to be transparent and publish research findings and programme updates.</p> <p>Publish the Engagement report showing how we have designed the campaign by working with patients, the public and others to ensure the campaign is right within the available financial envelope.</p> <p>Gain sign off for the campaign plan from our assurance groups, which clearly shows how we will reach different groups and communities.</p> <p>Work with others who have successfully targeted the whole population (such as the census team at ONS) to learn from their best practice.</p> <p>Ensure we are open about our need to target audiences for whom health inequalities would be exacerbated should they disproportionately opt out.</p>
<p>Negative media coverage leads to a loss of confidence from either the GP profession or the public, which</p>	<p>Seek proactive support from the GP professional bodies before launch, in order to build confidence among GPs and the public</p>

<p>drives a loss of confidence in the approach from ministers</p>	<p>Co-development of the programme and the campaign to ensure that key concerns have been considered and mitigated</p> <p>Proactive media campaign plan agreed with stakeholders before launch and seeking their active support to be ambassadors for the programme</p> <p>Ongoing transparency of approach so there are no surprises for the public or the profession</p> <p>Ongoing engagement with ministers to ensure they are kept fully informed and are aware of the potential risks and challenges impacting the programme or particular stakeholder groups</p>
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Conclusions / Summary

The most important elements for the successful delivery of the communications and engagement workstream are a continued commitment to transparency, a close co-production relationship with patients, the public, and GP staff to get the public awareness campaign right and continued listening and engagement with the programme Advisory Groups.

We also need to listen closely to our stakeholders and ensure that the programme is designed in a way which responds to those concerns and changes approach where required, being transparent about how and why we have made changes.

We are committed to meaningful engagement with the public and patients to test our language to ensure we can communicate in a way which gains cut through and which offers the right reassurance to the public and stakeholders. Our transparency materials and other detailed information must be available in formats which are accessible, easy to understand, and which can be provided in short, easy to understand headlines alongside the more detailed documentation.

We will need to be able to communicate confidently that we have met the Ministerial commitments, including an increased level of security and privacy through an enhanced secure data environment, such as a TRE, a reduction in burden on GPs, and a clear understanding of how GP data is used and by whom. This will be enhanced through real world examples.

Further to the recognition of the need for the NHS to talk about the benefits of the use of data to the system and patients more broadly, ahead of communicating any proposed change in use, resources have been focused on developing the ambient campaign. As per our overarching comms and engagement strategy, the learning from the delivery of that campaign will be used to inform the development of communications materials for future phases of the GPDPR programme.

The development of communications and engagement plans for future phases of the GPDPR programme, which includes the public awareness, will be brought to the Check and Challenge Group (and the programme’s other assurance groups), for input and sign-off, to validate the approach and success measures.

Annex 1

The following information has been provided to Check & Challenge members in support of this paper.

Supporting Document 1: Process to agree GDPR deliverables

Purpose

To propose a process which supports the programme, the Check and Challenge group and the stakeholders named in the letter to GPs in July 2021 (BMA, RCGP and NDG) to agree the deliverables which will ensure clarity on what will constitute meeting the commitments set out in that letter.

Background

When the GP Data for Planning and Research programme was paused in summer 2021, a set of commitments were made and meeting those commitments, agreed by the stakeholders named in the letter was a pre-requisite for the extraction of data to commence.

The programme has committed to working transparently and has been holding regular conversations with stakeholders since the reset was announced. Through those conversations we have come to a point where we now have a set of proposals for delivery and we want to crystallise this and be able to share it more widely, by developing written proposals for the Check and Challenge group and others to scrutinise and to agree. This is to ensure that there is clarity on what will be delivered to meet each commitment before delivery commences.

The documents won't seek to outline everything that we will deliver as a programme, only those elements which are outlined in the ministerial commitment and in many cases, we may go over and above those commitments in due course.

The proposed process

- Each workstream develops a short document describing how we have interpreted the commitments in the letter, what we will deliver to meet the commitments
- Each deliverable will be paired with associated metrics to measure successful delivery
- The documents will also show salient risks, mitigations, and considerations, outlining where further thinking and engagement has refined an approach or when one approach was chosen over another
- These documents will be shared with the Check and Challenge group for discussion, refinement and to seek agreement
- Once agreed, we will write formally to the British Medical Association, National Data Guardian, and Royal College of General practitioners to outline the delivery commitments and to ask them to formally endorse them
- Subject to discussion and agreement, we propose to publish the letter and the proposals on our website

Supporting Document 2: Programme Objectives and Approach

Programme Objectives – Top 5 conditions within Letter DRAFT - Initially Presented 10th Nov 2021

The 5 commitments outlined below are the primary 5 commitments recorded in the ministerial letter issued on 19th Jul 2021 and signed by Jo Churchill MP. These were presented to Check & Challenge members on 10th Nov 2021 and the principles and key deliverables related to each commitment were discussed. The GDPR Programme has been working towards the key deliverables throughout 2022.

The further content areas from the letter were assigned to each of the programme's three workstreams in addition to the 5 below. These were shared and discussed with Check & Challenge members between 10th Nov 2021 and 8th Dec 2021.

Wording present in Letter to GPs signed by Ministers	Principle of Commitment	Key Deliverables to address
<ul style="list-style-type: none"> the ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded; <p>(Opt-outs)</p> <ul style="list-style-type: none"> the backlog of opt-outs has been fully cleared; <p>(Opt-outs)</p>	<ul style="list-style-type: none"> Data will be deleted if / when patients opt out therefore no opt-out deadline is required for data collection. 	<ul style="list-style-type: none"> Previously collected data will be removed from domain 0 within an agreed timeline of new Type 1 opt-out being received Patients will be able to confirm that Type 1 opt-out has been received and retro deletion has been actioned (TBC)
<ul style="list-style-type: none"> a Trusted Research Environment has been developed and implemented in NHS Digital; <p>(Data Management, Access and Governance)</p>	<ul style="list-style-type: none"> A TRE through which GP Data can be accessed has been developed by NHS Digital that adopts best practice, has a clear definition and governance structure that is agreed by the profession. 	<ul style="list-style-type: none"> Provide proof to stakeholders that all opt-out requests between 12 May 2021 and 1 Sep 2021 through Contact centre have been actioned and cleared Provide evidence that sufficient processes are in place to manage future demand through Contact Centre, including spikes
<ul style="list-style-type: none"> patients have been made more aware of the scheme through a campaign of engagement and communication. <p>(Comms)</p>	<ul style="list-style-type: none"> Through a broader engagement and communication campaign, which GDPR-specific content is broadcast through, public awareness and understanding of the programme reaches a threshold that allows informed opt-out / remain decisions to be made by the majority of patients. 	<ul style="list-style-type: none"> Formal confirmation reached with key data users, profession and NDG that TRE meets the conditions within Letter to GPs TRE is able to service majority of initial use cases TRE stood up which adheres to agreement of required functionality with key data users, profession and NDG
<ul style="list-style-type: none"> data extraction will not commence until we have met the tests. <p>(Comms)</p>	<ul style="list-style-type: none"> GDPR extraction will not commence until we have satisfied primary commitments above 	<ul style="list-style-type: none"> Formal confirmation reached with BMA, RCGP and NDG that Comms Strategy is sufficient to address the challenge of patient/public/healthcare community understanding of GDPR Formal alignment reached on scope of GDPR-specific Comms Strategy as opposed to required broader data communications Clear set of measurements and targets agreed with BMA, RCGP, NDG and other stakeholders, to be used to measure success of Comms Strategy Evidence provided that targets have been met, to allow agreement with BMA, RCGP and NDG to be reached that data collection can commence
		<ul style="list-style-type: none"> Formal confirmation reached that agreed set of key stakeholders will be sufficient to provide alignment that data collection can commence Formal confirmation reached with agreed set of key stakeholders on discrete set of conditions that must be met to allow data collection to commence with support from key stakeholders Formal alignment received that all agreed conditions have been met to allow data collection to commence

Appendix – Programme Objectives Process

DRAFT - Initially Presented 10th Nov 2021
Updated for Presentation 18th Jan 2023

Overview

The purpose of defining a set of Programme Objectives from the Letter to GPs was to build clarity and specificity around the deliverables and approaches of the programme, and to ensure alignment with stakeholders that the programme actions are actively addressing the commitments and conditions set out in the letter.

The programme undertook an exercise to segment the letter into a set of 5 key commitments and 21 further statements (including 10 duplicate statements) and drafted a set of clearer delivery objectives against each commitment/statement. These objectives were originally presented to Check & Challenge members on 10th November 2021, and the programme has been working towards these objectives throughout 2022.

Current Position

The Jan/Feb 2023 Check & Challenge sessions aim to formally underline all progress made in 2022 and position the programme to meet the commitments fully in 2023. It is critical that the programme gains stakeholder consent that the current approaches and designs (discussed with Check & Challenge members) will meet the commitments as we do not want to waste resources by building solutions that stakeholders do not support.

Previous Work and Next Steps

- Iterative review of Programme Objectives for each programme workstream with Check & Challenge stakeholders
 - Communications and Engagement – 10th Nov 2021 (COMPLETE)
 - Opt-outs – 24th Nov 2021 (COMPLETE)
 - Data Management, Access and Governance (TRE) – 8th Dec 2021 (COMPLETE)
- Review Objectives with Patient and Public Panel for feedback regarding outward communication and engagement – 9th Dec 2021 (COMPLETE)
- Review Objectives with IG Expert Liaison Group for feedback relating to IG commitments – 21st Dec 2021 (COMPLETE)
- Continue to iterate based on stakeholder feedback, targeting formalisation of Objectives (Staggered based on programme delivery) – **Ongoing**
- Ongoing alignment with key stakeholder groups, presenting material and progress against objectives – **Ongoing**
- Use Objectives to ensure stakeholder alignment that programme is delivering/has delivered against commitments – **Ongoing**
- Data collection to commence once all Programme Objectives have been confirmed and communicated as complete