

**Ref:**

National Data Opt-out Programme/Programme Board/Paper 02

**Title:**

National Data Opt-out Programme – Setting Approach

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**Purpose:**

The purpose of this paper is to bring the Programme Board up-to-date on discussions regarding the inclusion or not of setting capability within GP systems for the national data opt-out.

**Background:**

The National Data Opt-out Programme Board has been considering since 5 October 2017 whether functionality for setting national data opt-outs should be included in GP clinical systems. On the 14 December 2017 a decision was taken not to include this functionality subject to further testing with the GP profession.

**Key Points:**

The Royal College of General Practitioners (RCGP) have subsequently been engaged regarding this decision. They are clear they do not want additional burden on GP Practices from administering the national data opt-out. However, they have sought assurances that accessibility needs can adequately be met through other channels available, and that they can perform their role as data controllers for upholding national data opt-outs.

**Actions Required by the Programme Board:**

The Programme Board is asked to receive the report, and to:

- Note the action plan to respond to points raised by RCGP;
- Note the risks and mitigation plans in place; and
- Approve that GP System suppliers are re-engaged immediately on the basis of providing Upholding functionality only.

**Circulation:**

Programme Board attendees only.

**Dates considered by Programme Board:**

28 February 2018 (Potential Disclosure)

## Introduction

1. The National Data Opt-out Programme (NDOP) has been developing a multi-channel approach for allowing patients to set national data opt-outs through a national offer of a digital platform, a digitally assisted service and a non-digital service. In considering a number of emergent factors, such as the potential burden on GP Practices, the Programme Board have been reviewing since 5 October 2017 whether an additional channel for setting in GP Practices should be provided or not.
2. Following membership review of the 'National Data Opt-out Programme: GP Systems for Setting - Discussion Paper' the Programme Board agreed on 14 December 2017 to focus the setting solution on the digital platform, digitally assisted and non-digital service only. However, it highlighted that testing should take place with the Royal College of General Practitioners (RCGP) to get their views on this decision.
3. This paper brings these discussions up-to-date.

## Background

4. The Programme Business Case (PBC) for the NDOP programme was approved by the Technology and Data Investment Board (TDIB) on 17 February 2017. It considered a range of options for meeting the critical success factors and spending objectives. The preferred option for providing a non-digital channel of setting national data opt-outs was through GP practices AND the national back office. This direction was further evaluated and endorsed in the Outline Business Case (OBC) approved by TDIB on 29 September 2017.
5. The NDOP has progressed the delivery of a setting channel in GP Practices through the GP Systems of Choice (GPSoc) Requirements and Validation Engagement (RAVE) process. This covered requirements for the following:
  - The Setting and Viewing of National Data Opt-outs via GP Systems
  - The Upholding of National Data Opt-outs via GP Systems
  - The Setting and Viewing of National Data Opt-outs via Patient Facing Service Applications
6. A series of Foundation Workshops and consultations were held between May and August 2017 involving GP system suppliers, the GP Profession, and other key stakeholders. The feedback received shaped the final requirements that were issued to GP System Suppliers on 8 September 2017.
7. The availability of solutions to meet these requirements to the (then) public launch timescale of March 2018 was highlighted as a risk at the Programme Board held on 5 October 2017. Further work was requested to understand the impact of not having a GP offering available to different patient groups. A paper was considered by the Programme Board on 9 November 2017, where it was recommended that further work was undertaken to understand whether it is possible to offer a full service to the public for setting national data opt-outs through national digital, digitally assisted (including patients being guided through the process on the phone) and non-digital (patients complete a form and submit proof of ID) channels without the need for GP system changes.

8. This evaluation was set out in ‘National Data Opt-out Programme: GP Systems for Setting - Discussion Paper’ considered by the membership. This highlighted the case for change:

**Reducing the burden on GP Practices under pressure** – Although the digital service for the national data opt-out is likely to reduce burden by replacing some of the paper based opt-out processes that exist today (e.g. Type 2s), consideration is needed of the new burden from making available functionality to opt-out in GP Practices.

**Empowering patients** – The Secretary of State for Health signalled at Expo in September 2017 the shift in power from doctor to patient as patients use technology to put themselves in the driving seat of their own healthcare. Through the eight digital commitments, including preferences, the emphasis is on patients to be enabled to undertake transactional tasks such as opting-out themselves.

**Simplifying the communication to the public** – A universal offer to patients within England to be able to set their preferences through GP Practices will be challenging to communicate to the public when this functionality is introduced at different times by different GP system suppliers.

**Reducing the degree of change** – In shifting from GP Practices away from processing national data opt-outs to sign-posting patients to other channels, the degree of change is reduced in terms of staff training, process change and implementation support. It has been highlighted by GPs that much of this change has been signalled as taking place over the winter pressures period.

**Delivering value for money** – The opportunity to reduce the level of changes required to GP systems, as well as the associated change, whilst increasing benefit through reduced burden potentially improves the value for money for the national data opt-out.

9. At the Programme Board held on 14 December 2017, the group agreed to pursue setting through a national solution only, subject to some final testing with the GP profession.

### Testing with the GP Profession and Next Steps

10. The programme formally approached the RCGP on 9 January 2018 to understand their views. Their response highlighted the following:

- There was support for not making available the ‘GP Assist’ channel in order to avoid burden on GPs in administering the collection of the national data opt-out;
- They proposed that there should be on-going impact assessment work once the national data opt-out is up-and-running to ensure that particular groups are not excluded as a result of not having this channel;
- It was felt by the profession that GPs may still have a significant role to play in making patients aware of, and to understand the choice and its effects, and this needed to be taken in to account;
- Clarification was required on the ability for GPs to check that national data opt-outs had been applied to meet their duties as data controllers.

11. A follow-up meeting was held on the 25 January 2018 between the RCGP and the programme to discuss and clarify these points. It was noted that:

- The programme are actively engaged with accessibility groups on a range of issues including the routes to set a preference. This would be used to identify any accessibility concerns for particular groups.
- The upholding part of the GP system changes remains in-scope, and the requirements for GP system suppliers will need to support GPs to be assured that national data opt-outs are being applied appropriately;
- There is a wider piece of work needed on ensuring GP Practices as data controllers have guidance on putting robust contracts in place with data processors, including clear instructions on processing national data opt-outs and where liabilities would fall.

12. The following action plan is being taken forward on the back of these discussions. It should be noted that GP Practices will not be expected to uphold national data opt-outs from 25 May 2018, but at a later date to be agreed.

Issue	Action	Owner
Accessibility – ensuring accessibility of national data opt-out.	On-going engagement with accessibility groups through Public Engagement Strategy.	Rachel Merrett
	On-going user research of digital and non-digital services.	Susie Day
Upholding – providing assurance to GPs that opt-outs being applied.	Ensure incorporated within scope of requirements for GP systems suppliers.	Scott Grayston
Upholding – governance on data-processing for GPs of national data opt-outs.	Work with NHS England team and BMA/RCGP to ensure clear guidance on arrangements GP Practices should put in place with data processors.	Rachel Merrett

## Risks and Issues

13. The risks and issues plus mitigations are set out below:

Risk/Issue	Mitigation
Risk that the burden on informing patients on data use and the national data opt-out falls to GP Practices.	All programme communications will direct patients to a national web-site or national telephone number. This is a citizen focused initiative and is about the whole health and care system playing an effective role in communicating the national data opt-out rather than just GP Practices alone.

Risk/Issue	Mitigation
Risk that some GP Practices will want to offer patients the ability to opt-out in the surgery.	The national data opt-out can be set digitally from any location where the internet can be accessed. If individual GP Practices want to offer services to help particular patients to use the core digital offering then this is possible without using the GP system.
Risk that some patients will need to visit their GP Practice to obtain their NHS Number or update their contact details.	<p>The programme will work closely with the RCGP and other programmes to promote the benefits for patients of having up-to-date contact details e.g. clinical correspondence and appointment reminders.</p> <p>The NHS Number can be obtained through Patient On-Line services, and the wider benefits (e.g. appointments and repeat prescriptions) of registering for such an account can be promoted as part of this engagement.</p>
Risk that some GPs may want the ability to discuss data sharing preferences with patients.	There are a range of preferences, opt-outs and consents in health and care, not all of which are held on GP systems. A policy paper considering the issues regarding clinicians being able to access the national data opt-out set by citizens is currently being developed for 'check and challenge'.
Risk of increased pressure on the contact centre which may lead to poor response times, and negative media reporting of this.	The programme will work closely with the contact centre to plan for effective capacity to meet expected demands.

### Actions required of the Programme Board

14. The Programme Board is asked to receive the report, and to:

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- Note the risks and mitigation plans in place; and
- Approve that GP System suppliers are re-engaged immediately on basis of providing Upholding functionality only.