Opt-out commitments update

GP Data for Planning and Research

Document filename:	**Opt-outs Commitments Progress Overview**		
Project / Programme	**GPDPR**	Workstream	**Opt-outs**
SRO	**Tim Donohoe**	Status	**Final**
Owner	**Andrew Thorne-Marsh**	Version	**1.0**
Author	**Mark Roberts**	Version issue date	**28/03/2023**

Improving lives with 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 Opt-out elements of the programme *(as confirmed with the Check & Challenge Advisory Group on 24th 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 an overview of all progress made to date in relation to the ministerial commitments related to opt-out
- Check & Challenge members ratify that the designs and forward approach defined will meet the ministerial commitments, and when they are delivered as defined *(alongside all other key commitments),* then approval will be provided to begin the 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.

Opt-outs

Ministerial Commitment(s)

The commitment wording below 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)***:**

- 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
- The backlog of opt-outs has been fully cleared

Further opt-out ministerial letter wording:

- The plan to retire Type 1 opt-outs will be deferred for at least 12 months
- We are in the process of working with colleagues across general practice to develop a way of simplifying and centralising the opt-out process in order to remove this burden on practices
- Patients will be able to change their opt-out status at any time

Programme Interpretation:

- Data will be deleted if / when patients opt out, therefore no opt-out deadline is required for data collection
- The backlog of NDOPs and Type 1 requests, specifically those within the NHS Contact Centre and General Practices that built up prior to July 2021, is considered to be cleared
- A service will be designed by NHS Digital to reduce the burden on General Practices of processing type 1 opt-outs and allow patients to opt-out/in efficiently
- Opt-in/out journeys should be equally efficient, accessible, and simple to progress

Delivery approach

The delivery approach to meeting the opt-out commitments has been split into three distinct areas. These are:

- **Backlog clearance**: Proactive management of the clearance of the NDOP backlog (in partnership with the NHS Live Services team) and monitoring of opt-out metrics to allow time for GPs to clear Type 1 backlog
- **Retrospective deletion:** Design and implement the technical functionality to automatically register when a patient has changed their opt out and to delete their data from the main GPDPR database
- **Type 1 Digital Service:** Design a centralised digital self-service platform, informed by public user research and stakeholder feedback, to reduce burden on GPs from Type 1 opt-outs

Progress against delivery approach

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

Deliverable	Outputs and success measure(s)	Progress to date
Backlog clearance	Provide proof to stakeholders that all opt-out requests between 12 May 2021 and 1 Sep 2021, applied through the NHS Digital contact centre, have been actioned and cleared Provide evidence that sufficient processes are in place to manage future demand through Contact Centre, including spikes Provide time for GPs to clear any Type 1 backlog raised directly at practices by reducing the likelihood of spikes driven from programme activity and monitoring NDOP levels for any spikes caused by external factors	NDOP backlog confirmed as closed and crisis team disbanded in September 2021 GPs provided with one year to close off any remaining Type 1 backlog NDOP levels monitored to confirm no further spike occurred between September 2021 and September 2022 Check & Challenge members formally notified in September 2022 that programme has met backlog commitment Report produced to provided required detail to key stakeholder groups regarding commitment being met. Will be shared with Check & Challenge for initial review in Mar 2023 and publish on NHS Digital website following sign-off from all key groups
Retrospective Deletion	Design and deliver a means by which data will be deleted from the TRE when a patient applies a Type 1 opt-out, even if that data has been collected prior to the opt-out being submitted.	Technical design agreed which will remove all new Type 1 opt-outs from Domain 0, subsequently deleting the patient record from each onward domain Records will not be deleted from stores where the patient data has already been used in research resulting in publication (for audit and replication purposes) Approach for capturing newly registered Type 1s requires daily, identifiable, feed of Type 1 opt-outs separate from the main GP data collection Build and implementation of solution will start once GPDPR

		delivery approach and timelines are established
Type 1 Digital Service	Understand the concept of any 'burden' the current Type 1 service causes practices, as well as the needs and expectations of the public in applying a Type 1 opt out. Design an appropriate solution that addresses practice burden and public requirements.	Technical design of online opt-out service agreed, enabling a patient to register their Type 1 opt-out via the NHS App or NHS.uk (in addition to the existing process of registering via a paper form via their GP practice) Technical design published on our website Solution uses GP Connect capability to push digital registration back into the GP System Supplier Build and implementation of solution will start once GPDPR delivery approach and timelines are established

Considerations

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

Risks and Considerations	Mitigations
There is a known challenge that the current Type 1 and National Data Opt-outs (NDOP) are too confusing for patients and public to understand. Our public research shows a lack of understanding of opt outs and the NHS Data Strategy has committed to reducing this confusion. This creates a risk that, although the infrastructure designed will meet the ministerial commitments, any major policy changes in this area may render our solutions obsolete or no longer fit-for-purpose.	Undertake further qualitative research to better understand where the confusion exists and workshop solutions with patients and the public as part of the Engagement Phase of the communications strategy. Provide the outputs of the research to the NHS Data Policy team in order to incorporate into future policy and action as it relates to patient opt-outs and the Data Strategy. Maintain alignment with Policy on their approach to meeting the Data Strategy commitments and ensure the solution implementation plans fully reflect their approach to ensure we provide a future-proofed solution as well as one that meets our individual ministerial commitments. If required, escalate challenges and priority conflicts to ministers for guidance on how to

	proceed, whilst maximising transparency of our actions with our stakeholder groups.
There is a risk that the GP community perceives the proposed opt-out service solution has not sufficiently reduced burden on GP Practices and therefore the commitments in the ministerial letter	Continue to engage with the Check & Challenge group and build on the user research already conducted to alleviate GP community concerns regarding the level of burden reduction
There is a risk of a further opt-out spike driven by factors outside of programme control that will increase the burden on GPs ahead of implementing the digital service or conducting the comms campaign. Although the infrastructure designed will meet the ministerial commitments, any major policy changes in this area may render our solutions obsolete or no longer fit-for-purpose, which is why the solution has not been implemented before the review of opt outs.	Current mitigations put in place following the NDOP spike should be robust enough to address any new central spike, however it should be noted that Type 1s will remain outside of programme control until a central service is implemented Programme to maintain ongoing discussions with GP profession to manage the impact of this risk, whilst reviewing plans for accelerating the implementation of the digital service alongside our engagement with data policy. It is worth noting that although the cause of any opt-out spike could come from any source, the most likely non-GPDPR programme cause would be through communications or actions by other areas of NHS England which could impact public views on data. As such, we are working closely together, to deliver an integrated approach to engagement and communications wherever appropriate and possible, and to consider sequencing and major delivery milestones as part of this process.
There is a risk that stakeholder groups may not accept the technical approach for retrospective deletion and push for deletion from historical studies rather than central database	Programme to clearly communicate rationale for current solution in an easy to understand and simple manner, with particular focus on the limits of data deletion for fully anonymised data or where existing legislative and policy provisions protect the use of data for research already underway or completed, even where informed consent has been removed. To this effect, the programme will review it’s public-facing documentation and build a standard and clear description around what retrospective deletion means in practice for data (i.e. a patient opting out would mean that their data would be deleted from the central database to ensure it can’t be used

	again in future unless they subsequently withdraw their opt-out) We are actively incorporating feedback into our approach, design, and communication documents and we are committed to continuing to seek feedback and ongoing support from Check & Challenge members as representatives from key stakeholder groups to mitigate wider challenge We will seek input, if required, from research community to add weight to requirement to only delete data for use from future studies, due to need to protect auditability and repeatability of any research conducted and because, in most cases the data was not identifiable so can't be identified to remove it. We will also engage with the research community to ask them to help us to transparently share this message as we communicate about this commitment
There is no specified time period included in the ministerial letter regarding the deferral to retire Type 1 opt-outs by at least 12 months.	The original assumption was that the deferral period was from September 2021 (the planned collection date at the time of letter issuance), but this has yet to be revisited given the programme has been focussing on establishing the plans, principles and designs regarding the technical elements of the ministerial commitments. The programme will need to align with Data Policy and Ministers to build a clear understanding around the forward approach for reviewing Type 1 opt-outs and any timelines associated with this.
There is an ongoing need for clear and transparent alignment between the GPDPR programme and Data Policy in relation to the commitments in regards to opt-outs made in the ministerial letter and the associated deliverables	The data policy teams position remains consistent with the data strategy commitment that; we will work with the public, the expert advisory group, the National Data Guardian (NDG) and other stakeholders to ensure that we have a simple opt-out system in place that provides clarity and choice, giving patients confidence, and ensuring data continues to support the functioning of the health and care system. The programme will look to maintain alignment with Data Policy and agree a clear deliverable outlining the policy position and forward roadmap for alignment with key

	stakeholders in parallel with creation of the required IG & legal documentation and GPDPR comms campaign.

Conclusions / summary

The programme team is confident that the work undertaken to date in addressing the opt-out backlog from May 2021 is sufficient to meet the commitment made within the ministerial letter. A comprehensive report has been prepared and will be shared with Check & Challenge members for review, feedback, and formal acceptance that this commitment has been met. Following formal acceptance, the full report will be published online.

The technical design for retrospective deletion (as presented and discussed with Check & Challenge members) provides the most appropriate solution to ensuring that patients recording a new opt-out preference are removed from the data set and are not included in any future planning & research, whilst maintaining the integrity of an historic or ongoing planning or research. The design work is fully complete and will be implemented once timelines for GPDPR are confirmed.

The service design for the Type 1 Digital Service (as presented and discussed with Check & Challenge members and other stakeholders) provides a potential self-service approach for patients to actively view and record their Type 1 opt-out preferences in real time. The solution has been devised in alignment with the current NDOP solution, to provide consistency of user experience, and has been influenced by user research conducted with patients and general public. When paired with the existing non-digital routes for patients to register a Type 1 opt-out (such as directly with their GP ither verbally or via paper form), this solution will ensure a fully accessible set of options for patients to exert their preference as to how their data is used and accessed. The design work is now complete, and build can be progressed when timelines for GPDPR are confirmed.

The GPDPR Programme asks Check & Challenge members to confirm this document provides an accurate overview of the discussions and progress to date towards meeting the ministerial commitments, and that the completed designs for retrospective deletion and the Type 1 digital service will meet their respective ministerial commitments if delivered as designed.

Annex 1

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

Supporting Document 1: Process to agree GPDPR 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 GPDPR 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
• 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; **(Opt-outs)**	• Data will be deleted if / when patients opt out therefore no opt-out deadline is required for data collection.	• 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)**
• the backlog of opt-outs has been fully cleared; **(Opt-outs)**	• The backlog of NDOPs and Type 1 requests specifically within Contact Centre built up prior to July 2021 is considered to be cleared.	• 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
• a Trusted Research Environment has been developed and implemented in NHS Digital; **(Data Management, Access and Governance)**	• 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.	• 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
• patients have been made more aware of the scheme through a campaign of engagement and communication. **(Comms)**	• Through a broader engagement and communication campaign, which GPDPR-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.	• Formal confirmation reached with BMA, RCGP and NDG that Comms Strategy is sufficient to address the challenge of patient/public/healthcare community understanding of GPDPR • Formal alignment reached on scope of GPDPR-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
• data extraction will not commence until we have met the tests. **(Comms)**	• GPDPR extraction will not commence until we have satisfied primary commitments above	• 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

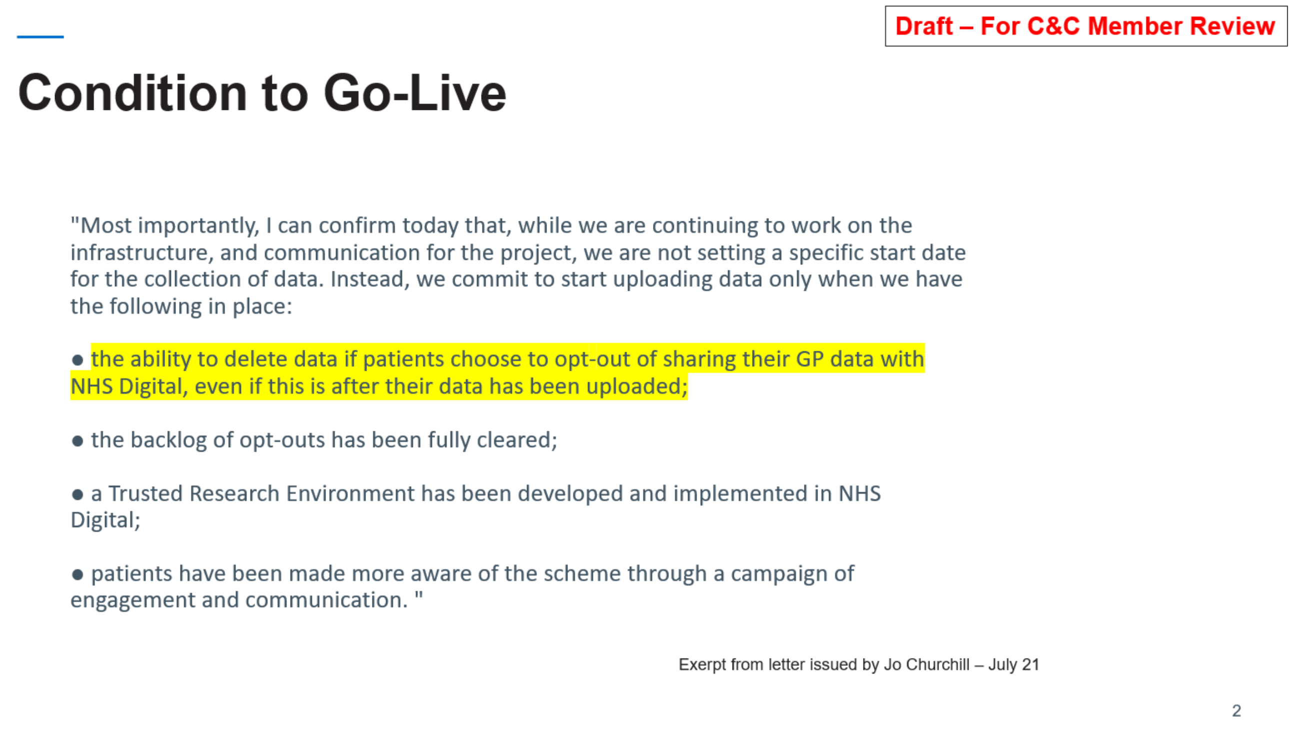
Supporting Document 3: Retrospective Deletion Supporting Information

Draft – For C&C Member Review

NHS Digital

Retrospective Deletions for GPDPR

Update for Check & Challenge



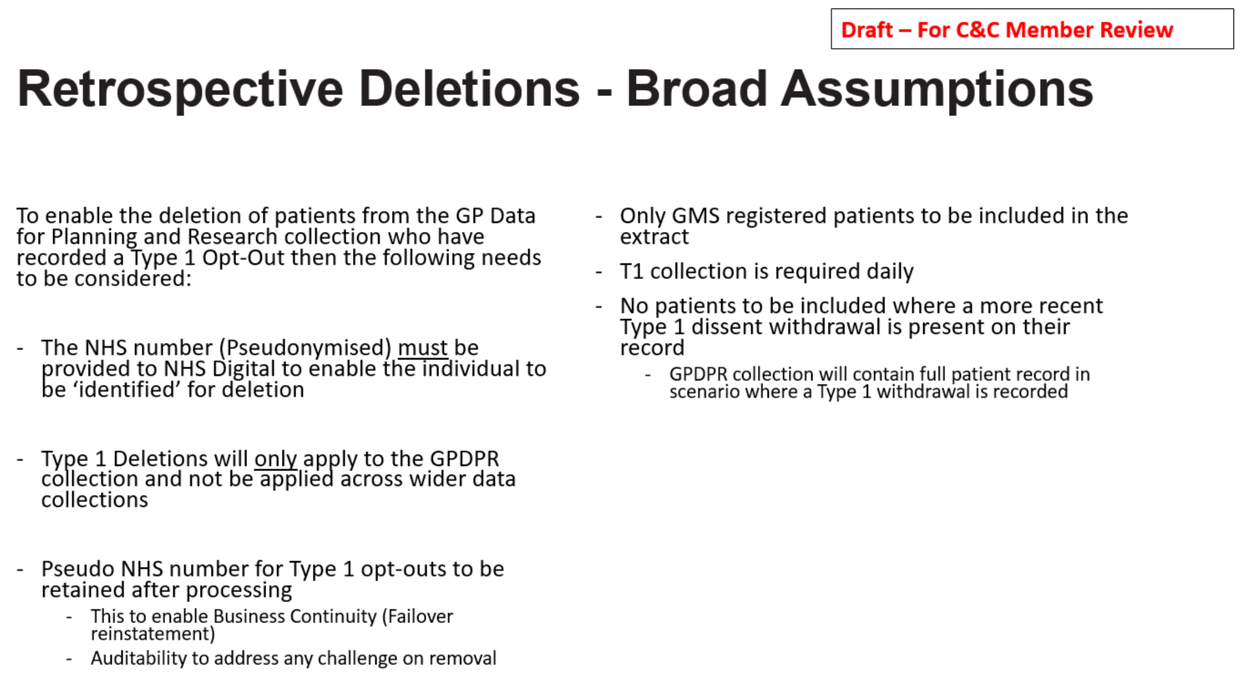
Draft – For C&C Member Review

Condition to Go-Live

"Most importantly, I can confirm today that, while we are continuing to work on the infrastructure, and communication for the project, we are not setting a specific start date for the collection of data. Instead, we commit to start uploading data only when we have the following in place:

- 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;
- the backlog of opt-outs has been fully cleared;
- a Trusted Research Environment has been developed and implemented in NHS Digital;
- patients have been made more aware of the scheme through a campaign of engagement and communication. "

Exerpt from letter issued by Jo Churchill – July 21

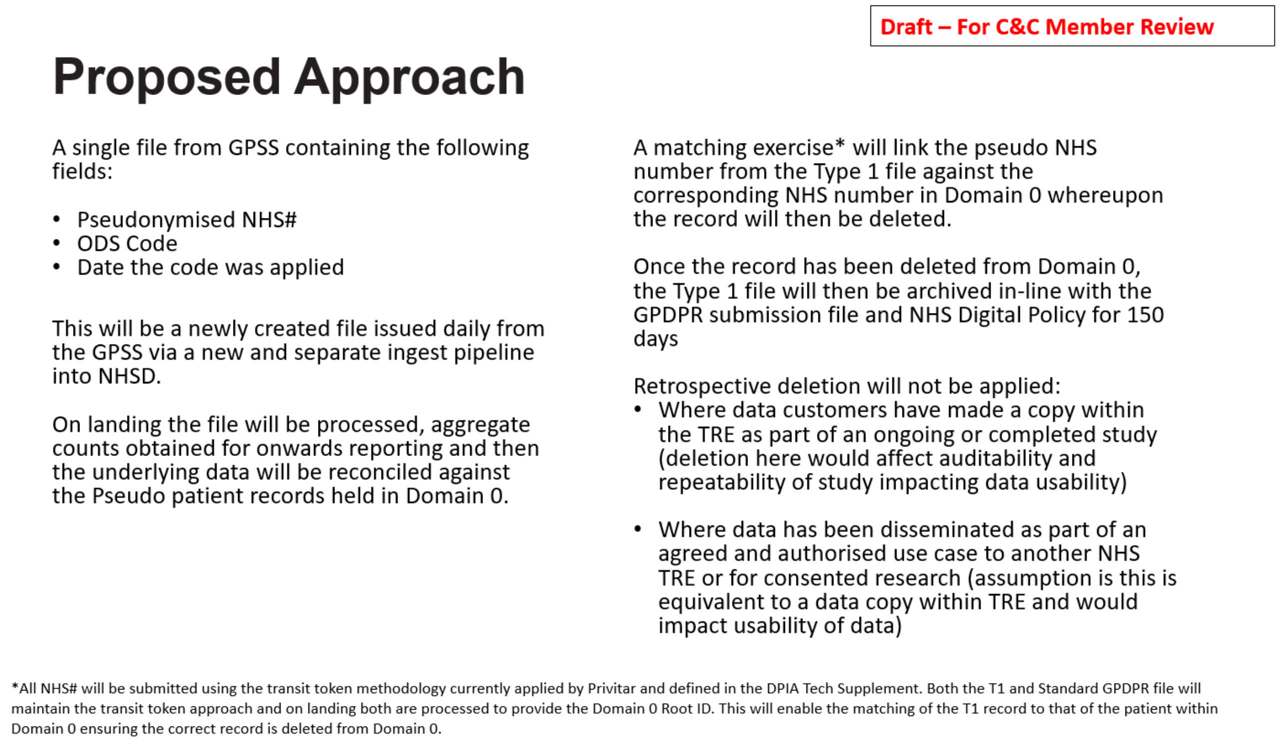


Draft – For C&C Member Review

Retrospective Deletions - Broad Assumptions

To enable the deletion of patients from the GP Data for Planning and Research collection who have recorded a Type 1 Opt-Out then the following needs to be considered:

- The NHS number (Pseudonymised) must be provided to NHS Digital to enable the individual to be 'identified' for deletion
- Type 1 Deletions will only apply to the GPDPR collection and not be applied across wider data collections
- Pseudo NHS number for Type 1 opt-outs to be retained after processing
  - This to enable Business Continuity (Failover reinstatement)
  - Auditability to address any challenge on removal
- Only GMS registered patients to be included in the extract
- T1 collection is required daily
- No patients to be included where a more recent Type 1 dissent withdrawal is present on their record
  - GPDPR collection will contain full patient record in scenario where a Type 1 withdrawal is recorded



Draft – For C&C Member Review

Proposed Approach

A single file from GPSS containing the following fields:

- Pseudonymised NHS#
- ODS Code
- Date the code was applied

This will be a newly created file issued daily from the GPSS via a new and separate ingest pipeline into NHSD.

On landing the file will be processed, aggregate counts obtained for onwards reporting and then the underlying data will be reconciled against the Pseudo patient records held in Domain 0.

A matching exercise* will link the pseudo NHS number from the Type 1 file against the corresponding NHS number in Domain 0 whereupon the record will then be deleted.

Once the record has been deleted from Domain 0, the Type 1 file will then be archived in-line with the GPDPR submission file and NHS Digital Policy for 150 days

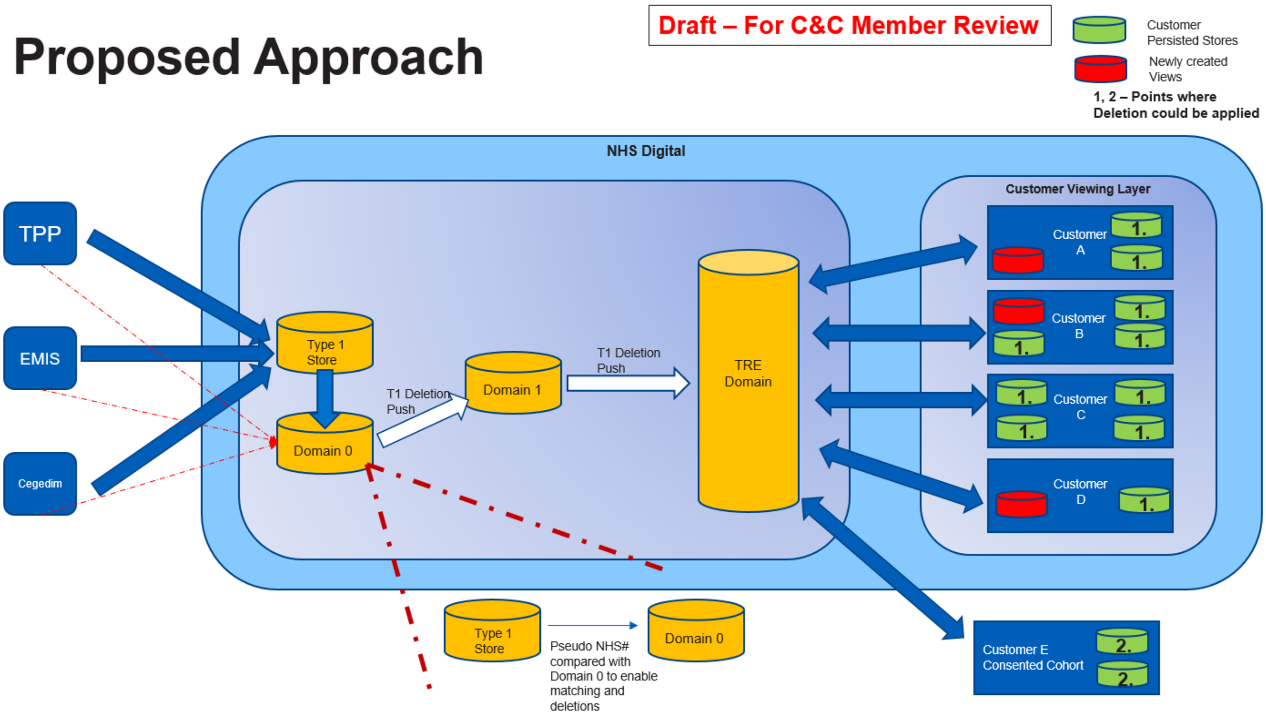
Retrospective deletion will not be applied:

- Where data customers have made a copy within the TRE as part of an ongoing or completed study (deletion here would affect auditability and repeatability of study impacting data usability)
- Where data has been disseminated as part of an agreed and authorised use case to another NHS TRE or for consented research (assumption is this is equivalent to a data copy within TRE and would impact usability of data)

*All NHS# will be submitted using the transit token methodology currently applied by Privitar and defined in the DPIA Tech Supplement. Both the T1 and Standard GPDPR file will maintain the transit token approach and on landing both are processed to provide the Domain 0 Root ID. This will enable the matching of the T1 record to that of the patient within Domain 0 ensuring the correct record is deleted from Domain 0.

Proposed Approach

Draft – For C&C Member Review



Draft – For C&C Member Review

Consent Consideration

Amend the Type 1 opt-out form to include a signed consent section at the bottom of the page that makes clear that:

- by completing the form the patient is giving consent to having their NHS Number sent to NHS Digital in pseudonymised form to enable the deletion of their data from the GPDPR collection.
- It needs to also make clear that a record of the pseudo NHS Number be retained for the for the following purposes
  - Business Continuity (Failover and Systems Re-instatement)
  - Auditability to address any challenge on removal and
  - that after the 150 days their pseudo NHS number will be deleted.

The wording and explanation will need testing as it could become quite complex but the main thing is to ensure a patient understands how and what is happening when they register the Opt-out

Proposal is to address this via detailed Privacy and Transparency information and not add complexity to the Type1 form by adding consent

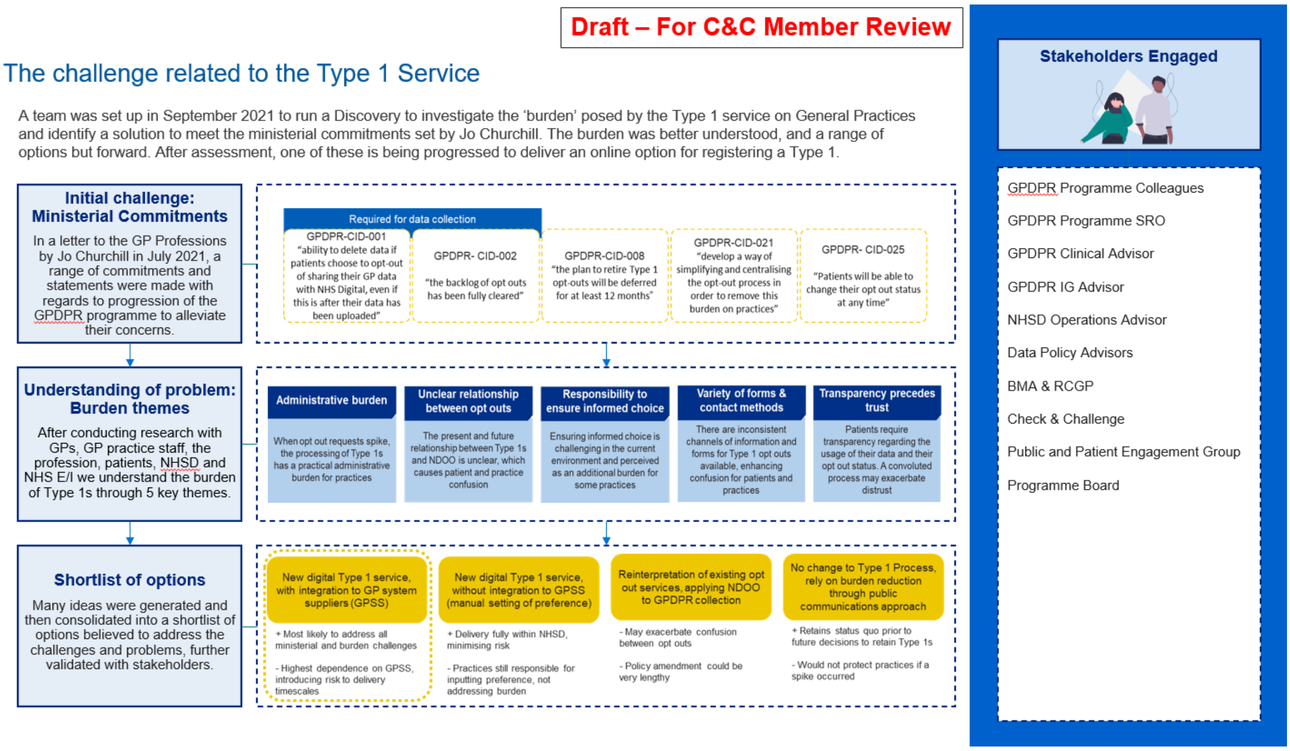
Supporting Document 4: Type 1 Digital Service Design Supporting Information

Draft – For C&C Member Review

NHS Digital

Type 1 Opt-out Service Design

Check & Challenge Overview Document



Draft – For C&C Member Review

The challenge related to the Type 1 Service

A team was set up in September 2021 to run a Discovery to investigate the ‘burden’ posed by the Type 1 service on General Practices and identify a solution to meet the ministerial commitments set by Jo Churchill. The burden was better understood, and a range of options but forward. After assessment, one of these is being progressed to deliver an online option for registering a Type 1.

Initial challenge: Ministerial Commitments

In a letter to the GP Professions by Jo Churchill in July 2021, a range of commitments and statements were made with regards to progression of the GPDPR programme to alleviate their concerns.

Required for data collection

- GPDPR-CID-001 “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”
- GPDPR- CID-002 “the backlog of opt outs has been fully cleared”
- GPDPR-CID-008 “the plan to retire Type 1 opt-outs will be deferred for at least 12 months”
- GPDPR-CID-021 “develop a way of simplifying and centralising the opt-out process in order to remove this burden on practices”
- GPDPR- CID-025 “Patients will be able to change their opt out status at any time”

Understanding of problem: Burden themes

After conducting research with GPs, GP practice staff, the profession, patients, NHSD and NHS E/I we understand the burden of Type 1s through 5 key themes.

- **Administrative burden** When opt out requests spike, the processing of Type 1s has a practical administrative burden for practices
- **Unclear relationship between opt outs** The present and future relationship between Type 1s and NDOO is unclear, which causes patient and practice confusion
- **Responsibility to ensure informed choice** Ensuring informed choice is challenging in the current environment and perceived as an additional burden for some practices
- **Variety of forms & contact methods** There are inconsistent channels of information and forms for Type 1 opt outs available, enhancing confusion for patients and practices
- **Transparency precedes trust** Patients require transparency regarding the usage of their data and their opt out status. A convoluted process may exacerbate distrust

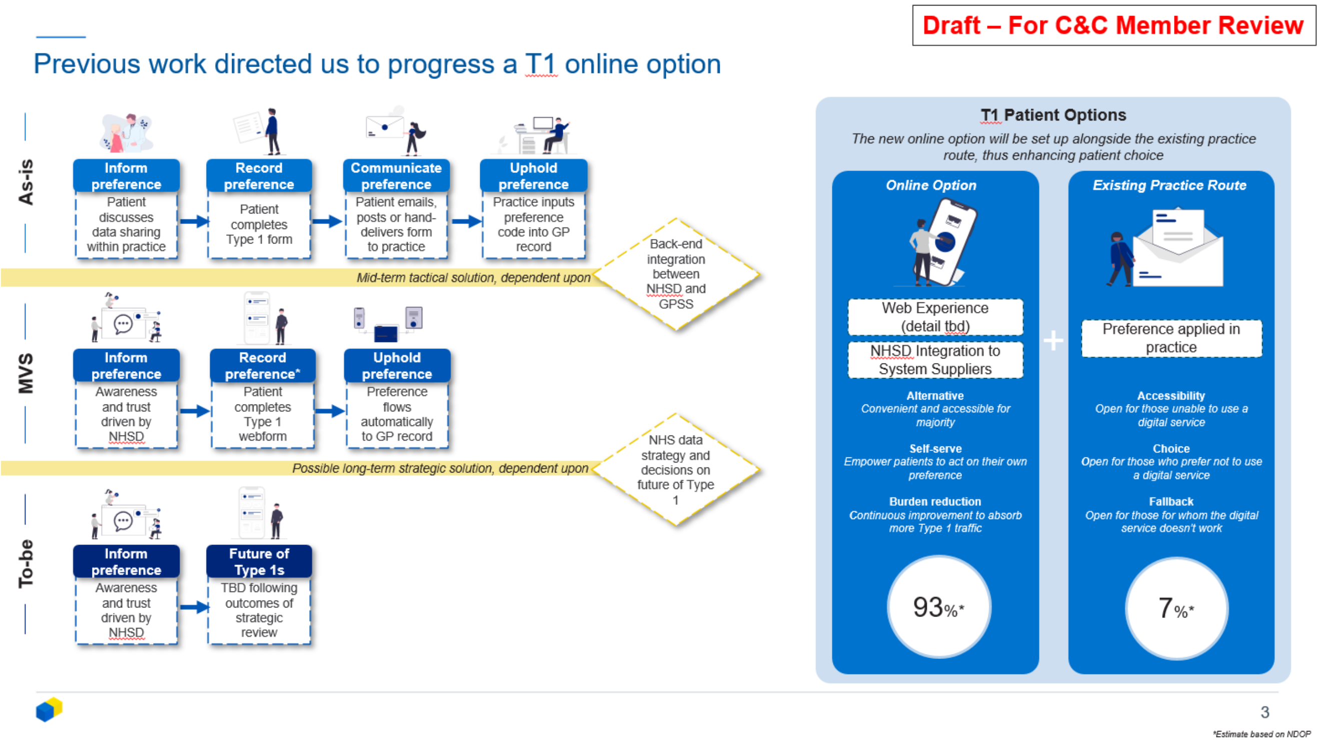
Shortlist of options

Many ideas were generated and then consolidated into a shortlist of options believed to address the challenges and problems, further validated with stakeholders.

New digital Type 1 service, with integration to GP system suppliers (GPSS)	New digital Type 1 service, without integration to GPSS (manual setting of preference)	Reinterpretation of existing opt out services, applying NDOO to GPDPR collection	No change to Type 1 Process, rely on burden reduction through public communications approach
+ Most likely to address all ministerial and burden challenges	+ Delivery fully within NHSD, minimising risk	- May exacerbate confusion between opt outs	+ Retains status quo prior to future decisions to retain Type 1s
- Highest dependence on GPSS, introducing risk to delivery timescales	- Practices still responsible for inputting preference, not addressing burden	- Policy amendment could be very lengthy	- Would not protect practices if a spike occurred

Stakeholders Engaged

- GPDPR Programme Colleagues
- GPDPR Programme SRO
- GPDPR Clinical Advisor
- GPDPR IG Advisor
- NHSD Operations Advisor
- Data Policy Advisors
- BMA & RCGP
- Check & Challenge
- Public and Patient Engagement Group
- Programme Board



Draft – For C&C Member Review

Previous work directed us to progress a T1 online option

As-is

Inform preference
Patient discusses data sharing within practice
→ **Record preference**
Patient completes Type 1 form
→ **Communicate preference**
Patient emails, posts or hand-delivers form to practice
→ **Uphold preference**
Practice inputs preference code into GP record

Mid-term tactical solution, dependent upon Back-end integration between NHSD and GPSS

MVS

Inform preference
Awareness and trust driven by NHSD
→ **Record preference***
Patient completes Type 1 webform
→ **Uphold preference**
Preference flows automatically to GP record

Possible long-term strategic solution, dependent upon NHS data strategy and decisions on future of Type 1

To-be

Inform preference
Awareness and trust driven by NHSD
→ **Future of Type 1s**
TBD following outcomes of strategic review

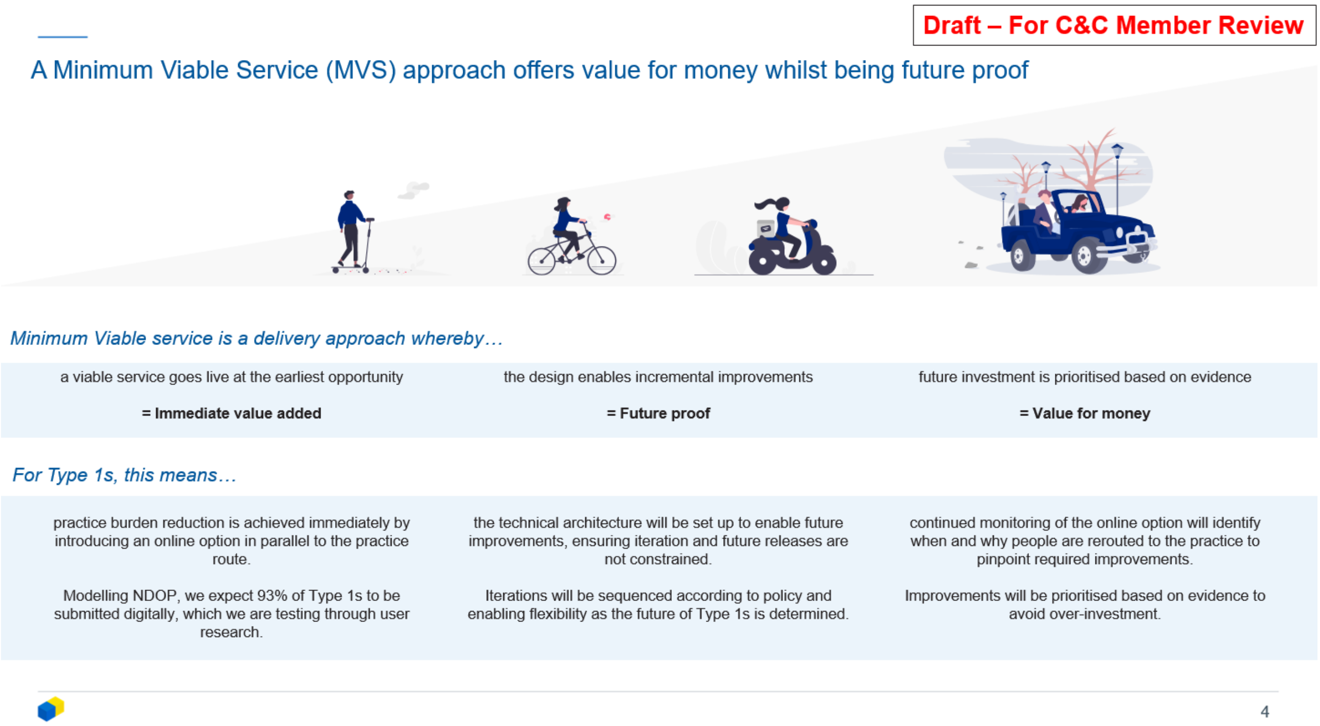
T1 Patient Options

The new online option will be set up alongside the existing practice route, thus enhancing patient choice

Online Option		***Existing Practice Route***
Web Experience (detail tbd) NHSD Integration to System Suppliers	+	Preference applied in practice
Alternative *Convenient and accessible for majority*		**Accessibility** *Open for those unable to use a digital service*
Self-serve *Empower patients to act on their own preference*		**Choice** *Open for those who prefer not to use a digital service*
Burden reduction *Continuous improvement to absorb more Type 1 traffic*		**Fallback** *Open for those for whom the digital service doesn't work*
93%*		7%*

3

*Estimate based on NDOP



Draft – For C&C Member Review

A Minimum Viable Service (MVS) approach offers value for money whilst being future proof

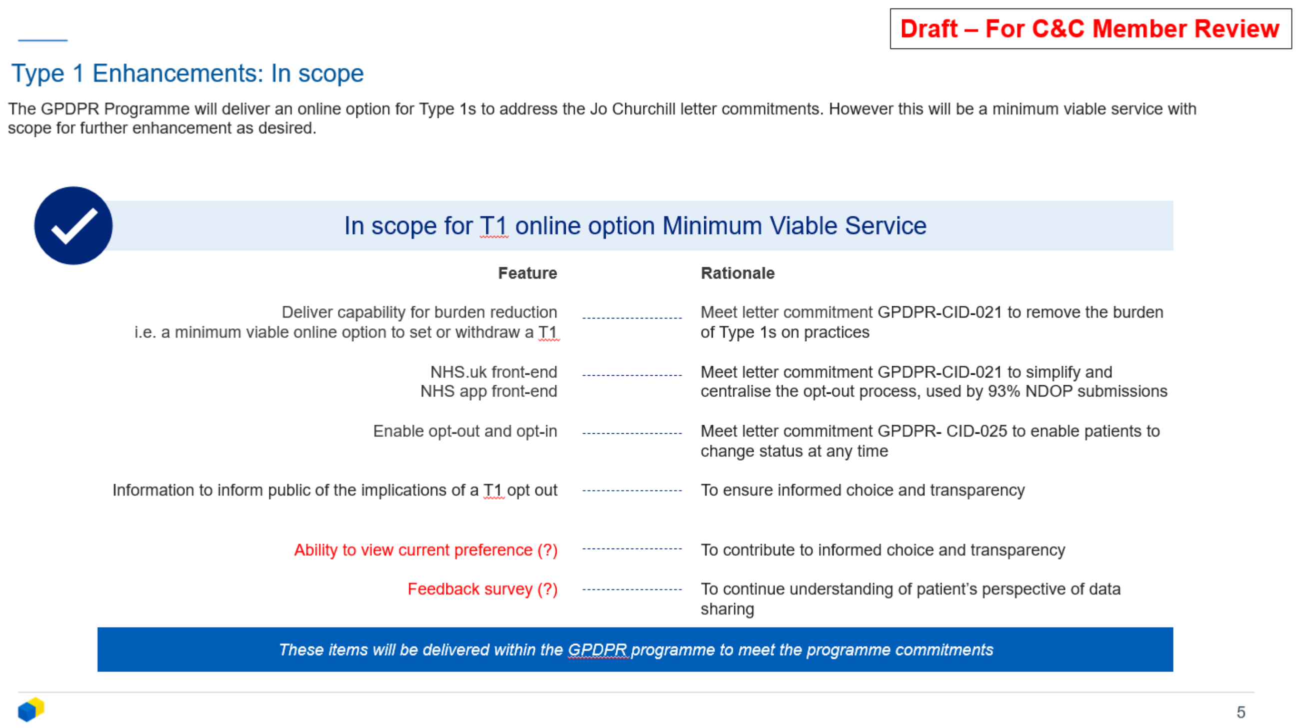
Minimum Viable service is a delivery approach whereby…

a viable service goes live at the earliest opportunity	the design enables incremental improvements	future investment is prioritised based on evidence
= Immediate value added	**= Future proof**	**= Value for money**

For Type 1s, this means…

practice burden reduction is achieved immediately by introducing an online option in parallel to the practice route. Modelling NDOP, we expect 93% of Type 1s to be submitted digitally, whilst we are testing through user research.	the technical architecture will be set up to enable future improvements, ensuring iteration and future releases are not constrained. Iterations will be sequenced according to policy and enabling flexibility as the future of Type 1s is determined.	continued monitoring of the online option will identify when and why people are rerouted to the practice to pinpoint required improvements. Improvements will be prioritised based on evidence to avoid over-investment.

4



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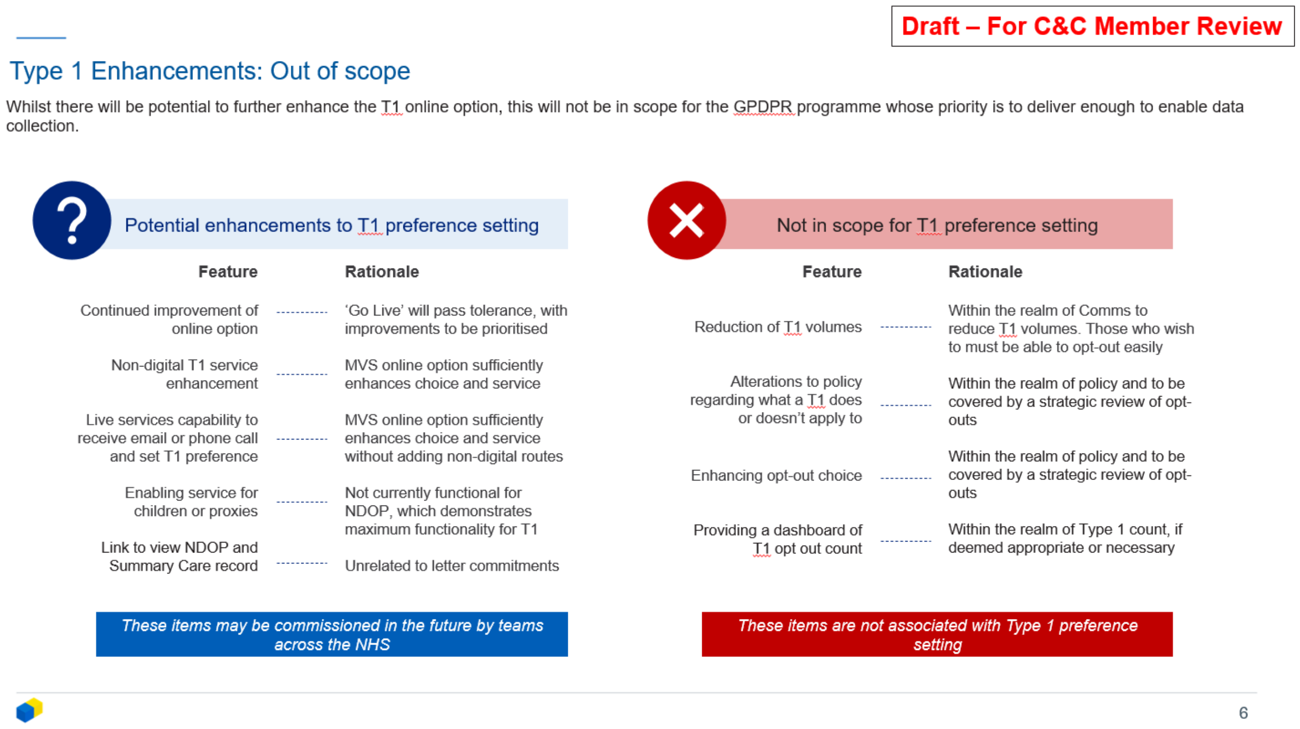
Type 1 Enhancements: In scope

The GPDPR Programme will deliver an online option for Type 1s to address the Jo Churchill letter commitments. However this will be a minimum viable service with scope for further enhancement as desired.

✓ In scope for T1 online option Minimum Viable Service

Feature	Rationale
Deliver capability for burden reduction i.e. a minimum viable online option to set or withdraw a T1	Meet letter commitment GPDPR-CID-021 to remove the burden of Type 1s on practices
NHS.uk front-end NHS app front-end	Meet letter commitment GPDPR-CID-021 to simplify and centralise the opt-out process, used by 93% NDOP submissions
Enable opt-out and opt-in	Meet letter commitment GPDPR- CID-025 to enable patients to change status at any time
Information to inform public of the implications of a T1 opt out	To ensure informed choice and transparency
Ability to view current preference (?)	To contribute to informed choice and transparency
Feedback survey (?)	To continue understanding of patient's perspective of data sharing

These items will be delivered within the GPDPR programme to meet the programme commitments



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Type 1 Enhancements: Out of scope

Whilst there will be potential to further enhance the T1 online option, this will not be in scope for the GPDPR programme whose priority is to deliver enough to enable data collection.

? Potential enhancements to T1 preference setting

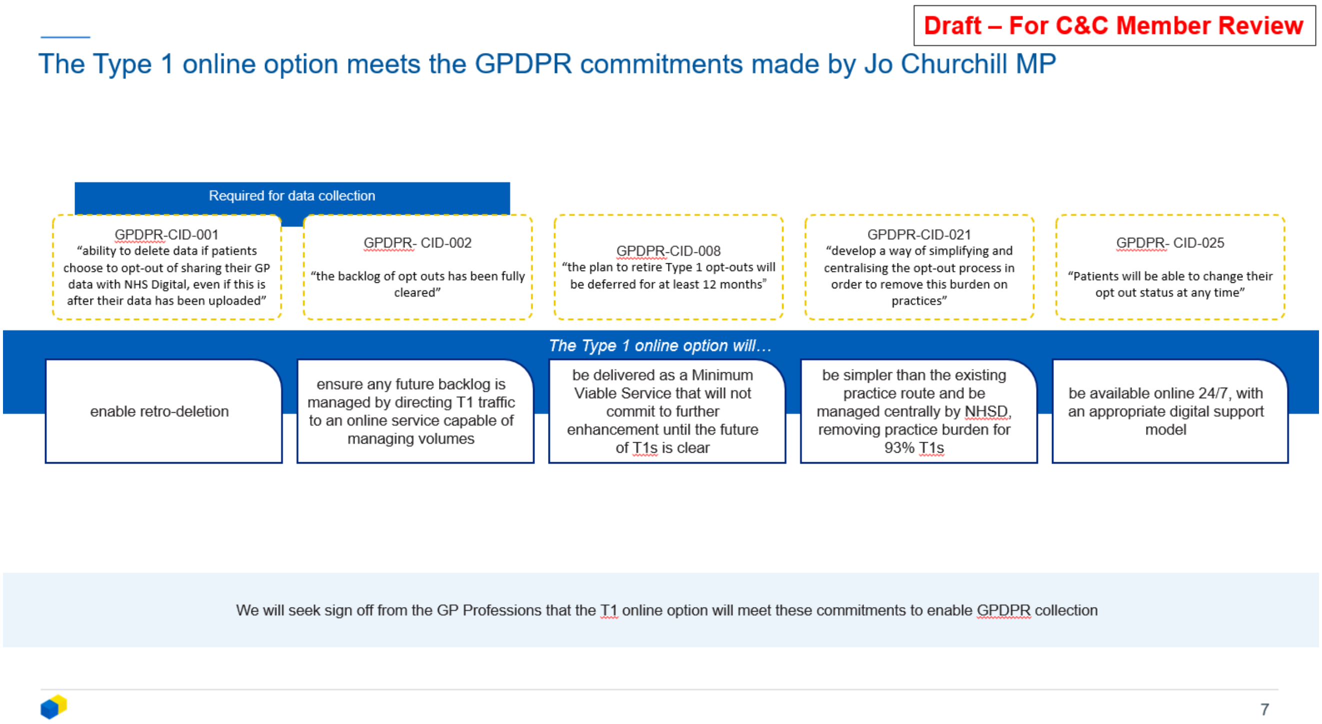
Feature	Rationale
Continued improvement of online option	'Go Live' will pass tolerance, with improvements to be prioritised
Non-digital T1 service enhancement	MVS online option sufficiently enhances choice and service
Live services capability to receive email or phone call and set T1 preference	MVS online option sufficiently enhances choice and service without adding non-digital routes
Enabling service for children or proxies	Not currently functional for NDOP, which demonstrates maximum functionality for T1
Link to view NDOP and Summary Care record	Unrelated to letter commitments

These items may be commissioned in the future by teams across the NHS

✕ Not in scope for T1 preference setting

Feature	Rationale
Reduction of T1 volumes	Within the realm of Comms to reduce T1 volumes. Those who wish to must be able to opt-out easily
Alterations to policy regarding what a T1 does or doesn't apply to	Within the realm of policy and to be covered by a strategic review of opt-outs
Enhancing opt-out choice	Within the realm of policy and to be covered by a strategic review of opt-outs
Providing a dashboard of T1 opt out count	Within the realm of Type 1 count, if deemed appropriate or necessary

These items are not associated with Type 1 preference setting



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The Type 1 online option meets the GPDPR commitments made by Jo Churchill MP

Required for data collection

GPDPR-CID-001	GPDPR- CID-002	GPDPR-CID-008	GPDPR-CID-021	GPDPR- CID-025
"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"	"the backlog of opt outs has been fully cleared"	"the plan to retire Type 1 opt-outs will be deferred for at least 12 months"	"develop a way of simplifying and centralising the opt-out process in order to remove this burden on practices"	"Patients will be able to change their opt out status at any time"

The Type 1 online option will…

enable retro-deletion	ensure any future backlog is managed by directing T1 traffic to an online service capable of managing volumes	be delivered as a Minimum Viable Service that will not commit to further enhancement until the future of T1s is clear	be simpler than the existing practice route and be managed centrally by NHSD, removing practice burden for 93% T1s	be available online 24/7, with an appropriate digital support model

We will seek sign off from the GP Professions that the T1 online option will meet these commitments to enable GPDPR collection

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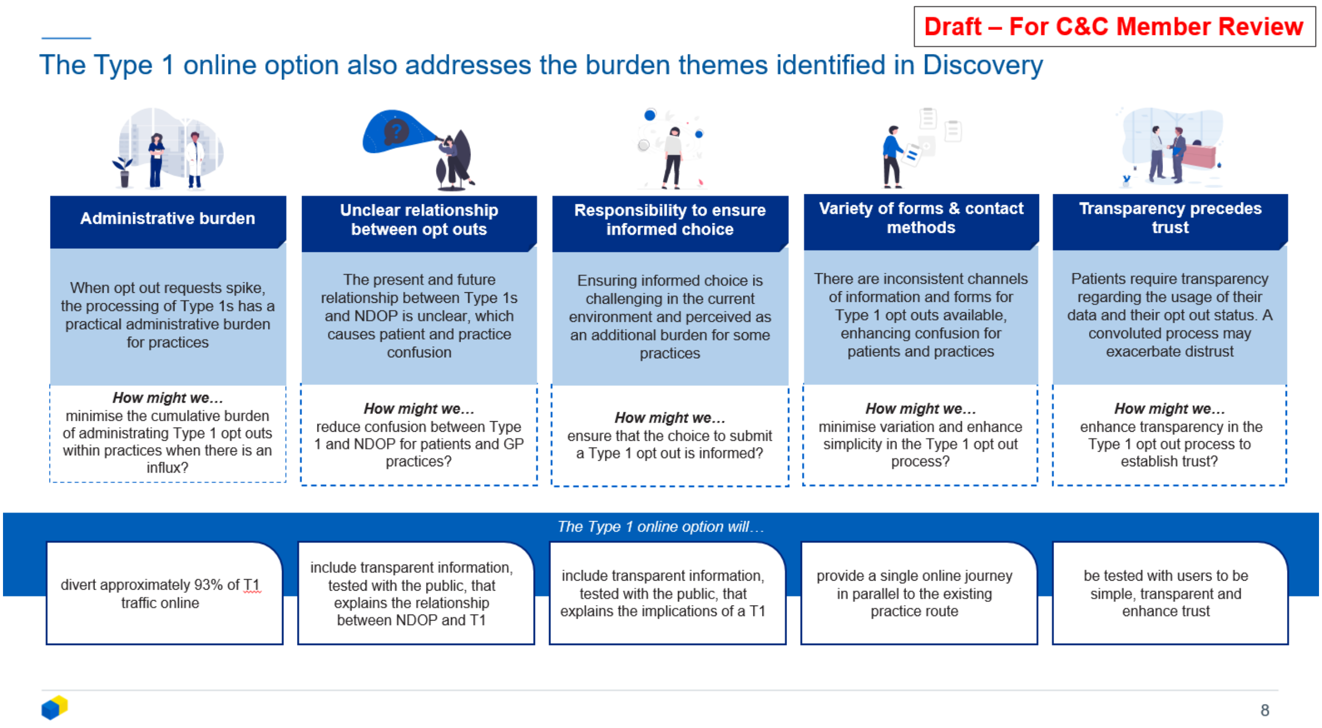

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The Type 1 online option also addresses the burden themes identified in Discovery

Administrative burden	**Unclear relationship between opt outs**	**Responsibility to ensure informed choice**	**Variety of forms & contact methods**	**Transparency precedes trust**
When opt out requests spike, the processing of Type 1s has a practical administrative burden for practices	The present and future relationship between Type 1s and NDOP is unclear, which causes patient and practice confusion	Ensuring informed choice is challenging in the current environment and perceived as an additional burden for some practices	There are inconsistent channels of information and forms for Type 1 opt outs available, enhancing confusion for patients and practices	Patients require transparency regarding the usage of their data and their opt out status. A convoluted process may exacerbate distrust
How might we… minimise the cumulative burden of administrating Type 1 opt outs within practices when there is an influx?	***How might we…*** reduce confusion between Type 1 and NDOP for patients and GP practices?	***How might we…*** ensure that the choice to submit a Type 1 opt out is informed?	***How might we…*** minimise variation and enhance simplicity in the Type 1 opt out process?	***How might we…*** enhance transparency in the Type 1 opt out process to establish trust?

The Type 1 online option will…

divert approximately 93% of T1 traffic online	include transparent information, tested with the public, that explains the relationship between NDOP and T1	include transparent information, tested with the public, that explains the implications of a T1	provide a single online journey in parallel to the existing practice route	be tested with users to be simple, transparent and enhance trust

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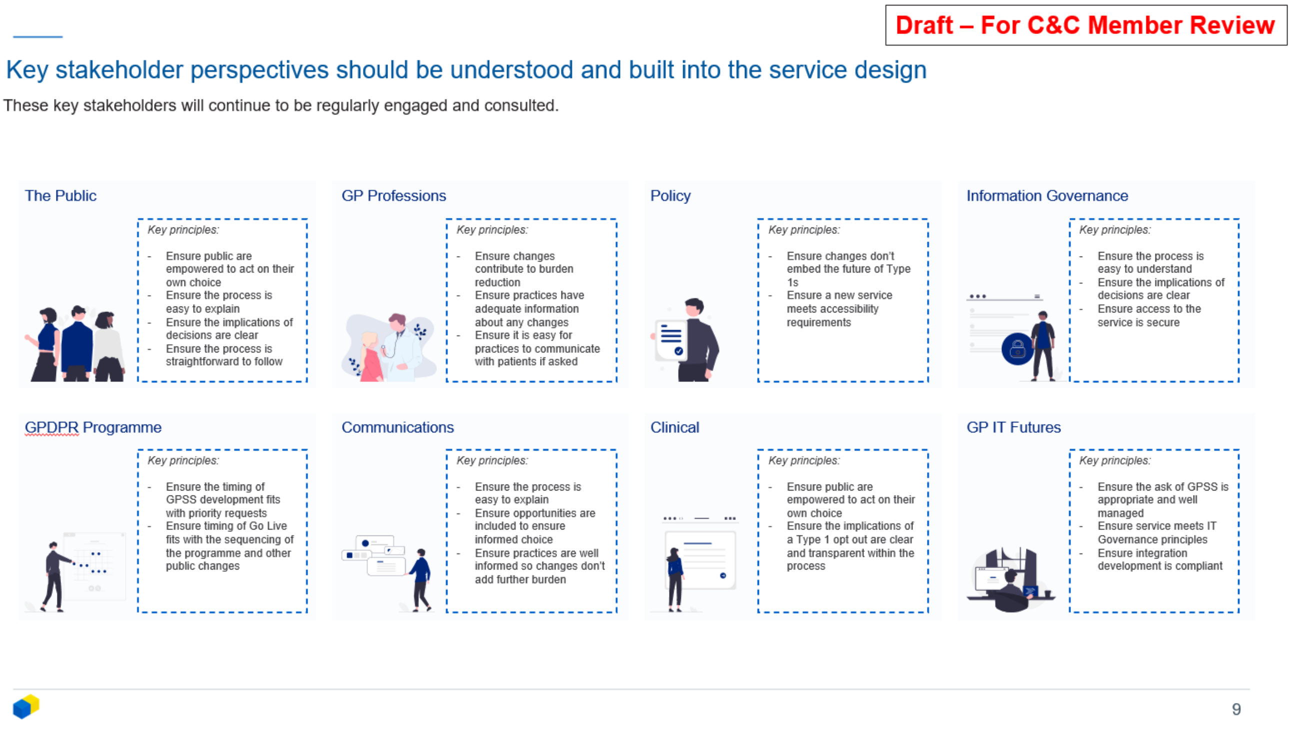

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Key stakeholder perspectives should be understood and built into the service design

These key stakeholders will continue to be regularly engaged and consulted.

The Public

Key principles:

- Ensure public are empowered to act on their own choice
- Ensure the process is easy to explain
- Ensure the implications of decisions are clear
- Ensure the process is straightforward to follow

GP Professions

Key principles:

- Ensure changes contribute to burden reduction
- Ensure practices have adequate information about any changes
- Ensure it is easy for practices to communicate with patients if asked

Policy

Key principles:

- Ensure changes don't embed the future of Type 1s
- Ensure a new service meets accessibility requirements

Information Governance

Key principles:

- Ensure the process is easy to understand
- Ensure the implications of decisions are clear
- Ensure access to the service is secure

GPDPR Programme

Key principles:

- Ensure the timing of GPSS development fits with priority requests
- Ensure timing of Go Live fits with the sequencing of the programme and other public changes

Communications

Key principles:

- Ensure the process is easy to explain
- Ensure opportunities are included to ensure informed choice
- Ensure practices are well informed so changes don't add further burden

Clinical

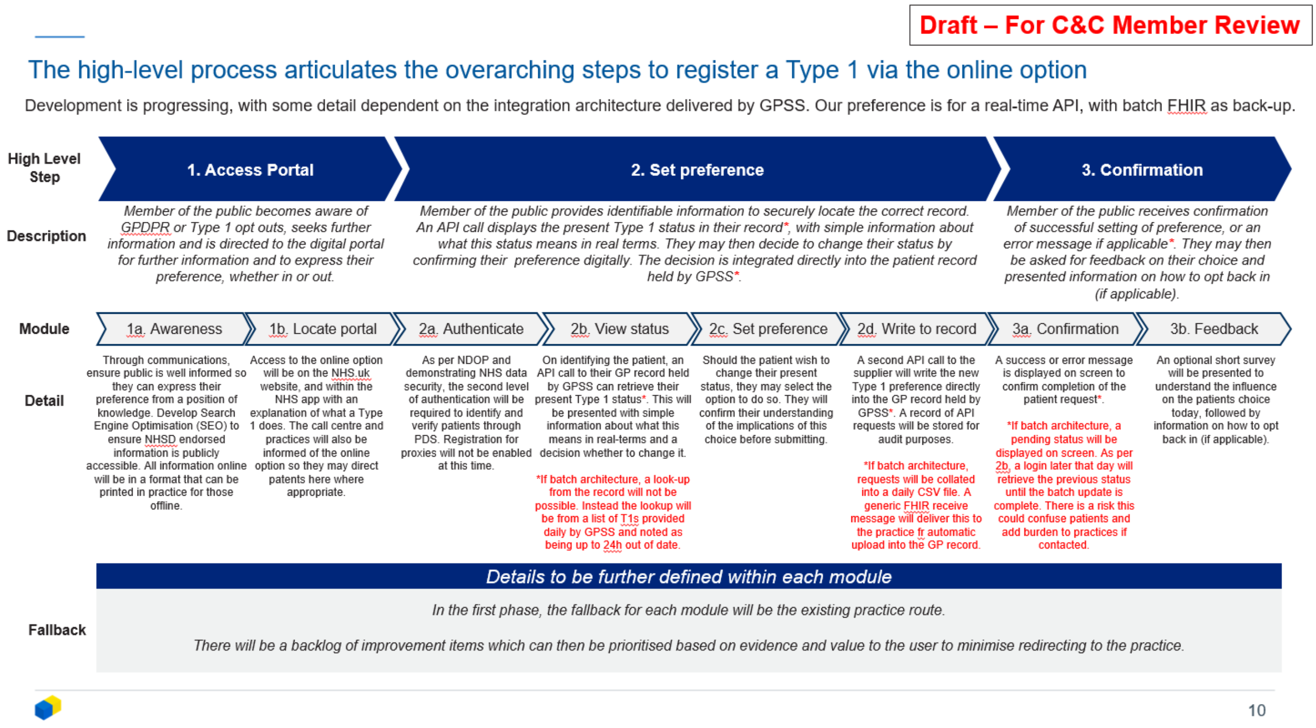
Key principles:

- Ensure public are empowered to act on their own choice
- Ensure the implications of a Type 1 opt out are clear and transparent within the process

GP IT Futures

Key principles:

- Ensure the ask of GPSS is appropriate and well managed
- Ensure service meets IT Governance principles
- Ensure integration development is compliant



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The high-level process articulates the overarching steps to register a Type 1 via the online option

Development is progressing, with some detail dependent on the integration architecture delivered by GPSS. Our preference is for a real-time API, with batch FHIR as back-up.

High Level Step	**1. Access Portal**		**2. Set preference**				**3. Confirmation**	
Description	*Member of the public becomes aware of GPDPR or Type 1 opt outs, seeks further information and is directed to the digital portal for further information and to express their preference, whether in or out.*		*Member of the public provides identifiable information to securely locate the correct record. An API call displays the present Type 1 status in their record*, with simple information about what this status means in real terms. They may then decide to change their status by confirming their preference digitally. The decision is integrated directly into the patient record held by GPSS*.*				*Member of the public receives confirmation of successful setting of preference, or an error message if applicable*. They may then be asked for feedback on their choice and presented information on how to opt back in (if applicable).*	
Module	1a. Awareness	1b. Locate portal	2a. Authenticate	2b. View status	2c. Set preference	2d. Write to record	3a. Confirmation	3b. Feedback
Detail	Through communications, ensure public is well informed so they can express their preference from a position of knowledge. Develop Search Engine Optimisation (SEO) to ensure NHSD endorsed information is publicly accessible. All information online will be in a format that can be printed in practice for those offline.	Access to the online option will be on the NHS.uk website, and within the NHS app with an explanation of what a Type 1 does. The call centre and practices will also be informed of the online option so they may direct patents here where appropriate.	As per NDOP and demonstrating NHS data security, the second level of authentication will be required to identify and verify patients through PDS. Registration for proxies will not be enabled at this time.	On identifying the patient, an API call to their GP record held by GPSS can retrieve their present Type 1 status*. This will be presented with simple information about what this means in real-terms and a decision whether to change it. *If batch architecture, a look-up from the record will not be possible. Instead the lookup will be from a list of T1s provided daily by GPSS and noted as being up to 24h out of date.	Should the patient wish to change their present status, they may select the option to do so. They will confirm their understanding of the implications of this choice before submitting.	A second API call to the supplier will write the new Type 1 preference directly into the GP record held by GPSS*. A record of API requests will be stored for audit purposes. *If batch architecture, requests will be collated into a daily CSV file. A generic FHIR receive message will deliver this to the practice fr automatic upload into the GP record.	A success or error message is displayed on screen to confirm completion of the patient request*. *If batch architecture, a pending status will be displayed on screen. As per 2b, a login later that day will retrieve the previous status until the batch update is complete. There is a risk this could confuse patients and add burden to practices if contacted.	An optional short survey will be presented to understand the influence on the patients choice today, followed by information on how to opt back in (if applicable).
	Details to be further defined within each module							
Fallback	*In the first phase, the fallback for each module will be the existing practice route.* *There will be a backlog of improvement items which can then be prioritised based on evidence and value to the user to minimise redirecting to the practice.*							

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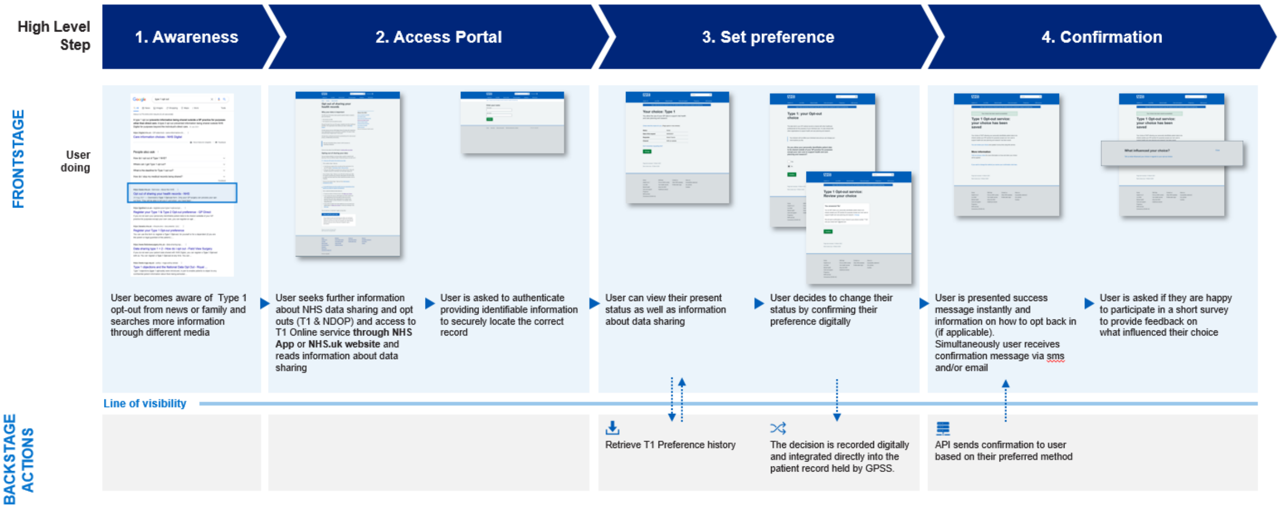
Service Blueprint

How the Service aligns to user need to opt-out through the NHS App or NHS.uk website
AWS RESTful real-time API



User becomes aware of Type 1 opt-out from news or family and searches more information through different media

User seeks further information about NHS data sharing and opt outs (T1 & NDOP) and access to T1 Online service **through NHS App** or **NHS.uk website** and reads information about data sharing

User is asked to authenticate providing identifiable information to securely locate the correct record

User can view their present status as well as information about data sharing

User decides to change their status by confirming their preference digitally

User is presented success message instantly and information on how to opt back in (if applicable). Simultaneously user receives confirmation message via sms and/or email

User is asked if they are happy to participate in a short survey to provide feedback on what influenced their choice

Retrieve T1 Preference history

The decision is recorded digitally and integrated directly into the patient record held by GPSS.

API sends confirmation to user based on their preferred method