Integrated Care Experience Survey Programme

Engagement Brochure

Version 1.2, November 2023

Contents

This brochure has been developed to provide all stakeholders with key information about delivery of the Integrated Care Experience Survey and Programme. The brochure is broken down into two sections:

Section 1 covers key top level information describing the Why, What, How and When for the survey.

Section 2 provides additional reference information and links of interest for specific stakeholders.

The brochure can be navigated via the links on this Contents page and via the ribbon and links on the top of each slide.

Section 1

Key Integrated Care Experience Survey Information

The need for an Integrated Care Experience Survey

Integrated Care Systems are now on a statutory footing:
One of the core purposes of ICSs is to tackle inequalities in experience of care, and one of the indicators for success will be the level of integration and partnership working as seen through the lens of local populations.

Public commitment:
There is a legal duty on ICBs to involve the public in decision making about NHS services. Many systems have a range of mechanisms to gather qualitative insight into people's experience and views of local services. But ICSs have also highlighted complexity and cost involved in running robust surveys that can gather regular insight into people's experience of integrated care.

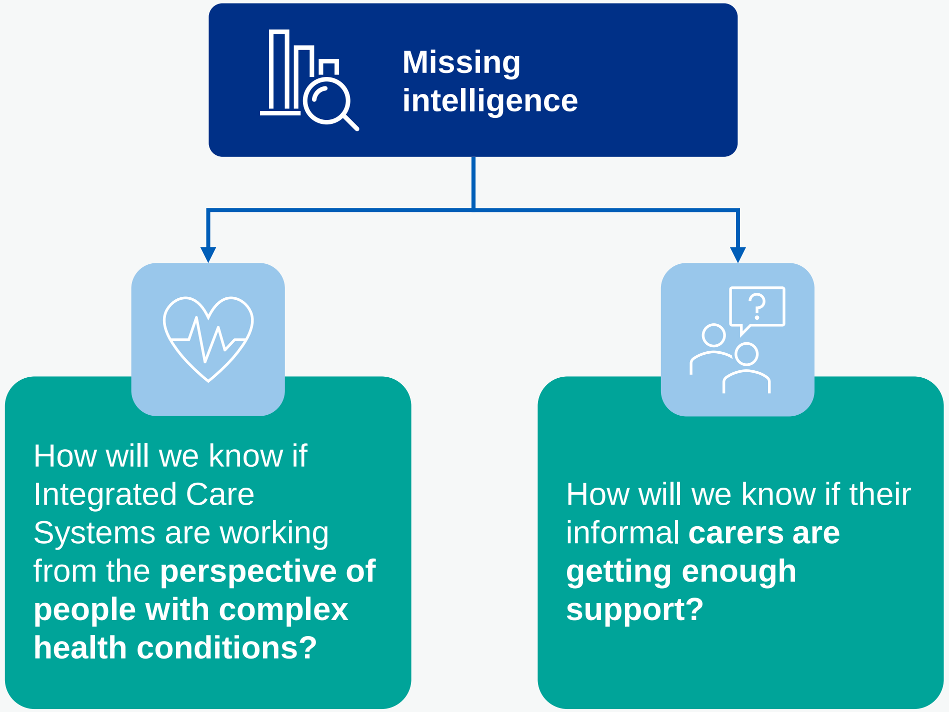
The Long-Term Plan (LTP) sets out the need for an integration measure:
The Long-Term Plan committed to “developing an integration index jointly with patient groups and the voluntary sector which will measure from patient's, carer’s and the public’s point of view, the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care.”

There is no current mechanism by which Systems can understand whether people are experiencing a benefit from integration:
The Kings Fund have consistently highlighted that **“the best way to understand whether integration is delivering results is through the eyes of people using services”**. Despite previous attempts, no other national survey measures people’s experience of integrated care.

Engagement over the last year with patient groups, VCSE organisations, DHSC, CQC, LGA and wider partners have shown strong support for establishing a new national measure of people's experience of integrated care to provide actionable intelligence to local teams and help understand the impact of ICSs nationally.

The NHS Long Term Plan (January 2019)

We will develop a new ‘integration index’ developed jointly with patients groups and the voluntary sector which will measure from patient's, carer’s and the public’s point of view, the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care.



Missing intelligence

How will we know if Integrated Care Systems are working from the **perspective of people with complex health conditions?**

How will we know if their informal **carers are getting enough support?**

The Integrated Care Experience Survey will address the requirement for Systems to understand progress on integration

The Integrated Care Experience Survey:

- Is a **survey targeted at specific at-risk population cohorts to measure and track the impact of new joined up, proactive, personalised and preventative care models**. It asks a limited number of questions about the use and experience of integrated health and care services. These questions have been co-designed with patient, carer and public groups, VCSE organisations and national bodies (across NHSE, DHSC, CQC, LGA).
- **Will initially focus on people with complex health and care needs**, recognising the importance of integrated services and proactive care to this group. People will be identified through GP records based on their electronic Frailty Index (eFI) score.
- **Will provide genuinely useful intelligence for local place and neighbourhood teams** to act on as well as a robust comparable dataset nationally across all ICSs.
- **Will be mobilised incrementally** in two phases – to find the most cost-effective long-term solution - and expected to run annually thereafter.
- **Will make data and actionable insights available to participating Systems and Places in near real-time** with the intent that these will help drive improvements to the way services across multiple agencies are planned, coordinated and delivered.
- **Includes two questionnaires** – one for **people/patients** and one for their **informal carers**. The **main themes covered include:**
  - Use of local health and care services
  - Personalisation and continuity of care
  - Experience of proactive care
  - The way health and care partners work together and share information.

We want the survey to be owned and supported by local system partners. The benefits to ICSs are:

- A nationally funded programme to provide systems with **near real-time access to quantitative and qualitative data on people's experience of using integrated health and care services.**
- **Genuinely useful information for local teams to support the design and tailoring of local proactive and integrated care models** and to track the impact from a patient perspective.
- **A source of quantitative and qualitative information to support development of place-based outcomes**, ICB Joint Forward Plans, ICP strategies and JSNAs.
- **An evidence-based understanding of how well integrated care is working and the impact of new health and care reforms in England**, as highlighted through recent NAO, select committee and PAC reports.
- **An understanding of how the triple aim is being delivered within particular population cohorts**, by linking the data with other sources of information about use of services and health outcomes.
- **Support from the NHS England / Ipsos / PA team to embed the new ICE Survey approach** and uplift system capability and capacity.
- The opportunity to **select additional questions from the question bank in order to tailor the survey questionnaire** to local priorities and need.

Phase 1 ICSs will have the survey run in their system first and benefit from greater support from the ICE Survey Programme team. They will get first access to quantitative and qualitative data on people's experience of using integrated health and care services

ICSs will be able to access near real time quantitative and qualitative data on people's experience of their local services

As part of the Integrated Experience Survey we will be developing **dashboard reporting to provide users access to their data in near real time**. This will enable each ICS to understand experience of integrated care and use the information to improve care outcomes and experience.

The exact dashboard design and functionality will be confirmed through engagement with national and ICS users during the programme. This will focus on designing a dashboard that provides information that supports decision making and agreeing the approach to data access across Systems.

The **dashboard is expected to have the following functionality**:

- Charts to explore individuals experience of care and views on care administration, care integration, waiting times and emotional support
- Ability to explore variation by a range of demographic variables
- Access to free text survey responses with granular detail on areas of good practice and suggested areas for improvement.

Dashboard illustration – final design and functionality to be confirmed during the programme

Integrated Care Experience Survey Overview

Filters: Age bracket | Gender | Ethnicity | Time period

SURVEYS SENT 15,321

TOTAL RESPONSES 4,385

RESPONSE RATE 29%

			PLACE 1	ICS	SIMILAR ICS	REGIONAL COMPARISON
RESPONSE RATE	*What was the overall response rate to the Integrated Care Experience Survey*		PLACE 1 39% PLACE 2 47% PLACE 3 32% PLACE 4 51%	45%	49%	43%
INTEGRATED CARE	*Did all the different people caring for you work well together to give you the best possible care and support?*	Yes, all	X%	X%	X%	X%
		Most	X%	X%	X%	X%
		Some	X%	X%	X%	X%
		No	X%	X%	X%	X%
		Don't know	X%	X%	X%	X%
CARE RATING	*Overall, how would you rate your care?*	Very good	X%	X%	X%	X%
		Fairly good	X%	X%	X%	X%
		Fairly poor	X%	X%	X%	X%
		Very poor	X%	X%	X%	X%
		Don't know	X%	X%	X%	X%
CARE OUTCOME	*Thinking about the last six months, has the care and support you received helped you live life to the best of your ability?*	Yes, completely	X%	X%	X%	X%
		To some extent	X%	X%	X%	X%
		No, not at all	X%	X%	X%	X%
		Don't know	X%	X%	X%	X%

Integrated Care Experience Survey:- The National Survey Offer for ICSs

01

Deliver accessible online-first survey, with ability to select local questions

02

Make survey data available to ICSs via dashboarding platform

03

Provide strategic support and advice to ICSs

04

Deliver actionable insights via robust processes

Ipsos and PA Consulting have been appointed to partner with NHS England to deliver the ICE Survey Programme. The team will:

- **Fund the survey and the National Survey Supplier**
- **Co-ordinate the ICE Survey programme providing**
  - Dedicated project management and IG resource
  - Data Processes and Flows
- **Provide IG leadership and support**
  - Handle national IG requirements and safeguards, including s251
  - Provide support for IG Data Sharing and Processing Agreements
- **Build, host and maintain the online questionnaire**
  - Ensuring an appropriate patient sampling approach
  - Scripted and tested on Ipsos in-house platform including accessibility
  - Support to select questions focussed on local interest
- **Handle secure Data flow to Dashboard Platform**
  - Daily flow of survey data from Ipsos to NHS England systems and Dashboard platform
  - Leverage existing patterns and processes to ingest data
- **Establish reporting products on the Dashboard Platform**
  - Establish reporting platform aligned to best practice
  - Develop reporting dashboards with ICS End User input
  - Provide ICS with access to Dashboard platform
- **Engage with ICSs to provide strategic support and advice**
  - Deliver checkpoint, onboarding and round table sessions
  - Provide dashboarding, data and analytics support to users

The programme is designed to maximise benefit to and minimise effort needed from systems – Issuing and handling of Survey will be managed by the ICE Survey Programme team.

Additionally, the ICE Survey programme team will work with ICBs at the outset to understand any requirement for provision of local project co-ordination resource (from CSUs).

We will need ICS teams to:

- **Engage with the programme team on the survey**, working with the NHS England, Ipsos and PA team to **agree key stakeholder roles:-**
  - **SRO**
  - **SPOC / Project Support**
  - **Data & Analytics Lead**
  - **IG Lead / DPO**
- **Help dock the work into local teams** responsible for intelligence and public involvement
- **Help coordinate local comms and engagement** across local stakeholders to secure buy in and awareness
- **Help co-ordinate specific engagement with general practice as data controllers for Phase 1** including appropriate handling of dissent notices and opt-outs.
- **Establish required data sharing / processing agreements as data owner** between ICB and its partner organisations (many ICS already have these in place)
- **Co-ordinate data transfer of selected sample** to Ipsos in accordance with agreed methodology and processes

Progress in mobilising Phase 1 Systems and confirming commitment

We have already engaged Systems:

NHS England, with support from NECS CSU (up until June 23) have already identified and engaged systems and stakeholders where datasets are sufficiently mature and where Systems have expressed an interest in taking part. Work to date has engaged at least one System from each region to take part in Phase 1 of the ICE Survey, namely:

- Norfolk & Waveney ICB
- Devon ICB
- Derby & Derbyshire ICB
- Lancs and South Cumbria ICB
- Durham Place within the North East and North Cumbria ICB
- Sussex ICB
- Bristol, North Somerset and South Gloucestershire (BNSSG) ICB
- South West London ICB

Engagement with these systems has explored:

The feasibility for the systems to take part from an Information Governance/GDPR perspective

- Key IG questions – Do systems have existing data sharing agreements (DSAs) and data processing agreements (DPAs) in place? Is there a need to setup new agreements?

Data availability and coverage

- Consideration and discussion around key data questions – Is there access to GP practice data? Who is the existing data processor?

We are looking to ensure that all the key stakeholders from each system are sighted on the progress of the work including a System **board level SRO**.

We now have some of the key enablers in place and are looking to firm up commitment from Systems to the Phase 1 survey.

> “Care is looking at you as a whole person – they ask how you are. They look at all your problems, not just one.”
>
> **Service user. Frailty**

> “They do work well together and the hospital’s got the phone number for my social worker and the duty social worker and the company I get my support worker from and they’ve got consent to contact them as well…”
>
> **Service User**

> “You would always hope that they’re working well together, wouldn’t you? And I suppose the patient is best placed to say whether they feel it is or not.”
>
> **NHS colleague**

Integrated Care Experience Survey: Progress to date

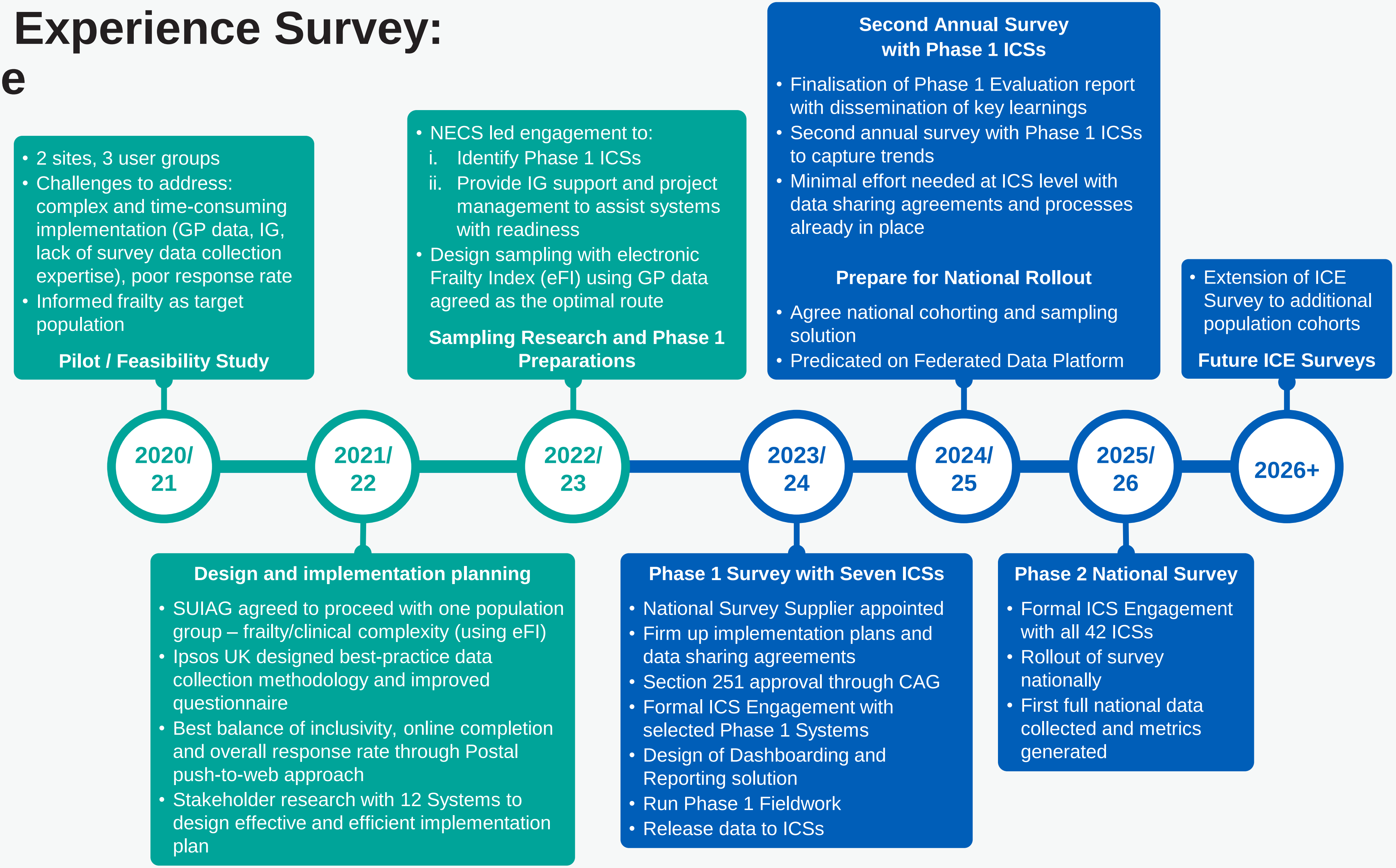
Integrated Care Experience Survey work has been running since 2020:

Extensive work has already been completed to test feasibility, design the survey, plan the implementation and do much of the groundwork with Phase 1 ICSs.

We are now ready to deliver the survey with phase 1 ICSs:

An Ipsos and PA Consulting partnership have been appointed as the National Survey Supplier and will partner with NHS England to deliver the survey Programme.

We are in final preparations to deliver the Survey with Phase 1 ICSs.



2020/ 21

- 2 sites, 3 user groups
- Challenges to address: complex and time-consuming implementation (GP data, IG, lack of survey data collection expertise), poor response rate
- Informed frailty as target population

Pilot / Feasibility Study

2021/ 22

Design and implementation planning

- SUIAG agreed to proceed with one population group – frailty/clinical complexity (using eFI)
- Ipsos UK designed best-practice data collection methodology and improved questionnaire
- Best balance of inclusivity, online completion and overall response rate through Postal push-to-web approach
- Stakeholder research with 12 Systems to design effective and efficient implementation plan

2022/ 23

- NECS led engagement to:
  - i. Identify Phase 1 ICSs
  - ii. Provide IG support and project management to assist systems with readiness
- Design sampling with electronic Frailty Index (eFI) using GP data agreed as the optimal route

Sampling Research and Phase 1 Preparations

2023/ 24

Phase 1 Survey with Seven ICSs

- National Survey Supplier appointed
- Firm up implementation plans and data sharing agreements
- Section 251 approval through CAG
- Formal ICS Engagement with selected Phase 1 Systems
- Design of Dashboarding and Reporting solution
- Run Phase 1 Fieldwork
- Release data to ICSs

2024/ 25

Second Annual Survey with Phase 1 ICSs

- Finalisation of Phase 1 Evaluation report with dissemination of key learnings
- Second annual survey with Phase 1 ICSs to capture trends
- Minimal effort needed at ICS level with data sharing agreements and processes already in place

Prepare for National Rollout

- Agree national cohorting and sampling solution
- Predicated on Federated Data Platform

2025/ 26

Phase 2 National Survey

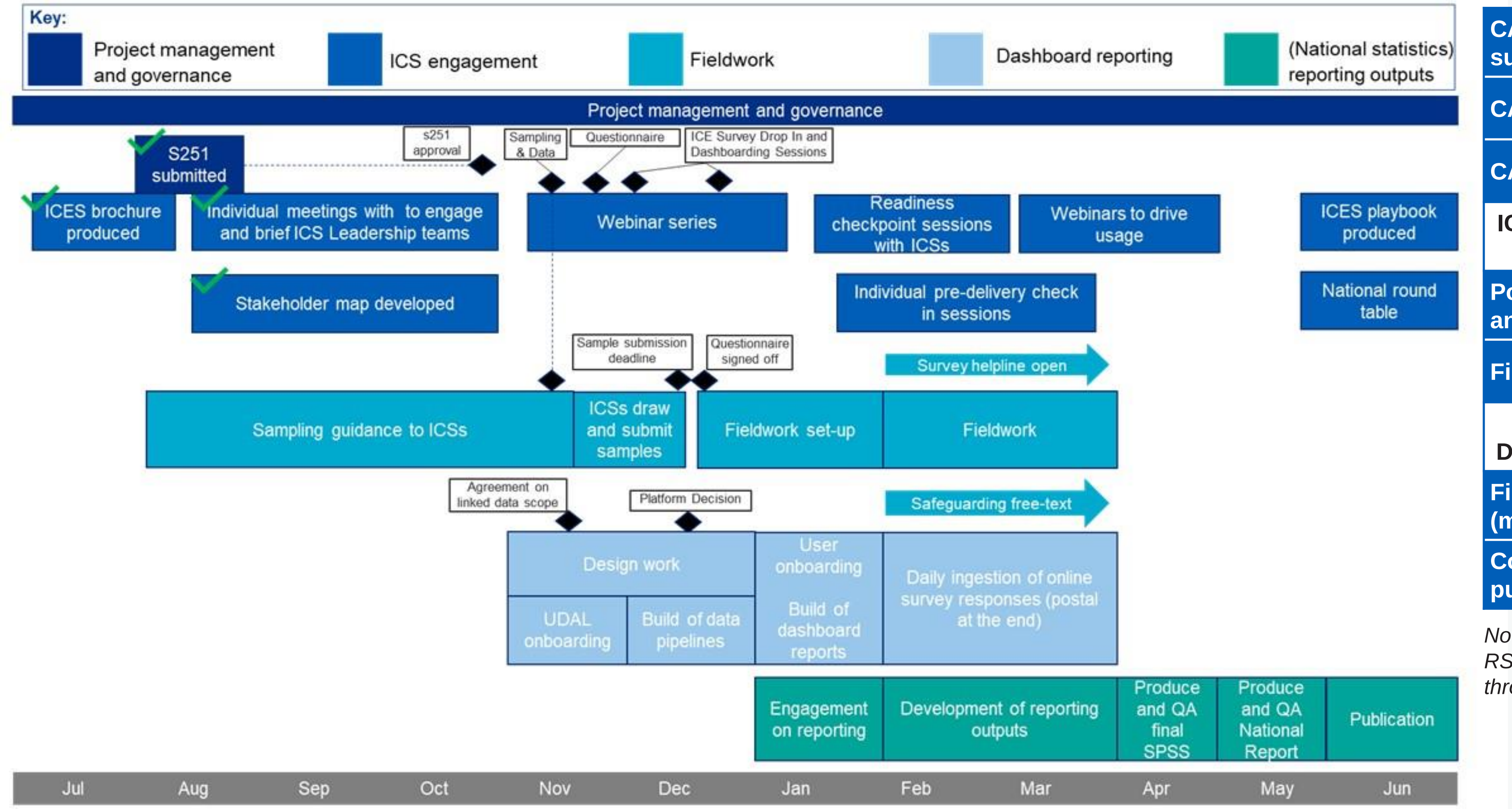
- Formal ICS Engagement with all 42 ICSs
- Rollout of survey nationally
- First full national data collected and metrics generated

2026+

- Extension of ICE Survey to additional population cohorts

Future ICE Surveys

Integrated Care Experience Survey programme:- Phase 1 Timeline and key survey dates



CAG application submission date	17th Aug
CAG meets	7th Sept
CAG approval	21st Sept
ICS fair processing notices displayed for min. 4 weeks before fieldwork	
Population sampling and cohort id by ICSs	Nov / Dec
Fieldwork starts	Early Feb 24
Results available in NHS England Dashboarding platform near real-time	
Fieldwork ends (minimum of 8 weeks)	Early Apr 24
Comparable data published	Jun 24

Note:- An Independent Evaluation Partner, RSM, has also been appointed and will engage throughout the ICE Survey programme

Section 2

Integrated care experience survey further information

Additional reference information setting out key requirements for the Integrated Care Experience Survey Programme

We need to be clear on the lawful basis for processing ICE Survey data, the data processing methodology and intended use of data:

The ICE Survey will invite people with multiple complex health needs to share their personal experience of integrated health and care services. The ICE programme will therefore handle personal data.

This section provides additional reference information and links of interest to specific stakeholders, with a focus on:

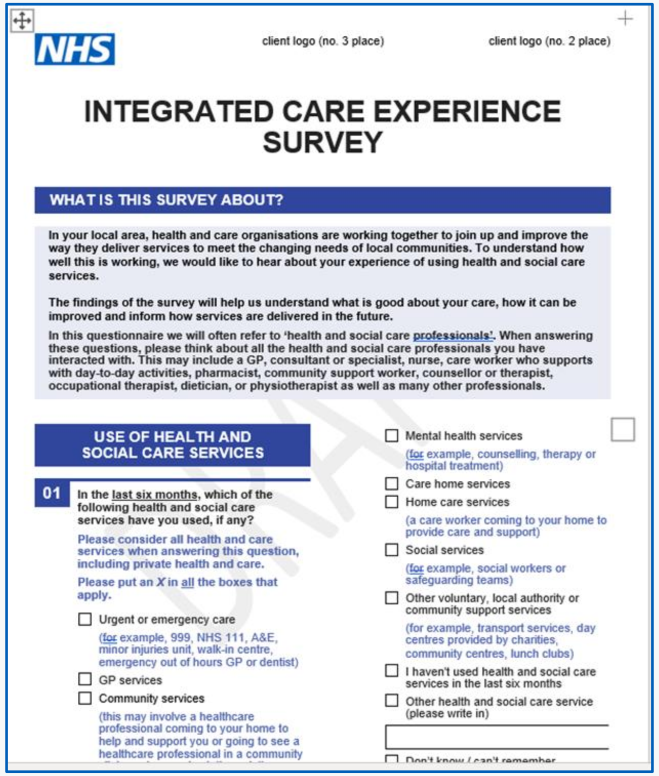
- Setting out the lawful basis for processing ICE Survey data
- Providing clarity on how data will flow and be stored securely
- Describing how the Programme intends to use the data as a foundation for driving System improvements
- Describing how we will deliver this work fairly to all people

This section includes further information relating to:

Note:- Where All is specified, it means the intended audience includes ICB Execs, SROs, SPOC / Project Support, Data & Analytics Leads, IG Leads and DPOs

Integrated Care Experience Survey approach

- The survey will use an **online questionnaire**, supplemented by **paper and accessible formats**, with a mailing strategy designed to encourage a good response rate.
- People living with complex health and care needs will be sent **invitation letters** inviting them to participate in the survey online.
- They will be sent up to **two reminder letters**, with the second reminder also including a **paper questionnaire**.
- Where a mobile number is available in the sample, people will also be **sent reminders by text message.**
- People will be asked to pass on an invitation to their carers.



client logo (no. 3 place) client logo (no. 2 place)

INTEGRATED CARE EXPERIENCE SURVEY

WHAT IS THIS SURVEY ABOUT?

In your local area, health and care organisations are working together to join up and improve the way they deliver services to meet the changing needs of local communities. To understand how well this is working, we would like to hear about your experience of using health and social care services.

The findings of the survey will help us understand what is good about your care, how it can be improved and inform how services are delivered in the future.

In this questionnaire we will often refer to 'health and social care professionals'. When answering these questions, please think about all the health and social care professionals you have interacted with. This may include a GP, consultant or specialist, nurse, care worker who supports with day-to-day activities, pharmacist, community support worker, counsellor or therapist, occupational therapist, dietician, or physiotherapist as well as many other professionals.

USE OF HEALTH AND SOCIAL CARE SERVICES

01 In the last six months, which of the following health and social care services have you used, if any?

Please consider all health and care services when answering this question, including private health and care.

Please put an *X* in all the boxes that apply.

☐ Urgent or emergency care
(for example, 999, NHS 111, A&E, minor injuries unit, walk-in centre, emergency out of hours GP or dentist)
☐ GP services
☐ Community services
(this may involve a healthcare professional coming to your home to help and support you or going to see a healthcare professional in a community
☐ Mental health services
(for example, counselling, therapy or hospital treatment)
☐ Care home services
☐ Home care services
(a care worker coming to your home to provide care and support)
☐ Social services
(for example, social workers or safeguarding teams)
☐ Other voluntary, local authority or community support services
(for example, transport services, day centres provided by charities, community centres, lunch clubs)
☐ I haven't used health and social care services in the last six months
☐ Other health and social care service (please write in)
☐ Don't know / can't remember

The **questionnaire** covers the following areas:

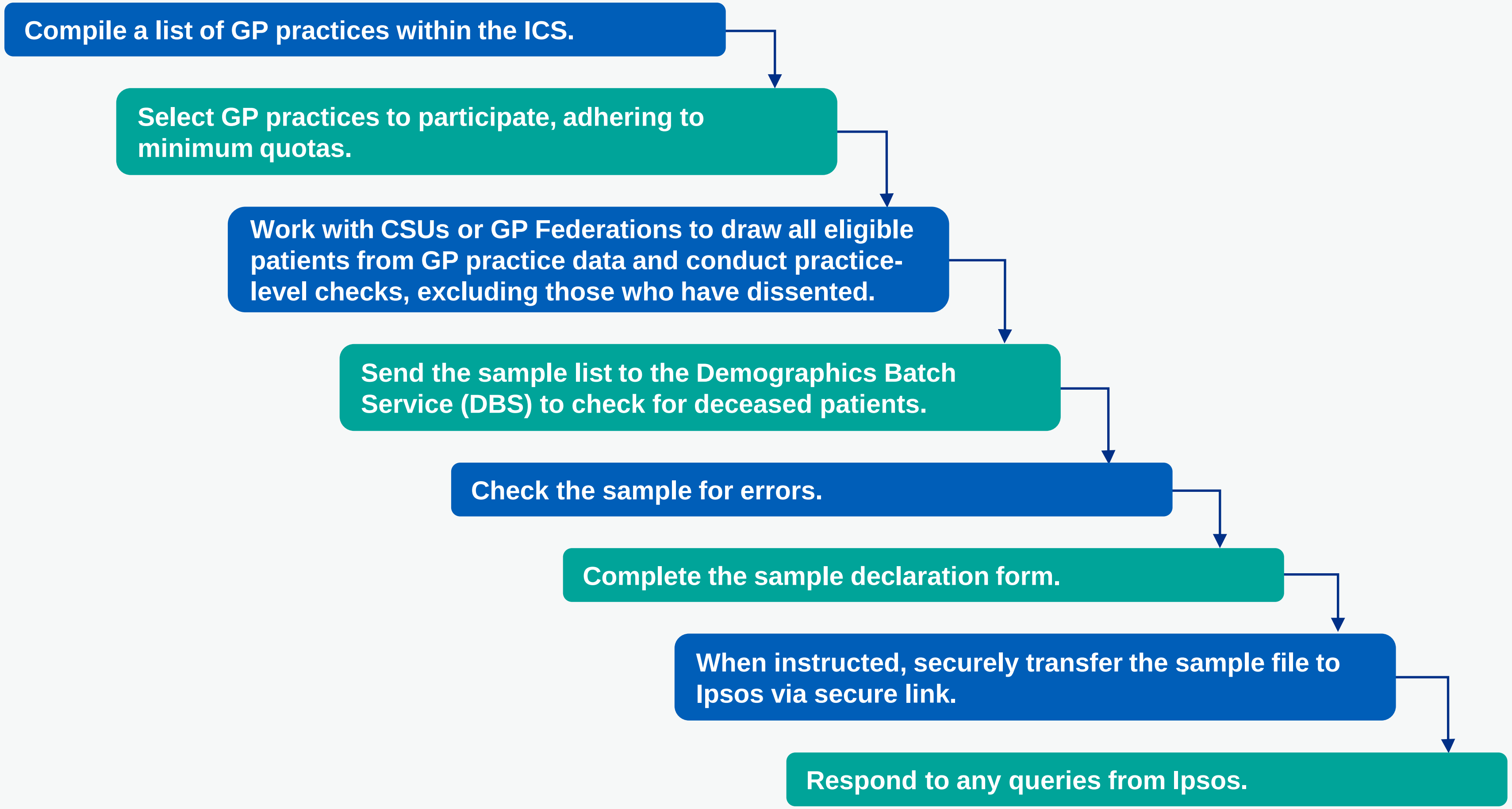
- Use of local health and care services
- Personalisation and satisfaction with care received
- Continuity and coordination of care, including information sharing across multiple health and care partners
- Proactive care
- Wellbeing and support (for carers)
- Demographics
- Free text fields
- Consent question allowing us to link the responses to secondary datasets to triangulate information about experience, outcomes and utilisation within the target cohorts.

1 **Mailing 1 (with URL to online survey)** → 2 **SMS reminder** → 3 **Mailing 2 (with URL to online survey)** → 4 **SMS reminder** → 5 **Mailing 3 (with paper questionnaire)**

Sampling approach

- The survey will collect responses from a sample of eligible people in each ICS.
- To provide robust estimates for each ICS, we are aiming for responses from 1,000 people with complex needs per ICS, and 330 carers per ICS.
- To achieve this sample size, we will need a starting sample of at least 4,000 people per ICS and representative of the ICS population:
  - aged 18 or over;
  - with moderate or severe frailty, as defined via primary care e-frailty score (eFI), at the time of sampling; and
  - registered with the GP practice for 6 months or longer.

Each ICS will need to take the following steps:



Compile a list of GP practices within the ICS.

Select GP practices to participate, adhering to minimum quotas.

Work with CSUs or GP Federations to draw all eligible patients from GP practice data and conduct practice-level checks, excluding those who have dissented.

Send the sample list to the Demographics Batch Service (DBS) to check for deceased patients.

Check the sample for errors.

Complete the sample declaration form.

When instructed, securely transfer the sample file to Ipsos via secure link.

Respond to any queries from Ipsos.

The lawful basis for carrying out the survey

Lawful basis:

For GDPR purposes NHS England's lawful basis for processing is Article 6(1)(e) '…exercise of official authority…'. This is where processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. For special categories such as health data, the basis is Article 9(2)(h) '…health or social care…'.

Article 9(2)(h) stipulates:

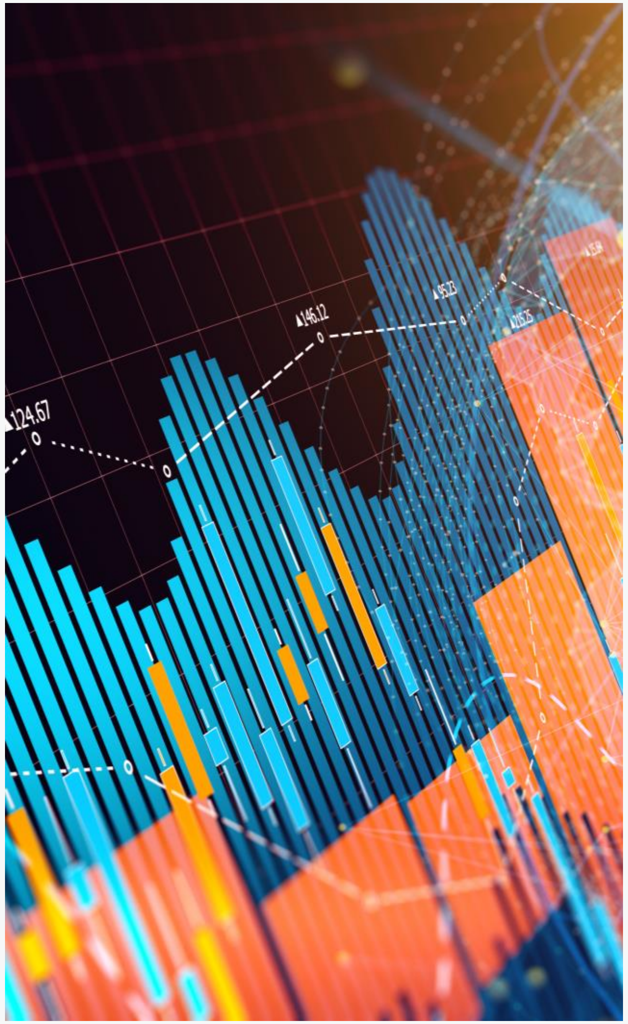
"processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3".

- NHS England and Ipsos have received provisional support for **section 251 support** (of the NHS Act 2006 and Health Service (Control of Patient Information Regulations 2002).
- NHS England have developed a programme level **Data Protection Impact Assessment (DPIA).** This will be a live document which will be updated as needed throughout the programme.
- Patients and carers who respond to the survey **consent** to the use of the information they provide in the questionnaire.

The support for use of confidential patient information: Section 251

Section 251 application: Key points

- NHS England and Ipsos UK have applied to the **HRA Confidentiality Advisory Group** for Section 251 support to carry out Phase 1 of the Integrated Care Experience Survey.
- Section 251 support is being requested as **confidential patient information** is required to conduct the survey activities without first seeking consent.
- During development of the survey every possible opportunity was taken to seek the views of patients regarding the use of their personal data without their consent for the purposes of running the survey. **No concerns were raised** by patients or patient groups (such as National Voices and Healthwatch).
- Access to patient identifiable data at Ipsos UK is **strictly controlled** on a need to know basis and the corporate security policy covers the people, physical and technical aspects of access. All staff are aware of their responsibilities in this regard and are contractually bound to comply with Ipsos UKs policies and specifically with the relevant legislation.
- Due regard has been paid to the information governance aspects of the survey and that the **data protection principles** have been understood and scrutinised carefully on the construction of the methodology for this survey.
- Patients consent to taking part in the survey by returning questionnaires and decline by not returning them or returning blank questionnaires. Patients are provided with confidentiality information within the survey materials.
- The survey materials emphasise that participation in the survey is entirely **voluntary**, provide details about the basis upon which the information will be held and processed and provide details of how to **opt out** of the survey.
- Participating ICBs will be provided with communication materials to inform the cohort of the activity and their right of objection. Local communications will be agreed with each of the participating ICB communications teams. The materials are intended to be displayed for up to 6 weeks prior to fieldwork commencing.



How people will be identified to take part

- To generate the sample, all eligible records need to be drawn from the GP Practice Data using the **inclusion** and **exclusion criteria.**
- The data analysts will need to generate the datafile identifying the cohort population being targeted which will meet the criteria, agreed by the survey programme team, by using **the ICE Survey Sample Workbook 1.**
- Once the sample size has been achieved, two sample files are to be formed and these will be securely transferred to Ipsos separately.
- The **sample variables** will be linked to the survey responses and used for analysis of the data, for example, analysis of survey responses by eFI score, or gender and for identifying records for the deceased. The **mailing variables** will be used to send out the invitation letter, reminder letters and reminder texts.

Where to find further information:

- **The ICE Survey Sample Workbook 1 itemises all the variables needed to identify people with** moderate and severe frailty, based on the electronic frailty index score (eFI) as the agreed cohort for the ICE Survey, and the other data parameters required. **The variables that make up the eFI score will not be shared with Ipsos.**
- The **sampling instructions, dissent information** and **sample construction spreadsheets** contain more information about how to pull the sample, and which variables to submit in which file.

Inclusion Criteria

- Those permanently registered with the GP for at least 6 months
- Patients with a UK postcode inside or outside the ICS boundary of that GP practice.
- Those who may currently be in hospital.
- Those currently living in a care home.
- Those with a national **data opt-out**.
- Patients with **moderate or severe frailty**, defined via primary care e-frailty score.

Exclusion Criteria

- Patients with no frailty or mild frailty, defined via primary care e-frailty score.
- **Deceased** patients.
- Patients **<18 years old** at time of sampling.
- Patients **without a UK postal** address
- Any patient known to have requested their details are not used for any purpose other than clinical care or for this survey
- Those with a **type 1 opt-out**

Sample variables

- **NHS number** (for data linkage)
- **Postcode**
- **Age**
- **Date of birth:** format yyyymmdd
- **Gender:** should be coded in numeric
- **Ethnicity:** coded using the 17-item alphabetical coding
- **GP practice code**
- **ICS code**
- **Date of registration**
- **Electronic Frailty Index (eFI) score**

Mailing variables

- **Title:** Mr, Mrs, Ms etc
- **First name**: or initial where only this is available
- **Last name**
- **Address:** held as separate fields (e.g., street, area, town and county); using the current address on the practice's system.
- **Postcode**
- **Mobile number:** current mobile phone number listed on the practice's system

Ambition to link satisfaction levels back to actual integrated service provision data including proactive care

We hope to **enable the linking of survey responses with wider national and local data about health outcomes and utilisation of care to create a better understanding** of how the triple aim is being delivered through the lens of people and population groups.

Data will flow into NHS England’s Unified Data Access Layer (UDAL) and be made available initially on the Dashboarding platform, but in time is expected to transition to the Federated Data Platform so that it can form part of wider linked data to understand the progress being made in different population groups on outcomes, experience and value of care.

To do this, survey responses could be linked to information such as:

- Health condition pathway information
- Appointments across GP, community and secondary care services
- Use of social care services

We have included a question in the survey which asks for consent to link data.

NHS England Data Protection Impact Assessment (DPIA)

Key purpose

- To provide the nature, scope, context and purpose of the data processing and consider any risks and measures to mitigate those risks.
- To ensure personal data about patients is effectively protected and has the right safeguards built into the processes.
- To provide detail and clarity of what personal data we are intending to share and with whom.

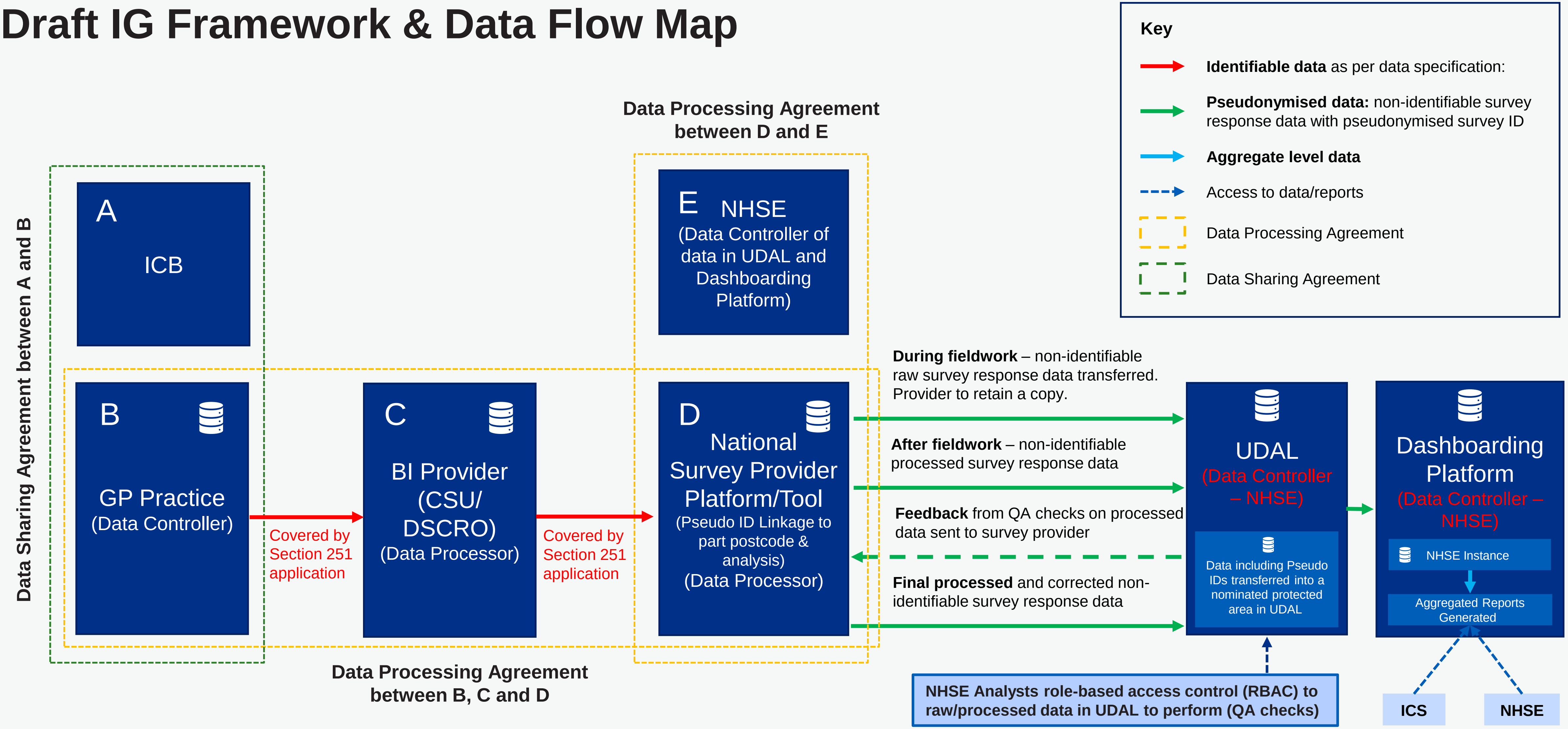
Summary points from DPIA

- Describes the lawful basis for processing the personal data.
- Provides details of the data controllers and processors involved in the delivery of the survey.
- Provides details of the parties who will have access to personal data to enable participation in the survey, send SMS reminders, etc.
- Provides details of safeguards adopted to ensure access to patient identifiable data will be restricted to the minimum number of personnel; all of whom have undergone training in data protection law, their duty of confidentiality under contract and in the care and handling of personal data.
- Small number suppression will apply to reduce the risk of re-identification.
- Access to free text data will be restricted to a small number of individuals within the ICB. No personal data is asked for in the free text field, however, it is recognised that there is a small risk of this happening.

Where to find further information

- TBC: e.g. FutureNHS

Draft IG Framework & Data Flow Map



Key

- **Identifiable data** as per data specification:
- **Pseudonymised data:** non-identifiable survey response data with pseudonymised survey ID
- **Aggregate level data**
- Access to data/reports
- Data Processing Agreement
- Data Sharing Agreement

Data Processing Agreement between D and E

Data Sharing Agreement between A and B

A
ICB

B
GP Practice
(Data Controller)

C
BI Provider (CSU/ DSCRO)
(Data Processor)

D
National Survey Provider Platform/Tool
(Pseudo ID Linkage to part postcode & analysis)
(Data Processor)

E NHSE
(Data Controller of data in UDAL and Dashboarding Platform)

Covered by Section 251 application

Covered by Section 251 application

Data Processing Agreement between B, C and D

During fieldwork – non-identifiable raw survey response data transferred. Provider to retain a copy.

After fieldwork – non-identifiable processed survey response data

Feedback from QA checks on processed data sent to survey provider

Final processed and corrected non-identifiable survey response data

UDAL
(Data Controller – NHSE)

Data including Pseudo IDs transferred into a nominated protected area in UDAL

Dashboarding Platform
(Data Controller – NHSE)

NHSE Instance

Aggregated Reports Generated

NHSE Analysts role-based access control (RBAC) to raw/processed data in UDAL to perform (QA checks)

ICS

NHSE

Draft Data Process Map

1. Data Processing Agreements will be put in place/existing agreements amended between each participating **GP Practice** and the relevant **ICBs data processor** to cover the purposes of the ICE Survey.

Each participating GP Practice (**data controllers** for the survey sample data)

Each participating ICBs data processor (**data processor for GP Practice** survey sample data)

2. The **ICBs data processor (for GP Practice data)** will use the survey sampling instructions to identify the required cohort for the survey.

The data processor will then extract a sample of up to 5,000 patients and populate the sampling construction worksheet (attached).

It is recommended that the data processor conduct deceased DBS checks prior to the next step.

3. The **ICBs data processor (for GP Practice data)** will each securely transfer their sample data, as detailed in (o), to Ipsos UK (survey supplier).

The National Survey Supplier, Ipsos UK, will be abiding the security and audit measures detailed in (v) to store and monitor access to the sample data sets that have been securely transferred and received from the ICBs data processors.

4. **Ipsos UK** will generate a unique survey identification code for each potential participant.

Prior to mailing out the invitation to the sample (circa 40,000 invitations)

5. **Ipsos UK** will conduct the deceased service users check to ensure only living people receive the invitation.

To cover time lapsed between sampling being drawn and invitations being constructed.

6. **Ipsos UK** will securely transfer the ‘Mailing file’ containing personal data to **Formara** for the paper survey invitations to be printed, packaged and sent out.

Only items authorised in the mailing file, as detailed in (o)

7. **Ipsos UK** will securely transfer the Mailing file containing personal data to **Text Local** to send the first reminder SMS – this will also occur for the second and third reminder SMS'.

This will contain data records of the participants who have a number in the mobile number field

Two days after the first paper survey invitation letters are sent.

Two days after the first reminder letters are sent.

Two days after the final reminder.

Before sending out reminders, Ipsos UK will update the Mailing file, to ensure that participants who have already responded are not listed. A respondent with a unique ID that has COMPLETED the survey (completed, partially completed or returned empty)

8. Before sending out the first reminder, **Ipsos UK** will update the Mailing file, to ensure that participants who have already responded are not listed.

This will also occur for the second reminder (the final mailing).

A respondent with a unique ID that has COMPLETED the survey (completed, partially completed or returned empty).

9. Before sending out the first reminder, **Ipsos UK** will update the Mailing file, to ensure that participants who have already responded are not listed.

This will also occur for the second reminder (the final mailing).

A respondent with a unique ID that has COMPLETED the survey (completed, partially completed or returned empty).

10. The online survey will be implemented using an industry standard online survey management system hosted by Rackspace UK. This is accessed and controlled by **Ipsos UK** employees only.

11. The online survey responses will be sent to **NHS England** from **Ipsos UK** into the **Universal Data Access Layer** (UDAL) throughout the fieldwork period. Only the survey ID will be transferred along with the survey responses

Paper survey responses scanned by Ipsos UK and added into the UDAL at the end of the fieldwork period

NHS England’s analysts will conduct quality assurance checks to ensure the survey responses have been mapped as expected

The survey ID ensures that where any amendments are required following the quality assurance checks, they can be applied correctly.

12. Survey data will flow from the UDAL into **NHS England’s** OKTA platform. Participating ICBs will be able to access their raw survey response data during fieldwork.

OKTA platform is the host for all NHS England’s Tableau dashboards) or the new FDP (Federated Data Platform) (if timings permit).

The dashboard will be designed, developed and hosted on the OKTA or FDP platforms.

13. Respondents’ free text comments will also be presented in the interactive dashboard to allow thematic analysis of the free text comments from the questionnaires.

A text analysis tool will be used create insight into the comments by grouping key words and phrases into themes.

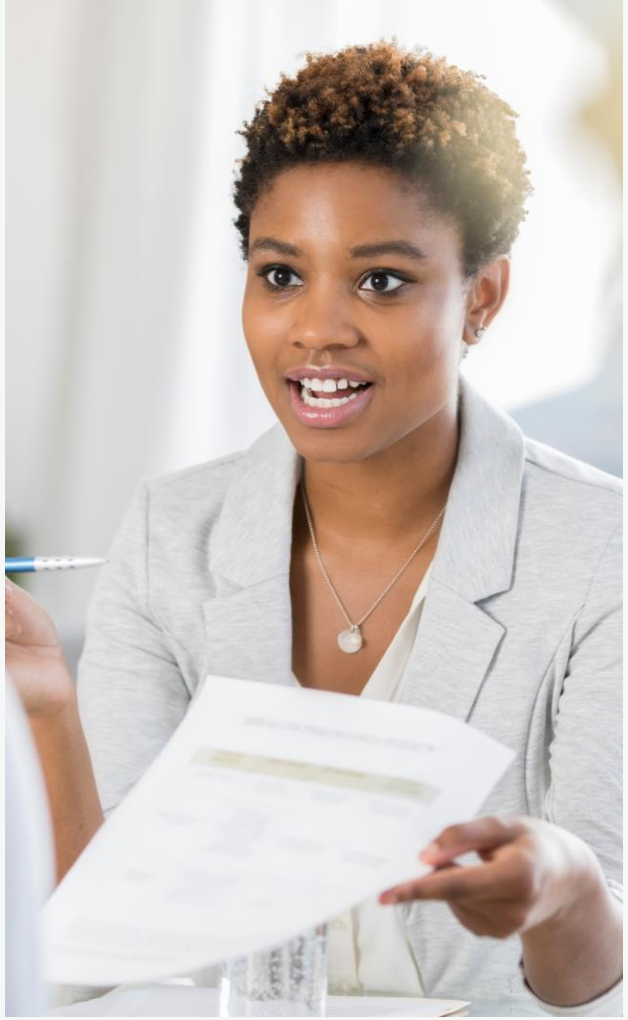
14. Once the survey fieldwork has closed, **Ipsos UK** will apply weightings to the data.

They will look at the original sample data metrics and the response metric data to apply statistical weighting to ensure the final data set is statistically significant.

15. NHS England will act as the **data controller for the survey returns**

NHS England will also act as the data controller for the contact details of respondents who state in the questionnaire that they are happy to be contacted again to complete further survey questions and/or to take part in research.

Programme Equalities and Health Inequalities Impact Assessment (EHIA)



Key purpose

- It is everyone's duty to ensure that all people are treated fairly in what we do and deliver across the NHS, particularly when we are developing new projects, services and initiatives. Equality and Health inequalities Impact Assessments (EHIAs) are a tool that helps the user to assess the impact of an emerging policy, practice, programme of work on the populations we serve – helping to identify issues of inequality in systems, practices and processes, which should be considered during development.
- To contribute assurance that we are meeting the legal duties around equalities and health inequalities, including the Public Sector Equality Duty (PSED) under the Equality Act 2010 and the Health and Social Care Act 2012.

Summary points from the EHIA

- Digital accessibility: In the first instance, participants will be invited to join via a posted letter with a unique web address for them to participate in the survey. The second reminder will also include a paper survey. Participants can also use a freephone number and speak to someone to respond to the survey. Enabling both digital and paper responses to the survey will help maximise responses.
- Languages: The survey is available in many different languages.
- Health inequalities: The survey is the first of its kind to ask the carer of patients (unpaid, family members) about their experience. It has been specifically designed to capture their care experience as well as their opinion of the experience of care of the patient. The survey should support systems in addressing inequalities.
- Health illiteracy: The questionnaire was cognitively tested to ensure that the questions are worded to receive the maximise understanding from all participants.

Where to find further information:

- Copy of EHIA available on FutureNHS page

ICS readiness checklist

IG

Have you tested and delivered data extraction of this kind and able to replicate this for this programme?

1. DPIA

Undertake a DPIA if necessary. We can help advise.
Familiarise yourselves with content of NHSE S251 and DPIA.

2. DPA and DSA

Ensure you have in place data processing/data sharing agreements that allow you to run queries on GP data and identify a data sample and share with the national survey supplier (see the data flow map in the brochure for further information).

Check locally agreed process and timelines for amending or signing off new DPA/DSA where needed.

3. IG Engagement:

Share details of this programme with your system digital transformation programme lead and incorporate into the work programme.

Test with the GP lead on your data/digital team whether additional engagement is needed before you can proceed with data extraction/processing. Schedule in early discussions at the relevant forums (e.g., GP leads meetings).

Review privacy notices and ensure they reflect use of the survey data for secondary purposes.

4. Process:

Clarify locally who selects the sample and how this occurs. You will need to consider opt in/opt out for GPs for this phase and the associated timeline. A supplementary guide with instructions will follow.

Check you have a process to issue dissent notices among GPs. Agree what other channels you will use to share information about this project with members of the public.

BI

Have you engaged business intelligence teams to support transfer of key data?

1. Speak to BI colleagues (GP data processor) to ensure they are able to extract, process, cleanse and transfer identifiable data.

Engagement

Ensure there is wider awareness of the programme and support for involvement.

1. Sharing brochure information on the programme with
    - Primary Care colleagues including Directors of Primary Care, PCN leads, GPs, GP Federations
    - Data Protection Officer/IG Lead
    - Business Intelligence lead
    - Engagement and comms leads
    - Caldicott Guardian
2. Consider raising awareness of your participation with:
    - ICS Executives, ICP Board
    - Health & Wellbeing Board
    - Digital transformation forums
    - Place-based partnership teams
    - System partners
    - Primary care forums
    - Local Medical Committee (LMC)
    - Healthwatch

Please note: The programme brochure can be a useful tool in introducing the integrated care experience survey.

Thank You

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