Joined up data, joined up care

Research on the use of data in Integrated Care Systems

White Tail

Understanding Patient Data

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Executive summary

Executive summary

The establishment of Integrated Care Systems (ICSs) in England promises to support new and more collaborative uses of data to deliver health and care services and support the health of local populations. These uses include the sharing of data between services to improve the delivery of individual care, but also a wide range of secondary uses including the planning, prioritising and tailoring of services based on population health needs, and the management and coordination of workforce capacity and patient flow across an ICS.

White Tail conducted a qualitative research project on behalf of Understanding Patient Data and the NHS Confederation to investigate the current state and future possibilities of data sharing and use within Integrated Care Systems and explore the challenges and enablers of development in this area.

The team interviewed 23 leaders in strategic and technical roles in 11 ICSs across all NHS England regions, followed by more in-depth case studies in four of these systems by speaking to another 21 participants from a range of relevant roles. Policy recommendations developed from this work were then presented and discussed at a roundtable with fifteen data leaders from a range of ICSs.

Key findings

A varied landscape

ICSs currently vary greatly in the extent to which they are currently linking and using data for purposes other than individual care. While some ICSs or parts of ICSs have large analytical datasets containing information from a range of sources – including primary, acute, community and mental health NHS providers and, in many cases, Local Authority social care data – others reported having no routine flow of data or sustained linked dataset, with one ICS we spoke to reporting no current flow of primary care data outside of Shared Care Records (ShCRs). These ICSs anticipated that the national Federated Data Platform (FDP) tool would provide them with some of that missing infrastructure.

This variation is mirrored in the size and nature of analytical teams, with larger and/or more developed ICSs having sizeable teams including some specialised data engineering and analytics roles, while others have small teams with very limited resource outside of performance reporting.

ICSs that have progressed more in this area have been developing this for as much as ten years, with steady investment in relationships, data management systems, analytical tools and information governance. Many have been supported through local or national data or innovation development funding. As a result, much learning already exists within the health and care system about effective ways to approach and manage this transformation, as well as about issues that remain a challenge.

Participating ICSs that have been able to develop in this way were more able to manage national and local demands for operational reporting without this impacting on their ability to develop data-led approaches to commissioning or population health management. ICSs that have not developed this large and delineated capacity said they remain more burdened by reporting requirements, with little capacity for strategic development.

ICSs with advanced technical infrastructure are already realising benefits from sharing data for individual care and analytical purposes. There is a risk that this variation increasingly impacts on the quality of care and public health services available to citizens in different parts of England – and sometimes within the same health and care systems where individual GP practices have not opted into system-level approaches. This carries the risk of exacerbating existing inequalities in access, experience and outcomes, as well as it making it very challenging for individuals to understand how their data is being used in the health and care system.

Challenges to progress

ICSs we spoke to perceived a lack of coherence in national policy in the area of ICS data use, with encouragement to develop local population health capabilities at times feeling in conflict with national plans to provide the FDP and ongoing demand for performance reporting. This perceived lack of clarity is causing stasis in some areas due to uncertainty about making investment decisions.

Participants argued that existing data legislation remains a significant challenge to the sharing and linking of data for analytical purposes, not least due to the fragmented nature of data controllership in England, with rich primary care data controlled by several thousand GP practices. Many ICSs described a lack of clarity of what is and is not lawful in this area, especially in the use of ShCRs as the basis of creating an analytical dataset.

The public has an important voice in this debate, and ICSs acknowledge that public understanding of uses of data is low and trust in data sharing practices can be fragile. While some ICSs have done targeted engagement to support specific information governance applications, on the whole there is a perception that much more needs to be done to achieve public support in this area.

Large parts of the analytical workforce, which for many years has mainly been tasked with operational analyses and reporting, will require upskilling in order to deliver new data functions, though there is great enthusiasm in the profession to make this transformation. Highly specialised roles, such as advanced data engineers and analysts are currently challenging to recruit and retain within current NHS roles and pay structures, such that a separate approach may be required to ensure the NHS acquires sufficient expertise in modelling and data management.

A further challenge exists around organisational culture and the wider use of data in decision making and care planning. Technical advancement has tended to outstrip ICSs' abilities to utilise insights generated by the new possibilities of data. Although there are areas of impressive, transformational work, wider realisation of the possibilities of data will require greater understanding, technical skills and confidence in the use of data by leaders, managers and clinicians.

Participants reported their use of data being impacted in some areas by poor data quality, especially in the recording of data in Electronic Patient Records (EPRs) and in the timeliness and depth of information provided in some ShCRs. In several instances this was driven by inadequate data software that can disincentivise engagement by clinicians.

Opportunities

The significant variation in the data maturity of different ICSs can potentially have an impact on care quality, but also provides an opportunity to utilise the good practice and learning from more developed ICSs to support development elsewhere in using patient data. Participants felt that the knowledge developed by more digitally mature ICSs, and the opportunity to develop relationships between ICSs, offered the potential to drive improvement at a national level in a way that is as yet unrealised.

While NHS England is understandably committed to rolling out a set of FDP products that promise in time to deliver numerous positive outcomes, several participants argued that for certain uses of data, approaches that have already been developed within the health service could be used as a "blueprint" and rolled out in ICSs. More generally, ICSs have developed a range of good practices that could be shared, with other ICSs given change management support to implement them.

Relevant areas of good practice described by participants included:

- approaches to organising analytical teams, such as investing in data managers to curate and maintain datasets, and protecting strategic analytical teams from operational reporting demands;

- approaches to providing analytical support to ICS programme priorities and/or to place-based teams;
- approaches to developing self-services analysis and reporting tools; and
- development of data strategies in alignment with wider ICS plans and priorities.

Recommendations for policy makers

The research has highlighted a number of challenges faced by ICSs in seeking to use data for individual care and secondary purposes. Based on the messages communicated by participating ICS data leaders, we have identified a series of actions that policymakers could take to support development in this area. Wider explanation and commentary around these recommendations is presented in the relevant section of the main report.

Public engagement and understanding

1) ***Support ICSs to engage with patients and members of the public on uses of data, including through increased collaboration, and ensure that local engagement is guided and informed by national and regional public engagement activities, such as the large-scale public deliberation and the forthcoming data pact.***

National and local data systems

2) ***Promote a stronger dialogue and increased communication between national teams and local data leaders on how national and local organisations can work in a joined-up way to deliver on national data priorities and serve the needs of local organisations.***
3) ***Help ICSs gain greater clarity about FDP functionality, plans and longer-term timelines for system-based use cases, especially regarding population health management, incorporation of primary care data, and re-identification of data by clinicians***
4) ***Work with ICSs to consider how technology budgets can be provided in ways that best reflect current and future digital and data costs and that support local decision making.***

Quality improvement and addressing variation

5) ***Working with ICSs, develop a national plan for data improvement aimed at supporting less developed ICSs and reducing variation in data maturity.***

6) Working with ICSs that have established successful techniques and processes, develop a range of good practice approaches to data development and implementation and agree a common channel for sharing good practice.

7) Support ICSs to consistently share code and accompanying technical documentation to minimise duplicative effort and promote collaborative approaches to technical development.

Information governance

8) Explore ways to simplify and clarify information governance requirements about data sharing between health and care organisations and within collaborative place-based partnerships for planning and population health purposes.

9) Work with ICSs to develop and share a resource outlining viable IG approaches for secondary use data sharing, including common use cases and their legal bases.

10) Where appropriate, work with ICSs to explore ways to streamline and reduce duplication in applications and approvals processes for secondary uses of data for planning and population health purposes.

Data quality

11) Work with ICS data users to review the current application of data standards in digital systems and tools and consider options for facilitating improvements in data quality, including by working with suppliers.

12) Consider supporting ICSs to use levers and incentives around the recording of data by healthcare providers, especially where certain priority data categories are under-recorded.

The supplier market

13) Provide support and guidance on the procurement of data systems and tools, such as through national guidance or frameworks.

The analytical workforce

14) Following the Hewitt review recommendations, minimise central reporting requirements on ICSs and prioritise development of processes for automating data submission (including through the FDP)

15) ***Informed by a national skills mapping exercise, develop and deliver a national training programme for analysts to serve future priority data requirements, as well as exploring ways to train early careers analysts in local and regional roles, for instance by expanding the current NHSE data analyst graduate trainee scheme to include placements in ICSs.***
16) ***Support the establishment of and recruitment to senior, non-managerial technical posts in highly specialised analytical areas.***

Cultural change

17) ***Develop change management and quality improvement initiatives to improve data literacy among leaders, managers and clinicians and promote the use of data-driven insights in decision-making.***

Introduction and methodology

About this report

This report, commissioned by Understanding Patient Data (UPD) in collaboration with the NHS Confederation, provides an overview of the current state of play of how Integrated Care Systems (ICSs) are working with patient data. Its findings are drawn from desk research and interview-based qualitative research with ICS data leaders conducted between January and April 2024.

The report is one of a suite of products, including a set of case studies, a plain English summary document and a set of policy recommendations, that collectively intend to articulate the different ways in which ICSs are collecting, using, and sharing patient data, and the opportunities and challenges they face.

Areas of focus include resourcing, information governance, interoperability, technical infrastructure, the applicability and impact of national policy, national support for achieving required standards, and the extent of public trust in this work, all as gauged by leaders working in ICSs. The report considers the sharing of patient data between NHS organisations, both locally and nationally, but also between NHS organisations and other entities such as local authorities, voluntary sector organisations and organisations engaged in conducting research.

The ultimate objective of the work is to broaden understanding of how data collection, sharing and usage are working at present within ICSs, and to underpin ongoing discussions, likely to continue in the coming months and years, about how best to use data to improve care and drive innovation, and how best to navigate concerns about privacy, ethics and legal requirements where the use of patient data is concerned.

Four overarching research questions were developed with Understanding Patient Data and the NHS Confederation:

1) What is the current state of sharing, accessing and using patient and other health and care service user data in ICSs?
2) Looking beyond current priorities, what are the main opportunities for using patient and other health and care service user data in ICSs?
3) What is the current state of sharing patient and other health and care service user data with organisations outside of the ICS, including national bodies (NHS England and DHSC), the Secure Data Environment network and other ICSs?

4) What are ICS leaders' perspectives on public and patient understanding of and attitudes about the use of patient data by ICSs?

Following on from desk research, the report outlines findings from the primary research including:

- Describing the current patient data landscape within ICSs;
- Identifying enablers that have supported current progress in using patient data;
- Outlining challenges ICSs currently face against progressing in these ways; and
- Highlighting future opportunities in the use of patient data, as well as the concerns of ICS leaders about realising these opportunities and their suggested actions to support this area of work.

Finally, a set of recommendations for policymakers is presented, drawn from the research interviews and subsequent roundtable discussion with ICS leaders.

Note: Throughout the report we refer to 'patient data' as a catch-all term. This should be primarily understood as routinely collected information that is captured through an individual's interactions with the health service or social care. However, the research is not limited to only routinely collected patient data and, where relevant, includes other data such as data collected by other local authority services, voluntary and community sector enterprises, and any other relevant local services.

This report will use the term 'individual care', rather than 'direct care', to refer to data that is used to prevent, investigate or treat a patient's health problem, in line with research conducted by Understanding Patient Data on the best words to use when talking about data. We will also refer to data in the singular ('data is' rather than 'data are'), as UPD's research shows that people find this easier to understand.

About us

White Tail is an insight and strategy consultancy specialising in the healthcare sector. We offer a range of services, including qualitative research and evaluation, stakeholder engagement, and strategy and policy development. We have particular expertise in the use of insight and intelligence in Integrated Care Systems, including Population Health Management, data and analytics infrastructure, and understanding user experience.

White Tail was founded in 2023 by Chris Branson. He previously spent nine years at NHS England, most recently as Head of System Development. White Tail comprises a number of skilled associates with extensive experience and expertise in social research methods, healthcare policy and digital transformation.

Find out more at www.whitetailconsulting.co.uk.

Understanding Patient Data is an independent initiative which aims to make the use of patient data more visible, understandable and trustworthy for patients, the public and health professionals. Based at the NHS Confederation, the programme seeks to bring transparency, accountability and public involvement to the way patient data is used.

Find out more about our work at www.understandingpatientdata.org.uk.

The NHS Confederation is the membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland. The members we represent employ 1.5 million staff, care for more than 1 million patients a day and control £150 billion of public expenditure. We promote collaboration and partnership working as the key to improving population health, delivering high-quality care and reducing health inequalities.

Find out more at www.nhsconfed.org.

List of abbreviations and glossary of terms

Term	**Definition**
AfC, Agenda for Change	NHS pay system and employment framework
BI, Business Intelligence	The methods, processes, technologies, and software used to collect, store, and analyse provider performance data
CCG, Clinical Commissioning Group	A disbanded statutory NHS body (effectively merged into replaced by the Integrated Care Board), previously responsible for planning and commissioning healthcare services for their local population
CSU, Commissioning Support Unit	Organisations formed as part of the Health and Social Care Act 2012 reorganisation tasked with providing support functions to CCGs including business intelligence and procurement services; CSUs perform data processing and reporting functions for a number of ICBs.
Data controller	As per Article 4(7) of the General Data Protection Legislation (GDPR), data “controller” means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data
EPR, Electronic Patient Record	A digital version of a patient's paper medical record
ICB, Integrated Care Board	A statutory NHS organisation responsible for arranging for the provision of health services in a geographical area, developing a plan for meeting the health needs of the area’s population and managing the NHS budget for that area
ICP, Integrated Care Partnership	A statutory committee jointly convened by Local Authorities and the NHS, comprised of a broad alliance of organisations and other representatives as equal partners concerned with improving the health,

	public health and social care services provided to their population
ICS, Integrated Care System	The overall health and care system served by the Integrated Care Partnership committee, and comprising all relevant health and care commissioners and services within the geographical area, including the NHS Integrated Care Board, local authorities, NHS healthcare providers, social care providers, voluntary sector organisations and other partners with a role in improving local health and wellbeing
Individual or Direct Care	As per the National Data Guardian Review definition, “A clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals”
FDP, Federated Data Platform	Recently procured software to enable health and care organisations to bring together data currently stored in separate systems; as well as the national platform, every hospital trust and Integrated Care Board (on behalf of their Integrated Care System) will be provided with their own “instance” of the FDP
HCP, Health and care professionals	Professionals who are licensed and accredited to provide regulated health or social care services
LA, Local Authority	Organisation responsible for public services and facilities in a geographical area, including social care and schools; ICSs usually comprise multiple local authority areas, and boundaries are not always coterminous
NHSE, NHS England	Organisation which leads the NHS in England
PHM, Population Health Management	An approach to supporting the health of a population by using data to identify, target and deliver tailored, preventative care to under-served groups and groups most at risk of deterioration

Place	Most ICSs are divided into a number of places, being (usually coterminous) geographical areas within the ICS comprising a partnership of service providers working together to design and delivery integrated services for the population in that area; the size of a place can vary greatly, often in relation to the size of the ICS, but is often aligned to a particular city, town or borough
Place level	Pertaining to the geographical area served by an individual place and/or to the group of health and care organisations and services working for the population of that area
QI, Quality improvement	A systematic change method and strategies to improve health care delivery
SDE, Secure Data Environment	Secure platforms for data analysis, hosted by NHS England at a national level and via a network of regional platforms
Secondary uses of data	Purposes other than individual or direct care, such as healthcare planning, research, or population health
Section 251	Section 251 of the National Health Service Act 2006 allows the Secretary of State for Health and Social Care to make regulations to authorise or require the processing of Confidential Patient Information for prescribed medical purposes and, in so doing, to set aside the common law duty of confidentiality
ShCR, Shared Care Record	A digital record bringing information about patients from different health and care organisations together in one place using information from Electronic Patient Records
System level	Pertaining to the whole geographical area of the ICS and/or to the group of health and care organisations and services working for the population of that area

Introduction

The establishment of ICSs on a statutory basis in 2022 formalised several years of geographically-defined partnership working between NHS and local government organisations that aimed to move away from the competition-based policies of the 2012 Lansley reforms. Instead, the project sought to achieve better collaboration between these mutually dependent organisations, as well as an improved integration of services, particularly for individuals with complex needs that straddle multiple health and care providers.

Closer collaboration between organisations planning and providing health and care services provides the possibility of greater insight into the needs and outcomes of different population groups, as well as a more efficient and effective use of resources. Effective utilisation of data is crucially important in helping to achieve these objectives. The innovative and impactful use of data during the COVID-19 pandemic for purposes such as vaccination prioritisation only served to underline the opportunities afforded by the sharing of data, and accelerated the ambition in this area, not least as a way to help lessen the continued pressures on health and care services. As such, the development of ICS data infrastructure and use has been made a priority for the health and care system, and promises made to support ICSs to achieve their four purposes of improving outcomes in population health and healthcare, tackling inequalities, enhancing productivity and value for money, and helping to support broader social and economic development.

Successive national policy statements, such as the government's *Data Saves Lives* strategy (DHSC, June 2021), have set out a vision and priorities for the use of data in the NHS and social care, including:

1) ensuring clinical and other care staff have access to comprehensive, up-to-date information about their patients;
2) providing local decision-makers with comprehensive population health information to support the planning, prioritising and tailoring of services; and
3) establishing a clear understanding of performance, resourcing and capacity across its health and care providers to support the efficient management of patient flows.

Each of these priorities, from the development of local Shared Care Records, to the use of Population Health Intelligence Platforms, relies on the joining-up of data from across ICS providers, establishing technological solutions, navigating important issues around legitimate data usage and privacy, and building new ways of working; both in terms of collaboration between different organisations and supporting staff to incorporate new uses of data and digital tools into their existing practices and decision-making. Last year's Hewitt review argued for ICSs to focus increasingly on upstream prevention, including Population Health Management (PHM) approaches, and emphasised the role of data in this ambition (Hewitt, 2023).

NHS England's Digital Maturity Assessments for 2023 were revealed to have not only shown that ICSs as a whole remain part-way on their journey to realising these goals, but that there is a great deal of variation in maturity across the different ICSs (Talora, 2023). This reflects not only ICSs at different stages of development but also a range of approaches to developing these important functions and tools, such as utilising different providers of digital infrastructure and software, or opting for different ways to pseudonymise data for planning purposes.

A key development in this landscape is the procurement by NHS England of a Federated Data Platform (FDP), which will allow national and local teams to bring together operational data from different systems in order to use it for a range of purposes. The FDP project aims to reduce requirements around manual data reporting and data sharing, thus freeing up analytical and administrative capacity, as well as supporting NHS organisations to use their collated data in a number of ways, but not without controversy. ICSs have been offered different levels of adoption of the FDP, from full utilisation of FDP services to minimal uptake of functions such as automated data flows. However, as independent statutory entities, the decision to implement the FDP is for each ICS to make locally.

All of this digital transformation is taking place against a backdrop of clinical and public concern over how confidential data is utilised in and around the health and care system. Previous attempts to consolidate NHS patient data into single national data stores – the care.data and GP Data for Planning and Research projects – ultimately failed due to concerns raised by the clinical community and by the public. While our understanding is that the FDP is not seeking to consolidate confidential data in this way, but rather enable better sharing and linking of data where there is a legitimate, established purpose, there are nevertheless concerns for how data will be used on the platform and to what extent the service providers will have access to this data.

ICSs remain in the early stages of the transition towards data-led approaches to the management of their population's health and system-wide coordination of services. This research project work explored precisely what the ICS data landscape currently looks like, what has enabled some ICSs to progress, what challenges remain, and what ICS leaders feel are the future opportunities in this area.

Methodology

We adopted a qualitative approach to enable an in-depth study of ICS leaders' perspectives on and experiences of sharing and using patient data. Fieldwork was divided into two phases:

1) Core interviews: we selected a sample of 11 ICSs to provide a range of perspectives, with two semi-structured online interviews to be conducted in each ICS.
2) Case study interviews: we selected a subset of four of the participating ICSs to be explored in greater depth, with up to four additional semi-structured online interviews to be conducted for each.

We then held a roundtable workshop with research participants and other data leaders in ICSs to support the translation of our research findings into policy recommendations. More detail on our research methods is presented below.

Desk research

A rapid literature review was conducted to identify existing research, strategy and policy documents, as well as relevant public-facing information. Two key word searches were conducted, using Google Scholar (179 articles identified) and PubMed (63 articles identified). Articles were also handpicked (23 articles identified), guided by existing White Tail knowledge and input from Understanding Patient Data.

Articles relating to use of patient data in England or in relevant wider UK settings published from 2020 onwards were eligible for inclusion. Articles relating to the use of patient data in private settings or related to specific disease pathways or patient groups were excluded at this stage for purposes of brevity.

Three researchers extracted relevant data pertaining to the research questions into an Excel spreadsheet tool and analysed the data for common themes. We used these findings to inform ICS sample selection and the development of the discussion guide.

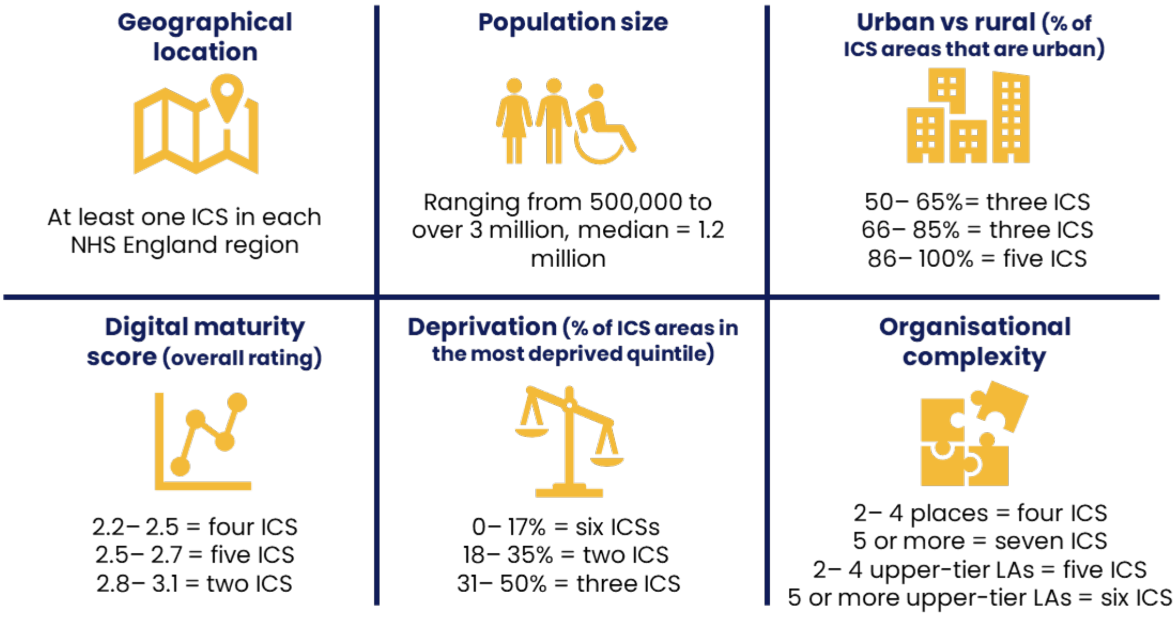
ICS Sample selection

Core interviews

A purposive sample of 10 ICSs was formed to provide a maximal variation sample based on the following characteristics: digital maturity score; geographical location; population size; urban vs rural; measure of deprivation; level of organisational complexity (Figure 1).

Two substitute ICSs were included to replace initially selected ICSs that were unable to participate. An additional ICS approached the research team to be included after publicising the study on social media, raising the total number of ICSs included to 11.

Figure 1. Summary of characteristics of the selected 11 ICSs.



Geographical location

At least one ICS in each NHS England region

Population size

Ranging from 500,000 to over 3 million, median = 1.2 million

Urban vs rural (% of ICS areas that are urban)

50– 65%= three ICS
66– 85% = three ICS
86– 100% = five ICS

Digital maturity score (overall rating)

2.2– 2.5 = four ICS
2.5– 2.7 = five ICS
2.8– 3.1 = two ICS

Deprivation (% of ICS areas in the most deprived quintile)

0– 17% = six ICSs
18– 35% = two ICS
31– 50% = three ICS

Organisational complexity

2– 4 places = four ICS
5 or more = seven ICS
2– 4 upper-tier LAs = five ICS
5 or more upper-tier LAs = six ICS

Population size, urbans vs rural, deprivation and organisational complexity measures from The Health Foundation (The Health Foundation, 2022); digital maturity score as reported in HSJ, 2023 (Talora, 2023). ICS areas analysed by constituent Lower layer Super Output Areas.

Case studies

Four case study ICSs were selected from the participating ICSs based on (i) evidence of good practice across key areas of interest (though very good practice was also evident in other participating ICSs) and (ii) availability to participate: Cheshire and Merseyside, Dorset, Frimley and North West London.

Participant selection

Core interviews

In each participating ICS, two interviews were targeted: one with a senior leader able to offer a strategic perspective on the use of data in the ICS and one with a leader able to provide technical and operational detail about this area. Potential participants were identified based on these requirements using Understanding Patient Data contacts, the NHS Confederation Integrated Care System Network, and existing contacts within the research team. In some cases, additional participants were selected using snowballing sampling following the initial interview. A list of participant roles and number of participants is presented in Table 1, below. These comprised people in both strategic and technical roles, although these categorisations varied by the precise nature of each position.

Table 1: The number of participants in different roles strategic and technical and operational lead participants by generalised job titles

Participant role titles (generalised)	**No. of participants**
Chief (Digital) Information Officer	6
Director/Head of Digital Transformation	3
Chief/Deputy Chief Medical Officer	3
Director of Strategy	1
Chief Analytical Officer/ Head of Insight and Analysis	3
Director/Head of Business Intelligence	3
Director/Head of Population Health	2

Case studies

Guidance was sought from the core participants on which individuals in the ICS would be most appropriate and relevant to interview to develop detailed case studies based on the particular area of focus for each case study. Participants included information governance specialists, local authority data leads, population health management programme leads, and public engagement leads.

Approach to confidentiality

Through discussion with the Understanding Patient Data team, it was decided that the participating ICSs would remain anonymous in order to improve the ability of the interviewers to elicit unbiased accounts from participants. In the interests of sharing best practice, it was decided that the ICSs participating as case studies would be named. This approach was outlined in the participant information sheet and reiterated at the start of each interview.

Semi-structured interviews

A semi-structured discussion guide, informed by the desk research, was developed with the team at Understanding Patient Data and the NHS Confederation (see the Annex). Interviews were conducted online using Microsoft Teams for a duration of up to 60 minutes. Interviews were recorded and transcribed and securely stored in White Tail Consulting's cloud, to be securely deleted upon completion of the analysis and reporting. A participant information sheet was circulated to all participants prior to the interview, and verbal consent was recorded at the outset of each interview.

Core interviews

Twenty-two interviews were conducted with 23 participants across 11 ICSs (including one paired interview) between 9th February and 19th April 2024. Two interviews were conducted in each of nine of the ICSs, and three interviews and one interview, respectively, in two other ICSs.

Case studies

Fifteen interviews were conducted with 21 participants across four ICSs (between three to five interviews in each ICS, with some interviews conducted with multiple participants) between 29th February and 19th April 2024.

Data analysis

Transcripts were coded in Microsoft Excel throughout the fieldwork phase using a framework developed deductively from the research questions. Excerpts and interviewers' reflections from transcripts were extracted by the respective interviewer into the spreadsheet framework. Weekly group analysis sessions were held to discuss findings and identify any gaps. Lines of enquiry and probes were adapted where necessary during fieldwork. The full coded transcript dataset was then analysed inductively to identify emerging themes; four overarching categories were developed through discussion to structure the findings:

- The current data landscape: description of the variation in progress across ICSs
- Enablers: factors or circumstances that have helped progress in ICSs
- Barriers: factors or circumstances that are hindering progress in ICSs
- Opportunities and concerns: forward-looking areas of opportunity and concerns around achieving this

Validation

A draft of this report was shared with five of the core research participants for the purposes of validating findings. Comments from these stakeholders were incorporated into the final version of the report.

Roundtable

An online roundtable was held on the 23rd of April to engage participants and stakeholders from other ICSs in the findings of the research and to refine a set of policy recommendations (see Recommendations for policy makers section below). Invitations were cascaded directly to core research participants and via Understanding Patient Data to non-participating ICS leaders. Fifteen strategic and operational stakeholders across 13 ICSs (including, but not limited to research participants) attended. Participant roles included: Chief Digital Information Officer, Director of Digital Transformation, Director of Data and Analytics, Director of Business Intelligence, Chief Analyst. This event was facilitated by White Tail and comprised of an overview of the research findings followed by a discussion of the draft recommendations. A more detailed overview of the research findings was circulated to participants before the session.

The draft recommendations were circulated to participants after the session and further comments were invited. White Tail and Understanding Patient Data then developed the final set of recommendations on the basis of this engagement and discussion.

Limitations

A qualitative approach with purposive sampling of ICSs to provide variation enabled in-depth insights into the fundamental and emerging issues pertaining to uses of patient data across a variety of ICSs. While data saturation is challenging to ascertain, the research team noted that new topics were not being raised in the final interviews. However, issues pertaining specifically to ICSs not in the sample may have been missed with this approach.

We considered a complementary survey as a method to collect a broader range of views across a wider range of ICSs; however, it was ultimately decided against, given the complexity of the topics to be explored and the contextual variation in approaches making a survey difficult to design and limited in value.

There is a possibility of selection bias, both at the level of ICSs and participants, which may mean that the perspectives included are more representative of those ICSs or participants with a higher capacity, interest, or perceived value in participating. Participation was limited due to the timing of the fieldwork (January – March 2024), with a few participants citing winter pressures and/or industrial action as limiting their ability to participate. However, only two of the initially selected ICSs were unresponsive or felt unable to participate, and these were replaced with substitute ICSs matched by relevant characteristics.

To address possible social desirability bias, following discussion with Understanding Patient Data, we decided that participation in the core phase of interviews should remain anonymous and this was emphasised by the researchers at the start of each interview; however, as ICSs participating as case studies are named this may have introduced an incentive to reflect only best practice in these instances.

Research findings

How ICSs are currently using data

This section describes the current data landscape in ICSs, covering variation in infrastructure, approaches to information governance and the uses of data. It also discusses different ways in which responsibility for data is distributed in ICSs, how the culture of using data varies, as well as the size and structure of data and digital teams. Finally, it discusses how ICSs are approaching making data available for use in research.

A wide and varied data landscape

In speaking to ICSs with a range of characteristics, as detailed in the methodology, above, we encountered wide variation in how ICSs are currently using patient data. While some ICSs have developed advanced systems for linking data from multiple sources for individual care as well as a range of secondary analytical uses, others have a much more basic provision of shared data for individual care, with one ICS we spoke to having little or no data sharing infrastructure for analytical purposes.

> *"I have a combined team of around between 80 and 90 people at any given time, but that covers things like primary care data quality, so working with GP practices to enhance primary care we have a data quality service with about 13 people associated with that."*
> ICS CHIEF ANALYTICAL OFFICER/HEAD OF INSIGHT AND ANALYSIS, NORTH WEST

This variation in data sharing infrastructure is mirrored by variation in the size and complexity of the analytical teams managing and using these datasets, with larger teams and more specialist roles in place where the data infrastructure is most developed.

In particular, data engineers were found to be particularly important in more developed ICSs in order to manage data systems, including data acquisition, cleaning, linking, storage and access.

We also observed important differences in how ICSs are organising their approach to managing data, especially with regard to coordination at system and place levels. While some ICSs are developing their data capabilities through central teams responsible for building and maintaining datasets and analytical tools, and for providing a range of analytical services (including sub-teams that are aligned to specific places in the ICS), some ICSs have much more delegation of autonomy with regard to organising and using data at place level, with significant variation in data infrastructure and resourcing between different places in the ICS. This has strengths and weaknesses when it comes to system-wide decision-making, since the digital leads for each of the different places may have to collectively agree on what to do.

> *"From a certain perspective, it works really well because everyone's bought into an idea. If we've decided we're doing something, it's only because everyone agrees it's the right thing to do. So in terms of progressing work, it's easier at that point because everybody's agreed to it. The problem is it takes a long time to get everyone on the same page to agree to something."*
> ICS DIRECTOR/HEAD OF DIGITAL TRANSFORMATION, NORTH EAST AND YORKSHIRE

A number of factors have contributed to this variation in the data landscape, including maturity and variation in the inherited data infrastructure, and the extent to which different ICSs have benefited from funding and support for data innovation over the preceding decade. The level of complexity of ICS formation (in terms of the number of component local authorities and legacy Clinical Commissioning Groups (CCGs) and the relationship between them) is a factor not only in the progress made in developing a shared infrastructure but also in how this is organised. This is further complicated by the need to coordinate with and/or merge with analytical teams in provider trusts who may have their own analytical tools and data systems in place. Where we observed an ICS's data infrastructure being primarily organised at place level, this was the result of pre-existing maturity in the relationship between the NHS and upper-tier local authority partners in one of the places in the ICS, such that it already performed as an autonomous area, unlike other places in the ICS, which require greater central support.

> *"What would work for [our most advanced Place] wouldn't necessarily work for [our least advanced Place] because they haven't got the capacity to do a lot of the work themselves. So they would rely on [central ICS] resources quite a lot to do the work on their behalf."*
>
> ICS DIRECTOR/HEAD OF DIGITAL TRANSFORMATION, NORTH EAST AND YORKSHIRE

More generally, we learned of a range of approaches that have enabled ICSs to progress with cross-organisational uses of data, as well as challenges that in many cases have acted as barriers to development. These are discussed in more detail in the subsequent chapters of this report. The remainder of the current chapter explores in more detail how ICSs are currently using data.

Data sharing infrastructure

The formation of ICSs introduced a significant opportunity for combining data from multiple sources in order to create a much more holistic understanding of patients and of the interaction of the constituent parts of the health and care system, including patients' journeys across different care providers. This activity of linking data can be broadly divided into two areas: firstly, combining an individual's information from multiple providers into a single record that can be accessed by any relevant provider at the point of delivering care to the individual – a Shared Care Record (ShCR) – and secondly, combining information from multiple sources in order to perform analyses.

Shared Care Records

The scale, sophistication and utility of the ShCRs in ICSs varies considerably, with differences in coverage, content and quality.

In some ICSs, the population routinely receives care from providers in neighbouring ICSs, and a ShCR has been developed across a geography covering multiple ICSs, the London Shared Care Record being perhaps the most obvious example. This means that, for example, when a patient visits a hospital in another part of London to their GP practice, the clinicians at that hospital will have access to key primary care information about the patient. Conversely, in some ICSs there are multiple siloed ShCR tools in place due to legacy contractual arrangements from former CCGs where, for example, the ShCR of a patient living in one of the ICS's constituent boroughs would not be available to a clinician working in a hospital in a different borough. As such, overcoming these ShCR boundaries over time is a priority for affected ICSs.

> *"We've invested in a whole data infrastructure [...] it's a systemwide piece of infrastructure which will allow us to join together all of our local data assets alongside the national data assets and undertake re-ID if required."*
>
> ICS CHIEF ANALYTICAL OFFICER/HEAD OF INSIGHT AND ANALYSIS, EAST OF ENGLAND

In the more advanced ICSs, the ShCR not only incorporates data from primary and secondary care NHS patient records, but also data from adult social care records. In some instances, insights developed from population health analyses of the linked dataset flow into the ShCR where this is seen as clinically beneficial, such as indicators from risk stratification processes. Other ShCRs are much more limited, particularly in regard to the incorporation of non-NHS care data.

The quality of the ShCR tools also varies, with one described by a participant as only containing “high level” information with a significant time lag, such that it was being used inconsistently by clinicians; another described their clinicians reverting to the EPR due to the consistent lag in data flowing to the ShCR, which can result in mistrust of it. More well-regarded ShCRs provide near-real time access to detailed information, with an interface that makes it straightforward for clinicians to use alongside their EPR.

Analytical data

Much of the focus on how data can be used in ICSs concerns its analytical applications, such as monitoring patient flow and care capacity across the ICS or identifying which groups of patients are most at risk of deterioration or unplanned episodes of care. These functions are performed on a de-identified dataset that is distinct from the ShCR.

> *“We've moved from it being a ShCR to a place where professionals can virtually work together and where we can integrate care so we can move [staff] to integrate around our residents.”*
>
> ICS DIRECTOR/HEAD OF DIGITAL TRANSFORMATION, SOUTH EAST

In the case of analytical datasets, the variation in is even wider than for ShCRs. The most advanced ICSs have multiple sources of data linked in a secondary use data warehouse, with regular flows of acute, community and mental health, primary care and adult social care data. A small number of ICSs have further sources of data linked in, such as children’s services and 999, with concrete plans to begin the flow of data from other local services, such as NHS 111, and services outside the ICS footprint, all with a view to gain greater understanding of people’s health and care needs and how best to support their wellbeing.

> *“We’ve started a few conversations with organisations outside of NHS and local government and so there's an ambition to add to this [data flowing into the analytical dataset] and to keep adding.”*
>
> ICS LOCAL AUTHORITY DATA LEAD, NORTH WEST

This linked data can then be interrogated on an analytical platform – a secondary use data environment that can facilitate different types of analyses – with individuals granted access to specific parts of the dataset depending on the use case. These platforms can be used to generate automated, replicable analytical outputs. While some ICSs have built or adapted their own data warehouses and analytical platforms and continue to have ownership of them, others outsource much of the management of this infrastructure to their Commissioning Support Unit (CSU) or to a private software provider.

> *"If we'd have had to have done that in house, I don't think we'd be where we are now again. [Our supplier] enables us to do things much more quickly than maybe we would have been able to."*
>
> ICS LOCAL AUTHORITY DATA LEAD, NORTH WEST

At the other end of the scale, some ICSs have much more limited flows of data for analytical purposes, with one ICS reporting no flow of primary care data for secondary use purposes, although this is a current priority. Some ICSs are likewise yet to build or procure a secondary use environment and analytical platform, such that analyses are produced on an ad hoc basis by a central business intelligence team and then shared to the team requesting the information via an aggregated data output with small numbers suppressed – a cumbersome process that requires certain manual aspects of quality assurance.

Less common than data flowing from a wide range of organisations, including local authorities, is this data being accessed and used by teams outside of the centrally coordinated ICS analytical team. We encountered a few instances of local authority teams beginning to use the ICS's linked dataset – but lack of familiarity with NHS data was observed to hinder this process – and did not hear of any other types of organisations, such as VCSE partners, routinely using this data.

Another key distinguishing feature of analytical maturity is the capacity for Population Health Management that results in the delivery of a care intervention by re-identifying individuals from the pseudonymised analytical dataset. This enables secondary analysis to select a cohort of patients who would benefit from a specific care intervention and for frontline clinicians to then access the identity of the selected individuals so that the care can be delivered. This is a complex process since it requires (i) data to be de-identified in such a way that it can later be re-identified (rather than identifiers straightforwardly being removed when anonymising the dataset, which is a much simpler process but not only rules out individual care uses but also any further data linkage), (ii) a data infrastructure that can link the analytical dataset with clinical workflows, and (iii) an information governance (IG) infrastructure that facilitates these processes without compromising data security or the legal use of data. Some analytically mature ICSs did not currently have the re-identification capability, while some less advanced ICSs did have a basic approach in place, using a single, fixed risk stratification tool on a CSU dataset, with a s251 notice in place to allow GPs to identify those selected.

Gaps in data provision

One aspect of variation in data provision to draw particular attention to is that of gaps in data sharing that can largely be explained by data controllership in general practice. In all of the ICSs we spoke to, including ICSs with advanced data sharing where data flows from multiple care sectors have been successfully established, there remain a handful of GP practices (in most cases fewer than five) who have not yet agreed to share their data for secondary analytical purposes, meaning these patients could be excluded from certain targeted care interventions based on risk stratification analyses. In some ICSs, where this decision has been made by a Local Medical Committee, this applies to patients at several neighbouring GP practices.

We also learned of certain areas within ICSs – especially where greater autonomy has been granted at Place level – where a ShCR is not currently established, or where certain GPs have not agreed to share data for this purpose, such that clinicians serving patients in one part of the ICS may have access to less information than clinicians in another part.

> *"The shared patient record has gaps and that has real profound implications for patient safety and the quality of care"*
>
> ICS DIRECTOR/HEAD OF POPULATION HEALTH, SOUTH WEST

Information governance

All of the ICSs we engaged with described information governance (IG) as a fundamental challenge for using data at system level, in terms of utilising data from multiple sources and providing access to data to users in different organisations. Arguably the extent to which IG has been prioritised over time is one of the most marked areas of variation across ICSs. The ICSs with the most mature shared data infrastructure speak of being on a journey for the last ten years, with IG at the core of this journey.

The more advanced ICSs have an IG infrastructure in place that enables a consistent flow of data into a managed data warehouse and the ability to grant

> *"Information governance is fundamental to the use of data. And, you know, we were an exemplar nationally. We started our journey of this integrated data warehouse a decade ago when there was no integrated care board, there was no integrated care system. The policies at that time did not even allow us to be bringing things like that."*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, LONDON

access to this data on a case-by-case basis. This reduces the burden of gaining access to data for new uses insofar as an overarching framework or charter has been agreed on by the data controllers, with new applications reviewed on a case-by-case basis. However, some participants pointed out that even with a strong IG framework in place, use case permissions remain a complex challenge for ICSs. An example cited was a patient flow tool that contains both patient level data and aggregate data, meaning that this single tool had different source data, different use cases and different users, some of whom were clinical, meaning that the tool required different IG permissions and considerations for different uses.

At the other end of the scale, in some ICSs, permissions to link data are sought anew each time, with no governance in place to support the ongoing use of data (and management of a data warehouse) for agreed purposes. This not only greatly increases the burden of gaining permissions and building datasets but limits the opportunity for exploring potential uses.

Approaches to building the dataset

Chief among the information governance challenges is the process of building the analytical dataset, where a number of different approaches have been taken from both a technical and information governance point of view. Analytical data will have confidential, individual-level data at its basis, but should be de-identified for the purposes of conducting analyses. In several of the ICSs we interviewed, the analytical dataset is derived from the ShCR through a pseudonymisation process. This de-identification process usually happens after data has already been shared and linked (for the ShCR individual care purpose), meaning that ICSs need to establish a legal basis for additionally processing the ShCR data in this way. This will depend on the purposes for which that the analytical dataset is being used. Some ICSs have limited their analytical uses to activities that result in individual care provision, seeking legal assurance on this basis. Other ICSs, who have wider secondary uses of linked data, have sought s251 support from the Confidentiality Advisory Group, which permits the lifting of the common law duty of confidentiality so that confidential patient data can be processed for an agreed purpose.

An alternative model is where the linked analytical dataset has been built independently of the ShCR and instead has been grown over the time on the basis of data sharing agreements in support of specific uses cases, using an overarching IG infrastructure to maintain and add dataflows to this central data infrastructure as new use cases are established. This approach can require much more lead-in time to generate a dataset from multiple sources but arguably the IG process is clearer since each flow of data must have a specific purpose in order to be established.

A further complication of building the analytical dataset is the treatment of patient opt-outs of data sharing. Where opt-outs are applied will depend on how the linked data infrastructure has been built, and whether it is being utilised for purposes other than individual care. In some cases, ICSs have asked care providers to apply opt-outs at source to ensure that they cannot flow into the analytical dataset.

Uses of data

Variation in the uses of data in ICSs mirrors the variation in data sharing infrastructure. In the more advanced ICSs, a wide range of uses are in place, which seek to derive insights from linking longitudinal datasets at the individual level in order to better understand a range of factors pertaining to population health and ICS performance.

A number of participants described using linked data from different sources – especially utilising the richness of primary care data – to conduct population health analyses, exploring inequalities in care access and outcomes and identifiable risk factors of unplanned use of services. These analyses can have operational uses, informing the planning or transformation of services, such as care pathway redesign, or can be applied to individual care by identifying cohorts of individuals through a risk stratification approach and designing interventions to support their health and wellbeing. At best, these analyses are combined with qualitative insight and patient engagement to inform the design of care for specific groups.

> *"[Our ICS priorities for data are] very heavily predicated on supporting significant service transformation and proactive care and integrated care and we've been using a population health data approach to really underpin that."*
>
> ICS CHIEF (DIGITAL) INFORMATION OFFICER, SOUTH EAST

> *"We will have population health jamming sessions [...] where you're diving into a problem [...] So we'll bring GPs together, acute trust consultants together, ED Consultants, and we work on the data and we come to an agreed synthesis and a trusted view of what we think is the insight"*
>
> ICS DIRECTOR/HEAD OF DIGITAL TRANSFORMATION, SOUTH EAST

Some ICSs also spoke of strategic use of analysis in line with ICS programme priorities, using the linked dataset to develop a more powerful and holistic understanding of issues pertaining to specific service areas, such as children and young people's care, or mental health care. A further operational use of data named by several participants was to drive system efficiencies, such as optimising waiting lists by removing duplication across lists and reviewing operating theatre and outpatient clinic utilisation.

Most common among all ICSs, however, was the use of data for local performance monitoring and reporting, which was described by many as historically the bulk of the workload for CCG analytical teams. Many participants described this as a transactional or reactive use of data, with an aspiration to increasingly automate processes to produce data reports in order to free up analytical capacity for other functions. However, in the less well-developed ICSs, the vast majority of analytical capacity was spent on operational reporting with one describing it as constituting 80% of their current activity. In many cases this was said to be driven by NHS England's demand for situation reports.

> *"The churn, the must dos, the asks, et cetera from the centre always trump other elements [...] So I tend to be sort of 70 to 80% operational stuff and 20% the strategic stuff unfortunately, which is hindering the timeliness of our goals."*
>
> ICS DIRECTOR/HEAD OF BUSINESS INTELLIGENCE, MIDLANDS

Organisation, culture and workforce

In ICSs with a more advanced data infrastructure there tended to be a digital and/or data strategy in place with close alignment with both the ICP's strategy and the ICB's joint forward plan. In ICSs which have successfully prioritised data, this data/digital strategy tended to be reinforced by clear promotion and sponsorship of the data agenda at the executive board level, such that it was viewed as a core aspect of care planning and delivery going forward. Conversely, in one ICS where a very influential executive sponsor was in place, the current absence of a data strategy meant that despite buy-in from a senior sponsor, corporate prioritisation of data was not well developed.

One important variation between the ICSs we spoke to was who in the ICS had ultimate responsibility for data, with this sitting in a range of executive roles, including Chief Digital and/or Information Officer (the most common), Chief Medical Officer, Chief Transformation Officer, and, in one case, Chief Financial Officer. Where executive responsibility for data sat was sometimes decided on for strategic reasons, for example to ensure that data is closely aligned to clinical or transformational priorities, but in other cases was a case of a legacy being continued. Our interviews suggest that the nature of executive leadership of data can have an influence on the extent to which data priorities are supported and resourced, as well as to which uses of data tend to be prioritised. What several participants described as proactive and transformational uses of data, such as prevention activities, tended to be championed in particular by Chief Medical Officers, Chief Transformation Officers and some Chief Digital/Information Officers. Where a Chief Financial Officer oversaw the data team, more transactional uses of data tended to be emphasized, such as performance management and reporting.

> *"They're all very senior and the leadership who are getting behind it [the data strategy] [...] And that's one of the most important things, because what they do is they develop that culture of trust but doing it for the right reason and also talking about it and communicating it well."*
>
> ICS DATA PLATFORM PROVIDER LEAD, NORTH WEST

More broadly, we observed variation in ICSs' culture of using data, in terms of the extent to which data is being built into clinical, operational and commissioning processes across the ICS rather than remaining the concern of specialist data and analytics teams. Even in the most advanced ICSs, this was recognised as a challenge, where the development of infrastructure has far outstripped the transformation of a culture for learning from and routinely using data in decision making. In the least well-developed ICSs, even the use of ShCRs by clinicians was described as limited, with participants describing a need to demonstrate the value of data tools to the workforce and support them to integrate them into their everyday working processes.

"I have what I call four functions underneath me, and each of the functions have a team. So the first function is a data management and data insight team [...] They are the data engineers who are responsible for acquisition of data, ingestion of data into data warehouses, linking the data."

ICS DIRECTOR/HEAD OF BUSINESS INTELLIGENCE, LONDON

In terms of the data workforce specifically, we once again observed very significant variation in scale, skills and organisation. The most advanced ICSs have coordinated analytical teams serving clearly delineated functions, including teams responsible for the curation of data, with members of staff with specialist data engineering skills.

Analytical teams were aligned to specific ICS localities and/or to specific ICS functions, such as finance and performance or clinical/transformation programmes. In some cases, analysts with specific population health or modelling skills had been engaged to lead more advanced analytical work, while another emergent area in more advanced ICSs was the development and maintenance of self-service analytical tools to enable ICS colleagues to access analytical reporting on an ad hoc basis.

"We have just literally gone to eleven staff and that's not eleven whole time equivalents because we have got a couple of part times in there and a few years ago it was down at six [...] We have now a dedicated resource available to the more analytic side of things, so PHM, health inequalities we've got dedicated one whole time equivalent and the rest of the team are on answering operational demands"

ICS DIRECTOR/HEAD OF BUSINESS INTELLIGENCE, MIDLANDS

Less advanced teams were much smaller, meaning they were not always able to offer dedicated support to specific ICS programmes or localities. They also tended to have fewer specialist roles and specialist work programmes, and often outsourced some of their analytical processes to their local CSU, particularly when advanced technical skills were required.

Data sharing for research

The most digitally mature ICSs described themselves as playing a leading role in the development of their regional Secure Data Environment (SDE). Where their existing data warehousing system had the capability of fulfilling the technical requirements of an SDE, ICSs were either planning to host the SDE for their entire region or contribute to a collective regional SDE built around the data warehouses of themselves and their neighbouring ICSs.

> *"So we had a conversation with [the other two ICSs] and said we will put in a North West bid, but our bid is based on retaining 3 ICS level SDEs but with a wrapper that allows us to federate them on the occasion that you need a bigger population."*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, NORTH WEST

Conversely, the least advanced ICS we spoke to had very limited engagement with their regional SDE. Their involvement in this project was felt to be poor, with it feeling like those leading the SDE were simply telling them what they needed to do and taking their data, with the process perceived by participants to be lacking in transparency and openness.

Enablers of progress

We identified a number of factors that are supporting the successful development of data sharing infrastructure and a culture of using linked data to improve care planning and outcomes.

A supportive environment

Many participants argued that the policy context of ICSs has been important in enabling collaborative work on the sharing of data, with a move away from competition rules. Beyond this, more specific regulatory and contractual changes were cited as helping to accelerate progress in this area, with changes during the COVID-19 pandemic explicitly mentioned. For example, one participant linked the suspension of Payment by Results contracting as enabling their ICS to have "a more sophisticated conversation" with its providers about how to deliver better care for patients. Likewise, the Control of Patient Information (COPI) notice introduced by the Secretary of State at this time, which required the sharing of confidential patient data to help tackle the COVID-19 pandemic, had an important impact in ICSs where new data infrastructure was built to support this need. More generally, the use of linked data under this notice helped demonstrate to stakeholders some of the potential of linking data in this way and thus supported engagement and generated buy-in among ICS leaders and data controllers. On the other hand, some ICSs reported that data sharing activities were negatively impacted during the pandemic in terms of disrupting the development of relationships and establishment of IG arrangements.

"For us, just from a data perspective, it really accelerated us […] I think we'd still be talking about data sharing agreements and information governance now, if it hadn't been for the pandemic."

ICS LOCAL AUTHORITY DATA LEAD, NORTH WEST

One clear advantage enjoyed by the more advanced ICSs for creating an enabling environment is the existence of a clear data strategy that is aligned with wider ICB and ICP plans and priorities, such that the development of data use in the ICS is clearly recognised as a key to the ICS fulfilling its purposes around improved outcomes, inequalities, productivity and so on.

The goal is for data to be seen as central to care planning and delivery, such that consistent investment is made in its development and a culture of data use among clinicians and managers emerges over time. As noted in the previous chapter, this can be supported by senior sponsorship and responsibility for data residing with an executive with wider commissioning responsibilities, such as a Chief Medical Officer or Chief Transformation Officer, though we observed other well-functioning models in which a Chief Digital/Information Officer works collaboratively with their peers on a transformation agenda.

While funding was more often spoken of as a challenge than an enabler, some more advanced ICSs have benefitted in the past from successful funding bids that have provided protected investment in this area, using this to trial technology or to protect staff to pursue strategic projects.

Trust and governance

A clear and strong message from ICSs that have developed a shared data infrastructure is the importance of consistent engagement with local data controllers about the sharing of data and long-term investment in developing IG approaches and agreements that can support the use of linked data. Two ICSs talked about spending several years on developing the IG and data infrastructure that they are now benefitting from. In both cases, they talked about detailed and consistent engagement with data controllers in order to build trust about how the data will be used, as well as IG support to understand and address risk and liability. This sustained engagement was viewed as fundamental for ultimately achieving data sharing agreements to support planned uses of data. In these ICSs all but a very small number of GP practices had agreed to overarching data sharing frameworks.

> *"We spent years building trust, like literally 10 years building trust, so our GP providers and local authorities contribute data."*
>
> ICS CHIEF (DIGITAL) INFORMATION OFFICER, SOUTH WEST

Several systems described the development of an overarching IG framework or charter that data controllers sign up to as an important step for achieving IG arrangements that support the establishment and growth of a shared dataset. All new data sharing applications can then refer to the terms of this framework, thus lessening the IG burden when new uses of data are to be reviewed and ensuring a consistent set of rules are applied. This appears to be a model suitable for adoption by other ICSs in order to streamline these processes.

Being a fundamental component of the data architecture, investment in the assurance of local IG arrangements was also cited by many as essential for achieving agreement with data controllers and supporting conversations about proposed uses of data. One ICS reported it had taken two years to get their IG framework legally ratified, while another described seeking senior legal advice about their approach and then refreshing this a few years later.

Another successful approach for ensuring trust and shared ownership mentioned by some ICSs is to ensure that data sharing providers remain part of the ongoing governance of the data, either as part of the decision-making forum that judges applications for new uses of data (with the local GP population usually delegating responsibility to a small number of representatives), or by allowing them to opt out of specific uses of their data as they see fit.

Finally, while a range of approaches to developing linked analytical datasets were discussed, arguably the most promising method for the purpose of building local buy-in is that of a use case-based model, where a new linked data flow is established on the basis of a clear new purpose and the dataset builds over time in this case-by-case basis.

> *"Clinical leads wanted to develop a diabetes dashboard as the next use case since diabetes is a prominent use case in the sector. Then we said right, in order to develop the key care metrics for a diabetes dashboard, can we do it based on linked primary care and acute. Then the diabetes team said no, because a lot of diabetes care gets provided in community. We need community linked with acute and primary care, that's when community data came on board."*
>
> ICS DIRECTOR/HEAD OF BUSINESS INTELLIGENCE.

The use case-based model of growing the analytical dataset means that each time a new flow of data is added, a clear discussion and process has taken place with the relevant data controllers and other stakeholders, which can help ensure all are clearly sighted on what is happening and why. While this approach may require a longer-term approach than the use of an existing ShCR as the basis of an analytical dataset, it ensures that data controllers participate in the decision around each stage of the construction of the linked dataset.

Public engagement on uses of data in ICSs

All of the ICSs that we spoke to acknowledged that it was necessary to engage with the public and ensure there is trust for uses of patient data. However, in the majority of ICSs we spoke to, limited engagement had taken place with the public on how their data is or is planned to be used at system level, apart from where this was a required part of a governance process. ICSs cited a lack of time or resource to build engagement into their development activities, although many praised the quality of their internal communications and engagement teams and felt that the ICS would be able to manage engagement activities as and when it wished to pursue. them. Most ICSs spoke of a desire to focus more on engagement in the future and to increasingly make this a routine aspect of developing and implementing new uses of data.

In some cases, a certain amount of engagement had taken place specifically to support applications for s251 agreements to enable a ShCR to be used to create a secondary use dataset for risk stratification or other population health management activities, or to help inform an ICS's legal stance on how they are processing data for these purposes. Focus groups and deliberative events with local citizens tended to form the basis of these engagement activities, but other modes of communication and engagement included the provision of information online, and the use of adverts on public transport. Some participants said these activities were periodically refreshed to provide ongoing assurance.

A number of ICSs cited the OneLondon deliberative work as an example of good practice in this area, where proposals for a region-wide ShCR and other possible uses of data were explained and deliberated over the course of four days with a sample of the population. Most of the participants were aware of the expertise available in their ICS engagement teams and felt they did have the internal capability to either conduct engagement work or successfully procure it.

> *"Those hundred Londoners [from the OneLondon deliberative work] would not be representative of the lived experiences of people in [an ICS at the other end of the country]."*
>
> ICS CHIEF (DIGITAL) INFORMATION OFFICER, SOUTH EAST

All of the ICSs we spoke to believed ICSs have a responsibility for engagement with the public when it comes to local initiatives, such as a change to specific services, although views were mixed about where responsibility should sit for issues in common. Some felt that engagement about issues that affect all ICSs, such as the use of data in ShCRs or the use of linked data for population health analyses, such be nationally led so as to avoid cost of duplication. Others saw the responsibility as sitting with the ICS as part of the governance around their role in linking data and using it in specific ways. One participant said they would not feel confident in work led nationally and that they would always want to take local responsibility for engagement. Others pointed out that populations differ and as such ICSs do need to understand views in their local area.

Workforce

Some ICSs emphasised the importance of having separate teams in place for strategic and operational analytics. The demand for situation reporting and performance analyses, from both internal ICS and NHS England teams can often risk longer-term analytical work being neglected. This burden was noted in the Hewitt review, which argued that automation of SITREP and other reported data through the FDP could make a real difference, but also recommended the removal of duplicative, unnecessary or less important reporting requirements (Hewitt, 2023). This is likely to take some time to be implemented and make an impact, and as our research suggests, these burdens remain, hence it can be helpful to ringfence some resource for strategic analysis to ensure that reporting pressures do not inhibit progress in this area.

> *"If you don't create the space for strategic intelligence it just gets completely mopped up in tactical stuff, so the strategic intelligence team covers population health more generally and its brief is to check we are doing the right things, not just doing things right"*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, NORTH WEST

Some participants thought there was a potential role for the NHS graduate trainee scheme to offer system-level training placements for trainee data analysts. This had the potential to widen the available pool of junior analysts for ICSs as well as creating a pipeline of analysts with experience at system level in the longer term. Further suggestions on workforce from research participants included making templated standard job specifications more widely available to reduce duplicated effort at system level and broadening access to data training for non-specialists in ICSs so that they would be able to "self-serve" by understanding and accessing relevant data.

Interoperability

Interoperability of different IT systems such as EPRs, ShCRs and GP systems was felt to be of less significance than in previous years in terms of preventing the flow of data or the communication of different tools, because data engineers are more able than before to solve this issue. Nevertheless, several participants noted the benefit of having the same IT tools being used in different organisations within the ICS in terms of the efficiency of processes and minimising the burden of having to develop and implement ways for different data systems to talk to each other. As such, it was recommended that over time ICSs try to seek the alignment of the software being used by their different provider organisations as existing multi-year contracts expire and they are able to re-procure.

Challenges for progress

Interview participants identified a number of current challenges perceived to be limiting their ability to make progress. These included: tensions between local priorities and national funding, priorities and new initiatives; ICS culture, collaboration and leadership; the fragmentation of digital and data infrastructure; workforce needs; uncertainty with information governance; public trust; inadequate 'buy-in' of value of data by health and care professionals, and; data quality issues.

National funding, priorities and new initiatives

A recent report by the NHS Confederation highlighted governmental short-termism as a barrier to ICSs focusing on the long-term goals of integration, equity and prevention (NHS Confederation, 2023b). Several participants echoed these findings, noting that funding for digital and data has been short-term, unprotected, fragmented and is often incongruous with national policy. National expectations are also perceived by some as too focused on performance, targets and new initiatives, such as FDP implementation, and misaligned with ICB prevention and proactive care responsibilities. As a result, several ICBs have struggled to develop or sustain a long-term digital and data strategy, with participants noting that national funding can 'distort' progress or put ICBs on a reactive footing. Echoing the Hewitt review, our findings revealed that this is limiting the extent to which some ICSs are able to invest in necessary transformation technologies and processes.

> *"I think there is a propensity for organisations to remain reactive and less strategically focused. As much as people say they want to be proactive unless something changes naturally in the way that people are managed and how they're looked at, and how funding these schemes work, that is very, very reactive."*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, EAST OF ENGLAND

While participants particularly from less digitally mature ICSs expressed muted enthusiasm for the possible benefits associated with recent data sharing initiatives (namely the Federated Data Platform (FDP) and Secure Data Environments (SDE)) (see Future Opportunities section, below), these were outweighed by uncertainty around their purposes, capabilities and timeframes. With respect to FDP implementation, ICSs with less mature digital and data infrastructure reported delaying building a local single data platform, viewing investing resource at this stage as a potential duplication of effort.

Several participants from ICSs of higher digital maturity highlighted the additional administrative IG burden associated with storing multiple instances of patient data across EPRs, ShCRs, local PHM platforms, the FDP and SDEs and providing access to a diverse range of users for different (or indeed similar) purposes. Overall, for more advanced ICSs, a perceived lack of a national single strategic view and narrative across these initiatives is perceived to be at best acting as a distraction and creating unnecessary work, and specifically in relation to the FDP, at worst threatening hard-earned trust from system partners and the public, posing a risk of increased opt-out rates, reduced data flows and compromising the statistical utility of current platforms. As such, these ICSs wish to understand more clearly the purpose and benefits of the FDP through clearer and more detailed dialogue with national bodies.

> *"I suppose if it was going to benefit you, so if you didn't have anything locally, it might be seen differently because it is a bonus at that point. But we've, you know, we've got tools already across each of our places. So it does feel like an extra burden."*
>
> ICS DIRECTOR/HEAD OF DIGITAL TRANSFORMATION, NORTH EAST AND YORKSHIRE

Clear communication regarding the purpose and intended benefits of these new digital and data initiatives, aimed at both the public and ICSs, was seen as vital for addressing these current challenges. Participants from nearly all ICSs stressed the importance of national bodies understanding the implications of these new national initiatives, particularly the FDP and SDEs for their ICS, specifically the time and resource needed to adopt and embed them.

Fragmentation of digital and data infrastructure

On a practical level, to varying degrees, ICSs are still faced with a "jumble of data architecture" for both individual care and analytical use. Several ICSs have multiple ShCRs procured across various providers and with whom they are tied into long-term contracts, and others reported geographical gaps in ShCR implementation in some areas of the ICS, while many ICSs have multiple place-level analytical data platforms and teams, especially operating within acute Trusts. Substantial effort is therefore necessarily being invested into levelling up parts of the ICS, which is limiting the resource needed to focus on developing system-wide initiatives. One participant expressed concerns that they had *'missed the critical path to change'* with respect to implementing a single ShCR given the extent of fragmentation within their ICS; this is presenting challenges for the quality of individual care, particularly for patients accessing services across different parts of the ICS.

Culture, collaboration and leadership

Compounding the challenges presented by fragmented and short-term funding and policy is the shift to collaborative partnership working in a milieu of legacy CCG culture, leadership and data infrastructure. Agreement on a system-wide data strategy continues to be complicated in some less mature and more organisationally complex ICSs by different legacy place- or neighbourhood-level data priorities, leadership and ongoing place-level projects. From some participants' perspective, some trusts or existing place-level partnerships need persuading to give up control of their approach to data. Participants emphasized the time needed to re-configure teams, consolidate resources, and develop working relationships and trust across providers to move away from place- and neighbourhood-level ring-fencing and intra-ICS competition for resources.

> *"We call ourselves systems and yet behave in silos and then we wonder why we fall apart again."*
>
> ICS DIRECTOR OF STRATEGY, NORTH EAST AND YORKSHIRE

One ICS with a strong place-level identity is intentionally operating a data strategy at place- as well as at system-level, with data agreements to link national datasets with GP data at place-level. Further consideration may need to be taken where there is appetite for a more devolved ICS to determine at which level priorities should be set and teams established.

ICSs with less mature collaborative partnerships and/or with a less well-defined system-wide data strategy seemed to be facing higher barriers to developing the necessary data sharing agreements across organisational-boundaries to support system-wide initiatives such as ShCRs and PHM analytical platforms.

> *"There's ideas about direction of travel […] But because the system isn't massively effective and isn't massively collaborative, the role of an ICB and the role of a provider organisation, it's a little bit unclear"*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, EAST OF ENGLAND

With respect to leadership, while there was ample evidence of where ICB leaders are championing digital and data programmes effectively, a few participants queried whether their ICS was appropriately equipped to use data and insight systematically to create strategy and evaluate impact. Some participants in technical roles expressed dissatisfaction where they perceived ICB leaders in their systems had limited bandwidth for translating data insights into strategy and policy and were not necessarily bought in to the value of data for delivering on ICS priorities. Participants also highlighted a lack of recognition at ICB Board level that revenue investment, for workforce and software licenses, is becoming a greater need than capital investment, particularly as data infrastructures become more complex and uses of data diversify. As a result, ICSs lacking strong leadership which appear not to have been able to prioritise investment into building system-level analyst teams is further widening the gap between the most and least advanced ICSs. This is fundamentally perceived as an organisational development challenge which requires a leadership and cultural change process to address.

Use of data by health and care professionals (HCPs)

The challenges around developing a collaborative culture, the fragmented data infrastructure, and IG uncertainty are manifested at the 'frontline' in how HCPs use data. While some ICSs have managed to embed a 'data-led culture,' participants from several ICSs suggested that the sub-optimal use of ShCRs or PHM dashboards by HCPs is due to a lack of buy-in of the value of 'top down' initiatives, concerns about IG, and/or practical and technological interoperability barriers impeding easy access to multiple interfaces, which are often outdated, given time and capacity pressures across the NHS. According to participants, the use of data by HCPs has not developed at the same pace as analytical capabilities and system-level ambitions regarding the use of data, and there has not been commensurate and coordinated quality improvement (QI) initiatives to drive the adoption of ShCRs and other data tools by HCPs.

> *"Do we even have the right people who have been given capacity to do it [HCPs using data tools routinely]? […] There are people with capability but they're not given the capacity. So if we are sat here and think GP's are going to do something about it, I think we're dreaming, aren't we?"*
>
> ICS DIRECTOR/HEAD OF BUSINESS INTELLIGENCE, LONDON

> *"So the disparate number of systems can be a challenge as well, because why would you want to log into three different systems when you could just do it from one?"*
>
> ICS DATA PLATFORM PROVIDER LEAD, NORTH WEST

Significant transformation work is required to embed new PHM and other data tools in clinical workflows, training HCPs to use them routinely, and developing a culture of using data to support decision-making. Participants noted that GPs in particular face constraints on time and tend to be more apprehensive regarding data protection which hinders their willingness to adopt proactive data-led initiatives. Practical approaches mentioned by participants as helping to streamline the use of PHM and data tools into primary care included: the introduction of specialist care navigators to manage dashboard analysis; integration of dashboards into ShCRs; integration of risk stratification tools into ShCRs. However, the broader issues persist, with providers facing substantial performance pressures.

Workforce

Nearly all ICSs stressed the importance of building analytical teams with strong technical capabilities, where the types of expertise sought was dependent on the level of ICS digital and data maturity and the extent of outsourcing. Some of the skills commonly mentioned by more advanced ICSs, which are currently lacking, included scenario modelling, data science, and AI skills. The challenge of offering analyst salaries within the NHS Agenda for Change (AfC) pay scale which are sufficiently competitive with private sector salaries has been cited as a key barrier to attracting talent, with calls for a re-think of national workforce funding mechanisms to address this. A common suggestion was introducing a pay scale for digital, data and technology (DDaT) professionals outside of current AfC bands, which tends to reward management responsibility in its higher grades rather than technical seniority and is out of step with private sector salaries for comparable roles which are particularly high in DDaT roles. However, some ICSs are tackling this barrier by focusing on publicising the public value and interesting nature of the work, alongside opportunities to engage with partners across and beyond the ICS, including local universities, to help attract and retain people with advanced analytical skills.

> *"The skills are scarce and in demand, and if we're serious about optimising care and understanding the data and behaviours then we need to employ people with the expertise to do this."*
>
> ICS CHIEF (DIGITAL) INFORMATION OFFICER, SOUTH EAST

Analytical capabilities are perceived to be particularly limited in ICSs that have relied heavily on outsourcing of the majority of processing and analytical functions to third parties, such as CSUs or external proprietary solutions. While this has not historically been an issue where analytical functions have been limited to operational reporting, the need for in-house analytics capacity and capabilities is growing as ICSs diversify their uses of data and as linked datasets become more complex.

Workforce resourcing is constrained further in ICSs that have smaller budgets for digital and data and allocate a significant proportion of their analytical resource for operational reporting. 'Increasing demands on Business Intelligence teams, both from multiple national teams as well as from within the ICS to support strategy and planning, are compounding these workforce challenges. Participants highlighted a lack of coordination of demands, particularly from national teams. Automated reporting solutions therefore represent a key area of opportunity for ICSs without these capabilities, with several participants noting the potential for the FDP to provide this capability as recommended by the Hewitt Review (Hewitt, 2023).

Information governance

Uncertainty caused by current guidelines, laws and regulations concerning the sharing and use of patient data was perceived by participants as a barrier to progress and/or as an unnecessary administrative burden consuming significant resources. Certainty is needed specifically around what data can be shared across organisational boundaries, for what purposes and under what legal bases, in order to reduce perceived risks and foster trusting collaborative partnerships within local health systems. Causes of uncertainty were perceived to be twofold: an inherent feature of the law and a lack of coherence and clarity in national policy.

> *"We have a combination of legal provisions which have not been thought through in a holistic manner, so they've just been layered one on top of the other."*
>
> ICS CHIEF MEDICAL OFFICER, SOUTH WEST

With respect to the law, several participants highlighted that the piecemeal and subjective legal provisions that make up data protection law and the lack of a holistic legal framework make it challenging to interpret what can and cannot be done within their local context and for borderline use cases. A minority of ICSs have relied on contracting external legal advice to provide assurances to how their data flows are set up and how data is used, in addition to setting up teams of IG professionals, both of which are perceived to be avoidable financial overheads. While the majority of participants acknowledged that the law does, on paper, allow them to carry out what they wanted to do provided the necessary agreements and approvals were in place, there was consensus that it created unnecessary barriers to overcome to share data across organisational boundaries.

The perceived punitive nature of the law was itself described as creating a culture of fear within data controllers of the consequences of potential data breaches. Data and digital being perceived as a "risky business" is threatening the establishment of its value at ICB level in some systems lacking strong governance structures.

A perceived lack of coherence and clarity in national policy guidance and advice was also highlighted as a source of uncertainty, with participants noting that it is not serving the intended purpose of clearly communicating the legal requirements around data sharing and use. Participants said inconsistencies in guidance from different national bodies and lack of a single voice were to blame, with several participants calling for a single policy statement on what NHS and LA organisations were legally permitted to do, in the context of what national policy was aiming to achieve with respect to sharing and using patient data in ICSs.

> *"So again, it comes back to that initial point of it's great there some guidance, but there's no right answer and within there being no right answer, it's up to every organisation to do it independently and that causes issues."*
>
> ICS CHIEF ANALYTICAL OFFICER/ HEAD OF INSIGHT AND ANALYSIS, EAST OF ENGLAND

There is also variation in the interpretation of what is considered as secondary uses of data versus uses of data for individual care, with several participants remarking that this distinction was unhelpful, calling instead for the public interest test to be applied more sensibly. Two ICSs gave examples of using data for individual care which involved using their PHM data to conduct risk stratification to identify patients most at risk of hospital admission and providing these lists to GPs to enrol them in certain initiatives.

In the absence of improved clarity on what ICSs can and cannot do with patient data, uncertainties around IG and differences in appetite for risk both between providers within ICSs and between different ICSs are continuing to drive inequities in the quality of care that can be delivered to patients. For instance, there is variation in capabilities around the use of ShCRs across providers for individual care, or the use of data to optimise care pathways or deliver targeted interventions. This also poses a risk to public trust if the public perceive variation in provision of what care they can receive in their ICS compared to a neighbouring ICS as a result of not having the correct IG in place.

Data quality

A direct and very important barrier to the use of analytics is data quality, since all of the benefits of innovative uses of data rely on high quality, complete information that is consistently labelled and recorded. Participants recounted that data quality issues can arise due to limitations with EPR systems which are outdated and lack necessary nuance in data fields. Several examples were raised that have pressing implications for the ability to address health inequalities and illustrate the issue: some EPR systems have only one field to record both sex and gender, meaning people who are transgender may not be offered sex-based screening, and binary recording of important characteristics, such as whether someone is a carer or whether they are experiencing homelessness, meaning the impact on someone's life cannot be accurately captured.

Clinicians have an active role in recording data in patient record systems and the perceived inadequate recording of certain data fields in EPRs on the part of clinicians can drive poor quality recording of data, further entrenching variation. In particular, participants highlighted that ethnicity data is often not recorded routinely by some providers resulting in patchy data and limiting the analyses that can be conducted. Some participants suggested implementing national schemes to incentivise data quality, particularly for community health and care services, while others noted the improvements in data quality they had observed by demonstrating the value of data to the people recording it.

The lack of standardisation of EPR systems particularly those used by community health and care services was also raised as a barrier to increasing the diversity of data flowing into ShCRs and PH platforms while maintaining data quality. Besides technical interoperability issues, the data cleaning processes required are more time consuming and this is one of the key factors driving the resource required from data management teams in ICSs with more established dataflows. Data gaps were also attributed to challenges with linking datasets without NHS numbers, for example from local authority and charity organisations, and integrating text data into quantitative datasets, including, for example, notes from social care teams about someone's wider needs and circumstances.

Public trust

Participants generally did not perceive public trust to be a current barrier to delivery in their systems but were acutely aware of its sensitivity to discourse around new data initiatives and the implications of its erosion, such as potential increases in National Data Opt-Out rates. The limited nature of current public engagement work in most systems beyond online communication could be explained by their view that the gap between current public understanding of patient data uses in the NHS and the reality of these uses is so wide that it inhibits effective engagement activity relating to expanding the uses of patient data. For example, a few participants elaborated that they are hesitant to engage with the public on ShCRs as they believe the public already assume that data sharing across providers is in place; as a public dialogue or basis for a 'social contract' has not been established within ICSs, jumping then to engaging the public about sharing data via the FDP, for example, is more challenging.

> *"I think we should have a stronger social contract with our communities about the way we work with their data, because I think the pendulum [of public trust] has swung […] So the only way it'll keep swinging is if we build the trust, and that's the social contract that your data will be used in sensible and proportionate ways"*
>
> ICS CHIEF MEDICAL OFFICER, NORTH WEST

Nevertheless, most participants emphasised the importance of carefully designed communication to inform patients and the public about how their data is being used and the need to embed this into routine communication as well as active engagement work. Several participants noted the heightened need for such communication as their data flows became more complex and the uses of data diversified, for example incorporating data from broader LA organisations such as education and policing.

Many of the advanced ICSs acknowledged that their uses of data had perhaps advanced more quickly that their engagement with the public on these issues and understood that this was something they need to do as soon as possible. Feelings were mixed however, about whether this constituted a risk: some participants were not concerned, feeling that the public would support these uses of data, while others expressed anxiety about how the public would feel about how far the ICS had gone on data use and sharing. A further concern related to the risk that inaccurate or sensationalised media reporting on patient data uses in the NHS, along with inaccurate information shared on social media, had the potential to damage public trust. It was suggested that this kind of misinformation would need to be countered sensitively.

While opt-out levels and dissent about data sharing remained limited, some participants mentioned receiving queries and complaints around the FDP and its supplier. These participants had some concerns that negative public discourse around the increasing private sector involvement in patient data is a threat to the trust placed by residents and patients in their ICSs, and emphasised the need for clear messaging from national leaders on such national initiatives. This may be tackled as part of the Department for Health and Social Care and NHS England large scale public engagement programme starting this year.

Future opportunities for the use of data

Interview participants identified potential opportunities relating to improving the way activities involving patient data themselves are carried out, such as automating more aspects of the data gathering process and expanding the functionality of data systems to achieve more ambitious goals. Participants also identified longer term opportunities relating to democratising data by enabling greater access to analytical tools and outputs, making greater use of artificial intelligence to deliver specific functions, and benefitting from research activities carried out by external partners in different ways.

Automation

At present, the requirement to clean, upload and share data manually, and to present it, is time-consuming and laborious for data teams. Automation of data flows for reporting was viewed by several participants as a potential way to decrease this burden, but only if kept under review to ensure that automation did indeed generate less work.

A further potential use of automation was in the automatic collection and coding of GP data, such as the production of routine notes – one participant with a medical background felt that future tools in this vein would free up GP time and improve data quality and standardisation.

> *"What we are trying to do with the system intelligence, the BI dashboard is to make it more and more responsive where a clinician, if they want to take a population health approach, can actually ask a question that the AI can enable and answer and find the results for"*
>
> ICS CHIEF MEDICAL OFFICER, SOUTH WEST

Several participants highlighted the role of dashboards as being potentially valuable. These people ranged from primary care clinicians to strategy leads and in a minority of ICSs, we saw evidence of tools that participants described as interactive dashboards being used by clinicians to analyse patient cohorts and develop some focused prevention activities.

Automation of visualisation and dashboarding functions offers a route to broaden access to data, and to "make self-service easier", as one participant put it – with the promise of automation not limited to operational reporting, but also believed to include offering standard types of analysis, such as cutting data by patient types or focusing in on specific parts of the ICS.

Some participants in technical leadership roles felt this would free up analytical resource, since fewer staff would be needed to manage tools, support user access to them and manually create reports and analyses. One suggested this freed up capacity should be used to analyse a larger number of datasets for trends and patterns, activity that was not taking place at present because of insufficient staff resource. A further potential benefit would be increasing buy-in for the approach from a wider range of system stakeholders.

Expanded functionality

Several participants spoke about using qualitative data (e.g. qualitative user feedback, or interview- or focus group-based research with patient or service user groups) alongside patient data for different purposes. Incorporation of text-based descriptive data, such as notes in social care records into databases for population-level analysis was viewed as being potentially helpful, but sensitive, by one participant working in a strategic role supporting ICSs' work on population health. However, this person felt that choices would need to be made about what social care information was shared into a platform to protect confidentiality, and noted that text-based data was difficult to codify and analyse.

Using "insight" data in different ways was mentioned by multiple participants – this data is usually generated through qualitative research conducted by ICSs with patients and service users locally. Whereas one participant described how qualitative research data gathered by an insight team at the ICS was used to produce insight reports, which could be analysed alongside patient data, another spoke of using linked data to identify patient groups who may need additional support and then directing the insight team to find out more about their needs. A further suggestion was to build in evaluation functions to better understand the impact of interventions.

> *"We can use the linked data to identify groups of people who share demographic and geographic characteristics [...] We [name of the insight team] then go and talk to those people or those communities and try and understand what's going on because we won't get that from our data."*
>
> ICS DIRECTOR/HEAD OF POPULATION HEALTH, SOUTH WEST

Democratising data for staff and patients

A consequence of suggestions to automate visualisation and dashboarding functions is that insights from patient data will be made accessible to a much wider range of staff, since fewer staff hours will be required to prepare data for display via dashboards. This was viewed as a particular benefit by some participants – for instance it was felt that GPs would benefit from accessing this information in more depth, as well as staff in individual providers and those working at the "place" level within ICSs. This democratisation can lend itself to even more effectively targeted population health management and health inequalities work through involving a wider range of staff in these activities.

Similarly, by making more data available to patients and inviting them to contribute to their ShCR in different ways, one participant felt that patients would benefit from an opportunity to improve the way their care is provided. This participant described how their ICS was considering an approach to enable patients to upload three pieces of key information to their record that the patient him or herself would select. Potential examples included a list of important medications, or something not directly related to that person's healthcare but still important to note, such as their own caring responsibilities. This information could be shared with a wide range of providers within the ICS, so that if they were unable to highlight points of particular importance with a new provider, this information would be readily available within the record.

Using artificial intelligence for modelling and predictive functions

Artificial intelligence (AI) was viewed by one participant as potentially removing the need for tools like the Python programming language within the NHS data landscape. Instead, a smaller number of AI experts would be required to manage the technology and audit its outputs (to avoid bias and other potential issues), alongside a larger team that is able to manipulate the AI to perform specific analytical tasks.

In terms of the specific tasks that AI might be used for, multiple participants within the same ICS spoke of the potential to use AI and machine learning

> *"A lot of clinicians are starting to think about how they can make improvements and do things differently, either through proactive care or efficiency or effectiveness opportunities […] We think that's where some of the artificial intelligence and machine learning and natural language processing could come into its own […] We want it to inform decisions, take actions and support transformation."*
>
> ICS CHIEF (DIGITAL) INFORMATION OFFICER, SOUTH WEST

technology for prospective modelling of the impact of potential changes to how services are provided. One participant in a technical role expressed concern that negative perceptions of AI might affect support for valid machine learning approaches.

Focused research activity

Different ICSs are at different stages in terms of their thinking about allowing access to data for research purposes. One participant floated the idea of generating revenue to support the running of the shared care record by allowing researchers to use the anonymised dataset.

Another spoke of working closely with local universities as well as generating qualitative research data from within the ICS. One participant hoped that through accessing more opportunities to share data with academic partners, they might be able to direct research activity towards challenges faced by the health system in a more purposive way.

Concerns relating to future uses of data

Alongside these opportunities, research participants also highlighted concerns for the future. Issues highlighted generally related to ensuring that the role of patient data was understood at the right level, and that where more advanced ICSs had forged ahead with locally designed schemes, participants would not want to give these up in order to use nationally-provided solutions they feel may not be as useful.

Patient data as "panacea"

One specific concern, which the participant who raised it acknowledged was a long way ahead, was the risk that routinely collected patient data would become viewed as a "panacea" to answer all questions about the health and care system rather than being part of a suite of tools including insight activities and other research.

The Federated Data Platform

ICSs that had made significant progress in developing their own data warehousing and processing systems saw a potential threat in the FDP. One described this situation by saying that as locally developed systems become better established, the case for using national systems becomes weaker. Ultimately, a point will be reached where for an ICS in this situation to engage with the FDP would require double running (operating both the FDP and the ICS system), which ICSs are not currently resourced to do. A different participant contrasted the difference between the way staff costs relating to having on-site data experts were accounted for versus a subscription to an externally procured data platform. This participant feared that staff costs were potentially more susceptible to cuts because they did not constitute a simple fee.

However, there was a general scepticism that without primary care data flowing into the FDP it will not be a useful tool for population health management (PHM) purposes, and instead only capable of acting as an acute Trust tool. By mandating an externally sourced solution with “too many failing compromises,” concerns were raised that FDP implementation may stifle and delay innovation in ICSs that do not have existing PHM platforms and also prevent more mature ICSs from sharing their own solutions with other ICSs. Several participants argued that these solutions, which have been developed by ICSs in-house, are (at least at present) more fit for purpose for system needs.

> *“They sell it as a population health tool [the FDP], and it absolutely, simply isn’t. It’s an acute-focused data tool.”*
>
> DIRECTOR/HEAD OF BUSINESS INTELLIGENCE, SOUTH WEST

Furthermore, a perceived lack of clarity around whether primary care data will at some point be incorporated in the FDP alongside acute trust data is adding to uncertainties around the purposes of the platform (for example, the extent to which it can support PHM aims) and concerns regarding its potential to erode GP and public trust without careful and coordinated communication. Indeed, several participants reported emerging pockets of concern among GPs and the public in their ICSs regarding the FDP, specifically the Palantir brand, and attributed this to lack of clear messaging around purpose and procurement.

More broadly, a few participants expressed concerns that while the FDP is not positioned as a performance management tool, it may ultimately be used as such by national bodies, and this would risk the finely balanced collaborative partnerships underpinning data sharing agreements within their ICSs. These ICS leader participants emphasized that the ‘hard-earned trust’ with providers and other data controllers was built on the basis that their data would be used to make progress on specific co-developed goals; this trust could be compromised if national teams started using the data to monitor provider performance and issue ICS leaders with new goals to improve performance, as this would alter the power dynamics held between ICS leaders and provider leads.

Conclusion and recommendations

Conclusion

Sharing, using and storing patient data is increasingly integral to planning and providing care in the NHS, but significant variation remains in the extent to which ICSs have been able to prepare the ground for these changes.

While some ICSs have devoted significant time and resource to building their own data management functions, others' work is at a much earlier stage of development, with an expectation that an off-the-shelf solution will soon be available via the FDP.

ICSs with advanced technical infrastructure are already realising benefits from sharing data for individual care and analytical purposes. There is a risk that this variation increasingly impacts on the quality of care and public health services available to citizens in different parts of England – and sometimes within the same health and care systems where individual GP practices have not opted into system-level approaches. This carries the risk of exacerbating existing inequalities in access, experience and outcomes.

More advanced ICSs also have concerns about the consequences of this variation for them, with some fearing that as generic data management packages become available, national-level support for their own locally tailored approaches could decrease.

People in several ICSs spoke of the potential for AI to improve the efficiency of data aggregation and analysis tasks. Although concerns were expressed about the public perception of AI and the risk that using AI might cause alarm among members of the public, concerns among participants tended to focus on issues such as accuracy of AI-led analysis of text, and the need for experts who understand AI processes in detail in order to monitor and manage bias and other errors.

For all ICSs, information governance is a challenge and despite increasing volumes of guidance, a lack of certainty over the application of different rules and requirements endures. This has the potential to impede progress through risk aversion, as well as posing a legal risk to any ICSs that inadvertently misinterpret laws and regulations. Clarifying these rules across the board and simplifying them where possible would greatly benefit the patient data agenda.

Overall, a perceived lack of a national single strategic view and narrative across information governance activities (as evidenced by some ICSs telling us they had sought independent legal advice) is perceived to be at best acting as a distraction and creating unnecessary work, and at worst threatening hard-earned trust with ICS partners and the public. This poses a risk of increased opt-out rates, reduced data flows and compromising the statistical utility of current platforms.

Threats to public trust are significant if our participating ICS leaders' sense that levels of public understanding of how data management works within the NHS are low is correct. Participants were concerned that the low level of data sharing that exists at present would come as an unwelcome shock to patients and service users who are used to accessing large volumes of data at their fingertips in other areas of their lives. On the other hand, ICSs must ensure that data is always being shared and used for the benefit of patients, since excessive or unnecessary sharing of data could add to some existing concerns about proportionality and privacy, potentially undermining public trust.

Local ICSs and the national NHS potentially face a complex and multifaceted communication challenge. They will need to explain to members of the public why permissions are needed to share data between different NHS organisations for the purpose of care, while at the same time outlining approaches to seeking consent for third party uses of data such as research, and clarifying why these are different from individual care uses.

A further challenge, and an opportunity, exists around organisational culture. While research participants spoke of some pockets of scepticism around their work, they were highly enthusiastic about the potential for patient data to improve both system-level activities and the quality of care provided direct to patients.

Differences in ICS structure across the country meant that patient data work was sometimes felt not to be taking place at the right level within an ICS, generally where this activity was too devolved, for instance being led at the level of the "place" rather than the "system". But there was a view that where the most senior leaders within an ICS had a good grasp of the potential of patient data, the potential for improvement was strong, and that the intrinsic interest, value and importance of the work meant that ICSs would be able to recruit high calibre staff. Therefore, ensuring every opportunity is taken to communicate the benefits of ICSs' work using patient data, from the board room to the waiting room, is likely to be key to the initiative's success.

As ICSs begin to realise more and more benefits from sharing data for individual care and analytical purposes, there is a risk that variation increasingly impacts on the quality of care and public health services available to citizens in different parts of England – and sometimes within the same health and care system – and that existing inequalities in access, experience and outcomes will be exacerbated.

Recommendations for policy makers

Our research has highlighted a number of challenges faced by ICSs in seeking to use data for individual care and secondary purposes. Along with examples of good practice or approaches that may help ICSs to navigate some of these challenges, we have identified a series of actions that policymakers could take to support development in this area. These recommendations reflect the messages communicated by participating ICS data leaders and were presented in draft form and discussed with ICS representatives at a roundtable on 23rd April 2024.

Public engagement and understanding

The role of public understanding and support remains fundamental to enabling data to be used in new ways in health and care. While ICSs have a responsibility to engage with their populations, much data activity involves issues in common, such that these local conversations would be greatly supported by the establishment of a national social contract with communities and the public around patient data uses. That said, national-level communication will need to be undertaken sensitively so the public has access to high quality information and so that the propagation of inaccurate information about using patient data is avoided where possible and challenged as required. Continued efforts to support public engagement, building on current activities such as the Department for Health and Social Care's Data Pact and forthcoming national large-scale public engagement activities, will be important to maintain progress.

1) ***Support ICSs to engage with patients and members of the public on uses of data, including through increased collaboration, and ensure that local engagement is guided and informed by national and regional public engagement activities, such as the large-scale public deliberation and the forthcoming data pact***

National and local data systems

There is appetite among ICSs for a true dialogue with national leaders about plans for aligning national and local data development. At present, ICSs perceive inconsistencies in guidance from different national bodies and a lack of a single voice. While visits by members of the national team to ICSs are valued, there is a sense that there is potential to do more to develop a clear vision that serves both system and national needs. This could potentially be pursued through regular engagement with groups such as the Chief Analytical Officers Network. This work should be mindful of avoiding unnecessary complexity in an architecture that spans locally developed systems, national and local instances of the FDP, and national and regional Secure Data Environments. It is also important that priorities are coordinated and balanced: for example, any increase in expectations around the development of data-led tertiary prevention and other population health approaches should be weighed against demand for operational outputs and processes and prioritised accordingly.

2) *Promote a stronger dialogue and increased communication between national teams and local data leaders on how national and local organisations can work in a joined-up way to deliver on national data priorities and serve the needs of local organisations*

In particular, ICSs desire much greater clarity on plans for the FDP and its future functionality, especially with regard to system-orientated applications. For example, ICSs that are yet to develop their own linked data platforms wish to understand more about the use of the FDP for population health management, including any plans for the incorporation of primary care data (within local instances of the FDP) and clinical re-identification, and the timeline for delivering this functionality. More generally ICSs need to know what they need to do in relation to the FDP and require sufficient information to inform local planning and investment.

3) *Help ICSs gain greater clarity about FDP functionality, plans and longer-term timelines for system-based use cases, especially regarding population health management, incorporation of primary care data, and re-identification of data by clinicians*

Many ICSs identified funding for data development and delivery as a persistent issue, especially due to short-term budgets and funding opportunities that do not support in-depth planning in advance. While an increase in a ring-fenced budget for data development is much desired, there are a number of ways in which the provision of budget in this area could be adapted in ways that better support ICSs. Where funding is made available, it would be helpful to enable greater delegation of budgetary decisions, so that ICSs can use funding in line with local needs and data plans. This could be in the form of a funding settlement that sets out high-level expectations but enables local determination of how those expectations will be reached. Given the timescales involved in developing data systems and processes, it would make sense for such funding arrangements to span three or more years. Related to this, ICSs stated they would like greater recognition of the ongoing and variable running costs of data and analytics. Some participants spoke of non-recurrent funding in the past to set up new systems without subsequent provision of funding for the maintenance of these systems. Increasingly, costs associated with data and analytics are revenue running costs rather than one-off capital expenditure, with analytical workforce salaries and software and service licences and subscriptions, such as cloud storage costs, being significant considerations for the running of advanced data systems.

4) *Work with ICSs to consider how technology budgets can be provided in ways that best reflect current and future digital and data costs and that support local decision making*

Quality improvement and addressing variation

The significant variation in the data maturity of different ICSs can potentially have an impact on care quality, but it also provides an opportunity to utilise the good practice and learning from more-developed ICSs to support development elsewhere in using patient data. Participants felt that the knowledge developed by more digitally mature ICSs, and the opportunity to develop relationships between ICSs, offered the potential to drive improvement at a national level in a way that is as yet unrealised. This could involve working with existing assets such as the AnalystX community and the Association of Professional Healthcare Analysts (AphA) and its Chief Analytical Officer Network to develop ideas and approaches.

5) *Working with ICSs, develop a national plan for data improvement aimed at supporting less developed ICSs and reducing variation in data maturity*

As part of this process, several participants argued that some approaches that have already been developed within the health service could be used as a "blueprint" and rolled out in other ICSs in ways that complement the wider nationally-led activity around the FDP. More generally, ICSs have developed a range of good practices that could be shared, with other ICSs given change management support to implement them. Some regional or local networks have emerged to help meet this need, with participants mentioning the Midlands' Decision Support Network and Dorset's Data and Analytics Centre of Excellence, and there are opportunities to do this at a larger scale. Relevant areas of good practice include:

- approaches to organising analytical teams;
- approaches to providing analytical support to ICS programme priorities and/or to place-based teams;
- approaches to developing self-service analysis and reporting tools for non-analytical members of staff, including managers and clinicians; and
- development of data strategies that complement and support wider ICS plans and priorities.

6) Working with ICSs that have established successful techniques and processes, develop a range of good practice approaches to data development and implementation and agree a common channel for sharing good practice

Finally, ICSs argued that there is currently a great deal of overlap in the data ingestion, analytics and reporting processes and techniques they are currently developing and that much duplication could be avoided if they were able to successfully share code for data curation and analysis, as per the Goldacre review recommendation on open working methods for NHS data.

7) Support ICSs to consistently share code and accompanying technical documentation to minimise duplicative effort and promote collaborative approaches to technical development

Information Governance

Information governance, particularly for secondary uses of data and data sharing between organisations, was identified as a significant challenge. which was seen as partially driven by the legal framework around data controllership pertaining to individual organisations. Participants felt there were a number of ways in which national teams can support ICSs in this space. The most common calls were for changes in the law to better align with national expectations for the uses of data by local health systems, including by acknowledging that ICSs act as collaborative partnerships, not simply as single organisations. There were also calls for clear guidance around the sub-licensing of ICB datasets and for carrying out clinical audits across organisations. Some of the specific suggestions made by participating ICSs regarding data controllership and uses included:

- establishing a single NHS entity for information governance purposes rather than holding data ownership at the level of individual providers;
- making NHS England a joint data controller with GP practices to address challenges regarding accessing primary care data;
- addressing fragmented data ownership across primary care more generally; and
- updating and clarifying definitions of individual care and secondary use to better serve data-led approaches to prevention.

8) Explore ways to simplify and clarify information governance requirements about data sharing between health and care organisations and within collaborative place-based partnerships for planning and population health purposes

More generally, ICSs called for nationally coordinated advice, or an 'IG Playbook,' on permitted approaches to data sharing, linkage and use, with clarity on common use cases and their legal bases, including models of pseudonymisation, re-identification and risk stratification. Instances where different approaches can be used, or where there may be important differences in context, should also be highlighted.

9) ***Work with ICSs to develop and share a resource outlining viable IG approaches for secondary use data sharing, including common use cases and their legal bases***

Another issue raised by ICSs was the perceived duplication of applications and approvals processes for the legal sharing and use of data for secondary care purposes, and the sense that some of these processes could be streamlined. If, for example, a s251 application is a viable and worthwhile route for enabling the legal use of data for secondary care purposes (at least in the short term), then it could be helpful for ICSs intending to use data in similar ways could be represented as a group. More generally, it would make sense to support ICSs to develop networks to share successful IG applications and other documentation to reduce duplicative effort across ICSs.

10) ***Where appropriate, work with ICSs to explore ways to streamline and reduce duplication in applications and approvals processes for secondary uses of data for planning and population health purposes***

Data quality

Many participants described certain data tools as inadequate for the inputting, sharing and use of patient data, especially some EPRs and ShCRs, often with an impact on the completeness and quality of data. The ease of use of multiple data tools by clinicians, particularly in non-acute settings, was seen as a significant limiting factor for improving data quality. In line with the recommendation made in the Hewitt review, NHS England should prioritise supporting ICSs to ensure that their data systems and tools conform to NHS and wider ICS standards around data quality, reporting and interoperability, including through ensuring the accountability of suppliers to these standards.

11) ***Work with ICS data users to review the current application of data standards in digital systems and tools and consider options for facilitating improvements in data quality, including by working with suppliers***

NHSE England should also consider the levers and incentives available to help improve the quality of data being recorded by healthcare providers, especially where there are notable data omissions. Some participants stressed the opportunity to use incentives similar to the Quality Outcomes Framework in primary care to drive the collection of specific priority under-recorded data such as ethnicity. Others, on the other hand, called for the leveraging of contractual requirements to impose penalties for poor recording of data.

12) ***Consider supporting ICSs to use levers and incentives around the recording of data by healthcare providers, especially where certain priority data categories are under-recorded***

The supplier market

Participants stated their organisations lack experience and expertise in the commissioning of digital and data tool suppliers. In particular, ICSs describe challenges in procuring services that can be adapted to specific local contexts and needs, with price often cited as the main driver of procurement decisions rather than consideration of quality and utility. As such, ICSs may benefit from support in commissioning and contracting with software providers. This could include guidance on expectations around suppliers and/or types of digital tool and system, procurement templates, and a national procurement framework with different suppliers and systems aligned to specific purposes.

13) ***Provide support and guidance on the procurement of data systems and tools, such as through national guidance or frameworks***

The analytical workforce

Most of our participants in technical leadership roles described analysts as remaining burdened by reporting requirements that restrict their ability to deliver analyses in support of transformational activities. This is particularly the case in ICSs that have smaller budgets for digital and data and that allocate a significant proportion of their resourcing to operational reporting. In line with the recommendations of the Hewitt review, efforts should be made by central teams to minimise operational reporting requirements on ICSs. Where automation of data collections can be delivered by the FDP, development of these processes should be prioritised, albeit not in such a way that this creates additional burdens for ICSs.

14) ***Following the Hewitt review recommendations, minimise central reporting requirements on ICSs and prioritise development of processes for automating data submission (including through the FDP)***

Along with having capacity to deliver other forms of analysis, the workforce will require upskilling in analytical areas that have previously not been part of their experience or training. A national training programme for analysts could potentially address some of the skills shortages and recruitment and retention issues encountered in this research. This could be informed by a national skills mapping exercise, which would take into account anticipated future developments and associated needs such as deployment of FDP tools and greater use of AI. The NHS graduate trainee scheme could also be helpfully used to channel graduate trainees with appropriate skills into ICSs to create a pipeline of analysts developing experience within ICSs.

15) ***Informed by a national skills mapping exercise, develop and deliver a national training programme for analysts to serve future priority data requirements, as well as exploring ways to train early careers analysts in local and regional roles, for instance by expanding the current NHSE data analyst graduate trainee scheme to include placements in ICSs***

Many participants also cited challenges with recruiting and retaining analytical staff with particular specialist expertise in data engineering practices or advanced analyses such as modelling due to the Agenda for Change pay scale and the absence of senior, non-managerial technical roles. ICSs should be supported to recruit specialists of this type, potentially working outside of Agenda for Change. The National Competency Framework for data professionals in health and care is a potentially helpful resource in this context. Template standard job descriptions could also be helpful to ICSs here to avoid ICSs needing to “reinvent the wheel” when recruiting to new posts such as those of data engineers and advanced analysts. A further potential route for developing expertise in this area is through the establishment of research practitioner posts in the field of health data science, analogous to existing clinical research practitioner posts, that could help ICSs to benefit from growing expertise and innovation in academic health data research, especially as the Secure Data Environment network begins to mature.

16) ***Support the establishment of and recruitment to senior, non-managerial technical posts in highly specialised analytical areas***

Cultural change

As noted by several participants, realising the potential of data will ultimately not only require the right data, tools and analysts, but a wider workforce that routinely uses these data tools and insights to guide their activities and decision making. This ultimately requires the establishment of new operating models for the commissioning, planning, design and delivery of care, as well as cultural change in the attitude to and use of data. Senior leaders within ICSs would likely benefit from a better understanding of the ways in which data can be used to transform or support system activities, and managers and clinicians would benefit from being able to access and use data insights. This could be through a "self-service" model, where commissioners, managers and healthcare professionals can access data and data-led insights through dashboarding and other tools. The wider workforce capacity in the system remains strained, however, so the process of supporting staff to learn these new skills and behaviours may take considerable time and analytical resource may still be required in the medium term to support colleagues to access the insights they require.

17) Develop change management and quality improvement initiatives to improve data literacy among leaders, managers and clinicians and promote the use of data-driven insights in decision-making

Annex

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Findings from the Desk Review

We reviewed 46 sources, published between November 2020 and January 2024. Table 2, below, summarises the number of items reviewed by source type (please see methods section above for further detail about the purpose of the desk review):

Table 2: Desk review sources

Type of source	Number of documents included
National policy document, report or communication (e.g. DHSC, NHS England, Office of the National Data Guardian)	24
Academic journal article	11
News article/opinion piece	5
ICS document	3
Grey literature (think tank report, conference paper, other)	3

We undertook analysis to explore the extent to which the identified literature was able to address our four key research questions.

1. What is the current state of sharing, accessing and using patient and other health and care service user data in ICSs?

The literature on the current state of patient and user data in ICSs focuses on digital maturity, as measured by NHS England, and on efforts to implement infrastructure and initiatives to deliver different elements of the national ICS digital/data ask, namely Shared Care Records (ShCR), data management systems to enable the linking and analysis of patient and other service user data, and workforce needs to underpin these.

Digital maturity

NHS England has identified achieving digital maturity as a key objective for ICBs (NHS England, 2020), since maximising the potential of patient data is central to meeting their populations' health needs. In the post-pandemic period, data and digital solutions such as the NHS app and online patient/clinician interfaces have increasingly been viewed as playing a role in the NHS's recovery (NHS England, 2022b). Guidance for ICBs on developing a joint forward plan calls for the implementation of more preventative and personalised care models through data and analytical techniques such as population segmentation and financial demand modelling.

To achieve this, a core level of infrastructure, digitisation and skills requirements are necessary and it is expected that these should contribute to achieving a digitised, interoperable and connected health and care system (NHS England, 2022c). In its 2023/24 planning guidance, NHS England (2023) sees its digital maturity assessments as key to achieving What Good Looks Like goals.

A report published in 2022 classed 21% of NHS trusts as “digitally mature,” but noted that 10% were still relying on paper, and in social care only 40% of service users had an electronic care record. And while basic ShCRs were in place in all but one ICS, these did not all include all individuals’ health and social care data (Department of Health and Social Care, 2022c). A report on the first set of ICS digital maturity assessment ratings, published in Health Service Journal in July 2023, suggested a relatively low level of maturity overall with only three ICSs scoring 3/5 or higher and ICSs in the West and South West being some of the worst performing. The highest performing region was the North East and Yorkshire (Talora, 2023).

Patient records and data sharing

Having an interoperable patient record is important for efficient and effective person-centred care and enables clinicians to meet the seventh Caldicott principle of sharing information for the purposes of patient care (Sullivan et al., 2023). Involving patients in electronic health records is also viewed as potentially facilitating better communication and enabling patients to have more control over their care, as well as enabling remote monitoring and data collection (Li et al., 2023). However, as of 2023, variations in patient access to Electronic Patient Records (EPRs) have been observed at primary care level (Sullivan et al., 2023), an issue which NHS England is targeting as part of its delivery plan for recovering access to primary care (NHS England, 2023e).

In 2022, the Department of Health and Social Care (Department of Health and Social Care, 2022c) proposed that each ICS should have a “functioning and single” shared health and adult social care record for each citizen by 2024, while the DHSC’s plan for digital health and social care contains an expectation that health and social care records should be digitised in all ICSs and NHS trusts by March 2025 (Department of Health and Social Care, 2022a). although this target is reported as having subsequently been declared “unachievable” (Lydon, 2023). All 42 ICSs now have shared health and social care records in place, although they are at varying levels of maturity (Digital Health, 2023).

NHS England has taken initial steps to clarify the data sharing landscape, setting out some guidance on information governance (IG) for ShCRs, differentiating between (a) sharing personal/confidential patient information between health and social care bodies *within* a ShCR for the individual care of patients/service users and (b) sharing personal/confidential patient information between health and social care bodies *across geographical boundaries* for the individual care of patients/service users (NHS England, 2021a).

A systematic review into barriers and enablers to access, linkage and use of local authority administrative data for population health research practice and policy (Moorthie et al., 2022) found technical challenges (interoperability and funding shortages), legal/ethical challenges (regulatory complexity), and funding and capacity challenges (lack of funding for data linkage, general lack of money and capacity constraints). Examples highlighted in this review include social care rarely using NHS numbers, regulatory complexity such as inconsistencies in the interpretation and operationalisation of data protection, and variations in information governance procedures between different local bodies.

Data management systems

In terms of ICS's data management systems, a Lancet Digital Health review (Zhang et al., 2023) found a patchwork of data sharing, with issues resulting from the delegation of technology procurement to local organisations, a failure to build national data infrastructure for secondary uses and a large number of separate data controllers (around 7,000 nationally), encompassing trusts and individual GP practices. The review also identified multi-stage data flow chains limiting transparency and public trust, a majority of data interactions failing to fulfil best practice for safe access, and aggregation of duplicate data assets.

Data and digital processes played a key role in the health service's response to the Covid-19 pandemic, leading to a greater focus on the potential for ICSs to use data and digital to drive system working, connect health and care providers, improve outcomes, and put the citizen at the heart of their own care (NHS England, 2020). The pandemic was felt to have changed staff and citizen mindsets about data and digital (Department of Health and Social Care, 2022c), but, where changes to patient data uses were insufficiently well explained to the public during the pandemic period, this was felt to have increased the rate of opt-outs (Department of Health and Social Care, 2022b).

NHS England has put in place the Federated Data Platform (FDP) as a route to establishing ICS data systems with common standards of reporting and connectivity. Four different adoption models have been set out for the FDP, alongside five use cases at national, system and trust levels (NHS England, 2023b).

Data workforce and role of networks

A survey of ICS digital leaders undertaken in June 2023 found that among the 16 who responded, levelling up was the highest local digital policy priority, followed by convergence of acute EPRs, and wider convergence between NHS organisations across the ICS. More than two thirds of respondents said a shortage of staff with the right digital skills was a barrier, and lack of focus on digital nursing leadership seemed a significant issue (Hoeksma, 2023).

Technical skills training in data analysis within public health intelligence teams, particularly around programming and data retrieval skills, has been identified as an important enabler of success, along with developing partnerships between public health and academia to capitalise on new skills and analysis techniques (Ford et al., 2023).

Where data sharing infrastructures have been built, researchers have found that pre-existing multi-organisational peer networks can be valuable in supporting the mobilisation of new approaches to sharing personal health data. Such networks were observed to provide a “social installed base” that could be built on, and were found to be emerging “organically” along patient flow patterns (Wilson et al., 2021).

2. Looking beyond current priorities, what are the main opportunities/ challenges for using patient and other health and care service user data in ICSs?

Where opportunities and challenges are concerned, the NHS has been ambitious in articulating future uses of patient and service user data, and outlining ways existing systems might be optimised so that data functions can be performed more efficiently. The Hewitt Review set out some of the clearest data goals, but other objectives are in place around achieving greater interoperability, using data to address the role of wider determinants of health in sustaining population health inequalities, and also delivering improvements in efficiency, quality and safety. In addition to meeting the challenge of delivering these goals, ICSs must navigate an extremely complex information governance landscape.

The Hewitt Review

The Hewitt Review addresses the role of data for ICS accountability, emphasising transparent data as an incentive for and an enabler of improvement (Hewitt, 2023). The review recommended increased automation of data provision, including replacing SITREPs and other reported data with automated dataflows from the FDP, taking real-time data required by NHS England and the Department of Health and Social Care (DHSC) from automated summaries and where possible, and processing data in such a way that it enables site-level analysis. The review also recommended a move toward greater collection of outcome data – including patient-reported experience and outcomes data – rather than the current focus on inputs and processes.

The review further proposed greater sharing of performance and benchmarking data held by NHS England with ICSs, as well as work by NHS England and the DHSC to remove duplicative and unnecessary data requests.

Interoperability

Interoperability in the NHS is understood to be an enduring challenge despite tangible improvements over the past 30 years (Sullivan et al., 2023). Challenges identified by Chief Clinical Information Officers in a study into the state of EPR system interoperability in England included institutional barriers such as gaps between the perspectives of clinical and administrative staff, data management related barriers such as insufficient time and incentives to record accurate, structured data, and business-related barriers such as the lack of a clear business case for EPR system vendors to incorporate interoperability (Li et al., 2023).

Various policy and strategy documents and plans at national and system level have outlined different steps to move towards greater levels of interoperability, including adherence to interoperability standards and processes across all partners within ICSs (NHS England, 2021b), development of supplier interoperability standards (NHS England, 2022a), and system-level open systems architecture standards and data management standards (Frimley ICS, 2023), enabling “fluid and secure” movement of data (Birmingham and Solihull ICS, 2023) and moving to a single health and care data architecture for data sharing (NHS Cheshire and Merseyside ICS, n.d.).

Where research has been conducted into the costs and benefits of different approaches, trusts with “enterprise wide” systems have been observed to have higher digital maturity, but at a higher cost (Phiri et al., 2023). Meanwhile, barriers such as legacy systems hindering sharing, absence of secure data transfer methods and lack of funding and capacity endure (Moorthie et al., 2022).

Wider determinants of health and population health management

Tackling health inequalities by addressing wider determinants of health is a key priority for the health system in England. For instance, guidance for Integrated Care Partnerships (ICPs) on the preparation of integrated care strategies calls on ICPs to draw from intelligence generated by providers and local communities as well as ICS data to identify opportunities to address wider determinants of health and wellbeing (Department of Health and Social Care, 2024). As part of this work, ICPs are expected to explore how data and information can be shared appropriately between ICS partners and across ICSs and how effectively health and care data is linked.

Facilitating this kind of data linkage, for instance via ShCRs, is seen as an important aspect of improving the health of more deprived communities, such as coastal communities (Asthana and Prime, 2023).

NHS England's 2022/23 planning guidance (NHS England, 2022a) required that ICSs should have the technical capability for population health management (PHM), including longitudinal linked data for population segmentation and risk stratification by April 2023. Department of Health and Social Care policy objectives include that by 2025, each ICS should have implemented a population health platform with care coordination functionality, using joined up data for planning, PHM and precision health, to include wider determinants of health (Department of Health and Social Care, 2022c).

Related to this point, some chief analytical officers have expressed concerns that overreliance on the FDP for some PHM tasks could increase health inequalities by reducing the ability of sector experts to address bias in the data due to its inherent incompleteness, leading to groups who are well served (and therefore well recorded) being overrepresented in the data. By automating analytical processes, they argue that tools such as the FDP can prevent analysts from completing processes to attempt to mitigate against these biases by drawing from additional datasets. In particular, the absence of the very detailed primary care dataset from the national FDP offer means that opportunities to identify and address bias, and thus improve the analytical models, will be limited. (Orlowski and members of the Chief Analytical Officers' Network, 2024).

Quality, safety and efficiency

A lack of clarity around a patient's health status can negatively affect patient safety through suboptimal care coordination, duplication of effort and more defensive medical practice (Li et al., 2023). By contrast, using technology-enabled care appropriately to collect patient data remotely is thought to be able to have a positive impact on patient safety and quality of care (Department of Health and Social Care, 2022b). Patient data is also envisaged to have a role in strategic functions such as pathway design and efficiency improvement (NHS England, 2021c).

Information governance

ICSs must have robust IG processes in place to be able to realise these goals. Some of the issues relating to the sharing of information across organisational boundaries are addressed in the 'Challenges' chapter, above, but issues relating to the processing of confidential patient information also relate to system-level functions.

NHS England has issued guidance, for instance, around which organisations can fulfil data controller roles in which circumstances (NHS England, 2023d), and approaches for linking sensitive datasets in health and social care transformation have been outlined in the literature (Boniface et al., 2022), but some questions remain, in particular over the acceptability of processing this data for different functions. In November 2022, the National Data Guardian issued a letter to ICBs and senior information risk owners warning of concerns over processing confidential patient information in ways that breach confidentiality and breach guidance based on the information governance framework for ShCRs (National Data Guardian, 2022).

This highlighted misunderstandings of legal guidance around the processing of confidential patient information, specifically around the inapplicability of implied consent to risk stratification, the requirement of the Confidentiality Advisory Group (CAG) approval to process confidential patient information for secondary use PHM analytical work, misunderstandings around NHS England risk stratification assurance statements, and potential risks of unlawful sharing of confidential patient information for secondary purposes within secure data environments (SDEs). As one of the steps identified to address this issue, NHS England was to develop a "core" section 251 risk stratification application with standardised conditions for ICBs.

Staff recruitment and retention

With a growing demand for expert data architects and engineers, recruiting and retaining the right staff, as well as developing the skills and professionalism of the wider data and digital workforce is likely to remain a priority for the NHS (Ghafur et al., 2023). The NHS Digital Academy is developing the next generation of digital leaders, and communities of practice are emerging to support learning (Department of Health and Social Care, 2022c).

3. What is the current state of sharing patient and other health and care service user data with organisations outside of the ICS, including national bodies (NHS England and DHSC), the Secure Data Environment network and other ICSs?

When considering the state of play regarding sharing data outside the ICS, a range of issues are evident in the literature. These can be considered in terms of local sharing (between NHS data owners and other organisations within an ICS) and national sharing (between NHS data owners and other organisations such as NHS England, and other users such as researchers).

Sharing with local organisations outside the NHS

A report on sharing data with the voluntary sector distinguishes between sharing data relevant for providing care, which can be done with implied consent, and sharing data for services broader than health and care, such as cookery courses or housing advice, where explicit consent to share is needed – the service user's right to object to sharing data with the voluntary sector is also highlighted (NHS England, 2022d).

Sharing with national bodies

Aside from points already addressed in the Hewitt Review regarding the need to automate and systematise data reporting between ICSs and NHS England, potential issues have been identified regarding correct practice for sharing patient/user information for secondary purposes, such as research, in a way that meets legal requirements.

Legal and IG frameworks can operate as a barrier to secondary use of public data, with under-utilisation partly stemming from "risk aversion when faced with the prospect of navigating necessary and important data governance processes" (Jones et al., 2023). However, the Goldacre Review (Goldacre and Morley, 2022) expressed concerns over pseudonymization as a secure and effective privacy method, arguing instead for what were then termed trusted research environments (TREs) as a solution for data security and public trust, with research and analysis taking place inside these heavily curated environments rather than data being shared.

Subsequently, the DHSC (2022) outlined policy guidelines for a national SDE to be piloted by NHS Digital, with four localities scoping regional level SDEs alongside an ambition to provide access to NHS health and social care data at a regional scale, maintaining confidentiality and ensuring connectivity to local communities and NHS teams. The potential value of this approach was demonstrated during the Covid-19 pandemic, when novel approaches to recruiting patients to trials (NHS DigiTrials and RECOVERY trial) were deployed (Department of Health and Social Care, 2022b).

4. What are ICS leaders' perspectives on public and patient understanding of and attitudes about the use of patient data by ICSs?

Ensuring that public trust in decisions about the use of patient data is built and maintained is a key objective of the health system. For instance, NHS England's delivery plan for recovering urgent and emergency care services identifies transparency as a function intended to build public trust for the use of data (NHS England, 2023c).

The FDP has already sparked concern among the public, with National Data Guardian Nicola Byrne acknowledging in a blog post that previous NHS data "setbacks and failures" have affected public trust. The blog highlights public concerns about ethics, privacy, likelihood of success, procurement and cost, as well as potentially contentious suppliers, and emphasises the importance of transparent communication by NHS England in assuaging the concerns of members of the public and healthcare professionals (Byrne, 2023).

Researchers have also explored the feasibility of initiatives such as "social licenses" as ways of legitimising the use of linked, anonymised patient data in the eyes of the public through obtaining support for proposed data uses alongside commitments to protections such as transparency and public involvement (Ford et al., 2020).

Other research with the UK public has found that the use of de-identified data without explicit consent is a "point of controversy", with failures in transparency and privacy in the current landscape that risk compromising public trust. While the majority of the UK public support the use of de-identified data for public benefit or to advance medical knowledge, there is more caution about data use for commercial profit and when transparency is low, patients cannot understand what inferences might be drawn from their data, undermining autonomy and trust (Zhang et al., 2023).

Focus group-based research with patients in Kent, Surrey and Sussex has found support for linking datasets to support joining up care and information, improving efficiency and improving healthcare provision, with concerns about missing and inaccurate data, data breaches and hacking, use of data by profit-making organisations, stigma and discrimination (Ford et al., 2022). That said, it has been acknowledged that some segments of public opinion are likely to remain unknown at present, since polls do not generally reach all communities (Ghafur et al., 2023). Elsewhere, discussion of the future of the NHS has explored the possibility of a social contract for the NHS (NHS Confederation, 2023a), a concept that has relevance for understanding how support for different uses of patient data might be demonstrated and maintained.

Discussion guide

Integrated Care System Data
A research project for Understanding Patient Data and the NHS Confederation

About this discussion guide

This semi-structured discussion guide has been developed following discussions between White Tail, Understanding Patient Data (UPD) and the NHS Confederation and from desk review findings. This guide is for interviews to be conducted with senior strategic and technical leaders within ICSs with the aim of gathering ICS leaders' perspectives on the current situation regarding the collection, use and sharing of patient data, best practice in this area, opportunities and challenges, and areas where improvement is needed.

Probes have been included where White Tail will explore particular topics of interest, however some questions are open-ended to allow interviewers to understand the participant's frame of reference and/or their view of the most important topics in that setting. White Tail interviewers will probe for further details to develop findings on the following areas of interest:

- Resources: funding, workforce capacity and expertise
- IG: consent, data controllership, and privacy, including pseudonymisation
- Interoperability
- Technical infrastructure
- Coherence and helpfulness of national policy
- National support for achieving required standards
- Public trust

Discussion guide

Introduction

A. *[Thank participant for their time and introduce self and White Tail]*

B. *[Brief overview of the project]*

   - Understanding Patient Data and the NHS Confederation, wishes to understand in greater detail ICS leaders' perspectives on the current situation regarding the collection, use and sharing of patient data, as well as best practice in this area, future opportunities, and challenges and areas where improvement is needed.
   - The research will lead to the development of a report and associated case studies, setting out the experiences of relevant strategic and technical leaders in ICSs, along with any policy recommendations or suggestions for further research that emerge from the fieldwork, which we hope will support policy development in this area.

- We have invited representatives from 10 different ICSs from all NHS England regions to take part in order to explore the diversity of contexts in which different ICSs are working.

Please note that when we say ‘patient data’ we are not only interested in the use of data collected by the NHS, but also service user data from any other relevant health and care services, such as local authority social care services. For shorthand I will just say ‘patient data’ in the interview, but whenever we use that term, we are including data collected from interactions with other providers.

C. *[Verbal consent]*

Before we start, can I check that you have read the participant information sheet and whether you have any questions at all?

To capture your verbal consent to participate, I will start recording now.

[START RECORDING]

Can you please confirm you are happy to proceed with this interview, and that you are happy to be recorded for transcription and note-taking purposes? The recording and transcription will be deleted at the end of the project.

Participant role

1. Could you tell me what your role is and which organisation you work for?
   a) How does your role interact with and relate to data sharing, access and use in your ICS?

Current use of data in ICSs

2. What are your current priorities with respect to patient data sharing, access and use?

3. At a high level, could you describe the most important aspects of the progress your ICS has made in the sharing, access and use of patient data?

4. How does data flow between different parts of the ICS, and for what purposes?
   Probe on:
      i. Secondary care
      ii. Urgent and emergency services (including ambulance trusts)
      iii. Primary care/ GP data
      iv. Mental Health or community care
      v. Local authorities
      vi. Social care
      vii. Other ICS partners, such as VCSE organisations

a) What would you say is working well and not so well at the moment in terms of data sharing between different parts of the ICS? And why?
   Probe on:
   i. Shared care records or EPRs and other data sharing for direct care

b) For the areas going less well, or where there are gaps, what have been the main challenges?
   Probe on:
   i. Funding, workforce capacity and expertise
   ii. IG, consent, privacy and data controllership, including pseudonymisation
   iii. Interoperability
   iv. Technical infrastructure
   v. Coherence and helpfulness of national policy
   vi. National support for achieving required standards
   vii. Public trust
   viii. ICB culture and governance, including senior leadership
   ix. Collaboration between the different partner organisations in the ICS

5. I'd like to ask you about some specific approaches to sharing and using data at the system level.

a) For each of the following, what would you say is working well and not so well at the moment?
   i. Development of a local analytical platform for using data
   ii. Use of data for population health management
      a. Does this include reidentifying individuals in order to deliver a care intervention?
   iii. Use of data for strategy and planning
   iv. Using and sharing data captured in the ICS for research, e.g. via an SDE Network

c) For the things that are going well, what has helped? Why?

d) For the areas going less well, or where there are gaps, what have been the main challenges?
   Probe on:
   i. Funding, workforce capacity and expertise
   ii. IG, consent, privacy and data controllership, including pseudonymisation and applying opt-outs
   iii. Interoperability
   iv. Technical infrastructure
   v. Coherence and helpfulness of national policy
   vi. National support for achieving required standards
   vii. Public trust
   viii. ICB culture and governance, including senior leadership
   ix. Collaboration between the different partner organisations in the ICS

Future opportunities for using data in ICSs

6. What's the long-term vision for the use of patient data in your ICS?
    a. What specific areas present a future opportunity?
    b. How would realising these opportunities benefit patients, the local area and the ICS?
    c. How confident are you these benefits will be realised, and why?
    d. What factors do you see as particularly important to achieving the long-term vision?
    e. [Interviewer to remind participant regarding anonymisation] What do you think the impact of the Federated Data Platform (FDP) will be?
    f. How do you plan to adopt the FDP? Why do you plan to take that approach?

    Where relevant, probe on:
    i. Funding, workforce capacity and expertise
    ii. IG, consent, privacy and data controllership, including pseudonymisation
    iii. Interoperability
    iv. Technical infrastructure
    v. Coherence and helpfulness of national policy
    vi. National support for achieving required standards
    vii. Public trust
    viii. Using and sharing data captured in the ICS for research, e.g. via SDE Network
    ix. Culture and governance including senior leadership
    x. Collaboration between the different partner organisations in the ICS

Sharing with/making data available to external bodies

7. We're also interested in hearing about how ICSs share data with organisations outside of the ICS, and the opportunities in this area. Could you tell me about how data flows from your ICS to the following organisations, and for what purposes?
    i. National bodies (NHSE England and DHSC)
    - Probe on use of real time data for improvement/accountability, as per the Hewitt review
    ii. The Secure Data Environment network (including the sub-national SDE in your region), to help ICBs meet their requirements to facilitate/promote research
    iii. Other ICSs in your region
    iv. Commercial or research organisations
    v. Any other organisations e.g. VCSE organisations contracted to provide care?

8. What would you say, if anything, could be improved to help data flow from your ICS to [each organisation mentioned] and are there future opportunities?
    Probe on:
    vi. IG, including data controllership

        vii. Data security, including pseudonymisation
        viii. Opt-outs
        ix. ICS strategy and leadership
        x. National guidance
        xi. The role of proprietary solutions

9. How clear are the requirements for seeking consent when transferring data across organisational boundaries? Do you have any particular concerns?

Patient and public understanding about and attitudes towards use of data

10. What do you think is the current level of public and patient understanding of the use of patient data in your ICS? Do you have any concerns about this?
    Probe on:
        xii. The role of ICS organisations as data custodians
        xiii. What their data is used for (direct care vs data for planning/secondary use)
        xiv. External data sharing

11. What do you see as local responsibilities and what as national responsibilities with respect to improving public and patient understanding about the use of data and/or gaining public support for the use of data?
    a. Is your ICS currently doing any work locally in these areas?
    b. Do you currently have any plans to work on these areas in future?
        i. If yes, which teams or roles would be involved in this work? [Prompt on central patient and public involvement team involvement if not specified]
        ii. If yes, would you consider partnering with any external organisations or experts to support patient and public involvement and engagement in this area?
        iii. If yes, what type of organisations or experts would you partner with? /If no, why not?
        iv. [If answer to b. is no plans to work on these areas in future] Why is this?

12. Have there been any queries or concerns raised to your ICS by patients/ service users and/or representative bodies about your use of patient data?

Wrap up

13. Is there anything that we haven't covered today which you think is important for us to know?

14. Do you have any questions for me or for White Tail?

    [STOP RECORDING]

[Thank participant and explain next steps]

- *Thank you for your time today, we really appreciate it. Here's a quick reminder on what we'll be doing with your data and what you can expect to happen next:*
    - *The transcription and recording from this interview will be stored securely and will be securely deleted following completion of the project.*
    - *We will be using this transcription, along with those from the other interviews conducted, to synthesise key themes and findings to write-up a report for Understanding Patient Data and the NHS Confederation.*
    - *We will not name you in any of the research outputs. We may summarise your individual views or quote from you, but we would not attribute these comments to you as an individual, or to your ICS in the main report. We may, however, provide a generic description of your role if this is relevant for contextualising the comment you have made. And while we will not name participating ICSs, we may refer to a specific characteristic of an ICS (such as its region) if this is relevant to a particular point.*
    - *As a second output, we will be developing detailed case studies as stand-alone documents to showcase work being done in certain ICSs. We will get in touch with you if we would like your ICS to be one of these case studies and explain the process in more detail. This will involve a further four interviews within the case study ICS, and we would ensure that you have consented separately for this part of the study.*
- *Finally, we'll be in touch mid-February to invite you and your peers from other ICSs to an online round table discussion in March to discuss the emerging findings of the research and help shape the recommendations of the report.*
- *You can read all of this information in the participant information sheet.*
- *Do you have any questions?*

Chris Branson, Helen Crump and Claire Maynard (April 2024)

White Tail

Understanding Patient Data