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