How Integrated Care Systems use data: plain English summary

Across England, local partnerships are bringing together health and care organisations including NHS Trusts and local authorities to improve health. These partnerships are known as Integrated Care Systems (or ICSs). One of the ways they are improving health is to make better use of patient data, so that the way health and care services are planned and provided can be improved.

This factsheet summarises research carried out by White Tail Consulting for Understanding Patient Data (UPD) to explore how ICSs are working with patient data at the moment, what is working well and what changes might be needed to help ICSs to do this better. We spoke to 11 ICSs from different English regions to find out how they have been using patient data, and produced detailed descriptions of work underway in four of the ICSs with the most advanced uses of data.

What is patient data?

Patient data is information about people who use health and care services, including about their health and aspects of their lifestyles. In this document, we use the term 'patient data' to refer to data that is routinely collected through a person's interaction with NHS services, social care services, or other related services provided or paid for by the public or voluntary sector.

Key terms

Data controller: The organisation, or individual/team within that organisation who decides how and why particular data should be processed and is responsible for the data.

Data protection: The process of safeguarding people's information.

Dataset: A collection of data.

Information governance: ways of working and rules about how personal information is used and governed. This includes legislation such as the NHS Act 2006 and the Data Protection Act 2018, as well as organisational policies to ensure data is kept safe and used appropriately.

Integrated Care System (ICS): a local partnership bringing health and care organisations together to develop shared plans and joined-up services. They are formed by NHS organisations and upper-tier local councils in that area, and also include voluntary sector organisations, social care providers and other partners.

Personal data: Information that relates to an identified or identifiable individual. Certain categories of personal data are deemed to be more sensitive than others, such as those relating to health care or criminal convictions.

Pseudonymisation: Techniques to remove information that identifies individuals (e.g. name, address, NHS number) from their data and replace it with a code. The key to the code is stored separately from the data. Pseudonymisation can later be reversed, using the key, so that data can be linked back to the individual at a later stage if needed, e.g. to deliver care.

Patient data is valuable to clinicians and other health and social care staff working in the NHS and in local authorities who are looking to improve how services are designed and provided. However, patient data contains sensitive information and it must be handled safely and securely to protect people’s confidentiality. Public organisations must follow laws and policies about how they use, store and share this information.

Patient data is often held by data controllers in different places, such as in your GP record, hospital record, and social care record, but it is important to be able to see the full picture of an individual’s history. ICSs play an important role in this by using “linked” patient data held by different organisations to provide the best care for individuals and help plan services.

Why is this important?

By looking at information about the people living in their area, ICSs can identify groups of patients with similar conditions or characteristics that may have an impact on health. This can help them to decide what services are needed for those people, and how to help them improve their health and wellbeing. They can also use patient data to make sure that individual patients are receiving the right care for their needs.

Where ICSs are able to connect NHS data to data from other public services such as local authority social care, they can build a more detailed understanding of the needs of different groups of people. Ultimately, this means they can work with partner organisations such as councils to provide services in a more joined up way for the local people who need them.

What did we find?

The ICSs we spoke to were at different stages in developing their plans for working with patient data. Some had already set up advanced ways of using and sharing data, while others were still thinking about how to do this. This means that in some parts of England, clinicians and managers have already created datasets that can be used to improve services, whereas in others, this work is less well-developed. Where ICSs have already made progress, there is the potential to share this learning with less advanced ICSs.

Some of the people we spoke to told us that the rules and regulations governing how patient data can be used are complex and that this can make it difficult for them to understand how best to move forward. ICS managers want their local populations to understand how their data is being used, and some have already carried out work to talk to the public about this. Many feel that more work is needed in this area.

How are more digitally mature ICSs developing approaches to using and sharing data?

We focused on four ICSs whose work on patient data is among the most well-developed. Short descriptions of their experiences and achievements follow.

Cheshire and Merseyside ICS

Cheshire and Merseyside ICS has developed a platform called the ‘Combined Intelligence for Population Health Action platform’, or ‘CIPHA’. Originally set up during the COVID-19 pandemic, CIPHA receives data from hospitals, GPs and community mental health services locally. The platform enables staff to analyse data so that decisions can be made about how services should be designed to meet the needs of groups of people with different needs. Although NHS data is being used well for these purposes, local authority social care data can only be used in a limited way so far.

The ICS has been able to use this data to tailor support for people with respiratory conditions living in areas where there is fuel poverty, and to help make sure people who are on waiting lists for operations are as healthy as possible before they have their operation, as this can help them to recover more quickly. The data used on the CIPHA platform is pseudonymised. To be able to reach out to people who might need extra support, doctors and other clinicians in Cheshire and Merseyside can re-identify their patients by connecting identifying information back up to pseudonymised data.

Cheshire and Merseyside has put robust governance arrangements in place, with a data access and governance group that meets regularly to discuss any legal or ethical questions relating to the use of patient data. It is also developing a social contract with local people, to build trust around the use of patient data, including by working with its ICS public board (a panel of local people), and through work with local universities and Healthwatch.

Dorset ICS

Dorset ICS has built an information platform to support clinicians and people working in care services to provide efficient and high quality care.

The Dorset Intelligence and Insight Service (DiiS) also helps people who design health and care services to make sure their services meet the needs of specific groups of local people. One success in this area relates to addressing the accommodation needs of people experiencing homelessness more quickly when they come out of hospital

The data stored in the DiiS platform, which includes information from GPs, hospitals, providers of community services as well as social care information, is refreshed every day. This means that it is sufficiently up-to-date to be used by GPs and other professionals to improve the care provided to individual people. An example of this is work that doctors have done in Dorset analysing prescribing data available through DiiS to identify issues with the way asthma inhalers were being prescribed. Doctors were able to analyse the data down to the level of the GP surgery to make sure that people with asthma were being prescribed inhalers that can help prevent asthma attacks as well as those that alleviate asthma symptoms. Where this was not the case, they informed the affected patients' GPs so prescriptions could be changed. Following this work, a reduction in admissions to emergency departments was noticed.

The platform protects the confidentiality of patients and service users by ensuring that patient data is pseudonymised. The only people permitted to find out the identity of individual patients in the ICS are those GPs or other professionals who are providing care directly for that person.

The ICS makes sure that local people's opinions are heard in relation to its work through its digital patient engagement group. This group is kept informed about DiiS's ongoing work and future plans. In future, the DiiS team hopes to include some data from the voluntary sector in DiiS, as well as incorporating new datasets such as those focusing on warmer homes coverage (relating to housing with lower energy efficiency) and air quality.

Frimley Health and Care ICS

Frimley Health and Care ICS has set up a programme of work focused on digital transformation, which it has called 'Connected Care'. This has three tiers of patient data – (1) a population health platform for understanding the needs of different people in the area, (2) a shared care record system that enables health and care staff to see all of the information from different services about their patients in a single place, and (3) a data platform that local people can use to provide their own health information, such as inputting their own blood pressure readings.

Hospitals, mental health services, providers of community services, local authority adult social care providers and the majority of local GP practices are sharing data under this approach. Building on work carried out during the COVID-19 pandemic to identify local people who were at greatest risk, Frimley Health and Care ICS has developed a series of initiatives to help vulnerable local people. These include frailty remote monitoring for local people who are at high risk of hospital admission, work to understand the needs of patients who are waiting to have a planned operation, work to determine where new services should be located based on where they are most needed, and work to focus GP health checks on the most vulnerable children with asthma who are living in poorly insulated homes.

Frimley Health and Care ICS has prioritised openness in its approach, carrying out 'show and tell' activities for local GPs to demonstrate the benefits of using patient data. It is also planning a public information campaign to tell local people about this work. So far, the remote monitoring scheme has been associated with reduced ambulance calls, lower numbers of people being admitted to hospital and local people reporting better experiences of care.

North West London ICS

Health and care services in North West London have joined together different sources of information about patients in a single place, called the 'Whole Systems Integrated Care' or 'WSIC' dataset. WSIC contains data about patients' use of acute, primary care, community and mental health NHS services, as well as local authority social care and children's services, some of which goes back several years.

This combined dataset helps staff understand much more about what different patients need and helps them identify who would benefit from care that could prevent their health getting worse and avoid them needing unplanned hospital treatment. It also enables staff to identify which patients are currently not getting all of the care they need, so that their care can be improved. Another important use of having data in one place is to track the flow of patients across the ICS and see where there are blockages to try and prevent delays or long waits for treatment.

North West London takes data protection very seriously. They took advice from a senior barrister known as a King's Counsel and worked with a lawyer with significant expertise in this area to ensure they built WSIC in the right way. Data can only be joined together in this way when the end goal of doing so is to improve care for individual patients. For example, community health services data was added to WSIC because a lot of diabetes care is delivered in the community and staff wanted to understand the experience of diabetes patients in order to improve their care. There are robust arrangements in place to protect the data in WSIC and most people who use the data are not able to see any data that identifies individual patients. Access to any identifiable data in WSIC is strictly limited to the doctors and other clinical staff that are providing care to those specific patients.

The ICS has run events to discuss how it wants to use data with local people and gauge their views about whether they support it and whether they have any concerns. In future, the health and care system in North West London hopes to bring data from emergency and urgent care services into WSIC, such as 999 and NHS 111 services. It also plans to host a regional platform to help researchers to access data in a way that protects patients' identities, and wants to use its WSIC data to predict what patients in the area will need in the future to help it use its budget as effectively as possible.