

WSIC Integrated Care Record FAQs

How your information is shared now

Today, all the places where you receive care keep records about you. They can usually only share information from your records by letter, e-mail, fax or phone. At times, this can be slow and sometimes things get lost on the way. This can result in clinicians not having up to date information. Patients may need to repeat details of medical history or medications in different settings and sometime undergo duplicate sets of investigations.

In North West London we're making improvements based on what people have told us they want from health and social care services. We can only do this if all the health and social care professionals involved in your care can share a summary of relevant information in your health and social care records.

With this joined-up or 'integrated' system, you'll be able to plan how you receive your care whether it's from your GP, local hospital or other local care services.

Everyone will know how you prefer to stay well and you will have more say over how and where you receive care.

We'll support people so they can remain independent and lead full lives within their community.

Whether you're visiting your GP, attending hospital or being seen at home by a care professional, we want to ensure you are looked after in the best way possible

FAQs on information-sharing at a glance

How will I benefit from sharing my information?

You won't have to repeat your health and social care information.

Care professionals will be able to find information when they need it.

You'll be able to avoid unnecessary appointments and tests.

You'll be more involved in decisions about your care.

You will be able to see your own information.

What information will be shared?

This information will include test results, medications, allergies and social or mental health information relevant to your care. The professionals treating you will be able to look at computer records of the care you get from other organisations, including your GP or the hospital.

This sharing of information will also help the health and social care system to work together to improve care services in North West London, through better planning and working in a more joined-up way.

There is a national programme you may be aware of, called Care.data, which looks at health records in order to conduct research into diseases, conditions and the quality of service the NHS is delivering. This information is not used for your direct care and is different to what we are proposing for the Integrated Care Record.

Who will see my information?

Only GPs, hospital doctors, nurses, social workers and other health and social care professionals, who are in direct contact with you, will have access to your health and social care records.

Sharing these records will help you to work together to make the best decisions about your diagnosis, treatment and care plan.

How is my information protected?

Your information is protected under the Data Protection Act 1998, which means your personal information will only ever be used to support your own direct care. It will not be shared with, or sold to, anyone else.

Can I opt out?

You'll be asked to give your consent each time health and social care professionals want to access your records in appointments and you can say no. If you are generally happy to share your information, you will consent to the following:

- Your care information may be shared with other professionals (for instance, acute consultants, mental health consultants, community health professionals, social care workers)
- Your care plan may be discussed at a meetings of professionals from a range of services in what are known as multi-disciplinary team case conferences
- Some care information will be made anonymous and shared with other organisations to help them improve services across the system

You can change your mind or 'opt-out' at any time to stop others seeing your information. If you want to do this, please tell your care provider you no longer want to share your information. Some care information will be made anonymous and shared with other organisations to help them improve services across the system

FAQs on information sharing in-depth

What information will the record contain about me?

The integrated care record has been designed to make relevant information available to the right care professional at the time they need it so you can get the best available care. Its purpose is to bridge gaps in communications between health and care organisations. This will improve care decisions and reduce repetition of tests or delays in discharge from hospital.

It will reduce patients and service users being asked to repeat their stories to different care staff and improve the information people caring for them know about their care plan.

To achieve this, the record will carry information on:

- Basic demographic information – for example: your postcode, age, GP practice details, whether you are a carer or receive care
- test results, medications, allergies and social or mental health information

The information we'll collect is based on the health and social care needs of the population and will be subject to change over time to meet the needs of the patients and service users of North West London.

All data we collect is covered by a legal agreement signed by the organisations providing your health and care services and will only be used to create your Integrated Care Record.

Where will the information be taken from?

Information will be extracted records from health and social care providers in North West London. This will be linked together to create the Whole Systems Integrated Care Record. Any provider that wants to use or contribute to the Integrated Care Record must sign up to our Whole Systems Integrated Care Information Sharing Agreement. The list of providers will include - but is not limited to - GPs, acute hospitals, mental health trusts and social services.

How many years back will the extract cover?

We will collect information from the last 10 years and link it to information from 2013-2014 to create a starting point at which your Integrated Care Record will be created. Sharing patient records will only happen once your care provider has signed our Information Sharing Agreement which contains the safeguards we have put in place to protect patient data.

The information we extract from your record will be the factual information contained in the read-coded sections of the GP system. Read codes are clinical terms which are the basic means by which clinicians record patient findings and procedures in health and social care IT systems across primary and secondary care. The information will not carry any commentary that may have been added in sections of the record where GPs and practice staff can make additional notes.

What data will be collected for people who've not stayed in hospital or needed social care?

We will have no information to collect if you've not been admitted to hospital or received social care at home.

In this case, your Integrated Care Record will be marked as "no activity". Your data may be made anonymous and used simply to help planners decide how much of which services are needed in your area given the requirements of the local population.

How will the integrated care record apply to people moving in to North West London for a long temporary stay - students for example?

Any patient registering with a GP practice in North West London will have an Integrated Care Record created for them unless they choose to opt out. They will have the same rights as all other patients.

Will I get a letter to tell me what my options are about sharing my information?

Our plan is to publicise the Integrated Care Record using posters and leaflets in health and social care facilities across North West London. We will also use our website <http://integration.healthiernorthwestlondon.nhs.uk> to communicate what the Integrated Care Record is and patients' rights to opt out.

We feel this will be more effective than writing to patients. In the vast majority of our early adopter projects, we're concentrating on patients with long term conditions who will regularly visit or be visited by their GP. As a result there will be opportunity for a discussion to learn more about the Integrated Care Record and your rights.

In addition, patients can choose to share their Integrated Care Record with care professionals when they are treated or given care.

How can I opt out of the system?

You can change your mind or opt out at any time to stop others seeing your information. If you want to do this, please tell your care provider you no longer want to share your information. Your choice will be noted on the computer system and your records will not be shared: this will mean that you will be opting out of the creation of your integrated care record. Your information will be deleted with the next upload of data.

Can I choose to withhold some of my information and, if so, how?

For the Integrated Care Record to be workable, we need to take all the information we require. So if there are facts you would rather not be shared, you should consider whether you'd prefer to opt out of having an Integrated Care Record.

If you change your mind and decide to have one at a later date a new Integrated Care Record can be created for you. Again, you will need to have a conversation with your GP to tell them that this is what you want.

We will not collect any information that is legally defined as “*sensitive*”. This includes abortion, rape, gender reassignment and incest among other things.

Can I stop certain people looking at my Integrated Care Record?

Yes. If you don't want specific services or individuals to be able to see your integrated care record, you can simply deny them permission to view it when they are providing your care.

Care professionals will be trained to ask for your consent before viewing your Integrated Care Record so you will have the opportunity to decide if you agree or not.

If you do agree, we have built safe guards into the system to ensure that each type of care professional can only read what they need to see in order to give you good care. This is what we call “role-based access”. For instance, a social carer will not be able to read your medical notes because there is no need or benefit in them doing that.

What is role-based access?

This describes restrictions placed on which parts of your integrated care record different professionals can see. Each type of professional will only be able to view information that is required for them to fulfil their specific role in your care. If information is not relevant to the type of care they provide you, they will not be able to access it.

Will highly personal data be collected?

We will not collect any information that is legally defined as “*sensitive*”. This includes data on abortion, rape, gender reassignment and incest among other matters. Please see ‘WSIC exclusion codes’ for further details.

Will my Integrated Care Record be shared with my employer?

We would only share information of this kind with an employer if you have explicitly agreed for us to do so. The Data Protection Act says all organisations have to ensure they do not release information that could cause serious harm or distress to an individual and each organisation

involved in the WSIC Integrated Care Record has to ensure it has checked all information before it is released to comply with the law.

How will information in my Integrated Care Record affect my insurance policies?

We can give you a complete assurance that your Integrated Care Record will not be shared with your insurer. In circumstances where you would like to share your health information with an insurer, you will need to provide explicit consent for this to happen. Your rights are protected by the Data Protection Act and all organisations participating in the WSIC Integrated Care Record are bound by the law. As a result they have teams of specialist staff and processes to provide assurances that data is not released accidentally.

How can you guarantee that my data will not fall in to the wrong hands?

We have a number of key safeguards in place to stop your information being accessed illegally. Our data warehouse, where your information will be stored, will comply with the standard used for national security.

Because the information is electronic and access is controlled by a professional's log-in and the access rights given to them, we can easily check that viewings of your record have been done properly. We will conduct regular audits to make sure that no one has read your data inappropriately.

There is the additional safeguard of your consent before your record is viewed – you can refuse to allow any care professional to look at your Integrated Care Record when they provide you with care.

NHS England and the Health & Social Care Information Centre are best placed to explain the safeguards they have put around collection, storage and use of anonymised "Big Data".

Will private companies who provide social care have access to my data?

Within local authorities, access to your information will, with your consent, be provided to qualified social workers who play a role in delivering the care you need. The information they will be able to see will be limited to what they require to do their jobs. This is called role-based access.

Similarly social workers and social care professionals who are part of a multi-disciplinary group delivering care to individuals will have access to some of the information on your record so they can support your treatment. Again, the data they will be able to see will be limited to what they need to perform their roles.

Elements of your Integrated Care Record could be shared with private companies or agencies contracted to provide care directly to you. The company would have to have signed up to our legally-binding Information Sharing Agreement before this could happen and individual staff members would need to be involved in providing care directly to you. The type of data they would be able to see would be limited to what they need to supply your care service.

Will voluntary organisations like charities be able to see my information if they're involved in my care?

Elements of your Integrated Care Record could be shared with voluntary sector organisations if they are contracted to provide care directly to you. The organisation would have to have signed up to our legally-binding Information Sharing Agreement before this could happen; individual staff members would need to be involved directly in supporting your well-being and the type of data they would be able to see would be limited to what they need to perform their role.

The Integrated Care Record is governed by an information sharing protocol and an Information Sharing Agreement which details what the signatory organisations are allowed to do with information once they have accessed it. Information may be shared on a need-to-know basis with private companies providing health and social care, where that company has a legitimate care relationship with the individual.

Only those organisations that are signatories to the Information Sharing Agreement will have direct access to the data. That access will only be to those organisations and individuals that have a direct care relationship.

Will my data be shared with any other organisations?

We will only share your information with health and care partner organisations that have signed up to our legally-binding agreement, which builds in safeguards to protect your confidentiality.

We will share extracts of anonymised information with the NHS Health & Social Care Information Centre along with NHS organisations across the country. This information helps healthcare planners to understand what types of services the NHS should provide and where, along with the amount of service provision to put in place.

We will comply with the “Anonymisation Code of Practice” drawn up by the Information Commissioner’s Office.

Will my data ever be sold for any reason?

No. Your data will not be sold to any organisation.

Will pharmacies have access to the data warehouse?

No, not yet, but that may happen in the future if it’s felt that sharing information would assist community pharmacists to provide a better service to you.

In the meantime, if you take medication, it will almost certainly be included in your Integrated Care Record as it’s the type of essential information that clinicians need to be able to treat you effectively and safely. That information will be taken from the records held at your GP or hospital or mental health service.

Will sharing my information with local authority social services mean it will also be shared with housing staff?

No. The Integrated Care Record will not be shared with housing or housing benefit departments. Only care professionals directly providing you with care can see your record and only with your agreement. If you do not wish to share information with your housing provider you can choose not to.

Will my anonymised information be sold to drug companies or research organisations?

No, anonymised data will not be sold to 3rd party organisations.

Who is responsible for correcting any errors in my information?

Under the Data Protection Act you have a right to have factually incorrect information changed or removed. If the information is not incorrect but you disagree with what has been recorded, you have a right to insert in your record your disagreement with the entry.

How can I make a complaint about how my data is being used?

The first thing to do is to raise your query with your GP or any of your care providers. If you are not satisfied with their response, you should contact the Information Commissioner's Office by calling 0303 123 1113 or via their website www.ico.org.uk

How do I complain if mistakes are made in my care because of errors in the Integrated Care Record?

You should first raise your complaint with the health or care provider responsible for the inaccurate entry to have it changed or removed. If you are not satisfied with their response you should contact the Information Commissioner's Office by calling 0303 123 1113 or via their website www.ico.org.uk

Patient Access and Consent

How can I see the information about me held in the data warehouse?

We are committed to making it simple for patients to view their own Integrated Care Record and we are developing a website that will enable you to log on and read the information.

How will you support people with learning disabilities to make an informed choice about sharing their information?

Care providers assisting people with learning difficulties will already have organisational policies and procedures in place to ensure that any consent is legitimately obtained, and that the patient's records are accessed lawfully under the Data Protection Act 1998.

The usual requirements for taking decisions on behalf of someone who lacks capacity will apply.

How will you make this all understandable for people?

We will publicise the Integrated Care Record and people's right to opt out in leaflets and posters in GP practices, hospitals and care providers' facilities.

We would advise older people, their families and carers to ask their care provider to explain how the Integrated Care Record works and answer their questions about confidentiality and opting out. We are putting together communications materials for GPs specifically to help them answer a range of questions around the data warehouse, Integrated Care Record and information governance.

How will people be informed about the new systems?

Leaflets and posters will be put up in care settings to inform patients of the WSIC and data sharing. There will also be dedicated web pages to help support patients and care providers.

Can patients be identified publicly by their NHS numbers as these will be used for the data warehouse?

Your NHS number will be used to link your records from different organisations to create your integrated care record. Your NHS number is not available to anyone other than you and the care professionals treating you. They have been vetted and given access to differing types of information based on the jobs they do with the sole intention of providing you with treatment and care.

Why are there two different types of information stored in the data warehouse?

This is because they have two different purposes. The first is to support the care and treatment you receive directly from NHS staff and other care providers when you are ill or recovering.

The second is to provide the statistics and analysis that the NHS needs to be able to plan how much of each type of service is required in each area. You could not be identified from this type of data as all information that might reveal your identity is removed.

The Integrated Care Record containing your name and details will support direct care and improve it because:

- Care professionals will be able to make **better informed decisions** about their patients
- Patients will only need to **tell their story once**
- GPs will be able to **track the care pathway of their patient** to ensure their patients receive the best possible care for them
- **Organisations can share information** between themselves so they will be able to learn more from each other and address common challenges arising from individual patients and the general local population's health

Anonymised data from the Integrated Care Record will support indirect care activities because it will:

- Provide a basis for **informing development of new models of care**. By understanding how we currently deliver care in terms of activities and costs, we can be informed on how we should change it
- **Provide business intelligence to manage the system effectively** i.e. be able to track activity, cost and operational performance
- **Allow health and local authority commissioners to set integrated capitated budgets** that allow us to move resources across the system and provide an incentive to take collective accountability of resources and outcomes

It is illegal for staff working in Clinical Commissioning Groups to see personal and sensitive data if the data is not used for a direct care purpose.

Will this system be for North West London only? What plans are there to tie it in with other areas?

Your Integrated Care Record will only be used in North West London. Anonymous data extracted from our data warehouse will be shared with the Health and Social Care Information Centre as part of its work to build a picture of the nation's health needs to support commissioning of services. This will not include your name or any details that could identify you.

