

**Sharing your health and
social care information:**
It's about making services
work better for you

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INTRODUCTION



We trust the NHS and social services with information about ourselves whenever we need their help. And we trust them to keep this information confidential.

We also expect that they constantly strive to improve their services and tailor them to our needs. What we may not always think about is that different services, even within the NHS, need to share information about us in order to give us the best possible care.

There is therefore a balance to be struck between protecting information and sharing it – appropriately, legally and with proper safeguards. I know that this is something that can feel worrying for people, not just patients but also the professionals that care for them who simply want to be sure that they are doing the right thing.

This is why I welcome this guide which clearly highlights some of the ways in which careful sharing of information is bringing significant benefits to people like you all over London.

— Dame Fiona Caldicott

Your information, your care

Whenever you go to your GP, or seek a social care service like home help, you tell them about yourself so that they can treat you or meet your care needs. In turn they make sure this important information is included in your notes. This makes perfect sense – after all, if you don't tell them what's wrong or what you think you need, they can't help you.

You expect the NHS and social services to protect this personal and clinical information and maintain your privacy. But you also probably expect anyone involved in your care to have access to it so that they can give you the care and treatment that you need. You might not think much more about what happens to your information beyond this.

Using and sharing your information

The fact is that the NHS and social services need to use – and sometimes share – this information not only for your own care and treatment, but so that they can improve what they do and design better services for everyone. This is why it is important to understand what can – and indeed should – happen with the information that health and social services record about you.

Protecting your privacy

What is important is that this information is governed by clear rules about how it is used and protected, and that everyone understands who has access to personal information and how and why they will use it.

Both the NHS and social services publish a Care Records Guarantee which tells you about how your personal information may and may not be used. See page 13 for links to the Care Record Guarantee.

PERSONAL INFORMATION

Personal information is any information which identifies you as an individual, such as your name and address, date of birth or your NHS ID number.

ANONYMISED INFORMATION

Anonymised information is information about you from which your identity cannot be determined, because personal identifiers (like name and date of birth) have been removed.

INFORMATION PROTECTION

Your personal information – as well as how it is used and who it is shared with – is protected under law by the Data Protection Act 1998, the Common Law Duty of Confidentiality and your right to privacy under the Human Rights Act 1998.

The power of information



Across London, there are examples of how data can reveal how people are using services.

Research and analysis

Researchers can use your personal and clinical information, but only with your consent - or because special permissions apply (e.g. checking quality of care). Once recognisable information, such as names, addresses and NHS ID numbers are removed, researchers and analysts can also use this anonymised data to improve services.

Researchers use data to explore how well different treatments and care approaches work for different people. For example, anonymised data from medical records is now being used to understand whether and when people experience adverse reactions to medication, and which treatments work best to slow down the symptoms of dementia in different groups of people.

How is data helping research?

- In Hackney, the number of Black Caribbean people who end up in hospital with cancer is higher than expected - this information is helping plan and improve services.
- In Brent, more people with mental health problems end up in hospital than elsewhere – possibly because there is also relatively low use of specialist mental health services.
- A lower percentage of babies receive a full set of immunisations in Merton than elsewhere in London.
- Bexley has a lower rate of emergency hospital admissions than the London average.

Sharing information matters

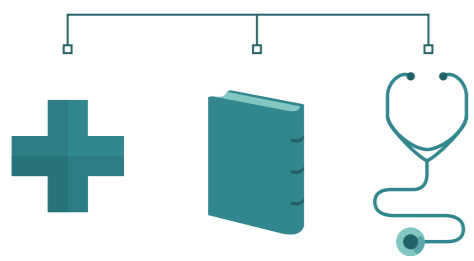
The idea of different organisations sharing your personal information can sound worrying. However, sometimes it is important that information sharing happens. To take a tragic example, the Baby Peter scandal was caused in large part by the failure of doctors and social workers to share information with each other. To take a more everyday example, many find it frustrating to have to repeat the same information over and over again to different health or care professionals. Some may have wondered why they didn't already have that information or worried that they forgot to say something important.

So, when might it be helpful for the NHS and social services to share information?

- When an elderly person has been in hospital after a fall, and then needs help at home
- When someone who has had a stroke needs ongoing rehab support and speech therapy
- When a person with mental health problems is being treated as an outpatient at the hospital as well as being supported by their community mental health team and visiting group therapy sessions

How sharing information is helping . . .

On the following pages, we tell you about five initiatives where the NHS and others in London are making a positive difference to people's lives by sharing information.



Joining up health and social care services in North West London

In North West London, people with diabetes and people over 75 years old are benefiting from a whole new way of organising the health and social care services they need. It's known as the Integrated Care Pilot and around 24,000 have chosen to be part of this project so far.



Making people's preferences count – end-of-life care

For those that sadly are facing the last months of their life, a project developed by the Royal Marsden NHS Foundation Trust called Coordinate my Care, aims to support people's preferences. The pilot has helped 3,130 people create end-of-life care plans with the professionals that look after them.



Keeping young people healthy

Tackling sexually transmitted diseases and avoiding unwanted pregnancy is a high priority in London. To help young people get the information they need, data from the C-Card scheme, run in 23 London boroughs, is shared between sexual health services in different boroughs.



Helping make London safer

Hospital A&E departments see thousands of victims of assaults every year. A new London scheme is looking at A&E data and sharing the findings with the police and local councils, so that action can be taken to reduce violent crime.

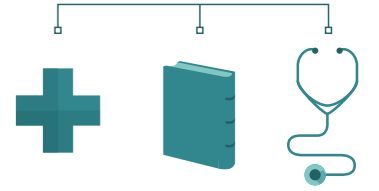


Using anonymised data for research

The biggest and best source of information on what treatments work for which people comes from real life clinical records rather than clinical trials. The CRIS tool developed by the Biomedical Research Centre at South London and the Maudsley NHS Foundation Trust allows researchers to access anonymised information from a huge database of mental health records.

CASE STUDY

Joining up health and social care services in North West London



People with diabetes and people over 75 years old are typically involved with a wide range of health and social care services – not just their GP but also hospital specialists, social services and, often, community mental health services. Too often, these services work independently of each other. This means that people can feel that they are being sent from pillar to post. More importantly, they also tend to be at a higher risk of ending up in A&E.

99% *Almost 99% of people invited to join the integrated care pilot have done so*

Seamless services

In North West London, people with diabetes and elderly people are benefiting from a whole new approach – one which makes sure that health and social services work together seamlessly to give them the best care possible and help to avoid them ending up in hospital unnecessarily. This is known as the Integrated Care Pilot. So far, around 24,000 people have chosen to be a part of this pilot and fewer than 300 patients have chosen not to be involved.

Pooling information

Across North West London, GPs, hospitals, social services and community mental health teams have made formal agreements to pool their patient and service user information according to a carefully controlled process. This pooling allows the system

to create a full medical and social care record more or less in real time for any patient that agrees to be involved. In turn, this means that any clinical or care professional that a patient sees can access all the information they need to make sure the patient gets the right care at the right time from the right service.

How does it work

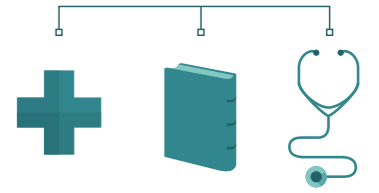
GP surgeries contact eligible patients to explain how the pilot works and to seek their consent. No personal information can be shared without individuals giving their explicit and informed consent to it – this means that they sign a form and indicate that they understand how their information will be used. In fact, many patients contacted are surprised to learn that this kind of information sharing doesn't already happen, even between NHS organisations.

KEY FACTS ABOUT THE NORTH WEST LONDON INTEGRATED CARE PILOT

- Sensitive health information is excluded, e.g. from sexual health clinics or about terminations or miscarriages
- No information about what benefits people receive is included
- Only professionals directly involved in providing care are permitted to access individual care records; and they can only see the records of people in their locality

CASE STUDY

Joining up health and social care services in North West London



People who work in health and social services are extremely aware of their responsibility for maintaining confidentiality. This can make them nervous about information sharing and worried about what is and is not allowed.

Andrew Thorne-Marsh, Programme Lead, says that some of their hardest work went in to reassuring the various NHS and social services providers that it was safe to share their information about patients and service users. Careful procedures for protecting the data, complying with legal requirements and ensuring it can only be used by those authorised to do so were put in place and formal contracts signed with each provider.

So, how does it benefit patients?

- Every patient in the pilot works with a named care coordinator to plan their care services for the next 12 months. This removes the risk of falling between the gaps of different services.
- In a recent survey, 94 per cent of patients on the pilot said they thought it was crucial for information to be shared across health and social care providers.
- 98 per cent said they felt more involved in decision making.
- An improved relationship with their GP was reported by 78 per cent of patients.

What about the professionals?

- Sharing information is helping health and care professionals work in different and more coordinated ways.
- With access to a full set of up-to-date information, GPs and social workers know at once if one of their patients has been admitted to hospital, outpatient doctors know why they are seeing a patient and people no longer have to repeat everything at every appointment they have.
- Professionals can work together to prevent people's problems rather than just reacting to them.

"It is a very good idea to have different people involved in your care. When you see the first doctor, they know where to send you and they have already shared your information to see what they will do for you."

Male patient, 56

"Our biggest and most gratifying challenge now is keeping up with the expectations of our patient user groups, who want more patients to benefit and more information to be included!"

Andrew Thorne-Marsh, North West London Integrated Care Pilot Programme Lead

"The important thing about integration is that it reduces fragmentation, lessens patients suffering and is more efficient."

Dr Amrit Sachar, Liaison Psychiatry Consultant

"Sharing information will sort a lot of problems, and the main problem is communication."

Male patient, 83

CASE STUDY

Making people's preferences count – end of life care



If we had the choice, around two thirds of us would prefer to die at home when the time comes - yet only around 20 per cent of people do so. Coordinate My Care (CMC), an initiative led by the Royal Marsden NHS Foundation Trust is seeking to address this issue. To date, 79 per cent of people who have a CMC record and who then died, did so in their preferred place.

“My patient of 95 found being on CMC a huge relief. The idea that she might end up being resuscitated in hospital was causing her real anxiety. Once she had shared her care plan, she felt she could relax.”

Ros Cook, Macmillan Nurse Consultant, Sutton and Merton Community Services

“CMC doesn't just have to be about end of life care. There is huge potential and we plan to develop the system so that it works for people with long-term conditions and dementia. The great thing is that it puts people in control.”

Dr Julia Riley, CMC Clinical Lead at The Royal Marsden NHS Foundation Trust

Making and sharing plans

CMC is designed to help people with life-limiting illnesses express their wishes and preferences for how and where they are treated and cared for as they near the end of their life. Most importantly it makes sure that any health or care professional legitimately involved in their care has access to this information, including in an emergency situation.

At the heart of CMC is a care plan that is developed by a patient with their nurse or doctor if, and when, both feel it is appropriate. The care plan contains information about them and their diagnosis, key contact details of their regular carers and clinicians, and their wishes and preferences in a range of possible circumstances.

Why does it matter?

The great benefit for patients is that neither they nor their family or carer feels they need to battle to make sure their wishes are respected. This is all the more important when conditions deteriorate at night or over the weekend, when their GP may not be available or their usual nurse is off. The care plan will tell ambulance control staff exactly what the patient wants to happen and what treatment they do and don't want to receive.

By the end of 2013, CMC plans to give patients and carers online access so that they can see and amend their plans at any time.

HOW A PATIENT'S FINAL REQUEST TO DIE AT HOME WAS HONOURED

A Wandsworth man with terminal cancer was quite clear about his wishes to die at home in his CMC care plan.

Just two days later his condition rapidly deteriorated and his daughter phoned 111. The call handler identified him on the system, and dispatched help.

The patient's daughter was advised that an ambulance was on its way, but it would not take her father to hospital, but simply administer pain relief and make him comfortable at home.

A Marie Curie nurse attended and some hours later the patient died at home as he had wished. The daughter later said she was grateful her father had been allowed to die in his place of choosing.



Protecting young people's sexual health

Access to condoms is key to reducing the levels of sexually transmitted diseases and unwanted pregnancies. One project gives young people a smart card to access free protection and advice, and the card data helps health professionals to monitor and evaluate the scheme.

"We're seeing other benefits we didn't think about before – young people being remanded in London go to Feltham Young Offenders Institute and before they are discharged they are signed up on the scheme and given information on outlets that are closer to home."

Adrian Kelly, Senior Public Health Strategist, Hackney

"With some of my most difficult clients in terms of engagement, the Come Correct session was the most happy and meaningful session because it had nothing to do with obligations and expectations but it was all about them and the acknowledgement of their individuality."

Youth support worker, One Housing Group

"Young people are really responding well to the scheme, they are coming to see me which is brilliant."

Youth support worker, One Support

Smart Cards

The Come Correct scheme is run across 23 London boroughs and issues young people with a C-Card - a smart card that allows users to "tap in", just like an Oyster card, at shops, youth centres, community pharmacies and GP surgeries across London to get free condoms and sexual health advice.

Young people can sign up either at their nearest access point or by giving basic details online and then finishing the process off at an outlet. During registration, they receive a "talk and teach" on condom use and where to get them with their C-Card. The card contains no branding or personal details, just a single ID number and barcode linked to their details. This means they don't have to give out any personal information each time, they just need to carry their smart card.

C-CARD FACTS

- 313,000 condoms were given out last year.
- One in six condoms went to a young person outside their home borough.
- September 2012 saw a record number of young people sign up.
- Since the scheme's launch, the under-18 conception rate for London has been falling faster than any other region.

SIGNING UP TO INFORMATION SHARING

When they sign up for a C-Card, young people must give their consent to their information being shared for the purposes of monitoring the scheme. Only basic information is recorded, such as name, address and postcode, ethnicity and sexual orientation, as well as what advice and how many condoms they were given at registration.

A central database holds details on the cards registered and condoms issued – this means that boroughs can then access anonymised data to assess take-up and usage by their residents to help measure the value of the scheme.

However, only those places where a young person uses their C-Card gets access to their details – this means that their personal information is only shared on a strict need to know basis. Even so, young people can choose to join the scheme and remain anonymous under UK sexual health law.

CASE STUDY

Helping make London safer



More than 150,000 violent assaults take place each year in London. A&E departments deal with the results every day, and very often they see assaults that are never reported to the police.

“In Hackney, the A&E data is shedding new light on crime hotspots. We can now use information about the level of injuries caused by people using bottles as weapons on weekend nights in conversations about pub and club licensing conditions locally.”

Karen Law, Partnership Strategic Analysis & Performance Manager, Hackney Council

“A&E data helped us identify clusters of violent incidents that we were unaware of. Without this intelligence, there would have been no suggestion that those areas might require more attention.”

Stephen Forgan, Analyst, Greater London Authority

“We’ve seen some great results. One council used the data to protect its domestic violence unit from the impact of funding cuts. In another area, a pattern of bullying on a particular bus route was identified and the school was able to tackle it.”

Clare Charlton, Programme Lead, A&E Data Sharing

Identifying crime hotspots

Simply by recording key pieces of information from victims, it is soon possible to spot patterns in where and when different kinds of assault take place. Sharing this information with local police and council-led community safety partnerships means that action can be targeted like increasing patrols; placing Police Community Support Officers in A&E at key times; reviewing licensing of bars and pubs or even increasing lighting on key streets. In Cardiff, where this kind of information sharing has been in place longer, the A&E saw a 40 per cent reduction in the number of assaults they dealt with over a five year period.

Anonymity preserved

At the moment, 20 London hospitals are actively sharing this data, usually fortnightly or monthly, and seven more are in the process of setting up. The aim is for this initiative to cover all London boroughs. Each hospital takes its responsibilities for patient information very seriously and most have chosen to put formal information sharing agreements in place even though what they are sharing is information that does not identify them as victims. What they have found is that victims attending A&E typically expect to be asked these kinds of questions and are

happy to answer them. No one is required to respond if they prefer not to.

None of the information collected identifies the victims and it is separate from the police’s task of investigating and prosecuting offenders. The hospitals involved only share the information with the community safety team and local police.

WHAT SORT OF INFORMATION IS COLLECTED AND SHARED?

A&E reception staff or the triage nurse asks victims for:

- Their age, gender, the borough where they live and part of their postcode, e.g. NW6 1 or SE1 9.
- What time the assault took place
- The weapon used, e.g. bottle, knife, gun, other object or part of the body (fist, feet, head).
- Where it took place, e.g. pub, bar, club, their own or someone else’s home, on the street.

CASE STUDY

What works for whom? – aiding research



Doctors need to know which treatments are most likely to work for which kinds of patients. Their main source of evidence is usually clinical trials, which are formally required before a treatment can be licensed. But by far the greatest source of information about what works and what doesn't – like adverse reactions to drugs – actually lies in real life experiences.

The Biomedical Research Centre at South London and the Maudsley (SLaM) NHS Foundation Trust spotted the potential of the trust's electronic patient records as a tool for researching opportunities to change and improve clinical care. SLaM is Europe's largest single mental healthcare provider and serves a population of around 1.2m Londoners. What they came up with is called the Clinical Record Interactive Search Tool (CRIS) – a way for researchers to extract and automatically anonymise information from the Trust's records.

Privacy and security requirements have featured as much as technical challenges in developing CRIS:

- Patients have been involved from day one, and the committee that formally oversees the use of CRIS is chaired by a patient.
- Applications to use CRIS are strictly controlled and users are under a contractual obligation to the Trust.
- All personal identifiers are removed from the data and it cannot be taken from the Trust.
- SLaM patients can opt out of having their data in CRIS – they are also asked whether they would be happy to be contacted later about participating in research trials.

"Before CRIS, people were flabbergasted to learn that clinical data is not routinely used to look at which treatments work and which don't."

Matthew Broadbent, Clinical Informatics Lead, Biomedical Research Centre at South London and the Maudsley NHS Foundation Trust

QUICK ASSESSMENT

CRIS now contains more than seven times the amount of data on dementia drugs compared with what researchers generally regard as the best source of systematic evidence, known as Cochrane Reviews. This means researchers will be able far more quickly to assess how well those drugs work for which kinds of people.

LIFE IN FOCUS

Research using CRIS is changing the focus of care for people with severe mental health problems. It has shown that what makes the most difference to life expectancy is less about protecting people from the risk of violence, suicide and self-harm, and more about helping them cope better with the activities of daily living and avoiding self-neglect.

VIEWPOINT

Reviewing the rules on information sharing

Read more about the Caldicott 2 review at: WWW.CALDICOTT2.DH.GOV.UK

"I have no doubt that restrictive practices around information sharing have cost lives. We need to look at those not sharing information as well as those inappropriately using information."

Dr Mark Davies, Executive Medical Director of the Health and Social Care Information Centre

Information sharing is a hot topic right now. The rules on how information about patients is managed – known as information governance – are currently being reviewed by an independent panel of experts led by Dame Fiona Caldicott. This review, known as Caldicott 2, will be published in the spring of 2013.

Reviewing the rulebook

Back in 1997, Dame Fiona wrote the NHS rulebook on protecting patient information. She has now been asked to recommend how to ensure an appropriate balance between protecting patient information and using and sharing it to improve patient care.

Too much or not enough?

Technology makes data sharing far easier than it used to be – this makes people worry about how their data is being used and how safe it is. Others are concerned that fear and lack of understanding of privacy rules mean that there isn't enough information sharing. They say that health and care professionals too often decide that it is more important to protect a patient's confidentiality from a possible (but unlikely) breach than it is to use their information in ways that could significantly improve care and save lives. It is this balance between maintaining privacy and sharing information that is the focus of this new Caldicott Review.

Updating the NHS Constitution

The Constitution sets out patients' rights and what they can expect from the NHS. Work is underway to update the constitution and information sharing is one of the areas up for change.

Any changes will not change the law on confidentiality, but they are likely to be clearer about when and how information can be shared and used. For example, the revised constitution may reiterate that patients have the right to privacy and confidentiality, to have their confidential information kept safe and secure and to be informed about how their information is used. But it may also commit the NHS to ensure that all those involved in a patient's care have access to their information so that they can care for them safely and effectively – and to anonymise data and use it to support research and improve care for others.

These changes may seem subtle but they are also important. The hope is that they will remove the fear factor around information sharing, for professionals and patients alike.

A report by the Future Forum concluded that: "...not sharing information has the potential to do more harm than sharing it. It is also a major annoyance for patients who feel that they should not constantly have to repeat the same information about themselves as they pass along the treatment pathway."

NHS Future Forum, January 2012

ABOUT LONDON CONNECT

This case study was produced by London Connect, an information transparency project of the London Health Improvement Board (LHIB), a partnership set up by the Mayor of London, NHS London and London Councils and their stakeholders to improve the health of the capital's population. The London Connect project is delivered by Improvement Science London on behalf of the London Academic Health Science Centres (AHSCs).

FIND OUT MORE

www.lhib.org.uk/information-transparency

www.ico.gov.uk

www.caldicott2.dh.gov.uk

Details on the Care Record Guarantee can be found at:

www.nigb.nhs.uk/pubs/nhscrg.pdf

Read our previous guide on accessing your health records online at:

www.myhealth.london.nhs.uk/health-communities/general-practice/its-your-record



MAYOR OF LONDON

