Sharing our health data

The advantages, the concerns and the choices we can make

emma.whitby@healthwatchislington.co.uk 07984 445 668

The Healthwatch role in health and social care

As set out in the Health and Social Care Act 2012:

- Engage residents,
- Report their views,
- Visit services,
- Provide information and advice.

In addition:

- Digital inclusion.

- Newsletter: luke.buffery@healthwatchislington.co.uk

Healthwatch Islington's vision is of improved health and care outcomes for local residents.

We work closely with the Clinical Commissioning Group (CCG), Local Authority, statutory, private and voluntary sector in Islington championing the needs of local people.

We work with a range of minoritised communities through our Diverse Communities Health Voice partnership and co-Chair the borough's Challenging Inequalities work.

Join us at a virtual event

8th September, 13:30 – 15:00, virtual event:
‘Struggling to see the dentist’

Keep an eye on the web-site for information on further events, including an autumn workshop on the Covid ‘booster’.

A delay until four criteria are fulfilled

- the ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded
- the backlog of opt-outs has been fully cleared
- a Trusted Research Environment has been developed and implemented in NHS Digital
- patients have been made more aware of the scheme through a campaign of engagement and communication

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Who are NHS Digital

- Also known as the Health and Social Care Information Centre.
- Set up by the Health and Social Care Act 2012.
- “Safe haven” of health and care information with the power to collect information about us.
- The Secretary of State for Health and Social Care, and NHS England, can tell NHSD to collect and process information on specific topics, or through specific systems.

Who are NHS Digital

NHS Digital has two main responsibilities. They

1. run and manage computer systems that link different parts of health and care together with the aim of improving individual care
2. collect some specific health and care data to check how the health and care service is doing and to improve everyone's care (how does a treatment or policy impact)

To carry out these duties, they need to collect, store, use and sometimes share information about you.

What about GDPR?

(General Data Protection Regulations)

1. Your data is stored in your health records. The Health and Social Care Act 2012 sets out certain duties which mean that information about you can be shared with others. Usually data protection rules means we have to opt-in to plans to share our data, but for NHS Digital our data can automatically be shared unless we opt-out.

2. Our pseudonymised (see next slide) data can also be shared to help services plan care; for example to know how many of us are likely to be diabetic, understand likely demand for hospital care, managing outbreaks during the pandemic.

Pseudonymised?

Anonymous data means all identifiable information about us has been removed.

Pseudonymous data means that our data is coded, so that for general use it cannot be connected to us, but could be connected if there was a need (for example, discovery of an illness).

Hospital data sharing

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- NHS Digital holds all the data collected by hospitals in a central database called Hospital Episode Statistics (HES).
- It is used for planning and research at the moment and contains everything from what condition people have, the treatment they get, which hospital it took place at, the outcome etc.
- It “cannot be used for marketing or insurance purposes”.
- Whilst the NHS doesn’t sell the data it does impose a charge to fund the cost of making the data available to external organisations – like Universities, think tanks, pharmaceutical companies etc.
- The new programme would bring GP records in to the same place.

How can it help to share my data

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During the pandemic, sharing pseudonymised data on ethnicity, age and disability has helped colleagues across health develop an understanding of who is less likely to have been vaccinated, enabling more targeted promotion campaigns.

Health Inequalities can’t be measured (and responded to) as easily if we don’t share our pseudonymised data. Sharing data can help to make sure services are designed to meet local need.

Sharing data on specific health conditions can help local services understand demand, and plan accordingly.

How can it help to share my data

- Within the local (North Central London) NHS, services may sometimes ask to share your data <u>with your consent</u>.

- This is separate from the duties places on NHS Digital under the Health and Social Care Act.

- This can helpful so we don’t have to keep repeating our story.

What data will be shared

Data may be shared from the GP medical records about:

- any living patient registered at a GP practice in England when the collection started - this includes children and adults,

What data will NOT be shared

NHS Digital will not collect:

- patients' names or addresses (they WILL collect your postcode but pseudonymised
- written notes (free text), such as the details of conversations with doctors and nurses
- images, letters and documents
- coded data that is not needed due to its age - for example medication, referral and appointment data that is over 10 years old
- coded data that GPs are not permitted to share by law - for example certain codes about IVF treatment, and certain information about gender re-assignment

What residents tell us

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In previous engagement work the public have told Healthwatch that they are in favour of the NHS using their data for public health and service planning if they understand how this information will be used and can opt out if they so wish.

However, ongoing public support for this depends on complete transparency and clear communication from the NHS when things change.

This is part of the reason why NHS Digital's decisions made the news. They say they engaged certain groups, but it came as a surprise to many of us. And their information is confusing, which exacerbates mistrust.

Opting out

If you don’t want your identifiable patient data to be shared for purposes except for your own care, you can opt-out by registering a Type 1 Opt-out or a National Data Opt-out, or both. These opt-outs are different. Your individual care will not be affected if you opt-out using either option.

Type 1 opt-out: NHS Digital state they will not collect data about you from your GP practice (for service planning).

National Data opt-out: NHS digital will collect your GP data but will not share your identifiable (or confidential) patient data with any other organisations (research).

Opting out

If you wish to register a Type 1 Opt-out with your GP practice before data sharing starts with NHS Digital, this should be done by returning this form (click here) to your GP practice. You can use the same form to cancel your opt-out.

You can send the form by post or email to your GP practice or call 0300 3035678 for a form to be sent out to you.

Make your choice about sharing data from your health records - NHS (www.nhs.uk)

Or use the NHS app and opt-out at the click of a button.

Opting back in

You can decide to opt back in at a later date if you've opted out and then change your mind.

This is done in the same way as opting out, using the same form, via the GP or on-line or by calling 0300 3035678.

View from Healthwatch England

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> “Over the next few months we need to see a proper nationwide campaign on this, reaching out to people so they can make an informed choice about how their own individual medical records are used to support research. This is a complex issue, and so we will all be working with the NHS to help build awareness and understanding.”

Discussion

- NHS Digital talk about using our data in a Trusted Research Environment. What does a ‘Trusted Research Environment’ mean to you?
- What would give you confidence that NHS Digital was operating a ‘Trusted Research Environment’?
- In what ways should NHS England, NHS Digital and/or GPs raise awareness around data sharing with patients?
    - Who should lead the communications, and how should it be resourced?
    - How would we know there had been sufficient work to raise awareness?
    - How would we know there was sufficient impact from that work?

Next steps…

Awareness campaigns, how much should we do?

Talk to a healthcare professional if you have concerns, or send Healthwatch your questions.

Perhaps contact other local campaign groups to register concerns.