Q&A Summary

Webinar: Does the NHS sell my data?

Tuesday 27 September, 2022

The following questions were entered into the Q&A function during the webinar (shown in bold).

Where delegates or speakers entered written responses in the Q&A function, these are shown below, following the original question. These are "as written" and may not represent the position of use MY data.

Questions which were answered live during the webinar are listed at the end of the document.

Can you give some examples of social care data e.g. does it include local authority social services data?

See https://digital.nhs.uk/data-and-information/areas-of-interest/social-care

Most of the data that NHS Digital holds on social care is aggregate / survey data. But it's an area that has been overlooked and so important that we keep on emphasising that health and social care are inextricably linked.

It is important we distinguish between use of non-identifiable and identifiable personal/ patient data.

Why, please?

There is anonymous data, i.e. data in which no individual can be identified - but the sort of rich, linked health data at individual level that we're talking about is NOT anonymous. (If it were, it wouldn't be useful for all the good stuff!)

Generally speaking, anonymous data needs to be *aggregated* (i.e. grouped together in cells & tables, not individual rows of data) and any 'small numbers' removed (e.g. obscuring any cell with a value of 1 - 5 or so, which might allow individuals to be identified). Data treated like this can be published, e.g. as statistics - which NHS Digital does :)

Everything else is more-or-less identifiable, even if obvious identifiers like name & DoB have been removed (de-identified) or obscured (e.g. with a range or a pseudonym) - and is therefore recognised to be personal data under the law and, being such, all of the law and rules around personal data apply.

Understanding and responding to (inherent) biases in data is important when using data to support innovation and service planning.

Question was not answered

The figures on slide 11 - e.g. 60% of people approve of research orgainsations accessing data so society doesn't miss out - implies that a lot of people don't approve. What can be doen to honour these views?

People have a right to prevent *unnecessary* processing of their personal data. While it can be and is a public good, research is not *necessary* for the provision of a person's direct care. So there will always have to be an opt out.

What we can do is to respect people's choices, look after their data properly, and tell them what we have done with it - i.e. make sure every use of patients' data is consensual, safe and transparent - and the more trustworthy bodies are about this (i.e. demonstrating that they are competent, reliable and honest over time) the less likely people are to opt out.

Does using the term 'innovator' for research data users smack of 'commercial' language? do patients/public understand the different ways research is done? might be seen as trying to elide/hide use by academic/commercial users? there is such as history of obfuscation/unclear language here. I am in favour of all uses, with safeguards- but there is a huge risk that yet again the NHS is seen to be interested only in comemrcial benefit of data use.

Question was not answered

Does sharing in financial benefits open the question that they will want you to share the risk? Such as Sensyne, where the business model has put Trusts at risk/cost?

Why on earth should the NHS absorb or underwrite any corporate risk?

Sensyne Health has starkly illustrated why the NHS / NHS Trusts shouldn't speculate (e.g. receive shares in payment) AT ALL:

https://www.theregister.com/2022/08/17/nhs_hospitals_ai_losses/

Has it been made it clear about the level of patient data that is shared, e.g. record level, aggregate and whether it is identifiable.

Question was not answered

Kelly, what and who 'prevents' or gives you the biggest challenges to achieveing your vision? And what sort of time scale is realistic?

Question was not answered

I know there are errors in my medical records. What is being done so that it easy to correct errors so that research outcomes are reliable?

It's not easy to 'correct' errors as the existence of the error has to be preserved - it is part of the record and audit trail.

I think there is a need, where patients have the skills, for them to make sure they know what is in their record and then get the GP to correct it. This can be done; I have done it but it did involve pestering my surgery - which I regretted having to do. But of course we can't - yet - see our hospital data.

Ultimately these errors need to be corrected at source, which means flaging them to the originator of the record (i.e. GP / hospital) and that change being recorded as per Phil's response. But online access to records - which will increase - will make it easier to identify and correct.

If you are charging to recover your costs to grant access to the data, does that charge include other costs, such as your IGARD scrutiny committee, and the costs of doing audits once access has been granted?

Yes, we aim - in aggregate - to cover all the additional costs incurred in providing access.

Is it fair/sustainable that all the costs of auditing data use (which is important to see for public trust) falls to NHSD, and not those using the data?

The aim of our charging is to ensure that those additional costs do fall to the users rather than to the NHS.

Do we have example of where this is working well. Sharing patients data to better improve treatments?

I work for an Oxford university spin-out using NHS data to develop new drugs for patients with migraines and parkinsons. We couldn't do this without patient data and we are exceedingly careful

with the data, as a breach of confidentiality woudl probably mean our company woudl shut down (for reputation problems or the GDPR fine)

Do we have a good understanding of why some patients are worried about their data being shared? Do we have a clear picture of what they think might happen to them/the data? Without this we can never hope to persuade them of the benefits.

This is the question we are looking at with the GP Data Trust pilot project. @GPDT_Project

Do we have a good understanding of why some patients are worried about their data being shared? Do we have a clear picture of what they think might happen to them/the data? Without this we can never hope to persuade them of the benefits.

There are also a series of research projects which have looked at this topic before, including multiple Citizen Jury reports etc. https://www.adalovelaceinstitute.org/report/trust-data-governance-pandemics/   https://www.gov.uk/government/speeches/talking-with-citizens-about-expectations-for-data-sharing-and-privacy

re value- do we count social value of the intent as well as actuality of sharing our health data for community benefit?

Question was not answered

A post Covid survey carried ut by NHIR showed an increase in public awareness and confidence in research plus an increase in people willing to be involved in future research. Has any action been taken following these results? We patients take part in many surveys but rarely hear what impact our views have had.

Question was not answered

Data saves lives 2022 states that TREs are only a subset of the Secure Data Environments (SDEs) that are wanted and that they will be discussing with 'partners' exactly how these can be set up to maximise benefit from Shared Care data. There is also a statement that de-identified data will be able to leave the SDE. Also it seems that every Trust and ICS will have an SDE which surely will make it extremely difficult to keep data safe and secure?

Question was not answered

How do you balance increasing the impact of data by reducing cost (everyone in drug discovery uses UK Biobank which is cheap) and maximising the cash return to the NHS (very few start-ups can afford to work with Genomics England)?

Question was not answered

There's been several mentions of NHS data being sold internationally - how can the data leave the UK?

Once data has been disseminated (i.e. copied) it can then be passed to others. One example would be, e.g. CPRD, which services customers in the US and elsewhere:

https://www.theguardian.com/politics/2019/dec/07/nhs-medical-data-sales-american-pharma-lack-transparency

When it's said that 'data/insights should benefit patients and patient care' - does that include patients and patient care within other other health systems - eg ones which are 'for profit' including international ones?

Question was not answered

Many companies claim they are bringing their own tools and knowledgebase to the party - i.e. the NHS data is not the be-all-and-end-all. Can TREs handle this?

A properly built TRE will allow people to load in their own data as well.

No TRE will be able to support every piece of proprietary tooling that people have come up with, but a properly built one will have all of the standard tools, plus a variety of languages and frameworks that will permit more 'customised' processing.

Claiming you need to be given a copy of the population's health data just because you built a whizzy tool is not a justification at all! This speaks to my point on Machine Learning / Deep Learning - if people want to do specialised things with NHS patients' data, they should investing in building *the NHS's (TRE) capacity* so that ALL can benefit.

It is not at all unusual for a user to bring their own data and technologies into SAIL as part of their (approved) project. However, we always conduct a thorough review of these incomings, in particular any tools / software and if we can't inspect and understand how it works, we won't let it in. We also won't let it out again, is there is any chance it might contain any of our data hidden within it

Do we know what % of patients are actually concerned vs ambivilant towards their data being used ? Are people who are concerned more likely to voice their worries and therefore skew how representative their views are.

We should hopefully be able to cover some of this in the second part of the webinar, perhaps after Vicky has spoken

Agree that processes need to be much smoother. Bottom line is any patient can make a formal request under Art 16 UK GDPR and controllers need a process to implement.

Question was not answered

When you evaluate private companies seeking NHS data in terms of the value they can deliver, does their *reputation* feature in that equation?

Example: giving access/data to private companies that have a poor public image or change their name to hide poor practices may jeopardise public perception. Does this count against them?

For NHS D, we require organisations to meet a range of published standards and use data for the benefit of health and care. We do a lot of work to define who is the data controller - i.e. who is ultimately making the decisions - and that they have appropropriate security, are registered with the Information Commissioner, etc. Reputation isn't included directly in our standard - and is inherently subjective - but it's something we can consider, along with relationships with other companies - if we think it could risk delivering this public benefit. And we've got an ongoing discussion about whether we can formalise that.

Should we consider access to data by the companies who are setting up IT systems for data collection and sharing within the NHS? eg an NHS Federated Data Platform will soon be set up using about £360m of public money and the contract will go to a commercial company eg Palantir which will have access to a massive amount of patients' and other kinds of useful demografic data.

Setting aside Palantir for the moment, we should be careful to distinguish between companies that provide IT services and those that "make use" of patients' data. The NHS doesn't have its own GP patient record system, for example - GP practices buy one of the (NHS England approved) ones, e.g. EMIS Web, TPP SystmOne, or Cegedim Vision. It buys other software from other companies, from Microsoft 365 to the code used to run MRI scanners!

The questions raised by Palantir are more about its reputation - should the NHS *really* be working with a company that provides services to the intelligence services and dodgy regimes? - its business

model - Palantir's explicit aim is to become "the operating system for data" for the NHS and other parts of the UK Government (and other Governments too) - and the lack of transparency about what it *already* does, much less what NHS England intends it to do. (It's taken TWO YEARS for NHS England to publish just a list of the 150+ data "purposes" in Palantir Foundry.)

Let's be honest! If everyone (or a significant number) opted out of their data being used, any advantages would be lost. Additionally, we market the use of data to the public by making a big thing of it being anonymised but we all know that there are errors (human and technological) that mean this cannot be guaranteed. We have to decide that value to patients is such that's we take the associated risks and we have to take a leap of faith, trusting our digital colleagues.

Question was not answered

Many NHS and government users of our data are not looking at improving services, or outcomes but focusing on the costs of treatment, in order to look at how to cut/reduce services, this is called 'maximising value'. I have not seen any patient involvement looking at this type of use. Is this something that Use my Data are involved in?

Can you give an example please?

Question was not answered

David, congrats on all the great work SAIL's been doing - could it make sense to charge more than Full Economic Costing so that you can invest into expanding the scale and scope of your activities and also put benefit back to underlying contributors of the data, i.e. for them to have funds to directly drive better outcomes?

Question was not answered

Does David have any examples of successes having "pestered" users??

Question was not answered

Scotland and Wales are lucky at the moment in that they will not have data driven Population Health Management, essential for ICSs to work, being set up by a large number of private corporations on the Health Service Support Framework. Each ICS will have a data platform, ours is set up by Cerner which has just been bought out by the American giant corporation Oracle. EMIS has also just been bought out by the American giant healthcare corporation UnitedHealth for $1.5 billion.

Question was not answered

The last 2 presentations beg the obvious question; why not UK wide?

If, for instance, there is a Northern Ireland equivalent, data sets for rare diseases are likely to be statistically insignificant.

Health is a devolved matter. Also NI rare disease data will have significant meaning within the island of Ireland

Debbie, many thanks. Quite understand that health is a devolved issue. I think that has produced unintended consequences - segmentation of data across the UK. We need to think about UK wide applications, in my view.

Q for Roger - on the assumption that you publish a Data Access Register, how do you/intend to retain the anonimity of businesses when there is some public sensitiy around some businesses with perhaps poorer public reputations or more sensitive geographic locations.

Follow-on question from Phil Booth: Why should ANY company "retain anonymity"? Patients are not being given that!

Do David and Roger expect their organisations to be a key part of any new NHS strategy/structures in respect of data - to be 'given their heads' as SDEs or whatever?

Question was not answered

Re: question of maximising value point made by anonymous attendee earlier, please look at work done by Professor Muir Gray, Oxford University for the RightCare programme and the concept of 'allocative value' where limited resources (fixed budgets for ICSs) need to be spent in areas identified of greater value and that local populations will help to decide where 'cuts' to care can be made and money moved.

Question was not answered

Comment re individual-level notifications of data use: this is being piloted in cohort studies, like ours (NIHR BioResource), UK Biobank, Genomics England, that KNOW their participants.

and where these organisations have explicit consent for access to data (of "their" participants)

Question was not answered

Is the role of the National Data Guardian under threat? The proposals for the Information Commissioners office in the new Digital Bill do not build confidence that government sees that public confidence and transparency are critical? Is UMD involved in any discussion on the new Act?

I would hope so!

It took *YEARS* to get the NDG (back) onto a statutory basis, after Dame Fiona's previous role (Chair of NIGB) was abolished by the Health & Social Care Act 2012. From shortly after that until the Health and Social Care (National Data Guardian) Act was passed in 2018, the National Data Guardian and IIGOP existed at the behest of the Secretary of State.

The ICO simply isn't (legally) competent on many issues around health data - the Data Protection Act & UK GDPR are not the only relevant legislation; there's Common Law Confidentiality, and numerous NHS and Health & Care Acts - and so whatever the ICO becomes is going to *have* to relate to the NDG on such matters.

Could the Government create a more conducive environment by talking more in terms of beneficial outcomes (e.g. reduced waiting lists; improved survival rates etc.) rather than the usual emphasis on the money going in? From a patient perspective, I will always be more interested in proven improvements to patient treatment etc. as a result of use of my data than in any bottom line impacts.

Question was not answered

Why is NHS Digital merging with NHSE/ Transformation? Does this raise concerns?

Question was not answered

How can 'cashless' data transactions happen in the form of 'we'll give you the data and you give the NHS a real discount on any drugs/treatments that result'?

Question was not answered

The following questions were answered live during the webinar

How do you audit that 'fair value' has actually been acheived?

live answered

Is it really helpful to transparency and public buy-in to keep changing and renaming structures (e.g. PHE; NHS X; NHS Digital) and language (e.g. TREs; SDEs)?

live answered

Med Confidential's points about GP data access apps and what they are selling are interesting. Recognising that GP surgeries are private businesses and that the NHS App now exists should the Government stop GP surgeries using non NHS developed Apps?

live answered

The new Data Bill proposes that Government will have the powers to share data, separately from any NHS process. This is to boost income , or achieve other government aims.

live answered

If we need the private sector in order to help drive the innovations we want, innovations that should have massive value benefits for patients and (perhaps) the overall costs of delivering public health, wouldn't it make sense to see the costs of managing data access as a worthwhile investment of (a relatively small amount of) public money? This might move us away from the barriers and difficulties that charging for access can create and help maintain a focus on outcomes rather than process. It would also help us manage patient concerns about the NHS selling data. Sorry for wordy question!

live answered

One of the main aims of the Data Protection and Digital Information Bill is to facilitate commercial access to   personal data. How will measures such as the abolition of Data Protection Officers, and allowing data controllers to decide whether data is anonymous and beyond data protection law, etc, (and the inclusion of so many Henry VIII powers) be compatible with increasing patients' trust in how their data will be used?

live answered

Why would a company offer you more money not to share data Geoff, and thank you for not working alongside such companies,?

live answered

Vicky has used the term 'transparency' a few times - does the NDG subscribe to the use MY data definition of 'transparency'?

live answered