Patient Data

Arguments for and against selling (or giving away) NHS patient data are complex and fraught. Is it exploiting confidential patient records for private profits or a public resource that, with the proper safeguards, can be used to save lives?

Irrespective of how one answers that question, the NHS right now is collecting and sharing more patient data than ever before and that will only accelerate. To avoid the scandals of the past, a frank conversation with the public about industry access to this data, and what the NHS should expect in return, is needed.

Some patient data is aggregated nationally, mostly by NHS Digital, and shared with industry and academia. But there are big gaps, most notably in primary care, and much of it is messy and slow to collect. Past attempts to build a more useful national data set that might supercharge research and improve direct care have been spectacularly bungled (see Care.data).

In the centre, NHS Digital’s data services platform is replacing a hodgepodge of old systems as the landing pad for national patient data sets. Once there, the data is easier and faster to link, anonymise and share within the NHS and with researchers, both commercial and academic. NHS Digital is making changes to the collection of GP data that, according to one report, will benefit researchers “enormously”.

At the regional level, the local health and care records exemplars are meant to be doing the same. Each LHCRE will gather or link together individual patient’s information from different providers for local use (eg: direct care, planning) and to feed into the centre. To make this work, rules are being introduced to clean and standardise patient data nationally.

The conversation has even shifted from how NHS should control industry access to patient data, to how much it should be charging. Technology companies, in particular, are increasingly striking deals with NHS trusts to access patient data to test or develop their products.

There is now a code for all this – see this link ---

[https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology/initial-code-of-conduct-for-data-driven-health-and-care-technology](https://apc01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.gov.uk%2Fgovernment%2Fpublications%2Fcode-of-conduct-for-data-driven-health-and-care-technology%2Finitial-code-of-conduct-for-data-driven-health-and-care-technology&data=02%7C01%7C%7Ce0295c706fcb4ab39b2308d6a2ea9f36%7C84df9e7fe9f640afb435aaaaaaaaaaaa%7C1%7C0%7C636875525909420497&sdata=XdQpiW3HM5YWEcg0M1FiTZXzOv4nr%2Fj4Nt6tZ%2BN7XQU%3D&reserved=0)

The Department of Health and Social Care, worried the NHS is getting a poor return on its patient data, has now written a code[above] for ensuring the NHS will cash in on any “upside” from such arrangement. This may come from straight selling data, preferential access to any new tech developed using that data, or from trusts creating joint ventures with tech companies to commercially exploit the data (and, of course, to improve health and care).

How willing industry will be to pay for better access to NHS patient data remains to be seen (some large high-quality patient datasets overseas are free to access). But DHSC is advising NHS organisations to create “commercial strategy” for sharing patient data now, to ensure the NHS gets a fair piece of any action.

None of the above is secret but most of it will be news to the average patient on the street.

The National Data Guardian Dame Fiona Caldicott says the NHS should have a “no surprises” policy on using patient’s health data, but surprises persist. Last month, she said the “case for data sharing still needs to be made to the public”.

“Dialogue with the public about data use has not grown at the same speed as the capacity of technology,” she said. “Where there is a gap between expectations and reality, anxiety may grow about the use of patient data to support innovation.”