NHS patient data to be made available for sale to drug and insurance firms

19. Januar 2014

The Guardian

Privacy experts warn there will be no way for public to work out who has their medical records or how they are using it

Drug and insurance companies will from later this year be able to buy information on patients - including mental health conditions and diseases such as cancer, as well as smoking and drinking habits - once a single English database of medical data has been created.

Harvested from GP and hospital records, medical data covering the entire population will be uploaded to the repository controlled by a new arms-length NHS information centre, starting in March. Never before has the entire medical history of the nation been digitised and stored in one place.

Advocates say that sharing data will make medical advances easier and ultimately save lives because it will allow researchers to investigate drug side effects or the performance of hospital surgical units by tracking the impact on patients.

But privacy experts warn there will be no way for the public to work out who has their medical records or to what use their data will be put. The extracted information will contain NHS numbers, date of birth, postcode, ethnicity and gender.

Once live, organisations such as university research departments - but also insurers and drug companies - will be able to apply to the new Health and Social Care Information Centre (HSCIC) to gain access to the database, called care.data.

If an application is approved then firms will have to pay to extract this information, which will be scrubbed of some personal identifiers but not enough to make the information completely anonymous - a process known as "pseudonymisation".

However, Mark Davies, the centre's public assurance director, told the Guardian there was a "small risk" certain patients could be "re-identified" because insurers, pharmaceutical groups and other health sector companies had their own medical data that could be matched against the "pseudonymised" records. "You may be able to identify people if you had a lot of data. It depends on how people will use the data once they have it. But I think it is a small, theoretical risk," he said.

Once the scheme is formally approved by the HSCIC and patient data can be downloaded from this summer, Davies said that in the eyes of the law one could not distinguish between "a government department, university researcher, pharmaceutical company or insurance company" in a request to access the database.

In an attempt to ease public concern, this month NHS England is sending a leaflet entitled “Better Information Means Better Care” to 26m households, to say parts of the care.data database will be shared with "researchers and organisations outside the NHS" - unless people choose to opt out via their family doctor.

However, a leading academic and government adviser on health privacy said pursuing a policy that opened up data to charities and companies without clearly spelling out privacy safeguards left serious unanswered questions about patient confidentiality.

Julia Hippisley-Cox, a professor of general practice at Nottingham University who sits on the NHS's confidentiality advisory group - the high-level body that advises the health secretary on accessing confidential patient data without consent - said that while there may be "benefits" from the scheme "if extraction [sale] of identifiable data is to go ahead, then patients must be able find out who has their identifiable data and for what purpose".

Hippisley-Cox added that "there should be a clear audit trail which the patient can access and there needs to be a simple method for recording data sharing preferences and for these to be respected".

Davies, who is a GP, defended the database, saying there was "an absolute commitment to transparency" and rejecting calls for an "independent review and scrutiny of requests for access to data". "I am tempted to say that we will have 50 million auditors [referring to England's population] looking over our shoulder."

He said it was necessary to open up medical data to commercial companies especially as private firms take over NHS services to "improve patient care". Davies said: "We have private hospitals and companies like Virgin who are purchasing NHS patient care now. This is a trend that will continue. As long as they can show patient care is benefiting then they can apply."

But Davies accepted there was now a "need to open a debate on this".

He pointed out that a number of private companies - such as Bupa - already had access to some sensitive hospital data, although none had been able to link to GP records until now. He added: "I am not sure how helpful in the NHS the distinction between public and private is these days. Look at Dr Foster [which] is a private company that used data to show significantly how things can be improved in the NHS and revealed what was going wrong at Mid Staffs. The key test is whether the data will be used to improve patient care."

Campaigners warned many members of the public would be uneasy about private companies benefiting from their health data - especially when the spread of data will not be routinely audited. Phil Booth, co-ordinator at patient pressure group medConfidential, said: "One of people's commonest concerns about their medical records is that they'll be used for commercial purposes, or mean they are discriminated against by insurers or in the workplace.

"Rather than prevent this, the care.data scheme is deliberately designed so that 'pseudonymised' data - information that can be re-identified by anyone who already holds information about you - can be passed on to 'customers' of the information centre, with no independent scrutiny and without even notifying patients. It's a disaster just waiting to happen."

Booth said the five listed reasons data can be released for are exceptionally broad: health intelligence, health improvement, audit, health service research and service planning. He said: "Officials would have you believe they're doing this all for research or improving care but the number of non-medical, non-research uses is ballooning before even the first upload has taken place. And though you won't read it in their junk mail leaflet, the people in charge now admit the range of potential customers for this giant centralised database of all our medical records is effectively limitless."

NHS England said it would publish its own assessment of privacy risks this week and pointed out that one of the key aims of care.data was to "drive economic growth by making England the default location for world-class health services research".

A spokesperson said: "A phased rollout of care.data is being readied over a three month period with first extractions from March allowing time for the HSCIC to assess the quality of the data and the linkage before making the data available. We think it would be wrong to exclude private companies simply on ideological grounds; instead, the test should be how the company wants to use the data to improve NHS care."