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FEATURE

ARTIFICIAL INTELLIGENCE

Data, data everywhere: the challenges of personalised medicine

Can public trust in health record sharing be regained? Will clinicians end up frazzled data scientists? **Stephen Armstrong** examines healthcare's wrestling match with big data

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"One of the most important resources held by the UK health system is the data generated by the 65 million people within it," wrote John Bell, regius professor of medicine at Oxford University, in the government's life sciences industrial strategy published in August.[1]

"The development of platforms to enable de-identified health data to be appropriately used to research and develop technologies would be of great benefit to patients, to those managing the NHS, and to researchers attempting to develop new therapies or improve NHS care," continued Bell, who is also chairman of the Office for the Strategic Coordination of Health Research, which coordinates the research of the National Institute for Health Research and the Medical Research Council.

NHS records, he argued, are uniquely suited to helping develop powerful algorithms that could transform healthcare and seed an "entirely new industry" in diagnostics based on artificial intelligence (AI).[1] Bell's strategic goal for the NHS is to develop 50 separate programmes in collaboration with industry over the next five years, including large scale data analysis.

And yet—at a panel discussion organised by Stanford Medicine and the Royal College of Physicians that asked, "Are data and analytics the new medicine?" and just five days after Bell's strategy was published—experts from both sides of the Atlantic warned that serious problems lie ahead.

Issues with patient trust and technology

"Personalised medicine isn't overhyped," said Jem Rashbass, national director for disease registration and cancer analysis at Public Health England.

"It is spectacular when it works. It's important to find and identify the right people—and to do that you need molecular data and clinical data sets. But we have issues with patient trust, security, and technology to overcome first."

In theory, all patient and care records in the UK will be digital, real time, and interoperable by 2020, according to a 2015 speech by the health secretary, Jeremy Hunt.[2] All patients will be able to access their general practice records online in full, he has said, including allergies, drugs, blood test results, appointment records, medical histories, and all interactions with health and care services.[3]

In April, however, a report by health technology analysts Digital Health Intelligence[4] concluded that NHS hospitals won't be paperless until at least 2027.

And collecting data is causing stress for many clinicians, who say that their time with patients is suffering.

Data driven burnout

"More than 50% of physicians practising in the US are experiencing at least one symptom of burnout,"[5] said Lloyd B Minor, dean of Stanford University's School of Medicine.

"It's a national problem with a variety of causes—but the electronic medical record is the one most commonly cited."[6] At a medical technology conference in San Francisco in July, more than two thirds of doctors said that increased reliance on technology, such as electronic health records, served only to separate them from their patients.[7]

UK doctors agree. "15 years ago, when I was writing discharge summaries for my patients, I could write the summary in 10 minutes and send it on to their GP," said Giles Armstrong, a consultant in emergency paediatric medicine at London's Whittington Hospital. "Now my juniors are taking 45 minutes to input all the data from the admission. We're using all this medical manpower to input data."

Check-in at the airport

For Margaret Johnson, a consultant in respiratory medicine at the Royal Free Hospital in London and academic vice president at the Royal College of Physicians, technology is both the problem and the solution.

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"Sometimes I have four fields open on my screen when I'm talking to patients: I feel like the check-in desk at the airport," she said. "If there was an AI in the room—like Amazon's Alexa (a voice activated digital personal assistant)[8]—it might be able to record and transcribe the conversation without the doctor having to endlessly type, or retrieve and open x rays with speech commands."

Some US hospitals have considered using Alexa for transcribing medical notes,[9] but the software does not meet legal standards for manipulating patient health data.

Clinicians may not find AI is entirely on their side, however. "If you have junior doctors working with AIs analysing x rays to the same standard as a consultant, you will get care that's better: faster and cheaper," said Sam Smith, spokesperson at Med Confidential, which advocates for privacy of medical data. "To train an AI, you don't need everything, you just need enough. But what researcher ever said they didn't want more data?"

DeepMind undermined public trust

In the UK, several high profile data breaches have helped undermine public trust. Rashbass cited the 26 million GP records made accessible to strangers[10]; the Information Commissioner's Office (ICO) fining an HIV clinic £180 000 after it released data on 781 of its patients[11]; and the WannaCry ransomware cyberattack in May that shut down NHS computers across the country.

But it is the controversial deal between Google's AI subsidiary DeepMind and the Royal Free Hospital in 2015[12] that has caused the most harm, "because we tried to commercialise personal confidentiality without personal consent or societal endorsement," Rashbass said.

In July, Elizabeth Denham, the information commissioner, found that the Royal Free hospital did not comply with the Data Protection Act when it supplied the medical data of some 1.6 million patients to Google DeepMind to help the company develop an app, called Streams, that collates and analyses test result data to spot patients in danger of developing acute kidney injury on the ward.[13]

In February, the hospital published early data for 26 of its doctors and nurses using Streams, with the app alerting them to an average 11 patients at risk a day.[14]

"The project did immense good," Johnson said. "The renal team were there before the team looking after the patients knew anything was wrong. I'm sure that almost none of the patients would mind their data being used for that."

But the ICO disagreed. "It's welcome that the trial looks to have been positive," Denham wrote in July.[15] "Some may reflect that data protection rights are a small price to pay for this. But the shortcomings we found were avoidable. The price of innovation didn't need to be the erosion of legally ensured fundamental privacy rights."

Privacy impact assessments

Denham urged NHS trusts to carry out privacy impact assessments during planning for a new innovation or trial and to ensure any processing of personal data is legal. "Just because evolving technologies can allow you to do more it doesn't mean these tools should always be fully utilised," she said.

"In this case, we haven't been persuaded that it was necessary and proportionate to disclose 1.6 million patient records to test the application. You should consider whether the benefits are likely to be outweighed by the data protection implications for your patients."

In June, DeepMind signed a five year deal with Taunton and Somerset NHS Foundation Trust.[16] As well as being used to identify possible acute kidney injuries, the trust's Musgrove Park Hospital plans to use Streams as an electronic patient record of all relevant patient information, including radiology and blood tests.[17]

As part of its privacy impact assessment in April, the trust decided that "as patient data will be used for the purposes of direct care, patient consent will not be explicitly sought."[18] It also said that it would not be feasible.[18]

For Rashbass, this doesn't go far enough. "Patients have anxieties about the misuse of their data, especially when a commercial company is involved," he said. "We have damaged patient trust. It is a very difficult process to reverse. We need to go back a step, say we got this wrong, and then work with an appropriate group of patients and the public to determine value and risk."

In one attempt at redress, in August organisations including Diabetes UK, Arthritis Research UK, Cancer Research UK, the British Heart Foundation, and the Wellcome Trust launched an advertising campaign about the importance of sharing data from patient records with researchers.[12]

US patients are keener to share

According to Euan Ashley, professor of medicine at Stanford University, "there's a difference between patients in California asking what value their data can bring compared with UK fears about privacy and data.

"Over 45% of Americans have had some sort of breach of health records, but when people understand the benefits to them and their families they are happier to share."

In both the US and the UK, data sharing is hampered by incompatibilities among different systems. Attempts to overcome this have faltered; the NHS's attempt at a single centralised system to connect all care providers (the NHS National Programme for IT) cost £12bn (€13.6bn; $15.9bn) before it was cancelled in 2011.[19]

"The data are Balkanised, even in different systems within one provider," explained Rashbass.

"We currently have remarkably fragmented sources of data with multiple gatekeepers, because of the politics and culture of the health service," agreed Charlie Davie, managing director at NHS innovation group UCL Partners. Davie cited new initiatives for data collection, such as the Medical Research Council funded institute for bioinformatics Health Data Research UK, which was set up to collate multiple sources of data.

"To some degree, we're hoping to allow data to fulfil the role of an ideal village GP—able to take into account someone's family problems, if they live near a factory, if they're recently unemployed—just through knowing about their life," said Davie.

"Precision medicine is great, but precision prevention is more important. If we can get data about people's risk factors we could make and commission bespoke services before they develop problems in the first place. That has to be done as a co-design with communities and populations to ensure we're not creating a Big Brother society."

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