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Government's new NHS data plans welcomed by open source advocates, shunned by privacy experts



John Leonard

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'Data saves lives' report meets with a very mixed reception

The Department of Health and Social Care (DHSC) has released a draft policy document which lays out its plans for the use of patient data in the health and social care system

Entitled *Data saves lives: reshaping health and social care with data*, the foreword by Health Secretary Matt Hancock lists many ways that health data has helped tackle the pandemic, including creating the NHS app and the Gov.uk coronavirus dashboard.

The DHSC wants to understand how data can be used to drive understanding and transparency, the report says. It wants to "make appropriate data sharing the norm and not the exception across health, adult social care and public health", and to build the right foundations - technical, legal, regulatory - to make that possible.

And the report says it wants to bring "people closer to their data", making a commitment that "technology is in place to enable everyone across England to have easy access to their own health and care data and promises transparency about who is accessing their data and why."

It goes on to state a desire to integrate "local care systems with a culture of interoperable by default" and use data of those using adult social care services to improve those services.

Part of that will be making NHS software development open source by default, a measure that was welcomed by Amanda Brock, CEO of OpenUK.

"The NHS is a long-term user of open technology and the commitment to an open approach around NHS developments and infrastructure in both data and software is laudable," she said.

"Public money is invested into these projects, and so the results should be open, re-useable and understandable to all. Using open source licences for any new developments around software is a great step to provide this open-ness and of course essential to building sustainable technology."

Martin James, vice president EMEA of open source database firm Percona, called the move "a great step forward".

"With so much potential for data to improve healthcare, this is an exciting time for open source, and it is great to see the support demonstrated by the UK government," he said.

However, James cautioned that it would take a lot of managing, advising the NHS to set up an open source programs office (OPSO) specifically for this purpose.

But while the stated aims - greater transparency, scope for innovation a more joined up NHS, more data for research - are hard to fault, data privacy and consent must be at the heart of the strategy if it is to gain public trust.

Phil Booth, coordinator of medConfidential, is sceptical about the government's intentions, saying in a [statement](#): "Boris Johnson's Government says 'Data Saves Lives', but buried in the small print is a rather more dubious deal: 'If you want better care from your data, you must let us sell it!'"

Noting that the delayed 'GDPR' GP record extraction scheme, which was roundly criticised for poor communications and for consent being opt-out rather than opt-in, receives barely a mention, Booth said the end recipients of personal health data are still not clear.

"For over a year now, NHSE/X [NHS England and NHSX, a digital quango that is not part of the NHS] have refused to publish the list of projects and organisations to which they release data. The government claims benefits, but shows none at all - if this is 'progress', then evidence, transparency and good governance are clearly out of the window," Booth said.

Doctor Helen Salisbury, a GP and columnist for medical journal the *BMJ*, said in an interview with [GMB](#) today that the issue of patients consenting to their data being shared has not been adequately addressed.

"I do have concerns that they are mixing up two things," she said.

"One is the sharing of data between people who are actually directly caring for the patient, and that clearly is a good idea... But the second thing that they're talking about is collecting all the data into one place at NHS Digital in a big database, and making it available on application to researchers... and also pharmaceutical companies and other government departments."

Salisbury said she wanted to see the abilities for patients to choose what their data is used for.

"I think it needs a clear explanation to patients, and also clear choice, because we've been told this is about giving patients control. And that's precisely what we need, with patients needing a choice to say, 'I do want to share for my care, but I don't want it to go to pharmaceutical companies', for example."



Marcus Baw @marcus_baw · Jun 21, 2021



Replying to @marcus_baw

It really feels tone deaf of Gov't to push ahead with all this reform while GPs are completely inundated, and we aren't yet out of the pandemic by a long way.

Now is EXACTLY the 'time to slow down or pause for breath'



Marcus Baw
@marcus_baw

The rush to deregulate and assume the right to have patient data is unseemly and antithetical to the foundations of the medical profession.

Hippocrates would be spinning in his grave.

Imagine being the first country to completely break the most foundational rule of Medicine.

9:33 PM · Jun 21, 2021



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Marcus Baw, who chairs the Royal College of General Practitioners Health Informatics Group, said the plan - one of a number of reports on data sharing to have been published in a short space of time (with the Goldacre review into health data for research to due report shortly) - smacks of the government's desire to monetise health data.

"The rush to deregulate and assume the right to have patient data is unseemly and antithetical to the foundations of the medical profession. Hippocrates would be spinning in his grave. Imagine being the first country to completely break the most foundational rule of medicine," he tweeted.

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