

Cultural shift needed to keep trust in use of patient data by health technology

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A radical culture change in the NHS, and across the health data and medical technology community, is needed to make sure that the NHS can deliver the benefits of new health technologies that use patient data for care, and to retain public trust, says a new report¹ from the Academy of Medical Sciences published today.

The [report](#) outlines principles that must be adopted by the NHS and industry, including medical [technology](#) developers and regulators, so that [patients](#) can benefit from digital information about them being used in smarter, more joined-up ways to revolutionise healthcare and support life-saving research.

Putting into action the set of principles set out in the Academy's report will enable organisations, including the NHS and medical technology companies, to respect and protect the privacy, rights and choices of patients and the public. The principles will help provide safeguards to support [patient data](#) being used in ways that are fair, and will enable all NHS patients to benefit from the use of health technologies using patient data.

Health technologies that are becoming increasingly important include wearable devices, mobile phone apps and intelligent monitoring devices. Smart insulin pumps for diabetes, artificial intelligence assisted pregnancy ultrasound scans, and houses designed with smart technology to monitor and support dementia patients and their carers, are examples in the report where patient data are already being used to develop health

technologies.

The report highlights the potential of the NHS to become a world leader in the use of patient data for technologies to improve healthcare, and emphasises that patients and the public expect the NHS to keep control of patient data. It calls for action to be taken so the NHS can evolve into a system that learns from itself, feeding back [digital information](#) about patients and using technology to support, not replace, face-to-face healthcare. The NHS must also share in the wider benefits of contributing patient data for these new technologies.

Professor Carol Dezateux FMedSci, Chair of report Steering Group and Professor of Clinical Epidemiology and Health Data Science, Queen Mary University of London, said:

"Health technologies that use patient data have huge potential to improve our health and wellbeing. We are already seeing the development of wearable monitors linked to automated treatment that are revolutionising the lives of patients with long-term conditions such as diabetes. Our workshops with the public emphasised that they want to see the NHS deliver on the potential of data-driven technologies, giving better and safer health care for all."

A steering group of 12 experts, including leading clinical, biomedical and social scientists, legal, ethical and technology specialists, oversaw the development of the principles. The group based their discussions on a programme of dialogue commissioned from Ipsos MORI that explored public, patient and healthcare professionals' views on the future use of technologies that use patient data. Workshops were held in Cardiff, Sheffield and London, involving around 100 people from a wide range of backgrounds, some with long- and short-term mental and physical health conditions, and healthcare professionals including GPs, nurses, paramedics and hospital consultants. The Ipsos MORI report³ of these

workshops is also published today.

A follow-up meeting gave an opportunity for the NHS, regulators, funders, policy makers, data and medical technology companies and the pharmaceutical industry to contribute their views⁴. This Academy policy project was partly funded by a grant from the UK Department for Business, Energy and Industrial Strategy.

Professor Carol Dezateux added:

"The Academy report builds on what the patients and the public have told us matters most to them. By putting the public's expectations at the centre of the use of data-driven technologies, the NHS, scientists, researchers and developers will be able to work together to deliver maximum health benefits for all, while keeping [public trust](#)."

Dr. Kambiz Boomla, member of report Steering Group, GP in Tower Hamlets and Clinical Senior Lecturer in the Clinical Effectiveness Group, Queen Mary University of London, said:

"The National Health Service gives us the opportunity to join up all the information about patients wherever they are seen. Imagine a future where an appointment didn't start with repeating your medical history and medications because your health care professional has all that information up-to-date and accessible to them."

"Recently, at my GP practice in East London, an elderly lady with dementia and her daughter came to see me. Her daughter explained that her mother had been discharged from hospital after a fall when she had been told her mother's brain scan showed she had a blood clot on the brain. As she was becoming more confused her daughter was worried this was to do with the blood clot. In two clicks of my mouse, I was able—from the GP surgery—to see the brain scan report. It told me the

clot was old and was smaller than it had been. As a result, I didn't need to send her mother for another scan and could reassure her daughter immediately. Joined-up patient data improve patient experiences and healthcare as a whole and saves us all time in wasted trips and tests.

"My patients don't want to be told 'the robot will see you now': they want to see a human. However they understand that new technologies can allow patients and their carers to manage their own health better and free up clinician time for direct care. That is the future they want us to deliver."

Professor Lionel Tarassenko CBE FREng FMedSci, member of report Steering Group, Professor of Electrical Engineering and Head, Department of Engineering Science, University of Oxford, said:

"We are already seeing digital technologies that empower patients to manage their own health, for example by monitoring their own condition at home. Technology will only evolve and get more sophisticated to have a bigger impact on healthcare in the NHS in the next ten years.

"If we are going to reap the benefits of these advances, we must act now. We need to see a widespread increase in digital health literacy throughout the NHS, with the full involvement of patients and the public. We also need to think carefully how we regulate and evaluate digital health products, especially when they include artificial intelligence, so that healthcare professionals and patients know that they are safe and reliable, and improve patient outcomes."

Professor Sir Robert Lechler PMedSci, President of the Academy of Medical Sciences, said:

"This report is based on high-quality, in depth conversations with members of the public, hospital doctors, GPs and nurses. We are calling

for the NHS, regulators, industry and other key stakeholders to work together to adopt the principles set out in this report to make sure that patient data is used in a fair, transparent, safe and effective way.

"This report also highlights the opportunity for the NHS to evolve into a world-leading learning health system, where every piece of patient information is collected and learnt from using smart technologies, to improve the [health](#) of the population."

Provided by Academy of Medical Sciences (UK)

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