Using patient data for patients' benefit

Full partnership will help ensure that data really does save lives

Amitava Banerjee,[1] senior clinical lecturer, David Mathew,[2] patient and public panel member, Katherine Rouane,[3] patient

[1]University College London, London, UK

[2]University of Bedfordshire, Luton, UK

[3] London

Correspondence to: A Banerjee ami.banerjee@ucl.ac.uk

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The #datasaveslives campaign underlines the importance of health informatics research to public health.[1] There are many examples of "data driven" healthcare across the UK and elsewhere, such as increased use of machine learning in early diagnosis of tumours and automated risk prediction tools for cardiovascular disease built into electronic health records (EHR). Innovations are often labelled as "personalised" and "patient centred,"[2-4] but since all health data are personal and about patients, what does the terminology actually mean, and do these innovations benefit patients?

Routine healthcare data worldwide are designed for delivering care. Information from patients or health professionals may be recorded in written, spoken, or electronic formats, depending on the setting. Electronic health data come from a diverse range of sources, including health management information systems, disease surveillance, registries, hospital coding systems, pharmacies, laboratories, questionnaires, government coding systems, insurance claims databases, social media platforms, and other third parties such as mobile phone companies.

From banking and online shopping to booking holidays, other sectors are well ahead of healthcare in their use of technology and routine data for the benefit of the end user. The Wachter review of NHS information technology recommended better links between local and national health data to improve standards of care, as did the Caldicott review, with the proviso of improved public trust in data security.[5][6]

Worldwide however, government policy initiatives have focused largely on "paperless" records and cybersecurity, with little mention of the use of data for the direct benefit of patients . Patient benefit can be variably defined by research evidence of better outcomes, added value, quality improvement, increased safety, enhanced patient experience, or a combination of these. Add in the heterogeneity of routine health data, and the magnitude of the task becomes more apparent.

Much of the international discourse and media coverage around health data hinges around data security, privacy, and regulations. For example, in Europe, the General Data Protection Regulation intends to strengthen and unify data protection for individuals, committing organisations involved in healthcare to be transparent about how they use data.[7] Pressure is on hospitals and universities to optimise their use of routine data, but patients will be empowered only if they are involved in defining "patient centredness," a term often contrasting with their experiences as faceless hospital numbers in a busy clinic or on a crowded ward.

Some patients do not want their information electronically gathered or stored because of lack of clarity about future use and concerns about security (magnified by the recent NHS cyberattack). To many the digital world, social media campaigns, and hashtags are meaningless, intimidating, and a barrier to realistic engagement.[8] When patients neither know nor understand, they are unlikely to consent to use of their data. However, if patient benefit is explained, many will be happy to cooperate and expectations of risk, benefit and harm will be better managed.

As uptake of electronic health records increases, there are many opportunities to enhance use of routine healthcare data. Real time application in clinical decision making will improve quality of care, including through development of better risk prediction models, better monitoring of patient outcomes, and the "right data for the right patient at the right time."[9] Use of routine data can also reshape health and social care research by reducing costs[10], increasing generalisability (by incorporating real world populations), and boosting the translation of research into practice. In the UK, this vision is reflected in several strategic publications by government, research councils, and charities.[5, 6, 11, 12]

If efforts in many health systems to improve interoperability and to link data across sources and sectors are successful,[10] there is unprecedented scope to build "learning health systems.[13] These integrate and facilitate data capture and use across research, evidence based guidelines, and clinical care, ultimately increasing the value of routine data for individual patients.

Proper involvement and engagement of patients in the whole process, including access to data and user centred design of systems and research, has the potential to change the culture of data usage in healthcare, to reduce waste and redundancy, and to rebuild trust.[4 14 15] Finally, the optimism of data-driven care, whether in precision medicine or clinical decision support tools must be evidence-based and that evidence should be patient-centred.

The most patient-centred approach to data usage is to make best use of available data in a way that patients and the public want and expect. However, there seems to be a mismatch between clinicians and patients in the perception of benefit. A change in culture, and a clear strategy of patient engagement is necessary to reflect the beliefs and values of patients without creating an excessive burden for patients or clinicians, and ultimately to ensure that data really does save lives.

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