



Big Data for Better Outcomes

Report of an expert panel
discussion on:
Patient Engagement in Big Data
Initiatives

APRIL 2018, LONDON

Background

The Patient Engagement in Big Data Initiatives seminar was hosted on the 24th of April 2018 by the London School of Economics and Political Science Department of Health Policy and Imperial College London Institute of Global Health Innovation on behalf of the Big Data for Better Outcomes (BD4BO) initiative. The presenters were Kyle Bozentko, Executive Director of the Jefferson Center; Harpreet Sood, Associate Chief Clinical Information Officer at NHS England; Sarah Fox, Public Engagement and Involvement Officer at the Health eResearch Centre - Farr Institute; and Helen Bulbeck, Founder and Director of Services and Policy at braintrust. The panellists were: Brendan Krause, Vice President at OptumLabs; Sarah Deeny, Assistant Director at the Health Foundation; Chris Carrigan, patient advocate and researcher at Leeds Institute for Data Analytics; and Matt Murray, Research Engagement Manager at the Alzheimer's Society UK. The meeting was chaired by Søren Rud Kristensen, Senior Lecturer in Health Economics at Imperial College London.

In the first half of the seminar, the speakers presented on the challenges relating to patient engagement from four perspectives – patients, public bodies, health care researchers and developers of patient engagement methodologies. In the second half of the seminar, four panellists reflected on the challenges presented by the four speakers.

Summary of topics discussed

Communicating to the public

It was widely acknowledged by the panel members that the benefits of sharing and using patient data for research are poorly communicated to the public. Big data provides an opportunity to expand the idea of what it means to be a patient in health research - researchers can potentially change the paradigm of current research from studies that assess patients over a short fixed period of time to following patient journeys in the health system throughout their lives. In the context of rising chronic diseases and patients with multimorbidity, this research would have a positive impact on public health but they must be clearly communicated.

It was noted that the key challenge lies in communicating the health system level benefits of big data. It is straightforward to highlight the benefit of a particular therapy to a specific group of patients that will be directly impacted. However, convincing the public of population level health benefits based on average effects requires a more coordinated effort. A key factor would be to show how investments made to develop data infrastructure and analytics in the UK National Health Service (NHS) will ultimately help improve its sustainability and longevity as a whole. In addition, a clear distinction should be made between commercial and system-level benefits. If researchers, industry and health care decision makers communicate this message effectively, the public will be more likely to support big data initiatives.

Democratisation of data

The panel members viewed the democratisation of data in health care, where patients collect and use data for their own health and the health of their community, as a positive development. In recognition of this, researchers should give patients a voice and understand their health priorities and actively work with them throughout the research process. The current discourse

on data as something that is harvested, analysed and eventually presented to patients could be changed to include patients as willing contributors of their data that actively collaborate with researchers.

A potential challenge on democratisation is to reduce the currently embedded inequities in the health care system. Patients actively engaged in using their data are likely to be more technology literate, younger, living in less deprived neighbourhoods and of higher socio-economic status. The panel members agreed that it is important to ensure that these inequities are not propagated at the health care system level as the NHS encourages patients to engage with their own data to support self-management.

Evolving engagement methodologies

The panel members discussed the need to further develop patient engagement methods. Reporting on the impact and effectiveness of new engagement methodologies must improve to ensure their wider uptake within the research community. In addition, these methodologies should reach grass roots communities – for example through community centres - to gain deeper insights into how patients would like to engage in research initiatives.

The participants made a case for viewing patient involvement and engagement through the framework of altruism. It was argued that most patients would be willing to provide data, as long as the end goal for using the data was clearly defined. Data banks were suggested as suitable tools to allow patients to “donate” data, and these data banks would be particularly useful for smaller communities with very specific needs (e.g., rare diseases), giving them an opportunity to take the lead in driving the research agenda. However, since data banks don't capture the entire population, their value will be somewhat limited. Therefore, for the wider population, health systems should develop expectations in people's minds that patient data will be used in a clearly defined manner for the greater benefit of society. Importantly, similar expectations should be made from researchers using the data to be transparent and clear about the end goals, particularly if commercial applications are envisioned.

Data analytics

Further work is need to ensure that the data that are used and analysed are relevant to patients and the wider population within the health care system. The need to measure outcomes that are important to patients was discussed. It is easier to gather clinical data but measures on quality of life are substantially harder to collect. This deficiency can be particularly pronounced for some diseases like dementia, and researchers and health care systems must be mindful of this when developing big data initiatives.

Health care systems must also develop analytics that account for selection biases that might be introduced when utilising data. There is a possibility that the data currently available only captures people that are easier to reach, and as a result, does not capture important population level variations. Taking measures to improve the relevance of data analytics will have a positive effect on patient engagement.

Consent process – understanding the trade-off

The speakers raised questions about the current capacity and tools in the UK to keep track of what patients give consent to. As the sources of health data exponentially increase, the NHS and the public must weigh the pros and cons of a national opt-in versus opt-out strategy for patient data use. Cultural perceptions around data sharing will play a pivotal role in this discussion but in general, what people are willing to risk from sharing data will be lower if they do not perceive a direct benefit to them. Therefore, the impetus is on researchers and health care providers to provide assurances to the public that their data would be used in a safe and ethical manner and that this will not negatively affect them in the future.

Future prospects

The speakers recognised that managing the digitisation of the health care system will be one of the biggest challenges facing the NHS in the next decade. As computational capabilities advance, machine learning and artificial intelligence will play a prominent role in health care research. The scope of data required for this research will continue to widen. Thus, developing a cohesive governance framework in anticipation of these future requirements would be vital to ensure the ethical, safe and transparent use of patient data. Such a framework should address issues of data ownership, control and security. For commercial applications, the framework should establish requirements to clearly define end goals and objectives for products that are developed using NHS data – who will benefit and how some of these benefits can be re-invested in the NHS to benefit the wider patient population. A cohesive governance framework is also an opportunity to define a narrative and set expectations for the use of patient data in collaboration with patients – for example, by including a multi-stakeholder perspective on sharing data based on altruism and reciprocity. The framework should also establish best practices on patient involvement and engagement in research – for example, approving research proposals only if there are clinical and patient advocates supporting the project. The potential pitfalls and risks could also be transparently defined to manage expectations and increase trust between patients and researchers.