COMMENTARY

India and the United Kingdom—What big data health research can do for a country

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Abstract

Introduction: Big data and growth in telecommunications have increased the enormous promise of an informatics approach to health care. India and the United Kingdom are two countries facing these challenges of implementing learning health systems and big data health research.

Analysis: At present, these opportunities are more likely to be exploited in the private sector or in public-private partnerships (eg, Public Health Foundation of India [PHFI]) than public sector ventures alone. In both India and the United Kingdom, the importance of health informatics (HIs), a relatively new discipline, is being recognised and there are national initiatives in academic and health sectors to fill gaps in big data health research. The challenges are in many ways greater in India but outweighed by three potential benefits in health-related scientific research: (a) increased productivity; (b) a learning health system with better use of data and better health outcomes; and (c) to fill workforce gaps in both research and practice.

Conclusions: Despite several system-level obstacles, in India, big data research in health care can improve the status quo, whether in terms of patient outcomes or scientific discovery. Collaboration between India and the United Kingdom in HI can result in mutual benefits to academic and health care delivery organisations in both countries and can serve as examples to other countries embracing the promises and the pitfalls of health care research in the digital era.

KEYWORDS

health informatics, India, research, UK

1 | INTRODUCTION

The potential of health information systems to transform health care in all countries, regardless of income status, is not in question. The term, "learning health system," was coined by the Institute of Medicine in 2006 to describe information flowing easily between health care professionals, researchers, and policymakers to minimise waste and to avoid patient harm.[1] Big data (defined by the "7 V's": volume, velocity, veracity, variety, volatility, validity, and value), combined with growth in telecommunications, have increased the enormous promise of an informatics approach to health care.

However, even in high-income nations, there are few examples of truly integrated and continuous use of data in learning health systems. There are universal threats to "big data health research," which are

heightened in low-income settings, including lack of human and financial resources. India and the United Kingdom are two countries facing these challenges. The learning healthcare system (LHS) framework needs three core components to function at micro or macro levels: foundational elements; care improvement targets; and a supportive policy environment.[2,3] A fourth component, "active and continuous stakeholder and community engagement to improve the quality and value of health care within a community,"[4] has been added.

In this review, we will examine current and future efforts in both the United Kingdom and India to create these building blocks for LHS and the hurdles each country is facing. Collaborative approaches may be synergistic in improving the applications of big data in health care across two countries with a long history of joint scientific endeavour.

2 | FOUNDATIONAL ELEMENTS

Meaningful use of health data, and therefore an LHS, cannot occur even in one hospital, let alone across a country, without good data flows, for which (a) adoption of certified electronic health records (EHRs), (b) secure mobility of health information, and (c) reporting of quality measures are necessary.[5] In the United Kingdom, there has been a universal uptake of EHR in primary care, but adoption in secondary care has been more challenging, despite national implementation programmes such as the National Programme for IT[2,6] and the current "Paperless 2020" initiative.[7] In the United Kingdom and the United States, barriers to adoption have included cost and failure to demonstrate benefits for patients and clinicians.[2,8] Establishing EHR is necessary but not sufficient; buy-in from and training of health professionals are required for complete data capture. In addition to these factors, the scale and the diversity of providers and health care settings make roll-out of EHR even more difficult in the Indian context, where usability and speed of EHR are of far greater importance because of much higher patient turnover.[9] Although EHRs are available in many hospitals,[10] these tend to be private and specialist institutions. National and even state-level coordination of EHR has been elusive.[11] The high penetration of telecommunications and high use of mobile phones, mean that "mHealth," and mobile phone-based EHR may have greater traction than centralised EHR, although the former is mainly in research.[12] As blockchain and related technologies mature and undergo testing, there is potential for storage and processing of EHR data in a more efficient manner,[13] particularly in India.

Secure mobility of health information requires infrastructure and interoperability of information systems. Integration of real-time research data into the EHR is possible[14] but infrequent in the United Kingdom, sometimes leading to duplication of efforts in the form of disease-specific registries and audits (eg, National Institute of Cardiovascular Outcomes [NICOR][15] and National Cancer Research and Analysis Service [NCRAS][16]) and retrospective secondary data usage. The TRANSFoRm project, which was funded by the European Union and has developed an infrastructure for the LHS in European primary care, shows that interoperable standards for EHR are possible cross-nationally[17] but remains an exception rather than the rule in the United Kingdom. Interoperability is an issue in terms of IT systems within any given hospital or health care setting and standards used. Lack of interoperability between different

data resources throughout the patient pathway is a major impediment to informatics research. The Indian government has issued national EHR standards,[18] but a burgeoning private sector[19] and lack of data sharing in health care and research are further hurdles. Even in rural Indian settings, EHR can be deployed,[20] and the potential of real-world evidence is increasingly being recognised.[21] Despite the national EHR standards, low EHR adoption across private and public health care providers and low interoperability across technology developers and academics are significant issues.

Quality of EHR data is determined by multiple factors, including training of staff, acceptability of the EHR system to staff and patients, adequate physical and time resources, and adoption of standards, both for EHR and outcome measures. The quality of data ultimately influences the generalisability and applicability of research. In the United Kingdom, multiple disease-specific registries have been established, capitalising on the use of high-quality point-of-care data,[22,23] but there are still many opportunities to improve the validity of EHR data and its use.[24] Routine health data in low-income settings are important for evaluations, detailed measurement of implementation strength, primary health care organization, operational research, continuous quality improvement, and resource allocation.[25] Although there is a potential for large-scale EHR data to be transformative in terms of use in research and practice, it is not realised at present in India, where routine data are seldom used because of its suspect quality and the extent to which it is captured electronically.[19] For example, like many countries in greatest need of health metrics, India struggles to collect accurate statistics on births and deaths.[26] Despite the mandatory registration of births and deaths since 1969, only 86% of births and 70.9% of deaths were registered in 2013.[19] Until improved EHR data are available regionally and nationally, research registries[27] and modelling data from sources such as the Global Burden of Disease Study[28,29] will need to be used for research and practice.

3 | CARE IMPROVEMENT TARGETS

Clinical audit and research are related, but distinct entities with the former concerned with quality improvement, and the latter focused on science. Both audit and research are dependent on high-quality data and culture. An LHS will only be formed where EHR data are being used to improve health care with regular, if not continuous, review of targets. In the United Kingdom, EHR data are widely used for audit and research across disciplines and health care settings.[30-32] The standards and appropriate targets for improvement must be specified and agreed by stakeholders.[33] Audit and quality improvement is incorporated into the postgraduate training of most British doctors.[34] In addition, increased emphasis on informatics training in undergraduate and postgraduate health professional curricula will result in more staff with the ability to analyse and use the data. In India, the number and variety of quality improvement registries[35,36] and trials[37] are increasing, including involvement in international studies.[38] However, as already stated, unless EHRs become the norm rather than the exception, and until standards are adopted, India cannot move towards a true LHS at regional or national level. Moreover, compliance in reporting and implementation of local measures are

crucial, as illustrated by increasing clinical trials registration in India in recent years.[39]

4 | SUPPORTIVE POLICY ENVIRONMENT

In his recent review of health IT in England, Professor Bob Wachter issued a reality check to the National Health Service (NHS): "While there is great enthusiasm for using 'big data' to develop personalised approaches for individual patients ('precision medicine'), provide customised decision support to both clinicians and patients, and create 'learning healthcare systems (LHS),'[18] today all these goals are more promise than reality." Several important initiatives have been born out of this influential report. A Global Digital Exemplar programme is investing in leading NHS sites where outstanding digital innovation is occurring and developing in order to become role models for other institutions. The NHS Digital Academy will train and scale-up a cadre of professionals who will be able to take on leading HIs' roles in health organisations, eg, chief clinical informatics' officers and chief informatics' officers.[40] The newly formed Faculty for Clinical Informatics and the Federation of Informatics Professionals will formalise the roles and requirements for HI professionals. Across the United Kingdom, NHS "digital test beds," "innovation hubs," and "digital accelerators" are examples of new funding schemes to create a permissive environment for disruptive health care innovations. Finally, the Farr Institute of Health Informatics Research was established to increase research and capacity building in HI. Health Data Research United Kingdom (HDR-UK) has been established as a core-funded national institute to coordinate big data research in health care.

In India, the Public Health Foundation of India (PHFI) has established five academic arms—Indian Institutes of Public Health (IIPH). The school in Hyderabad has developed postgraduate HI programmes, with similar training activities are planned in the other IIPHs. The Indian Institutes of Technology is well known throughout the world for both practice and research in IT. Several cities in India have also become global hubs for IT start-ups and spin-outs, notably, Hyderabad and Bengaluru. "Digital India" is the national, government-led strategy to digitally empower Indian society, including health care, from EHRs to e-health.[41] Until now, the health care application of Indian IT expertise and capacity has been far greater in other countries than within India, whether in terms of staff (eg, IT consultants and software engineers) or services (eg, outsourcing of medical transcription and radiology reporting), although that may be changing. However, India currently spends below the World Health Organization (WHO) benchmark considered essential to secure basic health services ($34 per capita annually). It also has "mixed health systems syndrome" where the "public and private mix of health care delivery shows 'symptoms' of compromised quality and equity."[42] Reform will require measures within and outside the system, including IT. The poor public health care infrastructure and high relative inequalities in wealth, health, and access to health care in India represent hurdles and also opportunities for HI. At present, these opportunities are more likely to be exploited in the private sector or in public-private partnerships (eg, PHFI) than public sector ventures alone. In both India and the United Kingdom, the importance of HI, a relatively new discipline,

is being recognised, and there are national initiatives in academic and health sectors to fill gaps in big data health research.

India's personal identification programme issuing unique identifying numbers in the form of Aadhaar cards to all 1.2 billion of its citizens since 2010 illustrates the feasibility and the possibility well.[43] For example, the cards, numbers, associated biometric data, and the potential linkage to information from health and social care could result in step changes in reliability, collection, and use of data at country level. Universal health coverage[44] and Sustainable Development Goal[45] agendas are also likely to lead to greater harmonisation of EHR systems, data standards, and quality metrics.

5 | STAKEHOLDER AND COMMUNITY ENGAGEMENT

Perhaps the greatest challenge lies in convincing patients and the public of the value of big data research, to diagnosis, prognosis, discovery of new treatments, and health policy, to name a few,

at the same time as reassuring them of the security of that data. In the United Kingdom, lack of proper public engagement has been invoked as a contributory reason to failures of previous IT programmes, eg, care.data.[46] In India, although potentially to a lesser extent, similar concerns about privacy, data security, and ethics exist regarding EHR.[47] Whether service provision or research, inclusivity, accessibility, and equity are key themes, whether in the United Kingdom or India. If research or introduction of a new digital technology is perceived to widen the "digital divide" or existing health inequalities, then support from policymakers and public is highly unlikely.

The right legal and regulatory framework is a prerequisite for a well-functioning LHS. In the United Kingdom and Europe, the General Data Protection Regulations (GDPRs) are changing the playing field with respect to legal requirements for information security and transparency.[48] On the other hand, concerns have been raised that legal provisions for data protection in India are not sufficiently robust.[49]

Personal health records are one way in which individuals can be empowered to use their own health data. In the United Kingdom, NHS Digital is prioritising roll-out of access to personal health records with an interactive map of where they are available around the United Kingdom.[50] In India, there is no government policy for personal health records to date, but as universal health care is planned and implemented, the potential is clear.[51] Giving autonomy to localities and regions to use local and regional data in decision-making is an important means of illustrating the value of health data research (Avan, 2016 #2444[52]; India State-Level Disease Burden Initiative Cancer, 2018 #2415[29]; Newton, 2015 #2348[53]).

6 | CREATING THE RIGHT DATA ENVIRONMENT

Comparative examination of the four components (foundational elements, care improvement targets, supportive policy environment, and stakeholder and community engagement) of an LHS in the United Kingdom and India shows that although these two countries are at different stages in their journeys and face different challenges, there can be shared

learning. It is clear that all four components are necessary to have an LHS, which capitalises on available data for research. Overall, India cannot be an LHS without the functional elements, ie, widespread use of EHR and implementation of data standards, and the other factors will gain importance once this is established. In the United Kingdom, there are still significant barriers to universal EHR adoption, especially in secondary care, but the immediate challenge may lie more in stakeholder and community engagement. Just as the problems are not the same in both countries, the solutions will necessarily have to be different. For example, blockchain and mobile phones may be more pertinent to EHR roll-out in India than the United Kingdom.

The challenges are in many ways greater in India, but the following three potential benefits in health-related big data research will also be greater. First, there will be increased productivity because data, publications, and scientific insights can be developed in a timely fashion. India does not yet have the biomedical scientific output expected of a country of a billion people with growing economic and scientific influence, whether measured by publications or international grant funding.[54] Organisations of large data sets, big data analytics, and access to that data are at least part of the problem. In the United Kingdom, some of these issues are being tackled by open or standardised access to research databases, eg, UK Biobank and Clinical Practice Research Datalink, but secondary use and reuse are relatively uncommon in the Indian context. Another solution is moving the culture in both health and IT sectors towards one where academic outputs are valued on a par with financial and health outcome targets.

Second, a culture where research and clinical practice work together can create an LHS with better use of data and better health outcomes. Of all the dilemmas in HI research, this is perhaps the greatest in holding back the development of LHS, whether in India or the United Kingdom. On the other hand, implementation of HI in Brazil (eg, use of telehealth in connecting clinics with hospitals), Kenya (eg, telephone consultation service for HIV care), and South Africa (eg, use of mHealth application for treating TB) illustrates what is possible when national priorities and local needs are aligned, even with budgetary constraints.[55] However, none of these projects have scaled-up beyond pilot projects, and that will be required, especially in the Indian context.

Third, big data health research can help to fill workforce gaps in both research and practice, by facilitating training and helping in service planning. Within clinical and non-clinical workforces, there are skills' shortages in IT, data analytics, and other core areas, in both high-income and low-income settings. Particularly in India, where there is existing and new infrastructure, eLearning, and IT, should be further used in training, empowering, and supporting health professionals where numbers of teachers and trainers are a major constraint.[56]

Despite several system-level obstacles, in India, big data research in health care can improve the status quo, whether in terms of patient outcomes or scientific discovery. Lessons learned in the United Kingdom, including large-scale implementation of EHR or HI research initiatives such as HDR-UK, can be used to increase the likelihood of success when similar projects are advanced in India. Collaboration between India and the United Kingdom in HI can result in mutual benefits to academic and health care delivery organisations in both countries and can serve as examples to other countries embracing the promises and the pitfalls of health care research in the digital era.

CONFLICT OF INTEREST

A.B. has been an advisory board member for Novo Nordisk and Boehringer Ingelheim. Remaining co-authors have no conflict of interest.

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