Better care through better use of data in GP–patient partnerships

In 1988 Julian Tudor Hart prescribed ‘A new kind of doctor’, calling for data-intensive, community-responsive primary care.1 He argued for a realignment of primary care with the needs of populations rather than individuals; and for greater emphasis on prevention.1 These principles are largely ingrained in modern UK general practice: clinical commissioning groups (CCGs), the Quality and Outcomes Framework (QOF), and audit all require primary care to consider information about practice populations; and disease prevention is routine practice. The new era of ‘big data’ is likely to escalate further such approaches but may also change the conversation of primary care and population focus of primary care could be weakened through inequalities: the better off and the healthy may well find it easier to engage with the digital age.

TWO NEW KINDS OF DATA

We see two main types of new ‘big data’ impacting on primary care in future: active and passive. Active in situations where the user is consciously producing health-related data, for example, by interacting with apps, and passive where they are not, for example, accelerometer data from smartphones or smartwatches.

There is a plethora of apps already available, although relatively few that have been validated to provide credible data. The UK NHS is currently building a library of ‘approved’ apps, although the number of apps being developed is likely to outstrip the capacity for regulation and accreditation in the UK or other countries. Consequently, some apps, which are being used for both clinical research and care, have developed their own validation paths. In the UK, ClinTouch (www.clintouch.com) uses validated questions and methods to support patients with psychosis to monitor their symptoms, and alert their clinical team if a problem is suspected; Cloudy with a Chance of Pain (www.cloudywithachanceofpain.com) collects symptom data from patients with arthritis directly from their smartphone to investigate the association with weather. PatientView (www.patientview.org) is a website that enables patients with kidney disease, inflammatory bowel disease, or diabetes to view their medical records, and add symptoms and patient-reported outcomes. Internationally, Singapore’s Ministry of Health provides a range of web-based and smartphone apps for patients (www.healthhub.sg), and in primary care, Apple Health enables patients to access their electronic medical record and input physiological measurements (compatible with various different vendors). Apps can also provide evidence-based treatments recommended by clinical guidelines, such as cognitive behavioural therapy (CBT), which provide data on usage and adherence.2

By contrast, passive data may be collected from a variety of sources. Smart electricity meters collect data that might be used to predict whether older patients have fallen or have a change in daily living pattern indicating they have run into problems.4 Studies from the US demonstrate that analysis of social media may identify symptoms related to disease outbreaks5 or mental health problems.6 Location technologies in mobile phones can track patients with dementia and alert health services if they are in danger. Smartwatches can detect seizures or characterise tremors.7 Dotset boxes linked to the internet can provide useful insights into medication adherence. Everyday life is becoming routinely digital.

The primary care record could form a vital bridge between the active and passive data sources above — creating new insights for individual patient care, population care, and research. For example, analysing a patient’s home blood pressure readings may help identify white-coat hypertension and avoid unnecessary increases in medication; assessing a patient with depression’s adherence to smartphone-based CBT may identify alternative treatments; and knowing that a patient has not opened their dosette box of hypoglycaemic medications could explain their uncontrolled diabetes. Understanding changes in population patterns of physical activity could bridge primary care and public health approaches to health improvement. Trends in social media content and web searches for symptoms signal disease outbreaks and could help with immediate service planning. For research, more deeply connected data across multiple, better-characterised populations can transform (clinical) epidemiology and feed evidence deserts such as understanding the needs of patients with multiple conditions.

THREE BIG CHALLENGES

Big data, however, bring big challenges including: governance, evaluation, and unintended consequences. The governance regarding ‘active’ data sources is relatively straightforward, as users can give consent and see what the data are being used for, and by whom. If these data are used for...
unintended or unclear purposes, users can be made aware and objections subsequently raised. ‘Passive’ data are more problematic as users may not be aware they are generating health-related information. Dame Fiona Caldicott’s latest report asks us to reconsider the nature of consent and patient feedback on data uses. Possibilities include dynamic consent, whereby patients control consent continuously and receive information about the uses of their data. These challenges are not unique to medicine though. There is a general move towards citizens controlling their own data, and being able to see how their data are used across the spectrum of public and private services. The UK Department of Health’s new Connected Health Cities initiative reuses wider civic digital governance for better health data analytics (www.connectedhealthcities.org).

The second challenge is that new data sources require rigorous evaluation before introduction. For example, to employ smart electric meter data requires evidence that has not yet been generated. Telecare research may or may not be relevant. These are complex interventions where research may or may not be relevant. The Health Cities initiative reuses wider civic digital governance for better health data analytics (www.connectedhealthcities.org).

CONCLUSION

In a more connected world, there are new opportunities to link data to primary care records that go beyond the traditional paradigm of ‘big’ health data. The UK is ideally placed to reveal important new understanding about the interactions of biology, behaviours, and environments — and primary care is at the heart of that nexus. Like Hart, we see no dividing line between research and care quality improvement, and therefore call for an honest conversation with patients and citizens about the value of the data they generate. This should build on the strong traditions of using primary care data for these purposes, but should also evolve to connect with community-based data sources that can provide a bigger picture of health and care. However, these new opportunities also pose big challenges, and careful evaluation and negation of unintended risks are vital.

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Competing interests

The authors have declared no competing interests.

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