A new conversation of primary care fuelled by data

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In 1988 Julian Tudor-Hart prescribed “A New Kind of Doctor”, calling for data-intensive, community-responsive primary care.¹ He argued for a re-alignment of primary care with the needs of populations rather than individuals; and for greater emphasis on prevention.¹ These principles are largely engrained 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 further escalate such approaches but may also change the conversation of primary care between patients, practitioners and the public.

Systematic collection, collation and analysis of data were core to Tudor-Hart’s manifesto. In today’s primary care we have more advanced tools at our disposal. Electronic health records are the foundations on which we build alerts and reminders to guide decisions at the point-of-care. We have electronic templates to help capture key data on important conditions and care-pathways. These data can be extracted across specific IT systems for research (e.g. the Clinical Research Practice Datalink [CPRD], The Health Improvement Network [THIN], Q-Research and Research One in the UK; the NIVEL Primary Care Database in the Netherlands; or SIDIAP in Spain), and across populations to support service development (e.g. audit, OpenPrescribing.net) and incentivise activity (e.g. QOF in the UK, the Primary Health Organization [PHO] Performance Programme in New Zealand, or Practice Incentives Programme [PIP] in Australia).

Traditionally, large-scale data extracts of NHS care records have been seen as the way to realise the more systematic and responsive primary care Tudor-Hart envisioned. The extracted records may be combined with other data at a national level such as hospital admissions and discharges from claims data, or official governmental statistics such as death registrations. More detailed information at regional level, however are more complex, especially across important boundaries such as between health and social care. This is unsurprising considering each local health system may host vast quantities of databases that record and support care.² Furthermore, the traditional paradigm of core minimum datasets is being challenged because multiple aspects of our daily lives are now linked by common technologies such as smartphones and smartwatches – generating health-relevant data invisibly, like patterns of movement, and interactively, like apps for symptom monitoring, medication reminders and access to primary care records. The potential to link primary care with the digital by-products of everyday life holds the promise of better prevention, self-care and monitoring. But the community 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, though relatively few that have been validated to provide credible data. The UK National Health Service (NHS) is currently building a library of ‘approved’ apps, however, 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.3

By contrast, passive data may be collected from a variety of sources. Smart electricity meters collect data that might be used to predict whether elderly patients have fallen or have a change in daily living pattern indicating that 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 Dosette 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 depressed patient’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 data. Dame Fiona Caldicott’s latest report asks us to reconsider the nature of consent and patient-feedback on data uses.8 Possibilities include dynamic consent, whereby patients control consent continuously and receive information about the uses of their data.9 These challenges are not unique to medicine though. There is a general move toward 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’s Department of Health’s new Connected Health Cities initiative links reuses wider civic digital governance for better health data analytics in this regard (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 which has not yet been generated. Telecare research may or may not be relevant. These are complex interventions where implementation and evaluation is difficult, but to ignore available and potentially valuable data that may improve care is arguably negligent. On the other hand, digital interventions have come unstuck where they are rolled-out without due evaluation and understanding, such as the Summary Care Record in the UK’s out of hours care. A major challenge for vendors of clinical information systems is the avoidance of data corruption or security breaches through linked apps, therefore very few apps are likely to be approved for connection.

Third is the digital cousin of “primum non nocere” (first do no harm), and the potential unintended consequences of introducing new ‘big’ data sources. An immediate risk from the explosion in connected health technologies is to exacerbate the ‘digital divide’ where the under-served are under-sampled – a modern equivalent of Tudor-Hart’s inverse care law. Older and poorer people may become more isolated as healthcare depends on consumption of domestic technologies. This would also impact on population health management and research, where the data samples are not representative of the population being served. A greater emphasis on ubiquitous over ‘nice to have’ consumer technologies is one way to mitigate the risk. Workload inflation is another risk – a blizzard of poorly or partially analysed data will further stretch primary care resources, which are already under considerable pressure. For example, daily blood pressure recordings transmitted via an app is not useful in every patient though still require processing, risking overwhelming clinicians. Systems should therefore be developed to ensure only essential information is conveyed, and that any associated additional workload on clinicians is adequately resourced. Furthermore, a lack of preparedness of primary care for more frequent observations may precipitate over-reaction, for example unnecessary hospitalisation when a COPD patient’s oxygen saturations sent via telecare benignly dips. Whilst in the research setting, more linked data may tempt researchers to ‘overfit’ and report spurious associations.

**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 well 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 Tudor-Hart, we see no dividing line between research and care quality management, and therefore call for an honest conversation with patients and citizens about the value of the data they generate for continuous care quality improvement. This should build on the strong traditions of using primary care data for research and care quality management, 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 are not without risk, and careful evaluation, and negation of unintended risks is vital.

**References**