Imperial College London

REFORM



The power of data to transform population health

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Reform was delighted to host a policy roundtable on how data can be harnessed to transform population health in March 2023, in partnership with Imperial College London's The Forum. The discussion was introduced by Dr Timothy Ferris, National Director of Transformation, NHS England and Dr Aldo Faisal, Professor of AI & Neuroscience, Imperial College London.

The intelligent use of data has the potential to vastly improve health and wellbeing outcomes. By reducing occurrences of ill health, providing personalised services, reducing inequalities and predicting future needs, digital transformation can help us move from a reactive to a proactive model of care.

The pace of innovation in this area has been rapid. Progress in artificial intelligence and machine learning, and initiatives to improve data collection and quality, provide real opportunities for health and care.

The potential of data

Participants identified four ways in which data can transform health: improving direct patient care, boosting population health, assisting long-term service planning and enhancing health research. In each case, there have been impressive pockets of innovation.

Improving direct patient care

Data can help transform direct care by developing a holistic understanding of patients' needs and providing better informed, more efficient services. For example, applying data-driven AI to diagnostics tasks such as reviewing mammograms has proven transformative. AI can review mammograms 30 times faster than a human with 99 per cent accuracy, a far higher level than any clinician. By speeding up existing processes and improving diagnostic accuracy, the use of new digital tools can therefore reduce the cost of providing care and improve quality.

Boosting population health

Most determinants of population health sit outside of healthcare such as the conditions in which we grow up, live and work. By integrating data, we can form a better understanding of the drivers of ill health and focus efforts on keeping people healthy rather than treating illness, enabling much earlier intervention. For example, algorithms can use existing personal administrative data to predict ill health, by observing patterns, rather than having to extract physiological data. Researchers at Imperial College, for instance, can accurately predict a decline in mental health using only credit card spending information.

Planning for the long term

Smart data use can also inform health and care organisations long-term planning decisions. Data can help better identify patients' current and future needs, enhance organisational management and identify which interventions work and which ones don't. For instance, the use of data to identify which proportion of patients are repeat users of A&E services but whose needs could better be met in other settings could inform decisions to commission alternative services.

> Enhancing research

Finally, the use of data and data-driven tools could further cement the UK's position as a world leader in medical research. Improving access to and the quality of data is an invaluable tool to health researchers. This is the case in academic settings – data can help researchers more accurately evaluate policy interventions – as well as in industry.

Machine learning, for instance, can significantly reduce the time and exorbitant costs associated with drug discovery by identifying patterns in pharmaceutical data.

The process of pharmaceutical research includes generating as many drug candidates as possible that have a high conversion to clinical development. This can be a very slow and inefficient process. Al can help identify the best compounds for drug discovery reducing the number of experiments conducted in the lab but still achieving the same number of developed drugs.

Accelerating the pace of change

Despite numerous pockets of game-changing innovation, data-led transformation within the health sector has been slow. Participants identified three major challenges that need to be overcome to accelerate the pace of change in this area: developing joined up datasets, increasing public trust and engaging clinicians.

Developing joined up datasets

Combining healthcare data has been surprisingly challenging. Participants noted that a

nationalised health system should provide significant advantages from a data join-up perspective. Under the NHS model, data from across the patient pathway could be collected and leveraged at scale, bringing major benefits to patients.

However, in practice, this has not occurred. The data divide between primary and secondary care remains stark and makes the UK an international outlier in this area. This means that hospital doctors may not have vital information about patients when they present in hospital settings. Those delivering and planning health services often do not have easy access to primary care data, a vital plank in improving population health management. GPs remain the controllers and owners of primary care data and have, in the past, been reluctant to share data with other parts of the system.

Join-up also remains a challenge when it comes to connecting healthcare data and information on population health collected by other services. Whilst data generated in the NHS has many uses in planning services and improving patient care, solely relying on healthcare data may entrench existing inequalities and biases by excluding those who do not access care. Population health planning requires the join-up of data from a range of public services, responsibility for which largely sits with local government. For instance, information on housing, the use of core public health services such as drug and alcohol rehabilitation, and adult social care all have value in planning more effective population health interventions.

A solution to both data join-up problems could lie in changing who controls the data within the system.

One alternative is to make patients the controllers of their data. Participants suggested that the NHS app, which already has I5 million

uses, could be the vehicle in which patients make decisions about their data.

Currently, patients do not have access to all of their own data. Allowing patients to access all relevant data could help foster public trust and improve data quality. For example, many healthcare datasets inconsistently code ethnicity. If patients had access to their own data, fixing mistakes like this would become easier and more accurate.

Another alternative is to allow Integrated Care Systems (ICSs) to become the data controllers. Most determinants of population health sit outside of healthcare such as in housing and employment. ICSs have links to both providers of healthcare and local councils, ideally situated to integrate data from public services organisations and primary and secondary care data. Additionally, joining up data from all 42 ICSs, to get a national picture, is a much easier feat than having to link data from more than 6,000 individual GP surgeries.

Making ICSs data controllers within the health system is complicated by the fact that they are relatively new organisations, which have not yet established a high level of public trust. Variation in levels of digital maturity between systems may also slow progress in this area. However, targeted investment and efforts to alleviate public concern over data sharing could pay dividends in the longer term.

Workforce trust and engagement

Workforce trust, or lack thereof, can also be a significant barrier to data collection. The medical workforce may fear that data may be used against them in the form of onerous performance management or clinicians may feel that data collection is not part of their job. This is particularly challenging because GPs are currently the controllers of primary care data, yet they have very little incentive to share it. A participant illustrated the extent of the problem using Greater Manchester's efforts to join up its GP data.Greater Manchester was only able to unify its primary care data by individually indemnifying 400 General Practitioners and assuring them that their data would not be used for performance management. This is not scalable at a national level, not least because some data may eventually – and should – be used for at least some types of performance management.

Further, GPs and those from local government have shown excessive risk aversion when it comes to data sharing even in cases where governance permits this. Clarifying information governance and simplifying instructions will go far when it comes to enabling a more open culture. Participants argued that we have the digital capabilities to enable digital transformation, but we do not yet have the governance infrastructure.

Public trust and trade-offs

One of the biggest challenges of data join-up within and outside the NHS is the lack of de-identifiable data available to the health system. This is mainly due to challenges in building public trust for data sharing. Past failures including the miscommunication of the General Practice Data for Planning and Research (GPDPR) scheme resulted in millions of people opting out of sharing their pseudonymised data.

Part of the problem is that most people overestimate how much data is being collected and shared. For instance, people assume that when they visit a pharmacy, pharmacists have access to their medical records when this is not the case. In fact, the NHS collects and shares much less when compared to similar countries' healthcare systems. This means that an emergency medicine doctor may not know the full medical history of patients presenting at the emergency unit.

This creates a range of problems. Not having a full picture of a patients' medical history can cause treatment provision that is less than optimal. A lack of data reduces the quality of care, limits the system's adaptability and prevents the NHS from evaluating its services. For example, participants noted that the lack of data collection and evaluation means that the NHS cannot properly judge the effectiveness of core services, such as the NHS III advice line.

Progress needs to be made to establish clarity and trust with the public. To address some of these issues, there needs to be a realistic conversation with the public about the trade-offs between privacy and healthcare quality. Additionally, the government should work with the NHS and the public to establish clarity around the purposes of data collection, analysis and sharing and how it will be used. For instance, it should be made explicit that only pseudonymised data can be used for all functions so that individuals are unidentifiable. In addition, having consensus about which medical professionals have automatic access to your full medical history (similar to how emergency doctors have access to organ donor information) and who patients can grant permission to provide more holistic care, such as pharmacists.

Although public trust can be a thorny issue, other parts of the health system, such as the NHS Organ Donor Register, have been very successful with communicating and fostering trust with the public. This suggests that the NHS could use some of the lessons learnt to lead a realistic national conversation on the value to individuals and the NHS of data sharing.



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