Developing a national learning health system

Dr Bryan McIntosh PhD, University of Bradford, School of Service Development and Improvement

There is increasing recognition among policymakers that health systems are no longer fit for purpose. Our hospital-centred systems, originally created to deal with communicable disease epidemics, are now faced with the challenge of delivering care to the exponentially increasing number of people living with (typically multiple)≈non-communicable disorders (NCDs).

Global economic stagnation has also contributed to the pressures facing health systems – such that there is an imperative to develop new models of care.

The need to establish learning healthcare systems, where the boundaries between care provision and service evaluation are blurred, and data science capabilities are simultaneously enhanced, is evident. Doing this would allow continuous cycles of quality improvement (*Figure 1*).

While some progress has been made in isolated health systems, this model of care has not yet been scaled anywhere on any national stage. Moreover, reflecting its US origins, the learning healthcare system model remains focused on the hospital sector. However, in the UK there is a need for a more overarching transformation of the ways in which health-related decisions are taken.

The case for a learning health system in which data are simultaneously used – at macro level to inform policy and planning decisions; at meso level to improve the organisation and deliver of care; and micro level to personalise care – is apparent. Such a comprehensive data-enabled transformation of care has not been attempted previously, and certainly not≈at scale across an entire nation, but it is clearly needed.

It is strategically important that those delivering healthcare both nationally and internationally develop an operational learning health system, in which there is a data-driven transformation of health policy and planning, service delivery and evaluation, and the personalisation of care.

Initial steps

There has been important progress towards this goal over the past three years. The NHS, in particular, needs to build on this vital foundational work ~~(Mohammed et al., 2016)~~, but to take this forward we need to do the following:

- Agree a national vision
- Align major funders
- Identify shared national goals
- Establish baselines
- Understand the needs of policymakers, professionals and patients — the stakeholders.

> *'Comprehensive data-enabled transformation of care has not been attempted previously, but it is clearly needed'*

A national vision

To develop a shared vision it is imperative to hold a series of consultative meetings centred on the need to move towards creating a national system and an agreed national vision to provide astrong mandate to move forward.

The meetings will need to involve a broad range of stakeholders, including policymakers, healthcare professionals, academics, patient charities and patients.

Align major funders

Draw together public, private, academic and political actors and other agents who can support the development of a clear vision, and a clear and coherent plan to take it forward.

Identify shared national goals

It is vital to identify goals that are clinically important and have widespread resonance with the diverse stakeholders.

Establish baselines

Undertake comprehensive assessments of long-term conditions. This will, first, involve identifying the relevant data assets and then undertaking detailed analyses of both the standalone and linked datasets to provide a national description of specific conditions and their outcomes.

The needs of stakeholders

Extensive consultative and qualitative work will ensure that there is in-depth appreciation of the data needs of the different stakeholders to support transformational change across the NHS. The work should involve access to near real-time estimates of disease burden, dashboards and benchmarking tools, and a variety of decision support tools.

The next stage

To move forward the NHS, in particular, will need to build on this formative work and develop detailed plans that will enable year-on-year improvements in, for example, national asthma decision-making, care processes and outcomes.

The next steps are to develop:

- A common data model for key asthma variables of interest and outcomes
- Standards for these data items, and staff training to ensure that these are adhered to reliably
- Integration of genetics/genomics, imaging and patient-generated, wearable and social media data
- The means to securely transmit, link and interrogate data in near real time
- A range of visualisation and decision support tools to facilitate, in real time, options appraisals, decision-making and analysis on an ongoing basis
- A cadre of transformational change agents who can exploit the data for policy, organisational and patient benefits
- Processes for annual appraisal of progress over the forthcoming five years until the goals have been achieved
- A course of action for extending this learning health system model to cover the spectrum of common NCDs in the UK and internationally.

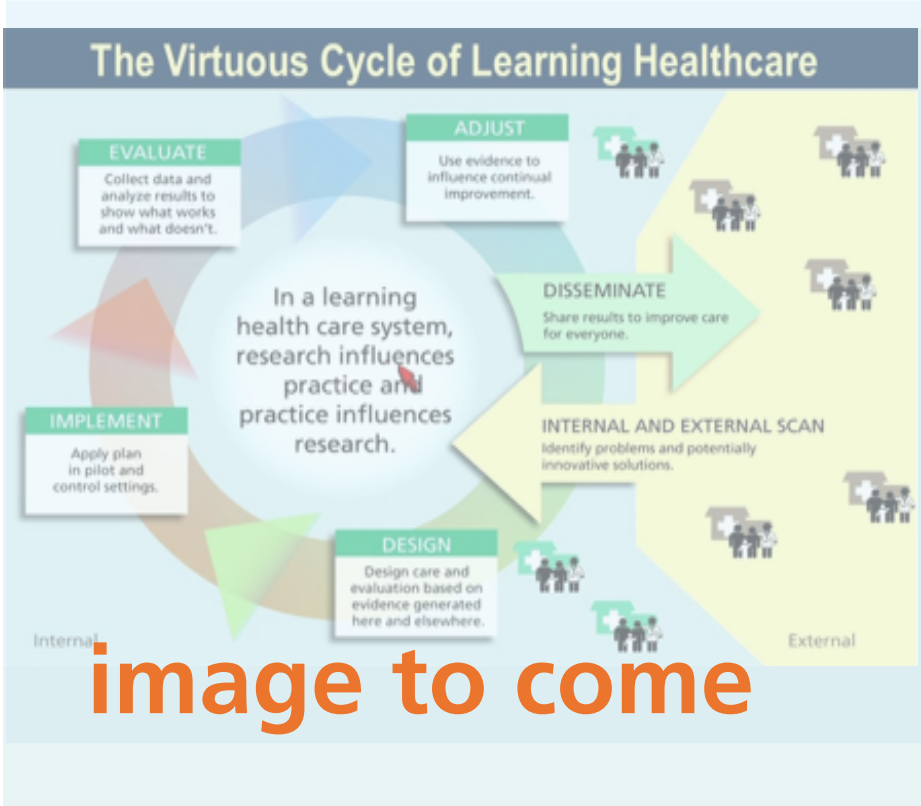

Figure 1: The National Academy of Medicine's learning healthcare system system (Institute of Medicine, 2007)

In conclusion, the ongoing challenge in relation to improving data, cost and quality is to understand what changes need to be made to existing structures and processes, so we can improve outcomes, enhance quality of patient care and maximise the value of precious resources.

There needs to be an understanding of a number of interdependent system challenges, with a specific process designed to address them. If this can be done, the capacity of every functional service and associated staffing levels, matched to meet variations in demand, can potentially be met.

The challenge is great, but the reward – financial and moral – will be just as great. In doing this, we can address some of the most pressing financial and quality imperatives facing the health service. BJHCM

References

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