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## RETHINKING HEALTH AND CARE SYSTEMS

# Data to knowledge to improvement: creating the learning health system

**Paige McDonald and colleagues** detail key domains, tools, and actions required to enact learning health systems for continuous intelligent improvement in healthcare

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Despite an increased focus on quality improvement in healthcare over the past 50 years, many of the same problems persist. This disconnect has been described as the 60-30-10 challenge: only 60% of care, on average, aligns with evidence or consensus based guidelines; another 30% of care is waste or of low value; and 10% of patients experience adverse events.<sup>1</sup> These statistics have persisted for over three decades.<sup>2</sup> Even with technology providing increasing volumes of data and more sophisticated analytical techniques such as machine learning and artificial intelligence, progress continues to be painfully slow.

Learning health systems provide a pathway towards continuous improvement and innovation in healthcare through the routine collection, analysis, and more timely use of data. The US Institute of Medicine first proposed the concept as systems in which “science, informatics, incentives, and culture are aligned for continuous improvement and innovation” in response to increasing complexity in healthcare and a need to improve the quality of care while reducing inefficiencies and costs.<sup>3</sup> Yet, a lack of practical guidance on how to enact such systems and a dearth of evidence indicating return on investment has led to justifiable scepticism about their achievability and prospective value.<sup>4</sup>

Despite this, properly implemented learning health systems locally and globally still have potential to improve healthcare delivery. While efforts have focused on the use of data, evidence based practice, and quality improvement, healthcare systems have not integrated these approaches for continuous learning. In this analysis we seek to clarify the concept of learning systems and provide examples of their application and outcomes.

### What makes a learning health system?

Learning health systems have been defined as health systems “in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice. As a result, patients get higher quality, safer, more efficient care, and healthcare delivery organisations become better places to work.”<sup>5</sup> Proponents claim that the development of learning health systems would contribute to a more sustainable healthcare system and a greater likelihood of delivering more “appropriate care.”<sup>6</sup>

Healthcare systems are enacting learning systems to various degrees and at scales ranging from local practice level to international networks.<sup>7-9</sup> In many improvement efforts, however, the mechanisms for organisational learning are an afterthought. As such, we draw on the examples of MQ Health (box 1)<sup>10</sup> and ImproveCareNow (box 2)<sup>11</sup> to highlight the sociotechnical advances that are needed to achieve learning health systems.

#### Box 1: MQ Health<sup>10</sup>

In 2021, MQ Health, a university based system in Australia, adopted a learning system approach in its general practice department to enhance patient experience, improve population health, reduce costs, and improve the working life of primary healthcare providers. The strategy included adopting an embedded researcher to collect and analyse practice data and work with business management and general practitioners on quality improvement initiatives.<sup>10</sup>

Several quality improvement initiatives were conducted related to engaging patients with the practice and their healthcare, such as piloting an app to help patients engage with their health records and to streamline the care process. Patient feedback was sought through online reviews and focus groups to inform learning and future improvement cycles. Multidisciplinary workgroups of both clinical and non-clinical staff were formed internally, while staff and senior leaders were encouraged to form research and other collaborations. The programme created affiliations with academic institutions to provide research, teaching, and learning opportunities.

#### Box 2: ImproveCareNow<sup>11 12</sup>

The ImproveCareNow Pediatric Inflammatory Bowel Disease Improvement Network was initiated in the US in 2007 and is now an international learning health system.<sup>11 12</sup> It comprises over 100 care centres across the US as well as in England, Qatar, and Belgium, with 980 paediatric gastroenterologists caring for over 30 000 patients. Sustained clinical remissions improved significantly across the network from 2016 to 2023.<sup>13</sup> Facilitators of success include a standardised system for data entry and collection across the network and adoption of an online database allowing data entry by different people in different places. In addition, the programme collaborated with patients to create new knowledge (such as digital resources describing experiences of patients who had ostomy) for sharing with the broader network community.<sup>12</sup> The model has been adopted to create multiple active learning networks for other paediatric conditions.

## Learning communities

The foundation of a learning health system, as exemplified by the MQ Health and ImproveCareNow cases, is a learning community. A learning community comprises a group of collaborators with appropriate expertise to define and tackle a health system problem, at whatever level. Learning communities should co-design their terms of reference to suit the specific purpose, and membership commonly includes administrators, researchers, data experts, clinicians, policy makers, and patients who have knowledge of the problem. Members are invested in exploring and solving a given healthcare problem and are empowered to set the direction, agree on priorities, reflect on performance, discuss failure, and drive action.<sup>14</sup> They engage in learning cycles in which they collect and analyse data to generate knowledge that will inform changes to improve care.<sup>15</sup> Learning systems can vary in scope, and the problems addressed can range from local care delivery challenges and individual patient engagement to disease surveillance or creating new standards of patient care through multi-institutional collaborative networks.

Learning communities must have the appropriate expertise and skills to engage in learning cycles. For example, data analysts can be available to support data collection and analysis, targeted to specific problems.<sup>7</sup> Alternatively, as in the case of MQ Health, an embedded research capability with training in data collection, analysis, and implementation can be valuable to a learning community as it can help identify specific data required to investigate problems, develop research methods for studying the problems, and define outcome and process measures to indicate improvement and change. Healthcare professionals with specific knowledge of a health or practice challenge are essential to reflect on current practice and evaluate opportunities for behaviour change.<sup>7</sup> Patients and carers enable learning systems by allowing their data to be used for the greater good, beyond their direct care.<sup>16</sup> Ideally, they also contribute to learning cycles as members of learning communities. For example, MQ Health invited patients to participate in focus groups and to sit within governance structures.<sup>10</sup> The role of patients in learning communities and the methods available to enable their involvement continue to evolve. There is no one size fits all. To participate fully, all members of the learning community must be provided with appropriate information and training.<sup>7</sup> Clinical educators are essential in preparing the future workforce with the knowledge and skills to engage in these roles.

## Technical building blocks

Learning health systems depend on learning cycles in which data are captured from practice, turned into knowledge, and then put back into practice.<sup>15</sup> Every care event or episode is digitally captured through routine data collection in electronic health records. Technology platforms such as patient registries or data warehouses generated by healthcare organisations, professional bodies, or research institutions (such as the registry and learning exchange platform of ImproveCareNow) are required for data collection, analysis, and sharing to support continuous improvement and learning.<sup>11 15 17</sup> Routinely recorded data from these systems can be linked with other data sources to inform learning cycles. For example, ImproveCareNow uses structured clinical encounter forms to standardise data collection across all patients in the registry.<sup>11</sup>

Data must be stored, accessed, and protected in a way that promotes trust. To achieve this, databases must be fit for purpose, be interoperable with other systems, and show provenance, transparency, adherence to the rule of law, and public interest.<sup>18-23</sup> Improvements are only achieved when practice related data become

useful knowledge, when that knowledge is applied in practice, and when resulting outcomes are captured as new data.<sup>24</sup>

Different study designs and artificial intelligence approaches have emerged that enable advanced quantitative analysis to transform data into knowledge.<sup>25-34</sup> More traditional quantitative, qualitative, or mixed-methods research can also be used within learning cycles.<sup>35 36</sup> For example, qualitative data can provide insight into the “why” and “how,” such as MQ Health’s use of focus groups to get patient feedback on improvements to an app designed to increase patient engagement with health records.<sup>8 10</sup>

Depending on the scale of the system and defined problem, knowledge can be used to inform practice through traditional means such as published papers, evidence based guidelines, or updated training curriculums.<sup>37</sup> New technological capabilities can also enable rapid dissemination through clinical decision support systems, often embedded within electronic health record systems.<sup>24</sup> Knowledge can also influence strategy and policy development and system level incentives such as pay-for-performance models. Existing institutional channels, such as librarians and knowledge management specialists, can coordinate and improve knowledge dissemination.<sup>38</sup>

## Strategy, structure, and process

In a learning health system, the strategic direction, purpose, goals, priorities, processes, and tools are co-designed by the learning community, which then directs the learning cycles.<sup>39</sup> Achieving and sustaining learning systems also requires organisational structures and governance capable of delivering the strategy.<sup>40</sup> For example, the ImproveCareNow community determined its purpose as transforming “the health, care and costs for all children and adolescents with Crohn’s disease and ulcerative colitis.”<sup>13</sup> Programme participants then encouraged collaboration between clinicians, researchers, patients, and parents to achieve that purpose, including creating and implementing the data collection tool at the heart of their learning activities. In learning systems, the organisational arrangements are designed to support engagement and collaboration among all stakeholders. Policies and processes are aligned to the strategic direction, provide guidance on how to participate in improvement and learning cycles, and identify measures of success.

## Culture

A learning health system requires a culture that values curiosity, continuous learning, improvement, and innovation.<sup>41</sup> In the ImproveCareNow initiative, a shared value of learning from every patient within the network drove the development and implementation of a standardised data collection tool to facilitate data sharing and analysis. A shared value related to patient engagement drove MQ Health’s piloting of an app to increase engagement and the use of focus groups with patients to identify lessons.<sup>11</sup>

Achieving this type of culture requires leadership to motivate staff to engage in learning cycles and to embrace the potential for behaviour and process change; this, in turn, is anchored in shared commitment to tackling the identified problem. Leadership can also ensure that the workforce has requisite knowledge and skills and that patients and families are included as important participants in building culture. However, leadership alone cannot achieve a learning health system; there is also a grassroots component collaboratively driven by individuals across the system with a desire for better knowledge and decisions in support of continuously improving care. Within such cultures, transparency and effective

communication can build trust, respect, and affective commitment. Recognition systems, outcome measures, policies, and procedures become visible indications of how learning is valued.<sup>42</sup>

### Behaviour change

Effective learning health systems adopt an evidence based approach to changing the behaviour of individuals and organisations towards data sharing, continuous learning, improvement, and innovation. This approach requires an understanding of the drivers of existing behaviour, as well as what has impeded these drivers previously.<sup>43</sup> Systematic and evidence based approaches to behaviour change are necessary to ensure that knowledge makes it into practice.<sup>44</sup> For example, the behaviour change wheel framework can be helpful for designing behaviour change interventions. It starts by developing an understanding of the factors driving the behaviour to be changed and links that to evidence based interventions likely to affect those drivers in the particular situation.<sup>43</sup>

### Complexity

The results of traditional linear approaches to implementing practice change or innovation are often not sustainable or scalable because they do not take account of the complexity of the health system or the proposed intervention.<sup>45</sup> Learning communities enacting learning cycles must appreciate the complexity of the problem under investigation as well as the constantly evolving systems into which any resulting intervention would be introduced. Identifying and managing complexity is critical to successful implementation of change. Fortunately, there are tools to help identify and manage complexity.<sup>46</sup> For example, the NASSS (non-adoption, abandonment, scale-up, spread, sustainability) framework provides a systematic, evidence based model to guide organisations in understanding and managing such complexity.<sup>45 46</sup>

### Enabling further adoption

Substantial investment is required to achieve learning health systems. Lack of investment, system inertia, local politics, inadequate organisational structures, limited access to fit-for-purpose data, and interprofessional rivalries can impede progress. Tools such as the NASSS framework can help to identify these challenges. Recognising the need for a repository of such tools, we have launched the LHS Toolkit, so practitioners can share tools and case studies that have been helpful.<sup>47</sup> Within the toolkit, tools are organised under components supporting the data-knowledge-practice learning cycle.

In 2013, the US National Science Foundation convened a multidisciplinary group of researchers to develop an early research agenda for learning health systems. It spanned 106 research questions and is organised around four requirements for a high functioning learning system.<sup>48</sup> However, the healthcare and technology landscape has changed enormously in the past decade. Understanding how to spread and scale learning health systems will require new research and policy agendas, integrating the sociotechnical aspects discussed above, at different scales, from local to global. [Box 3](#) lists key enablers and actions in realising this agenda.

#### Box 3: Key enablers and actions of intelligent learning health systems

##### Promote patient engagement

- Ensure that every patient can participate in the learning system
- Consider health and digital literacy as well as patient preference in all health and healthcare actions and decisions

- Include patient supporters (eg, families, significant others) in accessing and interacting with the system

##### Availability and access to data that are fit for purpose

- Data are captured, stored, accessed, protected, and used in a way that builds trust among patients, clinicians, and healthcare organisations despite competing commercial and strategic interests
- Quality and provenance of data are ensured, sharable, and understood between settings and put to use for the common good

##### Focus on generating and implementing knowledge

- Organisations establish mechanisms to generate, represent, share, and put knowledge into practice as rapidly and safely as possible
- Clinical decision support systems are used alongside existing knowledge dissemination channels
- Representative learning communities oversee the knowledge generating and implementation process<sup>1</sup>

##### Create organisational readiness

- Create appropriate incentives and legislation in the healthcare system to ensure provision of data and use of the knowledge emanating from them
- Provide appropriate training for healthcare professionals in evidence based practice, basic analytics, teamwork, and leadership<sup>36</sup>
- Stimulate culture and individual behaviours to embrace reflection, innovation, and continuous improvement

##### Stimulate learning systems at different scales

- Secure regional and governmental funding, policies, and processes to promote widespread progress beyond local organisations
- Adopt national or international standards governing the collection, representation, and sharing of data and knowledge

Our suggested actions to enable learning health systems represent a broad agenda for change. However, most of the requirements that support a learning system have been considered good practice for many years. While fully functional learning systems remain the exception, most health systems can celebrate at least some components, and all are learning to some extent, whether they label themselves a learning health system or not.<sup>40 49-52</sup>

The complexity of health systems means that each will become a unique learning system, influenced by its starting point, setting, location, culture, and structure. Focus on the enablers outlined in [box 3](#) will help to encourage consistency across different settings. Despite heterogeneity, several frameworks are available to help organisations understand the maturity of their existing learning systems and to identify areas for improvement.<sup>8 40 52 53</sup> Although daunting, adoption of learning health systems as a model for all healthcare systems can result in more patient centred, evidence based healthcare that will continuously learn and improve. Turning data into knowledge and then intelligent improvement, so that timely evidence based decisions are the norm, will not be easy but is an important endeavour for better care.

#### Key messages

- Learning health systems can help to improve quality, reduce cost, and engage citizens
- Learning communities comprising people with relevant experience and expertise, including patients, are the foundation of successful systems
- Learning communities co-design strategy and purpose, and identify the data and tools required to deal with a problem

- The goal for learning health systems is continuous, intelligent improvement in patient care.

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