Embedding Research in the Learning Health System

COMMENTARY

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ABSTRACT

To make research more impactful in the evolution of Canadian healthcare, the Canadian Institutes for Health Research have prioritized creation of learning health systems where research rapidly informs healthcare finance and delivery and vice versa. To make this vision a reality, substantial changes are needed in how researchers are trained, the environments in which they work, and the reward systems that are in place. Attention is needed on training researchers with a broader array of skills, the creation of partnered environments, the evolution of our ethical frameworks, and the creation of integrated funding.

THERE ARE PRESSING needs for impactful health services and policy research in Canada. Canadians face challenges every day in receiving safe and effective care that is reliable, timely and coordinated. They also increasingly expect, and deserve, excellent care experiences, all at a cost we can afford. Recent cross-country studies suggest that Canadian healthcare is lagging in many respects (Osborn et al. 2014; Schoen et al. 2013). Not only can scientists help discover better ways to deliver and finance care, they also serve another key role – as informed change agents who collaborate with leaders, managers and clinicians as they learn. The rich data landscape, now enabled by advanced health information technologies (HIT) and paired with cutting-edge analytic techniques, opens up unprecedented opportunities for

rapid-cycle learning that we have not seen before. The opportunities, too numerous to list, are layered at all levels – from the way that clinicians interact with patients and each other clear through to large-scale changes in provincial and federal health policies.

In this issue, Tamblyn et al. (2016) from the Institute of Health Services and Policy Research (IHSPR), part of the Canadian Institutes of Health Research (CIHR), outline their five-year research funding priorities. Their first priority is the most meaningful and ambitious: the creation of learning health systems and a new generation of researchers skilled in promoting rapid, on-the-ground health system transformation. IHSPR also places funding priority on eHealth innovations, community-based healthy aging and novel funding and finance mechanisms – all key learning themes needed to achieve the outcomes that Canadians want from their systems.

Almost a decade ago, the Institute of Medicine (IOM) first proposed the vision of the learning health system and defined it as "one in which progress in science, informatics and care culture align to generate new knowledge as an ongoing natural by-product of the care experience and seamlessly refines and delivers best practices for continuous learning in health and healthcare" (IOM 2007). They conceptualized a future where data collection, advanced analytics and learning is routinized within health systems that are then charged with externally disseminating and sustaining learnings and best practices. Supported by big data analytics, this vision challenges current thinking and calls for the fundamental integration of health services research, clinical operations, quality improvement, decision support and patient engagement. The products are learnings that are of immediate value for systems and their stakeholders. While much has been written about its potential (Etheredge 2007; Slutsky 2007; Smith et al.

2012), the concept is still largely hypothetical with only a few practical examples (Abernethy 2014; Flum et al. 2014; Greene et al. 2012; Psek et al. 2015; Solberg 2009), where research units, health systems, academic intuitions and funding bodies have deliberately partnered to embed researchers within health systems to promote rapid learning.

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Health System Learning and the Relationship to Research

To ground the role of research in health system learning, Greene et al. (2012) proposed a virtuous learning cycle with six nodes, where researchers partner with health system leaders, managers, analysts, improvement experts and clinicians. The utility of this model is because it underlays the needs for new training platforms and learning infrastructures. The first node, surveillance, is one in which the Canadian health services research community has traditionally excelled – assisting health system partners in identifying, scoping and understanding the nature of health service delivery issues and, at the same time, identifying and synthesizing the evidence base of potential solutions. At the second node, design, researchers assist health system partners to apply key lessons and then, cognizant of contextual realities, assist them to innovate, redesign and modify delivery system or financing mechanisms. Since improving patient experience is a core value, researchers also have a role in applying the emerging evidence in patient engagement methods (Absolom et al. 2015; Shippee et al. 2015) and human factors engineering (Wu et al. 2015). Not only do solutions need to be practical but they also must be cognizant of system capabilities, timelines, externalities and culture.

At the third node, implementation, researchers draw on methods from the emerging fields of implementation (Damschroder et al. 2009; Greenhalgh et al. 2004), complexity (Chandler et al. 2016) and improvement science (Berwick 2008) to assist health system partners successfully execute, iterate, spread and sustain changes in care delivery, finance and policy. Researchers play a particularly important role at the fourth node, evaluation. Strong evaluation designs are required that can be seamlessly inserted into regular care settings, use the data collected as part of regular operations and produce preliminary and final results on timelines needed for decision-making. Researchers are challenged to use realistic evaluation designs (Pawson and Tilley 1997) and exploit naturally occurring heterogeneities in populations and design fidelity. Evaluations also need to accommodate and enable iterative learning and continual improvement represented at the fifth node, adjustment. At the final node, dissemination, researchers partner with health system colleagues to share learnings with other organizations and systems. While there are many activities currently occurring in Canada at each of these nodes, the promise of sustained partnerships between researchers and health across these nodes has yet to be realized.

What Will the Next Generation of Researchers Need in Learning Health Systems?
New skills and approaches

Tamblyn et al. (2016) correctly point out that research embedded in the complexities of everyday care and decision-making requires new methods and approaches. Not only do researchers need advanced skills in areas such as realist evaluation and change management, they also need solid familiarity with other disciplines and approaches, including information science, leadership and management, industrial engineering and human-centered design. To embrace the possibilities of big data, researchers also need more training in inductive reasoning and pattern recognition (Krumholz 2014). In addition to new science skills, researchers must also perfect other "softer" skills, including leadership and communication abilities, so that they can effectively partner with personnel ranging from frontline clinicians to mid-level managers, to senior healthcare executives (Selby and Slutsky 2014). Appreciation for the roles that others play in a learning enterprise is essential. These players include quality improvement experts, health informatics specialists, business intelligence analysts and strategic planners. To address these new training needs and skills development, some high-performing health systems have created embedded post-doctoral positions with structured and experiential learning opportunities (Academy Health 2016).

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Partnered environments

To be most effective in learning health systems, researchers must be fully integrated into their internal environments where health problems are articulated, priorities and plans set, new initiatives developed and launched, and resultant changes managed. As organizational leaders set learning priorities, they need to deliberately partner researchers with internal teams focused on strategic planning, finance, healthcare operations, quality improvement, HIT, business intelligence and patient engagement (Psek at al. 2015). Development of both partners is needed: researchers need intimate familiarity with decision-making processes, organizational requirements and culture; and health systems

need to adjust their work streams to effectively accommodate research. Linking researchers with external partners is also key, including patient groups, community organizations, academic institutions and other health systems. External partnerships have many benefits, including raising funds, promoting cross-institutional collaborations and providing dissemination portals for learning.

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Big data and advanced analytics
Canadians have been historical world leaders in the development and access to large, population-based data repositories for use in health services and population health research (Chamberlayne et al. 1998; ICES 2016; Manitoba Centre for Health Policy 2016), but others are catching up (Dartmouth Institute 2013; McGlynn et al. 2014; Wallace et al. 2014). These investments provide the foundation for the big data needs of a learning health system, but more investments are needed. To fully realize learning opportunities, the big data need to be bigger with the addition of electronic clinical data (e.g., blood pressure readings and clinical notes), health service operations and financial data (e.g., workflows, staffing patterns, labour costs and web hits), information from other relevant sectors and programs (e.g., physical activity programs) and patient-reported data on outcomes and experiences. Not only do these data resources need to be hierarchically arranged but they also need to be easily aggregated at the appropriate learning unit, such as the operating room, physician's office or health region. The data also must be made available to researchers in time frames required for iterative learning and

organizational decision-making. Collaborators with expertise in big data analytics are required, including experts in data science, machine learning and data mining (National Research Council 2013). Not only are the big data resources relevant to the IHSPR community but they also have broad applicability to clinical effectiveness (McGlynn et al. 2014; Rosenthal 2014) and population health research (Bernstein et al. 2015).

Ethical frameworks and privacy protection
Because the concept of the learning health system deliberately blurs the boundaries between clinical practice, quality improvement, research and innovation, tensions are created to the extent of ethical oversight of research and governance structures. Since the release of the IOM report, healthcare ethicists have begun to challenge traditional divisions between research, quality improvement and clinical practice as no longer tenable. They have proposed new ethical principles that value continuous learning as a moral obligation (Faden et al. 2011, 2013). Likewise, with the prospect of even bigger data, privacy concerns and data use limitations are heightened and challenges magnified. Privacy concerns aside, many cultural barriers continue to exist in using everyday clinical and operations data to serve the public good through research (Larson 2013). Without deliberately addressing these issues, progress on creating a learning health system is sure to be slow.

Integrated funding streams and reward systems
Research funding bodies in Canada, including CIHR, have been at the forefront of developing novel ways to support researchers consistent with health system learning needs, such as adding requirements to integrate decision-makers, end-users and patients. However,

more refinements are now needed to make review times faster and more flexible, prioritize learning needs of health system partners at various levels and support young and mid-career professionals in learning new skills. In the new world of health system learning, it is reasonable to expect that health organizations themselves will directly invest research monies when research brings them near-term value in organizational efficiency, patient experience, quality of care or population health. For researchers to succeed in this learning environment, reward systems for researchers must also be rethought. Tenure-track career ladders need to change from valuing not only peer-review publications, grants and teaching but also contributions to rapid-pace learning, non-traditional dissemination activities and, importantly, demonstrable improvements in health and health systems.

It is encouraging to see that Canadian health research funders, particularly IHSPR, are willing to invest time and money into promoting the concept of the learning health system. To achieve this goal, however, health system leaders must also share the same vision and do their part in creating sustained partnership opportunities, infrastructures and funding streams. In the end, adopting a common learning culture is likely to be the most formidable challenge.

References
Abernethy, A.P. 2014. "Demonstrating the Learning Health System through Practical Use Cases." *Pediatrics* 134(1): 171–72.

Absolom, K., P. Holch, B. Woroncow, E. Wright and G. Velikova. 2015. "Beyond Lip Service and Box Ticking: How Effective Patient Engagement Is Integral to the Development and Delivery of Patient-Reported Outcomes." *Quality of Life Research* 24(5): 1077–85.

Academy Health. 2016. *Delivery System Science Fellowship*. Retrieved May 20, 2016. <http://www.academyhealth.org/Training/content.cfm?ItemNumber=13412>.

Bernstein, J.A., C. Friedman, P. Jacobson and

J.C. Rubin. 2015. "Ensuring Public Health's Future in a National-Scale Learning Health System." *American Journal of Preventive Medicine* 48(4): 480–87.

Berwick, D.M. 2008. "The Science of Improvement." *Journal of the American Medical Association* 299(10): 1182–84.

Chamberlayne, R., B. Green, M.L. Barer, C. Hertzman, W.J. Lawrence and S.B. Sheps. 1998. "Creating a Population-Based Linked Health Database: A New Resource for Health Services Research." *Canadian Journal of Public Health* 89(4): 270–73.

Chandler, J., J. Rycroft-Malone, C. Hawkes and J. Noyes. 2016. "Application of Simplified Complexity Theory Concepts for Healthcare Social Systems to Explain the Implementation of Evidence into Practice." *Journal of Advanced Nursing* 72(2): 461–80.

Damschroder, L., D. Aron, R. Keith, S. Kirsh, J. Alexander and J. Lowery. 2009. "Fostering Implementation of Health Services Research Findings into Practice: A Consolidated Framework for Advancing Implementation Science." *Implementation Science* 4(1): 50.

The Dartmouth Institute. 2013. "Health Systems Representing 70 Million Patients Meet to Develop and Implement Best Medical Practices." Retrieved May 20, 2016. <http://tdi.dartmouth.edu/press/press-releases/health-systems-representing-70-million-patients-meet-to-develop-and-impleme>.

Etheredge, L. M. 2007. "A Rapid-Learning Health System." *Health Affairs* 26(2): W107–18.

Faden, R.R., T.L. Beauchamp and N.E. Kass. 2011. "Learning Health Care Systems and Justice." *Hastings Center Report* 41(4): 3.

Faden, R.R., N.E. Kass, S.N. Goodman, P. Pronovost, S. Tunis and T.L. Beauchamp. 2013. "An Ethics Framework for a Learning Health Care System: A Departure from Traditional Research Ethics and Clinical Ethics." *The Hastings Center Report* 43(1): S16-S27. doi:10.1002/hast.134.

Flum, D.R., R. Alfonso-Cristancho, E.B. Devine, A. Devlin, E. Farrokhi, P. Tarczy-Hornoch, et al. 2014. "Implementation of a "real-world" learning health care system: Washington state's Comparative Effectiveness Research Translation Network (CERTAIN)." *Surgery* 155: 860–66.

Greene, S.M., R.J. Reid and E.B. Larson. 2012. "Implementing the Learning Health System: From Concept to Action." *Annals of Internal Medicine* 157(3): 207–10.

Greenhalgh, T., G. Robert, F. Macfarlane, P. Bate and O. Kyriakidou. 2004. "Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations." *Milbank Quarterly* 82(4): 581–629.

Institute for Clinical Evaluative Studies (ICES). 2016. *ICES Data Repository*. Retrieved February 6, 2016. <http://www.ices.on.ca/Data-and-Privacy/ICES-data>.

Krumholz, H.M. 2014. "Big Data and New Knowledge in Medicine: The Thinking, Training, and Tools Needed for a Learning Health System." *Health Affairs* 33(7): 1163–70.

Larson, E.B. 2013. "Building Trust in the Power of "Big Data" Research to Serve the Public Good." *Journal of the American Medical Association* 309(23): 2443–44.

Manitoba Centre for Health Policy. 2016. *Population Health Research Data Repository 2016*. Retrieved February 6, 2016. <http://umanitoba.ca/faculties/health_sciences/medicine/units/community_health_sciences/departmental_units/mchp/resources/repository/index.html>.

McGlynn, E.A., T.A. Lieu, M.L. Durham, A. Bauck, R. Laws, A.S. Go, et al. 2014. "Developing a Data Infrastructure for a Learning Health System: The PORTAL Network." *Journal of the American Medical Informatics Association* 21(4): 596–601.

National Research Council. 2013. *Frontiers in Massive Data Analysis*. Washington, DC: National Academies Press.

Olsen, L., D. Aisner, and J.M. McGinnis, eds. 2007. *The Learning Healthcare System: Workshop Summary (IOM Roundtable on Evidence-Based Medicine)*. Washington, DC: The National Academies Press. Retrieved May 20, 2016. <http://www.nap.edu/catalog.php?record_id=11903#toc>.

Osborn, R., D. Moulds, D. Squires, M.M. Doty and C. Anderson. 2014. "International Survey of Older Adults Finds Shortcomings in Access, Coordination, and Patient-Centered Care." *Health Affairs* 33(12): 2247–55.

Pawson, R. and N. Tilley. 1997. *Realistic Evaluation*. London, UK: Sage Publications.

Psek, W.A., R.A. Stametz, L.D. Bailey-Davis, D. Davis, J. Darer, W.A. Faucett et al. 2015. "Operationalizing the Learning Health Care System in an Integrated Delivery System." *EGEMS* 3(1): 1122.

Rosenthal, G.E. 2014. "The Role of Pragmatic Clinical Trials in the Evolution of Learning Health Systems." *Transactions of the American Clinical and Climatological Association* 125: 204–18.

Schoen, C., R. Osborn, D. Squires and M.M. Doty. 2013. "Access, Affordability, and Insurance Complexity Are Often Worse in The United States Compared to Ten Other Countries." *Health Affairs* 32(12): 2205–15.

Selby, J.V. and J.R. Slutsky. 2014. "Practicing Partnered Research." *Journal of General Internal Medicine* 29: S814–16.

Shippee, N.D., J.P. Domecq Garces, G.J. Prutsky Lopez, A. Wang, T.A. Elraiyah and M. Nabhan et al. 2015. "Patient and Service User Engagement in Research: A Systematic Review and Synthesized Framework." *Health Expectations* 18(5): 1151–66.

Slutsky, J.R. 2007. "Moving Closer to a Rapid-Learning Health Care System." *Health Affairs* 26(2): W122–24.

Solberg, L. 2009. "Lessons for Non-VA Care Delivery Systems from the U. S. Department of Veterans Affairs Quality Enhancement Research Initiative: QUERI Series." *Implementation Science* 4: 4.

Smith, M., G. Halvorson and G. Kaplan. 2012. "What's Needed Is a Health Care System That Learns: Recommendations from an IOM Report." *Journal of the American Medical Association* 308(16): 1637–38.

Tamblyn. R., M. McMahon, J. Nadigel, B. Dunning and E. Drake. 2016. "Health System Transformation through Research Innovation." *Healthcare Papers* 16(Special Issue, September): 8–19. doi:10.12927/hcpap.2016.24719.

Wallace, P.J., N.D. Shah, T. Dennen, P.A. Bleicher and W.J. Crown. 2014. "Optum Labs: Building a Novel Node in the Learning Health Care System." *Health Affairs* 33(7): 1187–94.

Wu, S., N. Duan, J.P. Wisdom, R.L. Kravitz, R.R. Owen, J.G. Sullivan J, et al. 2015. "Integrating Science and Engineering to Implement Evidence-Based Practices in Health Care Settings." *Administration and Policy in Mental Health and Mental Health Services Research* 42(5): 588–92.