

Research & Knowledge EXCHANGE

NOTES FROM A MEETING OF THE RESEARCH & KNOWLEDGE EXCHANGE ON THE LEARNING HEALTH AND SOCIAL SYSTEM (LHSS)

DECEMBER 4, 2023 12:30PM TO 2:00PM NT

Defining the LHSS and a discussion about health literacy

Understanding What We Mean When We Say "LHSS"

Dr. Robert Wilson, Associate Researcher, Faculty of Medicine, Memorial University, Manager of Quality of Care NL, Scientific Lead NL SUPPORT outlined the concept of a Learning Health and Social System (LHSS):

- The LHSS is a system in which science, education, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity.
- Best practices are seamlessly embedded in the delivery process, individuals and families are active participants in all elements, and new knowledge is generated as an integral by-product. The LHSS continuously uses evidence and engages the community as partners to inform and improve policy, practice and outcomes.
- The LHSS can be micro, meso or macro in scale. For example, a health care program, a hospital, and a national health care system can all be considered learning health systems, together, and as individual entities.
- In a learning health and social system, research influences practice and practice influences research. As such, it was noted that the LHSS is not a "product" that we can simply purchase for health and social care; rather, it is a process, a philosophy and a cultural shift to embed learning in all that we do to aim for continuous improvement.
- Link to presentation slides

Group Discussion

• Concept of continuous improvement is central to the LHSS

- We will need to establish metrics and evaluation from the outset
- Developing an asset map of the partners who need to be involved will be crucial
- Knowledge translation will be an essential component of the LHSS process.
- We're also looking at accountability frameworks and trying to evaluate the continuous improvement efforts. Within government and I guess I took some notes, while you're on your presentation, just things that kind of sit out to me and.
- The organizational culture and that shift will be essential. We will need to improve capacities for: evaluation, being transparent, sharing information, working collaboratively, sharing data
- Health system needs to understand that we can get a great deal of information from the community-based groups who that are collecting oftentimes better data than we are.
- The Treasury Board is responsible for the Transparency and Accountability Act in NL and efforts
 will need to be advanced to hold people accountable and to evaluate programs and projects as
 part of the LHSS approach. After Health Accord NL recommendations, NL has moved to one
 provincial health authority NLHS and they have created a VP position for developing the LHSS
 in NL (Kelli O'Brien, VP Transformation, LHSS). Activities now underway with symposiums, etc. to
 start fostering the culture.
- NL SUPPORT will be developing some courses so health and social system frontline workers can come in and start learning about this.
- Creation of Strategic Health Networks/ Quality Council approach will be useful in developing LHSS across the province
- Health system leaders are laying the foundation of where we have to go and how this will work; patience will be required as we figure it all out
- Department of Children Seniors and Social Development will be critical in connecting the social determinants piece, as will other government departments such as Education, Transportation, Municipalities, etc.
- Connecting with Community Sector Council will be essential for the social side of the equation

Resources

• People wanting to learn more about the LHSS can find a great list of resources in the Appendix of this document

Next Steps

To ground our mutual understanding of the LHSS and how it works, for the group's next meeting in January 2024, conveners Dr. Wilson and Dr. Barrett will speak about learning cycles. They will provide two examples based in NL: one from cardiac care and another from nephrology and will share the processes involved, Additionally, an example from Alberta in which clinical networks support learning cycles will be discussed, including considerations for resourcing teams, brining in context experts (including patients) and using structure to scale effective interventions.

Discussion about Health Literacy

Defining Health Literacy:

In 2008, Canada's expert panel on health literacy defined health literacy as, 'the ability to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life course.'

CDC in the United States updated their definition of health literacy in 2020 to include two separate dimensions

- 1. Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health related decisions and actions for themselves and for others.
- 2. Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health related decisions and actions for themselves and others.

Group Discussion

Summary

Overall, it was agreed that initiatives to improve patient literacy could be the subject of a learning cycle in the LHSS in NL. As an example, if evidence supports the role of patient navigators as a solution, we would collect the information on navigators and determine if improved outcomes are associated with the approach. If the approach is found NOT to work, then we would look into other potential tools, continually evaluating as we go. At out next meeting, we will discuss more real-world examples of learning cycles to illustrate this point.

The key issues discussed were how to improve health literacy using approaches that include navigators, patient and public health literacy awareness/ approaches, care provider communications would be important considerations as we develop the LHSS model in NL. The group sees potential for us to explore this topic further in future, beyond the patient aspect and into areas of organizational and research literacy.

For this meeting, the group discussed a range of issues/ approaches related to health literacy with a focus on personal health literacy:

Impact of poor personal health literacy

- Communication barriers have serious impact on the health and safety of patients. In terms of personal health literacy, research points to a large gap/ disconnect between what people are told by care providers within their healthcare appointments and what they understand/ act upon when they leave the appointment. Roughly only 40% of patients can recall what their doctor has told them after appointments. Obviously, limited literacy skills are predictors of poor health outcomes.
- Overall literacy is also a factor. Studies have also shown that when patients have low reading fluency, they understand less about their diseases, can be ineffective managing their own care, and are overall less likely to take preventive measures for their health.
- Limited health literacy affects health status, health outcomes, healthcare use, and health costs. The healthcare system relies on the assumption that patients can understand complex written and spoken information and that patients can navigate a complex medical system. Further, they are expected to manage complex care at home. If they do not understand health information, they cannot take necessary actions for their health or make appropriate health decisions.

- Care providers may present health information at a literacy level higher than their patients can grasp. Moreover, medical training comes with its own vocabulary (jargon) that can make it hard for health information to be understood.
- Poor health literacy leads to lack of adherence to medication regimens; missed appointments, laboratory tests, and referrals and improper health self-management. Patients with limited health literacy often end up back in a physician's office with more serious conditions or, worse, in the Emergency Department (ED).

Approaches to improve personal health literacy

- The gap between the literacy of clinicians and that of their patients must be bridged to achieve effective communication and understanding.
- Resources are available to help bridge these gaps:
 - The Health Literacy Place / Making it Easy is a Health Literacy Action plan for Scotland designed to rise to the challenge of responding to people's health literacy needs. The website, Health Literacy Place is a great resource: https://www.healthliteracyplace.org.uk/
 - Additionally, a group in the UK is dedicated to delivering health literacy through informed practice, primarily dedicated to building the evidence base for health literacy: <u>https://healthliteracy.org.uk/</u>
- Techniques for healthcare practitioners and for patients to improve communication skills are available here: https://www.healthliteracyplace.org.uk/toolkit/

Issues and approaches to personal health literacy and the LHSS:

- Group members suggested more time is needed to ask questions, more time is needed to ensure patients understand what they have been told.
- It was also suggested that the cultural impact of viewing the physician as an expert/ feeling ill equipped to ask questions can hinder patients from seeking clarity on their own healthcare
- The comprehensive school health framework being built with our health and education systems has a challenge in bridging different languages and cultures in education vs healthcare settings.
- Good early childhood education will be important in promoting literacy in health as is education in the perinatal stage.
- Tools that address diversity whether cultural, language or gender-based difference are important to develop to promote equity in health literacy
- It was suggested that a shared document to outline health information wold be helpful as would pamphlets/information guides that will help people at the time of diagnosis of a disease or chronic condition
- Another facilitator can be shared decision-making tools/patient decision aids that align with patient values. NLCAHR recently published a report on such tools as they relate to obstetrical care: https://www.mun.ca/nlcahr/chrsp/patient-decision-aids-in-obstetrics/
- Potential to draw on lessons learned/successes in past population health/public health campaigns (e.g. seatbelts, smoking cessation)
- Opportunities for family care teams, teams providing virtual care, and mobile care to connect people with opportunities in community and in government-for primary

providers to help bridge the gaps in understanding options — role for navigators and link workers/social prescribing to support health promotion.

- Literacy needs to allow time for conversations with patients and also needs to be promoted through the provision of services with cultural humility/sensitivity, gender-affirming care, Indigenous-informed practices, etc.
- Breaking down siloes among communities of practice will be an important goal in creating the LHSS in NL. It was suggested we work together and bring those common challenges to affect some of the change we are hoping to make. Social prescribing can be key to this process as well and can support improved health literacy initiatives.
- Evaluating progress with the patient experience (part of the Quintuple Aim) being put front and center is also a key goal of the LHSS; in terms of literacy, qualitative evaluations/listening to lived and living experience will be important.
- A diagnosis can be a great motivator for learning and improving health literacy. It was suggested that some ready to hand resources, shared with patients who have received a particular diagnosis, could be a useful approach.
- A culture of healthy living/ health literacy can be built; there are provinces in Canada where the culture overall, seems to have a great health focus (BC for example) how can we change the culture in NL? What kinds of literacies would need to be established to do that?

NEXT MEETING | JANUARY 2024 DATE TBA | EXAMPLES OF LHSS LEARNING CYCLES.

Appendix: Learning Health and Social System Resources

Description	Link to Resource
Building a Learning Health and Social System in Newfoundland & Labrador	https://youtu.be/SZ5Cow-U5Ws
Supporting Rapid Learning and Improvement Across Ontario's Health System	https://www.mcmasterforum.org/about- us/products/project/supporting-rapid-learning-and-improvement- across-ontario-s-health-system
Creating Rapid- learning Health Systems in Canada	https://www.mcmasterforum.org/docs/default-source/product- documents/rapid-responses/creating-rapid-learning-health-systems-in- canada.pdf
Creating a Rapid- learning Health System in Ontario	https://www.mcmasterforum.org/about-us/products/project/creating- a-rapid-learning-health-system-in-ontario
Creating a Pan- Canadian Learning Health System for Neurodevelopmental Disorders	https://www.mcmasterforum.org/about-us/products/project/creating- a-pan-canadian-learning-health-system-for-neurodevelopmental- disorders
Supporting Rapid Learning and Improvement for Select Conditions in Canada	https://www.mcmasterforum.org/about- us/products/project/supporting-rapid-learning-and-improvement-for- select-conditions-in-canada
Learning Health System Infographic	https://ssaquebec.ca/wp- content/uploads/2022/03/SSA_rectangle_details_twitter_pwpoint_avec- logo-SSA_en.png
What is a Learning Health System? Video	https://youtu.be/apeiC6f7JLU

Unite de soutien	https://ssaquebec.ca/en/the-unit/learning-health-system/
Quebec webpage	
Implementing the learning health system: from concept to action	https://pubmed.ncbi.nlm.nih.gov/22868839/
The Alliance for Healthier Communities as a Learning Health System for primary care: A qualitative analysis in Ontario, Canada	https://pubmed.ncbi.nlm.nih.gov/35488796/
Identifying requisite learning health system competencies: a scoping review	https://pubmed.ncbi.nlm.nih.gov/35998963/
The Science of Learning Health Systems: Scoping Review of Empirical Research	https://pubmed.ncbi.nlm.nih.gov/35195529/
A framework for understanding, designing, developing and evaluating learning health systems	https://pubmed.ncbi.nlm.nih.gov/36654802/
An Analysis of the Learning Health System in Its First Decade in Practice: Scoping Review	https://pubmed.ncbi.nlm.nih.gov/32191214/
Mapping the learning health system: a scoping review of current evidence. A white paper	https://researchers.mq.edu.au/en/publications/mapping-the-learning- health-system-a-scoping-review-of-current-ev

Everybody's talking about equity, but is anyone really listening?: The case for better data- driven learning in	https://ijpds.org/article/view/2125
health systems Gathering speed and countering tensions in the rapid learning	https://onlinelibrary.wiley.com/doi/full/10.1002/lrh2.10358
health system SCPOR supports two	
Patient-Oriented Research Learning Health System Projects	https://www.scpor.ca/lhs