Research & Knowledge EXCHANGE

NOTES FROM A MEETING OF THE **RESEARCH & KNOWLEDGE EXCHANGE ON THE LEARNING HEALTH AND SOCIAL SYSTEM (LHSS)**
OCTOBER 17 2024 12:30PM TO 2:00PM NT

Connecting Researchers and Health System Partners in the LHSS process

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Introduction to the topic by Dr. Brendan Barrett

- The focus of this Research & Knowledge Exchange is a learning health and social system (LHSS), a way to address challenges in healthcare delivery by creating learning cycles that will lead to quality improvements.
- At a recent meeting with health system leaders, we discussed how they might set up structures and governance for learning systems within the provincial healthcare system, acknowledging that we need to partner with the community organizations and patient partners as we do that.
- This meeting focused on how we can collaborate to maximize the impact of our combined skills and capacities, both within the health and community systems and also in the academic environment.
- Research within both the biomedical model and the humanities – will both be important.
- Research sometimes happens at a remove from day-to-day issues within the healthcare system.
- Within the healthcare system, people identifying problems and exploring improvements may not always have the research skills, time, or capacity to carry out research and analysis.
- This group aims to understand the capacities that are out there, what people are interested in doing; and how can we most effectively interact with each other and support each other within the LHSS framework.
- People working on the LHS in Alberta have taken steps to make it easier for academic researchers to interact with the healthcare system. We'd like to do the same here in NL.

Question #1 | Posed to people who work within the healthcare system:

What kind of activities would you see benefiting from input by academic researchers? What are you doing now or what do you anticipate doing where having researchers to partner with you would enhance your work?

Tina Edmonds, NL Health Services (NLHS) noted that Strategic Health Networks (SHN)/ Service Integration Teams (SIT) are translating evidence to practice on a consistent basis. This process will provide opportunities to connect the SHN and SIT partners with researchers, especially as NLHS works towards improved quality, risk management, and accreditation in health services.

- **Strategic Health Networks (SHNs)** are inter-professional groups with a provincial scope/ mandate to drive clinical and operational improvements in health outcomes and service delivery. SHNs bring people together, across professional groups and geographic locations or zones, to apply a provincial, strategic, and evidence-based lens to address issues and reduce unwanted variation in practices, processes, and outcomes and to support quality, consistency, and system sustainability. SHNs are now being established in a variety of areas including Care of Older Adults, Primary Healthcare, Surgical Services, Chronic Pain, and Emergency Care.
- **Service Integration Teams (SITs)** are being established to support programs that are delivered through a zone-based leadership model where SHNs are not in place. SITs will offer a mechanism for provincial coordination around operational issues, risk and quality improvement activities, implementation activities, and provide an avenue for zone counterparts to exchange information, problem-solve, discuss day-to-day operational issues, and collaborate on issues of mutual relevance.
- **Discussion:** Important to try and bridge the gaps that often arise between the generation of research evidence and its translation into changes in practice. The implementation piece is often the missing link, and delays often occur between the production of evidence and its communication out to decision makers and then to front line workers tasked with making a change in health services delivery.

Julie Sullivan, Director of a new SHN on Chronic Pain sees opportunities to work together, not just for her network, but for the other SHNs as well. She will reach out via email to initiate a conversation regarding how the SHN and the university can work together.

Angie Follett, Patient Adviser for NLHS noted that Patient and Public Partners are attempting to participate in processes that will lead to policy change. Patient advisors, can, however, feel that they are not doing "important research" and may sense that their contributions are perceived as being of a "lower rank" for decision makers. In terms of the impact of the work they do within healthcare, patient advisors may not always be sure of how their contributions lead to changes.

- Possible role for academic researchers to provide healthcare systems with a better sense of how to integrate patient advisory roles in the LHSS process.
- **Discussion:** NL SUPPORT is dedicated to amplifying patient perspectives in research. This unit is learning how to improve ways for patient partners not only to lead and to participate in research, but to know the impact they've had.
- The healthcare system is gaining a better understanding that while there has been some degree of engagement of the public, it has not always been carried out in meaningful ways. One key

aim of a learning health and social system will be to encourage meaningful engagement. There has been great willingness from the people in the healthcare system to move towards that model of meaningful engagement.

- A discussion about patient compensation was explored in the meeting chat. See Appendix.

Donnie Sampson, NLHS told u that a new Cardiac Care Program would benefit from academic research. A new NLHS online application called Get Ready has just been rolled out. The app was developed as the result of having a significant number of patients on waiting lists for cardiac surgery, with wait times being longer than we would want them to be. We recognize that being on wait list for cardiac surgery is stressful. The Get Ready Program is designed to provide regular check-ins. Right now, we have staff trying their best to call people, but staying on top of that task is extremely challenging.

- When people are waiting for cardiac surgery, we want to support them to move towards a state of readiness to make a change to their health before their surgery. With the Get Ready app, wait listed people are contacted to see if they would like to be signed up; if they are receptive, then they will be on-boarded to the program.
- The app has information about the importance of sleep, diet, exercise, well-being, psychological support, smoking cessation, etc. and information about how to get extra help with those things.
- NLHS has some client experience surveys built in to the app
- Whereas mail-outs were the standard before, NLHS did not know if recipients read the information; moreover, updating information was time consuming. The new app makes updates in real time and has checks to confirm understanding.
- A key outcome is that people will hopefully feel more supported and prepared for cardiac surgery. We also want to better assess how people using the app feel when they come in to have their surgery in terms of health and preparedness. Will they have fewer negative outcomes? What about their readmission rates?
- NLHS team hopes to assess whether and how the app may play a role in that journey for the patient. We see potential opportunities for research partnerships with that particular program.
- **Discussion:** A patient partner agreed that it will be important to reach out to people on wait lists.
- Suggested that we try to come up with some kind of process whereby people at the NLHS side of the table would be able to indicate that they are seeking research partners and to know where to go/whom to talk to at the university. Health system partners noted that the people managing this program will be supportive and engaged partners, with an eagerness to forge new research opportunities.

Matthew Cooper, Choices for Youth (CFY) discussed a national Learning Health and Social Systems Project. Matthew is the manager of impact measurement and engagement at Choices for Youth which has obtained a large CIHR grant for a national project to build out a learning health and social system that will capture learnings from integrated youth services that are running across the country.

- One area of particular interest is the question of engagement and how you build effective patient engagement. Engagement must center around trust. We need to acknowledge a lack of trust that often arises among patients and healthcare providers. The trust gap is not a "quick solution problem." Rather, it is more like the process of truth and reconciliation, a process that takes time—often a long time.

- One approach Matthew learned about recently about building engagement and building trust is to make an effort to ensure that the people who are using whatever system it is, whatever it is that you are asking them to participate in, you must make sure that they're involved in it, especially from the get-go. Co-creation is something that people talk about, bit that is also a more difficult and time-consuming way of doing things. It takes a long time. So when we're thinking about things like partnerships and we want to do things equitably and fairly, it takes a really robust approach. And so the implementation of research results often fails before it even gets started because there are so many layers that have to be built in order for it to have meaningful impact.
- **Discussion**: The group appreciated CFY coming on board for this discussion and encourages all participants to help us become a community of practice for learnings as your projects evolve. It was suggested that CFY could present this work to the group in future.
- NLCAHR and the conveners invite anyone in the group involved in projects like this to share their work with us. The Exchange can provide focus group opportunities for all research. We can help with methods discussions, with recruiting study participants, etc.

Rachel Tarrant, NLHS, spoke about the capacity for front-line workers to do research and seeks support with autism services evaluations and delayed diagnosis research. Rachel Tarrant is a clinical psychologist within the healthcare system working on the front line. She does not have any protected research time. While she has many research questions that she would like answered, (most especially program evaluation questions), she does not have the time to conduct her own research. She would appreciate having some academic connections to support that aspect of her work. Rachel asked to please reach out with any autism assessment or diagnostic delay research focus/interest: rachel.tarrant@easternhealth.ca

- **Discussion:** It was noted that building the LHSS will involve building capacity for the system to produce learning cycles and evaluate and produce quality improvements. The general issue for people in practice is finding capacity for "academic" activities when you are busy delivering services. A key challenge for the learning health system internally will be to harness the ideas of health workers like Rachel but without expecting them to actually do a whole research project on their own. Building the supports and the team around them may include an academic component together with a team of the people within your network structure to support the learning cycles.

PROGRAM EVALUATION RESOURCES

- Program Evaluations can be done through the Masters of Applied Psychological Services program. Dr. Catherine Button teaches a graduate level course where two students will come in and evaluate your program for free with the work overseen by academic expert and workshopped with the class. Contact cbutton@mun.ca
- NLHS has a provincial evaluation team as well organized under the leadership Kelli O'Brien and the Learning Health & Social Systems portfolio. The manager is Charlene Reccord, and she does all of the request intakes. Charlene.reccord@easternhealth.ca
- The Population/Public Health stream for the Master's of Public Health in Memorial's Faculty of Medicine involves courses and a capstone research project or practicum and can be completed in one year of full-time study. Master's of Public Health Practicums can be carried out in

community agencies or healthcare contexts. Program Co-ordinator, Dr. Alison Haynes (Population and Public Health stream) MPHcoordinator@mun.ca

Sources of Data for Community Sector/ Social Determinants of Health | It was noted by a researcher who had been unable to make it to the meeting that our health system is dominated by biomedical model and that there should be more of an embrace towards the humanities and the social determinants health. With this in mind, Robert Reid was asked to speak about Community Accounts Data and how it might have an impact on quality improvement within the community sector.

- Robert Reid is the Director of Stats NL on data development, data dissemination. Stats NL has information on social and economic topics on its webpage Community Accounts which has been designed around a well-being framework similar to determinants of health framework. The data can be accessed by anybody interested in looking at community and regional based well-being information.
- Community Accounts gathers mostly social and economic information (i.e., not a lot of the health information.)
- For example, government may ask Community Accounts to conduct population-based surveys on specific topics; at present poverty is the focus for a lot of data development.
- **Discussion:** If we want to move into a learning health and social system that focuses on the social determinants of health, we need to think more about what kind of data we can integrate to get broader perspectives. (e.g, linking poverty data with health and well-being outcomes)
- Stats NL has a close connection with Statistics Canada and can draw on their resources.
- Bailey Reid at NLHS noted that prevention and promotion teams across the province could certainly use Community Accounts data. She noted that there is potential for Community Accounts Data to be more effective for health system users by providing supports for navigating the website.
- Stats NL noted that in the past, they have run some training programs and used to do a lot of in-person training until COVID hit and they have not migrated to web-based training but that could be an opportunity for improvement.

Question #2 | Posed to people who work as researchers

In your experience with research, have there been barriers to engaging with the health system if you wanted to do work that requires some kind of partnership with people within the system?

Data Integration and Data Access seem to be consistent barriers to healthcare-related research in NL. We possibly need a legislative mandate to do this work in NL remains an issue.

- Looking at data issues over time, there seem to be waves of: "Yes. We should link everything to everything!".... followed by "Wait. We've got to consider privacy!" It's a tug of war but hopefully not an insurmountable barrier.
- In speaking with different research groups, we know that access to data can be a major challenge as can negotiating their way past the privacy barriers, filling out too many forms. If you do not work within the system, this can be difficult to navigate.

Building relationships takes time. NLCAHR, as a research unit, is unique in that its mandate is to partner with the healthcare system and to answer the research questions that the system would like us

to answer. If people find connecting with the health system to be a barrier to research, we have found that the number one facilitator in this process has been relationship- building and recognizing the importance of understanding who's doing what and where- a process that can take time and patience.

- Within our healthcare system, turnover and structural change result in navigating moving targets— a challenge from the researcher perspective. This challenge can be overcome by having really strong and long-lasting and sustained relationships with the people who work in the healthcare system.
- For NLCAHR, that involves checking in regularly with health system partners to determine if they have issues of concern; making sure our work is timely and relevant to them; being available to respond to their questions and willing to meet with them.
- **Discussion:** NLCAHR has been working with the healthcare system in such an integrated way for so long that we feel almost as much insiders as outsiders. We see NLCAHR as being an important conduit to bring community groups, health system partners, and researchers together to talk about how they can participate in the learning health and social system through this Exchange and in others too. We can be a broker to forging collaborations— a bridging mechanism between the sectors.
- On the other side of that coin, we have a diverse community of researchers and there's not always one place to find them, either! Forums like the Research and Knowledge Exchanges are one way to network/ meet researchers if you are on the health system side.
- We note opportunities for learners to work in collaboration with or on behalf of community groups in the learning health and social system. NLCAHR has had some success linking MPH students, as an example, with community agencies.

Timeliness of Data | Robert Reid noted that there are often criticisms from public partners and researchers about the timeliness of data. Stats NL faces barriers with both the quality of the data and its timeliness, especially when we talk about surveys or administrative data that seems to be a few years behind the curve.

- From a research perspective the challenge will be "when is the right time to let this go so that it can be impactful?"
- Robert Wilson noted that only a handful of databases provide information in real time. If you want to acquire health information for secondary use, there is a lag by the time data comes from its source system into what used to be NLCHI, and then they have to analyze data on their end before they can release it. Research is done at a certain pace that is not always supportive of rapid decision making.

Registry of Academic Research | It was suggested that a registry of academic researchers would be helpful.

- At Memorial, the Yaffle platform does this but is limited by the willingness of researchers to upload information to the site.
- NLCAHR looked into establishing a registry of academic researchers in health several years back and encountered many challenges, including researchers quite often not wanting to fill out yet another website, and then the challenge of keeping the information up to date.
- Memorial University Libraries are a great resource for people seeking to find local research.

- More relevant for the kinds of LHSS connections we are seeking would be our earlier discussion about making personal connections, recognizing that it is not a huge community of researchers that would be engaged with health here in NL.
- In Alberta they have research co-leads embedded in the Strategic Clinical Networks. Their health system has engaged specifically with researchers as part of the leadership within the health teams. That would be another idea to consider here.

Other Challenges/Barriers

- People in research have ideas and they just don't have connectivity enough to the system to get the right partnerships going.
- Healthcare or community workers may need a student to do some work, but the students need to be paid and they need supervision and their timelines/ availability may be different from project needs.
- Funding: People who are working in the university setting have a salary, so they're not really looking for personal funding support but they would need funding for hiring staff, data acquisition, publication costs, etc. It can be difficult to engage if you don't have the funding or the resources to do so. Funds could come from CIHR and the academic environment or they might come from the operational side- ideally a bit of both but there is a structural mismatch. CIHR will fund health research, but not evaluation; and yet the SPOR (Support for Patient Oriented Research) program is largely about engagement in system improvement and it may definitely require evaluation. Moreover, there is a divide at the ethics approval level. If you're doing health related research, you have to go through HREB or one of the other committees to get your work reviewed before you proceed. Whereas if you're doing program evaluation, they don't want to hear about it.
- Data literacy is another issue. People being apprehensive about looking at data and sharing data can be a huge issue.
- There are structural challenges. For the system to change, there will have to be some kind of evolution of these requirements; otherwise we will remain stuck in the old ways of doing things.

Potential Facilitators

Group Networking Events. Bailey Reid suggested bringing health system and academic partners together for a networking event.

- Rochelle noted that NLCAHR is hosting its 25th anniversary event on November 21st which will provide a place for health system and academic partners to meet each other.
- The SHARE Summit hosted by NL SUPPORT on November 12 2024 is their annual knowledge translation event and this year there will be a panel with a diverse group of people talking about learning cycles and teams and what is important for the various perspectives in terms of getting your learning cycle right.

Focus on Access. Making public meetings and events more accessible to people with different abilities and literacy levels will facilitate patient engagement. This can be everything from ensuring that your research is presented in plain language ways that are easily understood by readers, that research evidence is presented in a variety of formats that are useful to decision makers and ensuring that we harness technologies and supports that enable patient participation. Here, defining inclusivity is often an

event organizer's idea of what inclusivity is rather than asking the people who actually need to be included what they need, based on their experience.

Harnessing Connections through NLCAHR. The team at NLCAHR can broker collaborations. It's a big part of what we do. Contact rochellebaker@mun.ca with questions about connecting.

Research literacy approaches. All learning cycles require an understanding of the key issue. Sometimes if you ignore that piece and just jump to a change or a solution that you think will make things better without really understanding what's not working from the outset or what approaches are supported by evidence. Researchers may think of questions they are interested in which may or may not be relevant to the frontline healthcare worker and vice versa, the frontline people may be just so stressed with the day-to-day challenges that they can't focus on getting to the most effectively worded research question that can actually be answered by an evaluation or a research approach. This is where health and community system- academic partnership can be so critical. You can have brainstorming at the beginning with both parties there, along with their patient and public advisors, to really make sure that this is the right question and approach being taken.

There is a critical role for librarians in this process. Their expertise in helping people figure out the question they need to ask and then finding evidence is an essential role for the LHSS. Promoting the effectiveness and the expertise of librarians in getting to the root of good questions will be part of the process for sure.

List of Research Units at Memorial University. Health and Community Partners can connect with research units at Memorial here: https://www.mun.ca/research/extraordinary-research/research-units/

List of Leaders/ Organizational Structure / Strategic Plan at NLHS. Researchers can learn more about health system structures and transformation planning here: https://nlhealthservices.ca/wp-content/uploads/2024/09/NLHS_Strategic-Plan-2024-26_FINAL.pdf

List of Community Agencies in NL. The Community Sector Council publishes a great online directory of community agencies across NL here: https://cscnl.ca/directory/

LIST OF ACTION ITEMS FROM THE MEETING

- Rochelle Baker will contact Matthew Cooper at Choices for Youth and ask if CFY could present its national LHSS project to this exchange in future.
- NLCAHR and the conveners invite anyone in the group involved in projects related to the LHSS to share their work with us. The Exchange itself can provide focus group opportunities for research where you can pose questions and get diverse perspectives from people around this table.
- Rachel Tarrant would appreciate having some academic connections to support her work. Rachel asked exchange members to please reach out with any autism assessment or diagnostic delay research focus/interest: rachel.tarrant@easternhealth.ca
- People with questions about Community Accounts, including the need for training can contact Robert Reid: robertr@gov.nl.ca

APPENDIX |Group Chat comments on Compensation for Patient Partners

- Paying ppl for their time, (which can be done in a variety of ways) especially with cost of living so much as focus would be a great start. Ppl give less time because they have less of it to give, because it costs them too much in terms of resources to give. You can't pour from an empty cup, no matter how valid the purpose.
- Paying equitably has been a huge issue for us because if any youth are contributing any payment can cause issues with their Income Support. We're still looking for solutions beyond gift cards, which the Federal Government has just made essentially impossible to distribute as remuneration.
- This is something we have found tricky to juggle with adult patient partners as well! We want people to be engaged and to appreciate their contributions but need to be mindful of the tax implications of our payments and barriers associated with that
- A lot of the people who would love to become adult patient partners need to be met in a different way. I for one wouldn't be here if CODNL hadn't had access to a program that provided me with the tech to be here. They worked with me to make sure what i had what i needed rather than just provide me with a cash honorarium.
- CIHR patient partner compensation guidelines, for reference: https://cihr-irsc.gc.ca/e/53261.html
- NL SUPPORT patient partner appreciation guidelines for a local resource https://nlsupport.ca/wp-content/uploads/2024/09/NL-SUPPORT-Patient-Partner-Appreciation-2024-25-FINAL-signed.pdf