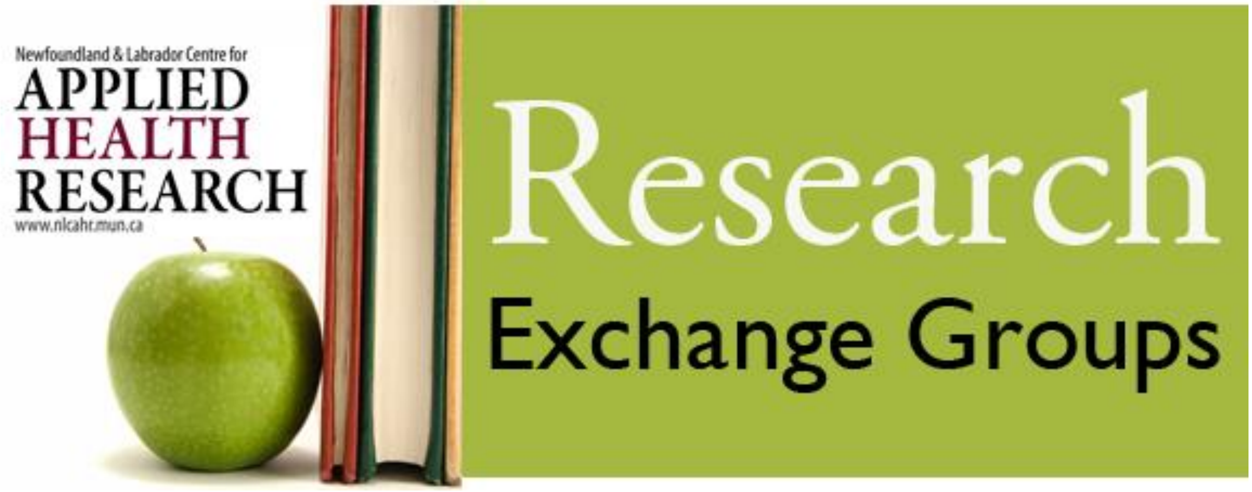

Notes from a meeting of the

RESEARCH EXCHANGE GROUP ON THE LEARNING HEALTH AND SOCIAL SYSTEM

October 24, 2023 12:30PM TO 2:00PM NT

The following is a summary of a collaborative exchange in which participants in the Research Exchange Group on the Learning Health and Social System discussed a variety of issues with a focus on planning and next steps for the group.

Key Decisions from the Meeting:

1. The group will meet once monthly at days and times that work for the majority (i.e. no rigid/scheduled day/time will be established). A Doodle Poll will determine the optimal timing for the next meeting, to take place between late November and early December.

2. The group's next three meetings will focus on the following themes:

    a. **Health Literacy and the LHSS** | What is a Learning Health and Social System? What role will literacy about health, wellness and research play in developing an effective LHSS in NL? How can these core literacies be improved?

    b. **Data Governance and Management for the LHSS** | Discussion with some data stewards from health and community care systems. What are the diverse types of data? Who holds them? How connected are they? Who has access? How do we work respectfully with First Nations/ Indigenous Peoples to recognize their data sovereignty?

    c. **Patient-Centred Approaches in the LHSS** | How can we effectively engage the voices of lived and living experience in the creation of the LHSS?

What is a Research Exchange Group?

Rochelle Baker introduced the concept of Research Exchange Groups, detailed online here**.** The groups bring people together from a variety of perspectives to exchange knowledge that includes but is not limited to research knowledge- lived and living experience, community and healthcare practice, program and policy knowledge are all respected and shared in this forum.

What is a Learning Health and Social System (LHSS)?

Convener Dr. Brendan Barret outlined the basic premise for the LHSS. He noted that the CIHR is funding research in this area and that both the Province and the NLHS are supporting efforts to develop a learning health and social system in NL.

- The *"social"* component of this approach recognizes the important role of social factors in the health of the population.

- The "learning" component recognizes a diversity of knowledge. While the conveners of this group come from a research background, the LHSS goes well beyond research. It's all about health and social practices. Figuring out what works best and using sources of information held by what might be called Population Knowledge Keepers as well as data collected as part of clinical care, or data collected as part of service delivery. Within the province, we are now looking at ways of using all those sources of data to understand problems and gaps, to assess them, and to introduce solutions.

- The "process" is generally thought of as moving in cycles (see process design below):
  - The issue is identified, whether by health workers/ decision makers analyzing existing data; through frontline staff experience; or when members of the public raise an issue.
  - LHSS leaders put together a team that is empowered to look at the issue more closely, to understand best practices, to uncover research findings in the area and to explore the nature of the issue locally.
  - The team then looks at various options for improvement.
  - The improvements are rolled out, possibly in a local context first, with the view to making practice and decisions more broadly across the system in the province.

[Link to information and video presentations through NL SUPPORT]

The Provincial Context

Dr. Barrett and Dr. Wilson are working with provincial health and community system leaders to help in their efforts to develop a learning health system. The social aspect will most likely be approached in partnership with community organizations, municipal governments, and interested publics. This Research Exchange Group will support these efforts by connecting with diverse partners and discussing their perspectives and issues. We will then work together with the healthcare system to try and craft policies and practices that improve health for all.

Ultimately, this Research Exchange Group is useful because it brings so many needed perspectives together around the same table.

Limitations

This Research Exchange Group is not a decision-making body. If participants think they have something that needs attention/ an issue to be decided on, we can discuss it here, we may be able to figure out who the right people to engage in helping to change practice or policy would be, but we wouldn't be doing that ourselves. We can certainly generate evidence and advocate for topics that we think are important to be addressed.

Background/Approaches to Developing the LHSS

Co-convener Robert Wilson is Program Manager of Quality of Care NL, a research and evaluation program at the Faculty of Medicine and Scientific Lead at NL SUPPORT which focuses on a patient -oriented research lens which in its latest iteration has a mandate to support a learning health and social system. Dr. Wilson pointed out that Learning Health System concept was introduced 15 to 16 years ago in the United States, but that developing a learning health *and social* system is quite unique. In Newfoundland and Labrador, the Health Accord NL made it clear that we need to focus on the social determinants of health as these have a great impact on health outcomes.

Dr. Wilson urged participants to think of a learning health and social system not as a *product*, but as a *process*—a process that will require perspectives from the widest possible range of stakeholders. He noted that the Research Exchange Group involves people across the full spectrum of health and social care and his hopes that the group can exchange ideas on how to support this learning health and social system.

Dr. Wilson and Dr. Barrett noted that the VP of Transformation: Learning Health and Social Systems at NLHS, Kelli O'Brien, is a participant in this exchange, which will provide a way for the group to keep abreast of, and to inform, policy making in this area at NLHS.

Participant Perspectives[1]

Dr. Kris Aubrey-Bassler, Director of the Primary Healthcare Research Unit (PHRU), in Memorial's Faculty of Medicine, is working with NL SUPPORT on a research grant proposing to develop a learning health and social system for primary care and is assembling proposals to two other funding competitions in a couple of weeks. While these proposals are not devoted exclusively to the LHSS, he noted that the LHSS is a significant component in these funding competitions. Agreeing that it is difficult to argue with the concept of a learning health system, Dr. Aubrey-Bassler noted that we will need to know more about what the LHSS actually looks like in a real-world setting. What tools do we have that constitute the learning health and system? What presumably electronic digital database tools are developed and used in regular practice? How can policy development to constitute learning health system roll out in a seamless way so that the concepts are integrated, well-used, and widely used? He is hopeful that this group can explore some of applications and frameworks for the LHSS in NL.

Dr. Suzanne Brake is the former Seniors' Advocate for NL and is now coordinating a Social Prescribing Research Project with SeniorsNL. She discussed the social determinants of health, as pointed out in the Health Accord, which highlight the intersection between aspects of social care (education, poverty

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[1] Participant input from Zoom Meeting Chat can be found in the Appendix

reduction, etc.) and population health. In her role as Seniors' Advocate, she recognized that we have built too many siloes among community and healthcare services and need to work to integrate the two. Social Prescribing is one way to connect social/ community-based programs with health and healthcare. This evidence-based practice has rolled out around the world and in other Canadian jurisdictions and is embedded into the UK healthcare system. Social Prescribing looks at the intersection between primary healthcare and access to supports in the community. SeniorsNL will be initiating a social prescribing project as a research project, with 3-year funding from a not-for-profit organization, that plans to work with family care teams in NL. The project has already hired two link workers to take on a navigator role that will link to resources in the community, which are non-clinical. For folks who have experience in healthcare, it may be useful to think about how to connect your patients to community supports and activities and to understand that there are interventions that promote better health outcomes and quality of life that fall outside of clinical domains. She urged healthcare providers to try to stay away from medicalizing words and language and to recognize the value of interventions that are non-clinical in nature. The project will be working with Quality of Care NL to develop its evaluation model.

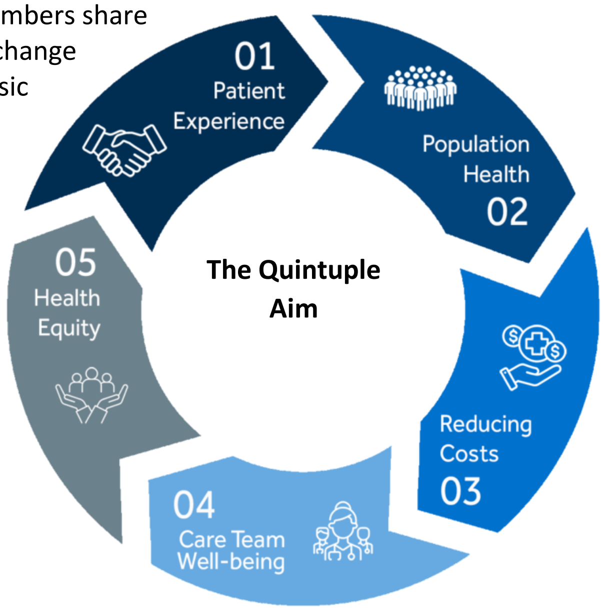
Rochelle Baker urged the group to have a look at Social Prescribing resources available through the Research Exchange Group on Arts and Health which made presentation to Health Accord NL to promote this model for the province:

- Evidence for Social Prescribing: Presentation by Dr. Jane Gosine of Memorial U with links to references
- A Compendium of Arts & Health Research and Programming in NL
- A Report on Social Prescribing for NL by Siham Sajed MPH
- The Health Evidence Network Synthesis Report (World Health Organization (WHO) on arts in health and well-being. Access the review here: Link to Review
- PaRx: Nature on Prescription: A Newfoundland & Labrador Social Prescribing Initiative

Dr. Barrett pointed out that the work Dr. Brake outlined could be made into a learning cycle as part of a learning health and social system.

David Thompson is a retired academic from Memorial University and his retirement group, the MUN Pensioners' Association, has a small discussion group called Health and Aging. And that meets once a month to talk about issues related to aging and health. Members share what they have learned from research and reading and exchange information, or they bring in a specialized speaker. The basic point is to share experience and research – a model of learning which mirrors that of the Research Exchange Groups program.

Rachel Tarrant works in the NLHS Eastern Zone where she conducts Autism Assessments. In her work, she is interested in learning how to best manage the patient experience. Having looked at frameworks of the learning health system, she notes that the outcomes the LHSS strives for are based on the Quintuple Aim.



Ms. Tarrant noted that workforce and patient experiences are outcomes of importance. T learn how to improve them, we will have to collect information.

She recently returned to Newfoundland from Ontario where she worked at Queen's University for a number of years. When she returned to this province, Ms. Tarrant noted some differences between NL and ON health systems. As an example, in her work conducting Autism assessments, she noted that waitlists in NL can be a couple of years long. She is trying to uncover ways to improve experiences for children whose parents are trying to get them diagnosed and understanding how these long wait times factor into patient experiences and impact access to services. She is hoping, through this group, to get some perspectives on how to manage the patient experience to ensure that patients in the province are getting what they need.

Within that context, Dr. Wilson noted that a research project was carried out in Western Health a few years ago on autism and telehealth.

Angie Follett, Client Patient Advisor with NLHS Urban Eastern Zone and Community-based Autistic Consultant, followed up on Ms. Tarrant's comments noting she is Autistic and gives presentations in the community to groups that are looking to integrate a more inclusive experience. She has prepared slide shows for both inside a health system and in community settings and offered to share this information with group members seeking to connect/ learn more. She noted that there are very few workers who are trained in the care of Autistic Adults, stating that her physical disability has qualified her for extra support that she might not otherwise access. From a patient perspective, she noted that because she is Autistic, she often needs help to manage health-related conversations. Ms. Follett further noted the importance of closed captioning and accessibility for persons with disabilities, pointing out that workplaces, social spaces, and public events are not often organized or designed with a disability lens, including the issue of HR policies for paid leave after a person has received an Autism diagnosis. Ms. Follett regularly shares her lived and living experience as a client patient advisor and is especially interested in geriatrics. One area of special interest is the intersection between Autism and Dementia.

To do: Rochelle Baker will invite Ms. Follett to share her lived and living experience with REG on Autism and will send her presentations from that group on Autism and the Aging Brain.

Sarah Perry is a graduate student at Memorial University who coordinated the Indigenous Languages Laboratory and Archive and who has a keen interest in communications. She spoke about wanting to explore how systems take data and lived experience and transfer these into knowledge (i.e., knowledge translation -KT or knowledge mobilization- KM). She pointed out that in terms of support for parents with Autistic children, there seem to be numerous gaps in this KT/KM process. Among these, Ms. Perry expressed concerns about accessing support on behalf of an Autistic child, noting that a parent often does not learn about the 2-year wait list for assessment until the child is in school and teachers suspect a problem/ disability, which adds delay upon delay in terms of early access to support. She noted that even with an Autism diagnosis, clear direction/communication about the implications of the diagnosis for children and families are lacking, as is access to care—parents are expected to know the solutions first in order to get information about appropriate services. When trying to communicate needs with the school system, there can be a lack of knowledge about both the overall issue and the ability to obtain support. She noted that people in both healthcare and educational settings really want to help, but expressed overall frustration about the impact on these issues for a child's social and school experiences. She acknowledged that completing the forms necessary for accessing care can be a barrier for people with disabilities. She acknowledged the importance of clinical supports for children, but also noted the need for parental support. She noted that help for parents in understanding Autism is a critical component of healthcare and stated that an Autism diagnosis has implications for the whole family, including an impact on the ability to work, increased poverty, higher rates of social isolation, etc.

Ms. Perry raised the important issue of connecting healthcare systems and educational systems as part of an integrated learning health and social system. The group will explore ways to connect with people working in provincial school systems and will make outreach to educators in future.

Dr. Barrett noted that when people are talking about developing systems and solutions, it helps tremendously to have people with living experience as part of the conversation so that you know what improvements are sought, know when tested improvements are working well and clearly connect improvements with patient needs.

To do: Rochelle Baker to connect Sarah Perry with the Research Exchange Group on Autism so that she can meet people who share some of the experiences she has described.

Rob Wells is a Newfoundlander living in Ottawa who retired from Memorial University after 32 years working in IT and educational technology at the University. He is new to patient-oriented research activities as a member of the NL SUPPORT Public-Patient Advisory Council as well as serving on other advisory groups in Canada. In researching the LHSS, he noted that the process/concepts often sound akin to those utilized in the private and public sectors as quality management systems. Mr. Wells implemented such systems in his professional career, once for the Marine Institute and once for an educational technology and teaching support unit at Memorial. He is interested in how the LHSS reflects the idea of continuous improvement, measuring what you are doing, using data to improve, measure and check in, noting how this approach had a tremendously positive impact on the organizations he worked with in both cases. He is hopeful that there are some key insights he can contribute, particularly around the importance of culture. Mr. Wells noted that we too often underestimate the role of culture when implementing learning systems. Key components of cultural change include making sure that people are empowered to suggest improvements, making sure that improvements are actually undertaken, measured and reported back. He sees this process as having the potential to transform healthcare in NL.

Dr. Barrett noted that working to better understand quality systems may be a direction for us to consider as a group - figuring out what kinds of helpful resources already exist/ their potential for adaptation, etc. without continually reinventing the wheel.

Fran Abbott was the coordinator of the Practical Nurse Program at NLHS, Eastern Zone and is a member of CORD, the Canadian Organization for Rare Disorders. She has an interest in the consistency of prescription drug coverage as a critical aspect of equitable healthcare in Canada. Having worked in the healthcare system for 44 years, she is now experiencing healthcare from the perspective of a patient, as opposed to a healthcare worker. She appreciates how difficult it can be to navigate healthcare systems and is learning about those challenges from the perspective of a patient, even though she thought she would have gained that understanding after 44 years in nursing. She sees lived and living experience as being of particular value and pointed out several key issues for patients, including: system navigation; the need to make paperwork and forms easier to fill out/ access; and issues with getting a timely diagnosis— all issues that certainly present for people with rare disorders. Ms. Abbott is also interested in how we might be able to share our patient health data with the other people involved in our care or with community care providers. At present, as a patient, she is responsible for coordinating complex care. Given that she is doing so after a long background of health system experience, she wonders how others are managing so many appointments with specialists and accessing other interventions. She noted that she does not have any access to her health record and finds that even when she makes specific requests (e.g., access to bloodwork results) her record is not always made available to her. Questions to consider are: Who is the data keeper? It can't be the family physician any more if so many do not have access to a family doctor. She is interested in how she can access her own health record and how we might improve gaps in that record.

Cindy Holden, RDH, MPH and oral health/ seniors' care researcher noted that people quite often do not monitor or study or understand their own health or have basic knowledge about health as the result of "leaving it in the hands of professionals" who are struggling themselves to learn how to coordinate care. Healthcare is very complex, but developing health literacy has to coincide with learning health and social systems- and should be a focus for future discussions. Research literacy is also critical—we are expected to make evidence-informed decisions— understanding what good evidence is, is an important part of that process. Ms. Holden advocated for the promotion of personal health literacy and beyond to systems literacies in various areas, as well as community literacy where people need to understand what's going on in our communities, noting that siloes are detrimental to the LHSS.

Kelly Heisz, Executive Director of SeniorsNL noted that health literacy is especially important when you discuss how health and social care are connected. Its implications can be very crucial if we are depending on people's understanding of what they are being told/advised by healthcare providers. Chances are that only about 40% of people actually understand what's being said to them. The outcomes in terms of wound care, medication use, taking care of yourself, coming back for appointments, etc., can be lost. Ms. Heisz provided a link to The Health Literacy Place in the UK. Which has been around for quite some time and offers good information. She noted that it will be timely to build literacy into our healthcare system as we're undergoing this process of health transformation in the province.

Mike Warren, Patient Adviser with NL SUPPORT asked if Dr. Barrett considers Newfoundland and Labrador to be on the cutting edge of developing the LHSS in Canada. Re we following any other province's lead? Are we leading in this area? Barrett noted that the answer is somewhat mixed, stating that at present, we do not have a comprehensive knowledge of what exactly is happening right across the country but are aware of some initiatives: Ontario, as an example, is taking a fairly organized and academic approach to developing this. Alberta was ahead of the game at the outset and had developed many of the processes that empower a learning health system and they have been doing learning cycles for quite some time. Here in Newfoundland and Labrador, we have the advantage of the health accord which has allowed us to look into it in more depth-- the Health Accord, together with the ongoing transformation of the health system have given us an excellent opportunity to take a deep dive into the LHSS and try and get it right from the start. At this point, the evidence base for the LHSS in countries or other distinct systems jurisdictions is not robust.

Pablo Navarro, Senior CHRSP Research Officer at NL Centre for Applied Health Research asked Dr. Barrett whether there are any local examples of the learning health and social system? Are there perhaps social system dynamics already in play in the healthcare system that we are expecting to scale up? Mr. Navarro was concerned that by describing the LHSS as being a singular thing, health and community stakeholders may think there is a lab somewhere in St. John's that does all the work, as opposed to the LHSS actually being a way/ a process of organizing and running a system that will be distributed throughout the entire province— that would include for example, a hospital in Grand Falls or the Labrador geographic zone, etc.

Need for Integration: Dr. Barrett noted that there will be room to adapt what already exists in local contexts but also for reinvention and integration within the system; as for instance with the inclusion of patient centeredness and patient engagement. While the four former health authorities have been doing patient engagement for a while, the approaches have often been fragmented. At this point, our healthcare system does not necessarily have an integrated process in place for fully and effectively engaging people and empowering them to really be part of decision-making. There is also huge potential for allowing front-line workers to have a voice—they see issues every day— but there is not really a great mechanism for bringing their issues forward.

Need for a Bridging Mechanism: Dr. Barrett noted the different issues raised today from patient perspectives, pointing out that while all of them are very important, from the perspective of health system leaders, how do you manage to sift through these issues and decide what comes first? A mechanism for priority setting will be important. Part of the learning health system often involves developing what is known as a "bridging mechanism" where ideas can be introduced and there is a prioritization method in place so that resources are effectively allocated to deal with issues as they arise. *Need for effective and appropriate resources:* Dr. Barrett then pointed out the team building aspect. As an example, some people might want to address an issue around Autism care. Who would you engage in that team? Which levels of decision makers? Which levels of care providers? What about community resources? Which people with lived experience should be brought together to work on the project? And then how do you resource that?

What we have in place now: Noting that we have quality improvement shops and research/innovation shops within the current health system, Dr. Barret was not as familiar with what is in place for improvements in the social care system. For instance, what exists in education? Bringing all these "shops" together and making sure that they function in an integrated way would be critical.

Looking at the LHSS as a process: Dr. Barrett stated that we should not think about the LHSS as one factory that is responsible for spreading information out of the system; rather we need to divide the process into macro, meso and micro levels. The macro level could be envisaged as a learning health system across the country or even within a single province. Then you can dive down to that micro aspect of learning how to improve one aspect of care (e.g. improving access to Autism assessments for children) that the LHSS will focus on in a single learning cycle. Another way to look at it would be that a program such as cardiac care, or a single provider such as a family physician, or a family care team clinic could use the process of a learning health and social system to make quality improvements. In that sense, the LHSS becomes a process development exercise.

The LHSS is ultimately a mechanism that everyone involved is familiar enough with that they can utilize it effectively. As such, implementation science will be involved. How do you develop a mutual understanding among stakeholders of what the LHSS is? Once you do, how do you put it into play/implement it? Mechanisms have to be developed for sharing all that sort of information with everyone.

Understanding Complexity: Dr. Barrett noted the complexity we discussed today around health care, community care and the connections between all of these layers is something we have to appreciate.

This process will take time and experimentation such that we will have to hopefully develop some good pilot examples. Then we can say, “when we did it this way, it worked really well!”

Dr. Barrett noted that a slow build does not mean an impossible build; nor does the process end up having to be fragmented and dispersed--we are seeking unity of purpose behind these initiatives.

Discussion about Health Literacy and the LHSS

- At the outset, members of this group will need a shared understanding of what a Learning Health and Social System is and what the vision for the LHSS in this province will be.
  Dr. Barrett will provide the group with a primer outlining the things we need to understand and know in order to create the cultural change required to build the LHSS in NL
- Need for improved health and wellness knowledge among NL patients and caregivers
- Need for improved research literacy among decision makers and clinicians
- Improving communication between care providers and patients/caregivers will be critical to improving health outcomes in NL
- Understanding patient and caregiver expectations and level of knowledge is key to providing effective healthcare.
- A group discussion about the role of literacy in creating the LHSS may uncover a chance to develop KT/KM about effective communications

Discussion about Health Data

- Group could hold a discussion with some of the data stewards from the system, including those holding data outside the health system as well. What are the diverse types of data? Who holds them? How connected are they? Who has access? How do we work respectfully with First Nations/ Indigenous Peoples to recognize their data sovereignty?
- The Patient Portal has been a work in progress at NL Centre for Health Information (NLCHI) and is close to completion. A patient partner at NL SUPPORT will be Patient #1 to test how it will work. The Patient Portal will give you web access to your own data, bloodwork and diagnostics, etc.
- Acquiring health data can be a complex navigation within the healthcare system as there are many different databases that pertain to different parts of the system. (e.g., pharmacy and hospital and emergency and community, long-term care, etc.)
- The Health Accord recommended providing a single health information system and our province is trying to strive towards acquiring that single system approach. Hopefully it will help with the process of patients’ acquiring their own information- and researchers, health and community partners having access to rich sources of data.

Discussion about Patient-Centred Approaches

- Patient experience and orienting the work of this Research Exchange Group with the patient at the center will be an important focus for this group— the idea that we always bring the exchange of knowledge and research back to the central question of “where does this fit with patient experience?”
- Understanding things from the patient perspective is an excellent way to build a broader and more inclusive learning health and social system.

APPENDIX – MEETING CHAT INTRODUCTIONS

- Brendan Barrett, NL SUPPORT, Fac Med, Group Co-convener
- Robert Wilson, NL SUPPORT, Fac Med, Group Co-convener
- Rochelle Baker, NL Centre for Applied Health Research, Research Exchange Groups Manager
- Fran Abbott, member of CORD, the Canadian Organization for Rare Disorders
- Natasha Pinsent - Signal Service Dogs. Interested in mental health and dogs! :P
- Angie Follett. Client Patient Advisor with NLHS. Urban Zone Eastern. Community based Autistic Consultant. I am also legally blind, hearing and mobility impaired. I am also a double book from the Summit. I left the room for the day though because they have yet to enact the captions option which means for the 2nd day I cannot participate equitably like everyone else. I also have a vested interest in geriatric care and mental health policy for neurodivergents.
- Susan Lemessurier Quinn, certified music therapist at the Janeway.
- Suzanne Brake Coordinator of the social prescribing research project, SeniorsNL
- Susan Stuckless, Research Associate with Quality of Care NL.
- Rob Wells, Patient Partner/Researcher, retired Memorial Administrator
- Ed Randell, Clinical Chief Pathology and Lab Medicine.
- Cheryl Etchegary, Health Policy Analyst, Quality of Care NL
- Pablo Navarro, Research Officer, NLCAHR
- Tracey Wells-Stratton; Program Evaluation Consultant with NL Health Services (and continuing coverage with Western Zone as Regional Manager - Research and Evaluation)
- Kris Aubrey-Bassler, Director of Primary Healthcare Research Unit at MUN and currently dabbling in developing a LHSS for primary care
- Sarah Perry, interested in neurodiverse communication (ADHD, Autistic, Neurotypical, Stuttering), especially in health care and education
- Rachel Tarrant - I work with NL health services eastern zone as a psychologist. Recently moved back from Ontario into a new position, and trying to tackle how to best manage patient experiences in an efficient clinically meaningful way.
- Cindy Holden - an advocate for interprofessional collaboration in health and my expertise is oral health. I have some experience in how popular and social media may be impacting health literacy at a personal and population level. However, I'm very curious of how this may apply to LHSS.
- Shauna Humphries, Primary Health Care Facilitator with Central Zone. I do a lot of work with Community Advisory Committees, identifying challenges that exist within our communities and how to help our residents live healthier lives.