WELCOME TO THE MARITIME SPOR SUPPORT UNIT:

Orientation Guide for Patient/Public Partners

April 14, 2023

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INTRODUCTION

WELCOME TO THE MSSU

We are thrilled to welcome you to our team! Thank you for choosing to join the Maritime SPOR SUPPORT Unit (MSSU) as a Patient/Public Partner.

Your expertise through your lived experience will be a valuable addition in our mission to improve the health of Maritimers through patient-oriented research. We appreciate your willingness to share your ideas with us and any part of your journey you may feel comfortable with sharing.

Sharing your voice can be a vulnerable experience, and we are committed to creating a safe and comfortable environment for all, with opportunities for growth and development to support you along the way.

We strive to create a sense of belonging and empowerment within our organization. We listen and engage with our diverse communities and know that having different perspectives inspires better ideas. When patients, researchers, and health care professionals work together, that's when we are truly able to make a difference in patients' lives.

We are happy to offer our support throughout your role as a MSSU Patient/Public Partner. If you need anything, feel free to contact our Patient Engagement Coordinators.

CONTACTS

PATIENT ENGAGEMENT COORDINATOR

PatientEngagement@MSSU.ca

OUR COMMUNITY

We have more than 50 staff working at five locations and are governed by committees that include representatives from government, health authorities, the research community, and patients and caregivers. We actively engage with our broader community including trainees and more than 150 MSSU Scientists.

Meet our People ↗

SCIENCE LEAD PATIENT ENGAGEMENT

Dr. Robin Urquhart- Dalhousie University, Nova Scotia

robin.urquhart@dal.ca

PATIENT/PUBLIC PARTNER COUNCIL CO-CHAIRS

Trudy Flynn- Co-Chair, Patient/Public Partner Council

Dr. Robin Urquhart - Dalhousie University, Nova Scotia

CONNECT ONLINE

ACKNOWLEDGEMENTS

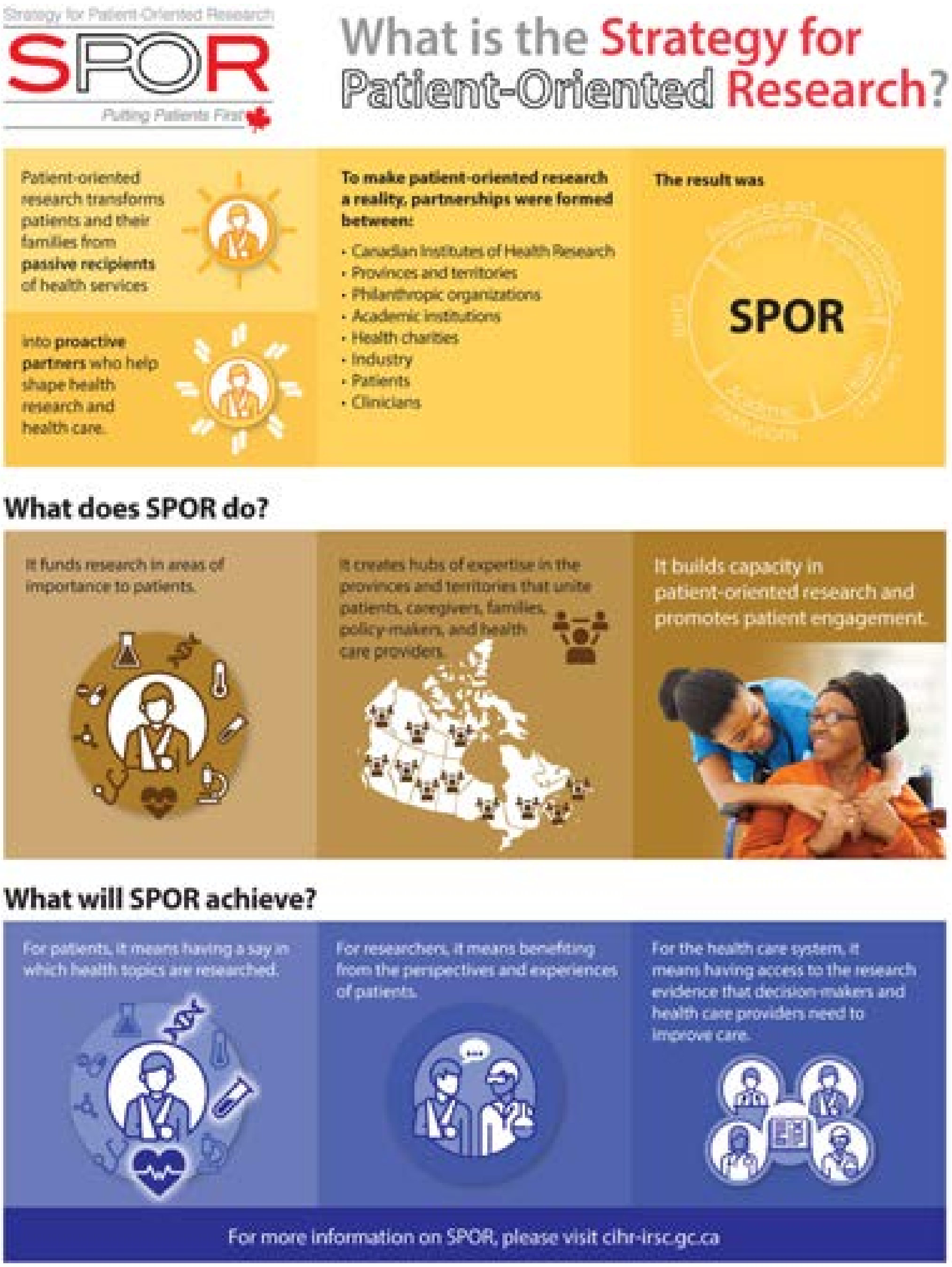
This Orientation Guide was developed by Linda VerLinden, Alan Doucet, Maggie Lyons MacFarlene and Lauren McLaughlin.

STRATEGY FOR PATIENT-ORIENTED RESEARCH

WHAT IS THE STRATEGY FOR PATIENT-ORIENTED RESEARCH?

Launched in 2011, the Strategy for Patient-Oriented Research (SPOR) wants to include patients and caregivers in research so that future policies in healthcare are relevant to the people who it directly effects. SPOR focuses on moving what health researchers know into what health care providers do, in other words, moving evidence into practice.

Infographic 1 - Strategy for Patient-Oriented Research



Strategy for Patient-Oriented Research

SPOR

Putting Patients First

What is the Strategy for Patient-Oriented Research?

Patient-oriented research transforms patients and their families from **passive recipients** of health services

into **proactive partners** who help shape health research and health care.

To make patient-oriented research a reality, partnerships were formed between:

- Canadian Institutes of Health Research
- Provinces and territories
- Philanthropic organizations
- Academic institutions
- Health charities
- Industry
- Patients
- Clinicians

The result was

SPOR

What does SPOR do?

It funds research in areas of importance to patients.

It creates hubs of expertise in the provinces and territories that unite patients, caregivers, families, policy-makers, and health care providers.

It builds capacity in patient-oriented research and promotes patient engagement.

What will SPOR achieve?

For patients, it means having a say in which health topics are researched.

For researchers, it means benefiting from the perspectives and experiences of patients.

For the health care system, it means having access to the research evidence that decision-makers and health care providers need to improve care.

For more information on SPOR, please visit cihr-irsc.gc.ca

STRATEGY FOR PATIENT-ORIENTED RESEARCH

WHAT ARE SPOR SUPPORT UNITS?

SPOR SUPPORT Units consist of patients and caregivers, researchers from different backgrounds, facilitators who specialize in research methods, and policy developers and decision makers. These units, including the MSSU, provide knowledge and support to patient-oriented research in their region, as well as assist with decision-making in health services.

The MSSU is the only SPOR SUPPORT Unit serving more than one province.

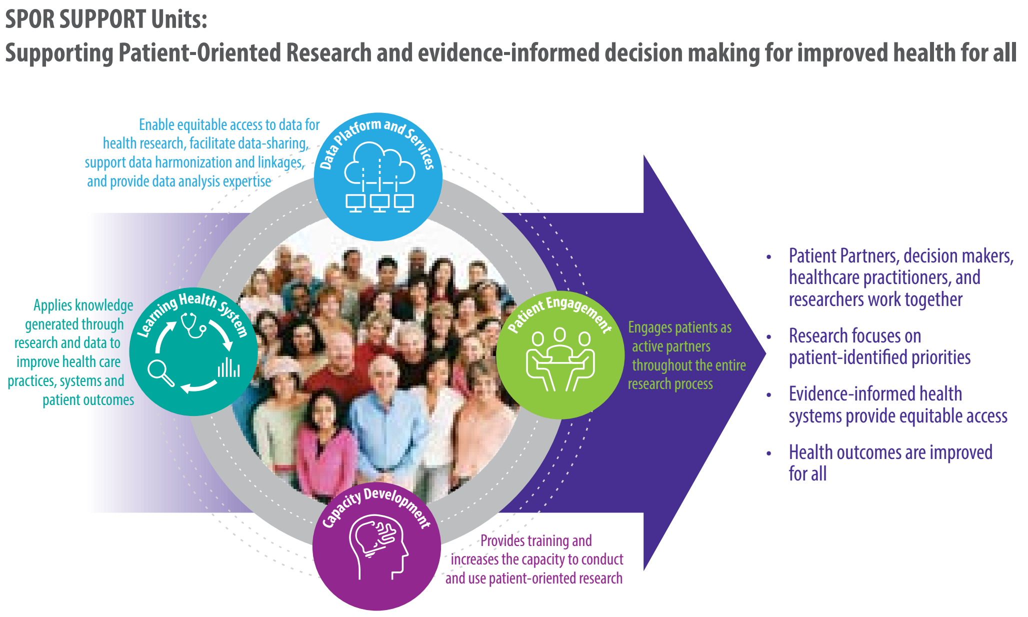
MARITIME SPOR SUPPORT UNIT

The Maritime SPOR SUPPORT Unit (or it's acronym, MSSU) was created by the Canadian Institutes of Health Research (or it's acronym, CIHR) with the Maritime provinces because they recognized that decisions in healthcare needed to be patient-focused and research evidence-based.

The MSSU brings people from PEI, New Brunswick, and Nova Scotia together to take part in patient-oriented health research. We work together with patients and caregivers, government representatives, healthcare decision makers, and researchers from all three provinces to share their experiences and knowledge that will help to encourage more people to get involved in patient-oriented research and encourage more people to get involved.

We are one of 11 SUPPORT Units (which stands for Support for People and Patient-Oriented Research and Trials) that form an important piece of the Strategy for Patient-Oriented Research (or it's acronym, SPOR). We receive funding from the CIHR which is then matched dollar for dollar by the three provinces.

Infographic 2- SPOR SUPPORT Units, CIHR



SPOR SUPPORT Units:
Supporting Patient-Oriented Research and evidence-informed decision making for improved health for all

Enable equitable access to data for health research, facilitate data-sharing, support data harmonization and linkages, and provide data analysis expertise

Applies knowledge generated through research and data to improve health care practices, systems and patient outcomes

Engages patients as active partners throughout the entire research process

Provides training and increases the capacity to conduct and use patient-oriented research

- Patient Partners, decision makers, healthcare practitioners, and researchers work together
- Research focuses on patient-identified priorities
- Evidence-informed health systems provide equitable access
- Health outcomes are improved for all

OUR RESEARCH

PATIENT-ORIENTED RESEARCH

Patient-oriented research (or the acronym POR) recognizes that patients (and caregivers) have lived experience of their health condition (or conditions) as well as the of the healthcare system. POR places value on this knowledge and acts on this by including patients on research teams as patient partners. Patient partners are connected with health care providers, decision makers, researchers, and other stakeholders to conduct research that is relevant and necessary to improve the health care related to their experiences.

The Canadian Institutes of Health (CIHR) Strategy for Patient-Oriented Research (SPOR) has advanced patient-oriented research in Canada. The MSSU is the result of this vision and commitment to engaging patients and caregivers in health-related research, and a part of the SPOR community.

The MSSU supports and conducts patient-oriented research across the Maritimes, including by helping Patient/Public Partners to engage in patient-oriented research across the Maritimes.

PATIENT-ORIENTED RESEARCH

- Engages patients as partners;
- Focuses on patient identified prioritities and improves patient outcomes;
- Is conducted in multi-disciplinary teams in partnership with relevant stakeholders;
- Aims to apply the knowledge generated to improve health systems and practice.

—Canadian Institutes of Health Research (CIHR)

PRIORITY RESEARCH PROJECTS

At the MSSU, our collaborative approach puts us in a unique position to create research teams that include people from several different personal and professional backgrounds—helping to guide patient-oriented research and help expand the practice across research teams in the Maritimes. Each year, we take an active role in research projects that address current provincial health priorities and inform health policy decisions.

How these projects are identified and completed is different between provinces. However, all three provinces identify topics for research by collaborating with key stakeholders including government, health authorities, and clinicians. These topics are then approved by our Provincial Steering Committees (PSCs), which include Patient/Public Partners and other health system partners like doctors and researchers.

Once a priority research project is accepted, our role can vary from helping with collaboration with Patient/Public partners, connecting researchers with health policy decision-makers, to leading the research and research teams ourselves.

If you would like to learn more about current research projects the MSSU supports, or which ones we have supported in the past, visit our **Project Page** ↗

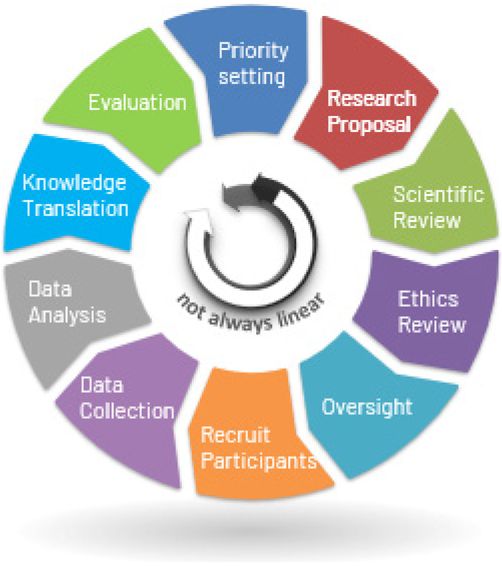
PATIENT ENGAGEMENT

WHAT DO PATIENT/PUBLIC PARTNERS DO?

In patient-oriented research, patients are not participants in a research study. Instead, patients and members of the public are partners on the research team. They collaborate with the teams to plan and do research. This could be done by helping tell the research community what is most important to answer, by identifying a research question and planning the research study, by collecting data and helping the research team understand it, or by sharing research results through presentations or connections with relevant groups.

As a Patient/Public Partner, you can choose an opportunity and the activities that interests you and fits with the time commitment that you are able to make. There are many opportunities that allow you to participate remotely, for example, by joining committee meetings online or through a teleconference.

Infographic 3- Patient/Public Partner Activities



Here are just a few examples of what MSSU Patient/Public Partners can be involved with:

- *Share your perspectives.* You share your experience with a health condition or receiving care. You may develop a speech or talking points, create a presentation, speak in front of an audience at a meeting or event, and/or answer questions.

- *Train researchers and other Patient Partners.* You may take part in a training conference or workshop. Depending on your interests and experience, you may co-lead a training session, present, and/or contribute to discussions.

- *Serve on a committee.* You can ask questions, discuss issues, and share ideas that others may not have considered. You will attend meetings (either in-person, by phone, or online), take part in discussions, and/or communicate through email.

- *Contribute to MSSU leadership and governance.* You may be invited to join one of the committees that govern the MSSU. You will attend regular meetings (in-person or by phone, or online), read background materials, contribute to discussions, and be a part of decision-making processes.

PATIENT ENGAGEMENT

CIHR SPOR PATIENT ENGAGEMENT FRAMEWORK

The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners. It is important to note that this Canadian Framework is a living document.

Visit CIHR SPOR Framework ↗

MSSU PATIENT/PUBLIC PARTNER COUNCIL

Established in May 2021, The MSSU Patient/Public Partner Council (PPPC) membership is made up of Patient/Public Partners from all three Maritime provinces, each of whom bring their own unique experiences, perspectives, and interests. Through regular virtual meetings, this council provides recommendations and feedback to MSSU's leadership and various committees to ensure that a diverse patient voice is incorporated into the MSSU's operations and research activities. Several key achievements of the PPPC include directly informing the activities and priorities for MSSU's Patient Engagement Workplan for 2022-2024, and advising on the ways in which we evaluate patient engagement within the MSSU.

The PPPC is co-chaired by a Patient/Public Partner and the MSSU Patient Engagement Science Lead.

If you are curious to learn more about how being a Patient/Public Partner works in practice, **read some of the interviews** with MSSU Patient/Public Partners or connect with a MSSU Patient Engagement Coordinator.

Who is the Patient/Public Partner in POR?

Any person with experience of a health condition or receiving health care. This includes both patients living with that condition as well as their caregivers such as family and friends.

The MSSU uses the term Patient/Public Partners, but other SPOR SUPPORT Units and research groups across the country may use other terms, such as Patient Advisors, Citizens, or Community Partners.

RESOURCES

HOW TO FIND RESOURCES

The MSSU has developed an online collection of guides, reports, webinars and tip sheets to help our community conduct and implement patient-oriented research. Our Patient Engagement resource collection holds links to many quality resources reviewed by our Patient Engagement team and Patient/Public Partners. If you can't find what you are looking for, reach out to a Patient Engagement Coordinator. We are happy to advise you of the best resources for the topic you are looking for. We have also included some commonly used resources in this orientation guide for you to review.

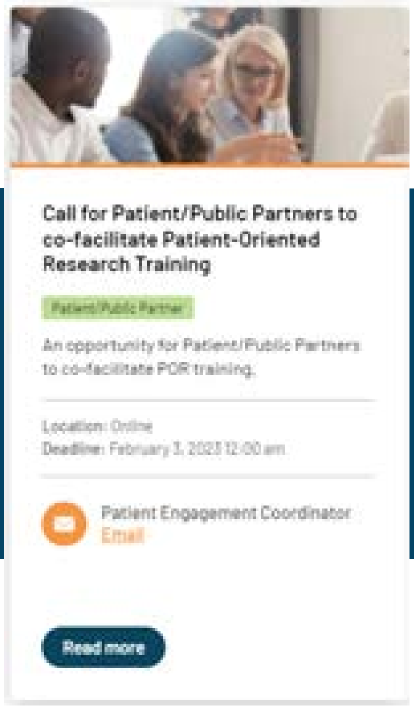
Online Resource Library ↗

PATIENT ENGAGEMENT OPPORTUNITIES

All opportunities for Patient/Public Partners will be posted on our opportunities webpage. They will also be shared in the MSSU newsletters and on social media.

Sign up for MSSU newsletter

Visit our opportunities webpage



Call for Patient/Public Partners to co-facilitate Patient-Oriented Research Training

An opportunity for Patient/Public Partners to co-facilitate POR training.

Location: Online
Deadline: February 3, 2023 12:00 am

Patient Engagement Coordinator
Email

RESOURCES

TOKENISM

Patient engagement is still relatively new to many health researchers and while it may not be their intent, this can sometimes lead to a less than fantastic experience for Patient/Public Partners. These poor experiences can lead to Patient/Public Partners feeling like they are being engaged to 'check a box' or as a 'rubberstamp' for the project, an experience that is often defined as tokenism.

It is important for everyone involved in a research engagement activity to be aware of what tokenism looks like so that if the patient engagement does feel or look tokenistic, the team can work together to find a solution and move towards a more meaningful engagement experience.

IF YOU FEEL AN OPPORTUNITY YOU ARE ENGAGED WITH IS TOKENISTIC, THERE ARE OPTIONS AVAILABLE TO YOU.

1. Meet with your MSSU Patient Engagement Coordinator to discuss the situation. The Patient Engagement Coordinator is here to listen to you, your challenges and support you and the researcher to best work together so that everyone feels comfortable and heard. You and the Patient Engagement Coordinator can come up with a path forward that you feel comfortable with. This may include, but is not limited to, providing clear recommendations, resources and/or coaching back to the research and/or team.

2. Share your concerns to the researcher and your liaison with the research team or committee. If you are comfortable, you can provide your perspective to your contact and share ideas on how the experience could be improved for you.

3. Choose to no longer be engaged. You can decline to continue to be engaged or be engaged in future activities at any point of time. We encourage you to try to work with the researcher(s) to find a solution that works for everyone, but if you have tried with no success, it okay to leave an engagement opportunity. If this is the option you feel is more appropriate for you, you can advise your liaison directly or work with the MSSU Patient Engagement Coordinator to share your decision.

Learn more: Tokenism in Patient Engagement

Read: "How Do We Move Beyond Tokenism in Patient Engagement"

CHARACTERISTICS OF TOKENISM

- Power imbalances between researchers and patients
- Low diversity among patients
- Inviting 'any' patient just to have a patient
- Inappropriate location, format, and timing of meetings
- Lack of role definition
- No clear expectations
- Engagement after a research proposal has been developed
- Lack of trust

RESOURCES

PATIENT-ORIENTED TRAINING

We're pleased to offer virtual Patient-Oriented Research Training based on the Patient-Oriented Research Foundations modules provided by Canadian Institutes of Health Research (CIHR). Training takes place over two half-day sessions.

The training provides an exciting and practical introduction to patient-oriented research, and patient engagement. Sessions are delivered with co-learning in mind, so we welcome participants from many diverse backgrounds, including researchers, healthcare providers, students and of course, Patient/Public Partners.

We encourage all Patient/Public Partners to participate in this training. If you are interested in registering for an upcoming session, please contact your Patient/Public Engagement Coordinator.

5 TIPS FOR RESPONDING TO A REQUEST FOR YOUR STORY

1. Reflect on your experiences

Are you ready to share your story emotionally? Ask yourself – am I too angry, too anguished to see what can be learned from my experience – if so, maybe it is too soon. Feel free to decline.

Can you pick out the key learning points from your experiences ? Do you know what went right, what went wrong and how it might have gone better? Can you learn more about what happened by talking with those involved or by doing some research? Provide yourself with the most robust understanding of your experiences.

2. Identify which stories you have

Within your experiences you may have more than one story. What are they? Can you pick them out based on key learning points? How long are each of your stories? How complex? Can you simplify them to make your points?

3. Get the practical information about audience, timing and format

Who is your audience and how many? Are you on a panel with others? Are you a key note at a podium with a microphone? Or kicking off a meeting? Is someone going to ask you in the middle of a meeting as you sit around a table? How long do you have to tell your story? Do you need to have slides to support your story? What slide format or size? Do you need to send slides in advance? Will there be questions? Are you comfortable with the technology from microphones to webinar software?

4. Select your story to fit the purpose

Why are you being asked to tell your story? Who will be listening to it? What is the goal of the event or group? What do you want them to learn from your story? What do you want them to change based on your experience? Learn about and understand the context and audience to make the most impact.

5. Prepare and practice in advance

Write out your story for the timeframe making sure that you are clear about the 1–3 points you want the audience to take away. Three points is the maximum people can remember to take away. Practice until you are comfortable and have nailed the phrases you want and have the timing down. Make sure you breathe and build in pauses so the audience can absorb. Being prepared does not take away from the authenticity of your experience and insights; it may enable you to make a stronger impact.

These tips were developed by the Patient Advisors Network. Learn more on their website.

RESOURCES

PATIENT/PUBLIC PARTNER APPRECIATION POLICY

The intent of this policy is to define the circumstances and set out the procedures to recognize and appreciate the time and effort of Patient/Public Partners engaged in activities with the Maritime SPOR SUPPORT Unit (MSSU).

Many Patient/Public Partners are active contributors with the MSSU and add significant value to our work and the work we support. To demonstrate our appreciation for the sharing of time and perspectives from our Patient/Public Partners, we provide offers of compensation for various MSSU activities our Patient/Public Partners are engaged with, including MSSU committees and priority research projects. The MSSU offers Patient/Public Partners in-kind opportunities as another way of showing appreciation, such as attendance at various select MSSU hosted workshops/conferences, Patient-Oriented Research Training and MSSU orientation.

Furthermore, the MSSU aims to strive for greater equity, inclusivity, and diversity among its Patient/Public Partners to more fully reflect the wider society that accesses healthcare. Recognizing Patient/Public Partners for their involvement is an intentional step in supporting equitable inclusion and participation by easing financial constraints.

An offer of appreciation, such as compensation, is not intended to reflect the market value of a Patient/Public Partner's contributions; it should, however, be seen as an expression of appreciation.

MSSU GLOSSARY

Our online glossary provides simple definitions for words and acronyms that are commonly used in health research, as well as a few terms that are specific to the MSSU and the Maritimes.

Many of these definitions were adapted from glossaries from the following seven organizations:

- Canadian Institutes of Health Research (CIHR)
- INVOLVE UK
- Research Data Canada
- Social Sciences and Humanities Research Council
- New Brunswick Institute for Research Data and Training (or the acronym, NB-IRDT)
- University of British Columbia
- Building Research for Integrated Primary Health Care Nova Scotia (or the acronym, BRIC NS)

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www.mssu.ca