BRIC | Patient partner orientation guide series

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HOW TO GET INVOLVED IN HEALTH RESEARCH

What is it all about?

BRIC NS
Building Research for Integrated Primary Care

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

What is a Patient Partner?

We use the term ‘Patient Partner’ to refer to a person with lived experience of the healthcare system, either directly as a patient or indirectly as a caregiver. Patient Partners actively participate as a member of a health research team.

You may have heard other terms used to describe patients and caregivers who are involved in research, including patient/family advisors, citizens, community representatives, or experience partners. While these terms are slightly different, they all recognize that you have an important role in shaping and guiding the research process.

About the Patient Partner Orientation Guide Series

Welcome to the Patient Partner Orientation Guide Series for patients and caregivers who are interested in becoming involved in healthcare research.

Information in the Guide Series has been adapted, with permission, from others such as INVOLVE in the United Kingdom. Patient Partners provided advice on how to adapt information for the Canadian context. They also helped identify information that people need when they first become involved in research.

The Guide Series is made up of three booklets:

1. A quick guide

This guide answers the main questions people ask when they first become engaged in research. It explains how you get involved in research, what you can expect and the difference you can make.

2. How to get involved in health research–What is it all about?

This guide gives some background information about research and Patient Partner engagement and why it is important to become involved. It also describes some ways that you can get involved in research.

3. Jargon Buster

This guide provides a glossary of words or terms commonly used in health research.

What is patient engagement in research?

Everyone benefits from research–not only scientific research in laboratories, but also research into health and social care. Research produces evidence about what works best. Patients, caregivers, policymakers, and healthcare professionals use this evidence to make decisions about treatments, care, and services.

When most people think about patients in research, they usually think about patients as research participants. **Research participants** are people who take part in a research study, for example by trying new medicines.

Patient engagement is different. Patient engagement means that patients or their family members/caregivers work together with researchers to help make decisions about what research gets done, how it gets done, and how the results are shared and used in practice. One way to conduct patient engagement is to have patients or caregivers included as members of the research team. These team members are called **Patient Partners** and they are very important to the research process.

> **The Strategy for Patient-Oriented Research (SPOR) is an initiative to support patient engagement in research across Canada. It is led by the Canadian Institutes of Health Research (CIHR), the federal funding agency for health research. SPOR promotes meaningful and active participation of Patient Partners in the research process. This means research is being carried out 'with' or 'by' Patient Partners, rather than 'to' or 'about' them.**

By becoming a Patient Partner, you can help make research more relevant for the healthcare system to improve the experiences of patients, caregivers and the public. You co-create research that is meaningful and minimize research that is not as helpful. By joining research teams, you could work with researchers, healthcare professionals and policymakers to improve the quality of health research and make a difference to the way health care is provided in the future.

"Your voice is needed." – Judy Porter, Patient Partner

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[1] Content for this guide has been adapted, with permission, from Buckland, S et al 2007 Public Information Pack. How to get actively involved in NHS, public and social care research. INVOLVE.

"My biggest achievement has been able to speak and share my story around the table." – Juanna Ricketts, Patient Partner

Why get involved?

Patient Partners have different reasons for getting engaged in research. For many, it is about making a difference and wanting to make healthcare better. Some people have been through difficult times and want to do something helpful with that experience. Others have had very good experiences and get involved to 'give something back.'

Patient Partners often say that research is more rewarding and fun than they expected. Research can give some people a new **sense of purpose**, by providing an opportunity to use their experience and knowledge to help make the future better for others.

Being on a research team has given Patient Partners **new knowledge**, from learning about how research works, what researchers are really like, and hearing about the latest research on different conditions. Some people use the knowledge they gain in other areas of their life, for example their careers or involvement with community organizations.

Being a Patient Partner allows people to develop **new skills** (such as public speaking) and provides them **opportunities to use their existing skills**. People do things they would never have imagined such as meeting with health officials. They sometimes go back to doing things their health prevented them from doing. Sometimes developing and reusing these skills helps people to find work or go back to work.

Many people enjoy the **sense of feeling valued** by a research team. People who have lost jobs because of their health often say they lost confidence in their abilities. Getting involved in research helped to remind them of what they can do. Patient Partners may also **gain confidence** over time and often look for ways to become even more engaged and involved.

Talking about their condition and/or care experience with research teams sometimes **provides people with a different way to cope**. They value being able to talk to someone who is genuinely interested in their condition and making use of what might have been a good or bad experience.

"It's so important to have patients involved because some of the most common-sense things are overlooked. When you live and work in a certain world, some practical things don't come to mind anymore. Having patients involved helps to ground the project. When you're in an academic or policy world you work in a bubble and you need all the people to bring their perspectives and concerns into the process."

- Larry Baxter, Patient Partner

Why do researchers want to involve Patient Partners in research?

In Canada, involving Patient Partners in health research is relatively new but it is becoming more and more common. SPOR requires that all research proposals include patients in order to receive funding for their project. Applicants must include information about how they have involved patients and/or community members in developing their proposal, as well as how they plan to involve them in carrying out their research.

Many researchers understand the benefit of working with Patient Partners. To them, it is not just about a funding requirement – you help the work be more relevant and helpful for people. Researchers want to listen and learn from their conversations with patients, caregivers and the public. **Your input makes the research grounded in real world experience.**

> *"I thought that my personal experiences throughout the Canadian healthcare system could greatly contribute to health research. As someone living with multiple chronic conditions and having constant interactions with various healthcare providers, this seemed a way that I could meaningfully contribute."*
>
> *– Kylie Peacock, Patient Partner*

What can I bring to the research process?

You can make a difference at any stage of research. Your contribution can help shape the planning and delivery of the research project. You have a powerful voice that can also influence others beyond the research team, including the research participants or the people who use the knowledge generated through research. Sometimes the contributions from Patient Partners, caregivers and members of the public determine whether a project gets funded, whether it runs successfully, and whether the results change healthcare practices.

You are an expert in your own life experience. Your knowledge from having been through your own care, or the care of others, is very valuable. Many researchers are healthcare professionals and will know a lot about treatment and services. They may also have textbook knowledge about your condition but, unless they have also lived through it, there may be gaps in their understanding. By contributing your experience and your views, you provide valuable input that would otherwise be missing.

Personal experience has led to many improvements to our healthcare system, including:

- Having a live person answering the phone lines for a mobile crisis service rather than an automated message
- Better communication between patient and clinic about the purpose of a short-term clinical service
- Increasing awareness about the need for culturally competent services and some ideas about how to do this
- Development of a health mentor program

Have I got the right experience to be involved?

If you get involved in research, you will not be expected to have technical knowledge of how research or the healthcare system works. You will pick that up as you go along. You already know all that you need to know, based on your experience of living with a condition, illness, or disability, using or navigating through services, or looking after someone else. The knowledge you have as a patient, caregiver or member of the public is what is unique about your contribution to the research team.

> *"You know a lot of stuff that the research team doesn't know, so don't feel like you're the one that doesn't know things. There's a lot of things you know that the team has overlooked or doesn't even know about. Your contribution can be so valuable. In some ways it can make or break the project, because if you don't connect with the community... research doesn't happen."* *– Larry Baxter, Patient Partner*

You do not need any special qualifications to be involved in research, but you may have skills from other parts of your life (for example, from working, volunteering or family life) that will be valuable. The combination of these skills and your knowledge and experience could make you the ideal Patient Partner. For example, in a research project involving women with ovarian cancer, one of the women drew on her skills in organizing events to help plan a final workshop for patients. She wasn't just a volunteer providing an extra pair of hands on the team. She used her experience as a patient as well as her organizational skills to help plan the workshop. She ensured it was easy for women with ovarian cancer to attend and that the workshop agenda would cover what other patients would want to hear about.

"It's a great experience to be able to be involved. Don't be afraid."

– Juanna Ricketts, Patient Partner

There are many types of research looking at hundreds of different topics. Research teams need to hear the views of people from different backgrounds. This means your experience might be more relevant for some projects than for others. It is about finding the projects that need input from people like you and roles that match your interests and experience. For example:

- Research looking into a new screening test for lung cancer wanted to involve members of the public who were smokers and ex-smokers, to contribute their views on the research
- Research that wanted to improve case management for patients with multiple chronic conditions wanted to hear from people who experienced these conditions
- Research looking to adopt or create tools to help people navigate social barriers (such as limited income) would like to hear from people who have experienced these issues
- Research focused on care provided to individuals as they approached the end-of-life wanted to hear from people with experience caring for a loved one at end-of-life

What advice can you give me for joining the research team?

Joining a research team as a Patient Partner for the first time may feel intimidating for some people, especially if the research environment is new. Remember that your contribution is important and valuable. Here are a few things to keep in mind:

- Researchers are people too and may be just as nervous about meeting you and getting everything right
- Remember that you are not expected to speak on behalf of all patients Simply draw on your own experiences and those of the people you know
- Never be afraid to ask questions. Sometimes a question that may seem simple and obvious is exactly what needs to be asked
- You might be able to open up discussions that might not have happened before

What can I expect of the people who involve me in their work?

As a Patient Partner, you should expect the other team members to work with you in a respectful and clear way the entire time.

When you first get involved, you will likely want to know more details about your role and commitments. One or two members of the research team will meet with you to talk about the needs for the project, the details about whether and how you will be compensated for your time, how you can get reimbursement for any expenses you incur, how to communicate with the team, and who to contact if you have any questions.

Researchers should also work hard to provide:

- Clear information about the engagement opportunity, and your role and responsibilities as a Patient Partner
- Clear information about payment for any expenses you have as a result of your involvement and about how to claim your expenses
- A choice about when and how to be involved
- A welcoming environment
- Practical support to make your involvement possible, for example booking accessible venues for meetings, providing paperwork in large font, involving you in meeting scheduling, considering things like parking and public transit
- A good working relationship based on mutual trust and respect
- Feedback on your involvement and appreciation for the difference you've made
- Opportunities to give feedback on your involvement and the impact of the work you have done

Sometimes you may feel like you need more support as a Patient Partner. In many cases you will be able to solve problems that arise by talking to a contact person or the lead researcher on your team. If for any reason you do not feel comfortable doing this, please feel welcome to reach out to BRIC NS or the Maritime SPOR Support Unit (MSSU) with any concerns. They can act as a bridge to the research team. Contact information can be found in the back of this guide.

Will I receive compensation for my role as a Patient Partner?

Compensation is a way to show appreciation for a Patient Partner's time, energy, and contribution. Compensation might take the form of honoraria, gift cards or in-kind gifts. Compensation for Patient Partners should not be looked at as payment for a job; compensation is not considered equal payment of equal value as compensation is not work pay. However, fairly compensating Patient Partners for their involvement is an important way to acknowledge a Patient Partner's contribution of time and expertise.

At the present time, some research teams may not have the funding to do this, and so your involvement may be on a volunteer basis. Other teams may be waiting for a funding grant to be received before you are able to be compensated. The details about compensation should be clearly described to you when you first get involved. Patient Partners should be advised if their time will be compensated or not, and what compensation is being offered prior to engaging with a research team, event or committee.

> **Patient Partners need to know that compensation such as honoraria is considered taxable income by the Canada Revenue Agency (CRA) and often a T4A could be issued to them. Compensation may affect their earnings if they are on social assistance, Canada Pension, Employment Insurance or receive Disability Allowances. It is advisable to seek information if you feel you will be impacted by accepting compensation. Please be advised that you are not required to accept payment if you do not want to; you will not be excluded from the research team if you refuse payment.**

Out-of-pocket expenses associated with a person's participation in the activity should be discussed with the organizing group. These expenses could include things such as: travel to the event, registration fees, accommodations (hotels) or covering meal cost. Reimbursement for your expenses is not considered taxable income.

What roles can I take on as a Patient Partner?

Your role in research can look very different depending on your own interests, comfort level and what work has already been done. While some details may already be decided when you join the team, there may be other ways you can help shape the research.

Most research teams tend to do a lot of work as a group. Some meetings may be in person. Some may be held over the phone or online. You will often be able to work in a way that suits you best, choosing roles that match your interests, experience and skills. If you sense that the research is 'out of your league' or unclear, you may want to discuss this with staff at BRIC NS, MSSU, or the research team lead. There may be ways of modifying the work to accommodate you better.

Below are some different tasks you might take on as a Patient Partner. You will not be expected to do all of these things, and you can expect to be given support and guidance by other team members.

Beginning the Research Process

- Helping researchers develop questions that are important to the people the research is designed to help
- Giving researchers new ideas for research
- Sharing experiences that would help inform the writing of a research funding proposal
- Inspiring and motivating researchers

Designing the Study

- Helping to design projects that make it easy for participants to take part
- Making sure the project respects the culture, needs, and experiences of the people taking part
- Helping researchers to avoid causing any distress to participants through their research
- Identifying how best to support people who take part in research
- Identifying potential problems in project plans and help to come up with solutions
- Helping review and/or write research proposals, personal statement letters, funding or ethics applications

Collecting and Analyzing Data

- Helping to recruit research participants who might be interested in the study
- Help design or modify survey questions or interview guides in order to improve how research participants understand what is being asked
- Helping to lead a group discussion, deliver surveys, or other ways to collect information
- Helping to review the data and working with researchers to make sense of the results

Sharing the Findings

- Helping to ensure that written materials are clear, easy to understand, and include the most important information
- Helping to apply the findings in the 'real world'
- Giving presentations or discussing your experience at conferences or meetings
- Writing articles for patient newsletters and posting on social media

While there are a variety of tasks you may work on as a Patient Partner, some are more common than others. Contributing to research proposals and reviewing written materials are two tasks that usually require Patient Partner input.

Contributing to research proposals

The research proposal is a document that outlines what the study aims to do, what participants will be involved, how data will be collected, and how the results coming from the research will be analysed.

When you are offered the opportunity to contribute to a research proposal, the other team members may ask you specific questions or just ask for any general comments you might have. They will want to know whether the research is important from your point of view and whether it is looking at the outcomes or results that matter most.

Reviewing written materials for patients and the public

You may be asked to comment on different documents created for participants, patients, and members of the general public, such as:

- Information about research that's underway to let people know the research is happening
- Posters, letters, and other items used to advertise the research project
- Patient information sheets that explain what taking part as a research participant will mean
- Journal articles, reports, and press releases used to share the results with patients and the public

Your task will be to comment on whether the information is:

- Written in a way that is easy to understand;
- Laid out in a format that is clear and easy to read; and
- Produced in a format that is accessible to the target audience, e.g. in large font if the target audience is likely to have visual problems.

You can go as far as you want in developing your skills and experience, working at local, regional or national levels, on small or large projects, for only a few weeks or over several years. You may be surprised at the range of opportunities that will be open to you.

How will privacy and confidentiality be protected?

It is important for research to be done in a way that does not harm participants, the public, or team members. To make sure the research is done in a safe and ethical way, most projects need to be approved by a Research Ethics Board (REB) before they can begin. To get approval, the research team must submit a detailed REB application to show how they will handle any ethical issues that may arise.

In health research, it is critical to protect the personal information about the people involved in a study, often referred to as research participants or subjects. Personal information can include names, contact information, medical history, or personal stories. Every study must have a plan in place to protect information that belongs to you, other Patient Partners, and the research participants of the study.

Privacy for you

When you support research, you may talk about your own personal experiences from time to time. Being a Patient Partner does not mean you agree to have these details shared outside the research team. When beginning your role as a Patient Partner, it can be helpful to ask yourself these questions:

- Do I know how my personal information will be protected by the other research team members?
- What information (if any) am I comfortable sharing with the research team members?
- What information (if any) am I comfortable sharing outside of the research team?

Privacy for others – maintaining confidentiality

As a Patient Partner, you may learn personal details about the people who are taking part in a study (research participants). For example, your role may be to find people to participate in the study or to talk to them about their experiences. It is important for you to protect people's information and not tell others about what you may hear or see in research activities. Sometimes this can be difficult, especially if you use social media or know some of the people participating in the study. Answering these questions with your research team can help you keep information safe:

- What system is in place to protect people's personal information?
- What can I do as a Patient Partner to help keep information private?
- What do I do if privacy is breached by me or another research team member?
- Do I need more support or resources to help me protect private information?

> *"The best thing about training opportunities was being in the same room as other team members and realizing they were getting the same training as you. It was a way to meet in a more informal setting than starting on a team."*
>
> *– Larry Baxter, Patient Partner*

What training and support might I be offered?

As with anything you do in life, how you contribute to the research team will depend on a number of factors: your enthusiasm for the research, your understanding of the issues being discussed and the ways you are made to feel a part of the process. You'll learn about the health topic being explored in depth and you'll learn from others with different experiences to yours. But you'll probably learn the most from actually doing it – 'learning on the job.' Don't be concerned if everything isn't perfect at the start. Your skills, understanding and confidence will increase over time.

Some formal training opportunities exist and are offered periodically. These might involve workshops on different topics such as Patient-Oriented Research or working in a research team. An orientation process is typical for each organization that involves filling out an application, an interview or meeting to establish your interests, and a training session (sometimes called orientation or onboarding) to make sure that you are comfortable with the research process.

Where can I find out more?

If you would like to get involved in research, there may be a number of opportunities that might suit you. Some of the organizations include:

Building Research for Integrated Primary Care in Nova Scotia (BRIC NS)
bricns@dal.ca
IWK Health Centre
pfcc@iwk.nshealth.ca
Maritime SPOR SUPPORT Unit (MSSU)
info@mssu.ca
Nova Scotia Health Authority (NSHA) Patient and Family Advisors
www.engage4health.ca/hub-page/pfa-hub

If you are in contact with health professionals, they may also be able to identify local and national research organizations that would be of interest to you.

Useful resources

BRIC NS: www.bricns.com
MSSU: www.mssu.ca
SPOR (Strategy for Patient-Oriented Research): http://www.cihr-irsc.gc.ca/e/45851.html
INVOLVE: www.involve.org.uk
PCORI (Patient-Centered Outcomes Research Institute):
https://www.pcori.org/engagement