



BRIC

Patient partner orientation
guide series



1 A QUICK GUIDE

This guide answers frequently asked questions
when first becoming involved in research

What is a Patient Partner?

In this document we use the term 'patient partner' to refer to a person with lived experience, or as a caregiver, who participates in health research as a team member. Terms which may be used by others include patient, family, citizen or public advisor.

What is the BRIC NS Patient Partner Orientation Guide Series?

Welcome to the BRIC NS Patient Partner Orientation Guide Series. This information has been brought together for members of the public, such as patients, caregivers and other users of healthcare interested in becoming involved in healthcare research.

Our guide series is made up of four booklets. Information we include has been adapted, with permissions, from others who have created similar type booklets such as INVOLVE¹ in the United Kingdom. Support and advice for changes to reflect our Canadian environment were provided by patient partners who worked with us to ensure we cover the kinds of information people need when first becoming engaged in research.

The four booklets in in this orientation guide series are:



1. A quick guide

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



2. What is it all about? Getting started.

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. Finding out more

In this guide we provide information about just some of the different organizations that support publicly funded health research in Canada and Nova Scotia. We also provide a brief overview of the steps involved in a research project.



4. Jargon Buster

Our jargon buster provides a glossary of some of the words or terms used in research, some of which we have used in our first three guides.

¹Content 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

What is patient engagement in research?

In Canada, the Strategy for Patient-Oriented Research (SPOR) defines patient engagement as the 'Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation.'



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

When members of the public, such as caregivers and people who have 'lived experience' as a patient, get involved in research, they work alongside researchers to help make decisions about what research gets done, how research gets done and how the results are shared and applied in practice. Being involved is not the same as taking part in research. It's not, for example, about being the person who takes a new drug in a clinical trial. It's about being a member of the research team that works together to design and run the study – a patient partner or advisor.

By becoming involved in research, you can help make research more relevant and useful to patients, caregivers and the public. By working with researchers, you will improve research and therefore make a difference to the way health and social care is provided in the future.

Research is defined as a well-ordered investigation or experiment that aims to find new facts and reach new conclusions. Health and social care research aim to find new knowledge that could lead to changes to treatments, policies or care.

What can I contribute to research?

Your knowledge from having experienced your own care, or the care of others, is of great value to researchers. Many researchers are healthcare professionals and will know a lot about treatment and services. They may also have text book 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 expertise that would otherwise be missing.

Examples of where you can contribute include:

- Making sure researchers are working on the most important question
- Helping to design projects that make it easy for patient partners to take part
- Making sure that any written materials are clear, easy to understand AND includes the most important information



Have I got the right experience to be involved?

There are many different types of research looking at hundreds of different topics. Researchers are likely to want to hear the views of a range of people from a variety of backgrounds. This means your experience might be more relevant for some projects than for others. It's about finding the projects that need input from people like you and roles that match your interests and experience.



“I feel a lot more confident in the importance and weight of my personal experiences than I did when I started this work. I believe team members truly appreciate my feedback and input.”

- Kylie Peacock, Patient Partner

What difference will I make?

You can make a difference at any and every stage of research. Your contribution will help shape the thinking behind the research and the planning and delivery of the project. You have a powerful voice that can also influence others beyond the research team, including the people who take part in the research and the people who use the results. Sometimes it's the contributions from involved patients and caregivers that determines whether a project gets funded, whether it runs successfully and whether the results change practice.

What will I be expected to do?

When you first get involved, you are likely to be asked to share your thoughts and views on the researchers' ideas and plans for their research, and any information written for patients or the public. You might do this in a number of ways. For example:

- Attending meetings with researchers
- Joining a group of patients and/or caregivers attached to the research project or supporting organization
- Becoming a member of a research team
- Commenting on written documents sent to you by post or email
- Be part of an advisory group or committee which help inform how research groups operate

Over time you may want to take your involvement further. 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. You may be surprised by the range of opportunities that will be open to you.



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

You can expect:

- Clear information about what is expected of you and your role
- A fair and open process of recruitment
- A good working relationship with the people who involve you
- Payment for any expenses including travel
- Practical support such as working in accessible venues
- A point of contact who can provide information and support on request
- Training and support along your journey to help you have your say

You may sometimes be offered payment for your time. At the present time this is often dependent on how the research is funded and the amount of time you are required to contribute to the project.

What training and support might I be offered?

Before you get involved you may be offered training in research or engagement. Depending on your experience, you're likely to find some forms of training more helpful than others. Everyone will have different things they want to learn. However, 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 greatly increase over time.

There should be at least one person, and often a team of people, whose job it is to support patient partners to be involved. They will support you in the way that meets your practical, emotional and information needs, perhaps giving you extra support at the beginning, and helping you develop your confidence over time.

Why do researchers want to involve patients and caregivers in their research?



In Canada, the requirement to involve patient partners in research is relatively new. However, in other countries, this has been a requirement for researchers applying for research funding for some years.

The Strategy for Patient-Oriented Research (SPOR), at the Canadian Institutes of Health Research (CIHR) requires that all proposals include patients as applicants on the grant. They must include information about how they plan to involve patient partners within the whole or various stages of the project. This means most researchers are very interested in doing patient engagement well.

At the same time, many researchers understand the added value of patient involvement. They want to listen and learn from what you have to say and will often make changes to their ideas and plans as a result.

How will I benefit from being involved?

People who have been involved in research say that the experience has been more rewarding and more enjoyable than they ever expected. It has given them:

- A new purpose and a sense of being valued
- New knowledge about how research works and the latest findings
- New skills as well as opportunities to use existing skills
- Increased confidence
- A different way to cope with their health condition
- New friends and a source of interest

Why do people decide to get involved in research?

People who get involved in research have different reasons for wanting to do so. Some people have had difficult experiences and appreciate being able to do something positive with that experience. Others have had very good experiences and see their involvement as an opportunity to 'give something back'. For most people, it's about wanting to make a difference – so that in the future, care will be better for the people who come after them.



“... For people who are new to getting involved in health research ... I suggest they pick something that they're familiar with – that makes the comfort level a lot easier.”

- Larry Baxter, Patient Partner

Where can I find out more?

You can find out more about patient involvement from the additional booklets that make up the BRIC NS Patient Partner orientation guide series. Within them we explain patient engagement in more detail, introduce you to some of the different organizations that support health research in Canada and Nova Scotia and explain some common research terms.

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Thanks

Thank you to our patient partners in Nova Scotia for their valuable suggestions and insights in helping to develop a useful and meaningful guide to becoming involved in research.