

**eConsult** BASE™

# Research Handbook for Patient Partners

**Dr. Clare Liddy's  
Research Program**

eConsult  
Family Medicine Education  
Dementia and Frailty  
Self-Management



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# Welcome to the Team!



Thank you for your interest in becoming a patient partner and welcome to the team!

First, let me tell you about myself and my work. My name is Clare, and I am a family doctor, Researcher, and Professor at the University of Ottawa's Department of Family Medicine.

As a family doctor, I have used my clinical experience to create a program of **research** with a focus on care that is high-quality and **person-centered**. Most of the areas that I look at come from day-to-day problems I talk about with my patients in the clinic. This led me to co-create the

**eConsultBASE™** Service, along with Dr. Erin Keely and Mr. Amir Afkham. Our goal is to improve access to specialist care in Ontario and across Canada.

Although **eConsult** is my main research focus, I also work on other research projects. They are detailed on pages 3 and 4.

So, where do you fit into all of this? I need partners like you who can bring their lived experience to the table and guide my team and me to ensure that our work truly helps **patients** and caregivers. I strongly believe that when researchers and patient partners join forces, talking and sharing thoughts about the healthcare system are more meaningful.

I know that patient partners play a key role in research because of their broad range of health care experiences, sometimes as patients and sometimes as caregivers to a loved one. I also value very much the other expert skills that you bring to our team. Your unique vision, views and knowledge are needed. You help us make sure that our research is relevant and aims to meet the needs of patients and caregivers.

You might find that being a patient partner is a good fit for you if you are curious about research, eager to make a difference in the healthcare system, and want to meet other people with similar goals. This small guide was developed to help you better understand research and your role as a patient partner on our Team.

I am looking forward to working with you.



Dr. Clare Liddy

# Why is primary care and family medicine research important?

Our team focuses on research in **primary care** and **family medicine**. Primary care is the first point of contact for people within the health care system. Primary care providers include family doctors, community pharmacists, optometrists, and nurse practitioners. They practice in many places, such as family doctors' clinics, community care, home care, and long-term care. Care provided by family doctors is called "family medicine". Family medicine, like all primary care, is based on a person's background (like their community and family). It is also focused on health promotion and the prevention of diseases over one's life course.<sup>1,2</sup>

Since patients get a lot of their care in primary care, more health research is needed to explore issues specific to this area, including family medicine. This includes such topics as education, prevention, and disease management. It also includes how people can receive treatment, therapy, and end-of-life care close to home. All of these topics are key to keeping people healthy and well throughout their entire lives. The work we do helps inform clinical practice, continuing medical education, and quality improvement in family medicine.



# What programs of research can I get involved in?

As a patient partner, you may have been asked to take part in one or more of the following areas of research: eConsult, Family Medicine Education, Dementia and Frailty, and Self-Management.

## eConsult

### What is eConsult?

eConsult is a web-based tool (almost like sending an email, but more secure) that lets family doctors and nurse practitioners ask specialist physicians questions about their patients' health. This helps them take better care of their patients, while they are waiting to see a specialist. Often, eConsult will take care of the patient's need so there is no need to see a specialist anymore.

#### STEP 1: Today



Your doctor or nurse practitioner sends a question to a specialist

#### STEP 2: Within 1 week



The specialist responds and provides advice

#### STEP 3: Usually 2–4 weeks



Your doctor or nurse practitioner uses the specialist's advice to provide care to you

OR



Your doctor or nurse practitioner refers you to the specialist

### How is our team involved with eConsult?

Our team continues to research different ways that eConsult improves quality of care. Our areas of special interest include chronic pain care, long-term care, dementia care, correctional facilities, rural and/or remote populations, and patients with complex circumstances. We now work closely with researchers from all over Canada to help them develop and study eConsult services in their own regions.

# Family Medicine Education

## What is Family Medicine Education?

Family Medicine Education is the process of teaching medical trainees how to be family doctors through a focused family medicine program. This program also includes continuing education for practicing family doctors and undergraduate trainees.

## How is our team involved with Family Medicine Education?

Dr. Liddy is a Professor and the Chair of the Department of Family Medicine at the University of Ottawa, which oversees all aspects of family medicine education and training. The work we do informs family medicine education planning, clinical practice, continuing medical education, and relevant projects within family medicine education.

# Dementia and Frailty

## What is Dementia?

Dementia refers to a group of symptoms that cause a gradual decrease in the ability to think and remember things. Symptoms may include memory loss, difficulties with thinking, language, and problem solving, and changes in mood or behaviour. Dementia can affect a person's ability to perform everyday activities and has a significant effect on caregivers too. Dementia is progressive, meaning that symptoms get worse over time.<sup>3</sup>

## How is our team involved with Dementia?

Our goal is to improve the quality of care for people living with (or at risk of) dementia or frailty by making access to specialist care easier. Much of our research focuses on the potential benefits of eConsult for people living with dementia and their caregivers.

## What is Frailty?

Frailty is a medical condition that reduces function and health in patients. It most often affects older adults. When someone is frail, coping with minor illnesses becomes more difficult. Frailty may cause rapid deterioration of a patient's health.<sup>4</sup>

## How is our team involved with Frailty?

Dr. Liddy leads the Champlain CARE Frailty Network to bring together researchers, patients, caregivers, primary care clinics, hospitals, long-term care homes, and the University of Ottawa's Department of Family Medicine. Together, all of us aim to improve frailty care across the Champlain health region of Eastern Ontario.



# Self-Management

## What is self-management?

Self-management emphasizes the role that patients have in managing their own healthcare. Research has found that patients involved in self-management feel more in control of their conditions and empowered to live healthier lives.<sup>5</sup> As a result, they have better outcomes and a higher quality of life.<sup>5</sup>

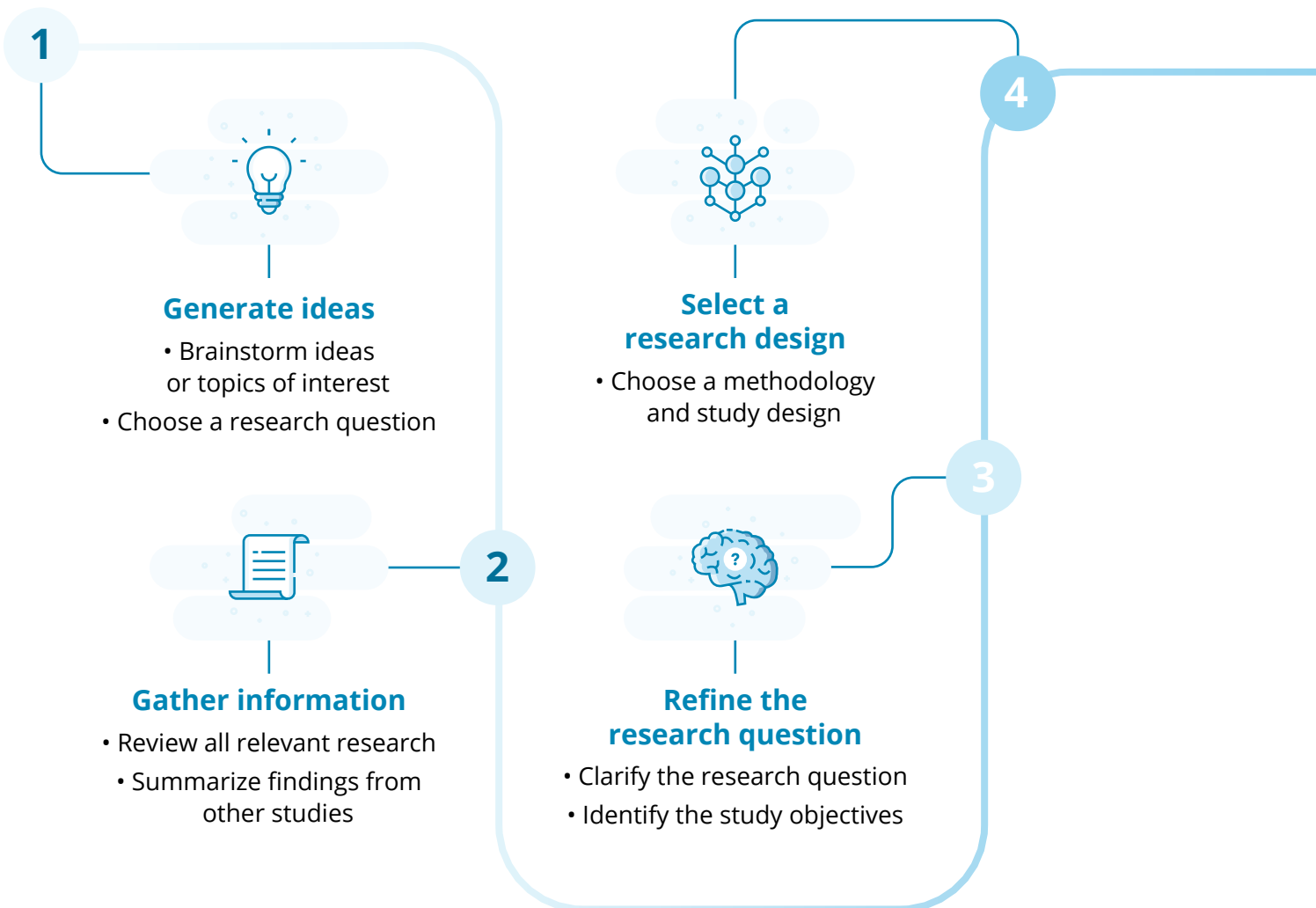
## How is our team involved with self-management?

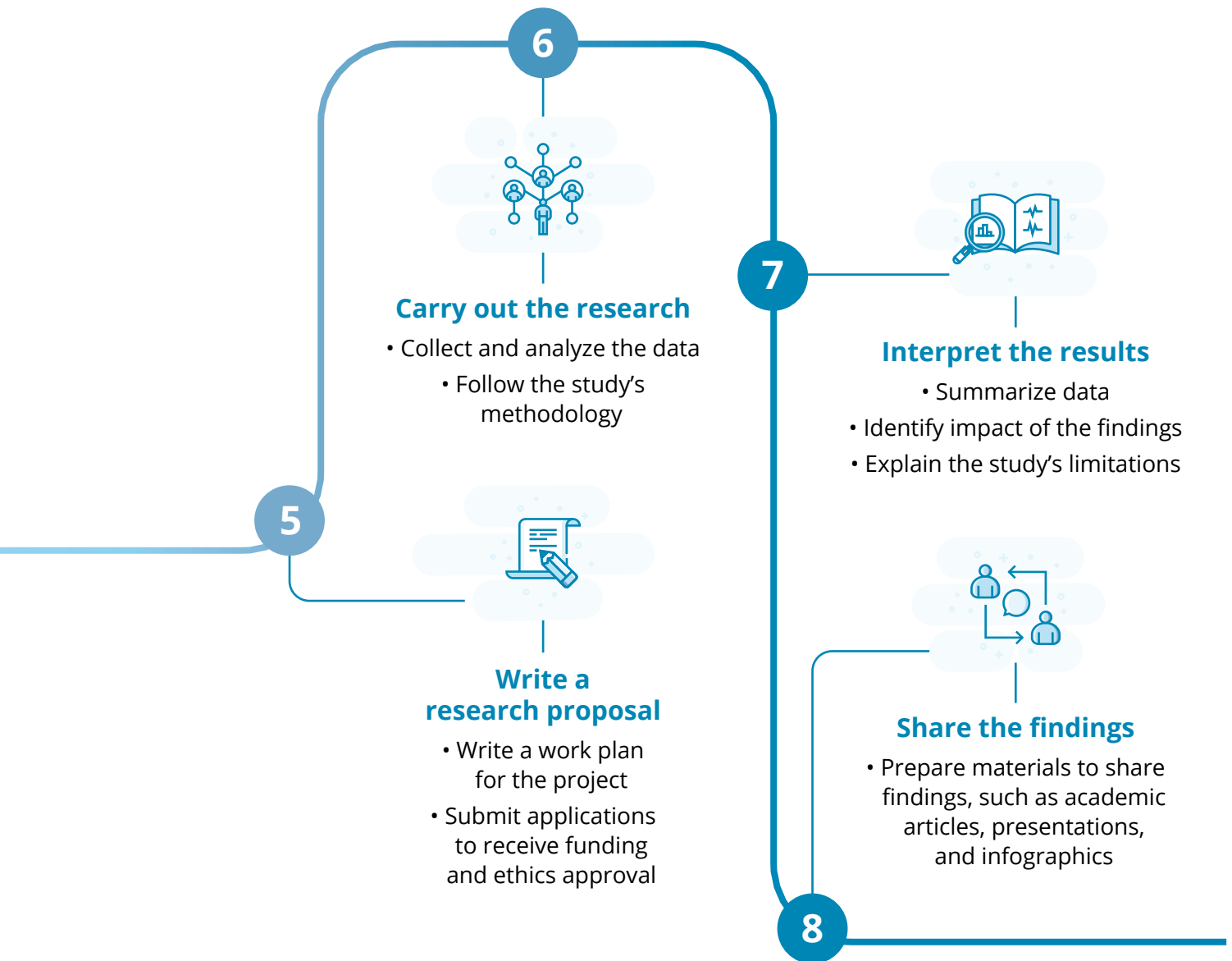
Our work with self-management is done together with Living Healthy Champlain, a regional organization supporting chronic disease self-management programs. Our research activities include evaluating chronic disease self-management programs and their impact on people living with chronic diseases. We are also interested in understanding who the programs are reaching and assessing how well the programs are delivered.

# I've never taken part in research before. How does it work?

**Research** is an important part of medicine's growth and development. Through research, we can find creative solutions to problems and challenges by better understanding them. When we conduct research, we follow a precise series of steps called the **research process**. In our case, following the research process allows us to gather facts that can help improve health care delivery and health outcomes.

## The research process





## Funding

Researchers can apply for funding to help them carry out their projects. There are different types of organizations that give funding (e.g. grant agencies, universities, government agencies and private companies)

## Research ethics

Research ethics is a set of guidelines and policies to make sure that research is done responsibly. This includes ensuring that all participants are safe and treated with dignity. Researchers must always get ethics approval before starting their study

# Who are patient partners?

## Why should I become a patient partner?

Patient partners have different backgrounds and health care experiences. Patient partners might be persons that live with or have lived with an illness, while others are caregivers or family members. Patient partners also have other backgrounds (like government, business, or being a student) that help them be good advocates for person-centered care.



### **Patient Partner with both eConsult in Long-Term Care and Dementia and Frailty**

“As a Volunteer Patient Partner, I have had opportunities to actively participate in a number of projects in Clare’s Research Agenda. I have made a valued and meaningful contribution to advancing quality healthcare through timely, equitable access to specialist opinions using eConsultBASE™ Services, and primary and community support for persons and their caregivers facing the challenges of frailty and dementia care. My participation in research over the last four years has been personally rewarding and I feel that I have and will continue to contribute to improving the quality of the healthcare experience.”



### **Patient Partner with eConsult Manitoba**

“Being a patient partner has given me the opportunity to have a voice in my care and to better understand the health care system. This role also played a big part in me accepting my own illness and has given me the self-esteem to share my experiences in order to advocate to improve the health care experience.”

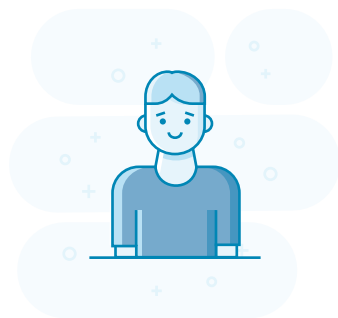
As a patient partner, you bring many skills to the table. Your lived experience in the healthcare system is essential to help guide our research. In addition to being experts in healthcare journeys, patient partners may have other skills they can use as well, like business insights and writing skills.

When researchers and people with lived experience partner in health research, conversations about the healthcare system have more meaning. Patient partners who are engaged help focus the research on what is important for the community to improve health care and the experiences of people within the health care system. This is called “**patient-oriented research**”.<sup>6</sup> We need your unique thoughts to ensure that our research focuses on the true needs of patients and caregivers.



### **Patient Partner with eConsult Alberta**

“I remember very clearly the email I received inviting me as a patient member from Patients for Patient Safety Canada to the very first eConsult forum in Ottawa, December 5, 2016. This was the start of a very exciting journey for me as I have been meaningfully involved in two forums as well as with other related initiatives since then, including as a co-author on several publications. I have watched with enthusiasm as eConsult has expanded steadily and progressively across Canada and realized how innovative and critical eConsult has become for patients and practitioners everywhere! I am very proud to be associated with this initiative!”



### **Patient Partner with eConsult Manitoba**

“The opportunity to share my opinions based on personal experience in the healthcare system, with like-minded patients, to make positive change, is a privilege. Clare’s research initiatives, like the development of this Patient Partner Handbook, have allowed me a voice to make positive contributions to the Healthcare System.”

## As a patient partner, what are my responsibilities?

Patient partners can be involved at all levels of the research process. This allows us to learn from each other and make sure that we focus on the true needs of patients and caregivers. Working together in this way is called **co-design**.

As a patient partner you may be asked to:



Give guidance to the research team



Attend meetings when possible



Participate in meetings by providing feedback and sharing your opinions



Be part of committees of researchers, policy makers, and other patient partners



Provide input and feedback on documents. No opinion is too small



Participate in planning how to share research findings



Respect the privacy of patient partners and other team members



Ask the research team for any information or support you need. No question is too small



## A Note on Privacy and Confidentiality

As a member of the research team, you have access to private data. You must follow the policies set by privacy offices within our institution and by the research ethics boards.

Always remember that:

- When collecting participant data, we are put in a position of trust. By using common sense and good judgement, we can make sure that the integrity of the research is maintained and private information is protected.
- Privacy also includes respecting and not repeating the stories and experiences shared by patient partners.

## How will the research team support me?

Research Team members take on the task of making sure that patient partners are supported and have what they need to be involved.

**If you choose to join our team, we will:**

- Listen to you
- Be patient and respectful
- Value your time
- Respect your privacy
- Recognize your expertise
- Communicate with you regularly
- Provide summaries of meetings and follow-up when someone was not able to attend
- Provide you with the resources you need to succeed
- Help you build new skills
- Create a safe and open environment for collaboration

# Who should I contact if I have questions?

For more information, please reach out to Clare at [CLiddy@uOttawa.ca](mailto:CLiddy@uOttawa.ca).



# Glossary

**Co-design:** A process where researchers, healthcare practitioners and patient partners come to together to create items for the research project, such as a survey.<sup>7</sup>

**Dementia:** Not a specific disease, but an overall term for a set of symptoms caused by physical disorders affecting the brain, such as Alzheimer’s disease or Parkinson’s disease dementia.

**eConsult:** A patient-specific question sent by a primary care provider to a specialist using a secure, web-based tool.

**eConsultBASE™:** The eConsult model that was developed by Clare, Amir, and Erin. The model is now spreading to different provinces and regions across Canada.

**Family medicine:** Ongoing primary care given to people of all ages across their entire lives. Family medicine is provided by a family doctor.

**Frailty:** A medical condition that reduces a person’s function and health.

**Patient:** This term is used to refer to both individuals living and receiving care in the community and residents in long-term care.

**Person-centered care:** A model of care that puts patients at the forefront of their personal health care by showing respect for and responding to individual values, needs, and wants to guide all care decisions. It allows patients to move freely along a care pathway with the support of caregivers, health care partners in primary care and other areas, health care organizations, and community services when needed most in their care journey. This is sometimes referred to as “patient-centered care”.

**Patient-oriented research:** Research that engages people with lived experience as partners to identify what is important to improve healthcare systems and practices.<sup>5</sup>

**Primary care:** Day-to-day healthcare given by a health care provider, such as a family doctor or a health care provider in a long-term care center.

**Research:** The act of answering important questions by gathering information in a way that can be repeated by other groups.

**Research process:** A series of steps taken to ensure the research is thorough and can be repeated by others.

**Self-management:** Emphasizes the role that patients have in managing their own healthcare. Patients benefit from being engaged in their own care.

# Acknowledgement

Many people have helped to develop this handbook. We thank all the patient and care partners that gave their time to share their knowledge, skills, and experiences, as well as to review drafts and provide input for this resource. Creating this handbook was possible because of your commitment.

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Prepared by: Jessika Hammond, Mary Helmer-Smith, Tess McCutcheon, and Clare Liddy

## Endnotes

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