# Patient Partnership Guidelines: McGill Primary Care Practice-Based Research Network

## 1 OVERVIEW

This document serves as practice-based guidelines for building and sustaining patient partnerships in research and clinical practice. These guidelines are based on the experiences of patient partners, researchers, and clinicians, as well as a review of the scientific literature. Creating patient partnerships is beneficial for all parties involved and ultimately leads to meaningful outcomes for patients, researchers, and clinical practice[1].

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*** The quotes in this document are from patient partners of the McGill Primary Care PBRN group.*

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# 2 EXECUTIVE SUMMARY

*"Patient partnership in research is when researchers work together with people with lived expertise, or experience, of a health condition to do research. The Institute of Genetics now uses the term patient partnership instead of patient engagement because we believe this term better reflects the value of patient contributions to research. Patient partnership activities can be varied, but the value of those activities is always high*[1]*."*

**Who are patient partners?**

- Individuals who have lived experience with a disease/condition and the healthcare system, whether it be as a patient or in a caregiver capacity
- With training, individuals learn to extract and share insights from their care experiences with researchers and clinicians to bring the patient perspective to light

**Roles of patient partners might include**

- Share the patient experience in the health system
- Provide insight on patient and community needs
- Contribute to project proposals and act as a sounding board for ideas
- Lead or assist with research tasks (e.g., patient recruitment)
- Tailor scientific and clinical messaging for the public in a simple manner

**Essential steps for involving patient partners**

- Take time to choose the right patient partner for your project
- Build trust and create a safe space for patient partners' voices
- Communicate and involve patient partners as often as possible

**On boarding**

- Explicitly and collaboratively define the roles and responsibilities of each member of the team, prior to project commencing
- Provide patient partners with training on what patient partnership entails and on how to effectively communicate their ideas and insights
- Take the time to get to know your patient partners' interests and availabilities

**Impact of Patient Partner Involvement**

- Alignment of research and clinical practice with the general public's needs and goals
- Meaningful engagement and involvement of the general public in research

# 3 FOUNDATIONS OF PARTNERSHIPS

## 3.1 Vision

Participatory research with patient partners is essential to conducting and producing meaningful research[2]. By working with patient partners who have lived experience with the healthcare system, research and clinical practice is better aligned with patients' values and experiences.

To guide equitable partnerships, collaboration, clear communication, and conscious awareness of power imbalances is critical. Respect, support, and empowerment are fundamental for successful patient partnerships.

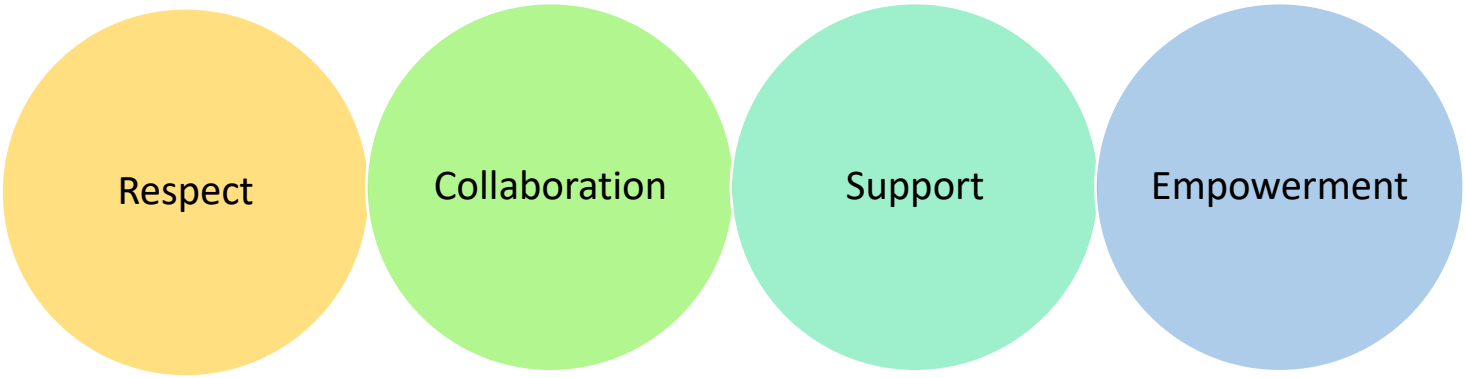



*Figure 1: Four foundational elements for successful patient partnerships.*

## 3.2 Fundamentals of Patient Partnerships

At the heart of patient partnership is the appreciation and acknowledgement of the experiential knowledge that patient partners bring to the team. This requires researchers and clinicians to understand and respect different types of knowledge and ways of knowing, often differing from academic norms.

Equally important to patient partnership is effective collaboration between partners, researchers, and clinicians. For effective collaboration, the roles and expectations of each team member must be clearly defined. Attention must also be given to team dynamics and

the power of each team members' voice. To ensure that the voices of patient partners are heard, it is helpful to have more than one patient partner at the table.

Additionally, it is necessary to have a person who acts as a point of contact for patient partners to help liaise between patient partners, researchers, and clinicians. This point of contact can be a patient partner lead or the research facilitator (see section 4 for details).

> *I had a very nice discussion with a lady on the phone about this geriatric project, but I haven't heard from her [again], and I don't know whom to contact to find out what is happening with the project.*

## 3.3 Fundamentals of Communication

To help support patient partners along the learning curve of research, clear and regular communication is essential. Central to clear communication is the use of plain language, stripped of any academic or medical jargon[3,4]. Partners should also be kept in the loop, with regular meetings, email correspondence, and important project updates. To support partners capacities to engage in meetings and events, all relevant documents and materials should be shared with them beforehand. By doing this, partners can participate in the meetings and events more meaningfully.

## 3.4 Overview of Partnership

Established on trust, patient partners are recruited to a team as collaborators, not as study participants. To build such a relationship, factors such as power differentials and hierarchies need to be considered.

**Strategies to build trust include:**

- Acknowledge that new patient partners may be unfamiliar with research practices and encourage them to ask questions
- Actively listen to patient partners[3]
- Explain scientific jargon and acronyms to break down traditional academic barriers[5]
- Create a space for all team members to share their thoughts and emotions[6]
- Value all contributions[4,7]

> *I was quite shy and embarrassed at the first meetings, especially online, so I didn't speak. There were a dozen doctors with PhDs and I was alone as a patient partner.*


*Figure 2: Foundations of patient partners in research: recognizing complementary expertise*

**To address power differentials and create bilateral relationships:**

- Create a safe space for the explicit discussion of power differentials and the differences in knowledge at the beginning of a partnership
    - Guided questions or facilitated discussions can be used to explore how these dynamics may impact decision-making, communication, and collaboration
- Establish ground rules that promote active listening, empathy, and mutual respect, ensuring all voices are heard and valued
- Ask researchers and clinicians to reflect on why they want to involve and collaborate with patient partners, moving beyond funding requirements[8,9]
- Acknowledge and address the traditional research hierarchy[10]
- Have a facilitator who can bridge the gap between the various collaborators
- Have the meeting facilitator summarize meeting points and voice it back to all team members to ensure there is mutual understanding and that any misunderstanding or remaining questions can be addressed

## 3.5 Stages of Engagement and Involvement

Patient partners can contribute to different stages of the research process, with varying levels of involvement. For example, patient partners may be involved in the conceptualization of projects or in developing messaging strategies for knowledge translation and dissemination. Levels of involvement can range from periodic consultations to active co-creation and governance at the decision level. This engagement approach ensures that research benefits from the unique insights and experiences of patient partners, leading to more comprehensive and impactful outcomes.

> *I am not very interested in sitting in a meeting talking about strategy. I want to work on tools that real patients will read.*

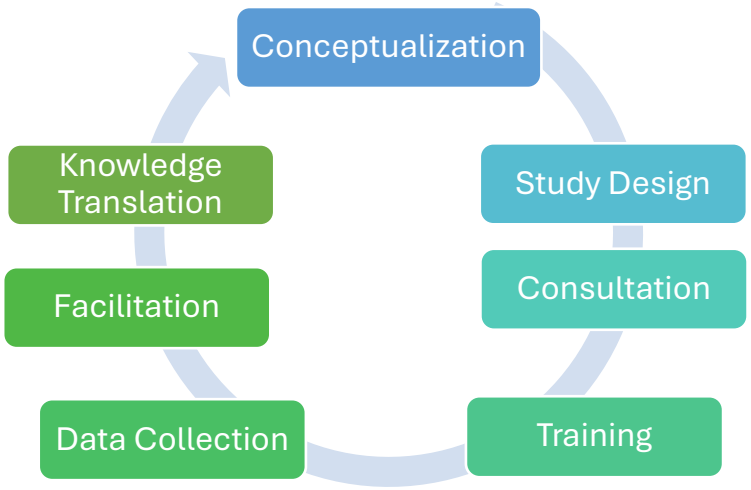



*Figure 3: Different stages of the research process that patient partners can contribute to.*

For more information on different stages of engagement, visit https://ssaquebec.ca/nouvelles/une-feuille-de-route-interactive-pour-les-equipes-de-recherche-est-desormais-disponible-en-francais/.

## 3.6 Motivations and Expectations

At the beginning of the partnership, it is crucial to have transparent discussions with patient partners about their motivations and expectations for participating in research projects[6,11]. Understanding why they want to be involved and what they hope to achieve helps ensure meaningful collaboration. Most often, patient partners involvement stems from altruistic motivations, but may also include skill development (e.g., research skills), to provide insight from their experiences, or social motivations[7]. However, it is also important to assess whether potential patient partners are able to sufficiently detach themselves

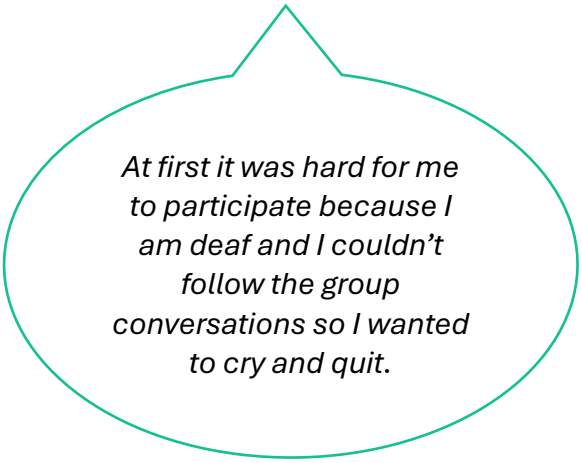
from their personal experiences. While personal experiences can inform their contributions, individuals must also demonstrate the capacity to consider broader perspectives.

Similarly, researchers and clinicians should communicate their motivations for and expectations of working with patient partners[12]. Doing so ensures that patient partners are fully informed about why their participation is being sought out and how it will contribute to the broader goals of the project. Consequently, patient partners can make an informed decision about whether the project is a good fit for them.

## 3.7 Diversity, Equity, and Inclusion

At the beginning of a project, it is important that principles of diversity, equity, and inclusion extend to the recruitment and involvement of patient partners[13,14]. However, A lack of diversity in patient partner recruitment remains a prevalent issue in both research and clinical projects[14–16]. Recruiting a diverse group of patient partners can be challenging due to various barriers including time commitments, financial constraints, language barriers, literacy levels, digital and physical accessibility, and other systemic and structural factors[14,17]. These barriers are particularly pronounced for racialized individuals, Indigenous Peoples, and other marginalized communities, who have been historically excluded from research and experience deep-rooted mistrust in the healthcare system[14].

To foster an inclusive environment, the research team must understand and accommodate patient partners' needs[18]. An equity-oriented approach during the partnership should be adapted where health inequities are recognized, and individual needs are addressed[16]. It is beneficial for a team member to meet individually with patient partners *prior* to the start of the project to discuss any accommodations or resources they may need[14,16]. For example, this could include providing an American Sign Language (ASL) interpreter, ensuring meetings spaces are physically accessible, and or offering flexible scheduling and virtual participation options to reduce barriers to engagement.



# 4 ROLES AND RESPONSIBILITIES

## 4.1 Patient Partners

Patient partners help to ensure patients' needs and goals are reflected in the project. Consequently, the patient partner role requires dedication and comes with many responsibilities.

**Responsibilities:**

- Attend and participate in meetings
- Consider and listen to others' ideas
- Get involved in group activities and training sessions
- Be willing to learn and expand knowledge
- Ability to detach from one's own healthcare experience
- Show the desire to co-construct with the team, not advocate for a cause or for oneself
- Maintain confidentiality of data/project
- Contact the mandated impartial person or the project manager in case of a problem

## 4.2 Patient Partner Lead

In certain projects and or teams, an experienced patient partner may be invited to take on a more significant role with more responsibilities. As the patient partner lead, they act as a point of contact for other patient partners, lead recruitment activities, provide training, develop material and patient partner knowhow, participate in outreach activities, and oversee knowledge dissemination. It is beneficial to have a lead patient partner involved on a yearly basis for building sustainability.

**Responsibilities:**

- Recruit patient partners and get to know their interests and strengths
- Train, support, and involve patient partners in projects that interests them
- Foster a sense of belonging in the group of patient partners
- Create opportunities for patient partners to be involved in the research and clinical community
- Promote patient partnership in the research community and foster collaboration in teams
- Establish guidelines to ensure effective collaboration between patient partners and research teams

## 4.3 Research Facilitator

The research facilitator helps to ensure the active involvement of patient partners in research projects. They utilize collaborative methods to seek out patient partners' expertise and help to ensure that traditional research barriers are broken down by providing research support.

**Responsibilities:**

- Facilitate collaboration: Foster and support collaboration between patient partners, researchers, and clinicians. For example, identify opportunities for patient partners to join a research project and ensure they are supported throughout the collaboration.
- Project support: Align research questions and priorities to reflect patients' needs and goals. Organize and facilitate workshops to exchange ideas and feedback.
- Capacity building: Provide guidance and support to patient partners on research methodologies, study design, data collection, and analysis.
- Knowledge translation: Collaborate with patient partners to tailor and disseminate research findings to the public.

## 4.4 Administrative Coordinator

The administrative coordinator plays a key role in managing the logistical aspects of the research project. They ensure coordination of project activities and communication among team members.

**Responsibilities:**

- Project coordination: Schedule meetings, manage project timelines, help plan in-person events and coordinate patient partners' travel to these events.
- Project communication: Ensure timely communication and correspondence with patient partners, sharing project updates and findings.
- Manage patient partner database: Create and manage a database with patient partner information (availabilities, hours worked, preferred languages, project participation).
- Administrative support: Assist in preparing and distributing project-related communications, reports, and presentations.
- Finance support: Monitor project budgets and expenses and process patient partners reimbursements.

## 4.5 Research Director

The principal researcher is ultimately responsible for how patient partners participate in a project. In the context where patient partnership has become a norm, it is critical that the principal researcher understands and articulates to team members how patient partners contribute. Patient partners are typically engaged at the beginning and toward the end of the project. At the beginning they help guide the project objectives, tailor methods for patient recruitment, and review patient-facing material. At the end of the project, they can help interpret findings and help tailor messages about findings for the public. Therefore, it is Important that patient partners remain connected with the project and research team during the life of the project.

**Responsibilities:**

- Orientate the patient partner(s) to the project goals, methods, and approximate timeline.
- Clearly outline the envisioned role and contribution for the patient partner
- If relevant, provide administrative support for the patient partner to be named on the research team for the grant application (e.g., get a knowledge user identification, prepare letter of collaboration).
- Present the patient partner to other team members and clarify their roles on the team
- Protect budget and resources to facilitate and compensate patient partner participation. Typically, participation is as a partner at the decision table; occasionally patient partners may be paid for a role in executing part of the project (e.g., interviewing other patients, recruiting other patient partners).
- Once funded, designate an impartial person as a project manager to whom the patient partner can refer for conflicts or discomfort related to their participation. Such a person does not need to be a member of the research team and would help to solve conflicts
- Ensure that contact is maintained throughout the life of the project, even when active patient partner contribution is not needed.
- Actively empower and solicit the patient perspective in meetings.
- Provide information and learning resources as requested to support autonomy.

## 4.6 Clinical Director

When clinicians engage in projects with patient partners, they take on additional responsibilities beyond traditional clinical care.

**Responsibilities:**

- Work with the patient partners to define clear goals and objectives for the project, ensuring alignment with both clinical and patient-centered outcomes.
- Offer necessary education and training to the patient partners, equipping them with the knowledge and skills required to actively participate in the project.
- Empower the patient partner to take an active role in decision-making, problem-solving, and advocacy within the project, promoting a sense of ownership and empowerment.
- Adhere to ethical principles and guidelines throughout the project, protecting the rights, privacy, and confidentiality of the patient partners.
- Set realistic expectations with patient partner regarding their involvement, time commitment, and potential outcomes of the project.
- Acknowledge and address any power differentials between the clinician and the patient partner, ensuring that the partnership is based on mutual respect, trust, and equity.
- Recognize and celebrate the contributions of the patient partner to the project, acknowledging their expertise and commitment to improving healthcare outcomes.

## 4.7 Creating a Partnership Agreement

To ensure all members of the team understand each other's roles and responsibilities, it is recommended to construct a partnership agreement with each patient partner to clearly outline roles and responsibilities on paper[20]. The process should be done *with* the patient partner, as this co-construction process builds trust.

# 5 ONBOARDING

## 5.1 Recruitment

The recruitment of patient partners should be community orientated, aiming to reflect the geographical, sociocultural and linguistic diversity of the community the research is geared towards. Therefore, recruitment efforts are typically most successful when led and facilitated by patient partners, as they are often perceived as more approachable to community members[8]. Managing diversity and multiculturalism within a group (e.g., language) is always a challenge and can be facilitated by recruiting multilingual/multicultural research assistants[12,21].

Recruitment is one of the most important steps for successful partnerships as involving the right people makes a difference in the process and the outcomes. To identify the right kind of patient partners, take the time to get to know their interests and availabilities. To start the collaboration and build trust, patient partners can initially be involved in smaller projects. Overtime, they will become more knowledgeable of the research process and learn how to contribute their experience.

For certain projects, it can be beneficial to have different roles for various patient partners and or to bring new patient partners in at different points. For example, patient partners with less or more experience working on research projects. Having different roles and levels of involvement can bring new ideas to the project.

General criteria for selecting patient partners:

- Can distance themselves from their own illness\disease
- Active listener
- Strong communication skills
- Desire to contribute to common good
- Basic technology and computer skills
- Willingness to collaborate
- Respectful of others

Patient partners can be recruited from community associations, organizations, committees[22–24], social media[5], and events[6]. Additionally, recruitment may occur through clinical, research, and organizational networks, websites, and professional recommendations.

*Consult an example of a patient partner interest form*

It is important to remember that different methods of recruitment may be used depending on the project and team, i.e., whether its project specific or generic. This will impact who is best suited to lead the recruitment.

*Consult an example of an intake form*

## 5.2 Assessment of Potential Patient Partners

To assess potential patient partners, an interview can be held either online or in-person. Two team members should be present for the interview, including at least one patient partner. One person facilitates the interview, and the others observes and poses follow-up questions. A description of different aspects to observe during the interview can be found in the interview guide.

*Consult an overview of the recruitment process*

## 5.3 Creating a Bank of Patient Partners

The creation of a bank (database) of patient partners to effectively manage information about patient partners and their involvement in projects. This database enables partners' demographics, expertise, and participation in various projects to be tracked. By doing so, patient partners who are best suited for specific projects can be identified and referred, accordingly. Additionally, to facilitate meeting planning, the database should also capture patients' availabilities and language preferences.

To gather this information, a registration form for accepted patient partners has been created. This form collects relevant demographics (e.g., age, gender, ethnicity), expertise or relevant experiences, and any specific preferences or interests regarding project involvement. Additionally, it captures their availabilities and frequency of contact preferences. This allows the coordinator to contact appropriate patient partners when opportunities arise. Maintaining confidentiality of this database is paramount and it should be updated regularly.

# 6 TRAINING & SUPPORT

To help ensure successful partnerships, patient partners, researchers, and clinicians may need to receive basic training, ideally all together.

> *I was a little lost at the first meeting. I was not sure what the goal of the project was and what they meant by qualitative research, and I was a bit shy to disturb everyone.*

## 6.1 Patient Partner Training

Patient partner training must reflect the learning curve – with time, comes experience. Initially, a basic training session on the foundations of patient partnerships should be given to provide an overview of what being a patient partner entails, how patient partners can contribute to the research process, and competencies of patient partners[4,5,20,25]. As their involvement progresses, further training might be necessary. To support new patient partners along this learning curve, they can be paired with experienced patient partners[13].

Training can be delivered in-person or online. It should be engaging and should provide opportunities for the partners to introduce themselves and get to know other partners and members of the team. During this initial training, facilitators should be alert to any undesirable behaviours – for example, partners sharing too much about their personal experiences.

Patient partners should be consulted on what additional training they may like to receive[5]. This training is often highly valued by partners. Examples of supplementary training include:

- Organizational policies
- Research practices
- Clinical workings
- Facilitation techniques
- Writing workshops
- Teleconference platforms

Here are a few tools:
https://www.understandingresearch.ca/
https://www.comprendrelarecherche.ca/
https://ceppp.ca/en/resources/
https://ssaquebec.ca/nouvelles/formations-sur-le-partenariat-patient/

## 6.2 Researcher & Clinician Training

Researchers and clinicians should be familiar with the content of patient partner training and ideally, they should attend the training with patient partners. They can also seek out basic training or guides on working with patient partners. This training covers the fundamentals of patient partnership[8], reflectivity exercises on power dynamics, removing academic and clinical barriers (medical jargon)[3], and strategies for forming equitable partnerships. However, the training will depend on the individual's experience.

Experienced patient partners can also provide training to the researchers and clinicians. Part of this training should cover the idea of the different types of knowledge that patient partners and clinicians bring to the project, and how this is often complementary. For example, patient partners have experiential knowledge of managing and living with an illness, whereas a clinician may have medical and empirical evidence on how to manage a disease.

## 6.3 Activities for Patient Partner Involvement

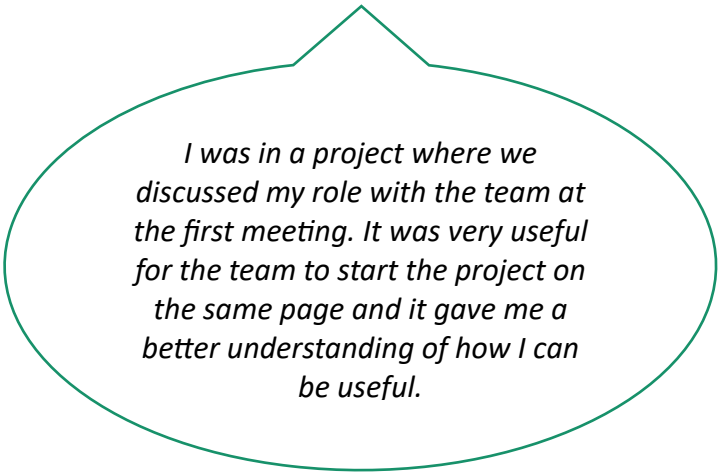
Meetings are the most frequent activity to involve patient partners; however, there are many other activities, such as focus group discussions, interviews, workshops, and lectures. For larger groups, Fishbowls or seminars may be used. For smaller groups, one may use roleplay, storytelling workshops[20], deliberative dialogues, etc. Helpful facilitation techniques can be found here https://www.liberatingstructures.com/[20].

*I participated in a fishbowl activity with four other patient partners. A researcher presented the project to be funded and we discussed the pertinence and potential for patient involvement in the project between us, while researchers observed. At the end, the researcher gave a summary of what they heard from us. There were a lot of things they hadn't thought of. It was a very nice experience!*

## 6.4 Best Practices for Supporting Patient Partners

To support patient partners in their roles, it is important to provide them with any documents that will be discussed during the meeting or event beforehand. Likewise, after meetings, it is useful to provide brief summaries of the events, highlighting lessons learned and next steps. Other considerations for supporting patient partners include:

- Allocate time towards **building relationships**, such as informal talking, reflecting together[3]
- Remember that patient partners are **living with a health condition**
  - Account for patient's schedule, accessibility, and changing needs and availabilities[6,8,27]
  - Arrange catch-up meetings[5] or share meeting minutes/notes
- Provide **regular and timely updates** to patient partners even when there are not activities going on
  - Patient partners feel reassured when they know what will happen and that it actually happens when expected
- Make sure funding proposals and project **results are shared** with patient partners
- Pay attention to the conditions which foster communication and interaction[11] – group size and meeting modalities[26]
- Provide patient partners with feedback on the contributions they made and their added value



# 7 SUSTAINING PARTNERSHIPS

To sustain patient partners' involvement in projects, it is important to keep partners regularly engaged, to compensate them for their involvement and participation, and to regularly share project updates and results with them.

## 7.1 Engaging and Maintaining Interest

To maintain the interest of patient partners:

- Send out newsletters to keep them informed
- Hold in-person networking events
- Advertise various involvement opportunities
- Offer learning opportunities for patient partners
- Invite them to research events
- Host meetings at places where their children can play
- Create a community of practice for patient partners to share their experiences

*I belong to a very nice group of patient partners, and it is a pleasure to meet them regularly to get the project moving.*

## 7.2 Compensation & Recognition

Patient partners must have their involvement and participation both compensated and recognized[8]. Compensation needs to be discussed and planned ahead of time so patients can be paid in a timely manner, conveying respect for the patient partners' time and contributions.

Compensation and recognition can be both financial[3,5,8,11] and non-financial[6,24,28]. Financial acknowledgment may include a salary, honoraria, gift card, or scholarship[6,13,29]. Make sure to inquire about patient partners' preferences for renumeration and agree on an hourly rate and payment schedule. It is important to track patient partners hours. Reimbursement for expenses incurred to participate in events can also be provided. This may include travel and parking[22] fees. Compensation may also be provided to cover fees for Internet and cellphone use. These finances needed to be planned and incorporated into research budgets[9,10]. Meanwhile, non-financial acknowledgments should not be ignored as patient partners usually get involved for an altruistic manner[7]. This might include authorship in journal publications, formal acknowledgements in publications, newsletters, and annual reports. Additionally, a recognition event, personal thank you notes, and emails are always appreciated!

*After contributing to the development of a questionnaire for patients living with a chronic disease, I received a cheque by mail, but nobody ever told me if the questionnaire was used and if our contribution made a difference.*

## 7.3 Sharing Results

While sharing research results with the scientific community, clinicians, and general public is very important, it is also essential to share results with patient partners as well. This helps patient partners to see the difference their contribution makes. Additionally, it is nice to add a more personal and detailed summary, including how it was welcomed by different groups.

*I participated for three months on a funding proposal, attending weekly meetings with the research team. I don't know if the proposal was accepted or if the project will keep going. Why did I do all that, I wonder? Did it serve something?*

## 7.4 Evaluation

Evaluation and reflection are essential steps within the philosophy of participatory research. Importantly, evaluation is not a test; its' aims are not to assess partners' contributions, but to ensure maximal engagement. Therefore, evaluations should not only be conducted at the very end of the project, but also conducted throughout the project.

Evaluation might include:

- Assessing partners' level of engagement. If a reduction in their engagement is observed, stop and reflect on what went wrong, then address it to regain their level of engagement.
- Validated questionnaires to evaluate the partnership, such as the Public and Patient Engagement Evaluation Tool (PPEET) questionnaire[13]
- Examples of other useful tools are the Dillon's CORE questionnaire[30].

Additionally, evaluation should go both ways. This means that patient partners should be able to self-evaluate their own experience on the research project, and to express their concerns. This can be done by sending out an anonymous feedback forum.
*See an example of a feedback form*

## 8 IMPACT OF PATIENT PARTNERSHIPS

Involving patient partners in research projects is beneficial to all parties, ranging from individuals, communities, organizations, and the healthcare system. This section provides a summary of benefits extracted from the literature.

# 9 THE BENEFITS OF INVOLVING PATIENT PARTNERS

**In Research**

- Capture diverse voices and experiences, strengthening the representativeness of the data and the relevance of the findings[8,12,22]
- Identify meaningful research questions to patients and communities, reducing wasteful research[4,31]
- Create more trusting relationships with the community and avenues to engage the public and share findings[31,32]

**In the Healthcare System**

- Share the patient perspective and underscore the value of patient-centred care[12]
- Increase the accountability of the healthcare system to respond to patient needs and improve the care experience[8,20]
- Help shape and adapt clinical practices and policies to reflect patient needs[27]

**For Researchers and Students**

- Strengthen collaboration skills and capacity to communicate clearly in simple terms[22,26]
- Enhance capacity to lead teams with various skill sets and needs[22,26]
- Build empathy and understanding of patients' realities[12,22]
- Adapt approaches and methods to different needs[22]

**For Patient Partners**

- Foster feelings of empowerment, self-confidence, satisfaction, and belonging[5,7,22,25]
- Provide opportunities for contribution and achievement[5,7,22,25]
- Expand social and professional networks and learn new perspectives from peer patient partners
- Improve understanding of their condition and learn coping and self-management strategies[22,25,27,31]
- Acquire new skills and increase career opportunities and enhance CVs[5,7,32]

*I learned so much at the last training session on respiratory infections. We had the chance to have a real doctor give the course and answer our questions.*

**In the Community**

- Expand social and professional networks among different patients, communities, researchers, and healthcare professionals[25]
- Increase access to meaningful and relevant research findings[22]
- Destigmatizes health conditions[5]

## 10 FUTURE OF PATIENT PARTNERSHIP

Since the concept of patient partnership emerged around a decade ago[33], it has slowly developed in the field of healthcare research and clinical practice. However, it is still in its infancy; its applications have not yet been widely implemented throughout these fields, such as education programs and doctoral research[34].

For instance, researchers often learn about the idea of patient partnership independently via scientific literature, as it does not yet exist in textbooks. Therefore, we foresee a future where patient partnership can be expanded into the education field. For example, embed patient partnership courses into universities[26] so that future researchers can easily involve and collaborate with patient partners throughout their thesis work. Moreover, assemble patient partners advisory panels for the selection of future medical students and even future medical professionals[21] would be a great step forward.

# 11 APPENDIX

**Patient Partner Recruitment Process**

1. Patient partner lead or research facilitator email patient partner: briefly introduce themselves, thank individual for their interest, and share link to **patient partner application** https://forms.office.com/r/PBgHGDbc8D

2. Patient partner lead or research facilitator call individual based on their availability indicated on application. During call, assess individual's computer capacity – ask if they've used Zoom or Teams before. Based on answer, schedule a follow-up interview either in-person or over zoom.

3. Patient partner lead along with another patient partner complete an informal interview with applicant. Probe on the following:
   **Life experience with a disease**
   - Can you talk to us about yourself?
   - Can you briefly describe your experience in the health system, as a patient or a caregiver?
   - What helped you or made a difference in your experience? or something that made it worse?
   - Did you get involved in your care? How?
   - In your opinion, what would help our health system work better? (advocacy)

   **Abilities/Attitude**
   - Have ever participated in a project as a patient partner?
   - Can you tell us about it?
   - What is important for you when working in a team?

   **Knowledge/Motivation**
   - How do you think you could benefit from working with us? (motivation)
   - What is your availability in general? Day/night, hours per week
   - Do you have health conditions that we should take into considerations? (transportation, attention spend…)

   **Optional**
   - Are you comfortable meeting online, sending/receiving emails, reading documents on the computer?

4. If individual is recruited, ask them to complete the following **intake form**: https://forms.office.com/r/nezaCXb8MY

5. Once 3-6 new patient partners have been recruited, complete a 1hr **Patient Partner Training Session**. At end of session, share a **remuneration form** and ask patient partners to sign the consent form.

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