PWLLE Partnerships Guideline V1

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1. Purpose

The Marathon of Hope Cancer Centres Network believes that the integration of persons with living/lived cancer experience (PWLLEs) in research can enhance the quality of that research and ensure that it addresses genuine needs and priorities of those intended to benefit from that research: individuals who experience cancer and their caregivers. **The purpose of this guideline is to provide Network members with guidance on how to meaningfully and respectfully involve PWLLEs in their research programs and projects.**

2. Introduction

The Marathon of Hope Cancer Centres Network (MOHCCN, or 'the Network'), led by the Terry Fox Research Institute and the Terry Fox Foundation, unites researchers, clinicians, PWLLEs, administrators, funders, and other partners across Canada to accelerate precision oncology for the benefit of all cancer patients. The Network supports diverse research projects across Canada, with a particular emphasis on genomic profiling, novel technologies, health equity, and translation to clinical practice.

The Network's Patient Working Group (PWG) is a group of more than 30 individuals with living/lived cancer experience and diverse backgrounds. The mandates of the PWG are to (1) help guide Network activities to ensure they address and respond to the needs and priorities of those with living/lived cancer experience; and (2) to develop a pan-Canadian education campaign related to precision oncology and share perspectives of people living with and after a cancer diagnosis, as well as those of their caregivers, more widely in the research and clinical communities and with the broader public.

3. Common terms

A PWLLE (person with living/lived cancer experience) may have received one or more cancer diagnose(s); may be in active treatment for one or more cancer(s); may have finished treatment: may be in remission and/or have no evidence of disease, possibly identifying as a "cancer survivor"; may be a caregiver or parent for one or more person(s) including a child (children) who has (have) or has (have) had cancer;); or may describe their experience with cancer in myriad other ways.

The MOHCCN considers a PWLLE partnership to be one where a researcher or research team involves one or more PWLLE(s) in a research project and/or research program. The scope and nature of the partnership can vary widely, as described in more detail below.

PWLLE partners (sometimes referred to as 'patient partners') are PWLLEs who are collaborators on a research project or program. Note that this is distinct from PWLLE (or patient) participants in a research project, such as individuals who complete a research survey or who participate in a clinical trial. Although PWLLEs can act as partners and/or participants in different contexts, partners are collaborators who are involved in the research process itself.

The MOHCCN subscribes to the International Plain Language Federation's definition of plain language: "a communication is in plain language if its wording structure, and design are so clear that the intended readers can easily find what they need, understand what they find, and use that information." This definition is adaptative and means that plain language can take different forms in different contexts. As described in more detail below, the Network strongly encourages researchers to cultivate methods of communication that are accessible to non-experts in their field and to individuals whose first language may be different from the language in which the research is presented. This does *not* mean that researchers should 'dilute' or over-simplify information to communicate with wider audiences, including

PWLLEs, but rather frame it in a way that is more accessible. The MOHCCN and the PWG recognize that this is a challenging skill to foster, and commit to ongoing bidirectional learning with Network members.

4. Key principles

A. PWLLE partnerships can enrich any research project – at all stages

PWLLE partnerships are valuable across the full spectrum of research, from fully fundamental through to clinical research programs. Although the motive for this type of partnership may be more evident for (pre-)clinical research, people with living/lived cancer experience can also bring valuable insights to research programs that lie further from patient care. **The Marathon of Hope Cancer Centres Network and the Patient Working Group strongly encourages all research teams to actively engage with PWLLEs, tailoring to the needs and circumstances of their unique research program or project.**

As defined above, a PWLLE partnership is a collaboration: PWLLEs *become members of the research team* and contribute their unique expertise. This enhances the diversity of ideas and perspectives within a research team and helps ensure that research is patient-centred and addresses questions relevant to people experiencing cancer – even when it is far removed from the clinic.

We recommend that research teams involve PWLLEs at the earliest possible stages of research projects and programs. Researchers should not involve PWLLEs because they *must* (e.g. in response to a grant proposal that requires one or more PWLLE/patient partner(s)), but should recognize the value that these partnerships can bring – and provide real opportunities for PWLLE partners to contribute throughout the project.

Here are some examples of how PWLLE partners can contribute to a research program and/or project:

- Be involved in the early stages of research design, acting as a sounding board and sharing ideas about the types of research questions that meaningfully address the genuine needs and priorities of people experiencing cancer.
- Help with patient/participant recruitment.
- Help build rapport with relevant groups and communities.
- Help create connections with advocacy groups, health organizations, etc.
- Help create and/or review communication materials, especially those aimed for a general audience (e.g. plain language summaries, public presentations, government/policy documents).

B. Persons with living/lived experience are more than their diagnosis

PWLLEs evidently bring valuable living/lived experience to research teams and projects, providing key insights into how cancer diagnoses and treatment journeys affect those who experience them. However, when bringing PWLLEs into a research project and/or team, it is important to remember that these persons have full lives outside of their cancer experience — prior, during, and after their immediate cancer diagnosis and treatment.

When engaging with potential PWLLE research partners, researchers should take care to have a discussion with the prospective partners about what skills and experience they would wish to bring to the partnership beyond their living/lived experience, if any. For example:

- PWLLEs with a communication background may be particularly interested in helping craft knowledge translation materials (e.g. plain language summaries, grant proposals, posters, oral presentations)
- PWLLEs who are engaged with other groups and organizations (e.g. support groups, advocacy organizations) may be interested in helping with outreach, for example to aid in participant recruitment
- PWLLEs with their own research and/or clinical experience may be interested in helping draft ethics proposals, study protocols, etc.

As outlined in the next section, open communication is critical. Researchers should ask pertinent questions about PWLLEs' interests and expectations, and not make assumptions about the scope of expertise that prospective partners can bring to the team. While some PWLLE partners will have an interest in contributing their varied skills and experience, both personal and professional, others may prefer to keep the partnership more limited. While either approach (or a variation of them) is valid, it is imperative that researchers entering into a partnership with PWLLEs *ask* their new collaborators for their preferences and respect their request.

C. Communication is key

When establishing a new research partnership with one or more PWLLE(s), it is imperative that researchers *create opportunities for open communication and engagement* so that all parties can come to an agreement about expectations and next steps. Throughout the partnership, researchers should be careful to avoid jargon, overly technical language, and excessive use of acronyms. Inclusive communication is a powerful tool to truly integrate PWLLE partners into the research team and to provide them with opportunities to contribute.

The questions outlined in the section 5A ("Helpful tips – Questions to guide the partnership") can help researchers prepare to reach out to PWLLEs to invite them to join a research partnership. Researchers should consider these questions – along with any other relevant to their particular circumstances – to clearly describe their request and set a strong foundation for the partnership, should it go forward.

Communication throughout the partnership should be open, respectful, curious, and flexible. Following the principles outlined above, open and curious communication can help the partnership grow and all parties find new opportunities for collaboration. The suggestions provided in section 5C ("PWLLEs are in place: What now?") can help guide researchers on this path.

5. Helpful tips

A. Questions to guide the partnership

Here are some questions that researchers should consider when contemplating establishing a new research partnership with one or more PWLLE(s).

i. How many PWLLEs are you looking to engage with?
   - Please note that we recommend involving at least two PWLLEs in a research partnership. This provides some redundancy in the event one person needs to take time away (e.g. for treatment) and supports broader representation.

ii. Are you looking to engage with PWLLEs with specific experiences or backgrounds, or from specific geographic locations or communities?

- e.g. Is it important for the PWLLE partner to have experience with the specific cancer type you are studying or with a particular living/lived experience (e.g. chemotherapy, immunotherapy, precision oncology, rare cancer)? Do you want to engage with someone local to you to facilitate in-person interactions, or are virtual meetings generally sufficient?

iii. Are you looking to involve PWLLEs in a specific project, or in your research program more generally?
- Involving PWLLEs in a research program can help foster longer-term relationships, supporting more meaningful engagement and partnerships. In some cases, involvement in a specific, time-restricted project may be appropriate; however, in general we recommend involving PWLLEs in broader research programs where possible (including where the PWLLEs in question express interest in this type of partnership).

iv. What are your expectations for this collaboration? Consider the time commitment (e.g. monthly virtual meetings, reviewing written materials) and the type of input you are seeking. Although the goals of the partnership will likely evolve over time, researchers should establish preliminary expectations before engaging to help all parties decide whether the partnership is right for them. For example, researchers may be looking for support with:
- Developing a research question or broader program;
- Assessing project progress, ensuring that the research remains patient-centred;
- Participant recruitment; and/or
- Knowledge translation following project completion

v. How will PWLLE partners be recognized and/or financially compensated for their time and effort (e.g. hourly or quarterly honorarium, authorship)?
- In general, we recommend that PWLLE partners be offered financial compensation in recognition of the time and effort they contribute to the project/program.
- Researchers may wish to follow compensation guidelines from the Canadian Institutes of Health Research and the Canadian Cancer Society to develop their own standard for compensation commensurate with contributions made by PWLLE partners.

B. Where and how to find research partners

Research partnerships with PWLLEs are becoming increasingly common, and many institutions now have staff dedicated to supporting this type of collaboration. Researchers who have existing relationships with PWLLEs may wish to ask them if they either have interest in a research partnership, or may know others who do. Researchers without existing relationships should first reach out to their networks (including their institution) to see if connections can be facilitated; for example, fundamental researchers may have clinical collaborators who know PWLLEs who would be interested in a research partnership.

For researchers who need to look further afield, additional resources exist and are being developed. You may consider the following options:

- The Canadian Cancer Survivor Network has a directory of PWLLEs who have completed their Science of Cancer course and who may be interested in research partnerships.

- Your regional SPOR SUPPORT Unit may have resources or offer consultation services to help you find PWLLE partners (you can find links to all regional units here).
- There are many patient advocacy organizations who focus on specific cancer types or demographics and who may share partnership opportunities with their members. We encourage Network members to seek out organizations whose missions are relevant to their own work.

It is important to remember that establishing a PWLLE partnership – and, especially, doing so well – will take time. We encourage researchers to start their search for PWLLE partners as early as possible so that they can be involved early on in the project (see section 4A above).

C. Next steps

You've found one or more PWLLEs potentially interested in partnering with you on a project or program. **Now what?** Following are some tangible actions researchers can take to build a meaningful and respectful partnership.

Establishing the partnership:

i. Organize a "meet-and-greet" meeting with the prospective PWLLE partner(s). This should be a one-on-one or small team meeting ahead of inviting the PWLLE partner(s) to a larger team/group meeting.
   - Researchers should consider what information is needed to help PWLLEs better understand the project or program and be ready to engage with the larger team/research group. A brief summary of the proposed research, delivered in plain language, along with time for questions and discussion, is central to setting a good foundation for the partnership.
   - Researchers can use the questions outlined in section 5D to help guide this meeting. We recommend that researchers work with PWLLE partners to draft terms of reference for the partnership. This document should include, as appropriate: expectations for the partnership, and from each party; meeting schedule/frequency; and contact information.
   - Similarly to onboarding any other new member of a research group, it is helpful to discuss general group dynamics and expectations with new PWLLE partners.
   - While some PWLLE partners will have extensive experience with research partnerships and be familiar with research processes, for others such a partnership may be a new experience. Researchers should be prepared to support PWLLE partners with relevant information and clarifications as needed.

ii. Add PWLLE partners to team/group meetings, as appropriate, as agreed upon.

iii. Identify a designated contact person that PWLLE partners can reach out to if they have questions outside of scheduled meetings.

Maintaining the partnership:

i. Maintain regular contact with PWLLE partners, following an agreed-upon schedule.
   - Although each partnership will differ in terms of expectations and levels of involvement, as a general rule, researchers should stay in regular contact with PWLLE partners, similarly to any other collaborators. The frequency of 'regular' contact may differ by context, and should be discussed as per above.

- Researchers should ensure that major project updates, such as a grant proposal being accepted or rejected, an academic publication in progress or ready for submission, etc. are communicated to PWLLE partners in a timely fashion.
- PWLLEs partners should be encouraged to reach out to their designated contact with any emerging questions and/or concerns.
- It is important to remember that PWLLEs may also be managing ongoing treatment, screening appointments, and/or caregiver duties. Researchers and PWLLE partners should regularly check in to ensure that the partnership workload is appropriate, and researchers must be flexible where possible.

ii. Invite PWLLE partners to relevant group meetings and include them in presentations (conferences, virtual seminars, etc.) as appropriate.
- As/if needed, separate one-on-one (or smaller team) meetings may be warranted to provide additional opportunities for PWLLE partners to ask questions, raise concerns, or initiate discussions not relevant to the wider group.

iii. The terms of reference should be reviewed by the researcher(s) and PWLLE partner(s) on a regular basis (e.g. yearly), and updated as needed.

Concluding the partnership:

i. Either party (researcher or PWLLE partner(s)) may need to end the partnership for various reasons. This should again be approached with open communication, clarity, and mutual understanding.

6. Additional resources

Below is a list of resources that researchers can use to learn more about best practices regarding PWLLE partnerships. This list only includes resources open to all. It is not exhaustive, and will continue to be updated periodically. The Patient Working Group welcomes suggestions for resources to be added to this list (these can be sent to PWG coordinator Clare Dean, cdean@tfri.ca).

A. Training programs

- WE-SPARK Health Institute
  - LEARN program
- Strategy for Patient Oriented Research (SPOR)
  - Alberta SPOR Patient Engagement in Patient-Oriented Research Certificate
- CIHR Institute for Musculoskeletal Health and Arthritis
  - Patient Engagement Training Program

B. Toolkits and resource lists

- LabPartners
  - Guiding Framework for Patient Engagement in Preclinical Laboratory Research
  - Terms of Reference template
  - Additional resources
- Strategy for Patient-Oriented Research (SPOR)

    - PASSERELLE National Hub in Capacity Development for Patient-Oriented Research (bilingual)
    - CIHR Patient Engagement Framework
    - Patient Expertise in Research Collaboration
    - Patient-Oriented Research Project Planning Tool (Saskatchewan Centre for Patient-Oriented Research)
- Centre d'excellence sur le partenariat avec les patients et le public / Centre of Excellence on Partnership with Patients and the Public (bilingual)
    - Resources
    - Evaluation Toolkit
- Cancer Research UK
    - Patient and public involvement toolkit
- Doctors of BC & BC Ministry of Health Specialist Services Committee
    - Meaningful Patient Partner Engagement - A Guide for Projects and Committees
- UHN KITE Research Institute - Pride in Patient Engagement in Research (PiPER)
    - PiPER Toolkit
- Canadian Cancer Society
    - Patient and Community Engagement Resources
- Women's College Hospital - Equity Mobilizing Partnerships in Community (EMPaCT)
    - Resources (includes bilingual resources)

C. Academic publications

- Gandhi et al. (2025) A new framework for engaging patients and the public in basic cancer research. *Nature Reviews Cancer*. doi: 10.1038/s41568-025-00898-5
- Farrell et al. (2024) Advancing Research Alongside Patient Partners: Next-Generation Best Practices for Effective Collaboration in Health Research. *Current Oncology*. doi: 10.3390/curroncol31110513
- Richards et al. (2025) The ultimate power play in research - partnering with patients, partnering with power. *Research Involvement and Engagement*. doi: 10.1186/s40900-025-00745-9
- Foster et al. (2025) Identifying challenges and enablers to engaging patients in preclinical laboratory research: an interview study. *Research Involvement and Engagement*. Doi: 10.1186/s40900-025-00818-9

7. Concluding remarks

The PWG wishes to remind researchers that engaging with PWLLE partners provides a valuable opportunity to enhance the research process and increase the likelihood that cancer research — regardless of its stage, from fundamental to clinical studies — will bring tangible benefits to people impacted by cancer. PWLLE partnerships also help build new connections and collaborations, and remind us all of the deep importance of the work we do together.

We recognize that this guideline provides a lot of information, and that PWLLE partnerships may be new to some researchers. We encourage everyone to approach these partnerships with curiosity and kindness and as an opportunity to learn and expand perspectives. Thank you for reading, and for pursuing authentic

and meaningful collaborations with people with living/lived cancer experience. On behalf of PWLLE partners, we truly look forward to working with you.

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