

## **[preclinical project name] Terms of Reference**

**Name of Group:** [preclinical project name] Patient Partner Panel

**Purpose of this document:** This terms of reference document is intended to be co-developed by all members of the team to help guide how we plan to work together. This document is also meant to be a 'living' document, meaning elements can be updated throughout the project as needed to suit the needs of the team and to provide the most up to date information.

### **Purpose/role of group**

- Objective of the [preclinical project name]

[brief paragraph describing aim of laboratory work in non-technical language]

- Objectives of the Patient Partner Panel

The objective of Patient Partners is to provide input and perspectives on the project, at their discretion/interest/ availability, to shape this research program. This will include, but not be limited to, the development of documents, toolkits, and resources.

### **Opportunities for Patient Partner Involvement**

As preclinical research is a novel area for patient engagement, we plan to co-identify how best to work together, and activities that work towards the goals and priorities of all members. To date, we have had several discussions to brainstorm ideas for patient engagement. In general, activities will aim to allow Patient Partners the opportunity to provide insight and support based on lived experience (or other expertise they have) when contributing the deliverables proposed below. In the coming months, we plan to continue discussions and update this list of activities as needed. We also note that involvement can be based on interest and availability to ensure feasibility, and will consider patient partner priorities and schedules.

**Terms of Reference:** A Terms of Reference document will be co-developed by team members to outline a set of shared expectations. An initial draft will be created by [names (title or role)] using a template developed by the Blueprint Translational Research Group. The draft will then be circulated to all panel members for input. We will plan to update the terms of reference annually (or more frequently if requested by team members).

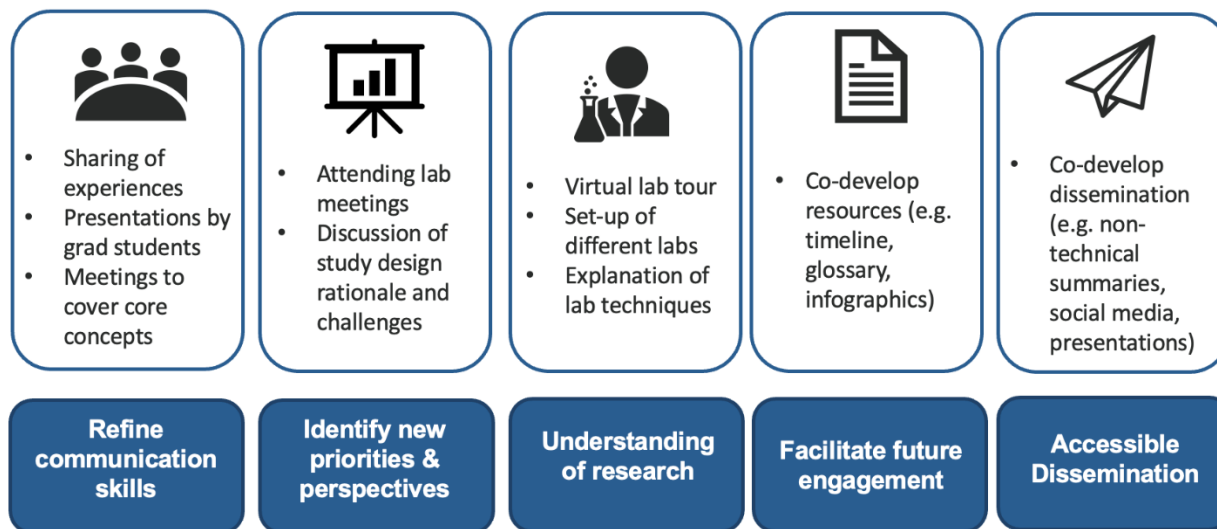
**Attending Meetings and Sharing Lived Experiences:** Patient Partners are welcome to attend both [preclinical project name] Core Laboratory meetings (focused on experimental results, held monthly) as well as meetings focused on Patient Engagement (held every 4-6 weeks). During these meetings Patient Partners are welcomed to share their lived experiences and perspectives (if comfortable and at their own discretion). These meetings will aim to allow Patient Partners an opportunity to gain a better understanding of the scientific background of the project in addition to a greater understanding of the project itself. Additionally, this will allow for researchers to acquire an improved understanding of the impacts of sepsis on patients and caregivers and may help to identify new ideas or ways that the research experiments can align with patient and caregiver priorities.

To date, discussions with Patient Partners have identified a few ideas for lab experiments (e.g. Currently adding outcome measures that are directly relevant to clinical assessment of patients with sepsis, such as [outcomes]).

### Learning and Capacity Building

- **Virtual Lab Tour:** This will allow Patient Partners to see where the research is being conducted and allow for comparison between different lab set ups. Additionally, during this lab tour researchers can explain how different equipment/techniques work. During this time, Patient Partners can ask further clarifying questions.
- **Training in Patient Engagement:** This will allow researchers (and patient partners if of interest) the chance to learn about suggested best practices in patient engagement. CIHR-Institute of Musculoskeletal Health and Arthritis has recently developed a free online, certificate-based module (more will be released over time). Once an account is created, individuals can go through the module at their own pace. Available here: <https://lms.udutu.ca/LMSPortal/Account/Logon?orgCode=IMHA>

**Accessible Communication & Resources:** Patient Partners and researchers can work to co-develop resources to cover core concepts, such as non-technical summaries, a glossary and an infographic to share with the general public regarding pre-clinical study design, research techniques, or patient engagement strategies in preclinical research. The team can also work together to identify and co-develop communication strategies that are accessible to a wide audience (e.g. social media posts, presentations).



**Figure 1. Possible Opportunities and Aims for Engagement**

**Additional Projects/Ideas:** Patient Partner ideas for additional projects can be added here. In brainstorming additional ideas, we will aim to consider activities at the ‘Consult’ and ‘Empower’ levels of engagement (see Figure 2 below).

- **Sharing our stories with hospital staff, researchers, graduate students and med students:** This can be done in a number of different formats, including verbally at conferences, written in a blog post format or through a video recording. The intent of this is to bridge the gap between patients, medical staff, and researchers and to provide further insight into different patient experiences.
- **Exploring patient needs and priorities in sepsis research** (\*may want to check if there is any existing literature on this, or could be a scoping review)
- **Long-term effects of sepsis on patients and their families** – noted because personal experiences have had long lasting effects on future health care decisions for example
- **Knowledge Translation:** We can work together to support dissemination and knowledge exchange of research findings and information on sepsis. For example, we could build on the glossary, use social media, sharing stories...
- **Reflection on Impacts of Patient Engagement:** We will capture patient partner perspectives and impacts on the research through meeting minutes and an impact log. This will allow the team to reflect on how patient engagement has shaped/ impacted the research, as well as allow us to share this with other teams.

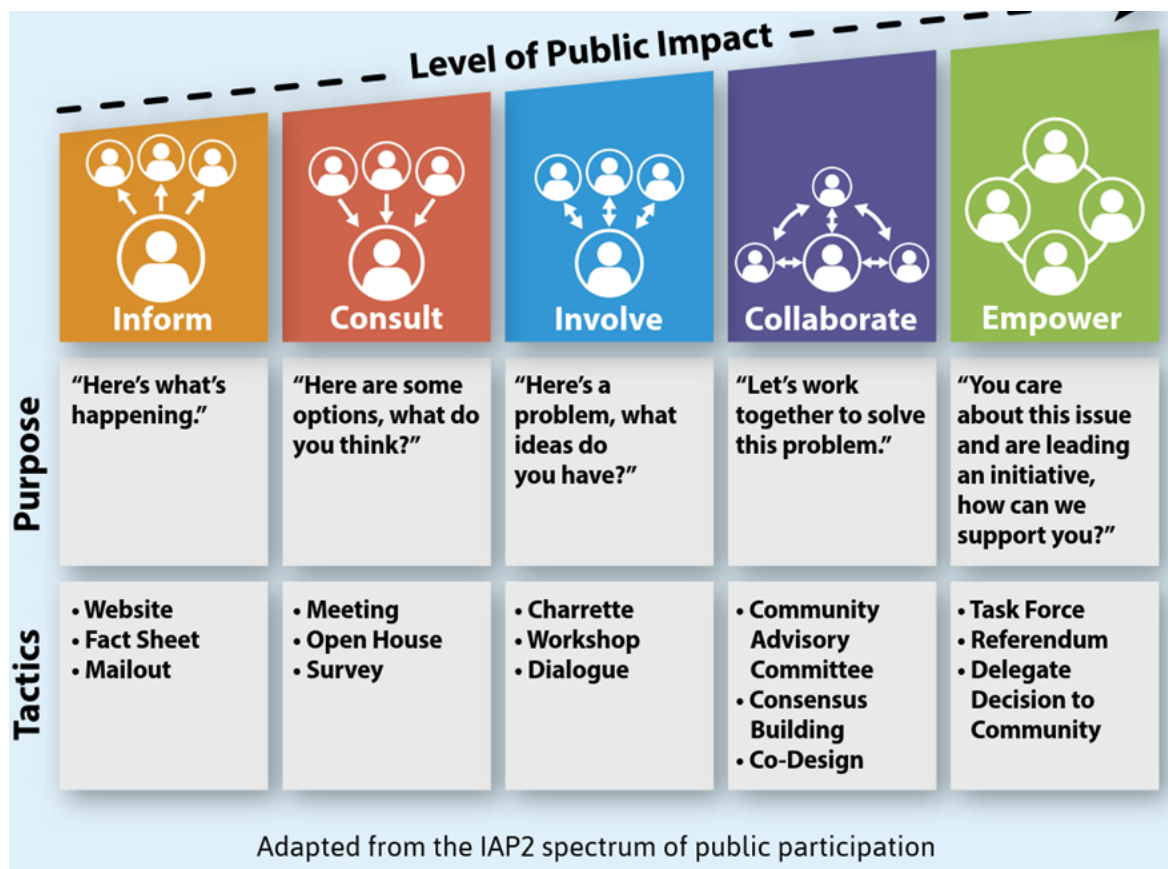


Figure 2. Levels of Patient Engagement (Source: [Google Images](#))

## **Patient Partner Membership**

**Recruitment Strategy:** Patient Partners have been recruited through [organization name].

- Who is the membership of the group open to?
  - 1) Patients with lived experience of sepsis
  - 2) Caregivers or family members of individuals with lived experiences of sepsis
- Planned number of patient partners

Currently, the panel encompasses four Patient Partners.

- Orientation Session

Upon recruitment, new Patient Partners will meet with at least one research team member for an orientation session. At this meeting, background science on the research project, as well as its overall goals and components will be provided for the Patient Partners to get a better understanding of the project.

- Length of the Patient Partnership Membership

- *How many hours per month?*

Patient Partners are welcome to attend the Patient Engagement focused 1-hour meetings once per 4-6 weeks, as well as the monthly [preclinical project name] Core Laboratory meetings; however, attendance can be based on individual availability and interest.

- *How many months of involvement?*

The funding period for the [preclinical project name] is until [date].

**Accountability:** [Name (title or role)] will be the main contact for the Patient Partners; however, [Name; Principal Investigator] will be copied onto every communication for consistency.

## **Review:**

- Terms of Reference

The terms of reference will be reviewed once a year or whenever a new member joins the team. The updated document will be circulated to all members of the team for their review.

- Patient Engagement

All team members will be asked to complete The Public and Patient Engagement Evaluation Tool (PPEET) several times over the course of the project (~3 times; project funded until [date]). This is an existing survey that can be used to gather feedback on the team's patient engagement strategy and help identify areas for improvement.

## **Working methods/ways of working:**

- Meetings

- *How will meeting topics be generated?*

Topics will be generated at least one week in advance of the scheduled meeting. Upon circulating meeting minutes from the previous meeting, members will be encouraged to respond with any potential discussion topics for the next meeting.

- *How and when will meeting documents be circulated?*

Meeting agendas and documents will be distributed in advance of the meeting by [names]. Action plans developed after meetings, or any meeting minutes will also be circulated by [names] following the meeting.

- *What will be the format of the meetings?*

The format of the meetings will be online in a combination of presentations, project updates and discussion. Meetings will occur on the platform Zoom, which is an online platform that will allow for the presenter to share their screen so everyone can see the presentation on their own computer screens. If Zoom fails or is being challenging, a member of the research team will be available to provide support and guidance. To ensure understanding of each team member, an overview in non-technical terminology will be provided at the start of each meeting. Our team strives to create a supportive environment, respectful of the fact that members will be coming from various backgrounds. As such, we encourage everyone to ask any questions they have.

- *Will non-members be invited to group meetings and if so, under what circumstances?*

Only group members have attended the meetings so far. However, if a non-member were to attend a team meeting, all members would be notified in advance when the agenda is distributed.

- *Who will provide secretariat for the group?*

This may rotate meeting to meeting amongst members of the research team.

- Sharing of information and resources (including confidential materials)

Information and resources will be predominantly shared through e-mail.

*How will confidential materials and copyright issues be identified and dealt with?*

All members of the team are expected to keep study materials, and confidential discussions, private (within the group) as these may involve intellectual property. If any issues regarding confidentiality or copyright arise, these will be discussed at the team meetings and the terms of reference will be updated to solve and prevent future issues.

- Compensation/Honoraria

Compensation will be discussed individually. Frequency will be based on individual patient partner preferences. When determining rates of pay, the documents developed by the following organizations will offer guidance:

- [organization name]

- Reimbursement of Expenses

Patient Partners will be reimbursed for all travel expenses incurred to attend group meetings /events, including parking, transportation, accommodations, and hospitality. Information regarding eligible reimbursement expenses for each meeting will be shared with Patient Partners upon invitation to in-person meetings, conferences, etc. As much as possible, patient partners will be reimbursed for expenses in advance of the meeting/event.

## **Definition of Terms**

Initial Patient Partner meetings will aim to clarify key laboratory and sepsis research terminology and background information, in addition to the overall goal and components of the research project. Please never hesitate to ask or email for clarification; if you are unsure, it's likely others are unsure as well! Patient Partners may also request further one-on-one meetings with the research staff and project leaders if they wish to learn more or would like clarification on a topic. An overview of terms/background information in non-technical language will be presented at the beginning of each meeting to ensure understanding of all team members.

## **Glossary**

**Patient Partners:** Community members who work with researchers to improve the health research process.

**[preclinical project name]:** [summary and aims of the preclinical project in non-technical language]

**Sepsis:** The body's extreme immune response to an infection where the immune response damages the body's tissues which can lead to organ failure and potentially death.

\*Definitions of other common health research terms may also be found on the CIHR Jargon Buster website, available here: <https://cihr-irsc.gc.ca/e/48952.html>