



PCAC Update 2021

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AGM: November 2021

FRAMEWORK

&

MANDATE

SPOR Framework for Patient Engagement in Research

- Establish areas for engagement to be adopted by all partners
- Guiding principles:
 - *Inclusiveness*
 - *Support*
 - *Mutual Respect*
 - *Co-building*

To engage patients and family members in all aspects of the Network: research design, research conduct, results interpretation, priority setting, knowledge translation, and decision-making.

● **Desired outcomes:**

- *Inclusive mechanisms and processes*
- *Respectful collaboration*
- *Experiential knowledge is valued*
- *Research is informed + co-directed by patients*
- *Common goal of quality research*

88 people contacted
56 with LD and 13 family member
8 joined the PCAC

32



**PCAC
Members**

Areas for Engagement

Advisory Roles

Providing feedback and input through surveys and discussions.

Pillar 1, 2, 3, 4

Processes for Engagement

Priority Setting Process

GRIPP2 Reporting
Guideline

Inclusive Material



Research

Design/Development

Different levels of engagement (co-design and collaboration)

Decision-Making

Executive Committee
Pillar Leads Committee
Pillars Co-Chairs

AGM and LD Awareness
Month

Outcomes 1: Research

Pillar One

5 PCAC reps, and 2 co-chairs

Priority Setting Process-priorities, translation to research question, research objective, research design.

Pillar Two

3 Pillar Reps and 1 Co-Chair
PCAC reps in 3 working groups

2 Research Consultations



Pillar Three

3 Pillar Reps and 1 CO-Chair

Three working groups with rep consultations

Pillar Four

8 Pillar Reps and 1 Co-Chair

BD Working Group
6 Research Consultations conducted for input and partnership

Outcomes 2: In Process and Structure



- Outreach to learn from and work with different voices (e.g. advocacy groups, Indigenous People) in different creative ways.
- Effort on creating a community of partners, a safe space to discuss and share ideas on the Network work and beyond.
- Mediation and Liaison work between scientists and patients.
- Connecting PCAC members with Scientists (and vice versa), for ongoing and future projects.
- Compensation guidelines, priority setting process, GRIPP2, and conflict resolution plan.
- Orientation sessions for new members.

Challenges

Not the best
timing

Engaging in the
aftermath does not
lead to the best
results.

Being at different
“locations”

Different understandings
of the levels of
engagement

Competing priorities
and health

COVID research,
caregiver roles, LD
symptoms



2021-2022 Plan



- Increase representation in P3, and P2.
- Increase diversity of voices (e.g all provinces, advocacy groups, Indigenous Peoples).
- Strengthen processes of inclusion for patients at different roles in the Network
 - Develop inclusive material across Network
- Strengthen processes of communication for patients
- Create opportunities for engagement:
 - *The PCAC door is open: come and present, discuss your work and ideas, get feedback, open a conversation*
- Educate on engagement methods and concepts and evaluate engagement in the current projects through GRIPP2
- Peer Reviewed Paper



Questions and Comments