OPERATIONALIZING HEC'S APPROACH TO PATIENT ENGAGEMENT & PARTNERSHIP: A CO-DESIGN INITIATIVE

Report of the Project Team - November 2022

Prepared by UHN OPENLAB

PROJECT BACKGROUND

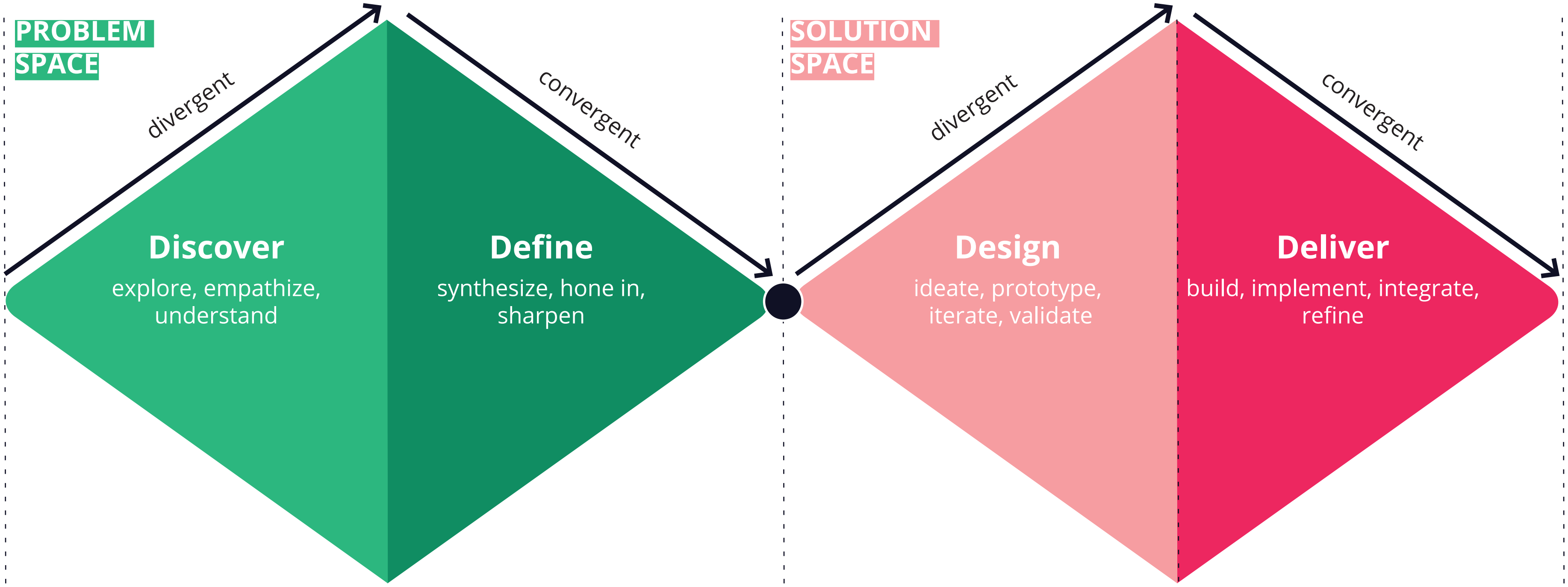
Healthcare Excellence Canada (HEC) is a not-for-profit pan-Canadian healthcare organization with a purpose to shape a future where everyone in Canada has safe and high-quality healthcare. HEC is committed to embed the lived experience of patients, caregivers, and communities in its work as one of the key perspectives to improve quality and safety. Building off the legacy and strength in engagement of its two founding organizations, Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute, HEC has the opportunity now to fully articulate its new path forward, using its approaches to patient engagement to provide clarity of roles and expectations for all involved.

To do this, HEC engaged with a broad range of stakeholders to co-develop a framework of approaches for engaging patient partners and patient groups in its work. The goal of this work was to co-develop recommendations for partnership that are clear, equitable, inclusive, transparent and that enable patient partner community growth in size and diversity, to support meaningful engagement across HEC.

OUR PROCESS

The project followed the first diamond of the **Double Diamond Framework**. It had two phases, Discover - an exploratory phase where we went broad and aimed to get insight from many people across four groups of interest, and Define – a synthesis phase where we worked together with a steering committee with membership from the four groups of interest to provide deeper input into areas identified during the Discover phase.

The Double Diamond Framework



Engagement Methods

Our project team engaged with people from four groups of interest:

- Patient Partners
- Representatives of Patient Groups
- Engagement Professionals
- HEC Staff

During the Discover phase, engagement activities included interviews (31), group conversations (8 groups with 43 participants total), an open text survey (7), and the option to provide input asynchronously by email (2).

During the Define phase, a steering committee with 23 members including patient partners, representatives of patient groups, HEC staff and engagement professionals met three times for two-hour design-based sessions to dig into important topics that came through the Discover phase findings. Consultations were also held with the Patient Engagement and Partnership team (PEP), the Safety Strategies and Programs team and Senior Leadership Team (SLT) to get their input and advice on what the project team should keep in mind when forming their recommendations.

Project Team

A project team of 4 Patient Partners and 4 HEC Staff worked together with OpenLab staff to design and oversee the project in its entirety.

The project team has designed and has provided oversight to all aspects of this initiative, including the co-development of materials, the design and content of engagement activities, recommendations for content to bring for discussion to the steering committee, and has now synthesized the findings to co-produce this set of recommendations.

WHO WE HEARD FROM

From the 92 people engaged, including members of the project team and steering committee, 61 (66%) completed an anonymous demographic survey. Many patient partners who were engaged had dual or triple roles and brought multiple perspectives. For example, some patient partners were also members of patient groups. Although they did not participate as representatives of those groups, they spoke about their experiences as both individuals and patient group members. Additionally, a number of engagement professionals possess experience as patient partners, and view their roles as patient, family, group representative and engagement professionals as intersecting.

The following descriptive demographic data is combined for the 66% of participants who responded to the survey. Although there is general diversity in the respondents, we recognize that a large portion of those engaged were highly educated and do not self-identify as part of an under-represented group, highlighting the need to increase the diversity and equity of the community of patient partners at HEC[1].

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[1] Abelson J, Canfield C, Leslie M, *et al* Understanding patient partnership in health systems: lessons from the Canadian patient partner survey BMJ Open 2022;12:e061465. doi: 10.1136/bmjopen-2022-061465

Total Survey Participants: **61**

39
patient partners

12
representative of a patient group

26
engagement professionals

7
HEC staff

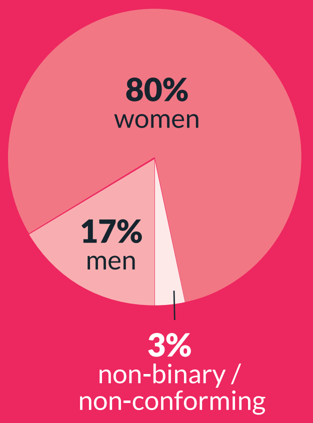
1
prefers not to answer

33%

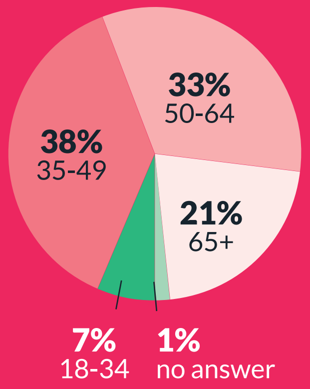
of participants identify as having more than one role or perspective

Participant Demographics at a Glance

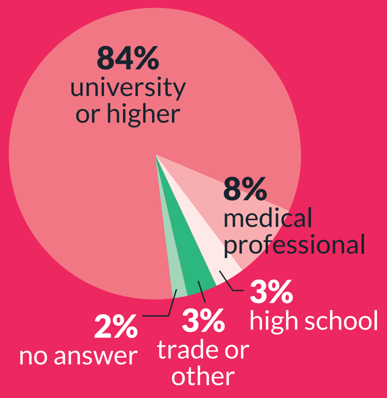
GENDER



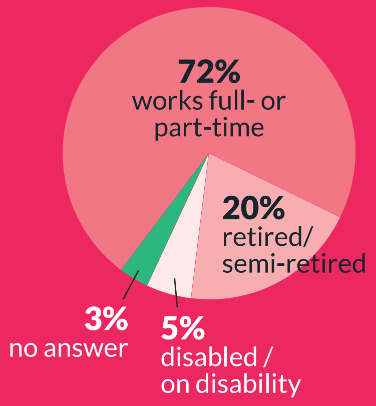
AGE



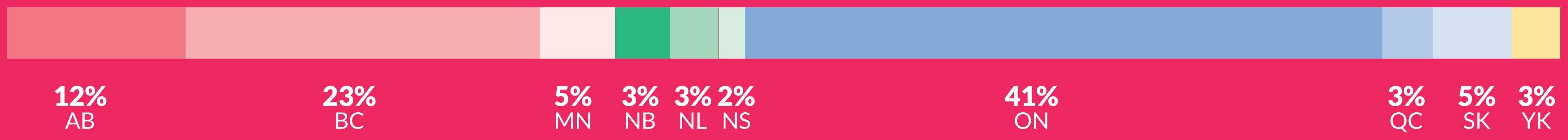
EDUCATION



EMPLOYMENT



PROVINCES & TERRITORIES



Participant Demographics in Detail

		Number	%
Gender	Man	10	16.4%
	Woman	49	80.3%
	Non-binary / Non-conforming	2	3.3%
Age	18-34	4	6.6%
	35-49	23	37.7%
	50-64	20	32.8%
	65+	13	21.4%
	No Answer	1	1.5
Rural / Remote Community	Yes	14	23.0%
	No	47	77.0%
Language	English	58	95.2%
	French	2	3.3%
	English & French	1	1.5%
Education	University or higher	51	83.6%
	Medical professional	5	8.2%
	Trade or other post-high-school training	2	3.3%
	High school	2	3.3%
	No answer	1	1.6%
Employment Status	Work full time or part time	44	72.1%
	Retired or semi-retired	12	19.7%
	Disabled/ On disability	3	4.9%
	no answer	2	3.3%

		Number	%
Self-reported income compared to others in Canada	Lower	8	13.1%
	Same	25	41.0%
	Higher	23	37.7%
	No answer	5	8.2%
Identify as a caregiver (unpaid)	Yes	30	49.2%
	No	28	45.9%
	No answer	3	4.9%
Self-Identify as part of the following groups	Person identifies as having a disability	17	27.9%
	LGBTQ2S+	5	8.2%
	Person of colour/visible minority/Racialized group	7	11.5%
	Indigenous	1	1.6%
	None of the above	31	50.8%
Health Condition	Chronic Illness	13	21.3%
	Physical disability	10	16.4%
	Mental health condition/disability	7	11.5%
	Learning or developmental disability	2	3.3%
	Person who has difficulty hearing	5	8.2%
	Person with low vision/ vision loss	2	3.3%
	No answer	22	36%

WHAT WE HEARD

Participants discussed structures that worked well; what was missing; factors HEC should consider when determining which patient partners and patient groups to work with; having an equity approach and creating safe spaces; and support for patient partners and staff.

Throughout the entire project there were two emerging principles that remained consistent throughout the design process:

1. **Have an equity, diversity and inclusion focus that continually asks what perspectives are needed**
2. **Have a growth mindset that leverages what has worked and past learning, monitors the current situation, needs and opportunities, and adjusts structures and approach to achieve HEC's goals**

About the Findings & Recommendations

They follow four iterative steps by which engagement and partnership happen: (1) Plan, (2) Recruit, (3) Act, and (4) Evaluate.

They include the input from all the engagement throughout the Discover & Define phases.

They reflect an ideal near-future state given where HEC currently is. You may not achieve all the recommendations every time, for every engagement, right away.

Past ways of working may need to evolve given these recommendations.

Step 1: Plan

The first step in operationalizing the framework is planning. Planning for engagement begins with determining the purpose of why you want to engage and moving from there to determine how you will engage, who will be engaged, and how that will be evaluated. When working in and with communities, research ahead of time to learn what is being done by those communities. During this planning phase, it is also important to consider the time, resources, and budget that will be needed for relationship building with patient partners and communities and for including engagement in initiatives and making sure that capacity is in place to sustain relationship building over time. **HEC is encouraged to work towards planning for patient engagement and partnership as part of every initiative.**

In addition to planning for engagement on HEC initiatives, HEC has a role to play as a convenor or catalyst, to help connect individual patient partners who may or may not be members of patient groups from across the country by building a community of patient partners. Participants noted that collaborating with other pan-Canadian health organizations (PCHOs) in creating the community would add value to patients wanting to engage at the national level[2].

Recommendations

1. Dedicate budget, resources, and time for building relationships with patient partners and communities and for supporting patient engagement and partnership for each team and initiative at HEC. Include planning for patient engagement and partnership as part of every initiative.
2. Create guidelines and resources to support staff and patient partners in their engagement work together at HEC[3].
3. Explore the potential of a single point of entry and having a single community of patient partners with other Pan Canadian Health Organizations[4].

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[2] Key learning partners for this item that were identified by participants and project team members are the Patient Voices Network (PVN) and Patients for Patient Safety Canada (PFPSC)

[3] Recommended guidelines include communication, compensation, onboarding, project lifecycle, and having difficult conversations. Details related to these guidelines are provided in Appendix B.

[4] Key partners to engage for this item that were identified by participants and project team members are Patient Advisors Network (PAN) and PFPSC

Step 2: Recruit

Once there is clear articulation about the purpose of the engagement, consider what perspectives are relevant and how they can be captured. **Consider what communities will be impacted by the work and find ways to include people from those communities.** Balance a more collective voice while intentionally building relationships with communities who experience the most inequity related to each initiative.

Diversity can mean many things. What is important is to have participatory discussions on an initiative by initiative basis about what perspectives are important and need to be included.

For recruitment to HEC initiatives, start with the purpose of engagement on an **initiative by initiative basis** and consider what perspectives need to be included so that the right people are engaged at the right time and for the right purpose. Generally seek diverse perspectives, which often means going out into communities. It would be helpful for HEC to build relationships with many communities and with many patient groups, to learn about them and to share opportunities and recruit widely and flexibly, so that you can reach the right people for each initiative. For each initiative recruit broadly, allowing patient partners to self-identify interest and related experience.

Prompts when discussing diversity:

- Geography (across Canada including urban, rural and remote)
- Gender
- Age
- Sex
- Race
- Type of healthcare experience (parts of the health system)
- Type of healthcare experience (variety of illnesses including both physical and mental health and those with more severe illness)
- All types of disabilities
- Inclusion of those who have less experience and opportunities to engage
- Inclusion of caregivers
- Inclusion of youth
- Inclusion of those with social issues affecting health such as precariously housed, low-income, and various family dynamics
- Inclusion of all communities
- Other

It would be beneficial for HEC to have staff and leadership reflect the diversity that they want to see in patient engagement and partnership.

For recruitment to both the community of patient partners and to specific HEC initiatives, relationship building by going into communities is important. **When engaging with communities, meet them where they are.** You can start relationship building by asking to sit at their tables to listen and learn from them. Start with community associations and organizations that support underserved populations (e.g. food banks). Eventually, relationships can develop to a point where there are shared goals identified within an area and projects are approached with shared agendas and decision making. It is beneficial for recruitment methods to be flexible and adaptable to reach a broad audience, beyond virtual means, which may be particularly relevant for some HEC focus areas, e.g. older adults. For example, using paper flyers shared in community organizations that target groups of interest may be an effective approach to reach those who have not been engaged before. Patient groups should remain autonomous from HEC, but come

Recommendations

Building a Community of Patient Partners

4. Have an open invitation for individual patient partners and members of patient groups to join a community of patient partners
5. Have an explicit goal of welcoming and including people who have never been involved before
6. Build and expand upon your existing network of patient groups and community associations

Engaging Patient Partners in HEC work

7. For each initiative, include the perspectives of people that will be most impacted by the work. If appropriate, consider engaging a patient group to contribute to a portion of the initiative.
8. Share opportunities widely with the whole patient partner community and beyond and list them on a webpage.
9. Bring people to your tables, but also go to their tables. Identify a ‘most impacted’ group for each initiative and sit at their table to learn from them. Consider adding flexibility of the timing of meetings (i.e. outside of typical business hours) to allow for attendance of more diverse patient partners.

R7

Q&A: When is it appropriate to consider engaging a whole patient group?

Patient groups should remain autonomous from HEC, but come together on initiatives when there is alignment of purpose, focus, skill set, or the group has relationships with people who have perspectives relevant to the initiative.

In cases when HEC is working with a patient group, continue to ensure diversity in engagement both within and beyond the group. When working with a patient group, the following components were identified as necessary:

1. Clarity around roles and scope
2. Consistency for relevant organizational guidelines being upheld (e.g. translation, compensation, codes of conduct)
3. Being clear about who owns the product or data
4. Being clear about reciprocity
5. Understanding of how the group operates (e.g. how they recruit for EDI)
6. Mechanisms that will be used to reach the broader group
7. Understanding or training for group members on how to mobilize the collective of the group and what it means to represent the group
8. A terms of reference or similar document of understanding
9. Conflict of interest - understanding various types of conflicts, being specific on what that means and how it will be addressed

The steering committee spent time discussing two specific structures for working with patient groups including: (1) putting out calls for applications from patient groups to work on topics of interest, and (2) providing ongoing support of funding or resources to support the functions of specific patient groups. The steering committee felt that both structures were not in line with an equity approach. The committee felt that for each initiative, it is most important to consider the individual perspectives that are relevant and to reach out to multiple groups to recruit as each patient partner in a group has their own unique perspective (e.g. minority patient partners) and competencies. **Having exclusive relationships or support to any specific groups that result in the exclusion of other groups or patient partners is not recommended**.

Step 3: Act

Patient engagement and partnership can happen in many ways and will differ when working broadly with the patient partner community, when engaging patient partners or patient groups to work on HEC initiatives, and when going into communities.

Engaging the patient partner community - In addition to sharing opportunities for engagement and learning with the patient partner community, it is important to hear the ideas about quality and safety that come from the patient partner community. It would be helpful for HEC to find ways to collect, track, and save these ideas. They can inform future strategy, among other things. HEC can also play the role of connector, sharing the ideas with other PCHOs and quality and safety organizations. Be clear about how ideas are shared or used.

Engaging with patient partners on HEC initiatives - When it comes to bringing people to engage with HEC consider what they will need to partner meaningfully. Offer diverse opportunities and approaches for participation. Commit to and be clear about how decisions are made and what influence the engagement has to make change. Offer resources and support to create safe spaces considering trauma informed engagement practices. Continue to explore additional roles and ways to engage patient partners.

Recommendations

Building a Community of Patient Partners

10. Create opportunities for mentorship and networking
11. Explore platforms for collecting ideas from the patient partner community[5]
12. Consider new roles that patient partners could take on at HEC, such as patient partner community ambassadors.

Engaging patient partners in HEC work

13. Have a wide variety of ways that patient partners are engaged throughout HEC (e.g. in strategic and operational planning) and throughout initiatives across the continuum of engagement (e.g. as coaches, advisors, working and steering group members[6]).
14. Build staff and patient partner capacity for engagement through training, communication, shared learning, development of resources, and structures and support that create safe spaces.
15. Explore the creation of a standing structure linked to the focus areas and/or HEC governance ensuring clarity of purpose and identification of decision-making authority[7]

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[5] Including ThoughtExchange.com, careopinion.org and the SPOR Evidence Alliance platform (https://sporevidencealliance.ca/submit-a-request/suggest-a-health-topic-for-research-en/)

[6] HEC's guiding principles for engagement are in development

[7] Key learning partner for this is SPOR

R12

A potential new role

Having patient partners in a new role of community ambassador. If this idea is to be successful, there needs to be sufficient support, commitment, vision, and dedicated time for the community and ambassadors.

The group recommended the creation of new roles of HEC community ambassadors. Ambassadors would have a role within the patient partner community with the purpose of bringing in members from their local community into the HEC partner community. The role is designed to increase the diversity of perspectives in the community and to relieve burden from having individual members representing their entire community. Ambassadors could also act as mentors to other members of the patient partner community and be a safe contact to come to with any questions or concerns.

R15

A potential new structure

Having a standing advisory structure was identified as a potential opportunity and explored in more depth with the steering committee. Below is the example structure the committee came up with as a potential example.

The group recommended a subcommittee of the board supported by three advisory committees, one for each focus area. The subcommittee of the board would have a co-chair model of 2-3 patient partners and a rotating governor. Governors are embedded in the structure to learn more about the patient perspective, so the burden is not entirely on the patient partners. The focus-oriented groups will report into the subcommittee of the board. The sub-committee of the board would be strategy-focussed and the three focus committees would be operations-focused.

R14

Q&A: What training and learning opportunities and supports were suggested throughout this project?

Participants felt that staff would benefit from having the opportunity to become patient engagement and partnership champions in a similar way to what is done with other skills at HEC (e.g. cultural competency). Training and learning opportunities suggested for staff included:

- coaching from the patient engagement and partnership team, that is mandatory for anyone new to patient engagement
- learning modules and shared resources through existing platforms such as D2L and SharePoint
- a Teams channel for discussing the topic
- drop in sessions with the patient engagement and partnership team and patient partners
- shared training on equity, Indigenous ways of working, and trauma-informed engagement with patient partners

Participants also noted the need for a robust orientation for patient partners that included expectations and roles. Patient partners and staff would benefit from trauma informed engagement practices that create safe spaces for engagement through resources, support and capacity building. It would be helpful for patient partners to have relationships with at least two staff or mentors (with at least one being neutral with the purpose to support them (e.g. a PEP team member)). Patient partners would also benefit from the creation of profiles that include the ways they like to work, their interest areas, triggers or areas where they do not want to work, and the support they need to feel safe and participate. Patient partners would appreciate learning opportunities to help build their capacity for engagement at HEC including topics such as:

- HEC and its work
- patient safety and quality improvement
- research
- public speaking
- the health system
- leadership

Step 4: Evaluate

The importance of evaluation was made clear throughout this project, including the need to continuously review and evaluate engagement and partnership across the organization and adjust as needed. Some ways suggested to measure success include tracking outputs from HEC that have been co-produced with patient partners or where there has been involvement, to assess perspectives of patient partners, that the engagement efforts were culturally, emotionally, and psychologically safe, and that the engagement helped advance HEC's strategy and goals. In the future, when relationships with communities are more developed, the definition of what success means and how you will know when you are successful may change.

Recommendations

16. Track and measure the quantity, quality, and impact of patient engagement and partnership throughout the organization
17. Bring together a group for continuous improvement of the patient engagement and partnership framework
18. Set up systems to encourage honest reflection and purposely ask staff and patient partners how things are working. Provide anonymous options

APPENDICES

Appendix A:	Recommendation list
Appendix B:	Guidelines for the patient engagement and partnership team to create
Appendix C:	Project team membership and patient groups who participated in this project

1.

APPENDIX A

Recommendation List

Step 1: Plan

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Step 2: Recruit

Building the patient partner community

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Engaging patient partners in HEC initiatives

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14. Build staff and patient partner capacity for engagement through training, communication, shared learning, development of resources, and structures and support that create safe spaces.
15. Explore the creation of a standing structure linked to the focus areas and/or HEC governance ensuring clarity of purpose and identification of decision-making authority

Step 4: Evaluate

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APPENDIX B

Guidelines for the patient engagement & partnership team to create[8,9]

Guideline Topic	Details shared throughout the project
Communicating with patient partners	• Have ongoing and regular communication. • Use multiple media (written, oral, video), especially for sharing opportunities. • Use plain language and avoid acronyms.
Budgeting for compensation and expenses of patient partners	• Include both monetary and non-monetary compensation and recognition that is flexible and makes the process easy for patient partners and staff. • Follow the compensation guidelines at HEC for how much to compensate patient partners for various activities. • Include reimbursement for any expenses they need to participate, including childcare and transportation. • Provide technology if needed. • Recognition could include certificates and letters of support. • For patient groups, ask them what they need to participate. This may include administrative support. • Let people know about the potential impact of compensation to social benefits and other programs.
Engagement throughout the project lifecycle	• Steps mentioned include recruitment through evaluation. • Include what methods to use when. • Include roles and responsibilities of teams and of the patient engagement and partnership team.
What to consider when onboarding a patient partner	• Questions to ask including supports needed and training they may benefit from
How to have difficult conversations	• Working through challenges and conflicts are an important part of creating safe and ethical spaces for engagement

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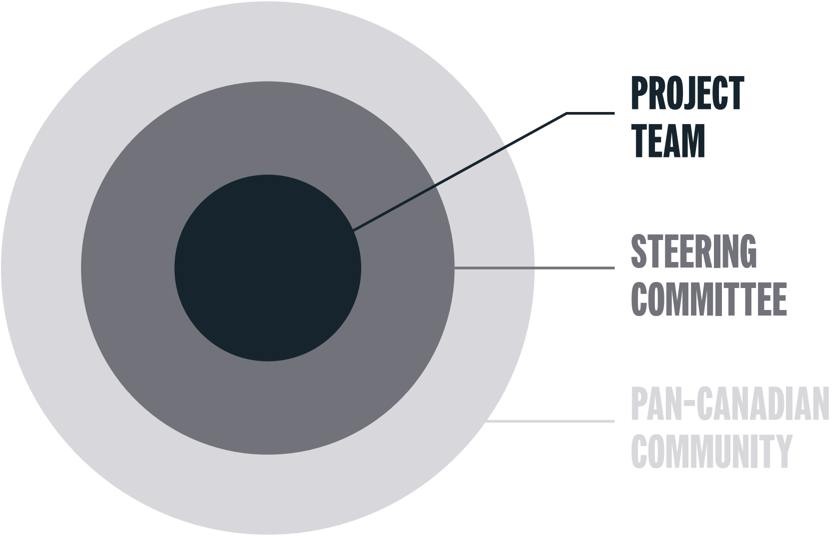
[8] There are many groups that have helpful resources that can be leveraged including other Pan-Canadian Health Organizations, the BC Patient Voices Network, SPOR Support Units, and other patient groups such as the Diabetes Association of Canada.

[9] Many of these guidelines are already in progress.

APPENDIX C

Project Team Membership and Patient Groups who Participated in this Project



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Penelope Hedges
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Maggie Keresteci

Patient Partner Representatives of Patient Groups

Theresa Malloy-Miller representing Patients for Patient Safety Canada
Anne O'Riordan representing Patient Advisors Network
Heather Thiessen representing Health Standards Organization and Accreditation Canada
Zal Press representing Patient Commando
Roger Stoddard representing Canadian Medical Association's Patient Voice
Maria Klement representing Patient Voices Network
Judy Birdsell, Alex Harrison, and Gail Mackean representing Imagine Citizens

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Lauren Junkin
Nicole Pollack
Kathryn Graves
Denise McCuaig, Metis elder supporting HEC staff

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Tammy Hoefer, BC Patient Voices Network
Caroline Wong, Center of Excellence on Partnership with Patients and the Public

The project team acknowledges the time and expertise of the many engagement professionals, patient partners and patient groups that participated in the steering committee and throughout the discover phase. Thank you!