

Patient-oriented research creating impact for those living with diabetes?



Diabetes Action Canada

Preventing complications. Transforming lives.



What is Diabetes Action Canada?

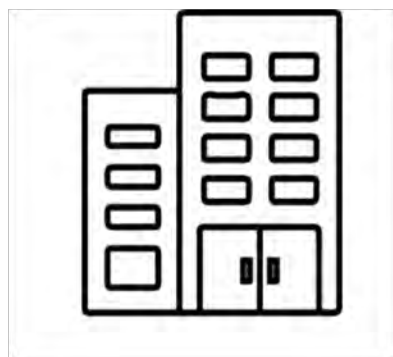
- A national diabetes research network with 217 members, 97 of whom are Patient Partners.
- Research programs are developed with the **meaningful** involvement of people living with diabetes.
- Our goals are focused around working with those living with or affected by diabetes to prevent the complications of diabetes, with a major focus on the most vulnerable in our society.
- Funded by the Canadian Institutes for Health Research (CIHR) and through philanthropic support.



ABOUT Diabetes Action Canada



97 Patient Partners



29 Partners



8 provinces



120 Researchers



10 Programs

Our greatest assets are our Patient Partners



Patient Engagement – Why?

- Patients are people using the health system while they are managing a health issue
- Experiences go beyond living with the condition
- Best feedback on where to focus research priorities and improve experiences
- Research is more relevant, useful and person-centred
- Increases the uptake of new evidence in practice and policy
- Reduces wasted resources

Patient Engagement – Do's and Don'ts



1 Treat patient partners as equals. Patient partners are experts in their own right.

✓ **DO** recognize that patient partners' lived experience will provide valuable insight that a researcher/medical professional may not have.



2 Patient partners do not want to be included in a tokenistic manner - they want to be a true part of the project.

✓ **DO** invite patient partners to engage in all parts of the project and be sure to ask for their input. Example: A round table method ensures that everyone has an opportunity to speak.

✗ **DON'T** invite patient partners onto the project because you "have" to and then ignore the potential for their valuable contribution.



3 Clearly set out expectations from the beginning of the project, so that expectations are managed for both patient partners and researchers.

✓ **DO** ensure that the researcher makes a welcome call to each patient partner to explain the project and increase confidence and understanding.

Patient Engagement – Do's and Don'ts



4 **Involve patient partners from the beginning of the project.**

✗ DON'T invite patient partners into projects when most decisions have already been made.

✓ DO involve patient partners right from the beginning to help shape the research objectives.



5 **Don't waste the patient partners' time.**

✗ DON'T get patient partners to review information or provide feedback if it's not going to be considered and used in the project.



6 **Carefully consider the number of patient partners you want to involve in the project.**

✓ DO involve at least two patient partners in every project. Too few can feel intimidating and/or isolating for the patient partners, while too many can slow down progress. If there is a need to have many patient partners involved, consider organizing them into smaller groups.

Patient Engagement – Do's and Don'ts



7 Keep communication open and ongoing throughout the entire project.

✓ **DO** keep patient partners informed of each step of the project including end results and publications. **Examples:**

- Invite patient partners to meetings, even if they are administrative, but allow the patient partner the ability to opt out if they are not integral to the meeting; be sure to update patient partners on any meetings that they don't attend.
- Do ask patient partners if they want to be included in publications as co-authors.



8 Refrain from using jargon and acronyms in communicating with patient partners.

✓ **DO** provide explanations and terms of reference to patient partners prior to meeting so they can follow the discussion.

✗ **DON'T** use acronyms during meetings because it is alienating for patient partners.

Patient Engagement – Do's and Don'ts



9 Make space for patient partners to speak up.

✓ **DO** ask each patient partner for their feedback at the end of every topic or point of discussion. **Example:**

- At the end of the meeting, ask patient partners if they have any additional questions. But never wait till the end of the meeting to ask for feedback. This should happen throughout the meeting.

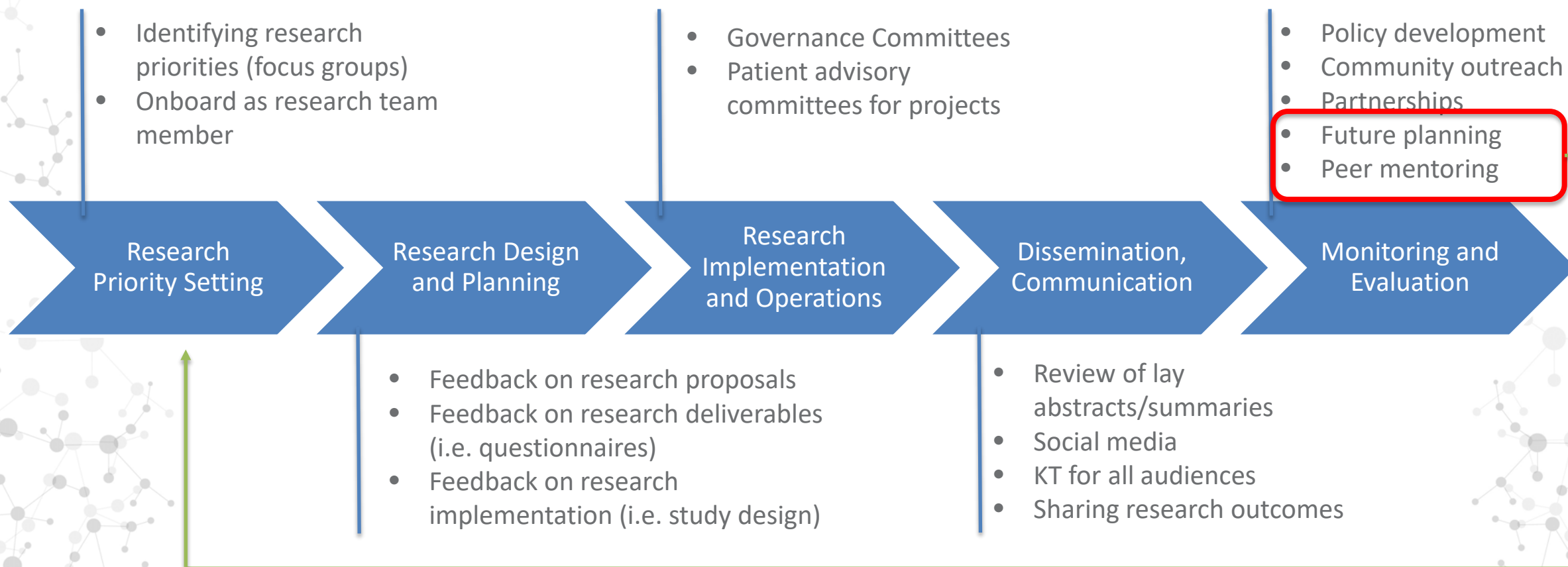


10 Materials and event spaces must be accessible.

✓ **DO** have a conversation with patient partners to assess any accessibility issues and provide appropriate accommodations. This conversation should be incorporated into the welcome call. **Examples:**

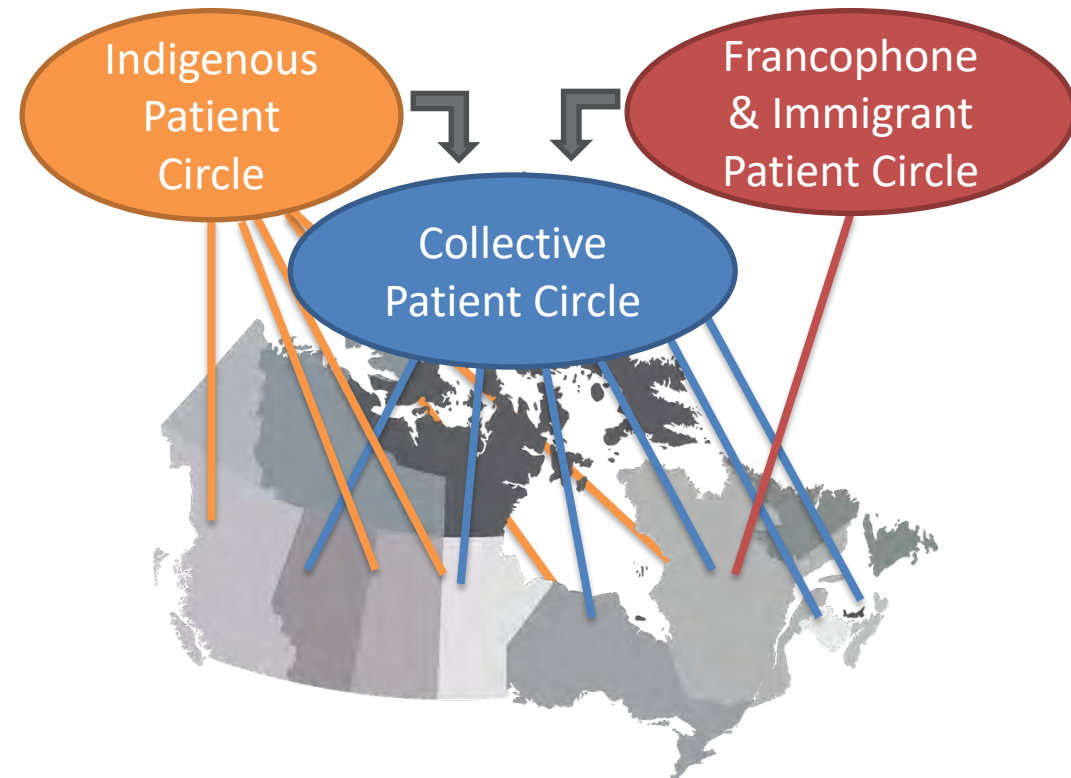
- Provide written materials that follow the Diabetes Action Canada Accessibility Policy.
- For persons who are visually impaired, include text descriptions of graphics and tables, so that screen reading software can read the text.

Patients Engagement – When?



Formalizing Patient Engagement

Three Patient Circles established representing the diverse Canadian population with diabetes



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ORIGINAL RESEARCH PAPER

WILEY

Diabetes-related complications: Which research topics matter to diverse patients and caregivers?

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Health Expectations 2018; 21 549-559

The national survey used to establish our Network's research priorities was published by **Dr. Joyce Dogba** and is among the most downloaded for the journal *Health Expectation*

Patient Engagement – How?



DAC has 97 Patient Partners and targets recruitment to those who are impacted most by diabetes

DAC helps its members recruit Patient Partners to research opportunities

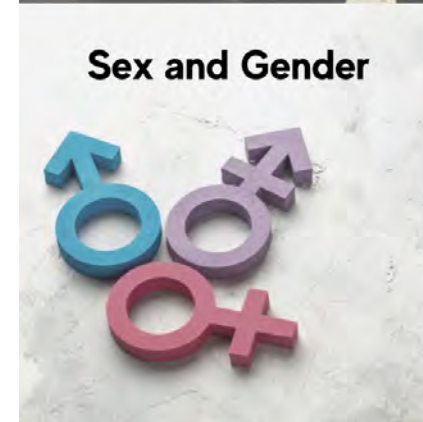
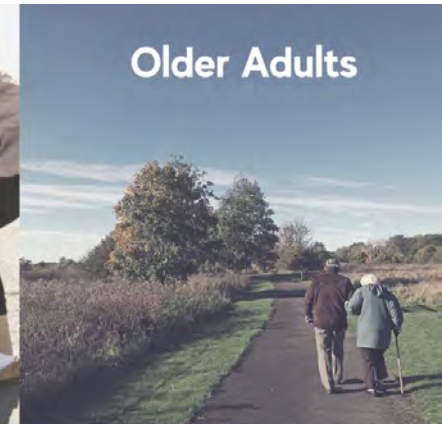
DAC monitors the patient engagement experience for both Patient Partner and Researcher

Patient Partners are compensated for their time and expertise and acknowledged for their work

A Sampling of our Programs

Diabetes Action Canada supports programs that work toward our goal of preventing complications:

- Indigenous health
- Older adults with diabetes
- Supporting those living with T1D
- Preventing blindness
- Amputation prevention
- Mental health supports for those with diabetes
- Harnessing data to improve outcomes



Thank You!

- Diabetesaction.ca
- info@diabetesaction.ca
- @_diabetesaction on Twitter

