

Do's & Don'ts:

Guidelines for Researchers, Patient Partners and anyone new joining Diabetes Action Canada!

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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.



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.



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.



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.