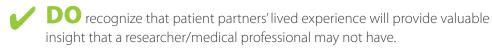
# Do's & Don'ts:

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

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



- Clearly set out expectations from the beginning of the project, so that expectations are managed for both patient partners and researchers.
- ensure that the researcher makes a welcome call to each patient partner to explain the project and increase confidence and understanding.



- Involve patient partners from the beginning of the project.
- **DON'T** invite patient partners into projects when most decisions have already been made.
- po involve patient partners right from the beginning to help shape the research objectives.



- 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.









## 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.



# **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.





### 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.





#### Make space for patient partners to speak up.



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







#### 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.



