



## Patients as Partners in Research - Evaluating the Patient Partnership in Research Projects Initial Survey

### Purpose

The patient partner surveys are designed to collect information to help us understand the actual experience of patient partners when they partner with researchers on a project as members of the research team. The questions are practical and look to identify behaviours that support productive partnerships.

Help us to understand your experience of partnering on a research team in the past 12 months so we can learn what patient partners could use for support in future. This is the first of 3 surveys we will ask you to complete: an initial one early in your involvement, one during the middle of the project and one near the end when the results are done and being sent out.

### About this survey

*This survey is an adaption of Patients as Partners in Research: Patient/ Caregiver Surveys developed by Alies Maybee, Brian Clark, Annette McKinnon and Emily Nicolas Angl, Patient Advisors of Patient Canada. The original survey was funded by Ontario SPOR SUPPORT Unit, which is supported by the Canadian Institutes of Health Research and the Province of Ontario. This work is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. ©2017*

### \*1.2 Please indicate which Can-SOLVE CKD research project your response is associated with:

Reminder: If you are involved in multiple Can-SOLVE CKD research projects, please complete one survey for each of the projects that you are invited to provide feedback on.

- Project 1.1A Defining CKD risk in youth with diabetes (ADDIT) [Dr. Farid Mahmud & Dr. James Scholey]
- Project 1.1A Improving renal complications in adolescents with type 2 diabetes through research (iCARE) [Dr. Allison Dart]
- Project 1.1B Screen, triage, treat: Optimal approaches to CKD case finding in Indigenous communities [Dr. Paul Komenda]
- Project 1.2 Personalizing treatment of patients with ADPKD [Dr. York Pei]
- Project 1.2 The SPOR Canadian GN Registry (CGNR) and Translational Research Initiative [Dr. Heather Reich]
- Project 1.3A Integrating risk-based care for patients with CKD in the community [Dr. Navdeep Tangri]
- Project 1.3B Individualized risk prediction to support shared decision-making for management of heart disease [Dr. Matthew James]
- Project 2.1A Cell therapy for advanced diabetic kidney disease (DIRECT) [Dr. Richard Gilbert]
- Project 2.1A Clinical trials of promising re-purposed drugs/ compounds for ADPKD [Dr. York Pei]
- Project 2.1B Aldosterone inhibition and enhanced toxin removal in hemodialysis patients (ACHIEVE) [Dr. Michael Walsh]
- Project 2.2: Dialysis symptom control (DISCO) [Dr. Michael Walsh]
- Project 2.2: Etiology of pruritus during dialysis [Dr. Christopher McIntyre]
- Project 2.2: Patient-reported outcomes clustered RCT (EMPATHY) [Dr. Jeffrey Johnson]
- Project 3.1A Restructuring kidney care to meet the 21st century patients (Triple I's) [Dr. Marcello Tonelli]
- Project 3.1B Targeted deprescribing in patients on hemodialysis to decrease polypharmacy [Dr. Marisa Battistella]
- Project 3.2 Strategies to enhance patient self-management of CKD [Dr. Brenda Hemmelgarn]
- Project 3.3A Improving patient knowledge about treatment options [Dr. Joanne Kappel]
- Project 3.3B Increasing the use of living donor kidney transplantation [Dr. Amit Garg]
- Registry of persons with kidney disease Considering participation in Research Database

### \*1.3 Are you a Patient Partner or a Researcher?

(Researcher refers to principal and co-investigators, study coordinators, research associates and trainees.)

- Patient Partner
- Researcher

Patient Partner Survey

**\*2.2 Have you had training on patient-oriented research, e.g. Foundations in Patient-Oriented Research Modules 1, 2, and 3?**

- Yes  
 No

**\*2.3 Was the project described to you before you started working with the team?**

- Yes  
 No

**\*2.4 Did you and the project lead and/or team together discuss your role on the team?**

- Yes  
 No

**\*2.5 Were the roles of the other members of the team explained to you?**

- Yes  
 No

**\*2.6 Were you involved in the development and wording of the research question?**

- Yes  
 No

**\*2.7 Were you asked to draft the Patient Engagement section of the work plan?**

- Yes  
 No

**\*2.8 Is writing parts of the work plan the sort of work you think you should be doing as a patient partner on the team? (select a point on the scale)**

- Never Definitely
- 
- 1 2 3 4 5 6 7

**Comments**

**\*2.10 How involved were you in discussing the planning of the project with the project lead or the team members? (select a point on the scale)**

- Not Highly  
involved involved
- 
- 1 2 3 4 5 6 7

**\*2.11 During the planning of the research, did you participate and contribute to the following:**

- Designing the methodology (the way the research is to be done)
- The way patients, caregivers or patient data are to be handled
- Planning the approach of patient engagement
- Planning the approach of recruiting patients/caregivers as study participants of the research
- Planning for how the results of the research will become known
- Deciding who are the key people who should get these results (sometimes called Knowledge Translation or KT) stakeholders
- Planning for the preparation of materials for patients
- Writing parts of the work plan beyond merely providing feedback on the drafts provided to you
- None Of The Above

**\*2.12 To what degree were you involved in any discussions around the outcomes expected from this research? (select a point on the scale)**

Not involved Highly involved

1  2  3  4  5  6  7

**\*2.13 In follow up to the previous question, is this the sort of work you think you should be doing as a patient partner on the team? (select a point on the scale)**

Never Definitely

1  2  3  4  5  6  7

**\*2.14 Does the research team work with you to accommodate for your challenges and ensure that it is easy for you to participate?**

(Example: Some patients and caregivers have challenges getting around because of fatigue, difficulty walking or seeing to find their way, or they use a mobility device like a wheelchair. Some need help providing transport or help with caring for a loved one.)

Yes

No

**Comments**

**\*2.16 Has the team discussed compensation with you?**

Yes

No

**\*2.17 What sort of compensation has been offered to you?**

Gift card

Honoraria or one-time payment

Regular salary or regular payments for the duration of the project

Other:

None Of The Above

**\*2.18 Have you received any compensation yet?**

Yes

No

**Comments**

**\*2.20 In your opinion, have your insights and comments impacted the decisions of the team? (Select a point on the scale)**

Never Definitely

1  2  3  4  5  6  7

**\*2.21 Did you feel the patient partnership was productive and enriched the process and outcome of the research project? (select a point on the scale)**

Not at all Definitely

1  2  3  4  5  6  7

**Comments**

**\*2.23 Do you feel you are equipped to contribute to your research project? (select a point on the scale)**

Not at all Definitely

**Comments**

**\*2.25 You have experience with the healthcare system as: (Pick all that apply)**

- A patient
- A caregiver
- Paid healthcare professional in any capacity
- Academic health researcher

**\*2.26 How did you learn about this project? (Select one)**

- Social media/website
- Through a friend/colleague
- Through the Can-SOLVE CKD Network
- Through an organization
- Invitation from a researcher
- Other:

**\*2.27 What made you decide to do this work?**

**2.28 Do you have any other comments you would like to provide?**

Researcher survey

**\*3.2 Have you had training on patient-oriented research, e.g. Foundations in Patient-Oriented Research Modules 1, 2, and 3?**

- Yes  
 No

**\*3.3 Did you have a discussion with the patient partners about their role on the team?**

- Yes  
 No  
 Don't know

**\*3.4 Were the roles of the other members of the team explained to the patient partners?**

- Yes  
 No  
 Don't know

**\*3.5 Were the patient partners asked to draft the Patient Engagement section of the work plan?**

- Yes  
 No  
 Don't know

**\*3.6 Is writing parts of the work plan the sort of work you think the patient partners should be doing? (select a point on the scale)**

- Never Definitely
- 
- 1 2 3 4 5 6 7

**Comments**

**\*3.8 How involved were the patient partners in discussing the planning of the project with you? (select a point on the scale)**

- Not Highly  
involved involved
- 
- 1 2 3 4 5 6 7

**3.9 If not involved, why not?**

**\*3.10 During the planning of the research, did the patient partners participate and contribute to the following: (Pick all that apply)**

- Designing the methodology (the way the research is to be done)
- The way patients, caregivers or patient data are to be handled
- Planning the approach of patient engagement
- Planning the approach of recruiting patients/caregivers as study participants of the research
- Planning for how the results of the research will become known
- Deciding who are the key people who should get these results (sometimes called Knowledge Translation or KT) stakeholders
- Planning for the preparation of materials for patients
- Writing parts of the work plan beyond merely providing feedback on the drafts provided to you

- Don't know
- None Of The Above

**\*3.11 To what degree were the patient partners involved in any discussions around the outcomes expected from this research? (select a point on the scale)**

Not involved								Highly involved
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1	2	3	4	5	6	7		Don't know

**\*3.12 In follow up to the previous question, is this the sort of work you think patient partners should be doing? (select a point on the scale)**

Never							Definitely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1	2	3	4	5	6	7	

**\*3.13 Do you work with the patient partner(s) to accommodate for their challenges and ensure that it is easy for them to participate?**

(Example: Some patients and caregivers have challenges getting around because of fatigue, difficulty walking or seeing to find their way, or they use a mobility device like a wheelchair. Some need help providing transport or help with caring for a loved one.)

- Yes
- No
- Don't know

**Comments**

**\*3.15 Have you budgeted for patient compensation?**

- Yes
- No
- Don't know

**\*3.16 Has the team and/or the project lead discussed compensation with the patient partners?**

- Yes
- No
- Don't know

**\*3.17 What sort of compensation has been offered to? (Pick all that apply)**

- Gift card
- Honoraria or one-time payment
- Regular salary or regular payments for the duration of the project
- Don't know
- Other:
- None Of The Above

**\*3.18 Have you provided compensation to your patient partners yet?**

- Yes
- No
- Don't know

**Comments**

**\*3.20 In your opinion, have your insights and comments of your patient partners impacted the decisions of the team? (Select a point on the scale)**

Never							Definitely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1	2	3	4	5	6	7	

**\*3.21 Do you feel you and your team are well prepared to work with patient partners on this research team?**

Yes

No

**Comments**

**\*3.23 Did you feel the patient partnership was productive and enriched the process and outcome of the research project? (select a point on the scale)**

Not Definitely

at all

1 2 3 4 5 6 7

**Comments**

**\*3.25 Do you feel your patient partners are equipped to contribute to your research project? (select a point on the scale)**

Not Definitely

at all

1 2 3 4 5 6 7

**Comments**

**\*3.27 How many years of experience have you had as a researcher? (Select one)**

under 5 years

between 5 to 10 years

between 10 to 15 years

more than 15 years

**\*3.28 What made you decide to do this work?**

**3.29 Do you have any other comments you would like to provide?**



Thank you very much for your participation! Your feedback is very valuable in guiding ongoing efforts in patient engagement. As such, a summary of the survey results from the project team will be shared with both the team and the Research Operations Committee.