



## ENGAGEMENT: HOW TO GET STARTED

### *GUIDANCE FOR THE RESEARCH COMMUNITY TO ENGAGE PEOPLE WITH LIVED EXPERIENCE IN SPINAL CORD INJURY*

Embedding the voice of people with lived experience into research programs can make research more meaningful and impactful for end users. Whether you are new to engaging people with lived experience, or just simply want to learn more about this emerging aspect of health and medical research, below are some basic resources that can help you design an engagement plan. This is not intended to be an all-inclusive resource, but an initial guide to help you get started.

## SECTIONS

- 1** How to start engaging people with lived experience
- 2** Questions to answer for advocates when recruiting
- 3** Compensation calculator and alternative payments
- 4** Resources
- 5** Recruitment

## 1

### HOW TO START ENGAGING PEOPLE WITH LIVED EXPERIENCE.

The National Health Council provides some great resources about consumer/patient engagement, an umbrella term used for engaging people with lived experience. Although engagement programs for drug development are more mature and therefore more prevalent in NHC's resources, the principles these resources describe also apply to the development of biologics, cell therapy and medical devices. In this resource center you will find a glossary of terms, principles and good practices, case examples and roadmaps.

This also includes a document titled "Tackling Representativeness: A Roadmap and Rubric," which is designed to address diversity and inclusion within engagement efforts. You may find the resource here:

<https://nationalhealthcouncil.org/issue/patient-engagement/>



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### QUESTIONS TO ANSWER FOR ADVOCATES WHEN RECRUITING

Approaching individuals to join your research program as a consumer advisor is not always the same for every program. But people with lived experience will need some basic information from you to decide whether or not to engage.

Whether you are building an advisory team, running a focus group or gathering consumer data through in-depth interviews, here are some basic elements to address:

**What Is the Project?:** Provide the program title and a brief description in lay language.

**Who Are We Seeking?:** Provide a short description of the potential candidates, e.g. level of injury, duration post, living with SCI or caregiver, race, ethnicity, age, gender and other demographics.

**What Are the Duties?:** Provide a short description of project tasks to be performed if selected. Include how the communication will be performed. Mention if there will be any travel. Describe how the candidate will be involved and engaged with this project. Mention the frequency of meetings.

**What Is the Time Commitment?:** Describe what is expected of the participant, expected hours or days of the commitment, any ad hoc engagements or scheduled engagements.

What is the length of the commitment?

What type of technology is needed for engagement?

What is the compensation?



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## COMPENSATION CALCULATOR AND ALTERNATIVE PAYMENTS

As with any member of the research team, advisors with lived experience should be compensated for their time with you. Their time and expertise is valuable.

Here are some resources to help understand how to compensate your advisors:

Published article in the Patient Experience Journal, "Patient partner compensation in research and health care: the patient perspective on why and how."

<https://pxjournal.org/cgi/viewcontent.cgi?article=1334&context=journal>

National Health Council: Compensation Tool.

<https://nationalhealthcouncil.org/patient-engagement-compensation-and-contracting/>

Alternative to payments:

In the United States, some individuals with lived experience may not be able to accept payment due to their specific situation. Regardless, you should work directly with each participant advisor.

In such a case, here are some suggestions for alternative payments:

- Gift cards such as Amazon, Visa or Mastercard
- Payment to a designated spouse or care partner
- Postal money order
- Donation to their favorite non-profit organization



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#### RESOURCES

NASCIC has been involved in two on-going projects that are excellent resources for engaging people with lived experience in SCI.

**The Integrated Knowledge Translation (IKT) Guiding Principles for Conducting and Disseminating Spinal Cord Injury (SCI) Research in Partnership:** <https://ikt.ok.ubc.ca/>

#### **COMING SOON! Community Engagement Project:**

NASCIC is currently developing an online course to educate people with lived experience and researchers on the importance of patient engagement and best practices for researchers on how to engage people with lived experience in SCI throughout the research process. The expected launch of this course is January 2022.

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#### RECRUITMENT

NASCIC is continually active in partnering on research projects that bring about positive change for persons living with SCI. Through our membership, NASCIC helps to facilitate recruitment for research participants, consumer advisory boards, focus groups etc.

<https://pva.org/find-support/national-service-office/>

For more information on our project partnership requirements and criteria, please visit - <https://nasciconsortium.org/projects/nascic-project-selection-guidelines/>