

# Patient Engagement in Research Community of Practice

## June 2023: Engagement in Knowledge Translation

This document provides a presentation summary about the engagement of people living with spinal cord injury/disease (SCI/D) in the development of the Bare Bones Podcast Series.

### Key Presentation Points

- The Bare Bones Podcast Series and associated handouts translate the clinical practice guidelines on Bone Health and Osteoporosis Management in Individuals with SCI/D into a more accessible format for the individuals, their family and caregivers.
- This podcast is an example of how people with lived experience can contribute their skills, beyond their lived experience, to develop more accessible knowledge translation products for others living with SCI/D.

### What did we discuss?

- **Engagement:** People with lived experience were engaged from the onset and throughout the development and delivery of the podcast series. This included producing the content, delivering orientation sessions, recording episodes, developing handouts, and obtaining and integrating feedback.
  - Team work and communication were fostered through role clarity as well as providing opportunities for growth among people with lived experience and researchers. Compensation was planned from the outset of the engagement.
- **Recruitment:** People with lived experience were identified through previous research participation, community events and conferences, and through staff connections.
- **Training & education:** People with lived experience developed a train-the-trainer model to support orientation and technological engagement.
- **Leveraging skills & talents:** One common attitude is that people with lived experience can *only* contribute their lived experiences to projects. The hosts and co-producers of the podcast demonstrate skills and abilities beyond their lived experiences.
- **Dual perspectives:** The research community can be hesitant to accept a person with lived experience as a researcher because their lived experience is viewed as a potential bias affecting the quality of the research. This dual perspective should be viewed as a strength as it can support creating safer environments for participants to take part in research.
- **Evaluation:** Additional people living with SCI/D will be part of the feedback and evaluation of the podcast and associated handouts.

### Relevant Resources on Patient Engagement in Research

- [The Integrated Knowledge Translation \(IKT\)](#): A webpage on the guiding principles to support partnerships and meaningful engagement in research in SCI.