HOW TO ENGAGE PEOPLE WITH LIVED EXPERIENCE IN SCI RESEARCH

1. RESEARCH QUESTION
   - Collaborate to develop and refine a question that matters to people with SCI
   - Involve people with SCI in the grant development and review process

2. FUNDING APPLICATION
   - Partner to design a study that people with SCI want to participate in

3. DEVELOP METHODS
   - Integrate people with SCI as equitable members of the research team

4. CONDUCT RESEARCH
   - Work with SCI networks to ensure your findings reach end-users and lead to real world impact
   - Include people with SCI in the analysis and/or interpretation of findings

5. DISSEMINATE
   - HOW CAN I HELP?
   - Collaborate to develop and refine a question that matters to people with SCI
   - Involve people with SCI in the grant development and review process
   - Partner to design a study that people with SCI want to participate in
   - Integrate people with SCI as equitable members of the research team
   - Work with SCI networks to ensure your findings reach end-users and lead to real world impact
   - Include people with SCI in the analysis and/or interpretation of findings
   - HOW CAN I HELP?
DOS AND DON’TS: OUR RECOMMENDATIONS

• **Engage broadly** — “If you’ve met one person with SCI, you’ve met one person with SCI”

• **Avoid tokenism** — Meaningfully involve people with lived experience throughout the entire research process

• **Set clear expectations** — Establish rules of engagement early on and revisit them regularly

• **Be aware of power dynamics** — Ensure all team members respect each other’s contributions

• **Treat everyone fairly** — Compensate everyone for their time, travel, expertise, and efforts

• **Recognize experience** — People who live with SCI are experts at living with SCI, and their knowledge needs to be honoured, explored, and integrated

• **Build capacity** — Support people with SCI to gain the necessary knowledge, opportunities, and skills to be meaningfully engaged in the research process

• **Remember that everyone has ownership** — Partners are co-authors

ONLINE RESOURCES

• Consumer Program Roadmap — praxisinstitute.org

• IKT Guiding Principles — osf.io/9mq24

• NASCIC — nasciconsortium.org

• IAP2 Spectrum of Engagement — iap2.org

• Engage 2020 Action Catalogue — actioncatalogue.eu

• George and Fay Yee Public & Patient Engagement Mapping Tool — chimb.ca

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