

HOW TO ENGAGE PEOPLE WITH LIVED EXPERIENCE IN SCI RESEARCH



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

CONTACT US

John Chernesky

jchernesky@praxisinstitute.org

Johnny Bourke

johnny.bourke@burwood.org.nz

John Shepherd

john.shepherd@mail.utoronto.ca

Heather Gainforth

heather.gainforth@ubc.ca

