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

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