

Module 11 – SCI 101 for Researchers

A Framework for Engagement: The IKT Guiding Principles

Engagement is not a one-size-fits-all activity. Different projects and research teams will need different amounts and types of input depending on what the research question is and what will be needed to take the work to the next step. NASCIC can help you determine how best to engage the community. In addition, the supplemental resources section of this course contains links to materials that describe several valid and well-tested approaches to engaging people with lived experience in research.

One set of best practices that has been developed specifically for SCI research are the Integrated Knowledge Translation Guiding Principles. Integrated Knowledge Translation, or “IKT,” is a model of collaborative research, where researchers co-produce research with research users (meaning people who would be expected to use the results of the research to make informed decisions). The goal is to ensure that research is translated into practice by sharing decision making with research users, who have unique expertise pertaining to the research topic, including knowledge of the context and the potential for implementation.

The approach has been used as a guide for conducting research in a range of disciplines spanning from healthcare and life sciences, to engineering, environmental science, and public transportation.

To address a gap between SCI research and practice, a multidisciplinary panel led by Heather Gainforth, Associate Professor at The University of British Columbia Okanagan, rigorously and systematically co-developed a set of 8 IKT guiding principles for conducting and disseminating SCI research in partnership with research users. The panel included SCI researchers, clinicians, people with SCI, representatives from SCI community organizations, and funding agencies. They used several data sources and formal consensus methods.

The intent is to support IKT partnerships to conduct quality and ethical research in spinal cord injury that is relevant, useful, useable, and avoids tokenism. Tokenism is the practice of making perfunctory or symbolic efforts to engage communities or individuals in research.

Heather Gainforth – Tokenism is a really disappointing aspect of research that can sometimes happen even out of the best of intentions. It happens when partners are asked to endorse research to legitimize it rather than actually giving them any real influence or control. At the end of the day, meaningful engagement is the antidote or the opposite of tokenism. If you are being meaningfully engaged, you should have decision-making power, which also means that tokenism is hopefully less likely to occur.

Here are the principles, in Dr. Gainforth's own words.

- Partners develop and maintain relationships based on trust, respect, dignity, and transparency.

Heather Gainforth – You need partnerships and relationships based on trust. It becomes hard to do the other aspects of the guiding principles and the other activities needed for a partnership if you are not working from a place of trust.

- Partners share in decision-making.

Heather Gainforth – If you have decision making power--both researchers and research users--the hope is that you're making decisions around, uh, topics, parts of the research that are meaningful to you. And from that perspective, you're combating tokenism in your work.

- Partners foster open, honest, and responsive communication.

Heather Gainforth – Really good communication is important for building trust. It is important for being able to share in decision making and being able to do the other principles.

- Partners recognize, value, and share their diverse expertise and knowledge.

Heather Gainforth – This principle highlights that not all knowledge comes with a PhD or is held at a university. That people's lived experience, that their knowledge of spinal cord injury, can come from so many places. And that that knowledge is valuable and important, and needs to be respected and recognized and, and used in the partnership.

- Partners are flexible and receptive in tailoring the research approach to match the aims and context of the project.

Heather Gainforth – This means that we are tailoring every aspect of the project to both the researchers' needs and the research users' needs. It might mean that we adjust timelines. It might mean that we adjust different measures that we might include so that everyone gets something out of the project that is meaningfully beneficial to them. And isn't providing unnecessary burden to one group or another.

- Partners can meaningfully benefit by participating in the partnership.

Heather Gainforth – This idea that the project should be personally or socially meaningful and means that we need to ask our partners, both the researchers and the

research users. Why is this project of interest to you? Why might it benefit to you? And can we find ways to work in benefit into the partnership and the project so that we all see a meaningful benefit? Otherwise, the question would be why are we on this partnership? And likely that if our cases were not meaningfully benefiting, this might be a tokenistic partnership or potentially might be something that isn't an ideal fit for us and might be a better fit for someone else.

- Partners address ethical considerations.

Heather Gainforth – Your organizations that are on the partnership might have different ethical standards or values that need to be considered. Some of the researchers might have their own integrity and ethical considerations that they also need valued. And we have to think about the power dynamics and the ethics of our actual partnership and how we work together.

- Partners respect the practical considerations and financial constraints of all partners.

Heather Gainforth – Doing research is challenging. Being in a partnership is challenging. Things will come up. So having conversations about practical considerations, adaptations that someone might need to be able to attend a meeting, or timelines that work for people and don't work for people, needs for childcare or assistive devices, can become important here that make things a little bit more practical and easy. There's also in terms of practicalities, what's practical for a research to do researcher to do. Sometimes I'm asked to do things by partners that are really, really interesting, but the feasibility's just not there. Also, we have to think about financial constraints. We are constrained by the grants that we work in, but our partners and, and research users also have financial constraints. So we need to think about this both from the grant and also how we meaningfully remunerate people, how we make sure we reward people for the work that they do on our partnership and that we try to make that as equitable as possible.

The panel recommends using these principles throughout the entire research process, and referring to them while reflecting on their approach and contributions so that they can adjust as necessary.

Next we'll go over specific Dos and Don'ts.