

Frequently Asked Questions

1. General questions:

- Who are these instruments intended for? The instruments available on this website are intended for use with patients.

2. Questions related to the license:

- Is it necessary to complete a licensing agreement? No, all of the self-care measures available on the website are free to use for non-commercial research purposes. It must be licensed for other purposes and cannot be re-distributed without permission.
- Do I have to pay a license fee? No license fee is charged.

3. Questions about the instruments:

- How often can the instrument be administered to my study participants? You can administer it as often as you need to. We typically ask patients to “Think about how you have been feeling in the last month as you complete this survey.” But that interval can be made shorter or longer depending on your study design.
- Can I modify the instrument to suit my purposes? No. Please do not modify any of the instruments available here except for the general introduction about study interval, as described above.
- Can the instruments be used in clinical practice? Yes, clinicians are encouraged to use the instruments to assess where your patients are having difficulty with self-care. In this manner, you can tailor your interventions to the specific issues your patients are experiencing.

What if I need to translate the instrument into another language? The following procedure should be followed:

- Notify Dr. Riegel that you want to translate an instrument into your language.
- Use the English version as a basis.
- Recruit a translator for the forward translation: English to new language.
 - The forward translator should have the target language as his/her mother tongue.
- Recruit a second translator for the backward translation: New language to English.
 - The back translator should have the original language as his/her mother tongue (i.e., English).
- The back translator must be blinded to the original version of the questionnaire. This is essential.
- Send the back-translated English version to Dr. Riegel for approval.

1. After we agree on a final version we can declare it an official version and possibly upload your version to this site

- Contact Dr. Riegel and arrange for her to review the blindly back-translated version of your instrument. Do not use it until she tells you that your translation is adequate for use. Once it is

approved, it will be made freely available to others who speak your language by posting it on the website with your contact information.

4. Questions related to implementation and support:

- How do I score the instrument? Instructions for scoring are available on the website.
- How do I confirm the reliability and validity of an existing translation available on the website? Contact the person who translated it.