TAND-SQ Checklist

Copyright and Conditions of Use

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Conditions of use

- The TAND-SQ is available for use free of charge and free of use for non-commercial purposes by families and individuals with TSC.
- Non-commercial researchers may use the TAND-SQ for research purposes with the author's written permission.
- The TAND-SQ may be used for commercial research purposes for a fee and signed contractual agreement.

Contact person with **contact details**

- For any enquiries regarding use of the TAND-SQ Checklist, please contact Prof Petrus de Vries, Dr Lucas Gutierrez-Lafrentz or Dr Nola Chambers at tandchecklist@gmail.com

Language of development

- The TAND-SQ was developed in British English.

Translations

- We have a structured process for managing non-commercial translation requests.
- Translations will be conducted as a joint project between the TAND Consortium, the requesters and a local patient representative organization, and subject to a signed contractual agreement.
- Please see a 10-step summary of the translation process below.
- Authorised translations will be posted on the TAND Consortium website (www.tandconsortium.org) for use by the TSC community under the terms of the Creative Commons 4.0 international license and terms and conditions noted above.

- Commercial translations are subject to an approval fee and fee for each language. Please contact us (tandchecklist@gmail.com) for further information.

10-Step Process for Non-Commercial Translations

1. **Kick-Off:** Contact the TAND-SQ Checklist Coordinator (tandchecklist@gmail.com) to request to do a translation. You will receive a contractual agreement, and we will agree on practical details such as timeline and communication.
2. **Confirm your local team:** Appoint a translator, a local patient representative organisation to work with you, and a back-translator.
3. **Initial Forward Translation:** Translate the TAND-SQ into your target language using the Forward Translation Template. If there is already an authorised translation of the TAND-L in your language, prepopulate those items to make the process more efficient.
4. **Patient Representative Review:** Have your patient representatives review the forward translation. Make revisions as needed, and keep a record of this process.
5. **Revisions Based on Feedback:** Incorporate the suggestions from the patient representatives and finalise the forward translation.
6. **Blind Back Translation:** Have someone who has not seen the original English version perform a blind back translation into English, using the Back Translation Template.
7. **Submit for Review:** Send the forward translation, back translation, and review comments to the TAND Checklist Coordinator. The TAND Consortium will review and may request some revisions.
8. **Final Typesetting:** Once the translation is agreed and approved by everyone, the TAND Consortium will prepare the typeset version.
9. **Final Approval:** We will ask you to check the final typeset version one last time.
10. **Release:** The authorised translation will be released for use and published on the TAND Consortium website. All copyright will remain with the TAND Consortium.

Digital versions

- We understand the need for electronic versions of the TAND-SQ for clinical and research purposes.
- **REDCap:** We have two REDCap versions of the TAND-SQ, a full version for clinical use and a streamlined research version. Both versions are available on request and subject to the conditions of use listed above and a signed contractual agreement.
- **Electronic Medical Records (EMR):** The TAND-SQ may also be incorporated into electronic medical records (EMR) for non-commercial research or clinical purposes subject to request and a signed contractual agreement. Please see below a 5-step summary of the digital conversion process.
- **Other Electronic use:** Please contact the team at tandchecklist@gmail.com for a case-by-case evaluation and collaboration plan.

- **Commercial use:** Electronic versions for commercial use are subject to an approval fee. Please contact us for further details.

5-Step Process for Digital Conversions

1. Contact the team at tandchecklist@gmail.com to initiate a request to use the TAND-SQ in a digital format.
2. Receive, review and sign the digital conversion contractual agreement.
3. Perform an initial conversion into your desired digital platform.
4. Provide screenshots of the conversion to the TAND Consortium for review and possible revisions.
5. On approval, your digital version can be used subject to the terms and conditions of the Creative Commons License 4.0. All copyright for all versions will remain with the TAND consortium.