



Instructions Regarding Use of the VTCAR Assessment Database and the VTAC/VTCAR Registry

What are the Assessment Database and Registry for?

The purpose of the **Assessment Database** through VTCAR is to serve as a centralized resource for VTCAR affiliated researchers and faculty. The database will be a central database of participants assessed in gold-standard ASD measures. Various behavioral, cognitive, and intelligence measures will be collected and subsequently stored for additional analyses or for use by other VTCAR researchers who may utilize those participants for future studies.

The purpose of the **Registry** is to create and obtain a research Registry of families affected by Autism Spectrum Disorders (ASD). The Registry will serve as a database of demographic information that can be used for participant recruitment and preliminary (pilot) data for future studies.

Who can make use of the Assessment Database and Registry?

The database is available to any investigator associated with a VTCAR faculty affiliate who seeks to use the Assessment Database for data analyses or participant recruitment (via the linked Registry IRB # 09-669) for a study. This includes faculty, approved research staff, and students (graduate and undergraduate) with VTCAR faculty support. For students, a VTCAR faculty advisor or supervisor must be named on the request form.

How do I obtain permission to use the Assessment Database and Registry?

You will need to first obtain IRB approval for your study. Once IRB approval is given, submit a completed *VTCAR Assessment Database/Registry Request* form to the VTCAR Research Coordinator via REDCap . The coordinator will reply with approval/disapproval. If approved, the coordinator then will identify participants in the Assessment Database who meet the investigator's designated inclusion/exclusion criteria as indicated on the request form (e.g., children between the ages of 7 and 12 diagnosed with autism or an autism spectrum disorder). The coordinator will contact the study investigator if further information is needed before participants can be identified. Individuals on the Assessment Database **are not to be** contacted more than once per month regarding potential studies. Additional contact is in violation of the Registry's IRB approval.

What are the Terms of Use of the Assessment Database and Registry?

It is the responsibility of any and all investigators using the Registry to record (in an ongoing log) the individual(s) contacted and the result of that contact (e.g., not available, enrolled). Individuals are not to be contacted more than once per month. The log must be available upon request to the VTCAR Research Coordinator.

The approval for use of the Assessment Database and Registry applies only to the study for which you are currently requesting it. If you wish to use the Assessment Database or Registry for another study, you must request approval separately for that study.

Please notify the VTCAR Research Coordinator when your study data collection is complete, and you will no longer be utilizing the Assessment Database or Registry.

Violations of any of these Terms of Use will result in the revocation of approval for use of the Assessment Database and Registry for all studies utilizing either the Assessment Database or Registry under that Primary Investigator.

Remember that those you are calling may be receiving phone calls from other investigators. We recommend that you are clear about the name of the study and your contact information when contacting those in the Assessment Database and Registry.

Request of Data

All data requests will be reviewed and approved by the primary Principal Investigator of the database, Dr. Angela Scarpa. The primary PI reserves the right to be a co-author on any publication or product which uses data from the Virginia Tech Assessment Database as agreed upon with the requestors. Authors should acknowledge the VTCAR Assessment Database when they publish or submit materials that use the data provided by the VTCAR Assessment Database, using the *Acknowledgement of Source* statement below.

Acknowledgement of Source

The data, either partially or in its entirety, used in this publication/document were made available by the Virginia Tech Center for Autism Research, Blacksburg, Va and have been used with permission.

Publication or Grant Submission Requirement

In accordance with the terms of use for this dataset, users of this data are required to deposit a copy of any published work, poster, presentation, thesis, dissertation, submitted grant proposal, or report based wholly or in part on these data within the Assessment Database Archive. Citations from the archive (but not the full reports) will be used internally for the VTCAR annual report and to provide stakeholders, affiliates, and potential funding agencies with information about the use of Virginia Tech Center for Autism Research resources.

Who do I contact if I have questions about the Assessment Database or Registry?

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