UNIVERSITY OF PENNSYLVANIA
RESEARCH SUBJECT
INFORMED CONSENT & HIPAA AUTHORIZATION FORM

Protocol Title: CCN Subject Database

Principal Investigator: Sharon Thompson-Schill
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3720 Walnut Street
Philadelphia PA 19104
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You have been invited to participate in a research study. In addition to the things the investigator has already explained to you, and to the consent forms you have signed, you are being asked to participate in a subject database: This database has been approved by the internal review board of the University of Pennsylvania. This database will include only information about you that is relevant to subject recruitment for neuroscience studies. Before you agree, these things include: Name, age, sex, DOB, telephone, address, email, education level, handedness, neurological and head injury history, previous and current medications, presence and/or type of visual loss, date(s) of previous study participation, and a listing of data collected. The database will also include a rating of your performance during your participation in the study. The researcher that is conducting the study you are a part of will rate your performance. This database is only accessible by authorized personnel working on fMRI studies. Information contained in the database will not be shared with anyone that has not been granted access to the database by the CCN fMRI Subject Database coordinator.

Your participation in this subject database is voluntary and not required for participation in the present study. If you later decide not to participate in the database, you are free to request that you be removed from it at anytime. Withdrawal from the database may prevent your future recruitment for studies conducted by other labs affiliated with the CCN. By agreeing to be a part of the database you are authorizing researchers to contact you for recruitment in future studies. If you have questions about your participation in this database or about your rights as a research subject, make sure to discuss them with the study investigator or members of the study team. You may also call the Office of Regulatory Affairs at the University of Pennsylvania at (215) 898-2614 to talk about your rights as a research subject.

What personal health information is collected and used in this study, and might also be shared (disclosed)?
The following personal health information will be collected, used for research and may be disclosed or released during your involvement with this research database:
-Name
-DOB
-Address
-Telephone number
-Email
-Education level
-Handedness
-Neurological or head injury history
-Previous and current medications
-Presence and/or type of vision loss
-Date(s) of previous study participation
-List of data collected
-Study performance rating

Why is your personal health information being used?
Your personal contact information is important for the University of Pennsylvania Health System and School of Medicine research team to contact you during the study, and for other research groups participating in the CCN database to contact you for future studies. The information listed above is collected as part of this research database and for the advancement of medicine and clinical care.

Which of our personnel may use or disclose your personal health information?
The following individuals and organizations may use or disclose your personal health information for this research project:
-The Principal Investigator and the Investigator's study team (other University staff associated with the study)

IRB APPROVAL FROM 12/13/2012 to 12/12/2013

-The University of Pennsylvania Institutional Review Boards (the committees charged with overseeing research on human subjects) and University of Pennsylvania Office of Regulatory Affairs
-The University of Pennsylvania Office of Human Research (the office which monitors human research studies)
-Authorized members of the CCN database

Who, outside of the University of Pennsylvania Health System and the School of Medicine, might receive your personal health information?
-As part of the study the Principal Investigator, study team, and others listed above may disclose your personal health information:

-Government agency and/or their representative: **National Science Foundation** The Principal Investigator or study staff will inform you if there are any changes to the list above during your active participation in the trial. Once information is disclosed to others outside the University of Pennsylvania Health System or School of Medicine the information may no longer be covered by the federal privacy protection regulations.

-In all disclosures outside of the University of Pennsylvania Health System and School of Medicine, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier unless disclosure of the direct identifier is required by law.

-In records and information disclosed outside of the University of Pennsylvania Health System and School of Medicine, you will be assigned a unique code number.

How long will the University of Pennsylvania Health System and the School of Medicine be able to use or disclose your personal health information?
Your authorization for use of your personal health information for this database does not expire. This information may be maintained in a research repository (database). However, the University of Pennsylvania Health System and School of Medicine may not re-use or re-disclose your personal health information collected for this database for another purpose other than the research described in this document unless you have given written permission for the Principal Investigator to do so. However, the University of Pennsylvania Institutional Review Board may grant permission to the Principal Investigator or others to use your information for another purpose after ensuring that appropriate privacy safeguards are in place. The Institutional Review Board is a committee whose job it is to protect the safety and privacy of research subjects.

Can you change your mind?
You may withdraw your permission for the use and disclosure of any of your personal information for research, **but you must do so in writing** to the Principal Investigator at the address on the first page. If you withdraw your permission to use your personal health information that means you will also be withdrawn from the research database and your information will be removed from the CCN database.

You will be given a copy of this Research Subject Authorization Form describing your confidentiality and privacy rights for this study. You will also be given the University of Pennsylvania Health System and School of Medicine's Notice of Privacy Practices that contains more information about the privacy of your health information.

By signing this document you are agreeing to participate in the database described above, and you are permitting the University of Pennsylvania Health System and School of Medicine to use and disclose personal health information collected about you for research purposes as described above.

_____	_____	_____
Subject's Name **[print]**	Subject's Signature	Date
_____	_____	_____
Witness **[print]**	Witness' Signature	Date