Columbia University Medical Center Information Sheet Online Consent & HIPAA Authorization

Attach to Protocol: IRB AAAI2752

Principal Investigator: Yaakov Stern

IRB Protocol Title: Exploring Cognitive Aging Using Reference Ability Neural Networks

Introduction and Research Purpose_____

You are being invited to participate in a research study at Columbia University Medical Center to understand how aging affects memory and other mental abilities. The purpose of this screening is to determine if you are eligible to take part in the study. If you agree to take part in this screening, you will be asked to complete an online questionnaire. These questions will ask about some topics that may be sensitive, such as your medical history and your use of alcohol and/or drugs. It will take approximately 5 to 10 minutes to complete. The research team will have access only to the information provided in this questionnaire. The screening data you provide will be stored in a secure recruitment database operating on a Collaborative Informatics Neuroimaging Suite (COINS) system, which has been carefully designed for data security. The screening data you provide will be stored in a recruitment database that is separate from the main study data. If you ultimately consent to participate in the study, the information you provide in this screener will be transferred to the main study database. If however you do not meet the eligibility criteria, or do not give consent to participate in the main study, your identifying information will be deleted from the recruitment database after six months have passed since its initial entry; this delay is to allow the researchers sufficient time to reach out to you and schedule your initial appointment. You are not expected to benefit directly from participating in this research study, however your participation may help people who suffer from neurodegenerative diseases and/or memory disorders in the future.

Confidentiality_____

Although every effort will be made to protect the confidentiality of your records, absolute confidentiality cannot be guaranteed. Also, according to the rules governing research procedures at Columbia, by agreeing to participate in the study, you grant permission for information about you obtained during the study to be made available to:

The investigator and members of their study team, Authorities at Columbia University Medical Center including the Institutional Review Board (IRB) who independently review studies to assure adequate protection of research participants, as required by federal regulations, The Federal Office of Human Research Protections (OHRP) and other government agencies that oversee the safety of human subjects. This research is sponsored by the National Institutes of Health, which will have access only to study results and to de-identified data.

Once your health information is disclosed to a third party (e.g. a pharmaceutical company participating in a study), federal privacy law may no longer protect it from further disclosure.

Please note that you may change your mind and revoke "take back" this authorization at any time for any reason. To revoke this authorization you must contact the Principal Investigator, Yaakov Stern, at 212-342-1350. However, even if you revoke this authorization, the researchers may continue to use and disclose the

information already collected, however new information will not be collected for this research purpose. Use of this information / your HIPAA authorization does not have an expiration date.

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

The Certificate cannot be used to refuse a request for information from personnel of the United States federal or state government agency sponsoring the project that is needed for auditing or program evaluation by the National Institute of Health which is funding this project or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA). You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to an insurer, medical care provider, or any other person not connected with the research, you must provide consent to allow the researchers to release it.

Whom Do I call if I have questions or problems?

If you have any questions or concerns about this study, you may contact Yaakov Stern at 212-342-1350. You do not have to participate in the research study. You can decide not to participate at any time. If you have any questions about your rights as a research subject, you can contact the Institutional Review Board at 212-305-5883 or visit the website at http://www.cumc.columbia.edu/dept/irb/info.html.

By clicking "I agree" below you are indicating that you are at least 18 years old, and you have read and understood this consent form and agree to participate in this research study, and that you understand that the answers you provide will be stored by the researchers even if you ultimately decide not to participate further in the study procedures, and will be deleted within six months.

Please print a copy of this consent for your records.