TRANSMISSION COVER SHEET

SHEPHERD CENTER

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Name of Study: Rehabilitation Engineering Research Center for Wireless Technologies (Wireless RERC): User Centered Research

---

Dear Parent or Guardian:

The attached **Informed Consent Form** is designed to inform you about a research study that may be suitable for your child or individual for whom you serve as legal guardian.

Please review it, and if you consent to let your child or ward participate in the study, please sign on the second to last page. Also, if you would like to join our nationwide Consumer Advisory Network (CAN) of consumers with disabilities and consumers involved with disabilities, please indicate on the last page.

Please return signed Informed Consent Forms to John Morris, Ph.D.

Email: john_morris@shepherd.org

Fax: 404-350-7596

U.S. Mail: John Morris
Research Department
Shepherd Center
2020 Peachtree Road, NW
Atlanta, GA 30309

SHEPHERD CENTER

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM WITH AUTHORIZATION FOR RELEASE OF PROTECTED HEALTH INFORMATION

Name of Study: Rehabilitation Engineering Research Center for Wireless Technologies (Wireless RERC): User Centered Research

PROTOCOL#: 410-A

Principal investigator: Mike Jones **Project: #410-A/H12395**

Participant's Name: _____

Background
The Rehabilitation Engineering Research Center for Wireless Technologies (Wireless RERC) is committed to promoting equitable access to wireless technologies such as cellphones and mobile computers by people with disabilities. To fulfill this goal we seek to understand how people with physical, sensory, and cognitive disabilities use wireless technology, their needs and challenges using wireless technology, and the impact of wireless technology in their lives. The Wireless RERC is funded through a 5-year grant from the National Institute on Disability and Rehabilitation Research (NIDRR), which is part of the U.S. Department of Education.

Purpose
The purpose of this research is to assess how people with physical, sensory and cognitive disabilities use wireless technologies, and how these technologies affect their lifestyles and sense of well being and community participation.

Duration and Scope
The research involves completing a single survey that takes approximately 15-30 minutes to complete. The survey includes the sections on demographics and disabilities, wireless devices in use, wireless activities, and social activity and perceived social support.

Procedures
This research involves completing a single questionnaire either online, in a face-to-face interview, over the phone, or on paper. Before minors under age 18 can complete the survey, one of their parents or guardians must agree (provide consent) that the minor may participate by signing this form. Once consent is received, we will contact the parent or guardian to determine the best way to conduct the survey, unless already arranged.

Risks
The risks involved are no greater than those involved in daily activities such as using a phone or computer. We will be asking questions about you and your disability. If you feel uncomfortable answering specific questions, you can simply choose not to respond to those questions.

Right of Investigator to Withdraw
The investigator has the right to withdraw any participant from the study at any time. In all cases, there will be no penalty to you.

Benefits
There will be no immediate benefits to you. However, your participation will provide important information to researchers trying to understand how technology affects our lives.

Alternatives
The only alternative is not to be in the study. Your participation is purely voluntary.

Confidentiality
The data collected about you will be kept private to the extent allowed by law. To protect your privacy, your records will be kept under a code number rather than by name. Your records will be kept in locked files and only study staff will be allowed to look at them. Your name and any other fact that might point to you will not appear when results of this study are presented or published.

Cost
Participation in this study will incur no cost to you other than that associated with your time.

Compensation
You will not receive any compensation for completing this survey.

Voluntary Participation/Withdrawal
Your participation in this study is voluntary. You do not have to be in this study if you don't want to be. You have the right to change your mind and leave the study at any time without giving any reason, and without penalty. Any new information that may make you change your mind about being in this study will be given to you.

Source of Funding
This research is funded by a 5-year grant from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR), grant number H133E110002.

Research Questions
The core questions driving this research is whether and how use of wireless information and communication technology (ICT) impacts community participation and sense of social integration of adolescents age 13-18 with disabilities.

Questions about Participant Rights
If you have any questions about your rights as a patient in this registry, please contact Michael L. Jones, Ph.D., Chair, Shepherd Research Review Committee, 2020 Peachtree Road NW, Atlanta, Georgia 30309, (404) 350-7595 or Melanie J. Clark, Office of Research Integrity Assurance, Georgia Institute of Technology, (404) 894-6942.

Authorization to Use and Disclose Information for Research Purposes

Federal regulations give you certain rights related to your Protected Health Information (PHI). These include the right to know who will be able to get the information and why. The researchers must get your authorization (permission) to use or give out any health information that might identify you. Researchers include only the staff of the Wireless RERC working on this specific survey project.

What information may be used and given to others?
If you choose to be in this research project, the registry doctor will get personal information about you. The registry doctor may also get information about your health including responses to disability-related questions on the questionnaire.

Who might get this information?
The researchers may give your information to the sponsor of this research, the National Institute on Disability and Rehabilitation Research, U.S. Department of Education. "Sponsor" includes any persons or companies that are working for or with the sponsor.
Information about you and your health, which might identify you, may also be given by the researchers or the providers to a third party including the following:

- Auditors hired by the Shepherd Center, who may review this study to ensure compliance with funding guidelines
- The Institutional Review Board (IRB)
- Other parties as required by law

How will this information be used?

This information will be used solely to verify that your participation is consistent with the goals stated in the Wireless RERC grant.

Is my health information protected after it has been given to others?

Yes.

What if I decide not to give permission to use and give out my health information?

If you decide not to give permission to use and give out your health information, you cannot be included in this study.

May I withdraw or revoke (cancel) my permission?

You may withdraw from this study and cancel your permission at any time without giving any reason and without penalty.

May I review or copy the information obtained from me or created about me?

Yes. You may review or copy all information obtained from you or created about you. Please contact: John Morris, 404-367-1348, john_morris@shepherd.org.

Consent

Rehabilitation Engineering Research Center for Wireless Technologies: User Centered Research

I have read the information in this consent form (or it has been read to me). All my questions about the research and my participation in it have been answered. I freely consent to participate in this research study. By signing this consent form, I have not waived any of my legal rights.

For participants under 18 or participants unable to consent, consent must be provided by the *Legally Authorized Representative*:

_____ _____
Signature of Legally Authorized Representative Date

_____
Authority of Legally Authorized Representative
(e.g., parent, guardian, etc.)

Address_____

_____

Telephone_____

Email_____

NAME OF YOUR CHILD OR CHARGE: _____

Should we make contact directly? ○ Yes ○ No (If no, we will contact you)

If yes, how should we make contact with your child or charge?

○ Child's Telephone (please provide number): _____

○ Child's Email (email address)_____

○ School teacher or administrator (Name and school)

_____

○ Other (please specify) _____

(Official Use)_____ _____
Signature of Person Conducting Informed Consent Discussion Date

Participant's Initials: _____
Date: _____
PI: Michael L. Jones, Ph.D.

Please join our Consumer Advisory Network (CAN)

Would you like to help make wireless products better by joining our Consumer Advisory Network (CAN)? CAN members may be invited to participate in other surveys, focus groups, or testing of wireless products and services.

If you are the parent or guardian of a minor with a disability or a young adult with a cognitive limitation, we invite you to join our Consumer Advisory Network. As the parent of guardian of someone with a disability, you will be contacted to confirm that you give permission for your child or charge to participate in any new research project. Or, you might be invited to participate directly in a study because of your own experiences.

- ○ No, I do not wish to join the CAN. (Please click the "Submit Survey" button to submit your answers.)

- ○ Yes, I would like to join the CAN. (If yes, please sign below.)

Signature_____

----------Use the following only if applicable ----------

If this consent form is read to the participant because the participant (or legally authorized representative) is unable to read the form, an impartial witness not affiliated with the research or investigator must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the *participant* (or the *participant's* legally authorized representative). The *participant* (or the *participant's* legally authorized representative) freely consented to participate in the research registry.

_____ _____
Signature of Impartial Witness Date

Note: *This signature block cannot be used for translations into another language. A translated consent form is necessary for enrolling patients who do not speak English.*