Mrs. A and Mr. B

NCT02626910

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Title of the Research Study: Mrs. A and Mr. B
Consent for PWOD: SL
Unique Protocol ID: AD-12-11-4567
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You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate, there will be no loss of benefits to which you are otherwise entitled. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with your friends and family. If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form because in it you will find contact information and answers to questions about the study. You may ask to have this form read to you. At the end of this form, we will ask you to sign the consent form using your avatar name. If the avatar name is your real name or if your avatar name is well known, then you will be asked to create a new avatar with an anonymous name and be re-consented for the purpose of this study. This way, no information collected in Second Life can be linked to your actual name or to a well-known avatar name that can be linked to the actual name.

What is the purpose of the study?

The purpose of this research is to get your opinion about how health care access and quality may be affecting people with and without disabilities.

Why was I asked to participate in the study?

You are being asked to join this study because you are a person 21 years of age or older without a disability and you are not currently caring for a person with a disability.

How long will I be in the study?

The study will take place over a period of 3 years. You may be asked to participate in one or more focus group sessions. Each focus group session will last no more than 1 ½ hours. Researchers may participate in future activities with you and take notes on the conversations and behaviors.

Where will the study take place?

You will use your home computer or a computer somewhere else.

What will I be asked to do?

We will ask you to complete an online survey about your life circumstances and health. You may be asked to participate in one or more focus group sessions in Second Life with up to 5 or 6 other people.

In the focus groups, you will be asked about access to and quality of healthcare as you experience it. We also may show you research findings about healthcare and ask you what you think about those findings. You may be approached for follow-up conversations after the focus groups, and your conversations and behaviors may be observed.

What are the risks?

There are no known physical risks associated with this research study. The research includes the time and effort involved in answering questions about your own healthcare experiences. If you get tired, you can take a break and come back later. You can decide to stop participating at any time. You should not answer any questions that make you uncomfortable.

How will I benefit from the study?

There is no direct benefit to you. However, your participation could help us understand ways to improve access to and quality of healthcare, which can benefit you indirectly. In the future, this may help other people to live healthier and more independent lives.

What other choices do I have?

Your alternative to being in the study is to not be in the study.

What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary. There are no negative consequences should you not choose to participate.

When is the study over? Can I leave the study before it ends?

The study will last three years. You can stop completing the survey or leave the focus group session at any time.

How will confidentiality be maintained and my privacy be protected?

We will do our best to make sure that the personal information obtained during the course of this research study will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Your records will identify you only by avatar name. This means that the research team will not be able to contact you other than through your avatar. We will not have your actual name or address. Your privacy will be further protected by research analysts replacing your study avatar name with a study identification number.

Focus group sessions will be held in a non-public restricted access area within Second Life. As within any Second Life venue or any focus group session, the information you share can be read or heard by anyone in your focus group session. Consequently, we ask that you not share anything you are not comfortable disclosing in that venue. You can use the "instant message" function in Second Life to share information with the researchers that you do not want to share with other members of the focus group.

Information from the focus group session chat will be combined from many people. It will be analyzed by a research team and may be published or disseminated in other ways. The information you share with us will be shared with a researcher from the University of California, Irvine. If any publications or presentations result from this research, your avatar name will not be included. Occasionally, short quotes from the focus group session chat might be published. Any personally identifying information that you might have provided will be removed from those quotes.

What happens if I am injured from being in the study?

No physical injury will result from this research study. If a topic upsets you, you may leave the focus group session. We would also encourage you to contact any research team member to discuss your concerns or feelings. See contact information above or at www.healthcareequitability.org. Anything discussed will not be shared outside the research staff team.

Will I have to pay for anything?

There are no costs associated with participating in the research study.

Will I be paid for being in this study?

If you complete the qualifying survey, you will receive a thank you gift of 200 Lindens (worth about eighty cents in US currency). If you are invited to participate in a focus group session, you will receive a gift of 1000 Linden dollars (worth about $4.35 in US currency) for completing the session. These are small ways for us to say "Thank you for helping!"

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns, or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns, or complaints at the University of Pennsylvania by calling (215) 898-2614.

CONSENT:

Within Second Life, we will collect your consent using “gifting” of a notecard. Gifting the notecard is considered to be the same as getting your signature.

By “signing” this notecard and gifting it to the researcher, you will be:
- a. Agreeing to participate in this research and
- b. Telling us you understood this form.

Type your Avatar Name (as it appears in SEARCH):___________

Today’s date: ________

Name of Person Obtaining Consent: ___________