THE UNIVERSITY OF BRITISH COLUMBIA

Division of Urology

PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: **Effectiveness of Digital Storytelling in Increasing Living Kidney Donor Recruitment in Canada**

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Invitation
You are being invited to take part in this research study because you are or will be receiving a kidney transplant at Vancouver General Hospital.

Your participation is voluntary.
You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving. Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide if you wish to participate in this study.

Who is conducting this study?
This study is being conducted by Dr. Christopher Nguan and his team in the UBC Department of Urologic Sciences. This study is not receiving funds from an external agency or sponsor.

Background
In Canada, patients from racialized communities are 50 to 75 percent less likely than white patients to receive kidney transplants. Research has found several reasons for this difference, including a lack of culturally safe transplant education and limited time to provide individualized transplant education. Therefore, there is a need for new transplant education strategies to increase the accessibility of transplants in minority populations.

What is the purpose of the study?
This research study will investigate if a storytelling-based education program can be effective in increasing transplant accessibility in minority patient populations. Specifically, we will use videos from donors and recipients sharing their transplant stories and see if viewing these videos will change an individual's perspective on living donor kidney transplant. We will also ask for input on the video's clarity and cultural sensitivity.

We acknowledge that race and ethnicity are socially constructed concepts that are often misused. This study views race and ethnicity as social rather than biological variables. We also acknowledge the diversity of experiences and backgrounds that cannot be fully represented through discrete labels. The experience of one does not represent the experiences of the groups an individual is a part of. The findings of this study are restricted to the limited definitions of race and ethnicity in this study.

Who can participate in this study?
You may be able to participate in this study if you are:

- Waitlisted and newly referred kidney transplant candidates at the Vancouver Kidney Transplant Program
- 19 years of age or older
- Able to provide informed consent
- English literate
- Asian or Caucasian identifying

Who should not participate in this study?
You will not be eligible to participate in this study if you are:

- Unwilling to provide information on race or ethnic origin

What does the study involve?
You will be assigned a randomly generated subject ID that is not derived from any personally identifying information, nor the details of your operation. Whether or not you will be assigned to the Standard Education or Storytelling Group will occur via a computer-generated randomization and will be determined by chance (like the flip of a coin). This subject ID will be stored on master list alongside your date of birth to serve as a way of identifying you. This master list will be stored separately from the study data collected and accessible only by the research team.

At your initial clinic visit with your transplant surgeon at VGH, you will be asked to complete a 5-minute baseline survey on REDCap. You will then be randomly assigned to a storytelling or standard education group. In the storytelling group, you will be shown two videos from the Living Donor Storytelling Library and connected with the standard education materials. If you are assigned to the Standard Education Group, you will only receive the standard education materials. One month later, you will be emailed a second survey inquiring about your readiness and motivation to pursue LDKT. All questionnaires will be available electronically using REDCap, a secure research site. After all the data is collected, your responses will be collected and analyzed.

Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals. You should be aware that self-disclosing information on race and ethnic origin is not mandatory.

What are my responsibilities?
You will be responsible to complete two surveys one month apart from one another inquiring about your readiness and motivation to pursue living donation. If you are randomly assigned to the storytelling group, you will also be responsible in viewing two videos that are three minutes in length.

What are the possible harms and discomforts?
There are no known risks of harm of side effects in participating in the study.

What are the potential benefits of participating?
No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study. We hope that the information learned from this study can be used in the future to benefit other people with a similar disease.

What are the alternatives to the study participation?
If you choose not to participate in this study or to withdraw at a later date, your medical care will not be affected. Participation in this study will not change your transplant treatment or the care performed by your doctor. You can discuss these options with your doctor before deciding whether or not to participate in this research project.

What happens if I decide to withdraw my consent to participate?

You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let your study doctor know.

Can I be asked to leave the study?

If you are not able to follow the requirements of the study or for any other reason, the study doctor may withdraw you from the study and will arrange for your care to continue. If you are asked to leave the study, the reasons for this will be explained to you and you will have the opportunity to ask questions about this decision.

How will my taking part in this study be kept confidential?

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Clinical Research Ethics board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. Further details about these laws are available on request to your study doctor.

Your de-identified research data may be published or deposited into a publicly accessible location at the time of publication. This data could include questionnaire responses and the number of donor inquiries or donor evaluations associated with you. At no time will identifying information, such as your name, birth date or street address be included in such data. This means that other researchers may analyze the data for different reasons other than those described in this consent form. Once the data is made publicly available, you will not be able to withdraw your data. The extent of the risk of you being identified through public data is unknown, but currently appears to be low.

What happens if something goes wrong?

By signing this form, you do not give up any of your legal rights and you do not release the study doctor, participating institutions, or anyone else from their legal and professional duties. If you become ill or physically injured as a result of participation in this study, medical treatment will be provided at no additional cost to you. The costs of your medical treatment will be paid by your provincial medical plan.

What will the study cost me?

You will not incur any personal expenses as a result of participation. You will not be paid for your participation in this study.

Who do I contact if I have questions about the study during my participation?

If you have any questions or desire further information about this study before or during participation, or if you experience any adverse effects, you can contact Ms. Meghan He at 604-838-1066.

Who do I contact if I have any questions or concerns about my rights as a participant?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598). Please reference the study number [H23-02077] when calling so the Complaint Line staff can better assist you.

After the study is finished

Your encrypted data will be kept for a minimum of 5 years. You will not be contacted after the study in finished.

Effectiveness of Digital Storytelling in Increasing Living Kidney Donor Recruitment in Canada (H23-02077)

Study Title: Effectiveness of Digital Storytelling in Increasing Living Kidney Donor Recruitment in Canada

Participant Consent

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I authorize access to my health records as described in this consent form.

I will receive a signed copy of this consent form for my own records.

_____	_____	_____
Printed Name of Participant	Participant Signature	Date
_____	_____	_____
Person Obtaining Consent	Signature of Person Obtaining Consent	Date

Was the participant assisted during the consent process?

☐ The consent form was read to the participant, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant (please check if participant is unable to read).

_____	_____	_____
Person Assisting in Obtaining Consent	Signature of Assistant	Date
_____	_____	_____
Printed Name of Investigator	Signature of Investigator	Date

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant's signature was obtained.