

Dear Kidney Patient/ Transplant Candidate/ Caregiver,

We are a group of researchers, health care providers and patients from the University of Montreal, University of Saskatchewan and the University of British Columbia. We are working on a project titled “*Identifying and Addressing the Educational Needs of Patients from Marginalized Groups on Less than Ideal Kidneys*.” We are wondering if you would be interested in participating.

Why is the study being done?

Transplantation is a life-saving therapy for patients with kidney disease but there is a gap between the supply of kidneys and the number of patients waiting for a transplantation. Meanwhile, there are numerous deceased donor kidneys which are not used and discarded. Most of the discarded kidneys are less than ideal since the deceased donor had medical conditions such as high blood pressure or diabetes. However, using these less than ideal kidneys for selected patients could be a novel strategies to increase access to kidney transplantation.

We have shown in previous studies that patients support the use of less than ideal kidney and that shared-decision making is important for patients and transplant professionals in the decision to accept or decline a deceased donor offer. Shared-decision making is a process where both the healthcare providers and patients participate in the decision making. However, patients require educational tool to provide clear information to engage in this decision-making process. Discussion and education about less than ideal kidneys that lack cultural sensitivity could contribute to mistrust in the allocation process. It is therefore of paramount importance to give the opportunity to the patients from marginalized populations to identify methods to develop educational resources tailored to their needs and realities.

The purpose of this study is to capture patients’ and caregivers’ perspectives from marginalized populations by race and ethnicity on less than ideal kidneys and their educational needs in order to develop new educational tool that will help patients to participate in the decision-making process to accept or not a less than ideal deceased donor kidneys.

Who may participate in the study?

You are eligible to participate in this study if you are at least 18 years old, you are from an Indigenous (First Nations, Métis, Inuit), or an historically marginalized community in Canada, and are either a:

- Transplant recipient
- Person who is waiting to receive a kidney transplant
- Caregiver

What does the study involve?

Participating in the study involves to taking part in a personal interview of about 45-60 minutes. The interview will be held in person, by phone or by videoconference with a member of the research team. Your transplant team will not know whether you have participated in this research.

Invitation Letter

This interview will be audio recorded and transcribed for analysis. Your recording will be coded and only the principal investigator will keep the key to the code.

What are the potential risks of participating?

There is no known risk in participating in the study other than that certain questions could raise emotions. Should that be the case, do not hesitate to contact us for assistance. You do not have to answer any questions that you are not comfortable with.

What are the potential benefits of participating?

By participating in this study, you will have the opportunity to share your knowledge on transplantation, less than ideal kidneys and information needed to accept a kidney offer. Sharing your knowledge allows to identify knowledge gaps around kidney offer acceptance, and to better understand what patients need to know to accept or decline a kidney from a marginal donor.

Funding:

A grant has been provided by the Kidney Foundation of Canada to assist with this project.

Compensation:

You will receive a 30\$ for participating in this study. After you have completed the interview, you will be asked to provide your contact information if you are interested in receiving the compensation.

IF you would like to participate or learn more, please, please contact Ms Noémi Tousignant at noemi.tousignant.chum@ssss.gouv.qc.ca or leave us a message at 514-890-8000, extension 26051. He will be happy to answer all your questions about this study.

- ***Please feel free to pass on this invitation letter to other patients or caregivers who may be interested in participating.***

Thank you for your consideration.

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