



Dear potential participant,

You are being asked to consider participating in a research study that involves sharing ideas about the research you think is needed to help improve the treatment and quality of life of people with kidney disease not yet on dialysis. Your responses will be used to identify the top research priorities of patients, care providers, clinicians and policy makers. The final list will be available on the web and will be presented to researchers and organisations that fund research.

Background/Objective:

A great deal of research is done that is intended to improve the lives of people with kidney disease. Because people with kidney disease and those who care for them live with their kidney disease and its treatment every day, we feel it is important to understand what their research priorities are.

The objective of this project is to identify the most important unanswered questions about the management of patients with kidney disease not yet on dialysis from the perspective of patients, caregivers, clinicians and policy-makers.

Description:

The survey will take you approximately 5 to 10 minutes to complete. The survey asks you to identify questions (about diagnosis, prognosis, treatment, and anything else) that you think should be studied through research.

The survey will be available for you to complete online (<http://fluidsurveys.com/s/jla-ckd/>) until January 31 2015. You can also complete the survey on paper.

Potential Harms and Potential Benefits:

There are no known harms associated with participation in this study. There are also no direct benefits to you for participating in this study. You will not be paid for completing this survey.

Participation and Withdrawal:

Participation is voluntary. If a question is not applicable to you or you feel uncomfortable answering, you do not need to complete the question. We would appreciate your responses to all questions; however none of the individual questions are mandatory. Your consent to participate in this study is demonstrated by your voluntary completion and submission of the survey. Completion and submission of the survey demonstrates that you understand the information regarding your participation and agree to participate. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. Due to the anonymous nature of the survey (e.g. there is no way to link your name to the responses); you cannot retract your survey once you have submitted your responses.

Confidentiality and Privacy:

All of the answers you give will be completely confidential and anonymous (we are not collecting your name or any other identifying information, and ask that you not provide information that may identify you). If you complete the survey on paper, your response will be retained in hard copy until study completion, after which the surveys will be securely destroyed. Access to the study data will be limited to the study investigators and their delegates.

The results of this study will be presented at conferences, seminars and other public forums, and published in journals. This study is funded by the Interdisciplinary Chronic Disease Collaboration (www.ICDC.ca).

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

If you have any questions about the study, contact the investigator listed below.

Please keep a copy of this document for your records.

Sincerely,
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