

Supervisor & Project Information Form

Please complete and return via email ONLY to gdip.hres@utoronto.ca by **Monday September 30, 2019**

Supervisor Information

MUST have unrestricted SGS appointment (appointment to supervise graduate students)

Name: Istvan Mucsi, M.D., Ph.D.	Email: istvan.mucsi@utoronto.ca
SGS Department: Institute of Medical Science	Field of Research: kidney transplantation/outcomes research/patient reported outcomes/health equity
Research Institution affiliation (if applicable):	Location of Work: Toronto General Hospital
Student contact time (number of hours per week YOU are available to the student for any concerns or to review progress: 2-4 hours per week during academic year and 6-8 hours per week during the summer	

Project Information (will be posted on GDipHR website for student access)

GDipHR candidates are invited to participate in this Health Canada "Health Care Policy Contribution Program" funded (Sep 2019 - Aug 2022) research project that was also nominated as one of the "Signature projects" of the Canadian Donation and Transplant Research Program (CDTRP).

TITLE: Improving Access to Living Donor Kidney Transplantation (LDKT) in Communities Marginalized by Race and Ethnicity in Canada

DESCRIPTION (MAX 500 WORDS): - word count 497

BACKGROUND: Access to kidney transplantation (KT) is dramatically reduced among racialized communities in Canada, with analyses reporting 50-70% lower likelihood of KT among Indigenous Peoples, East Asian, South Asian, and African Canadians compared to White Canadians (1-3). This inequity is most profound for access to living donor kidney transplantation (LDKT), which is the preferred treatment for many patients with end stage kidney disease (ESKD). **Despite several studies highlighting this issue, little has been done to address it;** therefore, these inequities still exist. African, East and South Asian Canadians are less likely to identify even one potential live donor (5) and are less likely to have discussed their need for a transplant with family or friends (6-9). The underlying reasons are not completely understood. Based on our research and consultations we will carry out the following program to increase **access to LDKT in racialized communities** through *systematic engagement with patients, donors, and community leaders* by developing and evaluating culturally competent and safe services to support access to LDKT.

First, we work with African and South Asian Canadians, next we extend our work to the Chinese Canadian community; we have already engaged patients, family members, professionals, community and religious leaders and organizations within all these communities.

METHODS: A **mixed methods study** will be completed to engage with transplant candidates, recipients, living donors, and community members.

Component 1: In qualitative research (focus groups, interviews) we will 1) identify barriers in the current care delivery model for education, support, and assessment for LDKT and 2) obtain feedback on how best to modify the current process to improve equitable access to LDKT.

Component 2: Using validated questionnaires in a relatively large cohort (n=~600) of patients with ESKD we will assess transplant knowledge, attitudes and readiness to consider and accept LDKT. We will also obtain information about knowledge and attitudes about transplant in the general communities using an eSurvey, translated to 8 languages used in these communities.

Hypotheses to be tested in the quantitative study: Compared to Caucasians, patients of South Asian or African Canadian background are less ready for LDKT at the time of presenting to the kidney transplant centre for evaluation. Furthermore, individuals from these communities have more hesitant attitudes about transplantation compared to Caucasian Canadians.

Component 3: With our community partners, patients, living donors, health care staff and administrators, we will develop **new clinical pathways** that may include:

- Culturally competent educational materials and methods of delivery (e.g. videos)
- Peer support networks of prior transplant recipients and donors
- Cultural competency training for transplant and donation health care staff
- Community based, trained navigators to work within transplant programs to facilitate culturally competent education and evaluation of transplant candidates and donors.

Component 4: **A one-year feasibility pilot** to evaluate the costs, benefits and feasibility of implementing culturally tailored clinical pathways to support LDKT.

KNOWLEDGE TRANSLATION: A national consensus conference will be organized with stakeholders from across Canada where the results of this work will be reviewed, and **consensus documents** will be produced.

If human subjects are involved, have the appropriate Research Ethics Board approvals been obtained?

Yes No Application Submitted (Date: _____)

Do you expect this work will be published within the 20 months?

Yes No Uncertain / Other

Although this is a large, long-term study, several components are already underway and **GDipHR candidates** can participate in and contribute to various stages and components of the project. Participant recruitment is planned in a stepwise manner for the various groups. Results for the various racialized communities will be published separately; the first manuscripts being planned to be submitted within 6-12 months and several to follow.

Student Roles & Responsibilities (please be as specific as possible)

Please indicate who will serve as the student's direct report for daily oversight (PI, PhD student, technician, etc...)

GDipHR candidate's role: Literature review; patient recruitment; data entry; participating in focus groups; quantitative analysis using STATA; qualitative analysis using NVIVO; preparing abstracts, posters for conferences; writing manuscripts.

The **GDipHR candidate** will be involved in patient recruitment, data entry and review of patient charts. With the help of our biostatistical team, graduate students and research associates, the **GDipHR candidate** will learn to run analysis on the data collected.

Because of the intense nature of the **GDipHR** program, the **GDipHR candidate** will report directly to Dr. Mucsi, supported by Ms. S. Macanovic (research analyst, student manager). Dr. Mucsi will dedicate 2-4 hours per week during academic year and 6-8 hours per week during the summer, all for 1:1 discussion of research project.

The student will become integrated into the Kidney Health Education and Research Group (www.nefros.net) that currently co-lead by **Drs. I. Mucsi** (transplant nephrology) and **M. Novak** (psychiatry) and includes a large multidisciplinary and interprofessional (transplant medicine, oncology, clinical epidemiology, clinical psychology, psychometrics, qualitative research, biostatistics) collaborative research network (>15 researchers in Toronto, Montreal, Calgary, Vancouver, Rochester, Chicago, Los Angeles, Memphis, Atlanta, Baltimore and Boston), patient and community partners.

Day-to-day research activities are managed by two research analysts (Ms. H. Ford and Ms. S. Chahal) and 2 part time research associates (Ms. N. El-Dassouki and Ms. E. Edwards). The student group is managed by our student manager/research education coordinator (Ms. S. Macanovic) and data team manager (Mr. N. Edwards). Currently we have one full time master's student (Ms. S. Dano) and we are currently actively seeking to recruit additional full time graduate (master's or PhD) students.

Our student group has ~20 part time undergraduate research students (volunteers and work-study, 10-12 hours/week during the academic year and more during the summer), ~ 15 part time undergraduate data/IT team members (biostatistics, data engineering, programming, IT development and communications).

Training support will be provided for the **GDipHR candidate** through our structured internal curriculum (archived presentations and webinars, and ongoing live seminars; topics include chronic kidney disease;

kidney and other solid organ transplantation; immunosuppressive therapy; patient reported outcomes; basics of biostatistics and clinical epidemiology; hands on STATA exercises, etc.) organized by our dedicated research education coordinator (Ms. Macanovic) and data team manager with a statistics background (Mr. Edwards), and supported by our biostatistician partner (Dr. N. Mitsakakis). The methodological training is designed to promote development of the students towards performing future, independent research.

The **GDipHR candidate** may also participate in additional training programs organized by the Canadian Donation and Transplant Research Program (<https://www.cntrp.ca/training>).

This **GDipHR candidate** will likely lead a group of undergraduate students in this project. Thus, an organized, independent-focused **GDipHR candidate** with strong leadership and communication skills is required.

Many of our previous shorter-term students generated abstracts from their research that were accepted as posters or oral presentations at various national and international conferences. Our longer term undergraduate students have already contributed to full original research manuscripts as co-authors or even first authors.