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 5 year (Oct 2019 - Sep 2024) CIHR funded project that was nomintaed as one of the "Signature projects" of the Canadian Donation and Transplant Research Program (CDTRP).

TITLE: Electronic Patient Reported Outcome Measures to Improve Patient Centered Solid Organ Transplant Care

DESCRIPTION (MAX 500 WORDS): - word count 462

Background. Solid organ transplant recipients (SOT) and professionals repeatedly identified management of physical and emotional symptoms as key priorities. Up to 40% of SOT recipients suffer from manageable emotional (depression, anxiety) and physical (chronic pain, fatigue) symptoms that impair their quality of life. Distress and symptom burden are also risk factors for non-adherence and poor clinical outcomes. Better addressing physical and emotional symptoms will improve adherence, quality of life and clinical outcomes. Patient reported outcome measures (PROMs) quantify physical and emotional symptoms. Electronic capture of PROMs (ePROMs) enables real-time evaluation of results. The Patient Reported Outcome Measurement Information System (PROMIS) computer adaptive testing (CAT) item banks have been developed by the NIH to assess domains that are relevant across chronic conditions. CAT improves measurement precision while reducing questionnaire burden.
In this project we build a patient-centered ePROM assessment and response toolkit and pilot test the feasibility of a trial with this toolkit to improve outcomes for transplant recipients.
Objectives:
1: Identify reliable, precise PROMs to measure PROMs relevant and important for transplant recipients and professionals;
2: Conduct a pilot study to evaluate the feasibility and acceptability of trial to test real time ePROM collection in routine transplant care.
Methods. We will start by synthesizing data obtained in scoping reviews and focus groups (currently underway) to identify symptoms relevant and important for transplant recipients and professionals. These results then will inform the adaptation of the Distress Assessment and Response Tool originally developed for cancer care **(Aim1)**. The adapted toolkit will include ePROMs and also decision support and management tools to guide clinicians.
Parallel to this, we will validate PROMIS CAT item banks in SOT (kidney, kidney-pancreas, liver, heart and lung) recipients (**Aim 2**): in a longitudinal study (n~300 participants/organ group) we will administer PROMIS CATs along with legacy questionnaires at 3 time points to determine construct validity, clinically relevant thresholds, and responsiveness. Once **Aim 1 and 2** are completed, we will hold a one-day consensus workshop with 60-80 stakeholders to finalize the ePROM toolkit (**Aim 3**).

In the last 2 years of the project we will conduct a pilot study (**Aim 4**) to assess the feasibility and acceptability of a large trial to test the effectiveness of using the ePROM toolkit to improve patient outcomes for SOT recipients.
Expertise: Our team has a documented history of productive research collaborations identifying core domain sets, and implementing PROMs to improve shared decision-making and treatment outcomes. The interprofessional team brings together multidisciplinary clinicians, health services researchers with expertise in psychometrics, ePROM use and implementation and evaluation.
Significance, deliverables, future directions: We will identify relevant ePROMs and methods to optimize their use in shared decision-making in transplant care and will inform the design of a fully powered trial to assess the effectiveness of ePROMs in transplant care.

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 organ groups. Results of the cross-sectional and longitudinal validation 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; 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 (reseach 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.