



## RESEARCH SCHOLAR PROGRAM – 2018

### SUPERVISOR & PROJECT INFORMATION FORM

Please complete and return, via email only ([crems.programs@utoronto.ca](mailto:crems.programs@utoronto.ca)) by **November 3<sup>rd</sup> 2017** (*forms received after this date will not be posted*).

#### Supervisor Information

Name: **Istvan Mucsi**

Email: [Istvan.mucsi@utoronto.ca](mailto:Istvan.mucsi@utoronto.ca)

Degree: **MD/PhD**

SGS Appointment (IMS, IHPME, LMP etc.): **IMS**

Academic Rank: **Associate Professor of Medicine  
research/patient reported outcomes**

Field of Research: **kidney transplantation/outcomes**

Research Institution Affiliation (if applicable): **none**

Allocation of student contact time (number of hours per week YOU are available to the student for any concerns or to review progress):  
**2-4 hrs/wk**

## **Project Information**

### **Title: PATIENT REPORTED OUTCOME TOOLS FOR BETTER ASSESSMENT AND PATIENT CENTERED KIDNEY CARE**

Description (max 500 words):

In this project we will validate the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) computer adaptive testing (CAT) item banks to assess physical symptoms and psychosocial distress among patients with chronic kidney disease (CKD). The results of this study will be used to prepare a pilot trial to assess the feasibility of using the PROMIS CATs for regular distress and symptom monitoring among patients with CKD.

Patient reported outcome measures (PROMs) improve the accuracy and completeness of clinical assessment and the prediction of illness trajectory. PROMS are significantly associated with clinical outcomes, and can elucidate physical, psychological or social concerns that require intervention. Routine electronic capture of PROMs is sustainable and economical, with potential for immediate scoring and presentation of results, facilitates the linkage of PROMs with electronic health records, and enhances communication in multidisciplinary care. To use PROMs to guide clinical management we need tools with superb measurement characteristics that are not burdensome. The measures developed by the NIH PROMIS program may provide a solution. Using PROMs in clinical care improves cancer outcomes: better overall survival and less hospitalization but this is yet to be confirmed in patients with CKD.

**Objective:** This study aims to validate the PROMIS Computer Adaptive Testing instrument as a clinically useful measure of depression, anxiety, fatigue, sleep, pain, social functioning, and physical functioning among patients with various stages of chronic kidney disease (CKD).

#### **Hypotheses:**

- 1: We expect that the correlation between the PROMIS CAT scores and scores obtained on established, widely used (“legacy”) instruments will be strong.
- 2: We expect that the PROMIS CAT scores will be statistically significantly different between patients with known differences in their clinical condition.
- 3: We expect that the agreement between “cases” identified with cut off scores on PROMIS CAT scales using the PROsetta Stone© crosswalk files and cut off scores of the legacy instruments will be almost perfect.
- 4: We expect that a difference of 3-5 point on the PROMIS CAT scores will reflect a minimally important difference in the appropriate clinical characteristics.

**Research Plan:** In a cross-sectional study we will recruit patients with various stages of CKD from outpatient clinics and dialysis units of four Toronto hospitals (interdisciplinary renal and specialty nephrology clinics, in-centre and home dialysis units, and an outpatient kidney transplant clinic). All together we will recruit 900 patients over about 18 months. We will administer the PROMIS CAT toolkit along with legacy questionnaires on tablet computers to all participants using questionnaires programmed on an electronic data capture system. Results obtained with the PROMIS CATs will be compared to results obtained with the legacy instruments and (1) convergent validity (2) test-retest reliability will be established and clinically meaningful cutoff points will be determined.

If human subjects are involved, have Ethics been obtained?

YES                       NO                       Application Submitted                       N/A

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

YES                       NO                       Uncertain

Student's roles and responsibilities (please be specific)

**Literature review; enrolling patients; collecting data using electronic data capture system; data entry, data cleaning; analysis of data using STATA statistical software; preparing abstracts, posters for conferences ; writing papers**

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

**Student will report directly to PI**