

**LETTER OF INFORMATION REGARDING:
Patient Reported Indicators Survey (PaRIS) – Ontario Pilot for OECD: Patient Survey**

Principal Investigator: Walter P. Wodchis MA, MAE, PhD
Funded by: Health System Performance Network (HSPN)

INTRODUCTION

You are being invited to participate in a research study that will use the Patient Reported Indicator Survey (PaRIS) to explore patient experiences and outcomes in primary care. This study is being conducted by Canada's Strategy for Patient Oriented Research (SPOR) Primary and Integrated Health Care Innovations (PIHCI) Network on behalf of Health Canada. It is part of an international survey led by the Organisation for Economic Co-operation and Development (OECD).

WHAT DO I HAVE TO DO?

We are asking you to complete a 30 minute survey. If you wish to participate, please complete the survey by clicking the on the link provided in the email. The survey will ask about your experiences with care and treatment by your primary care provider (for example, your family doctor or nurse practitioner). It will also ask you questions about your general health and demographic questions.

WILL I BENEFIT FROM THIS STUDY?

There is no compensation for your participation. There may not be direct benefits to you from participating in this study. However, the results from this survey will be compared nationally and internationally. Results from this survey may help others, such as primary care providers, staff, and policy makers improve practices.

WHAT ARE THE RISKS?

Your participation in this evaluation is voluntary. If you choose to participate there are no reasonably foreseeable risks to you.

WILL MY DATA BE KEPT CONFIDENTIAL?

Yes. No names or contact information is collected in the survey; rather a unique identifying number will be used. The survey link for this study will not collect the user's IP Address or location data based on that IP Address, as the "anonymize responses" function has been enabled. This function renders the IP Address irretrievable once the response is collected.

Staff at the primary care practice that you attend will not know whether you choose to take part in this study or not. The link to the survey is specific to your primary care provider. Please note that primary care providers will not have access to individual level data, and instead will receive aggregated, anonymized, statistical results which will help them improve the quality of care they provide. No identifying data will be used, and any data that is transferred outside of the province will be de-identified.

Deidentified data will be transferred from the provincial research team to the centralized Canadian institution, The Institute of Health, Policy, Management and Evaluation at the University of Toronto. The centralized institution will also transfer data to Ipsos MORI (UK, London) who will store the data and the Nivel (The Netherlands, Utrecht) where the data will be analyzed. Ipsos MORI is an accredited data center based in the UK and de-identified data will be stored there. Only authorized consortium and country staff will have access to study data through a secure on-line portal. After the project is completed, the OECD will receive and store an anonymous dataset on their secure server in Paris and various reports and (scientific) articles will be published.

Data from this project will be published and presented at conferences, however it will not be possible to identify you.

CAN I CHANGE MY MIND AFTER I'VE CONSENTED TO PARTICIPATE?

Your participation is voluntary; you have the right to choose to not participate, or to stop participating in this evaluation without having to provide a reason and without any consequence by exiting the survey link. You can also skip any questions that you are not comfortable answering. As this study is anonymous it will not be possible to withdraw or retrieve your survey once the survey has been submitted.

WHOM CAN I CONTACT FOR MORE INFORMATION?

If you have questions at any time about the study or the procedures, you may contact the Principal Investigator of this study, Dr. Walter Wodchis, Institute of Health Policy, Management and Evaluation (IHPE), University of Toronto at 416-946-7387 or walter.wodchis@utoronto.ca.

You waive no legal rights by participating in this research and confidentiality can only be guaranteed to the extent permitted by law. If you have questions about your rights as a participant, contact the Office of Research Ethics at the University of Toronto at ethics.review@utoronto.ca or 416-946-3273.

HOW DO I PROVIDE CONSENT?

By completing the survey, you are providing consent to participate in this evaluation.

Yours sincerely,



Walter P. Wodchis, PhD
Professor, Institute of Health Policy, Management and Evaluation
Principal Investigator, Health System Performance Network
University of Toronto
416-946-7387
walter.wodchis@utoronto.ca