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**PARTICIPANT INFORMED CONSENT FORM**

**Title of Study:** Canadian Evidence Based Guidelines to Improve the Health

of Homeless and Vulnerably Housed People

**Principal Investigator (PI):** Dr. Kevin Pottie, Telephone: 613-562-5800 ext. 2015

**Funding Agency:** Inner City Health Associates

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

**Why am I being given this form?**

We wish to improve the health of homeless and vulnerably housed people. We are planning to develop evidence based guidelines that would help health care providers deliver better and more appropriate services to people who are homeless or vulnerably housed. Through your participation in the Delphi consensus process, you will help us determine the priority conditions, sub populations and models of care delivery that we will scientifically review to develop the evidence based guidelines. This Delphi consensus represents the first stage of a guideline development process. The people leading this project are Dr. Claire Kendall, Dr. Vicky Stergiopoulos, Dr. Gary Bloch, Dr. Vivian Welch, and Dr. Peter Tugwell. You were selected as a participant for this Delphi consensus because you have been identified as having expertise in homelessness research and/or policy-decision making.

**Why is this study being done?**

Homelessness is a concern and a priority for many areas across Canada. Homeless and vulnerably housed people experience a high rate of physical and mental health problems compared to the general population. While Canada’s universal health care system helps to overcome financial barriers to access physician services and medications, people who are homeless or vulnerably housed have multiple other barriers to access and uptake these services. The medical complexity and mobility of the homeless population demands the development of evidence based guidelines for primary care delivery that will improve trust with homeless populations, partner with community agencies, and train and support front line providers on the complexities of caring for those experiencing homelessness. Comprehensive evidence based guidelines that would facilitate homeless health care service uptake are lacking or are focused on specific diseases rather than on the whole person. Furthermore, no such guidelines exist for our Canadian health system, which is different from other countries because it is a single payer health system, it includes social and housing support programs, and prescription drug plans for people on welfare or disability, and we have multilingual and multicultural populations. Evidence based homeless health care delivery has become a priority for the Inner City Health Associates and other inner city programs across Canada.

With this research project, we will work towards effective and resource-smart guidelines to improve health systems and service delivery for homeless and vulnerably housed populations in Canada. We estimate 20 participants will be enrolled in the study.

**How is the study designed?**

This survey uses the Delphi consensus method to reach an agreement with homelessness health experts and those with lived experience of homelessness and their advocates, on important topics and special populations that may benefit from specific guidelines. The Delphi includes three rounds (3 separate surveys) of consensus building. After each round, participants will get a short summary of expert opinions from the previous rounds and are asked to prioritize again. Participants are asked to respond in all three rounds.

Survey Monkey will host the online Delphi consensus survey. During the first round, you will be asked to agree on a set of core values that will guide the development of the guidelines and rank the importance of potential guideline topics. You will be invited to participate in round 2 and share your feedback in a second online survey. For example, you will be provided with your own responses from the first round, as well as summary of the group’s responses and you can see how your ratings compare. You will then be given a chance to modify your responses or explain why you responded in a specific way. To provide you with a summary of the group responses and your own priorities identified in the first survey iteration, we will ask that you provide us with your email address before the survey questions start.

In every round, the survey will take you 15-20 minutes to complete for a total of no more than 60 minutes for up to 3 consensus building rounds/surveys. After you finish the third survey, your participation in the study will be complete.

**What is expected of me?**

You will be asked to complete up to three consensus building surveys hosted online by Survey Monkey. In total, it will take approximately 60 minutes or less to complete. You may skip any questions that make you uncomfortable or that you do not wish to answer.

**How long will I be involved in the study?**

The entire study will take place between March 2017 and February 2019. However, your participation in the Delphi component of the study will last approximately 2 months, from March 2017- April 2017.

Your participation in the study may be stopped for any of the following reasons:

* The study team feels it is in your best interest.
* You have been unable to follow the study team’s instructions.

**What are the potential risks I may experience?**

Potential risks for participants are minimal, data will be de-identified (nobody will know who gave which answer), and your participation voluntary. Time to complete survey would be the only risk. You might not like all of the questions that you are asked. You do not have to answer any questions that make you uncomfortable.

**Can I expect to benefit from participating in this research study?**

You may not receive any direct benefit from your participation in this study. Your participation may contribute to Canadian evidence based guidelines to improve the health

of homeless and vulnerably housed people.

**Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?**

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without any negative consequences.

If you start to participate and later change your mind and choose to withdraw your consent, the study team will no longer collect your personal identifying information for research purposes. All data collected prior to your withdrawal may be removed from the study at your request.

**How is my personal information being protected?**

* All information collected during your participation in this study will be de-identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.
* Information that identifies you will be released only if it is required by law.
* Any documents leaving Bruyère Research Institute will contain only your unique study number. No identifying information will leave the Bruyère Research Institute. All data will remain de-identified and will only be reported in aggregate form. This includes publications or presentations resulting from this study.
* A Master List provides the link between your identifying information and the coded study number. The master list will be kept in a separate, password protected file on the project manager’s computer at the Bruyère Research Institute.
* For audit purposes only, your original study records may be reviewed under the supervision of Dr. Kevin Pottie’s staff by representatives from:
	+ the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
	+ the Ottawa Hospital Research Institute, and
	+ Bruyère Research Institute
* Research records will be kept for 10 years, after this time they will be destroyed.

**Will I be informed about any new information that might affect my decision to continue participating?**

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

**Who do I contact if I have any further questions?**

If you have any questions about this study, please contact Dr. Kevin Pottie at 613-562-5800 ext. 2015 or email the study staff at EShoemaker@bruyere.org.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) and Bruyere Research Ethics Board have reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson of the OHSN-REB at 613-798-5555, extension 16719, or the Chairperson of the Bruyere REB at (613) 562-6262 ext 1420.