Adherence Perception Project - Letter of Information for Implied Consent

Participant:

You are invited to participate in a study, entitled the *Adherence Perception Project*, that is being conducted by Simon Diemert EIT, Dr. Morgan Price MD PhD CCFP, and Dr. Jens Weber PhD P.Eng.

Simon Diemert is a graduate student in the department of Computer Science at the University of Victoria. Dr. Morgan Price is a professor in the Division of Medical Sciences. Dr. Jens Weber is a professor of software engineering in the department of Computer Science. If you have any further questions or concerns you may contact Simon Diemert via email at sdiemert@uvic.ca.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Master of Science – Computer Science. This research is being conducted under the supervision of Morgan Price. You may contact my supervisor at by phone at: 250-XXX-XXXX or via email at: morgan@leadlab.ca.

This research has been supported by an NSERC – Canadian Graduate Masters Scholarship.

Research Purpose:
The purpose of this research project is to examine Canadian health care provider, specifically physician, perceptions of medication adherence; i.e. what do providers think adherent medication taking behavior looks like for their patients. Currently, it is unclear whether physicians (as a community) have a consensus on what adherent medication behavior entails. The results from this study may: 1) inform future similar studies; 2) augment advanced models of medication adherence for HIT systems; 3) provide evidence to direct future research and education efforts in the area of medication adherence.

Importance of Research:
According to the World Health Organization, medication adherence is a global problem of "striking magnitude", it is known that patients may not take medications as prescribed, this often results in exacerbation of existing conditions and increased frequency of hospital visits. Medication adherence has been extensively studied for the last 40 years; recent research suggests the problem is multifaceted and extremely complex. One aspect of adherence is health care provider perception of adherence, to date it is unclear what level of agreement the health care provider community has on the definition of adherence. As these are the professionals "on the front lines" of health care, it is important to understand their working day-to-day definitions of adherence.

Participant Selection:
You have been selected to participate in this research because you are: 1) a practicing physician (medical doctor); 2) registered to practice in a jurisdiction within Canada; and 3) at least 19 years of age.

What is Involved:
If you consent to voluntarily participate in this research, your participation will include:

1. Providing your name, geographic region (province), and email address (this will be deleted once we have confirmed you meet the study criteria).
2. Logging into (using credentials we provide) a web application and consenting to participate in the research (reviewing this letter).
3. Completing a short tutorial on the use of the study web application.
4. Answering 5 – 10 medication adherence questions based on hypothetical patient scenarios.
5. Answering 5 (or fewer) survey style questions.

Your participation in the research will take between 5 and 20 minutes (including initial recruitment email correspondence) of you time. It may be completed from anywhere in which you have Internet access.

Inconvenience:
Participation in this study may cause some inconvenience to you, including: use of personal time to complete the study.

Risks:
There are no known or anticipated risks to you by participating in this research/study.

Benefits:
The results of this research may inform future work in the medical sciences in the area of medication adherence. This will improve the state knowledge regarding physician perception of adherence and potentially support future medication adherence initiatives.

Voluntary Participation:
Your participation in this research must be completely voluntary. If you do decide participate, you may withdraw at any time without consequences or exploitation. If you withdraw from the study, any data you have already provided may still be used.

Researcher's Relationship with Participants:
The researchers may have a teacher/student relationship to potential participants. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken:

- Your personal identifying information (name, region, email) with be maintained by a non-physician investigator (e.g. Simon Diemert).
- Your personal identifying information will be deleted once a non-physician investigator has confirmed you meet the criteria for the study.
- In all results from the research you will be identified by a unique alpha-numerical code.

Anonymity
In terms of protecting your anonymity, the research team will:

- Delete personal identifying information (name, region, email) once it has been confirmed you meet criteria for the study.
- Your results will only be identified by a unique alpha-numeric code.

Confidentiality:
Your confidentiality and the confidentiality of the data will be protected by:

- Storing all digital data/results on encrypted password protected media.
- Storing digital data/results within a physically secure location.

Dissemination of Results:
It is anticipated that the results of this research/study will be shared with others in the following ways:

- Published articles, chapters, posters, or books.
- Presentation at scholarly meetings.
- Thesis/dissertation/class reports or presentations (including public access via UVic library).

Future Use of Data:
The data collected in this research/study may be used for future studies and/or data analysis by other researchers. In all cases of future use, only anonymized data will be provided.

Disposal of Data:
Data from this study will be disposed of after 2 years from the end of the study; all data will be deleted/erased.

Contacts:
Individuals that may be contacted regarding this study include:

- Primary Contact - Simon Diemert via email at: sdiemert@uvic.ca
- Supervisory Contact – Morgan Price via email at: morgan@leadlab.ca

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

By completing and submitting the study questionnaire and survey, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Please retain a copy of this letter for your reference.

Best Regards,

Simon Diemert, EIT