

# Toward Empowering Diabetic Patients: A Perspective on Selfmanagement in the context of a Group-Based Education Program

QUT Ethics Approval Number 1900001024

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# Description

This study aims to investigate the potential of value co-creation in digital health platforms such as Online Health Communities (OHCs) for healthcare organisations. An OHC is a group of people who interact with each other in online environments about similar health issues. Users of these communities can informationally and emotionally support each other in their health journey. These types of supports play a significant role in the management of chronic disease such as diabetes. In this project, we aim to conceptualise the use of OHCs for diabetes. Therefore, in the first place, we will investigate some Reddit online public discussion forums of diabetic patients and base on the findings of this phase, we will conceptualise the use of OHCs for diabetes in the diabetes group education program at QUT clinic which includes diabetic patients' education in 10 weeks to help them discharge from the long waiting list of the hospitals. The main purpose of this project is to improve a better understanding of patient-driven healthcare innovation by identifying the potential of OHCs for healthcare organisations (QUT clinic) to leverage OHCs during the diabetes education program and keep patients connected to the program after discharge from the clinic.

## Why is the study being conducted?

This research project is being undertaken as part of a PhD study for Atae Rezaei Aghdam. The purpose of this project is to investigate the role of Online Health Communities (OHCs) in the value co-creation process and its potential for healthcare organisations.

## What does participation involve?

Your participation will involve an audio recorded interview at QUT or other agreed location that will take approximately 45 – 60 minutes of your time.

Questions will include:

- 1. How do you engage and participate in Online Health Communities (OHCs) in relation to your diabetes?
- 2. What are the benefits and challenges of using OHCs in relation to your diabetes?
- 3. How do you obtain online support from other members in OHCs in relation to your diabetes?
- 4. What value do you perceive and receive from OHCs in relation to your diabetes?

Your participation in this research project is entirely voluntary. If you do agree to participate you can withdraw from the research project without comment or penalty. You can withdraw anytime during the interview.

# What are the possible benefits for me if I take part?

It is expected that this research project will not benefit you directly. However, it may benefit the university and healthcare organisations as the results of our analysis will be used to provide guidance and framework to improve the better understanding and use of OHCs for co-creating value.

## What are the possible risks for me if I take part?

Your participation for the interview is low risk where only minimal discomfort and inconvenience occur due to allocating time to participate in the interview.

## What about privacy and confidentiality?

All comments and responses are coded under a unique identifier, which is stored separately to personal information (e.g. name), which will only be accessible to the research team. Any personal information that could potentially identify you will be removed or changed before files are shared with other researchers or results are made public.

As the research project involves an audio recording:

- You will have the opportunity to verify your comments and responses prior to final inclusion.
- The recording will not be used for any other purpose.
- Only the named researchers will have access to the recording.
- It is possible to participate in the research project without being recorded.
- You will be identified as a participant in this research only with your specific consent

Any data collected as part of this research project will be stored securely as per QUT's Management of research data policy. Data will be stored for a minimum of 5 years, and can be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

## How do I give my consent to participate?

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate.

## What if I have questions about the research project?

If you have any questions or require further information please contact one of the listed researchers:

Atae Rezaei Aghdam	atae.rezaeiaghdam@hdr.qut.edu.au	3138 4825
Jason Watson	ja.watson@qut.edu.au	3138 1656

## What if I have a concern or complaint regarding the conduct of the research project?

QUT is committed to research integrity and the ethical conduct of research projects. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on +61 7 3138 5123 or email humanethics@qut.edu.au.

Thank you for helping with this research project. Please keep this sheet for your information.