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Chief Investigator's Name & Title: Dr Annie Lau

Participant Information and Consent Form

Name of Project

Analysis of patient work conducted by patients with type 2 diabetes and multiple comorbidities.

Project Information

You are invited to participate in an observational study of the 'patient work' involved in self-managing type 2 diabetes and other conditions, using a combination of time-use diaries, a physical activity tracker, and a body camera.

The purpose of the study is to investigate the extra health-related work you undertake to accommodate your health conditions, such as taking medications, preparing meals, or making time to see doctors. We want to gain a better understanding of the daily routines of those living with type 2 diabetes and other health conditions, so that we can understand how to integrate healthcare interventions more seamlessly into our daily lives in order to improve health outcomes.

The study is being conducted by Dr Annie Lau (Ph 02 9850 2436 annie.lau@mq.edu.au), Dr Kathleen Yin (Ph 02 9850 2477 kathleen.yin@mq.edu.au), Prof Enrico Coiera (Ph 02 9850 2403), Dr Liliana Laranjo (Ph 02 9850 2426), A/Prof Kenneth Ho, Mr Wen Jun Liang (Bachelor of Engineering), Mr Joshua Haddrill (Bachelor of Engineering), Ms Isabelle Barnes (Bachelor of Clinical Science), Mr Joshua Jung (Bachelor of Clinical Science), Mr Christian Tran (Bachelor of Commerce and Arts), and Mr Jiawei he (Bachelor of Commerce and Arts) from Macquarie University's Australian Institute of Health Innovation, Dr Sanjyot Vagholkar from MQ Health General Practice, and Dr Teresa Harms and Prof Jonathan Gershuny from the University of Oxford (UK).

You will be given a \$60 shopping voucher as our appreciation for taking part in this study.

Participants are required to be consenting adults who:

- are able to speak, write and read in English;
- are aged 18 years and older;
- are diagnosed with type 2 diabetes and at least one more chronic health condition;
- are willing to fill in a Time-Use Diary for one day; and
- agree to wear the Edesix body camera on their person for one day.

If you decide to participate, you will be asked to complete three tasks:

- **Task 1 - Pre-study briefing session:** Attend a pre-study briefing session at Macquarie University, or a place of your choice (e.g. your home), where you will be given information about the study, asked to provide written consent if you are willing to participate, and complete two questionnaires about your personal information and your health (approximately 5-10 minutes each).

Afterwards, we will conduct an interview with you to better understand your health condition and existing patient work. This interview will be audio recorded for future analysis. You can terminate the interview at any point you want.

With your permission, we will take photos of your surroundings and the tools you use to manage your health (e.g. medications, devices, home environment).

Lastly, we will provide you with two pieces of equipment (Edesix camera and time-use diary), and show you how to use them for the second task of data collection. We will also provide you an explanation card where you can show it to members of the public who are enquiring about the study.

- **Task 2 - Data collection:** After the briefing session, you will be asked to wear the Edesix body camera during the waking hours of one (1) day, which will take video recordings of your daily activities for approximately 8 to 14 hours. No audio will be recorded.

We will also ask you to complete the time-use diary over the same day for 24 hours.

You have the right to remove the camera at any time.

(Please note: The Edesix body camera is encrypted to ensure your data is protected.

You are recommended to turn off the body camera during situations when anyone (including yourself) is dressing or undressing, using the bathroom or showers, or during any situations where privacy or recording is of concern.

Should you feel unsafe due to the presence of the body camera at any stage of the study, you should always prioritise your own personal safety and comfort above the study's requirements.)

- **Task 3 - Post-study debriefing session:** Immediately after the data collection day, we will ask you to attend a 1-hour post-study session at Macquarie University, or a place of your choice, where we will go through the videos together and conduct a debriefing session with you.

Please bring the two pieces of equipment with you on the day (Edesix camera and Time-Use Diary).

The video footage will be converted to images, and you will first view the images alone. You have the right to delete any (or all) of the images before the interview.

An interview (about 30-40 minute in length) will be conducted where the research team will ask you to describe your day, with assistance from the images. This interview will be audio recorded for future analysis, and you can terminate it at any point you want.

You will be asked to answer one (1) paper-based questionnaire about your experience during the study day (~10 minutes to answer).

Your confidentiality

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication or presentation of the results.

Only members of the research team will have access of the data. None of your video or photo images will be released to the public. In cases when we need to use video or photo images in publications or presentations, we will seek your permission first, and images will be blurred such that no one is identifiable.

The study data will be kept for a minimum of 5 years from the most recent publication date and will be safely stored on a password-protected computer locked in the study centre.

By signing this form, you are also consenting to the potential use of this data in future research, however the Macquarie University Human Research Ethics Committee must first approve any such future research before any of your data is used. The results of the study will be published in peer-reviewed journals and may be presented at scientific conferences.

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

Your participation in this study will not affect your relationship with Macquarie University, nor the clinical care you receive at the MQ Health General Practice Unit.

INVESTIGATOR/PARTICIPANT'S COPY

I, _____ have read (*or, where appropriate, have had read to me*) and understand the information above and any questions I have asked were answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

I **consent / do not consent** (*circle one*) for the research team to use my de-identified photos and video images in publications and presentations, provided that the persons in the images cannot be identified.

Participant's Name: _____
(Block letters)

Participant's Signature: _____ Date: _____

Investigator's Name: _____
(Block letters)

Investigator's Signature: _____ Date: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.