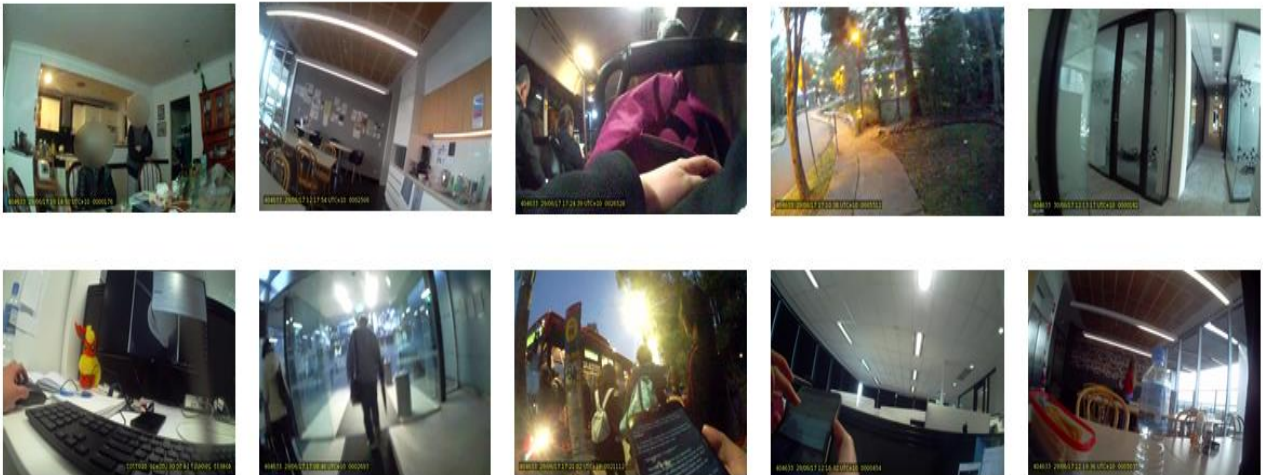


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## Information Booklet for Participants



If you have any questions about the study, please contact

Dr Annie Lau  
[annie.lau@mq.edu.au](mailto:annie.lau@mq.edu.au)  
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## **Information for participants**

Recently we invited you to take part in a research project investigating the amount of 'patient work' you conduct for Type 2 diabetes and other chronic health conditions. This information booklet is designed to fully inform you about the project before you agree to participate.

### ***About the study***

Living with a health condition does not come naturally. Following a diagnosis or medical interventions, patients and their families must undertake extra work to accommodate their health condition, such as making time to administer medications, visit medical professionals, or prepare meals.

The concept of 'patient work' describes these health-related tasks the patient must somehow integrate into their daily routine. When integrated poorly, these tasks have the potential to generate extra stress, contributing to non-compliance, and negatively affecting the health outcomes of the patient.

Type 2 diabetes is known to require significant amounts of patient work on a daily basis, and for patients who also have other health conditions, the amount of patient work can increase exponentially.

The aim of this study is to observe and document how patient work impacts individuals with type 2 diabetes and at least one other chronic comorbidity. The goal is gain a better understanding of the daily routines of those affected by 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.

### ***Do I have to take part?***

You are free to decide whether or not to take part in this study. If you agree, we will ask you to sign an informed consent form. If you agree and then later decide not to take part, you can leave the study at any time by advising the researchers of your decision. There will be no penalty to you for leaving the study at any time.

### ***Who can participate?***

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.

Exclusion criteria include:

- pregnancy;
- critical illness;
- end-stage disease;
- dementia;
- severe mental disorders that prevent participants from giving consent; or
- needing assistance with basic daily living such as reading, writing, dressing and eating.

## ***What would I have to do?***

If you decide to participate, we will ask you to complete three tasks:

- First, we will ask you to attend a pre-study session at Macquarie University, or a place of your choice (e.g. your home), where you will be given information about the study, 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). (Note: you can do these questionnaires in your own time).

Afterwards, we will ask you to tell us about your health and the activities you do for your health (approximately 1 hour). This interview will be audio recorded for future analysis. You can terminate the interview at any point.

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), where information identifying you (e.g. names on prescription label) will be masked.

- Next, we will give you two pieces of equipment to collect data about your day (body camera and Time-Use Diary).

We will ask you to fill out a Time-Use Diary for 24 hours, and wear an Edesix body camera during the waking hours of the same day (approximately 8-14 hours).

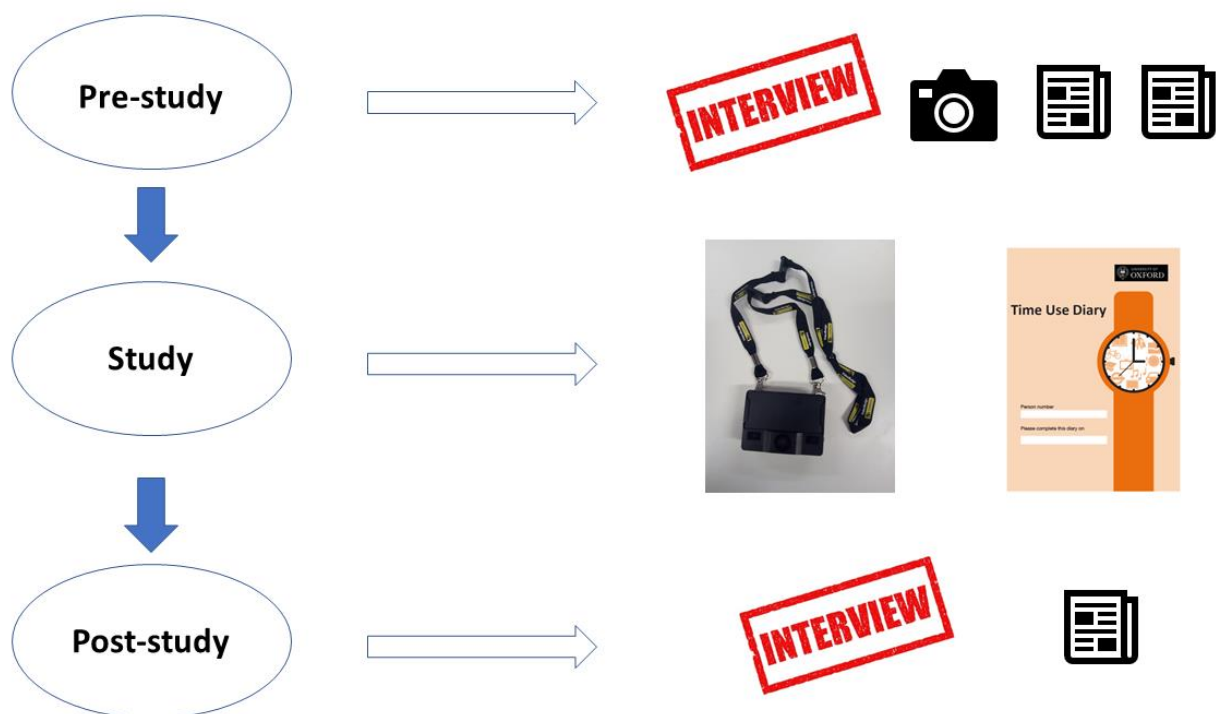
You are free to remove the camera at any time. Particularly, we recommend you to turn off the camera when anyone (including yourself) is dressing or undressing, using the bathroom or showers, during any situations where privacy is of concern, or any other time that you or others might feel uncomfortable.

If you are in the company of others (e.g. household members, friends and/or acquaintances), we ask you to seek permission from these third parties prior to video recording.

- Soon after data collection, you will be asked to visit the study centre at Macquarie University to return the diary and the data gathering tools, as well as for a post-study reconstruction interview. If you prefer to not travel, the research team will endeavour to visit you at your home (or your preferred location). This session will take approximately 1 hour.

The videos from the body camera will be downloaded onto a secure computer and you will be invited to view them alone. You may delete any or all of them without giving any reason. The researcher will not view any of the videos until you have done this.

We will ask you to look through the videos with us and tell us about your daily activities, especially health-related tasks. This interview will take approximately 30-40 minutes. We will also ask you to fill in a questionnaire about your experiences of wearing the camera and completing the Diary (approximately 10 minutes).



### ***What will happen to the information I provide?***

Your confidentiality will be respected at all times. All your data, including the videos will be stored on a password-protected computer. You will never be identified or have your image shown without your written permission. The results from this research project will be submitted for publication in academic journals and used to inform researchers on future work. Researchers outside this project may request to analyse your anonymised data, but will be required to follow the same highest standards of research integrity and ethics expected of Macquarie University researchers.

### ***Who will conduct the study?***

There are four researchers from Macquarie University conducting this study, who are available to answer any questions or concerns you may have:

- Macquarie University
  - Dr Annie Lau ([annie.lau@mq.edu.au](mailto:annie.lau@mq.edu.au) 02 9850 2436)
  - Dr Kathleen Yin ([kathleen.yin@mq.edu.au](mailto:kathleen.yin@mq.edu.au) 02 9850 2477)
  - Dr Liliana Laranjo ([liliana.laranjo@mq.edu.au](mailto:liliana.laranjo@mq.edu.au) 02 9850 2426)
  - Prof Enrico Coiera ([enrico.coiera@mq.edu.au](mailto:enrico.coiera@mq.edu.au) 02 9850 2403)
  - 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 (Psychology))
  - Mr Jiawei He (Bachelor of Commerce and Arts (Psychology))
- MQ Health General Practice
  - Dr Sanjyot Vagholkar
- University of Oxford
  - Dr Teresa Harms
  - Prof Jonathan Gershuny

### ***What are the possible benefits of taking part in this study?***

You will receive a \$60 shopping voucher as remuneration for participating in the study.

### ***What are the possible disadvantages in taking part in the study?***

We do not anticipate that participating in this project will have any significant effects on your lifestyle. If you do not want to answer any of the questions in the questionnaires or interview, you do not have to. You will also be able to check and delete any videos taken prior to the researchers viewing the videos.

It is possible that while wearing the camera you may be asked about the device by members of the public. In this case we suggest that you say the following:

*“I am volunteering for a research project. The device is a wearable camera and the images will be used to record my daily activities. I am happy to remove it if you would like me to.”*

We will provide you with a wallet-size card that includes this statement and contact information for you to show others if you wish.

Please remember to always prioritise your own personal safety and comfort above the study's requirements.

### ***What happens next?***

If you decide that you do not want to take part in the study, we thank you for taking the time to consider it.

### ***What if there is a problem?***

Approval to conduct this research has been provided by Macquarie University, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Committee at Macquarie University on (02) 9850 7854 or by emailing to [ethics@mq.edu.au](mailto:ethics@mq.edu.au).

All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

If you have a concern about any aspect of this project, please speak to a member of the research team: Annie Lau ([annie.lau@mq.edu.au](mailto:annie.lau@mq.edu.au) 02 9850 2436) or Kathleen Yin ([kathleen.yin@mq.edu.au](mailto:kathleen.yin@mq.edu.au) 02 9850 2477).