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Patient Work from a Context and Time Use Perspective – A Mixed-Methods Study Protocol

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Keywords:	Patient work, Mixed-methods study, Body-worn cameras, Time-use diary, Passive data collection, Burden of disease

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Patient Work from a Context and Time Use Perspective - A Mixed-Methods Study

Protocol

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Abstract:

Introduction: 'Patient work', a concept that encompasses patients' health-related behaviours and their contexts, forms the basis of patient-centred holistic healthcare. Passive observation, combined with in-depth interviews about health behaviours and motivations, has the potential to yield comprehensive insights about patient work. The purpose of our study is to pilot a novel research methodology that combines body-worn cameras, self-report time-use diaries, activity trackers, interviews, and questionnaires to capture the full range of patient work experienced by participants living with type 2 diabetes with chronic co-morbidities, potentially extending to populations with other chronic health conditions. Methods and analysis: This mixed-methods study involves a pre-study interview, a 24-hour period during which participants wear a passive data collection instrument (body-worn camera) and complete the time diary, and a post-study 'reconstruction' interview. Adult participants living with type 2 diabetes with at least one chronic co-morbidity will be recruited using purposive sampling to obtain a balanced gender ratio, as well as equal numbers of participants using insulin versus those using only oral medications. Interviews will be analysed using thematic analysis to identify any recurring themes regarding healthrelated activities, and data captured by digital devices will be used to identify the duration, time, context, and patterns of observed health-related behaviours. Ethics and dissemination: The study was approved by the Macquarie University Human Research Ethics Committee for Medical Sciences on 6th September 2017 (Reference Number 5201700718). Participants will carry a wallet-sized card that explains the purpose of the study to third parties, and can remove the body-worn camera at any stage. Before the poststudy interview begins, participants will view the camera images in private and to delete any unwanted (or all) images. Should any images be used in future publications or presentations,

identifying features such as human faces and names will be obscured.

Strengths and limitations of this study

- This is the first study that employs a mixed-method design using passive digital observation equipment, self-report time-use diaries, complemented with interviews and questionnaires, to document patient work.
- Using the body-worn camera may diminish the observer effect caused by having
 researchers observe participants in a private setting, as well as reducing the participant
 burden of having researchers in their homes for prolonged periods of time.
- The self-report diary complements data from the passive device by creating a holistic view of patient work carried out by the participant.
- The study is limited by the 24-hour data collection period, which may not include patient work that occurs frequently, but outside the observation period.

Keywords

Patient work; Mixed-method study; Body-worn cameras; Time-use diary; Passive data collection devices; Interviews; Burden of disease.

INTRODUCTION

For better or worse, living with chronic diseases changes people's lives. Following diagnosis or medical interventions, patients and their families often need to adjust their daily routines to accommodate their health condition, such as making time to administer medications, visit medical professionals, or prepare special meals.¹⁻⁴ The concept of 'patient work', derived from health ergonomics, describes the physical work conducted by the patient to manage their health, as well as the holistic sum of contexts (physical, social, mental, and organisational) that influence the work conducted.⁵⁻⁷

When integrated poorly into people's lives, patient work has the potential to generate extra stress, contributing to non-compliance to medical regimens and negatively impacting on patient health outcomes. ^{8 9} Currently, many health interventions are implemented without considering the *context* of a patient's life. Treatment and self-management recommendations, whilst given with good will, do not acknowledge the specificities of a patient's daily routine, household characteristics, physical environment, social obligations and roles, as well as internal perceptions, beliefs, and attitudes towards health. ¹⁰⁻¹³

Digitally-distributed health interventions specifically suffer from poor integration into patients' lives, as studies involving digital interventions (such as mobile applications) show significantly higher dropout rates than traditional, drug- or surgery-based trials, with some digital health intervention studies having retention rates as low as 1% by the end of the study period. Interestingly, participants in digital health studies report the devices' lack of effective integration and 'fit' into their daily lives as reasons for discontinuation. This suggests that clinicians and digital health advocates need to understand the impact of health

interventions within the context of patients' lives, as well as the internal, subjective thought processes that underpin patients' attitudes towards health-related changes.¹⁷⁻¹⁹

Patient work research

Previous patient work research has relied heavily on self-report methods (e.g. interviews, ^{17 20}) direct observation (e.g. researchers being present continuously in participants' homes and observing their behaviours), or theoretical modelling approaches (e.g. analysing macroergonomic elements^{21 22}). These data collection methods have been limited by the level of reliability in self-report data (e.g. social desirability effect) and the degree of discomfort participants experience during direct observation periods, including the high probability of observer effect.²³ These methodological limitations are therefore unlikely to capture the 'natural' routines and behavioural contexts of the participant.

In this study, we aim to address this methodological gap by capturing a wide range of health-related activities and contexts in people's home environments. We will use a mixed-methods approach of unobtrusive passive observation via an automated digital device (the body-worn camera), as well as patient self-reports. To this end, our study has adapted the protocols used and validated by Kelly et al., ²⁴ ²⁵ which were employed in research projects conducted by the Centre for Time Use Research (CTUR) and the British Heart Foundation Centre on Population Approaches for Non-Communicable Disease Prevention, both at The University of Oxford. The protocol utilises a unique combination of body-worn cameras, accelerometers (Axivity AX3), self-report time-use diaries, interviews, and questionnaires to obtain holistic data regarding the participants' physical activities and contexts – techniques which have been applied across population groups to study human behaviour. ²⁴ ²⁶⁻²⁹ It is anticipated that

applying such a mixed-methods methodology in a healthcare setting would enable a more comprehensive investigation and understanding of patient work.

Type 2 Diabetes and Other Co-morbidities

To validate using this mixed-methods research protocol, we will focus on the daily lives of people with type 2 diabetes, with at least one chronic co-morbidity. The nature of type 2 diabetes, which impacts the entire metabolic process, means that patients need to carry out a variety of different activities to control their diabetes. These may include diet modification, ³⁰ weight management, ³¹ exercise, ³² complication prevention, ³³ blood glucose tests, ³⁴ and insulin injections. ³⁵ Metabolically related co-morbidities such as high cholesterol, cardiovascular diseases, and kidney malfunctions ^{36,37} are frequently present in people living with type 2 diabetes, which warrants the inclusion of co-morbidities to reflect the true extent of health behaviours. Co-morbidity is frequently a criterion for exclusion in research studies, suggesting that our study will give rare insights into the lives of people living with type 2 diabetes, as well as a greater understanding of patient work in patients with chronic co-morbid conditions.

This protocol paper therefore aims to describe a novel research methodology – body-worn cameras, self-reports, and time-use diaries – as an approach to studying patient work in people living with type 2 diabetes and co-morbidities, potentially extending to populations with other chronic health conditions.

AIMS

The aim of this paper is to test and validate a novel cross-disciplinary mixed-methods approach in the investigation of patient work conducted by people living with type 2 diabetes

and at least one chronic co-morbidity. The approach will use passive a data collection instrument to allow objective measurement, which will be complemented by subjective reporting. Data collection will involve self-reported data (semi-structured interviews and time-use diaries) as well as objective measurements (questionnaires, photos, and video footage), as well as striving to minimise participant burden,

METHODS

The study has been approved by the Macquarie University Human Research Ethics Committee, approval number 5201700718.

Sample and recruitment

Eligible participants are: (1) adults aged 18 years and older; (2) consenting adults who can speak, write and read English; (3) have been diagnosed with type 2 diabetes and at least one chronic comorbidity; (4) willing to complete a time-use diary for one day; and (5) agree to wear the Edesix body-worn camera for one day. Exclusion criteria include adults who currently are experiencing: (1) pregnancy; (2) critical illness; (3) end-stage disease; (4) dementia; (5) severe mental disorders that prevent them from giving informed consent and; (6) dependence on others for basic activities of daily living, such as dressing and eating. Participants will receive \$60 in Australian Dollars of shopping vouchers as remuneration.

Up to 40 participants will be recruited with balanced numbers of participants using only oral medication and those using insulin to control diabetes, in order to capture a full range of patient work at various degrees of diabetes. The number of participants chosen was informed by previous qualitative studies in the field of patient work. This sample size also offers the power to achieve rich and nuanced data, while keeping in mind the complexities and the

different time intervals between data points for each data capture tool. ⁶ ¹⁷ ²⁰ Previous patient work studies analysed 60-80 hours of interview or direct observational data per study. This study will capture approximately 2 hours of interview data and 5000 images per participant. Therefore, a sample size between 30 and 40 participants would be comparable to the depth of data captured by previous studies.

Recruitment, which commenced in September 2017, will continue to be carried out via the Macquarie University general practice clinic, and via general practitioners and endocrinologists in the surrounding suburbs. These medical practitioners manage a large and diverse patient base, stretching across the northern Sydney suburbs and covering a wide range of cultural and economically diverse population groups.

Promotional flyers will be distributed to the medical practices and will include general study information and a link to the study website, where potential participants will be able to check their eligibility criteria (www.tinyurl.com/patientswork). The study will also be promoted on the Macquarie University Facebook page and via an emailed newsletter associated with the University. Healthcare practitioners will not be notified if their patients have agreed to participate in the study to uphold patient anonymity and confidentiality and reduce the possibility of behavioural change.

General practitioners and endocrinologists involved in recruitment will also send invitation letters to eligible patients, with a study reply slip included in the envelope. Patients interested in participating will be asked to return the pre-paid reply slip with their contact details so that a member of the research team can contact them.

For initial contact, the research team will telephone potential participants, confirm the participants' understanding of the study eligibility criteria, assure confidentiality and anonymity during the data-collection phase of the study, and address any questions or concerns. This approach will minimise participant contact with the research team and clinicians during recruitment, and mitigate coercion during recruitment. While self-nominated participants may be subject to participation bias, high completion rates and compliance are likely.

Participants will be given the Participant Information Booklet (Supplementary 1: Information booklet) during a pre-study, individualised briefing session, which involves an interview that will take approximately one hour. Following the pre-study session, data will be collected from participants over the course of 24 hours. Immediately following data capture period, participants will be invited to a post-study session with a reconstruction interview that will take 30 to 40 minutes (Figure 1).

Data collection instruments and equipment

Time-Use Diary

The self-report time use dairy is a validated tool.²⁴ The diary that will be used in this study is the Harmonised European Time Use Diary³⁸ (UK version) originally developed by Eurostat and used by 25 countries for national time-use studies. Participants will complete the diary in their own words over one 24-hour period. The diary is divided into 10-minute intervals and participants record: (1) the main/primary activity in which they were engaging; (2) other (secondary/simultaneous) activities that were occurring at the same time; (3) their location (e.g. home, clinic, shops) or if travelling, the mode of transport; (4) who they were with or whether they were alone; (5) whether they were using digital equipment (e.g. mobile phone,

computer); and (6) how much they enjoyed the activity (Supplementary 2: Time-Use Diary). As data from the diary is self-reported, the diary can be used to complement the objective activity data collected via the body-worn camera.

Photos

With permission from the participant, photos of the participant's medications, medical devices, and their home surroundings will be taken to inform the researchers about the participant's physical environment. Should the participant reside in a physical environment that can affect their healthcare (e.g. a house with stairs with a risk for falls, medications placed in locations difficult to reach), these issues will be noted and taken into consideration in the context of patient work. Participants will be alerted should an immediate and significant risk be identified.

Body-Worn Camera

The body-worn camera (Edesix VB-300, Edinburgh) will automatically record silent continuous video footage. It can be attached to clothing and/or worn on a lanyard. The camera captures data regarding the daily activities in which the participant is engaged.

Questionnaires

Three questionnaires will be administered during the study. In the pre-study session, a basic demographic questionnaire will be administered to obtain information about the participant's age, gender, health conditions, length of time since diagnosis, list of medications taken, and employment status. The questionnaire takes about 10 minutes to complete (Supplementary 3: Demographic Questionnaire).

A second questionnaire, the Multimorbidity Illness Perceptions Scale,³⁹ will also be administered in the pre-study session. The scale has been validated statistically as a measure of the burden of co-morbidity. It was developed to capture the perception of patients with co-morbidities about their health, including the emotional effects of the conditions, treatment burden, prioritisations between conditions, restriction of activities resulting from their health conditions, and perceived causal links between health conditions.³⁹ The Scale takes approximately 5 minutes to complete (Supplementary 4: Multimorbidity Illness Perceptions Scale).

Finally, a participant experience survey will be administered during the post-study session to assess the methodology employed, using the participant's feedback and experience regarding the time-use diary and body-worn camera. The participant will be asked to provide feedback regarding any issues they experienced while wearing the digital device, the reaction of other people towards the device, and whether they felt the device involved too much work. This is estimated to take approximately 10 minutes (Supplementary 5: Participant Experience Survey).

Pre-study session

Prior to the pre-study session, participants will have given the study team their oral consent during telephone calls to confirm the time and place of the pre-study session. Participants will be provided with the Participant Information Booklet (Supplementary 1: Information booklet) and will sign a written informed consent form (Supplementary 6: Informed Consent Form) before any data are collected. Participants will have the right to decline at this stage and to remove consent at any time throughout the project if they choose.

Ideally, the pre-study interview will occur in the participant's home in order for researchers to note physical, organisational, and ergonomic factors that may affect the health-related work conducted by the participant. Two researchers will make the home visit (to ensure researcher safety) to interview the participant. If they prefer, participants may come to Macquarie University for the interview.

Following consent and before the beginning of the pre-study interview, participants will also be asked to complete two brief questionnaires. The first is the demographic questionnaire (Supplementary 3: Demographic Questionnaire), and the second is the Multimorbidity Illness Perceptions Scale³⁹ (Supplementary 4: Multimorbidity Illness Perceptions Scale).

Pre-study interview

After the completion of the questionnaires, a semi-structured interview will be conducted to gain detailed information about the participant's life history, medical history, and existing factors that impact patient work. Participants will be invited to talk about their health and lifestyle, with the areas of focus in the interview separated roughly into life history, social life and mental health, physical health and medical history, physical environment, and organisational effort and attitude (Supplementary 7: Pre-study Interview Example Questions). The interview will be audio-recorded with the participant's permission, to assist with later data coding and thematic analysis (e.g. daily activities, their rationale behind such behaviours, and the factors that influence why they behave in such a manner).

Lastly, the participant will be provided with the body-worn camera (Edesix VB-300, Edinburgh) and Harmonised European Time Use Surveys UK Time-Use Diary.³⁸ Participants

will be instructed on the use of these tools. Photographs of the participant's medications, medical devices and home environment will also be taken at this stage.

Participant self-recording data collection

During the 24-hour study period, participants will be asked to wear the camera around their neck on a lanyard during waking hours (12-16 hours). The Time-Use Diary will be completed by the participant over the course of the same day for 24 hours. Participants will be given instructions (Figure 2) to re-charge the camera overnight or if the battery becomes low.

Post-study session

A post-study session will occur immediately after the 24-hour study period has concluded. The camera footage will be downloaded and converted into images using software developed in-house, with one screenshot taken for every 10 seconds of footage. The participants will be able to view all their images alone before the research team views them, allowing the participant to delete any or all unwanted images.

Post-study 'reconstruction' interview

The participant will then be interviewed for approximately 30 – 40 minutes (Supplementary 8: Post-study Interview Example Questions) along with their images. Participants will be asked to describe the study day, using the screenshots and time-use diary as prompts to direct the discussion, with a focus on health-related tasks. The interview will also be audio recorded with the participant's permission to allow for thematic analysis of coded transcripts.

After the interview, the participant will be asked to complete the Participant Experience Survey (Supplementary 5) and provide feedback of the study process.

DATA ANALYSIS

Both qualitative and quantitative data will be gathered during the study and will include a mixture of subjectively reported and objectively collected data sources. While data gathered using the different instruments and methods will focus on different aspects of patient work, the varied sources are anticipated to be complementary. For example, self-reported data regarding physical activities via the time-use diary can be enriched through an examination of the screenshots from the body-worn camera. At the same time, screenshots from the camera may be difficult to analyse without an understanding of the participant's physical environment or motives behind their observed actions, which will be complemented by the home visits and interviews.

Utilising multiple types of data, the project generates a holistic report of patient work conducted by people living with type 2 diabetes in terms of observed physical work, organisational efforts, burden of disease, and attitudes and beliefs underlying health behaviours.

Quantitative data analysis

Time-use data collected from participants using the body-worn camera will be analysed alongside information from the time-use diary.

The Multimorbidity Illness Perceptions Scale will be analysed using SPSS® (IBM, New York, USA) to assess the perceived burden of disease from the participants.

Qualitative Data Analysis

Both pre-study and post-study interviews will be transcribed verbatim. Analysis of the interview transcripts will be conducted using the NVivo® thematic analysis software package (NVivo, Melbourne, Australia). Two members of the research team will independently code the transcripts in a systematic manner. Any coding discrepancies between the two researchers will be resolved through reaching a consensus. Certain extracts or quotes from the transcripts may be provided to illustrate discovered themes in the interviews.

The Time-Use Diary data will be analysed in conjunction with the camera screenshots. The daily activities reported in the Time-Use Diary and observed via the video footage will be coded using a standard time-use coding frame⁴¹ to assess the duration, frequency, timing, and pattern of the participant's activity through the day. The data will be coded using the Harmonised European Time Use Surveys activity frame to classify activities.

Screenshots will be extracted automatically (1 screenshot every 10 seconds) from the video footage. Images will be tagged using the TensorFlow⁴² and/or ClarifaiTM (New York, USA) Application Programming Interface, which automatically generate tags that identify objects within the image and describe content of within the images. The tags will be sorted according to the activities in the Harmonised European Time Use Surveys code system to allow for easier calibration between different types of data.

Photographs of the participant's medications, medical devices, and home environment and screenshots from the video will provide context to the interview. The photographs will also be used to give contextual feedback regarding the participant's existing patient work, particularly ergonomic factors.

ETHICS AND INFORMATION DISSIMATION

Ethical considerations arising from this study are addressed below.

Consent and freedom to withdraw

Participants' questions or concerns regarding the study will be addressed individually and with all due diligence. Participants will be free to withdraw from the study at any point, and will be able to remove the body-worn camera at any time during the study without giving a reason. The decision to join the study will have no consequence on their relationship with either Macquarie University or their health professionals. Patients will not be under any coercion to participate in the study.

Third-party and bystander consent

The research team will provide participants with a wallet-sized card that includes the statement below with contact information of the research team, which can be shown to others (to reduce the psychological burden of the participant when faced with a potential confrontation) should anyone approach the participants to ask about the camera.

"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."

The participants will also be reassured that they can turn off the body-worn camera at any time during the day. Should anyone request the video recordings to be deleted, we will ask participants to take note of the date and time that requests were made, and to assure the enquirer that the related recordings will be removed at the post-study session. Participants are also asked to inform their household members, friends and acquaintances that they will be

participating in the study, and to seek permission from these third parties prior to video recording.

Personal privacy

Participants will be asked to keep the body-worn camera off during situations when anyone (including themselves) is dressing, undressing, using the bathroom, showering, or during any situations where privacy is of concern. Participants will be advised that they should always prioritise their own personal safety and comfort above the study's requirements.

Furthermore, participants will be able to view and delete any (or all) of the extracted images before the researchers view any of the images or videos at the start of the post-study session. The videos will be deleted immediately after images are extracted. Only members of the research team will have access to the images. None of the video or extracted images will be released to the public, academic peers, or to participants. Should participants provide written informed consent for the research team to use their images in publications or presentations, the images will be blurred such that no one is identifiable.

To ensure the participant's privacy, their name and other identifying information will be removed in the photos of the medications.

Participant feedback

Participants will be asked about their experiences of wearing the camera during the post-study interview. A survey to assess the participant's experience with the diary and the bodyworn camera (Supplementary 5) will also be administered. Participants will be provided with contact details of the research team (email and phone number) for contact during the study.

Psychological support

In the unlikely case that participants become psychologically distressed during either of the interview sessions, a staff member with counselling experience will be present in both interviews to deal with any anxiety the participant may experience. Should participants experience high levels of distress during the study day, they will be advised that they should immediately attend their local hospital emergency department, general practitioner, and/or call Lifeline or Emergency Services.

Identification

Participant identities will not be masked during data collection. Participants will be individually identifiable due to the small sample size. However, their identities will only be known to the research team, and only members of the research team will have access to identifiable data (such as photos). Data will be separated from contact details and stored in separate locations.

Information dissemination

Great caution will be taken in the handling and storage of the data by the research team so that risks to privacy are minimised, in accordance with the Australian Code for the Responsible Conduct of Research. Only members of the research team will have access to the data. The videos will be downloaded into a secure browser in a password-protected computer or secure Macquarie University servers. All physical copies of surveys and questionnaires will be locked in secure cabinets at Macquarie University. The data will be held for a minimum of 5 years. Anonymity will be upheld throughout reporting, and participants will only be referred to by their participant number.

CONCLUSION

This study will test a novel mixed-method approach using a digital data collection device, interviews, time-use diaries, and questionnaires to investigate the nature and extent of patient work in participants with type 2 diabetes with at least one chronic co-morbidity. Results from this study will serve to assess whether passive observation of participants via a body-worn camera, combined with self-reported activities using the Time-Use Diary, and open-ended interviews will result in more holistic and informative coverage of patient work.

Author's contributions:

Study conceptualisation: AL, EC; Study design: AL, KY, TH, JG; Data collection instrument preparation: KY, TH, AL, LL; Recruitment and liaison: KH, SV; First draft: KY, AL; Draft revision: all authors provided feedback and approved the manuscript.

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- Technical: The screenshot extraction and tagging system was developed in-house by Mr
 Wen-Jun Liang and Mr Joshua Haddrill, two work placement students from the Faculty of Engineering at Macquarie University.
- Study: Mr Joshua Jung, Ms Isabelle Barnes, Mr Jiawei He, and Mr Christian Tran (work placement students from Macquarie University) assisted with participant recruitment, home visits, and administrative tasks.

- Participant recruitment: Professor Bernard Tuch and Dr Priscilla Wong, who assisted with recruitment at the early stages of the study.
- The authors would like to thank the study participants for their valuable time and input.

Competing interests:

Some participants may be recruited via the Macquarie Health General Practitioner clinic and Macquarie Hospital, where SV is practicing as a general practitioner and KH is practicing as an endocrinologist, respectively. Therefore, the two team members may be responsible for the treatment of some participants. However, SV and KH will not know whether a patient is a participant unless the participant informs them.

Figure 1: Flow diagram illustrating the tasks involved at each stage of the study.

Figure 2: Instructions provided to participants regarding the operation of the body-worn camera.

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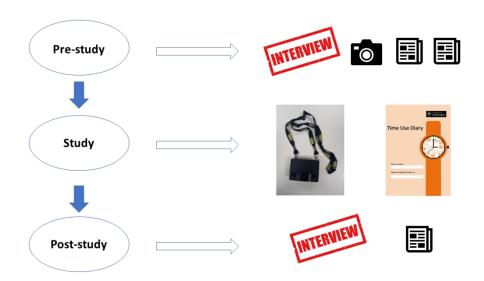


Figure 1: Flow diagram illustrating the tasks involved at each stage of the study. $108 x 60 mm \; (300 \times 300 \; DPI)$

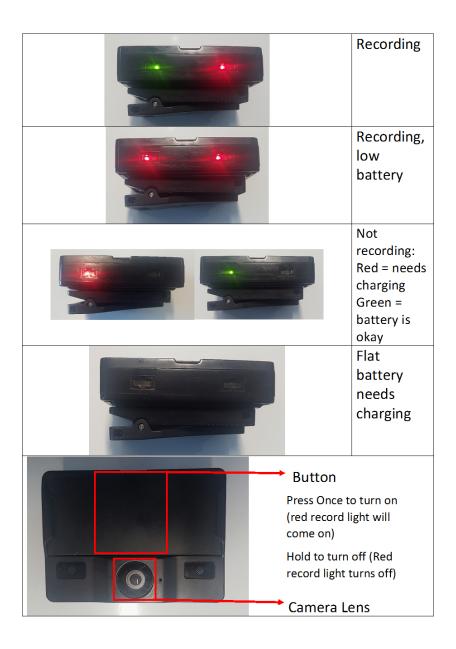


Figure 2: Instructions provided to participants regarding the operation of the body-worn camera. $77x112mm (300 \times 300 DPI)$



Information Booklet for Participants





















If you have any questions about the study, please contact

Dr Annie Lau <u>annie.lau@mq.edu.au</u> Telephone: (02) 9850 2436

Dr Kathleen Yin <u>kathleen.yin@mq.edu.au</u> Telephone: (02) 9850 2477



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 incompliance, 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.

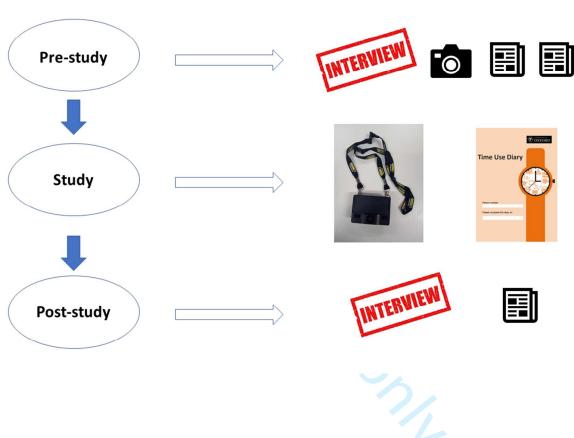
If you are in the company of others (e.g. household members, friends and/or acquaintances), we ask you to seek permission from these third parties prior to video recording.

 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 02 9850 2436)
 - Dr Kathleen Yin (kathleen.yin@mg.edu.au 02 9850 2477)
 - Dr Liliana Laranjo (liliana.laranjo@mg.edu.au 02 9850 2426)
 - Prof Enrico Coiera (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?

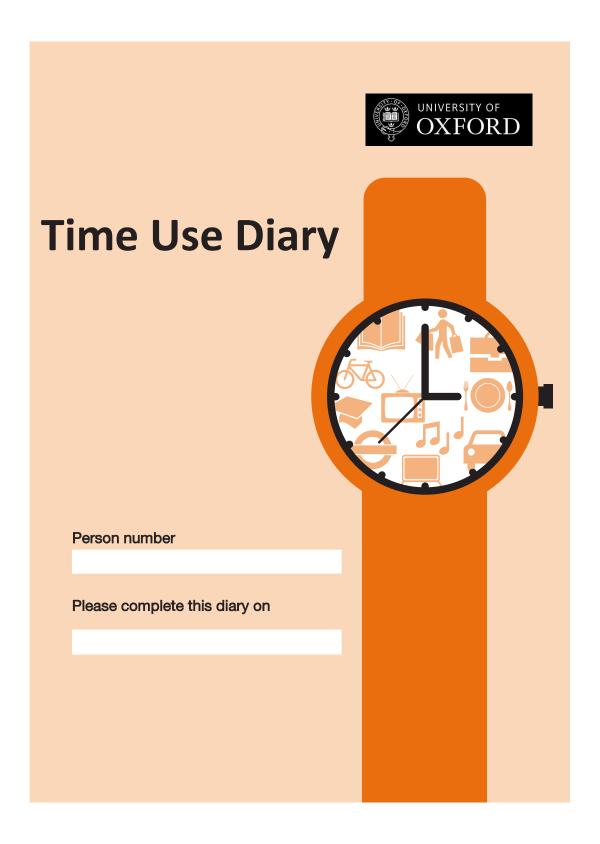
If you decide that you do not want to take part in the study, we thank you for taking the time to consider it.

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.

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 02 9850 2436) or Kathleen Yin (kathleen.yin@mq.edu.au 02 9850 2477).



Diary instructions

Please read the instructions below to help you fill in your diary. There is also an example of a filled in diary on the next page to help you.

When should I fill in the diary?

- The front of the diary tells you which day we would like you to complete the diary for.
- The diary starts at 4am and covers 24 hours, with three hours on each page
- Please take the diary with you during the day and fill it in every now and then when you have a spare moment. For example on the bus or train, at lunchtime or while you wait for someone

Completing the diary

What were you doing?

- In this column, record what you consider to be your main activity for each 10 minute period.
- If you were doing more than one activity at the same time, only record the main activity in this column.
- If you did one thing after another during the 10 minutes, record the activity that took the most time.
- If you were doing something you feel is too private to record, please write "personal".

- You don't need to record exactly what you were doing during work time.
- Please record what you did during breaks. For example, "Lunch break, had lunch" or "Lunch break, • If you have more than one job, please record which one you were working at.
- Include any work you've taken home and completed at home

School / college

- Please record whether you study at home or attend classes / lectures.
 - Include the type of study, such as secondary school, university etc.
 If the studies are part of paid work, please note this in the diary.

Housework and childcare

 Please record what you were really doing. For example, "Cooked supper", "Washed the dishes", "Put ny child to bed", "Mowed the lawn", "Cleaned the house", "Washed the car"

Sleeping

Please record any occasions during the night when you weren't sleeping. For example, if you have woken up and are doing nothing, reading or caring for children etc.

- If you were reading, please record what you read. For example, "Read a newspaper", "Read a magazine", "Read a book
- If you were reading on a tablet or e-reader such as a Kindle, please remember to fill in the 'Did you use a smartphone, tablet or computer?' column.

Help to other households

- If you were helping someone who lives outside of your household, either totally or in part, please report
- For example, if you helped a friend repair their house, record this as "Helped friend repairing house". If you bought a neighbour some food while you did your own shopping, please record this too.

f you did something else at the same time, what else did you do?

- You should use this column to record any activities that you were doing at the same time as your main activity. These are called secondary activities.
- For example, if you were looking after your child (main activity) and watching television at the same time, then you would record "watching television" in this column
- . Don't forget to record secondary activities during lunch or coffee breaks during work or while travelling. It is up to you which activity you think is the main activity and which is the secondary activity

Did you use a smartphone, tablet or computer?

- Please record in this column whether you were using a smartphone, tablet or computer while you were doing either the main or secondary activity and how long you were using it for. For example, if you were travelling to town on the bus and were checking emails on your smartphone then record how long you
- Draw a line or arrow to indicate how long you spent using your smartphone, tablet or computer.

Where were you?

 This column is to record where you were during the activity and if you were travelling, what your mode of transport was. For example, "at home", "at work", "by car"

Were you alone or with somebody you know?

- Please indicate whether you were alone or together with somebody you know.
- To be together does not necessarily mean that you actually do things together but rather that somebody else was around.
- Draw a line or arrow to show how long you were alone or with somebody you know. This may change during an activity. For example, somebody might leave or arrive.
- 'Children aged 0-7'. If you were with a child aged older than 7 years who lives with you then record this in the • If you were with a child aged 7 years or younger who lives with you, record this in the column Other person' column.
 - If you were with a relative that doesn't live with you, record this in the 'Others you know' column.

How much did you enjoy this time?

- Please write in how much you enjoyed the time on a scale of 1 to 7, with 1 meaning you didn't enjoy it at all and 7 meaning that you enjoyed it very much.
 - Your level of enjoyment may change during an activity. If so, please record the new level of enjoyment

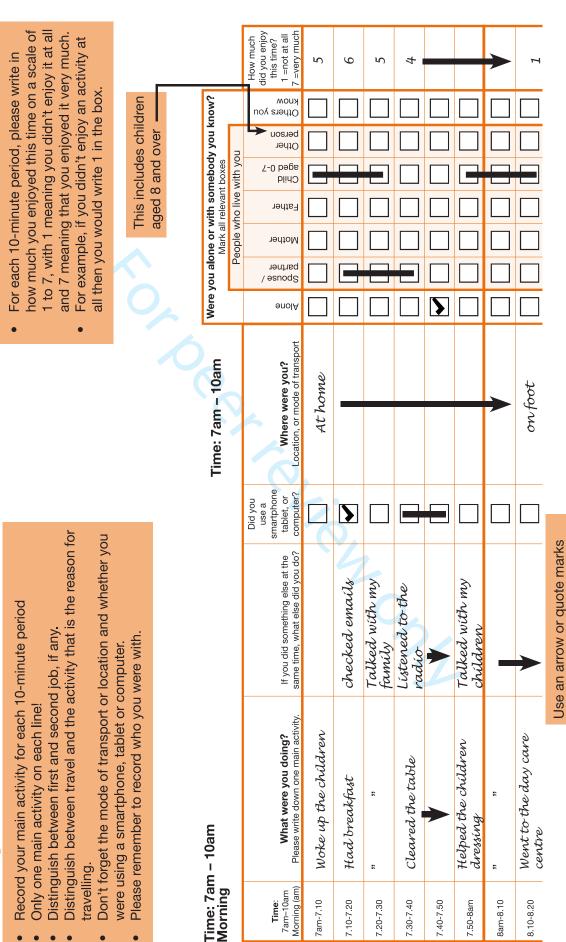
Checklist

- When you have finished filling in your diary, please answer the checklist questions at the end of the
- There is also a checklist to remind you of the key things to remember to record.

Example

•

Don't forget the mode of transport or location and whether you



to record that an activity lasted

longer than 10 minutes.

Time: 4am – 7am	n – 7am			Time: 4am – 7am	Were	Were you alone or with somebody you know? Mark all relevant boxes	ne or w Mark all	ne or with somebod Mark all relevant boxes	ebody y	you kn	ow?	
Early mo	rning					Pe	sople wh	People who live with you	ith you			
Time : 4am-7am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Derson Orner	√ . σ Know Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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6.50-7am									П			

Time: 7am - 10am	1 – 10am			Time: 7am - 10am	Were	you alo	ne or with somebod Mark all relevant boxes	ith son relevant	Were you alone or with somebody you know? Mark all relevant boxes	you kn	ow?	
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Time : 7am-10am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Derson Other	Kuow Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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Time: 10a	Time: 10am – 1pm			Time: 10am - 1pm	Were	you alo	ne or with somebod Mark all relevant boxes	ith son	Were you alone or with somebody you know? Mark all relevant boxes	you kn	ow?	
Late morr	ning / early afternoon					Ğ	People who live with you	no live v	vith you			
Time: 10am-1pm Morning / Afternoon (am/pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child	Derson Other	Kuow Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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Time: 1pm - 4pm	n - 4pm			Time: 1pm - 4pm	Were	you alc	one or with somebod Mark all relevant boxes	rith son relevant	Were you alone or with somebody you know? Mark all relevant boxes	you kn	ow?	
Afternoon						ď	eople w	no live ≀	People who live with you			
Time : 1pm–4pm Afternoon (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Derson Other	know Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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Time: 4pn	Time: 4pm – 7pm			Time: 4pm – 7pm	Were)	/ou aloi	ne or with somebod Mark all relevant boxes	ith som elevant	Were you alone or with somebody you know? Mark all relevant boxes	/ou kn	Sw?	
Late after	rnoon / early evening					Pe	People who live with you	o live w	ith you			
Time : 4pm-7pm Afternoon / evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Otherson Other	Kuow Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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Time: 7pm – 10pm	n – 10pm			Time: 7pm – 10pm	Were)	ou alor	Je or w Jark all r	Were you alone or with somebody you know? Mark all relevant boxes	ebody Doxes	you kn	ow?	
Evening						Pe	ople wh	People who live with you	ith you			
Time : 7pm–10pm Evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bartner Spouse /	Mother	Father	Child aged 0-7	Derson	✓ → Ö: →	How much did you enjoy this time? 1 =not at all 7 =very much
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9pm-9.10												
9.10-9.20												
9.20-9.30												
9.30-9.40											П	
9.40-9.50											П	
9.50-10pm												

	edfoM	Mother Mo	Fathe	Child							

Time: 1am – 4am	n – 4am			Time: 1am - 4am	Were	you alo	Were you alone or with somebody you know? Mark all relevant boxes	ith som elevant k	ebody y	you kno	Swc	
Night						Pe	People who live with you	o live w	ith you			
Time : 1am-4am Night (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bsrtuer Sbonse /	Mother	Father	Child aged 0-7	Otherson	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
1am-1.10										П	П	
1.10-1.20									П	П		
1.20-1.30									П	П		
1.30-1.40				~					П			
1.40-1.50									П	П		
1.50-2am												
2am-2.10				* / (П	П	П	
2.10-2.20				, O.,					П	П		
2.20-2.30			Z						П			
2.30-2.40		7										
2.40-2.50		C										
2.50-3am												
3am-3.10		1										
3.10-3.20									П			
3.20-3.30												
3.30-3.40									П	П	П	
3.40-3.50										П	П	
3.50-4am											П	

Diary Checklist

- 1. Now and then during the diary day 1. When did you fill in the diary?
- 2. At the end of the diary day
- 3. The day after the diary day
- 2. Did you feel rushed this day?
- 2. No
- 1. An ordinary day 2. An unusual day

3. Was this an ordinary or

an unusual day?

- What kind of day was this day?
- 1. A workday
- 3. A day off

2. A school or college day

- 4. A sick leave day
- 5. An annual leave day
- 6. On leave for other reasons
- 7. None of the above

- Please go through the diary again and check the following:
- Please check that you have noted only one main activity on each line and that there are no empty time periods.
- Have you marked clearly your employment working hours, even if you worked at home?
- Have you recorded all travel and modes of transport?
- Have you marked the duration of secondary activities, if any?
- Please check that you have always completed the 'Were you alone or with somebody you know' column.



	Participant	Information Questi	onnaire	
			Date:	
*Email:				
Date of Birth:		Sex :		
Health conditions:	0,			
List of medications being taken:				
_		7		
_		4		
Length of time since diagnosis:			37	



	BMJ Open
	MACQUA University
1 2	What is your employment status?
3 4 5 6 7 8 9 10 11	In paid employment Full-time student Unpaid work experience Retired On parental leave Doing domestic work (homemaking, looking after the children etc.) Unpaid work experience Retired On parental leave Other (specify)
13 14 15 16	Would you like to be contacted to receive feedback on the study?
17 18 19 20	Yes No
21 22 23	Would you like to be contacted for future research?
24 25 26	Yes No No
27 28 29 30	
31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55	*Please note, <u>all</u> of the information in this questionnaire, including contact information, will only be used for research purposes and will <u>not</u> be passed on to third parties.
56 57 58 59 60	For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

The Multimorbidity Illness Perceptions Scale (MULTIPleS)

with mult	estions are about the thoughts and feelings that people iple long-term conditions sometimes experience. Please ow much you agree with each statement by circling one	Strongly Disagree		•	Strongly Agree
1	One of my conditions is more serious than the others.	0	1	2	3
2	Time spent managing my conditions has made it more difficult to carry out my usual activities.	0	1	2	3
3	I feel so overwhelmed by the treatment for one condition it is hard to manage any others.	0	1	2	3
4	The causes of my conditions are linked.	0	1	2	3
5	It is difficult to take all my medications the way I am supposed to.	0	1	2	3
6	Time spent managing my condition has limited my activities.	0	1	2	3
7	One of my conditions is more worrying than the others.	0	1	2	3
8	Taking different medications for each of my conditions has caused me problems.	0	1	2	3
9	I don't like mixing medications for different conditions.	0	1	2	3
10	Having more than one condition makes my treatments less effective.	0	1	2	3
11	One of my conditions has caused another.	0	1	2	3
12	One of my conditions dominates the others.	0	1	2	3
13	My conditions interact with each other.	0	1	2	3
14	Having more than one condition makes it difficult to get the best available treatment.	0	1	2	3
15	Time spent managing my conditions has reduced my social life.	0	1	2	3
16	One of my conditions has more of an impact on my life.	0	1	2	3

			ngly				ongly gree
17	Having more than one condition makes me unhappy.	0	1	2	3	4	5
18	Having more than one condition makes me more anxious.	0	1	2	3	4	5
19	Having more than one condition makes me angry or frustrated.	0	1	2	3	4	5
20	Having more than one health problem makes me feel sad.	0	1	2	3	4	5
21	Having more than one condition makes me more irritable.	0	1	2	3	4	5
22	If I feel sad or depressed, managing my conditions is a struggle.	0	1	2	3	4	5

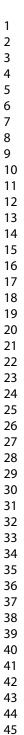


PARTICIPANT EXPERIENCE SURVEY

EDESIX BODY CAMERA

Did you experience any of the fo	llowing p	roblems v	vhile you	were
wearing the camera?				
	Never	Some- times	Often	Always
Forgetting to wear the camera				
People's reaction to me wearing				
the camera				
Discomfort wearing the camera				
Problems with the camera				
slipping/moving about				
Difficulty understanding the				
camera instructions				
Frustration with the length of				
time I had to wear the camera				
Being uncertain about whether				
the camera was turned on				

wearing the camera?	







TIME USE DIARY

Did you experience any of these problems when completing the diary?				
	Never	Some-	Often	Always
		times		
Remembering to fill in the				
diary				
Forgetting what I did during				
the day/evening				
The length of time it took to			A	
complete the diary			10x	
Completing all sections of				
the diary				() /-
Understanding the diary				
instructions				

Do you have any additional comments about your experience of
completing the time use diary?
,

PARTICIPATING IN THE STUDY

Were there any	y aspects of the study that you particularly enjoyed?
Were there any	y aspects of the study that you disliked?
How did you fir	nd the 'reconstruction interview' experience?
What motivate	d you to participate in the study?
Do you have ar	ny other comments or suggestions?

Centre for Health Informatics Australian Institute of Health Innovation Faculty of Medicine and Health Sciences MACQUARIE UNIVERSITY NSW 2109



Phone: +61 (2) 9850 2436 Email:annie.lau@mq.edu.au

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 o2 9850 2436 Kathleen annie.lau@mg.edu.au), Dr Yin (Ph kathleen.yin@mq.edu.au), Prof Enrico Coiera (Ph 02 9850 2403), Dr Liliana Laranjo (Ph o2 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 had read to me) and understand the inform I have asked were answered to my satisfaction research, knowing that I can withdraw from research at any time without consequence. I I form to keep.	. I agree to participate in this further participation in the
I consent / do not consent (<i>circle one</i>) for the identified photos and video images in publication that the persons in the images cannot be identified.	ns and presentations, provided
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 (O2) 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.

Pre-study interview questions

The pre-study interview will be conducted in the following steps:

- 1. The research team will explain the study to the participant.
- 2. The participant will read and sign the consent form.
- 3. The participant will be asked to complete a basic demographic survey (approximately 5 minutes).
- 4. The participant will be asked to complete the Multimorbidity Illness Perceptions Scale (approximately 10 minutes).
- 5. A semi-structured interview (approximately an hour) will be conducted with the participant regarding the health-related tasks they are engaged in. The interview will be audio recorded to allow for analysis.
- 6. With the participant's permission, the research team will take photographs of the participant's current medications, medical devices, and their surroundings.
- 7. The participant will be instructed to the use of the Edesix body camera and the Time-Use Diary.
- 8. The participant will also receive an instruction card to explain what the study is about if members of the public enquire about it.

Life History

Examples:

- How was your health as a child or a young person?
- How was the health of your family?
- How have your health conditions affected your job?

Social Life & Mental Health

Examples:

- Has your health ever affected your interactions with your friends?
- How do you feel about the impact (or lack of) your health had on your social life?
- Can you tell me a bit about your mental journey when you were diagnosed / started on this treatment?
- Do you feel differently towards your health conditions and meds now than you did before?

Physical Health & Medical History

Examples:

- What health conditions do you have?
- What medications do you take? And how often?
- Do you know much about your health conditions?
- Did you go research on your medications/conditions yourself?
- What kind of food do you have to watch out for due to your health?
- With your level of mobility, how do you find exercise?

Physical Environment

Examples:

- How do you find going up and down the stairs?
- Who does your cooking/laundry/gardening?

Organisational efforts & Attitude

Examples:

- Do you have domestic help? Paid or unpaid?
- Has the physical layout of your house / any other place affected your ability to take care of ? re your opinions about ye.
- What are your opinions about your medications and your doctors?

Post-study interview questions

The post-study interview will be conducted in the following steps:

- 1. The participant will return the Edesix body camera and Time-Use Diary.
- 2. Data from the body camera will be downloaded to a secure computer.
- 3. The video from the body camera will be converted into screenshots, with one screenshot taken for every 10 seconds of video footage.
- 4. After video download and screenshot conversion, the videos will be deleted, and the participant will view the screenshots alone, and has the right to delete any or all the images.
- 5. The research team will conduct a 30 40 minutes interview with the participant, where he/she will describe the study day, with the assistance of the images and the Time-Use Diary, focusing on any specific health-related activities (e.g. Cooking, exercising, social activities).
- 6. The interview will be audio recorded to allow for thematic analysis.
- 7. The researchers may also ask participants to clarify the activity in any screenshots that may appear ambiguous (e.g. ceiling images may imply napping on the sofa).
- 8. The researchers will also check that the time-stamp on the screenshots match the activities reported in the Time-Use Diary (if not, annotate the Time-Use Diary or ask participant questions for clarification).
- 9. The participates will complete the Participant Experience Survey, and give feedback regarding the study.
- 10. The participant will be remunerated with a \$60 Westfield shopping voucher for their assistance.

Questions for the semi-structured interview:

Examples

- Tell us about your day.
- Was this a typical day? If not, what was different on this day?
- What time did you start / stop filling in the Time-Use Diary?
- What time did you start / stop video recording?
- Around what time did you wake up and go to bed last night?
- How did you sleep during the study night?
- Do you always do [activity] at this time of the day?
- Is this the kinds of food you usually eat for breakfast/lunch/dinner?
- You spent a long time doing [activity] yesterday. Is this how long you usually take to do [activity]?
- Do you always do [activity] at [location]?
- Are there changes you would like to make to your daily routine?

BMJ Open

Patient Work from a Context and Time Use Perspective – A Mixed-Methods Study Protocol

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Keywords:	Patient work, Mixed-methods study, Body-worn cameras, Time-use diary, Passive data collection, Burden of disease



- 1 Patient Work from a Context and Time Use Perspective A Mixed-Methods Study
- 2 Protocol
- 3 Kathleen Yin¹, Teresa Harms^{2, 3}, Kenneth Ho⁴, Frances Rapport¹, Sanjyot Vagholkar⁴, Liliana
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21 Word count: 3951

Abstract:

2	Introduction: Self-management is widely promoted but less attention is focused on the work
3	required from patients. To date, many individuals struggle to practise self-management.
4	'Patient work', a concept that examines the 'work' involved in self-management, is an
5	approach to understanding the tasks, effort, time, and context from patient perspective. The
6	purpose of our study is to use a novel approach combining non-obstructive observations via
7	digital devices with in-depth qualitative data about health behaviours and motivations, to
8	capture the full range of patient work experienced by people with type 2 diabetes and chronic
9	co-morbidities. It aims to yield comprehensive insights about "what works" in self-
10	management, potentially extending to populations with other chronic health conditions.
11	Methods and analysis: This mixed-methods observational study involves a i) pre-study
12	interview and questionnaires, ii) a 24-hour period during which participants wear a camera
13	and complete a time-use diary, and a iii) post-study interview and study feedback. Adult
14	participants living with type 2 diabetes with at least one chronic co-morbidity will be
15	recruited using purposive sampling to obtain a balanced gender ratio and of participants using
16	insulin and those using only oral medication. Interviews will be analysed using thematic
17	analysis. Data captured by digital devices, diaries and questionnaires will be used to analyse
18	the duration, time, context, and patterns of health-related behaviours.
19	Ethics and dissemination: The study was approved by the Macquarie University Human
20	Research Ethics Committee for Medical Sciences (Reference Number 5201700718).
21	Participants will carry a wallet-sized card that explains the purpose of the study to third
22	parties, and can remove the camera at any stage. Before the post-study interview begins,
23	participants will view the camera images in private and can delete any images. Should any
24	images be used in future publications or presentations, identifying features such as human
25	faces and names will be obscured.

Strengths and limitations of this study

- This is the first study that employs a mixed-method design using passive digital observation equipment, self-report time-use diaries, complemented with interviews and questionnaires, to document patient work.
- Using the body-worn camera may diminish the observer effect caused by having
 researchers observe participants in a private setting, as well as reducing the participant
 burden of having researchers in their homes for prolonged periods of time.
- The self-report diary complements data from the passive device by creating a holistic view of patient work carried out by the participant.
- The study is limited by the 24-hour data collection period, which may not include patient work that occurs frequently, but outside the observation period.

2.

14 Keywords

Patient work; Mixed-method study; Body-worn cameras; Time-use diary; Passive data collection devices; Interviews; Burden of disease; Chronic disease; Type 2 diabetes; Chronic co-morbidity; Self-management; Patient experience; Patient; Consumer.

INTRODUCTION

Self-management is widely promoted but less attention is focused on the work required from patients. It is a constant commitment of learning new skills, breaking old habits, and managing different emotions over the length of the illness.[1] Patients and their families often need to adjust their daily routines to accommodate for their health condition, such as making time to administer medications, visit medical professionals, or prepare special meals.^[2-5] Yet, many individuals struggle to practise self-management effectively, especially for those with long-term chronic conditions.[6-8]

Past studies reported on the barriers and challenges to self-management, focusing on patients with multiple chronic conditions,[6, 7] the difficulty involved in self-management,[8] time invested,[9] competing priorities,[10, 11] support sources required,[12] and how self-management differs between the patients' and healthcare professionals' perspectives.[13] Yet, few studies reported on the actual 'work', or the tasks involved, from the patient, as well as whether self-management fits within the patient's context.

When self-management is poorly integrated into people's lives, the work required has the potential to generate additional stress, contributing to non-compliance and negatively impacting on patient health outcomes.[14, 15] Unfortunately, many health interventions are currently implemented without considering the *work* involved from patient perspective or the *context* of a patient's life. Treatment and self-management recommendations, whilst given with good will, often fail to acknowledge the specificities of a patient's daily routine, physical environment, social obligations, as well as internal beliefs and attitudes.[16-19] In parallel, digital health interventions hold the promise to improve self-management. However, numerous studies evaluating digital self-management interventions showed a high participant

1 dropout rate, with some studies having retention rates of 1% by the end of the study

period.[16, 19-21] Specifically, participants reported the devices' lack of 'fit' into their daily

3 lives as reasons for discontinuation.[22]

5 Understanding whether there is a dissonance between patients' existing routines and the work

6 involved in self-management is important to overcome barriers and challenges. The concept

7 of 'patient work', derived from health ergonomics, describes the tasks (physical and

cognitive) conducted by patients to manage their health, as well as the holistic sum of

contexts (physical, social, mental, and organisational) that influence the work conducted.[23-

10 25] It is an approach to understanding the actions people take (or not take) in self-

management. While self-management focuses on the strategies people employ, patient work

breaks down these strategies into day-to-day tasks and examines how the effort and time

involved, as well as the contextual and ergonomic factors, affect the way self-management is

practised and why some tasks are carried out while others are neglected.

16 The purpose of this study is to examine the *patient work* involved in living with multiple

chronic conditions, focusing on the daily lives of people with type 2 diabetes and chronic co-

18 morbidities.

Patient work research

21 Previous patient work research had focused on patients living with cardiovascular diseases

such as heart failure and stroke. [24-26] However, no studies have focused specifically on

people living with more than one chronic condition.

- In addition, previous patient work approaches relied heavily on self-report methods
- (interviews[27, 28]), direct observation (researchers being present continuously in
- participants' homes), or theoretical modelling (analysing macro-ergonomic elements[29,
- 30]). These data collection methods are limited by the level of reliability in self-report data
- (e.g. social desirability effect) and the degree of discomfort participants experience during
- direct observation.

- The need for direct observation by researchers also meant the duration of visits had to be
- limited, ranging from 30 minutes to 1 hour at a time, [30] making these short periods unlikely
- to capture the 'natural' routines of participants as there is high likelihood they could be
- affected by the observer effect.[31] To our knowledge, no studies have utilised digital devices
- that automatically and non-obstructively collect data on patient work over a longer
- timeframe.

Type 2 Diabetes and Other Co-morbidities

- The nature of type 2 diabetes, which impacts the entire metabolic process, means that patients
- need to carry out a variety of different activities. These may include diet modification,[32]
- weight management, [33] exercise, [34] complication prevention, [35] blood glucose tests, [36]
- and insulin injections.[26]

- Metabolically-related co-morbidities such as hyperlipidaemia, cardiovascular diseases, and
- renal disorders[37, 38] are frequently present in people living with type 2 diabetes,
- warranting the inclusion of co-morbidities to reflect the true extent of patient work. Co-
- morbidity is also frequently a criterion for exclusion in research studies, suggesting this study

1 could give rare insights into the lives of people living with type 2 diabetes, as well as a

greater understanding of self-management in patients with chronic co-morbid conditions.

AIMS

- 5 This study will investigate the patient work conducted by people living with type 2 diabetes
- and at least one chronic co-morbidity. It will address three gaps identified in the literature:
- 7 the few studies reporting the 'work' involved in self-management from patient perspective
- 8 (patient work), the methodological gap in using digital devices to collect data non-
- 9 obstructively on self-management activities and contexts over a longer time frame (24-hour
- period), and focusing on people with complex challenges to self-management (those with
- 11 multiple chronic conditions).

METHODS

- 14 This is a mixed-methods, observational study that involves three stages: i) pre-study
- interview and questionnaires, ii) a 24-hour period during which participants wear a camera
- and complete a time-use diary, and a iii) post-study session with interview and study
- 17 feedback. The project is approved by the Macquarie University Human Research Ethics
- Committee (approval 5201700718). Our study adapted the protocols used and validated by
- 19 Kelly et al., [39, 40] which were employed in research projects conducted by the Centre for
- 20 Time Use Research (CTUR) and the British Heart Foundation Centre on Population
- 21 Approaches for Non-Communicable Disease Prevention, both at The University of Oxford.

Sample and recruitment

- Eligible participants are: (1) aged 18 years and older; (2) consenting adults who can speak,
- 25 write and read in English; (3) have been diagnosed with type 2 diabetes and at least one

chronic co-morbidity; (4) willing to complete a time-use diary for one day; and (5) agree to wear the body-worn camera for one day. Exclusion criteria include those who are currently experiencing: (1) pregnancy; (2) critical illness; (3) end-stage disease; (4) dementia; (5) severe mental disorders that prevent one from giving informed consent and; (6) dependent on others for basic activities of daily living such as dressing and eating. Participants will receive \$60 in Australian Dollars of shopping vouchers as remuneration. To capture patients at various stages of diabetes, forty (40) participants will be recruited, with balanced gender ratio, and balanced numbers of participants using only oral medication and those using insulin. The number of participants chosen was informed by previous qualitative studies in patient work. [27, 28] This sample size offers the power to achieve rich and nuanced data, while acknowledging the different time intervals between data points for each data capture tool. [24, 27, 28] Previous patient work studies analysed 60-80 hours of interviews or direct observations per study. [27, 28] This study will capture approximately 2 hours of interview data and approximately 5000 images per participant. Therefore, a sample size of 40 participants is comparable to the depth of data captured by previous studies. Recruitment will be carried out via Macquarie University general practice and general practitioners and endocrinologists in the surrounding suburbs. These medical practitioners manage a large and diverse patient base across northern Sydney and cover a wide range of culturally and economically diverse population groups. Promotional flyers will be distributed to the participating medical practices and includes

general study information and a link to the study website, where potential participants can check the eligibility criteria (www.tinyurl.com/patientswork). The study will also be

promoted on the Macquarie University Facebook page and via an emailed newsletter
 associated with the University. Healthcare practitioners will not be notified if their patients

agreed to participate in the study to reduce the possibility of coercion.

5 Databases of medical practices involved in recruitment will be searched to identify eligible

6 patients for the study. Only personnel employed by the medical practices will conduct these

searches. Participating healthcare practitioners will also send invitation letters to eligible

8 patients, with a pre-paid reply slip included. Patients interested in participating will be asked

to return the reply slip with their contact details, so a member of the research team can

10 contact them.

consent before data collection commences.

Telephone calls will also made to eligible patients to inform them about the study. If during the initial phone call the potential participant agrees to consider participating, the researcher will send a detailed email to the participant with a digital version of the information pamphlet as well as a link to the study website. The potential participant then either agrees to participate or declines. If the potential participant agrees to participate, the researcher will arrange a suitable time for interviews to occur. All participants will provide written informed

Initial contact for all participants will be a telephone call conducted by the research team, to check whether the participant fits the eligibility criteria, assure confidentiality and anonymity during data-collection, and address any questions. This approach will minimise participant contact with the research team and clinicians. While self-nominated participants may be subject to participation bias, high completion rates and compliance are likely.

Patient and Public Involvement

- 2 The concept study was conceived during a 1-day Consumer Symposium conducted at
- 3 Macquarie University, where 10 health consumers gave feedback and critique regarding
- 4 health research.

- 6 Health Consumers New South Wales, a patient advocacy group, was then consulted
- 7 regarding consumer engagement and advice was given to the researchers regarding consumer
- 8 involvement during study conception, recruitment, analysis to dissemination.

- 10 A pilot trial of the protocols with the equipment was conducted with two patients. Summaries
- of the findings were presented to the participants.

- During study conception, the researchers also engaged with Healthdirect, a national
- organization providing digital health information for health consumers, and the Northern
- 15 Sydney Primary Health network and local GP network, which has a consumer council.

- 17 Results will be disseminated to these bodies, which will have broader implications to policies
- directed to consumers. Publications arising from the study will also be forwarded to each
- 19 participant via emails.

Data collection instruments and equipment

- The study will be carried out in three stages as described in Figure 1 and Table 1. Utilising
- 23 multiple types of data, the study generates a holistic report of patient work conducted by
- people living with type 2 diabetes and chronic co-morbidities in terms of observed physical

work, organisational efforts, burden of disease, and attitudes and beliefs underlying health
 behaviours.

Table 1. Data collected at different stages during the study

Pre-study	Data collection (24-hour)	Post-study
 Interview (1-hour) Participant demographics questionnaire Multimorbidity Illness Perceptions Scale[41] Photos of participant's home (where appropriate) 	 Body-worn camera Time-use diary (Appendix 1) 	 Reconstruction interview (30-40 minutes) Participant experience questionnaire Researcher's notes

- 6 The following instruments and equipment will be used for data collection.
 - Time-use diary The self-report time-use dairy is a validated tool[39] and the version used in this study is the Harmonised European Time Use Diary[42] (UK version). For details of the time-use diary, please see Appendix 2. This method of using free-text time-use diaries to self-report activities has high statistical validity and good acceptance rates with volunteer participants (ranging from 56% to 100%[39, 43]).
 - Photos With permission from the participant, photos of their medications, medical devices, and home surroundings will be taken to inform about the participant's physical environment. Should the participant reside in an environment that can affect their healthcare (e.g. a house with stairs and a risk for falls), these issues will be taken into consideration. Participants will be alerted should an immediate and significant risk be identified.
 - Body-worn camera The body-worn camera (Edesix VB-300, Edinburgh) will
 automatically record silent continuous video footage. It can be attached to clothing
 and/or worn on a lanyard. Previous studies with body-worn cameras showed high

degrees of acceptability, with acceptance rates ranging from 70% to 100%[39, 43, 44], especially when participants are reassured they can remove the camera if they

feel the recording may intrude upon their privacy[39, 43].

- Demographic questionnaire The demographic questionnaire (Appendix 3) will be administered during the pre-study session and takes about 10 minutes to complete.
- The Multimorbidity Illness Perceptions Scale The Multimorbidity Illness Perceptions Scale [41] (Appendix 4) is validated statistically and was developed to capture the perception of patients with co-morbidities about their health.[41] Illness perception is known to affect and predict health-related behaviour, to the extent that patients who perceive their diseases as more controllable are more likely to engage in adaptive strategies [45], thus directly affecting the patient work they engage in. The Scale will be administered during the pre-study session and takes approximately 5 minutes to complete.
- Participant experience questionnaire A participant experience questionnaire (Appendix 5) will be administered during the post-study session. This is estimated to take approximately 10 minutes.
- Researcher notes: a summary of each participant will be written up within a week after the post-study session, summarising the researcher's observations of the participant, home context, and any feedback from the participant at different stages of the study.

Stage 1: Pre-study session

- Prior to the pre-study session, participants will be provided with the Participant Information
- Booklet (Appendix 1) and will sign a written informed consent form (Appendix 6) before

data is collected. Participants have the right to decline at this stage and to retract consent at

2 any time throughout the study.

4 Ideally, the pre-study interview will occur in the participant's home for researchers to note

5 ergonomic factors. To ensure researcher safety, two researchers will make the home visits.

Participants may come to Macquarie University for the interview if they prefer.

8 Following consent and before the pre-study interview, participants will also be asked to

complete the demographic questionnaire (Appendix 3) and the Multimorbidity Illness

10 Perceptions Scale[41] (Appendix 4).

12 Pre-study interview

13 After the completion of the questionnaires, a semi-structured interview will be conducted to

gain information about the participant's life history, medical history, and existing factors that

impact patient work. Participants will be invited to talk about their health and lifestyle, with

areas of focus separated into life history, social life and mental health, physical health and

medical history, physical environment, and organisational effort and attitude (Appendix 7).

18 With the participant's permission, the interview will be audio-recorded to assist with data

coding and thematic analysis (e.g. daily activities, rationales behind behaviours, and factors

that influence why participants behave in certain manners).

22 Lastly, participant will be provided with a body-worn camera and the Harmonised European

Time Use Surveys UK Time-Use Diary (Appendix 2),[42] together with relevant instructions.

24 Photographs of the participant's medications, medical devices and home environment will

also be taken at this stage.

2	Stage 2: Participant self-recording data collection

- 3 During the 24-hour study period, participants will be asked to wear the camera around their
- 4 neck on a lanyard during waking hours (12-16 hours). The time-use diary will be completed
- 5 by the participant over the course of the same day for 24 hours. Participants will be given
- 6 instructions (Figure 2) to re-charge the camera overnight or if the battery becomes low.

8 Stage 3: Post-study session

- 9 A post-study session will occur immediately after the 24-hour study period has concluded.
- 10 The camera footage will be downloaded and converted into images using software developed
- in-house, with one screenshot taken for every 10 seconds of footage. The participants will be
- able to view all the images alone before the research team views them, allowing the
- participant to delete any or all unwanted images.
- *Post-study 'reconstruction' interview*
- The participant will be interviewed for approximately 30-40 minutes after data collection
- 17 (Appendix 8). Participants will be asked to describe the study day, using the screenshots and
- time-use diary as prompts, with a focus on health-related tasks. The interview will be audio
- recorded with the participant's permission to allow for thematic analysis of transcripts.
- 21 After the interview, the participant will be asked to complete the Participant Experience
- 22 Questionnaire (Appendix 5) and provide feedback on the methodology.
- 24 DATA ANALYSIS

1 Both qualitative and quantitative data will be gathered and analysed. The varied data sources

are complementary and focus on different aspects of patient work. For example, self-reported

data regarding daily tasks via the time-use diary can be enriched through an examination of

4 the screenshots from the camera.

Quantitative data analysis

- 7 Video recordings from the body-worn camera will be automatically converted into series of
- 8 10-second screenshots, which are then processed for analysis of daily activities (e.g. eating,
- 9 sleeping). These screenshots will be tagged using the TensorFlow[46] and/or ClarifaiTM (New
- 10 York, USA) Application Programming Interface, which automatically generate tags that
- identify objects and describe content within the image (e.g. a lady and a car). A subset of
- these tags will be manually verified for accuracy.

- 14 Time-use diary data will be analysed in conjunction with camera screenshots. Participants'
- activities reported in the time-use diary and observed via screenshots will be coded using an
- adapted version of the Harmonised European Time Use Surveys activity frame [47], and
- assessed for the duration, frequency, timing and patterns.

- 19 Questionnaire data (participant demographics, study feedback, and the Multimorbidity Illness
- 20 Perceptions Scale) will be reported using descriptive and inferential statistics. All statistical
- analyses will be conducted using SPSS® (IBM, New York, USA).

Qualitative Data Analysis

- Both pre-study and post-study interviews will be transcribed verbatim. Analysis of the
- 25 interview transcripts will be conducted using the NVivo® thematic analysis software package

- 1 (NVivo, Melbourne, Australia).[48] Two members of the research team will independently
- 2 code the transcripts in a systematic manner. Any coding discrepancies between the two will
- 3 be resolved through reaching a consensus.

- 5 Photographs of the participant's medications, medical devices, and home environment and
- 6 camera screenshots will provide context to the interview. The photographs will also be used
- 7 to give contextual feedback regarding the participant's daily activities, as revealed in the
- 8 video recordings and time-use diaries. Notes taken by researchers after the post-study
- 9 interview for each participant will be used to help with photo and qualitative data analysis.

ETHICS AND INFORMATION DISSIMATION

12 Ethical considerations arising from this study are addressed below.

Consent and freedom to withdraw

- 15 Participants' questions or concerns will be addressed individually and with all due diligence.
- Participants will be free to withdraw from the study at any point and can remove the camera
- at any time during the study day without giving a reason. The decision to join the study will
- have no consequence on their relationship with either Macquarie University or their health
- 19 professionals.

Third-party and bystander consent

- 22 The research team will provide participants with a wallet-sized card that includes the
- 23 statement below with contact information of the research team, which can be shown to others
- 24 (to reduce the psychological burden of the participant) should anyone approach the
- 25 participants to ask about the camera.

2 "I am volunteering for a research project. The device is a wearable camera and the images

3 will be used to record my daily activities. I am happy to remove it if you would like me to."

5 Should anyone request video recordings to be deleted, we ask participants to take note of the

time that requests were made, and to assure the enquirer that the related recordings will be

7 removed at the post-study session. Participants are also asked to inform their household

members, friends, and acquaintances about the study, and to seek permission from these

9 parties prior to recording.

11 Personal privacy

Participants will be asked to keep the body-worn camera off during situations when anyone
(including themselves) is dressing, undressing, using the bathroom, showering, or during any
situations where privacy is of concern. Participants will be advised that they should always

prioritise their own personal safety and comfort above the study's requirements.

Furthermore, participants will be able to view and delete any (or all) of the extracted images before researchers view the images or videos at the start of the post-study session. The videos will be deleted immediately after screenshots are extracted. Only members of the research team will have access to the screenshots. None of the video or screenshots will be released to the public, academic peers, or participants. Should participants provide written informed consent for the research team to use their images in publications or presentations, the images

will be blurred such that no one is identifiable.

1 '	To ensure the participant	's privacy, names and	l other identifying in	formation will be removed

in the photos of medications.

Participant feedback

- 5 Participants will be asked about their experiences in the study during the post-study
- 6 interview. A questionnaire to assess the participant's experience (Appendix 5) will also be
- 7 administered. Participants will be provided with contact details of the research team (email
- 8 and phone number) for contact during the study.

Psychological support

- In the unlikely case that participants become psychologically distressed during either of the
- interview sessions, a staff member with counselling experience will be present in both
- interviews to deal with any anxiety the participant may experience. Should participants
- 14 experience high levels of distress during the study day, they are advised that they should
- 15 immediately attend their local hospital emergency department, general practitioner, and/or
- 16 call Lifeline or Emergency Services.

Participant Identification

- 19 Participant identities will not be masked during data collection. Participants will be
- 20 individually identifiable due to the small sample size. However, their identities will only be
- 21 known to the research team, and only members of the research team will have access to
- 22 identifiable data. Data will be separated from contact details and stored in separate locations.
- 23 No identifying information about the participant will be published or presented.

Information dissemination

1 Great caution will be taken in the handling and storage of the data by the research team so

that risks to privacy are minimised, in accordance with the Australian Code for the

3 Responsible Conduct of Research. Only members of the research team will have access to the

data. The videos will be downloaded into a secure browser in a password-protected computer

or Macquarie University servers. All physical copies of surveys and questionnaires will be

6 locked in secure cabinets at Macquarie University. The data will be held for a minimum of 5

7 years. Anonymity will be upheld throughout reporting, and participants will only be referred

8 to by their participant number.

10 DISCUSSION

At the time of writing, the study had engaged 40 potential participants and 23 participants

completed the study, more than half of the number of participants the study aims for.

14 The reasons some potential participants did not take part in the study included: declined

consent due to personal reasons (which the participate did not disclose), unable to

16 communicate in English to a sufficient standard (as judged by the researcher during the initial

phone call), too busy with work, too busy due to full-time care of family members, going on

a holiday, was sick on the scheduled visit and withdrew from the study, was not home when

the researchers visited and withdrew from the study. No participant who completed the study

had withdrawn their consent to date.

22 Completion rates for the time-use diary is very high, with 21 out of 23 participants

23 successfully filling the diary throughout the study day. The two participants who did not fill

in the diary did so during the post-study interview, with the assistance of recorded footage.

- 1 All participants complied to continuous camera recording. There was a variation of camera
- 2 recording time between participants, due to some participants turning the camera off for some
- 3 periods of time out of privacy concerns.

- 5 One challenge the study had faced was communicating camera operations effectively to the
- 6 participants. Some participants had difficulty turning off the camera and charging the camera
- 7 battery due to reasons such as forgetfulness and confusion regarding the orientation of the
- 8 camera buttons. To address the issue, the research team had devoted more time during the
- 9 pre-study interview to physically demonstrate how to use the camera, which had successfully
- improved participant understanding of camera operations.

12 CONCLUSION

- 13 This study will test a novel mixed-method approach using a digital data collection device,
- 14 interviews, time-use diaries, and questionnaires to investigate the nature and extent of patient
- work in participants with type 2 diabetes and chronic co-morbidity. Results from this study
- will serve to assess whether passive observation of participants via a body-worn camera,
- combined with self-reported activities using the time-use diary, and semi-structed interviews
- will result in more holistic and informative coverage of patient work.

Author's contributions:

- 21 Study conceptualisation: AL, EC; Study design: AL, KY, TH, JG; Data collection
- preparation and analysis plan: KY, TH, AL, LL, FP; Recruitment and liaison: KH, SV; First
- 23 draft: KY, AL; Draft revision: all authors provided feedback and approved the manuscript.

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3 Competing interests:

- 4 Some participants may be recruited via the Macquarie Health General Practitioner clinic and
- 5 Macquarie Hospital, where SV is practicing as a general practitioner and KH is practicing as
- 6 an endocrinologist, respectively. Therefore, the two team members may be responsible for
- 7 the treatment of some participants. However, SV and KH will not know whether a patient is a
- 8 participant unless the participant informs them.
- Figure 1: Flow diagram illustrating the tasks involved at each stage of the study.
- 11 Figure 2: Instructions provided to participants regarding the operation of the body-worn
- 12 camera.

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Total Contract of the contract

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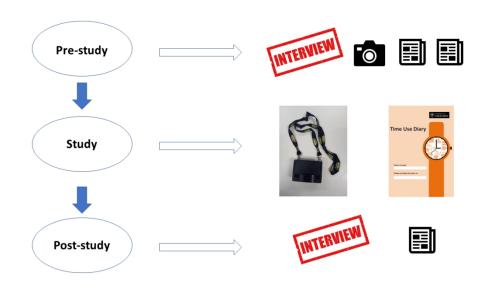


Figure 1: Flow diagram illustrating the tasks involved at each stage of the study. $108 x 60 mm \; (300 \times 300 \; DPI)$

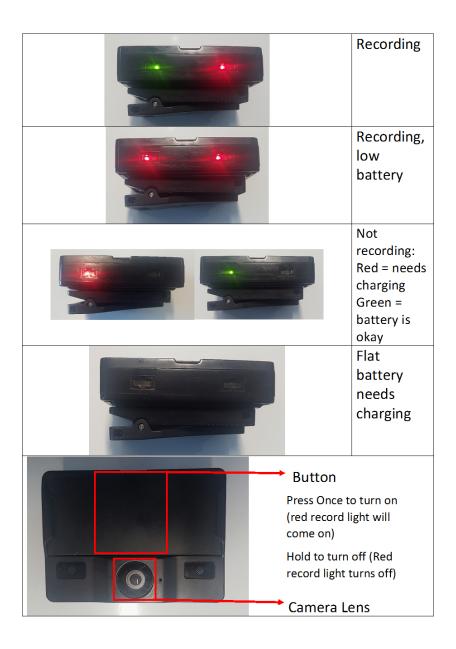


Figure 2: Instructions provided to participants regarding the operation of the body-worn camera. $77x112\text{mm} \; (300 \times 300 \; \text{DPI})$



Information Booklet for Participants





















If you have any questions about the study, please contact

Dr Annie Lau <u>annie.lau@mq.edu.au</u> Telephone: (02) 9850 2436

Dr Kathleen Yin kathleen.yin@mq.edu.au
Telephone: (02) 9850 2477



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 incompliance, 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.

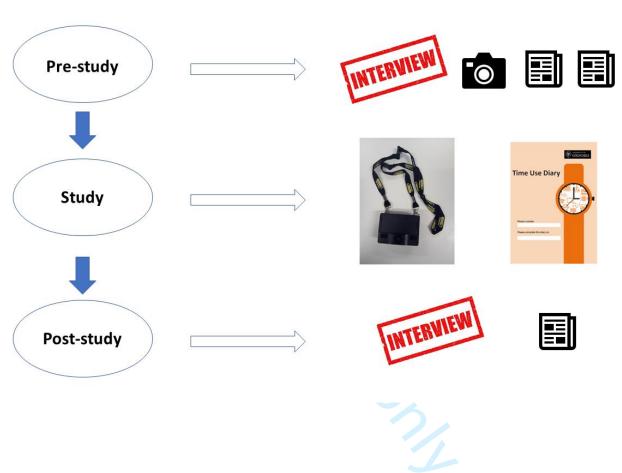
If you are in the company of others (e.g. household members, friends and/or acquaintances), we ask you to seek permission from these third parties prior to video recording.

 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@mg.edu.au 02 9850 2436)
 - Dr Kathleen Yin (kathleen.yin@mq.edu.au 02 9850 2477)
 - Dr Liliana Laranjo (liliana.laranjo@mq.edu.au 02 9850 2426)
 - Prof Enrico Coiera (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?

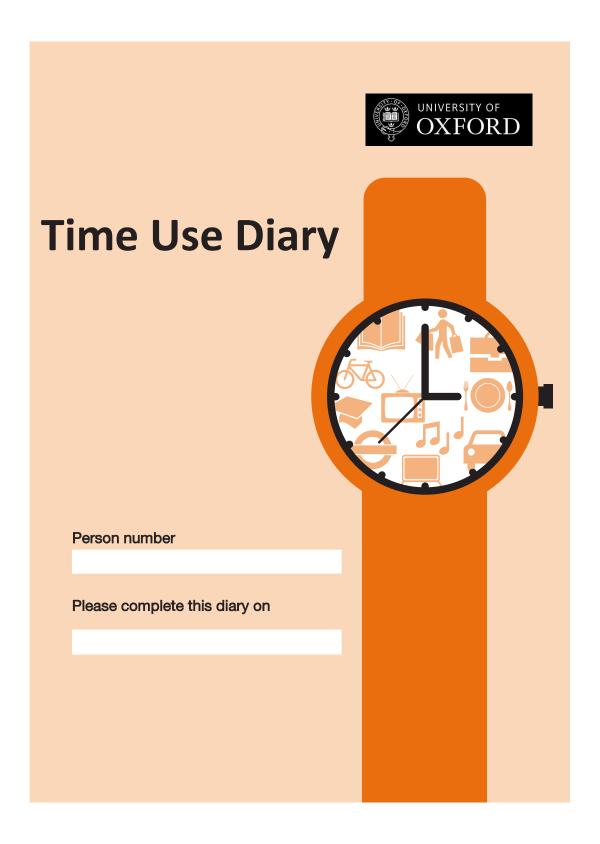
If you decide that you do not want to take part in the study, we thank you for taking the time to consider it.

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.

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 02 9850 2436) or Kathleen Yin (kathleen.yin@mq.edu.au 02 9850 2477).



Diary instructions

Please read the instructions below to help you fill in your diary. There is also an example of a filled in diary on the next page to help you.

When should I fill in the diary?

- The front of the diary tells you which day we would like you to complete the diary for.
- The diary starts at 4am and covers 24 hours, with three hours on each page
- Please take the diary with you during the day and fill it in every now and then when you have a spare moment. For example on the bus or train, at lunchtime or while you wait for someone

Completing the diary

What were you doing?

- In this column, record what you consider to be your main activity for each 10 minute period.
- If you were doing more than one activity at the same time, only record the main activity in this column.
 - If you did one thing after another during the 10 minutes, record the activity that took the most time.
- If you were doing something you feel is too private to record, please write "personal".

- You don't need to record exactly what you were doing during work time.
- If you have more than one job, please record which one you were working at.
- Please record what you did during breaks. For example, "Lunch break, had lunch" or "Lunch break,
- Include any work you've taken home and completed at home

School / college

- Please record whether you study at home or attend classes / lectures.
 - Include the type of study, such as secondary school, university etc.
 If the studies are part of paid work, please note this in the diary.

Housework and childcare

 Please record what you were really doing. For example, "Cooked supper", "Washed the dishes", "Put ny child to bed", "Mowed the lawn", "Cleaned the house", "Washed the car"

Sleeping

Please record any occasions during the night when you weren't sleeping. For example, if you have woken up and are doing nothing, reading or caring for children etc.

- If you were reading, please record what you read. For example, "Read a newspaper", "Read a magazine", "Read a book
- If you were reading on a tablet or e-reader such as a Kindle, please remember to fill in the 'Did you use a smartphone, tablet or computer?' column.

Help to other households

- If you were helping someone who lives outside of your household, either totally or in part, please report
- For example, if you helped a friend repair their house, record this as "Helped friend repairing house". If you bought a neighbour some food while you did your own shopping, please record this too.

f you did something else at the same time, what else did you do?

- You should use this column to record any activities that you were doing at the same time as your main activity. These are called secondary activities.
 - For example, if you were looking after your child (main activity) and watching television at the same time, then you would record "watching television" in this column
- . Don't forget to record secondary activities during lunch or coffee breaks during work or while travelling. It is up to you which activity you think is the main activity and which is the secondary activity

Did you use a smartphone, tablet or computer?

- Please record in this column whether you were using a smartphone, tablet or computer while you were doing either the main or secondary activity and how long you were using it for. For example, if you were travelling to town on the bus and were checking emails on your smartphone then record how long you
- Draw a line or arrow to indicate how long you spent using your smartphone, tablet or computer.

Where were you?

 This column is to record where you were during the activity and if you were travelling, what your mode of transport was. For example, "at home", "at work", "by car'

Were you alone or with somebody you know?

- Please indicate whether you were alone or together with somebody you know.
- To be together does not necessarily mean that you actually do things together but rather that somebody else was around.
- Draw a line or arrow to show how long you were alone or with somebody you know. This may change during an activity. For example, somebody might leave or arrive.
- 'Children aged 0-7'. If you were with a child aged older than 7 years who lives with you then record this in the • If you were with a child aged 7 years or younger who lives with you, record this in the column Other person' column.
 - If you were with a relative that doesn't live with you, record this in the 'Others you know' column.

How much did you enjoy this time?

- Please write in how much you enjoyed the time on a scale of 1 to 7, with 1 meaning you didn't enjoy it at all and 7 meaning that you enjoyed it very much.
 - Your level of enjoyment may change during an activity. If so, please record the new level of enjoyment

Checklist

- When you have finished filling in your diary, please answer the checklist questions at the end of the
- There is also a checklist to remind you of the key things to remember to record.

Example

•

how much you enjoyed this time on a scale of 1 to 7, with 1 meaning you didn't enjoy it at all and 7 meaning that you enjoyed it very much. did you enjoy 1 =not at all =very much For example, if you didn't enjoy an activity at How much this time? For each 10-minute period, please write in 5 9 5 4 all then you would write 1 in the box. Were you alone or with somebody you know? киом This includes children Ofhers you aged 8 and over berson Other People who live with you Mark all relevant boxes aged 0-7 Child Esther Mother bartner / əsnodS ənolA • Location, or mode of transpor Time: 7am - 10am Where were you? Athome onfoot smartphone computer? tablet, or Did you use a **** Distinguish between travel and the activity that is the reason for Don't forget the mode of transport or location and whether you If you did something else at the same time, what else did you do? checked emails Talked with my Talked with my Listened to the Record your main activity for each 10-minute period children Distinguish between first and second job, if any Please remember to record who you were with were using a smartphone, tablet or computer. famíly Only one main activity on each line! Please write down one main activity. Woke up the children Went to the day care What were you doing? Helped the children Cleared the table Had breakfast 33 dressing Time: 7am - 10am centre travelling. . Morning Morning (am) 7am-10am Time: 7am-7.10 7.30-7.40 8am-8.10 8.10-8.20 7.10-7.20 7.20-7.30 .40-7.50 7.50-8am

to record that an activity lasted Use an arrow or quote marks longer than 10 minutes.

Time: 4am – 7am	n – 7am			Time: 4am – 7am	Were	Were you alone or with somebody you know? Mark all relevant boxes	ne or w Mark all	ne or with somebod Mark all relevant boxes	ebody y	you kn	ow?	
Early mo	rning					Pe	sople wh	People who live with you	ith you			
Time : 4am-7am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Derson Orner	√ . σ Know Others you	How much did you enjoy this time? 1 =not at all 7 =very much
4am-4.10										$\overline{\Box}$	П	
4.10-4.20									П	П	П	
4.20-4.30									П	П		
4.30-4.40				/						П		
4.40-4.50									П	П		
4.50-5am											П	
5am-5.10				<u> </u>					П	П	П	
5.10-5.20				, O.					П	$\overline{\sqcap}$	П	
5.20-5.30									П	П		
5.30-5.40		7							П	П		
5.40-5.50		Ç							П	П		
5.50-6am									П			
6am-6.10									П	$\overline{\Box}$	П	
6.10-6.20									П			
6.20-6.30												
6.30-6.40										П		
6.40-6.50												
6.50-7am									П			

Time: 7am – 10am	n – 10am			Time: 7am - 10am	Were)	Were you alone or with somebody you know? Mark all relevant boxes	e or wil 1ark all re	ne or with somebod Mark all relevant boxes	sbody ye	on knov	<i>ç</i> .	
Morning						Pec	phe who	People who live with you	th you			
Time : 7am-10am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	partner Spouse /	Mother	Eather	aged 0-7 Other	Ofpers you	How much did you enjoy this time? T = not at all E = 7 = very much	much Lenjoy Ime? t at all
7am-7.10												
7.10-7.20									П			
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Time: 10a	Time: 10am – 1pm			Time: 10am - 1pm	Were	Were you alone or with somebody you know? Mark all relevant boxes	ne or with somebod Mark all relevant boxes	th some	ebody y	on knov	6.
Late morn	ning / early afternoon					Pe	People who live with you	o live w	th you		
Time: 10am-1pm Morning / Afternoon (am/pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7 Other	Ofpers you	How much did you enjoy this time? 1 =not at all T =very much
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10.30-10.40											
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12.50-1pm											

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Afternoon						ď	eople w	no live ≀	People who live with you			
Time : 1pm–4pm Afternoon (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Derson Other	know Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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3pm-3.10		1									П	
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3.50-4pm											П	

Time: 4pn	Time: 4pm – 7pm			Time: 4pm – 7pm	Were)	on alo	Were you alone or with somebody you know? Mark all relevant boxes	ith som	ebody boxes	you kr	9wor	
Late after	rnoon / early evening					Pe	People who live with you	no live w	/ith you			
Time: 4pm-7pm Afternoon / evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Ofher Derson	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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6.50-7pm												

Time: 7pm – 10pm	n – 10pm			Time: 7pm – 10pm	Were)	/ou alor	Were you alone or with somebody you know? Mark all relevant boxes	th some	ebody you	you kno	ow?	
Evening						Pe	People who live with you	o live wi	ith you			
Time : 7pm-10pm Evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child	Other Derson	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
7pm-7.10										П	П	
7.10-7.20									П	П		
7.20-7.30								П	П	П		
7.30-7.40				~					П			
7.40-7.50								П	П	П		
7.50-8pm											П	
8pm-8.10										П	П	
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8.20-8.30			Z						П	П		
8.30-8.40		7										
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8.50-9pm												
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9.30-9.40									П	П	П	
9.40-9.50										П	П	
9.50-10pm										П	П	

Time: 10pm - 1am	ım – 1am			Time: 10pm - 1am	Were)	on alo	Were you alone or with somebody you know? Mark all relevant boxes	ith som	ebody ooxes	you kr	9wor	
Night						Pe	People who live with you	no live w	ith you			
Time : 10pm-1am Night (pm/am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child aged 0-7	Ofher Derson	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
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12.30-12.40												
12.40-12.50												
12.50-1am												

Time: 1am – 4am	n – 4am			Time: 1am - 4am	Were	you alo	Were you alone or with somebody you know? Mark all relevant boxes	ith som elevant k	ebody y	you kno	Swc	
Night						Pe	People who live with you	o live w	ith you			
Time : 1am-4am Night (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bsrtuer Sbonse /	Mother	Father	Child aged 0-7	Otherson	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
1am-1.10										П	П	
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3.30-3.40									П	П	П	
3.40-3.50										П	П	
3.50-4am											П	

Diary Checklist

- - 2. At the end of the diary day
- 3. The day after the diary day
- المستوادية المستوادية
 - 2. Did you feel rushed this day?
- 2. No
- 3. Was this an ordinary or an unusual day?
- 1. An ordinary day
 2. An unusual day
- 4. What kind of day was this day?
- 1. A workday
- 2. A school or college day
 - 3. A day off
- 4. A sick leave day
- 5. An annual leave day
 6. On leave for other reasons
- 7. None of the above

Please go through the diary again and check the following:

- Please check that you have noted only one main activity on each line and that there are no empty time periods.
- Have you marked clearly your employment working hours, even if you worked at home?
- Have you recorded all travel and modes of transport?
- Have you marked the duration of secondary activities, if any?
- Please check that you have always completed the 'Were you alone or with somebody you know' column.



	Participant Information Questionnaire
	Date:
*Email:	
Date of Birth:	Sex :
Health conditions:	
List of medications being taken:	
_	
_	7
Length of time since diagnosis:	



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			A A	MACQ Univers
What is your emplo	oyment status?			
	ent		Unpaid work experience Retired On parental leave Other (specify)	
Would you like to b	e contacted to receive	feedb	eack on the study?	
Yes	No			
Would you like to b	e contacted for future	resea	rch?	
Yes	No			
			tionnaire, including conta oses and will <u>not</u> be passe	

The Multimorbidity Illness Perceptions Scale (MULTIPleS)

with mult	estions are about the thoughts and feelings that people iple long-term conditions sometimes experience. Please ow much you agree with each statement by circling one	Strongly Disagree		+	Strongly Agree
1	One of my conditions is more serious than the others.	0	1	2	3
2	Time spent managing my conditions has made it more difficult to carry out my usual activities.	0	1	2	3
3	I feel so overwhelmed by the treatment for one condition it is hard to manage any others.	0	1	2	3
4	The causes of my conditions are linked.	0	1	2	3
5	It is difficult to take all my medications the way I am supposed to.	0	1	2	3
6	Time spent managing my condition has limited my activities.	0	1	2	3
7	One of my conditions is more worrying than the others.	0	1	2	3
8	Taking different medications for each of my conditions has caused me problems.	0	1	2	3
9	I don't like mixing medications for different conditions.	0	1	2	3
10	Having more than one condition makes my treatments less effective.	0	1	2	3
11	One of my conditions has caused another.	0	1	2	3
12	One of my conditions dominates the others.	0	1	2	3
13	My conditions interact with each other.	0	1	2	3
14	Having more than one condition makes it difficult to get the best available treatment.	0	1	2	3
15	Time spent managing my conditions has reduced my social life.	0	1	2	3
16	One of my conditions has more of an impact on my life.	0	1	2	3

			ngly	_		Strongly Agree	
17	Having more than one condition makes me unhappy.	0	1	2	3	4	5
18	Having more than one condition makes me more anxious.	0	1	2	3	4	5
19	Having more than one condition makes me angry or frustrated.	0	1	2	3	4	5
20	Having more than one health problem makes me feel sad.	0	1	2	3	4	5
21	Having more than one condition makes me more irritable.	0	1	2	3	4	5
22	If I feel sad or depressed, managing my conditions is a struggle.	0	1	2	3	4	5

MACQUARIE University

PARTICIPANT EXPERIENCE SURVEY

EDESIX BODY CAMERA

Did you experience any of the following problems while you were			
Never	Some- times	Often	Always
ν,			
	7		
		Never Some-	Never Some- Often

Do you have any additional comments abo	out your experience of
wearing the camera?	

1	
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1	2
1	3
1	4
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1	0
1	7 8
1	8
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4	1
-4	2

44

45 46 47



TIME USE DIARY

Did you experience any of the diary?	ese probl	lems when	completi	ng the
	Never	Some- times	Often	Always
Remembering to fill in the				
diary				
Forgetting what I did during				
the day/evening				
The length of time it took to				
complete the diary				
Completing all sections of				
the diary				
Understanding the diary				
instructions	N.			

Do you have any additional comm	ents about your experience of
completing the time use diary?	
,	

PARTICIPATING IN THE STUDY

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44

5 6	Were there any aspects of the study that you particularly enjoyed?
7	
9 10 11	Were there any aspects of the study that you disliked?
12 13	
14 15 16	How did you find the 'reconstruction interview' experience?
17 18	
19 20 21	What motivated you to participate in the study?
22	
23	
24252627	Do you have any other comments or suggestions?
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35 36	
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39 40	
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42 43	3
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Centre for Health Informatics Australian Institute of Health Innovation Faculty of Medicine and Health Sciences MACQUARIE UNIVERSITY NSW 2109



Phone: +61 (2) 9850 2436 Email:annie.lau@mq.edu.au

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 kathleen.vin@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,
	the information above and any questions
I have asked were answered to my sa	atisfaction. I agree to participate in this
research, knowing that I can witho	draw from further participation in the
research at any time without consequ	uence. I have been given a copy of this
form to keep.	
	one) for the research team to use my de-
1	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.

Pre-study interview questions

The pre-study interview will be conducted in the following steps:

- 1. The research team will explain the study to the participant.
- 2. The participant will read and sign the consent form.
- 3. The participant will be asked to complete a basic demographic survey (approximately 5 minutes).
- 4. The participant will be asked to complete the Multimorbidity Illness Perceptions Scale (approximately 10 minutes).
- 5. A semi-structured interview (approximately an hour) will be conducted with the participant regarding the health-related tasks they are engaged in. The interview will be audio recorded to allow for analysis.
- 6. With the participant's permission, the research team will take photographs of the participant's current medications, medical devices, and their surroundings.
- 7. The participant will be instructed to the use of the Edesix body camera and the Time-Use Diary.
- 8. The participant will also receive an instruction card to explain what the study is about if members of the public enquire about it.

Life History

Examples:

- How was your health as a child or a young person?
- How was the health of your family?
- How have your health conditions affected your job?

Social Life & Mental Health

Examples:

- Has your health ever affected your interactions with your friends?
- How do you feel about the impact (or lack of) your health had on your social life?
- Can you tell me a bit about your mental journey when you were diagnosed / started on this treatment?
- Do you feel differently towards your health conditions and meds now than you did before?

Physical Health & Medical History

Examples:

- What health conditions do you have?
- What medications do you take? And how often?
- Do you know much about your health conditions?
- Did you go research on your medications/conditions yourself?
- What kind of food do you have to watch out for due to your health?
- With your level of mobility, how do you find exercise?

Physical Environment

Examples:

- How do you find going up and down the stairs?
- Who does your cooking/laundry/gardening?

Organisational efforts & Attitude

Examples:

- Do you have domestic help? Paid or unpaid?
- Has the physical layout of your house / any other place affected your ability to take care of
- What are your opinions about your medications and your doctors?



Post-study interview questions

The post-study interview will be conducted in the following steps:

- 1. The participant will return the Edesix body camera and Time-Use Diary.
- 2. Data from the body camera will be downloaded to a secure computer.
- 3. The video from the body camera will be converted into screenshots, with one screenshot taken for every 10 seconds of video footage.
- 4. After video download and screenshot conversion, the videos will be deleted, and the participant will view the screenshots alone, and has the right to delete any or all the images.
- 5. The research team will conduct a 30 40 minutes interview with the participant, where he/she will describe the study day, with the assistance of the images and the Time-Use Diary, focusing on any specific health-related activities (e.g. Cooking, exercising, social activities).
- 6. The interview will be audio recorded to allow for thematic analysis.
- 7. The researchers may also ask participants to clarify the activity in any screenshots that may appear ambiguous (e.g. ceiling images may imply napping on the sofa).
- 8. The researchers will also check that the time-stamp on the screenshots match the activities reported in the Time-Use Diary (if not, annotate the Time-Use Diary or ask participant questions for clarification).
- 9. The participates will complete the Participant Experience Survey, and give feedback regarding the study.
- 10. The participant will be remunerated with a \$60 Westfield shopping voucher for their assistance.

Questions for the semi-structured interview:

Examples

- Tell us about your day.
- Was this a typical day? If not, what was different on this day?
- What time did you start / stop filling in the Time-Use Diary?
- What time did you start / stop video recording?
- Around what time did you wake up and go to bed last night?
- How did you sleep during the study night?
- Do you always do [activity] at this time of the day?
- Is this the kinds of food you usually eat for breakfast/lunch/dinner?
- You spent a long time doing [activity] yesterday. Is this how long you usually take to do [activity]?
- Do you always do [activity] at [location]?
- Are there changes you would like to make to your daily routine?

BMJ Open

Patient Work from a Context and Time Use Perspective – A Mixed-Methods Study Protocol

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Primary Subject Heading :	Health informatics
Secondary Subject Heading:	Patient-centred medicine, Research methods, Qualitative research
Keywords:	Patient work, Mixed-methods study, Body-worn cameras, Time-use diary, Passive data collection, Burden of disease



- 1 Patient Work from a Context and Time Use Perspective A Mixed-Methods Study
- 2 Protocol
- 3 Kathleen Yin¹, Teresa Harms^{2, 3}, Kenneth Ho⁴, Frances Rapport¹, Sanjyot Vagholkar⁴, Liliana
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21 Word count: 3951

Abstract:

Introduction: Self-management is widely promoted but less attention is focused on the work required from patients. To date, many individuals struggle to practise self-management. 'Patient work', a concept that examines the 'work' involved in self-management, is an approach to understanding the tasks, effort, time, and context from patient perspective. The purpose of our study is to use a novel approach combining non-obstructive observations via digital devices with in-depth qualitative data about health behaviours and motivations, to capture the full range of patient work experienced by people with type 2 diabetes and chronic co-morbidities. It aims to yield comprehensive insights about "what works" in self-management, potentially extending to populations with other chronic health conditions. Methods and analysis: This mixed-methods observational study involves a i) pre-study interview and questionnaires, ii) a 24-hour period during which participants wear a camera and complete a time-use diary, and a iii) post-study interview and study feedback. Adult participants living with type 2 diabetes with at least one chronic co-morbidity will be recruited using purposive sampling to obtain a balanced gender ratio and of participants using insulin and those using only oral medication. Interviews will be analysed using thematic analysis. Data captured by digital devices, diaries and questionnaires will be used to analyse the duration, time, context, and patterns of health-related behaviours. Ethics and dissemination: The study was approved by the Macquarie University Human Research Ethics Committee for Medical Sciences (Reference Number 5201700718). Participants will carry a wallet-sized card that explains the purpose of the study to third parties, and can remove the camera at any stage. Before the post-study interview begins, participants will view the camera images in private and can delete any images. Should any images be used in future publications or presentations, identifying features such as human faces and names will be obscured.

Strengths and limitations of this study

- This is the first study that employs a mixed-method design using passive digital observation equipment, self-report time-use diaries, complemented with interviews and questionnaires, to document patient work.
- Using the body-worn camera may diminish the observer effect caused by having researchers observe participants in a private setting, as well as reducing the participant burden of having researchers in their homes for prolonged periods of time.
- The self-report diary complements data from the passive device by creating a holistic view of patient work carried out by the participant.
- The study is limited by the 24-hour data collection period, which may not include patient work that occurs frequently, but outside the observation period.

2.

Keywords

Patient work; Mixed-method study; Body-worn cameras; Time-use diary; Passive data collection devices; Interviews; Burden of disease; Chronic disease; Type 2 diabetes; Chronic co-morbidity; Self-management; Patient experience; Patient; Consumer.

INTRODUCTION

Self-management is widely promoted but less attention is focused on the work required from patients. It is a constant commitment of learning new skills, breaking old habits, and managing different emotions over the length of the illness.[1] Patients and their families often need to adjust their daily routines to accommodate for their health condition, such as making time to administer medications, visit medical professionals, or prepare special meals.[2-5] Yet, many individuals struggle to practise self-management effectively, especially for those with long-term chronic conditions.[6-8]

Past studies reported on the barriers and challenges to self-management, focusing on patients with multiple chronic conditions,[6, 7] the difficulty involved in self-management,[8] time invested,[9] competing priorities,[10, 11] support sources required,[12] and how self-management differs between the patients' and healthcare professionals' perspectives.[13] Yet, few studies reported on the actual 'work', or the tasks involved, from the patient, as well as whether self-management fits within the patient's context.

When self-management is poorly integrated into people's lives, the work required has the potential to generate additional stress, contributing to non-compliance and negatively impacting on patient health outcomes.[14, 15] Unfortunately, many health interventions are currently implemented without considering the *work* involved from patient perspective or the *context* of a patient's life. Treatment and self-management recommendations, whilst given with good will, often fail to acknowledge the specificities of a patient's daily routine, physical environment, social obligations, as well as internal beliefs and attitudes.[16-19] In parallel, digital health interventions hold the promise to improve self-management. However, numerous studies evaluating digital self-management interventions showed a high participant

1 dropout rate, with some studies having retention rates of 1% by the end of the study

period.[16, 19-21] Specifically, participants reported the devices' lack of 'fit' into their daily

3 lives as reasons for discontinuation.[22]

5 Understanding whether there is a dissonance between patients' existing routines and the work

6 involved in self-management is important to overcome barriers and challenges. The concept

of 'patient work', derived from health ergonomics, describes the tasks (physical and

cognitive) conducted by patients to manage their health, as well as the holistic sum of

contexts (physical, social, mental, and organisational) that influence the work conducted.[23-

25] It is an approach to understanding the actions people take (or not take) in self-

management. While self-management focuses on the strategies people employ, patient work

breaks down these strategies into day-to-day tasks and examines how the effort and time

involved, as well as the contextual and ergonomic factors, affect the way self-management is

practised and why some tasks are carried out while others are neglected.

The purpose of this study is to examine the *patient work* involved in living with multiple

chronic conditions, focusing on the daily lives of people with type 2 diabetes and chronic co-

18 morbidities.

Patient work research

21 Previous patient work research had focused on patients living with cardiovascular diseases

such as heart failure and stroke.[24-26] However, no studies have focused specifically on

people living with more than one chronic condition.

- In addition, previous patient work approaches relied heavily on self-report methods
- (interviews[27, 28]), direct observation (researchers being present continuously in
- participants' homes), or theoretical modelling (analysing macro-ergonomic elements[29,
- 30]). These data collection methods are limited by the level of reliability in self-report data
- (e.g. social desirability effect) and the degree of discomfort participants experience during
- direct observation.

- The need for direct observation by researchers also meant the duration of visits had to be
- limited, ranging from 30 minutes to 1 hour at a time, [30] making these short periods unlikely
- to capture the 'natural' routines of participants as there is high likelihood they could be
- affected by the observer effect.[31] To our knowledge, no studies have utilised digital devices
- that automatically and non-obstructively collect data on patient work over a longer
- timeframe.

Type 2 Diabetes and Other Co-morbidities

- The nature of type 2 diabetes, which impacts the entire metabolic process, means that patients
- need to carry out a variety of different activities. These may include diet modification,[32]
- weight management, [33] exercise, [34] complication prevention, [35] blood glucose tests, [36]
- and insulin injections.[26]

- Metabolically-related co-morbidities such as hyperlipidaemia, cardiovascular diseases, and
- renal disorders [37, 38] are frequently present in people living with type 2 diabetes,
- warranting the inclusion of co-morbidities to reflect the true extent of patient work. Co-
- morbidity is also frequently a criterion for exclusion in research studies, suggesting this study

1 could give rare insights into the lives of people living with type 2 diabetes, as well as a

greater understanding of self-management in patients with chronic co-morbid conditions.

AIMS

- 5 This study will investigate the patient work conducted by people living with type 2 diabetes
- and at least one chronic co-morbidity. It will address three gaps identified in the literature:
- 7 the few studies reporting the 'work' involved in self-management from patient perspective
- 8 (patient work), the methodological gap in using digital devices to collect data non-
- 9 obstructively on self-management activities and contexts over a longer time frame (24-hour
- period), and focusing on people with complex challenges to self-management (those with
- 11 multiple chronic conditions).

METHODS

- 14 This is a mixed-methods, observational study that involves three stages: i) pre-study
- interview and questionnaires, ii) a 24-hour period during which participants wear a camera
- and complete a time-use diary, and a iii) post-study session with interview and study
- 17 feedback. The project is approved by the Macquarie University Human Research Ethics
- 18 Committee (approval 5201700718). Our study adapted the protocols used and validated by
- 19 Kelly et al. [39, 40] which were employed in research projects conducted by the Centre for
- 20 Time Use Research (CTUR) and the British Heart Foundation Centre on Population
- 21 Approaches for Non-Communicable Disease Prevention, both at The University of Oxford.

Sample and recruitment

- Eligible participants are: (1) aged 18 years and older; (2) consenting adults who can speak,
- 25 write and read in English; (3) have been diagnosed with type 2 diabetes and at least one

1 chronic co-morbidity; (4) willing to complete a time-use diary for one day; and (5) agree to

2 wear the body-worn camera for one day. Exclusion criteria include those who are currently

experiencing: (1) pregnancy; (2) critical illness; (3) end-stage disease; (4) dementia; (5)

severe mental disorders that prevent one from giving informed consent and; (6) dependent on

others for basic activities of daily living such as dressing and eating. Participants will receive

\$60 in Australian Dollars of shopping vouchers as remuneration.

8 To capture patients at various stages of diabetes, forty (40) participants will be recruited, with

9 balanced gender ratio, and balanced numbers of participants using only oral medication and

those using insulin. The number of participants chosen was informed by previous qualitative

studies in patient work.[27, 28] This sample size offers the power to achieve rich and

nuanced data, while acknowledging the different time intervals between data points for each

data capture tool.[24, 27, 28] Previous patient work studies analysed 60-80 hours of

interviews or direct observations per study. [27, 28] This study will capture approximately 2

hours of interview data and approximately 5000 images per participant. Therefore, a sample

size of 40 participants is comparable to the depth of data captured by previous studies.

18 Recruitment will be carried out via Macquarie University general practice and general

practitioners and endocrinologists in the surrounding suburbs. These medical practitioners

manage a large and diverse patient base across northern Sydney and cover a wide range of

culturally and economically diverse population groups.

23 Promotional flyers will be distributed to the participating medical practices and includes

24 general study information and a link to the study website, where potential participants can

check the eligibility criteria (www.tinyurl.com/patientswork). The study will also be

1 promoted on the Macquarie University Facebook page and via an emailed newsletter

associated with the University. Healthcare practitioners will not be notified if their patients

agreed to participate in the study to reduce the possibility of coercion.

5 Databases of medical practices involved in recruitment will be searched to identify eligible

patients for the study. Only personnel employed by the medical practices will conduct these

searches. Participating healthcare practitioners will also send invitation letters to eligible

patients, with a pre-paid reply slip included. Patients interested in participating will be asked

to return the reply slip with their contact details, so a member of the research team can

10 contact them.

12 Telephone calls will also made to eligible patients to inform them about the study. If during

the initial phone call the potential participant agrees to consider participating, the researcher

will send a detailed email to the participant with a digital version of the information pamphlet

as well as a link to the study website. The potential participant then either agrees to

participate or declines. If the potential participant agrees to participate, the researcher will

arrange a suitable time for interviews to occur. All participants will provide written informed

18 consent before data collection commences.

Initial contact for all participants will be a telephone call conducted by the research team, to

check whether the participant fits the eligibility criteria, assure confidentiality and anonymity

during data-collection, and address any questions. This approach will minimise participant

contact with the research team and clinicians. While self-nominated participants may be

subject to participation bias, high completion rates and compliance are likely.

Patient and Public Involvement

- 2 The concept study was conceived during a 1-day Consumer Symposium conducted at
- 3 Macquarie University, where 10 health consumers gave feedback and critique regarding
- 4 health research.

- 6 Health Consumers New South Wales, a patient advocacy group, was then consulted
- 7 regarding consumer engagement and advice was given to the researchers regarding consumer
- 8 involvement during study conception, recruitment, analysis to dissemination.

- 10 A pilot trial of the protocols with the equipment was conducted with two patients. Summaries
- of the findings were presented to the participants.

- During study conception, the researchers also engaged with Healthdirect, a national
- organization providing digital health information for health consumers, and the Northern
- 15 Sydney Primary Health network and local GP network, which has a consumer council.

- 17 Results will be disseminated to these bodies, which will have broader implications to policies
- directed to consumers. Publications arising from the study will also be forwarded to each
- 19 participant via emails.

Data collection instruments and equipment

- The study will be carried out in three stages as described in Figure 1 and Table 1. Utilising
- 23 multiple types of data, the study generates a holistic report of patient work conducted by
- 24 people living with type 2 diabetes and chronic co-morbidities in terms of observed physical

work, organisational efforts, burden of disease, and attitudes and beliefs underlying health
 behaviours.

- 4 The 24-hour data collection is more likely to capture a more representative day compared to
- 5 previous patient work studies, which only captures patient activities for a few hours at most.
- 6 While it will be hard to find a day that is truly representative of one's life, the researchers ask
- 7 the participants to nominate a day for the study that the participants themselves consider to be
- 8 'normal'.

Table 1. Data collected at different stages during the study

Pre-study	Data collection (24-hour)	Post-study
 Interview (1-hour) Participant demographics questionnaire Multimorbidity Illness Perceptions Scale[41] Photos of participant's home (where appropriate) 	 Body-worn camera Time-use diary (Appendix 1) 	 Reconstruction interview (30-40 minutes) Participant experience questionnaire Researcher's notes

- 12 The following instruments and equipment will be used for data collection.
 - Time-use diary The self-report time-use dairy is a validated tool[39] and the version used in this study is the Harmonised European Time Use Diary[42] (UK version). For details of the time-use diary, please see Appendix 2. This method of using free-text time-use diaries to self-report activities has high statistical validity and good acceptance rates with volunteer participants (ranging from 56% to 100%[39, 43]).
 - Photos With permission from the participant, photos of their medications, medical devices, and home surroundings will be taken to inform about the participant's physical environment. Should the participant reside in an environment that can affect

- their healthcare (e.g. a house with stairs and a risk for falls), these issues will be taken into consideration. Participants will be alerted should an immediate and significant risk be identified.
- Body-worn camera The body-worn camera (Edesix VB-300, Edinburgh) will automatically record silent continuous video footage. It can be attached to clothing and/or worn on a lanyard. Previous studies with body-worn cameras showed high degrees of acceptability, with acceptance rates ranging from 70% to 100%[39, 43, 44], especially when participants are reassured they can remove the camera if they feel the recording may intrude upon their privacy[39, 43].
- Demographic questionnaire The demographic questionnaire (Appendix 3) will be administered during the pre-study session and takes about 10 minutes to complete.
- Perceptions Scale [41] (Appendix 4) is validated statistically and was developed to capture the perception of patients with co-morbidities about their health.[41] Illness perception is known to affect and predict health-related behaviour, to the extent that patients who perceive their diseases as more controllable are more likely to engage in adaptive strategies[45], thus directly affecting the patient work they engage in. The Scale will be administered during the pre-study session and takes approximately 5 minutes to complete.
- Participant experience questionnaire A participant experience questionnaire
 (Appendix 5) will be administered during the post-study session. This is estimated to take approximately 10 minutes.
- Researcher notes: a summary of each participant will be written up within a week after the post-study session, summarising the researcher's observations of the

participant, home context, and any feedback from the participant at different stages of
 the study.

Stage 1: Pre-study session

- 5 Prior to the pre-study session, participants will be provided with the Participant Information
- 6 Booklet (Appendix 1) and will sign a written informed consent form (Appendix 6) before
- data is collected. Participants have the right to decline at this stage and to retract consent at
- 8 any time throughout the study.

- 10 Ideally, the pre-study interview will occur in the participant's home for researchers to note
- ergonomic factors. To ensure researcher safety, two researchers will make the home visits.
- 12 Participants may come to Macquarie University for the interview if they prefer.

- 14 Following consent and before the pre-study interview, participants will also be asked to
- complete the demographic questionnaire (Appendix 3) and the Multimorbidity Illness
- Perceptions Scale[41] (Appendix 4).

- *Pre-study interview*
- 19 After the completion of the questionnaires, a semi-structured interview will be conducted to
- 20 gain information about the participant's life history, medical history, and existing factors that
- 21 impact patient work. Participants will be invited to talk about their health and lifestyle, with
- areas of focus separated into life history, social life and mental health, physical health and
- 23 medical history, physical environment, and organisational effort and attitude (Appendix 7).
- 24 With the participant's permission, the interview will be audio-recorded to assist with data

- 1 coding and thematic analysis (e.g. daily activities, rationales behind behaviours, and factors
- 2 that influence why participants behave in certain manners).

- 4 Lastly, participant will be provided with a body-worn camera and the Harmonised European
- 5 Time Use Surveys UK Time-Use Diary (Appendix 2),[42] together with relevant instructions.
- 6 Photographs of the participant's medications, medical devices and home environment will
- 7 also be taken at this stage.

Stage 2: Participant self-recording data collection

- During the 24-hour study period, participants will be asked to wear the camera around their
- neck on a lanyard during waking hours (12-16 hours). The time-use diary will be completed
- by the participant over the course of the same day for 24 hours. Participants will be given
- instructions (Figure 2) to re-charge the camera overnight or if the battery becomes low.

Stage 3: Post-study session

- A post-study session will occur immediately after the 24-hour study period has concluded.
- 17 The camera footage will be downloaded and converted into images using software developed
- in-house, with one screenshot taken for every 10 seconds of footage. The participants will be
- able to view all the images alone before the research team views them, allowing the
- 20 participant to delete any or all unwanted images.

- 22 Post-study 'reconstruction' interview
- The participant will be interviewed for approximately 30 40 minutes after data collection
- 24 (Appendix 8). Participants will be asked to describe the study day, using the screenshots and

- time-use diary as prompts, with a focus on health-related tasks. The interview will be audio
- 2 recorded with the participant's permission to allow for thematic analysis of transcripts.

- 4 During the second interview, the researchers will also ask the participant whether the study
- 5 day was 'normal' for them, and whether anything special occurred.

- 7 After the interview, the participant will be asked to complete the Participant Experience
- 8 Questionnaire (Appendix 5) and provide feedback on the methodology.

DATA ANALYSIS

- Both qualitative and quantitative data will be gathered and analysed. The varied data sources
- are complementary and focus on different aspects of patient work. For example, self-reported
- data regarding daily tasks via the time-use diary can be enriched through an examination of
- the screenshots from the camera.

Quantitative data analysis

- 17 Video recordings from the body-worn camera will be automatically converted into series of
- 18 10-second screenshots, which are then processed for analysis of daily activities (e.g. eating,
- 19 sleeping). These screenshots will be tagged using the TensorFlow[46] and/or ClarifaiTM (New
- 20 York, USA) Application Programming Interface, which automatically generate tags that
- 21 identify objects and describe content within the image (e.g. a lady and a car). A subset of
- 22 these tags will be manually verified for accuracy.

- 24 Time-use diary data will be analysed in conjunction with camera screenshots. Participants'
- activities reported in the time-use diary and observed via screenshots will be coded using an

- 1 adapted version of the Harmonised European Time Use Surveys activity frame[47], and
- 2 assessed for the duration, frequency, timing and patterns.

- 4 Questionnaire data (participant demographics, study feedback, and the Multimorbidity Illness
- 5 Perceptions Scale) will be reported using descriptive and inferential statistics. All statistical
- 6 analyses will be conducted using SPSS® (IBM, New York, USA).

Qualitative Data Analysis

- 9 Both pre-study and post-study interviews will be transcribed verbatim. Analysis of the
- interview transcripts will be conducted using the NVivo® thematic analysis software package
- 11 (NVivo, Melbourne, Australia).[48] Two members of the research team will independently
- code the transcripts in a systematic manner. Any coding discrepancies between the two will
- be resolved through reaching a consensus.

- 15 Photographs of the participant's medications, medical devices, and home environment and
- camera screenshots will provide context to the interview. The photographs will also be used
- to give contextual feedback regarding the participant's daily activities, as revealed in the
- video recordings and time-use diaries. Notes taken by researchers after the post-study
- interview for each participant will be used to help with photo and qualitative data analysis.

ETHICS AND INFORMATION DISSIMATION

22 Ethical considerations arising from this study are addressed below.

Consent and freedom to withdraw

- 1 Participants' questions or concerns will be addressed individually and with all due diligence.
- 2 Participants will be free to withdraw from the study at any point and can remove the camera
- 3 at any time during the study day without giving a reason. The decision to join the study will
- 4 have no consequence on their relationship with either Macquarie University or their health
- 5 professionals.

Third-party and bystander consent

- 8 The research team will provide participants with a wallet-sized card that includes the
- 9 statement below with contact information of the research team, which can be shown to others
- 10 (to reduce the psychological burden of the participant) should anyone approach the
- participants to ask about the camera.

- 13 "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."

- 16 Should anyone request video recordings to be deleted, we ask participants to take note of the
- time that requests were made, and to assure the enquirer that the related recordings will be
- removed at the post-study session. Participants are also asked to inform their household
- members, friends, and acquaintances about the study, and to seek permission from these
- 20 parties prior to recording.

Personal privacy

- 23 Participants will be asked to keep the body-worn camera off during situations when anyone
- 24 (including themselves) is dressing, undressing, using the bathroom, showering, or during any

- 1 situations where privacy is of concern. Participants will be advised that they should always
- 2 prioritise their own personal safety and comfort above the study's requirements.

- 4 Furthermore, participants will be able to view and delete any (or all) of the extracted images
- 5 before researchers view the images or videos at the start of the post-study session. The videos
- 6 will be deleted immediately after screenshots are extracted. Only members of the research
- 7 team will have access to the screenshots. None of the video or screenshots will be released to
- 8 the public, academic peers, or participants. Should participants provide written informed
- 9 consent for the research team to use their images in publications or presentations, the images
- will be blurred such that no one is identifiable.

To ensure the participant's privacy, names and other identifying information will be removed

in the photos of medications.

Participant feedback

- Participants will be asked about their experiences in the study during the post-study
- interview. A questionnaire to assess the participant's experience (Appendix 5) will also be
- administered. Participants will be provided with contact details of the research team (email
- and phone number) for contact during the study.

Psychological support

- In the unlikely case that participants become psychologically distressed during either of the
- interview sessions, a staff member with counselling experience will be present in both
- 24 interviews to deal with any anxiety the participant may experience. Should participants
- experience high levels of distress during the study day, they are advised that they should

- 1 immediately attend their local hospital emergency department, general practitioner, and/or
- 2 call Lifeline or Emergency Services.

Participant Identification

- 5 Participant identities will not be masked during data collection. Participants will be
- 6 individually identifiable due to the small sample size. However, their identities will only be
- 7 known to the research team, and only members of the research team will have access to
- 8 identifiable data. Data will be separated from contact details and stored in separate locations.
- 9 No identifying information about the participant will be published or presented.

Information dissemination

- Great caution will be taken in the handling and storage of the data by the research team so
- that risks to privacy are minimised, in accordance with the Australian Code for the
- Responsible Conduct of Research. Only members of the research team will have access to the
- data. The videos will be downloaded into a secure browser in a password-protected computer
- or Macquarie University servers. All physical copies of surveys and questionnaires will be
- locked in secure cabinets at Macquarie University. The data will be held for a minimum of 5
- years. Anonymity will be upheld throughout reporting, and participants will only be referred
- 19 to by their participant number.

DISCUSSION

- 22 At the time of writing, the study had engaged 40 potential participants and 23 participants
- completed the study, more than half of the number of participants the study aims for.

had withdrawn their consent to date.

- The reasons some potential participants did not take part in the study included: declined consent due to personal reasons (which the participate did not disclose), unable to communicate in English to a sufficient standard (as judged by the researcher during the initial phone call), too busy with work, too busy due to full-time care of family members, going on a holiday, was sick on the scheduled visit and withdrew from the study, was not home when the researchers visited and withdrew from the study. No participant who completed the study
- Completion rates for the time-use diary is very high, with 21 out of 23 participants
 successfully filling the diary throughout the study day. The two participants who did not fill
 in the diary did so during the post-study interview, with the assistance of recorded footage.
 - All participants complied to continuous camera recording. There was a variation of camera recording time between participants, due to some participants turning the camera off for some periods of time out of privacy concerns.
 - One challenge the study had faced was communicating camera operations effectively to the participants. Some participants had difficulty turning off the camera and charging the camera battery due to reasons such as forgetfulness and confusion regarding the orientation of the camera buttons. To address the issue, the research team had devoted more time during the pre-study interview to physically demonstrate how to use the camera, which had successfully improved participant understanding of camera operations.
 - **Author's contributions**:

- 1 Study conceptualisation: AL, EC; Study design: AL, KY, TH, JG; Data collection
- 2 preparation and analysis plan: KY, TH, AL, LL, FR; Recruitment and liaison: KH, SV; First
- 3 draft: KY, AL; Draft revision: all authors provided feedback and approved the manuscript.

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- Kingdom), Aiden Doherty (Nuffield Department of Population Health, University of
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- 17 University of Melbourne, Australia), Karen Milton (Norwich Medical School, University
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- Drafting the manuscript: Dr Theun Pieter van Tienoven from the University of New
 South Wales, for his valuable comments and suggestions on earlier drafts of the
 manuscript.
 - The authors would like to thank the study participants for their valuable time and input.

Competing interests:

- 9 Some participants may be recruited via the Macquarie Health General Practitioner clinic and
- Macquarie Hospital, where SV is practicing as a general practitioner and KH is practicing as
- an endocrinologist, respectively. Therefore, the two team members may be responsible for
- the treatment of some participants. However, SV and KH will not know whether a patient is a
- participant unless the participant informs them.
- Figure 1: Flow diagram illustrating the tasks involved at each stage of the study.
- Figure 2: Instructions provided to participants regarding the operation of the body-worn
- 17 camera.

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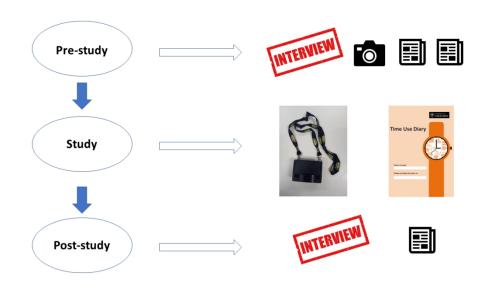


Figure 1: Flow diagram illustrating the tasks involved at each stage of the study. $108 x 60 mm \; (300 \times 300 \; DPI)$

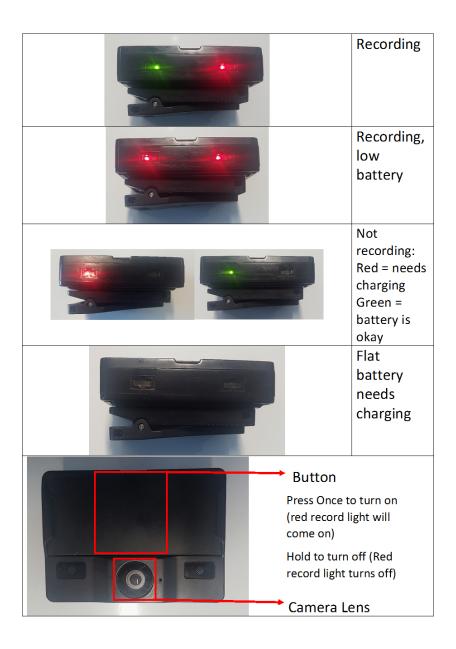
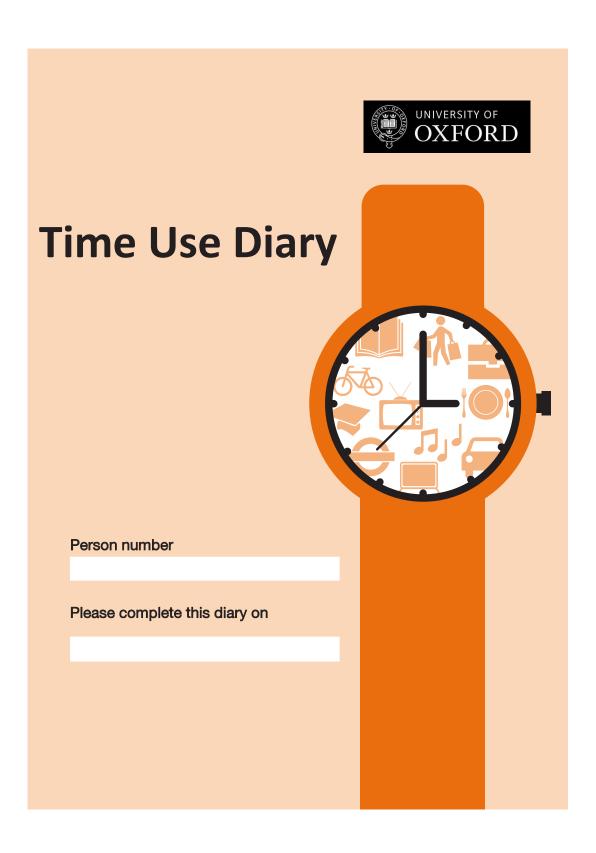


Figure 2: Instructions provided to participants regarding the operation of the body-worn camera. $77x112\text{mm} \; (300 \times 300 \; \text{DPI})$



Diary instructions

Please read the instructions below to help you fill in your diary. There is also an example of a filled in diary on the next page to help you.

When should I fill in the diary?

- The front of the diary tells you which day we would like you to complete the diary for.
- The diary starts at 4am and covers 24 hours, with three hours on each page
- Please take the diary with you during the day and fill it in every now and then when you have a spare moment. For example on the bus or train, at lunchtime or while you wait for someone

Completing the diary

What were you doing?

- In this column, record what you consider to be your main activity for each 10 minute period.
- If you were doing more than one activity at the same time, only record the main activity in this column. If you did one thing after another during the 10 minutes, record the activity that took the most time.

 - If you were doing something you feel is too private to record, please write "personal".

- You don't need to record exactly what you were doing during work time.
- Please record what you did during breaks. For example, "Lunch break, had lunch" or "Lunch break, • If you have more than one job, please record which one you were working at.
- Include any work you've taken home and completed at home.

- School / college
- Please record whether you study at home or attend classes / lectures.
 - Include the type of study, such as secondary school, university etc.
 If the studies are part of paid work, please note this in the diary.

Housework and childcare

 Please record what you were really doing. For example, "Cooked supper", "Washed the dishes", "Put my child to bed", "Mowed the lawn", "Cleaned the house", "Washed the car"

Sleeping

Please record any occasions during the night when you weren't sleeping. For example, if you have woken up and are doing nothing, reading or caring for children etc.

- If you were reading, please record what you read. For example, "Read a newspaper", "Read a magazine", "Read a book
- If you were reading on a tablet or e-reader such as a Kindle, please remember to fill in the 'Did you use a smartphone, tablet or computer?' column.

Help to other households

- If you were helping someone who lives outside of your household, either totally or in part, please report
- For example, if you helped a friend repair their house, record this as "Helped friend repairing house". If you bought a neighbour some food while you did your own shopping, please record this too.

f you did something else at the same time, what else did you do?

- You should use this column to record any activities that you were doing at the same time as your main activity. These are called secondary activities.
 - · For example, if you were looking after your child (main activity) and watching television at the same time, then you would record "watching television" in this column
- It is up to you which activity you think is the main activity and which is the secondary activity
- Don't forget to record secondary activities during lunch or coffee breaks during work or while travelling.

Did you use a smartphone, tablet or computer?

- Please record in this column whether you were using a smartphone, tablet or computer while you were doing either the main or secondary activity and how long you were using it for. For example, if you were travelling to town on the bus and were checking emails on your smartphone then record how long you
- Draw a line or arrow to indicate how long you spent using your smartphone, tablet or computer.

Where were you?

 This column is to record where you were during the activity and if you were travelling, what your mode of transport was. For example, "at home", "at work", "by car"

Were you alone or with somebody you know?

- Please indicate whether you were alone or together with somebody you know.
- To be together does not necessarily mean that you actually do things together but rather that somebody else was around.
- Draw a line or arrow to show how long you were alone or with somebody you know. This may change during an activity. For example, somebody might leave or arrive.
- 'Children aged 0-7'. If you were with a child aged older than 7 years who lives with you then record this in the • If you were with a child aged 7 years or younger who lives with you, record this in the column Other person' column.
 - If you were with a relative that doesn't live with you, record this in the 'Others you know' column.

How much did you enjoy this time?

- Please write in how much you enjoyed the time on a scale of 1 to 7, with 1 meaning you didn't enjoy it at all and 7 meaning that you enjoyed it very much.
 - Your level of enjoyment may change during an activity. If so, please record the new level of enjoyment

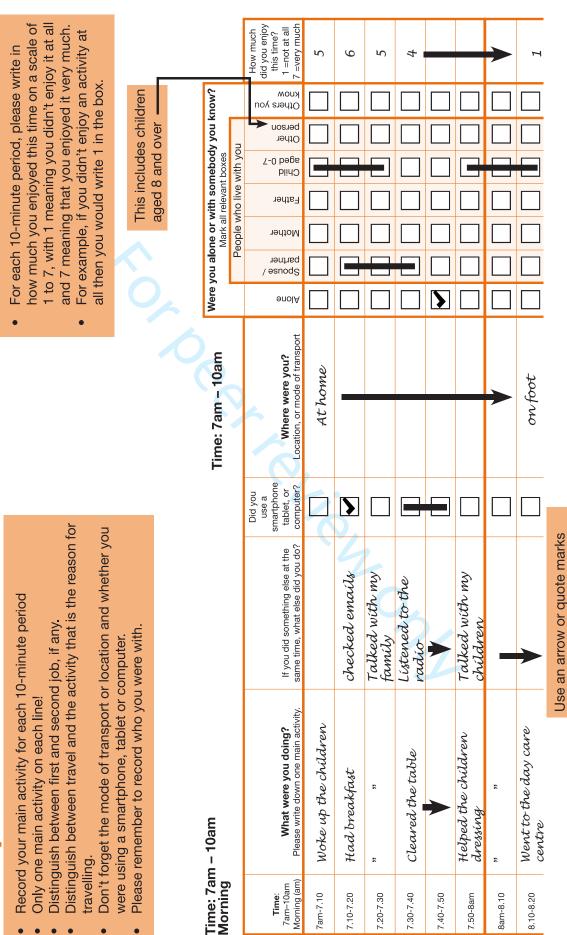
Checklist

- When you have finished filling in your diary, please answer the checklist questions at the end of the
- There is also a checklist to remind you of the key things to remember to record.

to record that an activity lasted

longer than 10 minutes.

Example



Time: 4am – 7am	7am			Time: 4am – 7am	Were	you alc	Were you alone or with somebody you know? Mark all relevant boxes	ith son relevant	boxes	you kno	ow?	
Early mor	ning					ď	People who live with you	vo live v	vith you			
Time : 4am-7am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child	Otherson	Others you ✓ .	How much did you enjoy this time? 1 =not at all 7 =very much
4am-4.10										П	П	
4.10-4.20										П		
4.20-4.30										П		
4.30-4.40												
4.40-4.50										П		
4.50-5am												
5am-5.10				<i>'</i>								
5.10-5.20										П		
5.20-5.30										П		
5.30-5.40		7										
5.40-5.50		C										
5.50-6am												
6am-6.10		1										
6.10-6.20		i.								П		
6.20-6.30												
6.30-6.40										П		
6.40-6.50												
6.50-7am											\Box	

Time: 7am - 10am	n – 10am			Time: 7am - 10am	Were y	Were you alone or with somebody you know? Mark all relevant boxes	ne or with somebod Mark all relevant boxes	omebody int boxes	you kn	ow?	
Morning						Peop	People who live with you	e with you			
Time : 7am-10am Morning (am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Father	Child aged 0-7	berson Otner	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
7am-7.10										П	
7.10-7.20										П	
7.20-7.30											
7.30-7.40											
7.40-7.50											
7.50-8am										П	
8am-8.10				<i>'</i>						П	
8.10-8.20										П	
8.20-8.30			Z								
8.30-8.40		2								П	
8.40-8.50		Ç									
8.50-9am											
9am-9.10		1								П	
9.10-9.20		i.								П	
9.20-9.30											
9.30-9.40											
9.40-9.50											
9.50-10am										П	

Time: 10a	Time: 10am – 1pm			Time: 10am - 1pm	Were	you alo	ne or with somebod Mark all relevant boxes	ith son	Were you alone or with somebody you know? Mark all relevant boxes	you kn	ow?	
Late morr	ning / early afternoon					Ğ	People who live with you	no live v	vith you			
Time: 10am-1pm Morning / Afternoon (am/pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Child	Derson Other	Kuow Others you	How much did you enjoy this time? 1 =not at all 7 =very much
10am-10.10										П	П	
10.10-10.20										П		
10.20-10.30										П		
10.30-10.40				/						П		
10.40-10.50										П	П	
10.50-11am												
11am-11.10				<u> </u>							П	
11.10-11.20				, O.						П	П	
11.20-11.30										П		
11.30-11.40		7								П	П	
11.40-11.50		C										
11.50-12pm										П		
12pm-12.10		1									П	
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12.30-12.40										П		
12.40-12.50												
12.50-1pm											П	

Time: 1pm - 4pm	n - 4pm			Time: 1pm - 4pm	Were)	Were you alone or with somebody you know? Mark all relevant boxes	e or wit ark all re	ne or with somebod Mark all relevant boxes	body yo	u know	0.
Afternoon	ر					Pec	ple who	People who live with you	h you		
Time : 1pm–4pm Afternoon (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bartner Sbonse /	Mother	Eather Child	aged 0-7 Other	Derson	How much did you enjoy this time? 1 =not at all 7 =very much
1pm-1.10											
1.10-1.20											
1.20-1.30											
1.30-1.40				~							
1.40-1.50											
1.50-2pm											
2pm-2.10				-							
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2.30-2.40		7									
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2.50-3pm											
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3.40-3.50											
3.50-4pm											

Time: 4pr	Time: 4pm – 7pm			Time: 4pm – 7pm	Were	you alo	ne or with somebod Mark all relevant boxes	rith sor relevant	Were you alone or with somebody you know? Mark all relevant boxes	you kr	ow?	
Late after	rnoon / early evening					Pe	sople w	ho live	People who live with you			
Time : 4pm-7pm Afternoon / evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bartner Spouse /	Mother	Father	Child aged 0-7	Other person	Others you	How much did you enjoy this time? 1 =not at all 7 =very much
4pm-4.10												
4.10-4.20												
4.20-4.30												
4.30-4.40												
4.40-4.50												
4.50-5pm				9								
5pm-5.10				* / C								
5.10-5.20												
5.20-5.30			Z									
5.30-5.40		7										
5.40-5.50		Ç										
5.50-6pm												
6pm-6.10		1										
6.10-6.20												
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6.30-6.40												
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6.50-7pm												

Time: 7pm – 10pm	n – 10pm			Time: 7pm – 10pm	Were	Were you alone or with somebody you know? Mark all relevant boxes	ne or with somebod Mark all relevant boxes	th som elevant k	ebody y	you kno	SW?	
Evening						Pe	People who live with you	o live w	ith you			
Time : 7pm-10pm Evening (pm)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	bartner Spouse /	Mother	Father	Child aged 0-7	Others you	✓ → G: → Know Vthers you	How much did you enjoy this time? 1 =not at all 7 =very much
7pm-7.10								П		П	П	
7.10-7.20								П	П	П		
7.20-7.30								П	П	П		
7.30-7.40								П	П			
7.40-7.50								П	П	П		
7.50-8pm				9				П				
8pm-8.10				* / (П	
8.10-8.20									П	П		
8.20-8.30								П	П	П		
8.30-8.40		7										
8.40-8.50		Ç							П			
8.50-9pm												
9pm-9.10		1										
9.10-9.20												
9.20-9.30												
9.30-9.40									П			
9.40-9.50												
9.50-10pm												

Time: 10pm – 1am	om – 1am			Time: 10pm - 1am	Were	Were you alone or with somebody you know? Mark all relevant boxes	ne or with somebod Mark all relevant boxes	th some	ebody y	ou kno	w?	
Night						Pe	People who live with you	o live w	ith you			
Time : 10pm-1am Night (pm/am)	What were you doing? Please write down one main activity.	If you did something else at the same time, what else did you do?	Did you use a smartphone tablet, or computer?	Where were you? Location, or mode of transport	ənolA	Spouse /	Mother	Father	Ofher aged 0-7	berson	Kuow Others you	How much did you enjoy this time? 1 =not at all 7 =very much
10pm-10.10										П		
10.10-10.20												
10.20-10.30									П			
10.30-10.40												
10.40-10.50									П	П		
10.50-11pm												
11pm-11.10												
11.10-11.20									П			
11.20-11.30			Z									
11.30-11.40		7										
11.40-11.50												
11.50-12am												
12am-12.10												
12.10-12.20										П		
12.20-12.30												
12.30-12.40										П		
12.40-12.50												
12.50-1am											П	

N.S		How much did you enjoy this time? I = not at all 7 = very much																		Г
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od ybc	you	aged 0-7																		L
omebo ant boxe	e with	Child	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	Ш	L
ne or with somebod Mark all relevant boxes	who liv	Father																		
one or Mark	People who live with you	Mother																		
Were you alone or with somebody you know? Mark all relevant boxes	"	Spouse /																		
Were		ənolA																		
Time: 1am – 4am		Where were you? Location, or mode of transport				~		9	<u> </u>	.0.										
		Did you use a smartphone tablet, or computer?									Z									
		If you did something else at the same time, what else did you do?										7	Ç							
ı – 4am		What were you doing? Please write down one main activity.																		
Time: 1am – 4am	Nignt	Time : 1am–4am Night (am)	1am-1.10	1.10-1.20	1.20-1.30	1.30-1.40	1.40-1.50	1.50-2am	2am-2.10	2.10-2.20	2.20-2.30	2.30-2.40	2.40-2.50	2.50-3am	3am-3.10	3.10-3.20	3.20-3.30	3.30-3.40	3.40-3.50	, ()

Diary Checklist

- 2. At the end of the diary day
- 3. The day after the diary day
- 2. Did you feel rushed this day?
- 1. Yes
- rushed this day?
- 3. Was this an ordinary or an unusual day?
- 1. An ordinary day
 2. An unusual day
- 4. What kind of day was this day?
- 1. A workday
- 2 A Jan 2ff

2. A school or college day

- 3. A day off
- 4. A sick leave day
- 5. An annual leave day
- 6. On leave for other reasons
- 7. None of the above

Please go through the diary again and check the following:

- Please check that you have noted only one main activity on each line and that there are no empty time periods.
- Have you marked clearly your employment working hours, even if you worked at home?
- Have you recorded all travel and modes of transport?
- Have you marked the duration of secondary activities, if any?
- Please check that you have always completed the 'Were you alone or with somebody you know' column.



Information Booklet for Participants





















If you have any questions about the study, please contact

Dr Annie Lau <u>annie.lau@mq.edu.au</u> Telephone: (02) 9850 2436

Dr Kathleen Yin kathleen.yin@mq.edu.au
Telephone: (02) 9850 2477



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 incompliance, 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).

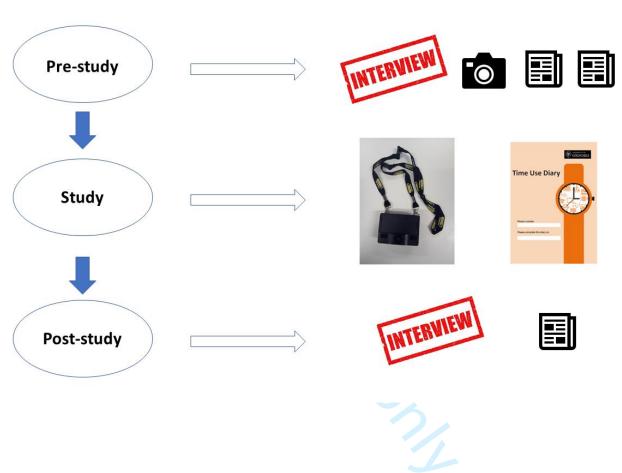
You are free to remove the camera at any time. Particularly, we recommend you to turn off the camera when anyone (including yourself) is dressing or undressing, using the bathroom or showers, during any situations where privacy is of concern, or any other time that you or others might feel uncomfortable.

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@mg.edu.au 02 9850 2436)
 - Dr Kathleen Yin (kathleen.yin@mq.edu.au 02 9850 2477)
 - Dr Liliana Laranjo (liliana.laranjo@mq.edu.au 02 9850 2426)
 - Prof Enrico Coiera (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.

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 02 9850 2436) or Kathleen Yin (kathleen.yin@mq.edu.au 02 9850 2477).



	Participant Information Questionnaire
	Date:
*Email:	
Date of Birth:	Sex :
Health conditions:	
List of medications being taken:	
_	
_	7
Length of time since diagnosis:	



	ВМЈ	Open		
			A A	MACQ Univers
What is your emplo	oyment status?			
	ent		Unpaid work experience Retired On parental leave Other (specify)	
Would you like to b	e contacted to receive	feedb	eack on the study?	
Yes	No			
Would you like to b	e contacted for future	resea	rch?	
Yes	No			
			tionnaire, including conta oses and will <u>not</u> be passe	

The Multimorbidity Illness Perceptions Scale (MULTIPleS)

	estions are about the thoughts and feelings that people	-		-	•
	iple long-term conditions sometimes experience. Please now much you agree with each statement by circling one	Strongly Disagree			Strongly Agree
number.	,	2.008.00			7.8.00
1	One of my conditions is more serious than the others.	0	1	2	3
2	Time spent managing my conditions has made it more difficult to carry out my usual activities.	0	1	2	3
3	I feel so overwhelmed by the treatment for one condition it is hard to manage any others.	0	1	2	3
4	The causes of my conditions are linked.	0	1	2	3
5	It is difficult to take all my medications the way I am supposed to.	0	1	2	3
6	Time spent managing my condition has limited my activities.	0	1	2	3
7	One of my conditions is more worrying than the others.	0	1	2	3
8	Taking different medications for each of my conditions has caused me problems.	0	1	2	3
9	I don't like mixing medications for different conditions.	0	1	2	3
10	Having more than one condition makes my treatments less effective.	0	1	2	3
11	One of my conditions has caused another.	0	1	2	3
12	One of my conditions dominates the others.	0	1	2	3
13	My conditions interact with each other.	0	1	2	3
14	Having more than one condition makes it difficult to get the best available treatment.	0	1	2	3
15	Time spent managing my conditions has reduced my social life.	0	1	2	3
16	One of my conditions has more of an impact on my life.	0	1	2	3

			ngly				ongly gree
17	Having more than one condition makes me unhappy.	0	1	2	3	4	5
18	Having more than one condition makes me more anxious.	0	1	2	3	4	5
19	Having more than one condition makes me angry or frustrated.	0	1	2	3	4	5
20	Having more than one health problem makes me feel sad.	0	1	2	3	4	5
21	Having more than one condition makes me more irritable.	0	1	2	3	4	5
22	If I feel sad or depressed, managing my conditions is a struggle.	0	1	2	3	4	5

MACQUARIE University

PARTICIPANT EXPERIENCE SURVEY

EDESIX BODY CAMERA

Did you experience any of the forwearing the camera?	llowing p	roblems w	vhile you	were
O _A	Never	Some- times	Often	Always
Forgetting to wear the camera				
People's reaction to me wearing				
the camera				
Discomfort wearing the camera				
Problems with the camera	•			
slipping/moving about				
Difficulty understanding the	ν,			
camera instructions	6			
Frustration with the length of				
time I had to wear the camera				
Being uncertain about whether		7		
the camera was turned on				

wearing the camera?	

Do you have any additional comments about your experience of



TIME USE DIARY

Did you experience any of the diary?	ese probl	lems when	completi	ng the
	Never	Some- times	Often	Always
Remembering to fill in the				
diary				
Forgetting what I did during				
the day/evening				
The length of time it took to				
complete the diary				
Completing all sections of				
the diary				
Understanding the diary				
instructions	V.			

Do you have any additional comm	ents about your experience of
completing the time use diary?	
,	
	0,

PARTICIPATING IN THE STUDY

Were there any aspects of the study that you particularly enjoyed?
Were there any aspects of the study that you disliked?
How did you find the 'reconstruction interview' experience?
What motivated you to participate in the study?
Do you have any other comments or suggestions?

Centre for Health Informatics Australian Institute of Health Innovation Faculty of Medicine and Health Sciences MACQUARIE UNIVERSITY NSW 2109



Phone: +61 (2) 9850 2436 Email:annie.lau@mq.edu.au

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 kathleen.vin@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,
	the information above and any questions
I have asked were answered to my sa	tisfaction. I agree to participate in this
research, knowing that I can withd	raw from further participation in the
research at any time without consequ	ience. I have been given a copy of this
form to keep.	
	one) for the research team to use my de-
1	publications and presentations, provided
that the persons in the images cannot b	oe 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.

Pre-study interview questions

The pre-study interview will be conducted in the following steps:

- 1. The research team will explain the study to the participant.
- 2. The participant will read and sign the consent form.
- 3. The participant will be asked to complete a basic demographic survey (approximately 5 minutes).
- 4. The participant will be asked to complete the Multimorbidity Illness Perceptions Scale (approximately 10 minutes).
- 5. A semi-structured interview (approximately an hour) will be conducted with the participant regarding the health-related tasks they are engaged in. The interview will be audio recorded to allow for analysis.
- 6. With the participant's permission, the research team will take photographs of the participant's current medications, medical devices, and their surroundings.
- 7. The participant will be instructed to the use of the Edesix body camera and the Time-Use Diary.
- 8. The participant will also receive an instruction card to explain what the study is about if members of the public enquire about it.

Life History

Examples:

- How was your health as a child or a young person?
- How was the health of your family?
- How have your health conditions affected your job?

Social Life & Mental Health

Examples:

- Has your health ever affected your interactions with your friends?
- How do you feel about the impact (or lack of) your health had on your social life?
- Can you tell me a bit about your mental journey when you were diagnosed / started on this treatment?
- Do you feel differently towards your health conditions and meds now than you did before?

Physical Health & Medical History

Examples:

- What health conditions do you have?
- What medications do you take? And how often?
- Do you know much about your health conditions?
- Did you go research on your medications/conditions yourself?
- What kind of food do you have to watch out for due to your health?
- With your level of mobility, how do you find exercise?

Physical Environment

Examples:

- How do you find going up and down the stairs?
- Who does your cooking/laundry/gardening?

Organisational efforts & Attitude

Examples:

- Do you have domestic help? Paid or unpaid?
- Has the physical layout of your house / any other place affected your ability to take care of
- What are your opinions about your medications and your doctors?



Post-study interview questions

The post-study interview will be conducted in the following steps:

- 1. The participant will return the Edesix body camera and Time-Use Diary.
- 2. Data from the body camera will be downloaded to a secure computer.
- 3. The video from the body camera will be converted into screenshots, with one screenshot taken for every 10 seconds of video footage.
- 4. After video download and screenshot conversion, the videos will be deleted, and the participant will view the screenshots alone, and has the right to delete any or all the images.
- 5. The research team will conduct a 30 40 minutes interview with the participant, where he/she will describe the study day, with the assistance of the images and the Time-Use Diary, focusing on any specific health-related activities (e.g. Cooking, exercising, social activities).
- 6. The interview will be audio recorded to allow for thematic analysis.
- 7. The researchers may also ask participants to clarify the activity in any screenshots that may appear ambiguous (e.g. ceiling images may imply napping on the sofa).
- 8. The researchers will also check that the time-stamp on the screenshots match the activities reported in the Time-Use Diary (if not, annotate the Time-Use Diary or ask participant questions for clarification).
- 9. The participates will complete the Participant Experience Survey, and give feedback regarding the study.
- 10. The participant will be remunerated with a \$60 Westfield shopping voucher for their assistance.

Questions for the semi-structured interview:

Examples

- Tell us about your day.
- Was this a typical day? If not, what was different on this day?
- What time did you start / stop filling in the Time-Use Diary?
- What time did you start / stop video recording?
- Around what time did you wake up and go to bed last night?
- How did you sleep during the study night?
- Do you always do [activity] at this time of the day?
- Is this the kinds of food you usually eat for breakfast/lunch/dinner?
- You spent a long time doing [activity] yesterday. Is this how long you usually take to do [activity]?
- Do you always do [activity] at [location]?
- Are there changes you would like to make to your daily routine?