**Appendix O: PARTICIPANT INFORMATION SHEET**

**TITLE:** Quality in General Practice - trial of a funding model in primary care.

The general practice you attend is taking part in a research study which is being conducted collaboratively by the University of Wollongong, Monash University and the University of Tasmania. The general practice you attend has sent this letter to you directly; your details have not been shared with the Universities who are conducting the research.

**INVESTIGATORS**

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| --- | --- | --- |
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**What is the purpose of the research?**

The study aims to evaluate the impact of an alternate approach to general practice, including a new funding model. The study will test whether changes such as longer consultations with the GP and rapid follow-up with the GP after significant health events (e.g. being in hospital) assist patients to have better quality of care and clinical outcomes.

**Why have you been contacted?**

For this study we are interested in older people and people with a chronic illness. You have been invited to participate in this project because the general practice you attend looked at your health record and identified that you are a regular patient at the practice and are either over 65 years of age or have been diagnosed with a chronic health condition.

**What will happen if you say yes?**

This study is a trial where two groups are compared. The general practice you attend has been allocated to the group that will offer you treatment according to the alternate approach. This may include longer visits with your GP or being seen rapidly for follow up after an event such as hospitalisation. In other practices in the study, the GP will be managing the care of their patients according to their usual approach. By comparing the two groups of practices we will be able to identify whether or not the new approach helps older people or people with chronic conditions to have better quality of care and clinical outcomes.

If you say yes and give permission on the accompanying consent form, your **linked health data** will be accessed by researchers for an additional five years following the trial to help compare long term outcomes across the two groups.

**What is linked health data?**

Statistical information (data) about population health exists in a number of NSW and Commonwealth databases, for example databases recording hospital admissions or the use of ambulance services. Information in these databases is de-identified to protect your privacy; this means we cannot tell who you are by looking at the health data. Data about your health can be ‘linked’ to help researchers understand health trends and problems. In this study, we would like to link data from our study (looking at an alternate approach to primary health care) with existing health data. Specifically we are hoping to link data from:

* Public hospital admissions, emergency department visits and death registry records
* Medicare Benefits Scheme (MBS) (your visits to health care providers)
* Pharmaceutical Benefits Scheme (PBS) (your use of prescription medicines)

Any de-identified information gathered from these sources will be treated completely confidentially and will never be used by us for any purpose other than for this research. The linked health data will be retained for five years and will be destroyed after the completion of the project.

**Who decides whether the researchers use your linked health data?**

You decide whether the researchers use your linked health data – it is not a compulsory part of the study. You can tick the box to opt-out of sharing your linked data on the research consent form. You can still take part in the study even if you choose not to share your linked health data.

In order to fulfil the strict requirements for data linkage, if you would like to share your information you will need to fill out two separate consent forms – one for the researchers and one for the Department of Human Services (DoHS) who hold the MBS and PBS data.

You will be asked to fill out a consent form authorising the study to access your complete Medicare and Pharmaceutical Benefits Scheme data as outlined on the back of the DoHS consent form. Medicare collects information on your doctor visits and the associated costs whilst the PBS collects information on the prescription medicines you have filled at pharmacies. The consent form is sent securely to the DoHS who hold this information.

**What will you be asked to do?**

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| What we will ask… | What it will tell us… | How we will get the information… |
| That you give permission to access your health data for the previous 12 months & for the 12 months of the trial.  That you give permission to access your linked health data for five years following the trial. Please note this is optional – you can still take part in the trail and choose **not** to have your linked data included. | The number and types of medical conditions you have, the number and length of your medical consultations, number of prescriptions provided, number of pathology and radiology results received and whether you have been hospitalised.  When you access and use the health system including any hospitalisations, use of the Medical Benefits Scheme (MBS) or Pharmaceutical Benefits Scheme (PBS). | Your practice will conduct quarterly audits of your health record and the research team will collect baseline and 12 month data  By accessing the Medicare Benefits Scheme, Pharmaceutical Benefits Scheme, the NSW, VIC or Tasmanian Hospitalisations and National Mortality Register. |
| That you complete a survey at the beginning and the end of the trial | Your views and experiences regarding your health and the health care you receive. | You will have to choice of receiving surveys by phone, post or online. The survey will take a total of about 30 minutes to complete. |
| That you take part in two 30 minute telephone interviews; one before and one after the trial (at least 12 months apart) | Your thoughts and ideas about what the trial might be like; your experience of participating in the trial. | A researcher will contact you to make a time for a telephone interview to take place. A member of the research team will conduct the interview over the phone. |

You will receive a $20 Coles Myer Gift Card each time you complete the three surveys & a $30 Coles Myer Gift Card if you take part in an interview. These cards are our way of saying thank you for giving up your time to take part in this research.

**Are there any risks or burdens?**

Aside from giving up your time, we do not expect any direct burdens for you associated with the study. If you consent to the use of linked health data, there is a small risk to your privacy because personal information is used in the linkage process. Strict measures are used to minimise this risk so that researchers never see your name, date of birth or address connected to individual health data. At the time of linkage, a unique personal identification number will replace your personal information.

Your involvement in the study is voluntary and you may withdraw your participation from the study at any time. You may also withdraw any data that you have provided up until analysis is completed. Declining to participate in the study will not affect your relationship with your medical practice, the University of Wollongong, Monash University or the University of Tasmania.

Findings from the study will be published in a report. A copy of the final report will be available to any interested person by contacting the researchers. It is also intended that the findings will be presented at conferences and in journal publications. You will not, under any circumstances, be identified (named) in any reports, publications or presentations arising from this research.

**What are the benefits of the research?**

We do not expect that there will be direct clinical benefits associated with this study. However, there may be benefits (ie longer or same day appointments) associated with the use of the alternate approach to care for those in the intervention group. We hope that participants will benefit from the knowledge that they have contributed to research that may help improve health care for others.

**FUNDING**

This project is funded by the Royal Australian College of General Practice.

**What happens if I don’t want to take part?**

Even if the general practice you attend enrols in the study, you must consent as an individual in order to take part. If you do not want to take part, and do not return the consent form provided, nothing about your normal care will change. We will not contact you again about this study.

**ETHICS REVIEW AND COMPLAINTS**

This study has been reviewed by the Human Research Ethics Committee of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UOW Ethics Officer on (02) 4221 4457.If you would like to know more about this study, or have any questions or queries, please contact Chief Investigator Prof Andrew Bonney (02 4221 5473).

If you are interested in taking part in the study we ask that you complete the consent forms included in this information pack.

Thank you for taking the time to read about the study.

Sincerely



Professor Andrew Bonney