

26 May 2017

Good Afternoon,

At Gold Coast Hospital and Health Service and Griffith University, we are interested in YOUR health and wellbeing. A group of leading edge researchers are studying how your health condition is managed and how we can provide recommendations to the health community to ensure you and others suffering long term conditions can receive the best service possible. Could you read the information below and see whether you would be able to fill out some of this information to help us ensure that Gold Coast Hospital Health services are world class. We also have a little reward for you if you are able to participate.

If you do decide to become part of our study and send us your responses **within a fortnight of receiving this invitation**, you will go into a draw to win one of 250 **\$20 gift cards** (redeemable at Coles, Myer, Coles Express, Target, Kmart, Liquorland, Vintage Cellars, 1st Choice Liquor Superstores and Officeworks). If you decide to complete the next round of surveys over the next 3 years, we will put your name in three further draws for Coles/Myer gift cards for **\$100** (at 1 year), **\$500** (at 2 years) and **\$1,000** (at 3 years).

Please turn over the page to see what the study involves and the assurances we have put in place to guarantee your privacy as well as how to contact us for further information.

Sincerely

Professor Paul Scuffham
Principal Investigator
Gold Coast Integrated Care Program Evaluation

WHY IS THIS RESEARCH/EVALUATION BEING CONDUCTED?

The Gold Coast Hospital and Health Service and Griffith University researchers are undertaking a project to evaluate alternative models of health care provision. Your experiences with health care is important to us in understanding how to design the most effective health care for the elderly and those with chronic and complex conditions such as diabetes, chronic obstructive pulmonary disease, renal and cardiac disease.

The research/evaluation will evaluate Gold Coast Hospital and Health Service activities to determine the impact, quality and effectiveness of models of care provided by Gold Coast Health Services. First, we will determine whether the Gold Coast Health Service model of care reduces overall costs to the Gold Coast Hospital and Health Service for chronic and complex health conditions.

The secondary aims of this evaluation/research are to evaluate whether the model of care:

- reduces unplanned admissions to emergency departments, and hospital inpatient episodes;
- improves clinical service quality including process and outcomes for high risk patients;
- improves patient experience and satisfaction with care;
- improves staff experience and satisfaction with care.

WHAT INFORMATION ABOUT YOU WILL BE COLLECTED?

We are asking you to consent to us accessing two types of information. The first is routine data collected and stored in the Gold Coast Hospital and Health Service records. The second is to consent to us accessing your Medicare (MBS) and pharmaceutical (PBS) claims data (form C) from the Commonwealth Government Department of Human Services. The list below outlines the information we would like to evaluate:

- Number of hospital and emergency department admissions, diagnosis, length of stay in hospital, number of specialty visits – collected 3 years retrospectively and for the duration of the evaluation (from March 2015 – December 2018) from Gold Coast Hospital and Health Service records;
- MBS and PBS claims information collected by the Commonwealth Government Department of Human Services.
 - For MBS claims, this includes: claim details (date of service, the Medicare item number, item description), costs (the charge by the provider, the schedule fee, benefit paid, patient out-of-pocket cost, whether the service was bulk-billed), service provider information (date of referral, your GP's provider number, your GP's postcode, hospital indicator for hospital services billed to Medicare). Data collected excludes information on the purpose of the visit to a GP or any medical condition you may have;
 - For PBS claims, this includes: claim details (item description, date of supply, date of prescribing, item code and description), costs (patient category, patient contribution, net benefit) and prescribing details (prescriber number, class of medicine).
- Health outcomes including quality of life collected upon commencement into the program through a short survey (form D), and again at 12 month intervals until December 2018;
- Patient satisfaction – assessed by a survey (form D) upon commencement into the program, and then again at 12 month intervals until December 2018;
- Costs – collected from Gold Coast Hospital and Health Service records, which include the number of hospital and emergency department admissions.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to fill out a consent form authorising the study access to your complete MBS and PBS data as outlined on the back of the consent (form C).

Medicare collects information on your doctor and specialists visits and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to the Department of Human Services who holds this information confidentially.

You will also be requested to complete a written survey (Form D) – one now, and then three more will be posted to you in the mail for you to complete and return in a reply paid self-addressed envelope at 12, 24 and 36 month intervals. Each survey will take approximately 10-15 minutes to complete. If you require any assistance in completing the questionnaire, please contact a member of the research team Lauren Ward on 1300 004 242 for assistance.

WHAT ARE THE EXPECTED BENEFITS OF THIS EVALUATION?

It is expected that this research will increase clinicians' and policy makers' understanding of how best to coordinate care for people with complex and chronic conditions, so as to provide the most effective healthcare. Information and data will be used to provide evidence of the impact of the care activities and provide an informed basis for review and future planning of services.

HOW WILL THE CONFIDENTIALITY OF MY INFORMATION BE KEPT?

The research team will gather information from Gold Coast Hospital and Health Services records, and MBS/PBS data from the Commonwealth Government Department of Human Services. Your personal information such as address, telephone number and date of birth, as well as questionnaire responses will be stored in a locked filing cabinet in a secure facility at Griffith University. Your information will not be shared with a third party unless informed consent is given. The collected information will be entered into a computerised database which will be protected by password. No identification of individuals will be published. Consent forms will be kept securely in a locked cabinet at Griffith University for seven years and then destroyed.

ARE THERE ANY RISKS TO ME?

There are no significant risks associated with participation in the evaluation/research project. All information will be de-identified and your identity will not be revealed to other parties.

YOUR PARTICIPATION IS VOLUNTARY

Involvement in this evaluation/research project is voluntary. If you choose not to participate it will not disadvantage you in any way and will not affect your relationship with the Gold Coast Hospital and Health Service, any health staff, your GP or the care provided to you. At any point you are free to withdraw from the study by contacting the research team (Lauren Ward on 1300 004 242 or l.ward@griffith.edu.au) and completing a *Revocation of Consent* form.

THE ETHICAL CONDUCT OF THIS RESEARCH

Gold Coast Hospital and Health Service and *Griffith University* conduct research in accordance with the *National Statement on Ethical Conduct in Human Research*. If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Research Ethics Coordinator on (07) 5687 3879 or email GCHEthics@health.qld.gov.au.

FEEDBACK TO YOU

At the completion of the study it is anticipated that the findings may be published in a research journal and presented at scientific conferences. Any publications and presentations would include de-identified data only and in no way identify individuals. A summary of the findings of the evaluation will be made available to you upon request.

PRIVACY STATEMENT

The information collected is confidential and will not be disclosed to third parties. Any information collected will be used for this project only. Anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 5585.

PRINCIPAL INVESTIGATORS

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QUESTIONS/FURTHER INFORMATION

Should you have any questions or comments about this evaluation at any point in time, please contact the following evaluation project representative: Lauren Ward at l.ward@griffith.edu.au or 1300 004 242.

PLEASE FILL OUT, SIGN AND RETURN FORMS B, C AND D IN THE REPLY-PAID ENVELOPE PROVIDED.

THANK YOU.