

Appendix 3 – CareTrack Information for Participants

SA PARTICIPANT INFORMATION SHEET

We invite you to participate in the study ‘CareTrack Australia: who gets what healthcare from whom and why?’ Your participation in this study is voluntary and is greatly valued.

What is the study about? CareTrack Australia is part of a National Health & Medical Research Council Program Grant for improving the safety and appropriateness of healthcare. Researchers from the Universities of New South Wales and South Australia are recruiting adult participants with at least one of the 22 medical conditions to determine who is receiving what care, from whom and why.

Background Although Australians currently receive good healthcare, there is considerable variation, and all the healthcare needed will not be able to be provided in the future unless we ensure that the funds available are spent in the best possible way.

How did we choose you? The telephone number we called you on was randomly selected from a list of numbers provided by Telstra. There was no attempt to match the number with a name or address. The address you provided us with was entered into a completely separate database and will be deleted at the end of our contact.

What will be asked? We will be asking you about your experiences with your healthcare providers over the past two years (all providers - including alternative practitioners): how many conditions you have, who manages them and if there have been any problems. You will also be asked some personal questions such as your age and gender. Your answers will be entered straight into a secure computer database. The interviewer will also request your consent to access your medical records to determine to what extent the care you have been or are receiving is inline with evidenced based care, and the records held by Medicare for the previous two years to assist us in contacting your healthcare provider/s

What if I am not sure that I want to participate? Your participation is voluntary and you may withdraw from the study at any time and your care will not be affected. There are no direct risks from your involvement. If you have decided that you no longer wish to participate in the study and would rather not be called again, please contact the survey supervisor on freecall 1800 355 534 so that we can remove your number from the call schedule.

What happens to my information? All records which contain identifying information (such as name and address) remain confidential and are stored separately (in password protected files) from information relating to your healthcare. All of the information collected will be kept securely at the Hunter Valley Research Foundation for a period of seven years. All study personnel with access to your healthcare records will strictly adhere to the relevant state and national privacy laws.

Data will be de-identified; all addresses and telephone numbers will be deleted. All analysis will be on a group basis; we will not release individual answers. When the study is complete, the results will be available to the public in summary form in publications and journal articles. As the study needs to be based on a good representation of the community, we hope you will agree to participate

Are there any risks associated with the study? It is possible that questions about your experiences with your healthcare and/or your healthcare providers could trigger unpleasant memories or cause emotional upset. If this happens, you might choose to terminate the interview and pull out of the study entirely, terminate the interview and continue at a later time, or request some numbers from the interviewer for independent assistance.

Who else can I contact at the University to discuss my involvement? This research has been approved by the Southern Adelaide Flinders Clinical Human Research Ethics Committee.

In addition the following Human Research Ethics Committees (HREC) have provided approval for the study to be conducted: Hunter New England, University of New South Wales, SA Health, Tasmania Health, ACT Health, Royal Adelaide Hospital HREC, Royal Australian College of General Practitioners, and The Queen Elizabeth Hospital/Lyell McEwin Hospital HREC.

Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, please contact:

- ❖ Tamara Hunt, on (08) 8302 1004 who is a member of the study team or
- ❖ Associate Professor Simon Carney, Chairman SAFC HREC on 8204 4507 or email research.ethics@health.sa.gov.au

Professor Bill Runciman

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