Appendix B

Helping people to choose wisely: Evaluating methods for shared decision making in populations with different levels of literacy

What is the study about?

We are doing a research study to try to work out what is the best way of helping people to work with their doctor to decide what to do about their health. It can be hard to think of questions on the spot or you might feel like your questions aren’t good enough. This study will look at some tools that help people feel more confident to ask their doctor questions and to explain their point of view and what they think is important.

Who is carrying out the study?

We are from the School of Public Health at the University of Sydney. Our names are:
- Danielle Muscat
- Jessica Smith
- Erin Cvejic
- Josh Zadro
- Kirsten McCaffery
- Edward Hoi-Fan Chang
- Marguerite Tracy
- Rachel Thompson

What will happen if I say that I want to be in the study?

You can decide if you want to take part in the study or not. Please read this sheet carefully so that you can make up your mind about whether you want to take part. Completing a question in the online survey is an indication of your consent to take part in the study.

You may stop completing the online survey at any point if you do not wish to continue, and we will not use your answers. You do not have to give a reason for not taking part. Once you have submitted your survey anonymously, your responses cannot be withdrawn.

If you decide that you want to be in our study, we will ask you to:
1. Complete questions online. For example, about your age, gender, language spoken at home, and answer some questions about a food label.
2. Watch a video or read some information about asking health questions.
3. Read a made-up scenario and pretend that you are visiting a doctor about a sore back.
4. Complete questions online about patient rights, how you feel about asking the doctor questions, and what you think of the tool provided to you in the study.
5. Write some questions you would want to ask the doctor in the pretend situation.
6. We will send you a follow-up survey one month later which will repeat some of the questions from the first study. This will likely take 5 minutes to complete. We will also provide you with a link to the information or health questions that you received so that you can download them if you would like to.

Will anyone else know what I say in the study?

Supplementary material
All of the information that we have about you from the study will be private. It will be stored in password-protected files on password-protected computers owned by the University of Sydney. We will write a report about the study and show it to other people but no one will know that you were in the study.

How long will the study take?

The study will take about 20 minutes.

Are there any good things about being in the study?

This study may help you think more about the questions you can ask when you visit the doctor. It can be helpful to understand more about your treatment options.

Are there any bad things about being in the study?

This study will take up some of your time, but we don’t think it will be bad for you or cost you anything.

By giving your consent to take part in this study you are telling us that you:

✓ Understand what you have read.
✓ Agree to take part in the research study as described above.
✓ Agree to the use of your personal information for the research purposes described above.

What if I want more information about the study or my involvement in it?

You can contact the researcher: Danielle Muscat
- Call: (02) 9351 7819
- Email: danielle.muscat@sydney.edu.au

You are also able to email and request a summary of the final findings be sent to you at the end of the study.

What if I am not happy with the study or the people doing the study?

The ethical aspects of this study have been approved by the HREC of the University of Sydney [Project Number 2018/965]. If you are not happy with how we are doing the study or how we treat you, then you can:
- Call the university on +61 2 8627 8176 or
- Write an email to human.ethics@sydney.edu.au