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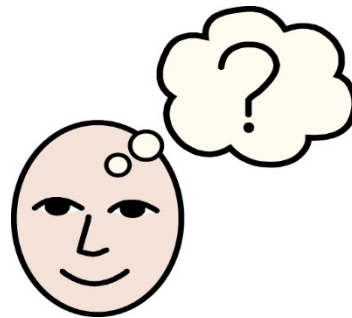
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**Study Information Sheet: Evaluating a revised Edmonton Symptom Assessment Scale for use with Culturally and Linguistically Diverse and lower literacy patients with cancer.**



Hello. Our names are:

- Dr Heather Shepherd, School of Psychology, The University of Sydney
- Dr Joanne Shaw, School of Psychology, The University of Sydney
- A/Prof Haryana Dhillon, School of Psychology, The University of Sydney
- Prof Phyllis Butow, School of Psychology, The University of Sydney
- Joanne Corcoran, Coordinator, SESLHD Multicultural Health Service
- Ms Lisa Woodland, Manager Priority Populations and Director, NSW Multicultural Health Communication Service
- Ms Chloe Lim, School of Psychology, The University of Sydney
- Ms Sharon He, School of Psychology, The University of Sydney

We are doing a research study to find out more about using pictographs (simple images or pictures) to measure health issues in patients who find it hard to read and understand English. This study aims to test if a pictorial scale using pictures to measure health symptoms, is acceptable to patients. This will help health professionals to know what problems patients have so they can give better care and support.

We would like you to be in our study because you may have difficulty reading and understanding health information in English.

You can choose if you want to take part in the study or not. You don't have to - it's up to you.

This sheet tells you what we will ask you to do if you choose to take part in the study. Please read it carefully so that you can make up your mind about whether you want to take part.

If you decide you want to be in the study and then you change your mind later, that's ok. All you need to do is tell us that you don't want to be in the study anymore.

If you have any questions, you can ask us or your family or someone else who looks after you. If you want to, you can call us any time on +61 2 8627 0828.

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

If you decide that you want to be in our study, we will ask you to do these things:

- Answer a questionnaire that asks you some questions about yourself, your age, how many years you went to school, college or university, your health, and if you find it easy or hard to understand health information.
- Complete a scale using pictures to measure health symptoms.
- Take part in an interview about how easy or hard you found it to complete the picture scale and what you think could make it better.

You will complete the scale and take part in the interview at the University of Sydney or online, via Zoom.

An interpreter may be involved in the study when needed.

When we ask you questions, you can choose which ones you want to answer. If you don't want to talk about something, that's ok. You can stop talking or answering questions at any time during the study or interview.

If you say it's ok, we will record what you say on an audio recorder.

### **Will anyone else know what I say in the study?**



We won't tell anyone else what you say to us, except if you talk about someone hurting you or about you hurting yourself or someone else. Then we might need to tell someone to keep you and other people safe.

All of the information that we have about you from the study will be stored in a safe place and we will look after it very carefully. We will write a report about the study and show it to other people but we won't say your name in the report and no one will know that you were in the study, unless you tell us that it's ok for us to say your name.

### How long will the study take?



The questionnaire will take about 10 minutes to do. Completing the scale and the interview will take about 30 minutes.

The study should take a **total of 40 minutes** of your time.

### Are there any good things about being in the study?

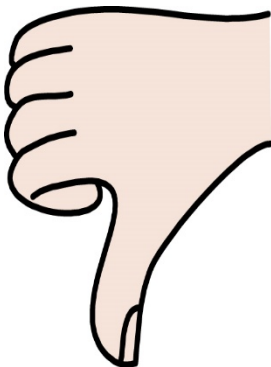


Your travel and parking costs will be paid back to you. This will be done with a voucher, up to \$50.

If you complete the study online, we won't be able to reimburse your travel costs, but we will send you a voucher, up to \$25, for participating and helping us with this study.

The project will help the broader community by understanding whether pictorial versions of health measures are ok for people who come from different cultural and language backgrounds or who find it hard to read and write.

### Are there any bad things about being in the study?



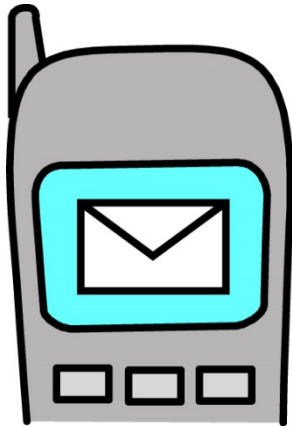
There is a small risk that you might be upset or distressed when talking about some health symptoms. If this happens, please let your interviewer know. If you feel upset after the interview is finished, please ask for help from your GP or another healthcare professional or call Lifeline on 13 11 14.

Costs associated with taking part in this study may include travel costs (e.g., public transport fares or parking fees), however this will be paid back to you when you complete the interview.

### Will you tell me what you learnt in the study at the end?

Yes, we will if you want us to. There is a question on the consent form that asks you if you want us to tell you what we learnt in the study. If you tick **Yes**, we will tell you what we learnt at the end of the study.

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



If you are not happy with how we are doing the study or how we treat you, then you or someone you trust can:

- **Call** the university on +61 2 8627 8176 or
- Write an **email** to [human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)

**This sheet is for you to keep.**

The pictures we used in this sheet are from Microsoft Clip Art and from the people at Inspired Services Publishing ([www.inspiredservices.org.uk](http://www.inspiredservices.org.uk)). They said it's ok for us to use them.