Appendix B

**Plain written version of participant information statement for people with intellectual disability (Victoria)**

**Effective Decision-Making Support for People with Cognitive Disability**

**Chris Lizzie**

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**03 9479 3041 03 9479 1954**

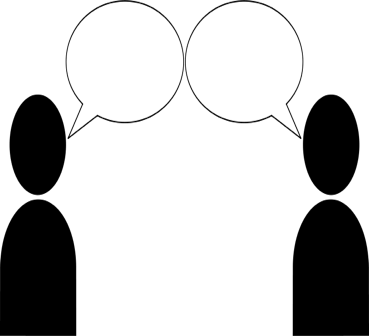
**About the project**

[](https://www.google.com.au/imgres?imgurl=https://cdn2.iconfinder.com/data/icons/windows-8-metro-style/512/decision.png&imgrefurl=https://www.iconfinder.com/icons/174766/decision_icon&h=512&w=512&tbnid=FtaADTUXTbXveM:&docid=U3etu2FBS5HVHM&ei=F_T9VojyD4y20gSvybLoBQ&tbm=isch&ved=0ahUKEwjI2Z-uyOzLAhUMm5QKHa-kDF04ZBAzCA0oCjAK)We all need support to make decisions. People with intellectual disability may need this support provided in different ways.

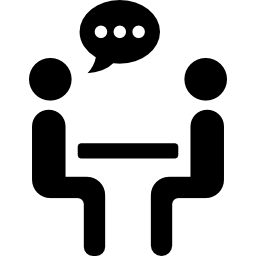
We want to understand the best way to support people to make decisions.

The research is being conducted by 4 universities who work together. The universities are:

* La Trobe University
* The University of Sydney
* The University of New South Wales
* Queensland University of Technology.

 We want to talk to people who have been helped to make decisions, or will be helped in the future.

We also want to talk to a person you have chosen to help you make decisions. The person you have chosen to help you to make decisions will attend classes to learn how to support you to make decisions about your life.

* We would like to interview you 5 times over the next year.
* We will ask you questions about what it is like being supported to make decisions.
* We will ask what you like, and what you don’t like, about this support.

The interviews will be held somewhere easy for you to get to. The interview will be about an hour.

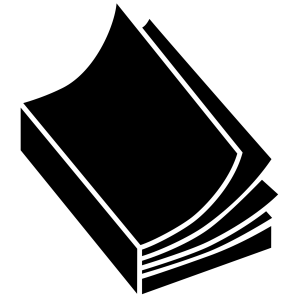
During the interview we will also help you to fill out a **survey**. This survey will take about 20 minutes. The other 40 minutes will be used for the interview.

The interview will be audio taped and then typed.

Everything we collect will be kept on a computer that only the researchers will be able to see.

**What we will do with the information we collect?**

The findings of the research will be written into a report and may be published in a journal or talked about at a conference.

People will not know that it is you in any of the reports or papers or presentations. We are happy to provide you with a copy of what is said in the interviews and with a copy of the final report and anything else that is written by us about this research.

This research is funded by the Australian Government through an Australian Research Council Linkage Grant. 12 organisations have also helped fund this research.

**Do I have to agree to be involved?**

No. You do not have to agree to be involved in the project and nobody will think badly about you if you do not want to be involved.

[](https://www.google.com.au/imgres?imgurl=http://www.kooziez.com/wp-content/uploads/2011/06/Stop-Sign.jpg&imgrefurl=http://ugi.dromhfg.top/c/black-and-white-stop-sign/19019744&h=2400&w=2395&tbnid=hje8VL3K1mFQyM:&docid=5PaWKNfVsdQV3M&ei=YvD9Vub1LIbTmAXWraPoDg&tbm=isch&ved=0ahUKEwjmrvrpxOzLAhWGKaYKHdbWCO04ZBAzCEkoRjBG)If you want to be in the research you can STOP the interview at any time. You can also say if you don’t want any of your information in the research. You can do this until 4 weeks after an interview.

If you decide to stop and do not want your information to be used you can contact Lizzie by email or phone who will help you fill in a form called “Withdrawal of Consent Form”.

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| **What if I want more information?** | |
| You can ring Lizzie | **Lizzie**  http://www.latrobe.edu.au/staff-profiles/data/images/photos/e5smith.gif  **03 94791954** |
| or you can **email** **Lizzie** | e.smith3@latrobe.edu.au |

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You can talk to us if you have any questions.

**Chris Lizzie**

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**03 9479 3041 03 9479 1954**

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You can ring **Sara** if you want to make a complaint or check if the research is ok. **Sara** is an ‘Ethics Officer’. Call **Sara** on **03** **9479 1443**.



Or you can **email**

[humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au)

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| **Contact details of all researchers** | |
| **Professor Christine Bigby**  Living with Disability Research Centre  La Trobe University  Email: [c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au)  Phone: 03 9479 3041 | **Professor Jacinta Douglas**  Living with Disability Research Centre  La Trobe University  Email: j.douglas@latrobe.edu.au  Phone: 03 9479 1797 |
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