



Participant Information Sheet
The Experiences of Volunteers who use Augmentative and Alternative Communication

Volunteering is very common among Australian adults. Examples include helping out at your local church, teaching others, delivering meals on wheels, and giving up your time to support a not-for profit organisation. Some people volunteer regularly, other people have only volunteered once. We would like to talk with people who use augmentative and alternative communication who have volunteered.

What is the study about?

You are invited to take part in a research project into the experiences of people who use augmentative and alternative communication who act as volunteers in their communities.

We want to learn about:

1. The reasons why people volunteer
2. The benefits that arise from volunteering
3. The ways in which people define successful and unsuccessful volunteering experiences
4. The barriers that people who use augmentative and alternative communication face when trying to work as volunteers
5. The skills and strategies needed to make volunteering a success

Through this study, we will develop recommendations for increasing opportunities and support for people who use augmentative and alternative communication who want to act as volunteers.

Who is carrying out the study?

This study is being conducted by David Trembath as part of his PhD, under the supervision of Associate Professor Susan Balandin and Leanne Togher at Faculty of Health Sciences, University of Sydney.

What does the study involve?

If you choose to participate, David Trembath will interview you on 2 separate occasions about your experiences acting as a volunteer. He would like to interview you at your home or another mutually convenient location, at times that suit you. David will ask you questions such as:

- How did you get involved in volunteering?
- Describe your experiences as a volunteer
- What were the positives and what were the negatives of volunteering?
- What skills do you think people who use augmentative and alternative communication need to volunteer successfully?

David will also collect information about your age, your volunteering experiences, the nature of your disability, your living situation, and your geographical location and access to transport. All information that he gathers will remain confidential and will not identify you. David will audio tape the interview with you and will type up a record of that interview which he will later analyse. The written copy of your interview will remain confidential and will not contain any identifying details about you (e.g., your name or place of work). You may listen to the audiotape of your interview or read the typed copy and delete any or all material you do not wish to be used in the study.

If you become tired or feel emotional during the interview, David will stop the interview to give you time to recover. You can then decide whether you want to continue with the interview or not. If you wish to discuss feelings or experiences raised in the interview in more detail, David will assist by referring you to a counselling service.

David would also like to visit you at the place where you volunteer, to get a better sense of the work that you do and to understand the benefits and challenges that arise for you in your voluntary work. You are allowed to say “no” to David observing, and this will not effect your participation in the study or your relationship with the University or other organisations. If however, you do agree to me observing you while you volunteer, David will also ask for permission from the organisation with which you volunteer. Following completion of the study, David will provide you with a report of the outcomes of the research including any publications that arise.

How much time will the study take?

Each interview will take approximately 1 ½ hours. You can take a break whenever you need one. A friend or family member is welcome to join you during the interview.

Can I withdraw from the study?

Participation in this study is completely voluntary. You do *not* have to participate, and should you choose to participate you can stop participating at any time. Participating or not participating in the study will have no affect on your relationship with the University of Sydney or any other service you access either now or in the future.

Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will see information about you (except as required by law). All information collected during the study will be stored in a locked office at the University of Sydney. Only the researchers will have access to audiotapes and written information. The combined results of interviews may be published in academic journals or presented at conferences; however the information will be presented in such a way that you will not be identified.

Will the study benefit me?

We hope that sharing your experience of working and volunteering will be enjoyable, and that through sharing your experiences you may be able to help other people who want to volunteer in the future. However, we cannot and do not promise that you or anyone else will receive any benefits from the study.

Can I tell other people about the study?

Yes, you can tell anyone about the study, including other people who might be interested in participating.

What if I require further information?

If you would like to participate or need further information please call David Trembath on (02) 9351 9870 or send him an email at D.Trembath@usyd.edu.au . You can also call Susan Balandin on (02) 9351 9334 or send her an email at S.Balandin@usyd.edu.au

What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, University of Sydney on (02) 9351 4811 or email G.Briody@usyd.edu.au