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Online Facebook Participant Information

Project title: Listening Together: On-line Community for the Hearing-Impaired Older Adults

Co -Investigator:

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Invitation

We would like to invite you to take part in a research study that is investigating whether an online Facebook community can help people with hearing loss to feel less socially isolated and to improve mental health. This is a collaborative research project between Ear Science Institute Australia (ESIA), WA Centre for Health and Ageing (WACHA), University of Western Australia (UWA) and Edith Cowan University (ECU). This study is part of a UWA Masters of Audiology Student Project for Ysraelle Tan (22261019@student.uwa.edu.au)

To be eligible for this study, you will need to be over the age of 18 and have a hearing impairment. If you have an untreated or acute mental health condition, you will be asked to not take part in this study. However, you will be provided with information about where you can find support for your condition. If you meet our criteria, you will be asked to complete an online survey relating to your demographic details, hearing loss, levels of social support, and mental health. The results from these questionnaires will determine whether you are eligible for the online component of the project.

What does participation involve?

If you think you are eligible and would like to participate in this study, please tick the consent section on the next page and email it back to the Principal Researcher, Dona Jayakody. You can then click on the Facebook page link provided in the email.

You will need to 'request' to join the closed Facebook page. Before joining the Facebook page, you will be asked to complete an online Survey relating to your hearing, social support, and mental health which will take approximately 30 minutes to complete. Your responses will determine if you are eligible for the Study. If you are eligible, you will be asked to read the 'About This Group' section which clearly states the Facebook Page is a part of a research study. You will also be asked to read and accept the 'Eligibility Criteria Section' and accept the 'Group Rules Section' before you are given



access to the Facebook page. If you are not eligible, you will not be given access to the Facebook Page.

The Facebook page will be a closed online community that will only be accessible to individuals who have been invited by the project researchers. You will be free to use your real, legal name or an alternative identity when you join the Facebook page. You will be asked to provide both your legal name, Facebook name, email address, phone number and GP contact details to the research team when you complete the online Survey. This information will only be accessible to the research team and will allow researchers to contact you or your GP if there are concerns about your safety or wellbeing.

All comments and posts and activities may be used for research purposes. The Facebook page will be moderated by the student researcher to ensure that discussions are supportive and safe. The platform will contain links to hearing loss information as well as other health-promoting materials designed to enhance your personal health and wellness.

It will be expected that you commit at least 15 minutes a day, 4 days a week, for 3 months, to the Facebook Group. You can take either an active role (eg. making posts and comments) or a passive role (eg. reading posts, looking at resources/links from the Group) or both, depending on your level of comfort. In addition, you will be asked to attend the weekly presentations that are organised and may take 30 minutes of your time each week.

If you are not familiar with Facebook or you would like more information on how to stay safe online, you are encouraged to visit the Australian Government “Be Connected” website (www.beconnected.esafety.gov.au) for information and learning resources on how to stay safe online. In particular, we would encourage you to read the article:

<https://beconnected.esafety.gov.au/quick-reads/how-to-stay-safe-on-facebook>

After a period of 3 months, you will be asked to complete the Online Survey again which may again take 30 minutes of your time. You will also be invited to complete an informal exit interview with one of the researchers. This interview will be completely optional with no obligation to take part. The interview may take up to 1 hour of your time. The purpose of the interview will be to explore how you experienced the study and the Facebook platform. You will be given the choice to complete the interview online (through Facebook direct messaging), by phone, or in person. If in person, please note that all COVID-19 government policies and procedures will be followed.

Possible benefits of participating in this research

Your involvement will allow us to determine whether a Facebook online intervention has positive effects on social isolation and mental health in older adults with hearing impairment.

Possible risks of participating in this research

The risks associated with this research project are minimal. Completing the short questionnaires is similar to what you would expect when completing an online survey.

There is a small possibility that an individual participant on the Facebook page may act inappropriately or say things that are distressing, insulting or offensive to other participants. This risk will be mitigated by:

- Participants consenting to the Facebook Group Rules prior to joining the Facebook page.
- Participants being warned, banned or blocked from the Facebook page if they do not adhere to the Facebook Group Rules.
- An online moderator screening and monitoring the online discussions whenever possible.

There is a possibility that you may use Facebook in an unsafe manner due to lack of familiarity with the online platform. To ensure that you have a safe Facebook experience, we recommend that you visit the following websites for advice:

www.beconnected.esfatey.gov.au

www.beconnected.esafety.gov.au/quick-reads/how-to-stay-safe-on-facebook

There is a possibility that we might come across results that may be of concern for your health and well-being. If you consent, clinically relevant information arising from your assessment will be forwarded to your treating GP. This will include the scores of the DASS-21 and the respective categories (no, mild, moderate, severe, extremely severe).

The exit interview may cause some inconvenience due to the duration (up to 1 hour) and travel (if you choose to meet in person). If you choose to do the exit interview in person, there is an added risk of possible COVID-19 exposure. However, please note that all COVID-19 government policies and procedures will be followed for in-person interviews. There is also the option of doing the interview online or by phone for safety and convenience.

Voluntary participation and withdrawal from the study

Participation in the study is completely voluntary. Your consent to participate may be withdrawn at any time without any reason given. If you withdraw from this study we will delete the collected data and Facebook posts.

However, please note that any data posted on Facebook will be subject to Facebook's data policies and that even if posts are deleted by the researchers, they may still exist on a Facebook server. You can read the Facebook data policy website if they would like to read more information about this (<https://www.facebook.com/policy.php>). You can also visit the Be Connected government website for information on how to set up their Facebook accounts in a way that maintains your privacy and safety:

- 1) <https://beconnected.esafety.gov.au/topic-library/social-media-apps/introduction-to-facebook>
- 2) <https://beconnected.esafety.gov.au/topic-library/social-media-apps/using-facebook>

Your privacy

You will be asked to provide your legal name, Facebook name/identity, email address, phone number and GP contact details when completing the online Survey. Your data will be stored in a confidential manner using the UWA Institutional Research Data Store (IRDS) in a password protected computer on a secure server. All information will be de-identified before it is stored. Information arising this project may be published but identifying details will not be used in any publication arising out of the research without the participant's consent. The data will be kept in line with the WA University Sector Disposal Authority (WAUSDA) in a non-identifiable format, in a password protected computer or a secure server."

The WAUSDA Guidelines 14.6.5 Conducting Research does not set a minimum retention period. Conducting research with outcomes that are classed as minor, not covered by other minor research classes are required to be retained for a minimum of 7 years after date of publication, or 7 years after conclusion of the project, whichever is later, then destroyed.

How the results and data will be stored?

The data will be stored using the UWA Institutional Research Data Store (IRDS) kept in a de-identified format in a password protected computer or a secure server for minimum seven years. Data will be destroyed seven years after the completion of the study or after the results have been published. Participant records will remain strictly confidential. Personal data will not leave the experimental database in a form that allows participants to be identified. The results of this research will be made available through conferences or professional scientific journals. Your rights under any applicable data protection laws are not affected.

Is there any cost involved for the participants?

There will be no cost involved in participating in this study.

Should you have any questions or concerns about the study, please contact Dr Dona Jayakody on 08-64570541.

Sincerely,

Dr Dona Jayakody
Ear Science Institute Australia
1 Salvado Road, Subiaco WA 6008
Tel: 08 64570541

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.



Consent Statement

I have read the information provided and any questions I have asked have been answered to my satisfaction. I agree to participate in this research project, realizing that I may withdraw at any time without reason and without prejudice. If I withdraw, I understand that my data will be removed from the study.

I understand that all identifiable information that I provide is treated as confidential and will not be released by the investigator in any form that may identify me unless I have consented to this. The only exception to this principle of confidentiality is if this information is required by law to be released.

To participate, please follow this link: <https://www.facebook.com/groups/418218646164752>

Thank you.