

**Plain Language Statement: Individuals**

Date: 16/12/2021

Full Project Title: Setting Recommendations: How should information about infectious disease outbreaks be shared in disability group homes? (Project reference #: HEAG-H 134\_2022)

**Principal Investigators (Deakin University):**  Dr Kate Anderson, Dr Joanne Watson

**External Investigator (Able Australia):** Dr Meredith Prain

**External Investigator (University of Waikato):** A/Prof Patsie Frawley

**Additional Researchers (Deakin University):** A/Prof Angela Dew, Dr Amie O’Shea, Dr Olumuyiwa Omonaiye, Dr Jennifer David, Mr Dion Williams and Ms Jenny Crosbie.

For further information, please contact:

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Email: kate.anderson2@deakin.edu.au

Phone: (03) 9251 7850

**Project Description**

This e-Delphi study is part of a research project examining health-related communication practices in disability group homes. We want to establish how information about COVID-19 and other infectious disease outbreaks should be communicated within group homes. This project will be conducted in the spirit of open mindedness and problem solving. It will help us to develop health-related communication strategies and resources for group home settings.

**What is involved in the e-Delphi study?**

An e-Delphi study is a type of research, where a panel of experts (people who have lived or professional experience about a topic) come to a decision about good practice. We are looking for group home carers/support workers, group home managers, and advocates for group home residents, who have at least 3 years’ experience in these roles, to take part in this research.

As an expert panel member, you would complete between 2 to 4 short, online surveys over 6 weeks. Each survey will ask you to rate how much you agree with specific recommendations about communication practice. For example: “Videos are a helpful way of sharing information about disease outbreaks in group homes”. You can also write a brief explanation for your ratings or suggest changes to the way the recommendations are worded. Your personal ratings or suggestions won’t be shared with anyone outside of our project team.

At the end of each survey, we will compare the ratings across the group to look for areas of consensus (agreement). Recommendations that most of the experts agree with will be kept and eventually shared with others in reports and published resources. If the experts can’t agree on a recommendation, it will either be rejected or re-worded. You will be asked to vote any re-worded recommendations in a later survey. We estimate that 3-4 survey rounds will be required for us to get a consensus and finish the research.

**Who can participate?**

You can participate in this study if you are:

* a **support worker in a disability group home** and you have supported residents with intellectual disability for a minimum of 3 years, OR
* a **manager in a disability accommodation service** that runs group homes, and you have a minimum of 3 years’ experience in that role, OR
* an active member of a **disability advocacy group or organisation** and you have supported or advocated for at least one group home resident with intellectual disability in the past 3 years. You may be a family member, volunteer, or working in a paid support role.

Please contact us if you are unsure about your eligibility to participate.

We will be recruiting up to 12 people for each expert group.

**Data Privacy and Confidentiality**

We will take the following measures to protect your privacy and that of your organisation:

* This consent form will be kept in a secure digital drive or locked filing cabinet that is only accessible to members of the immediate research team (Dr Kate Anderson, Dr Joanne Watson, and the project Research Assistants).
* We will not ask for your name, organisation, the names of people you support, or other identifying information in the survey.
* We will not share your name or other personal information with other experts in the research. We will not publish your name or other personal information in our research reports or publications.

Please note that you have a responsibility to protect the privacy of others. We request that you do not include residents’ names, organisation details, or other personal information in your survey responses.

**Benefits**

We cannot promise that you or your organisation will benefit by participating in this project. However, you will gain access to current research findings about COVID-19 communication priorities and strategies that may be of interest to your work. The results of this project may benefit your decision making and communication practises during COVID-19 and other health emergencies.

The findings will also be reported back to the Australian Government, to inform future research and funding priorities and policy directions concerning infection control and health messaging in group home facilities.

To acknowledge their contributions, participating experts will receive $20 for their first survey completion and another $30 for completing the whole e-Delphi study.

**Risks**

We will do all we can to keep your details private. We will do this by making sure anything published about the project does not include information that will be identifiable, such as names and locations. We do not know of any other risks from participating in this study.

We recognise that the COVID-19 pandemic has presented many challenges to those living in, working in, or managing group homes, and this can be difficult to reflect on. You can withdraw from this project at any time if you feel uncomfortable. Lifeline is a free online counselling service that support workers can call at any time on 13 11 14. For advice on any concerns relating to residents’ wellbeing and safety, you can also call the Office of the Public Advocate on 1300 309 337.

**Participation is voluntary**

Participation in this project is voluntary. If you do not wish to participate or would like to end your involvement in this project, there will be no penalty. In other words, you are free to make your own choice about being in this project or not.

Once you have submitted your survey, you will have one week to change your mind about participating. To withdraw your survey please contact Dr Kate Anderson via kate.anderson2@deakin.edu.au or 03 9251 7850, or return the withdrawal form enclosed with this document. After one week your survey can’t be removed from the study, but we can withdraw you from any future survey rounds.

Deciding not to participate or withdrawing from the study will not affect your relationship with the researchers or with Deakin University. Your organisation will not know who has or has not participated.

**Funding of the Research**

This project is paid for by the Australian government. The grant scheme that pays for the project is the national Medical Research Futures Fund (MRFF), under the **2020 Communication Strategies and Approaches during Outbreaks grant opportunity.**

**How can I find out about the results?**

We will share the results of each survey round with you. A final summary report will be sent to you when the project is finished. You can share the final report with anyone you like.

Please contact us (kate.anderson2@deakin.edu.au) if you do not want to participate in this study but you would like to learn about other research activities we are running on this topic.

**Complaints**

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

**Human Research Ethics Office**
The Human Research Ethics Office, Deakin University,

221 Burwood Highway,

Burwood Victoria 3125

Telephone: 9251 7129

research-ethics@deakin.edu.au

Please quote project number HEAG-H 134\_2022



**Consent Form**

**Project Reference Number:** HEAG-H 134\_2022

Full Project Title: Inclusive Health Communication in Specialist Disability Accommodation: e-Delphi study.

* I have read and I understand the attached Plain Language Statement, and I have been given a copy of the Plain Language Statement to keep.
* I consent to my participation in the online surveys according to the conditions in the Plain Language Statement.
* I understand that my participation is voluntary. I can say no to participating, and I can stop participating at any time.
* I understand that after I submit a survey, I will have one week to change my mind.
* I consent to the use of the de-identified survey findings in academic journal articles, conference presentations and other publications or public forums.
* I would like to be informed about the results from this study (optional)
* I would like to be informed aboutfurther research opportunities within this project (optional).

I confirm that I am a:

* Support Worker/Carer in a group home facility OR
* Manager of a group home facility OR
* Advocate who supports people who live in group homes

I confirm that I have at least 3 years of experience in this role. □ Yes □ No

Participant’s Name ………………………………………………………………………………………………………………..

Signature ……………………………………………………… Date ……………………………………………………………..

Preferred Contact Details (for future correspondence) …………………………………………………………

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**Withdrawal of Consent Form for Employee Participation**

*Please only complete if you wish to withdraw.*

Full Project Title: Inclusive Health Communication in Specialist Disability Accommodation: e-Delphi study

**Project Reference Number:** HEAG-H 134\_2022

I hereby wish to WITHDRAW my consent for my participation in the above research project.

I understand that my existing survey responses cannot be removed from the study after 1 week of my submitting them.

I understand that such withdrawal WILL NOT affect my relationship with Deakin University*.*

Participant Name …………………………………………………………………………………………………………………..

Signature ……………………………………………………… Date ……………………………………………………………..

**Please send this form to:**

Dr Kate Anderson

School of Health and Social Development

Deakin University, Burwood Campus

221 Burwood Highway

Burwood VIC 3125

Email: kate.anderson2@deakin.edu.au