



## Participant Information Sheet

### Researcher:

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- Dr Brett Scholz ([brett.Xcholz@anu.edu.au](mailto:brett.Xcholz@anu.edu.au)), ANU College of Health and Medicine.
- Prof. Vinh Lu, College of Business and Economics.
- Dr. Michael Chapman, Canberra Hospital, ANU College of Health and Medicine.
- Dr. Conal Monaghan, ANU College of Health & Medicine.

**Project Title:** Consumer Leadership in Palliative Care: A Ranking-Type Delphi and Systematic Framework Development

### General Outline of the Project:

- **Description and Methodology:** This study aims to develop a framework for the best practice of role delineation and training for consumer leadership in palliative care.
- **Participants:** Approximately 30 experts including care professionals, consumer leaders, policy specialists and researchers will participate in the research.
- **Use of Data and Feedback:** We can provide you with manuscript drafts if you would like to read and comment on them. The results of this project will likely be published in peer-reviewed journals. The results of the project may also be discussed at academic conferences, or as part of community presentations. If you would like to remain updated about how this research is shared (in article format, in presentations, etc.) please email us and we will share any research outputs with you as they are created.

### Participant Involvement:

- **Voluntary Participation & Withdrawal:** Participation is completely voluntary. You can withdraw at any time. There will be no repercussions should you wish to withdraw from the research. You may choose not to answer any of the questions we ask you.
  - Within 12 weeks after the last survey, you may request that any information you have provided not be used or to be edited, without needing to provide a reason and without prejudice. In this event, we will remove or edit all information you request for all future analysis and research outputs (presentations, publications, etc.). Since no identifiable information will be recorded, participants desiring data removal or editing must save their response summary after each survey and forward their requests to the primary investigator. Participants opting to discontinue the survey midway are advised to submit empty responses for the remaining questions to generate a summary of their provided answers if wish to edit or remove data in future.
  - However, please bear in mind that once your contributions have been analysed along with other participants' contributions, it may not be possible to reverse the influence your contributions have had on the study's conclusions. If this is the case, we will discuss it with you as soon as practicable.



- **What does participation in the research entail?** Should you agree to participate, you will be asked to take part in several rounds of questionnaires.
  - We will email each round of questions to you through a link to an online survey platform. We can discuss alternatives if you have difficulties with online surveys.
- **Location and Duration:** The surveys will be online. In the first round, we will ask you to tell us about your experience in consumer leader engagement and share your thoughts on the basic principles and objectives of consumer leadership. In subsequent rounds, we will ask you to provide feedback on the framework's key area of focus and implementation strategies and finally reach a consensus on the design put forward by participants in the earlier round of this study.
  - We expect that each round of questions will take participants around 20 minutes to complete. We expect that we will be asking you to participate in 4 rounds of questions.
- **Remuneration:** Participants will receive a \$20 coupon remuneration for each round of survey completed.
- **Risks:** Talking about dilemmas faced in the context of consumer work can be distressing and it is possible that you may encounter some discomfort when writing about your experiences in this project. You will be supported by a multi-level safety net that will be available in the event of any distress experienced. These levels include:
  - Peer support: Members of the research team are experienced consumer workers who are skilled in supporting people to access peer support services.
  - Personal and professional networks: If you become distressed during the survey, members of the research team can assist you in connecting with social, professional and support networks, which include mental health professionals, or with whom you are familiar or connected.
  - External support: If you are not already networked with support systems, available supports will be discussed and information on how to access these supports will be provided.
    - Please let us know if you experience distress.
- **Benefits:** This study aims to contribute to a growing body of research on consumer leadership, from consumer perspectives. This research will enable us to better understand the pros and cons of previous consumer leadership projects and how consumer leadership can be better promoted and supported in palliative care.
- **Will I hear about the results of this project?** Yes. We can provide you with manuscript drafts if you would like to read and comment on them. The results of this project will likely be published in peer-reviewed journals. The results of the project may also be discussed at academic conferences, or as part of community presentations. As mentioned in "Use of data and feedback", If you would like to remain updated about how this research is shared (in article format, in presentations, etc.) please email us and will share any research outputs with you as they are created.

#### **Confidentiality:**

- **Confidentiality:** Your email address is kept completely confidential by researchers conducting this research. This address will be stored separately from survey responses, for the purpose of keeping all collected information in the survey anonymous. Your survey



answers remain anonymous, with an unidentifiable code being used to connect the data across waves.

#### Privacy Notice:

- In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at [https://policies.anu.edu.au/ppl/document/ANUP\\_010007](https://policies.anu.edu.au/ppl/document/ANUP_010007) and it contains information about how a person can:
  - Access or seek correction to their personal information;
  - Complaint about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

#### Data Storage:

- **Where & how long:** All data management procedures will follow the Privacy Act 1998 (Cth) and the ANU Code of Research Conduct. Survey responses will be collected through an online survey platform and will not be able to be cross-referenced with the email you provided. All data will be stored in encryption software for 5 years from the date of data collection complete. The personal data of participants (your email address) will be destroyed at the end of the study.
  - The information you provide in this study may be analysed in several ways, resulting in publications. You will be able to read and comment on manuscripts for each of these publications. This being the case, please bear in mind that manuscript drafts may be accessed by other participants.
  - Please be aware that although we will de-identify any information you provide to us before analysis, direct quotes you provide may be used in publications or presentations. You will have the opportunity to review any direct quotes we plan to use before they are published or presented. If you do not want us to use any particular quote, because you feel it is identifying or for any other reason, please let us know and we will be able to remove such quotes, up until manuscripts are submitted for publication.
- **Handling of data following the required storage period:** All data will be destroyed after five years after study collection is finished.

#### Queries and Concerns:

- **Contact details for more information:** If you would like more information about the project, please contact the researchers: Zijian Wang at [zijian.wang@anu.edu.au](mailto:zijian.wang@anu.edu.au) or the supervising researcher at [Brett.Scholz@anu.edu.au](mailto:Brett.Scholz@anu.edu.au)
  - This research project has been approved by the Human Research Ethics Committee of the Australian National University. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you could contact the Manager, Human Research Ethics, Research Ethics and Integrity at [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)
- **Contact details if in distress:** If you feel that the content in this research impacted your emotional wellbeing, please discuss it with a professional. Here are some services that you can seek help from:



Service	Description	Contact
Mental Health Australia	An Australian Government website provides information on mental health services in Australia	<a href="http://mhsa.aihw.gov.au/home">http://mhsa.aihw.gov.au/home</a>
ACT Access Mental Health	24-hour mental health emergency access & support	1800 629 354 Or 6205 1065
NSW Mental Health Line	24/7 mental health line available to everyone in NSW	<a href="https://www.health.nsw.gov.au/mentalhealth/Pages/mental-health-line.aspx">https://www.health.nsw.gov.au/mentalhealth/Pages/mental-health-line.aspx</a> 1800 011 511

**Ethics Committee Clearance:**

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2024/511). If you have any concerns or complaints about how this research has been conducted, please contact

Ethics Manager

The ANU Human Research Ethics Committee

The Australian National University

Telephone: +61 2 6125 3427

Email: [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)