



## **PARTICIPANT INFORMATION SHEET**

### **Title:**

Online palliative care and end of life evidence and information: Understanding the role of CareSearch

### **Chief Investigator:**

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### **Other investigators:**

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**Description of the study**

CareSearch provides online access to trustworthy information and resources in palliative care. At the core of this activity is the synthesis and translation of published evidence relevant to palliative care practice for health professionals and for the community. The project already has established quality processes to guide the development of content and its preparation for use in an online format. This research aims to examine the outcomes and impacts of the availability of online palliative care information. This project is supported by Flinders University, College of Nursing and Health Sciences.

**Purpose of the study**

The aim of this research is to examine the value of online evidence and information to individual users and groups involved in the palliative care sector.

**The specific objectives are:**

1. To understand the value and outcomes of online palliative care knowledge to individuals through an online survey.
2. To examine webmetric pathways and incidental/passive data collection through the CareSearch and palliAGED websites.
3. To identify outcomes and impacts of an online palliative care knowledge resource from the perspective of health professional and health consumer organisations and of partner projects.

**Benefits of the study**

The anticipated benefits of this project include developing new evidence about the impacts and outcomes of access to online evidence and assess the role and contribution of the palliAGED and CareSearch websites to knowledge uptake and use within the palliative care sector.

**Participant involvement and potential risks**

If you agree to participate in this research study, you will be asked to:

- Complete an online survey.

**Withdrawal Rights**

You may decline to take part in this research study, and/or withdraw from the survey at any time. Although you will not be identified in any research products, the information collected in this survey may be published. All data collected in this survey will be securely transferred to and stored at Flinders University for five years after publication of the results. Following the required data storage period, all data will be securely

destroyed according to university protocols.

### **Confidentiality and Privacy**

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication, or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. You will not be named, and your individual information will not be identifiable in any research products without your explicit consent. No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

### **Data Storage**

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

### **Ethics Committee Approval**

The project has been approved by Flinders University's Human Research Ethics Committee (HEL5710).

### **Queries and Concerns**

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 2543 or email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).

Thank you for taking the time to read this information sheet.