



# CareSearch: Supporting Death, Dying and Bereavement Research in Australia

Rawlings D and Tieman JJ

Palliative & Supportive Services, Flinders University, Adelaide, South Australia

## Introduction

Research evidence can improve the care that is provided to patients approaching the end of their life and to their families and their carers. Research can inform how care is organised and delivered as well as help to develop national and local health policy. However, there can be challenges involved in researching the often complex field of death, dying and bereavement.

Researchers may use diverse research approaches to explore the question of interest. The work may build upon or challenge existing ideas and practices. There may be difficulty in recruiting sufficient numbers, and multi-site recruitment may need to be considered. There may be difficulties in managing the research processes and finding appropriate resources. Finding ways to see what other research is being undertaken may not be easy and finally, ensuring the community benefit from the findings may be challenging.

CareSearch provides information and resources to help with Death, Dying and Bereavement Research in Australia.

## Why CareSearch?

CareSearch is an online palliative care resource that facilitates access to evidence, provides trustworthy information for the general public and offers a range of tools and resources for clinicians, academics and researchers.

### *CareSearch and Bereavement*

Grief and bereavement are part of palliative care and as such are included within the CareSearch website.

Resources are shaped for the needs of various users. An overview of the state of the evidence on Bereavement is found in the Clinical Practice Section. Information is also provided for those affected by the need for palliative care in the For Patients and Families pages. Special search functionalities enable users to stay in touch with the latest literature.



### *CareSearch and Research*

From the initial conception of the research question to the final dissemination of results, CareSearch has resources to support researchers. These resources fit into the following categories

- > Knowing what already exists on a topic and finding relevant literature and evidence,
- > Collecting and analysing data, and
- > Communicating findings and sharing knowledge.

## Finding Literature

In developing a research proposal finding relevant literature to identify what is known is an important step. Three resources within CareSearch may be particularly useful.



**PubMed Topic Searches** have been constructed using a validated search filter to retrieve literature relevant to palliative care. This has been combined with expert searches on a number of topics relevant to palliative care including Bereavement and Prolonged grief. A hyperlink means the search is automatically run in PubMed.

A **Grey Literature database** capture six sets of palliative care information and evidence that can be hard to find, such as unpublished thesis and conference abstracts

The **CareSearch Review Collection** contains systematic reviews or structured literature reviews relevant to palliative care. They provide an overview of the state of the evidence. Bereavement, Death denying and Desire for death are just three of the topics being collected.

There is also pages looking at bibliographic databases, how to search and searching the web.



## Conclusion

CareSearch resources facilitate research across the palliative care spectrum. The CareSearch website is freely available at [www.caresearch.com.au](http://www.caresearch.com.au).

Those wishing to use the Research Data Management System or Professional Connect should contact the Project Team by emailing [caresearch@flinders.edu.au](mailto:caresearch@flinders.edu.au)

## Research Resources

### **Research Data Management System**

The data collection system has been developed to support research work within palliative care by providing access to a tool that:

- > Enables the online design of data collection forms and questionnaires
- > Allows for web-based and email-based form completion
- > Enables data entry from multiple sites with a single coordinating site
- > Provides for basic reporting of results with features such as percentages, graphs, and tables
- > Allows export of data to other programs such as Excel, Access or SPSS

A **Research Studies Register** of Australian research projects and studies in palliative care, provides a means of sharing information, developing linkages, preventing duplication and promoting awareness of current research.

Other Research Resources pages provide information on **grants and tenders** and on **how to conduct research**.

## Connecting and disseminating

**Professional Connect** provides a platform for groups, teams and networks contributing to palliative care to share information and work together through virtual engagement to share their knowledge and expertise. This can be particularly valuable for teams that are spread across multiple sites and organisations.

CareSearch also provides ways of communicating with intended users of the research from the development of the research idea to the publication of the results.



Planned communications can increase the likelihood of knowledge uptake. There are resources in the Finding Evidence section on **Dissemination Strategies, Publishing in Palliative Care and Contributing to CareSearch**.