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## **Palliative Care Knowledge for All Australians: Librarians' Work within a Multidisciplinary Team Creating a National Health Knowledge Network**

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### **Abstract:**

*This paper introduces Australia's CareSearch Palliative Care Knowledge network, outlining its information services, underpinning principle of evidence-based information and the contribution of librarians, integral to the multidisciplinary team.*

*CareSearch is a federal government-funded project to provide relevant and trustworthy information to clinicians, patients, carers and families about all aspects of palliative care. This subject touches all Australians at some point. The information provided must be accurate, accessible and tailored to users' needs.*

*CareSearch emphasises the importance of evidence-based information to support the best possible care for those at the end of life and their loved ones. CareSearch identifies and enables access to evidence and uses evidence-based research approaches in designing and developing the service.*

*This complex project employs a multidisciplinary skilled team, with a wide range of expertise including medicine, nursing, web technology, education, marketing and informatics.*

*Librarians bring information management expertise into the pool of skills in CareSearch, undertaking identification, classification and organisation of resources. They work with clinicians to ensure relevancy and accuracy, with website technicians for best practice navigation, and with marketing professionals for effective communication.*

*A key innovative aspect of CareSearch's information service provision is the creation of subject-based search filters to target the best available evidence about palliative care (and related topics) in the published medical literature. The librarians at CareSearch and its associated project Flinders Filters*

*follow established methodology to create and test search strategies using a gold standard set of references, advised by external clinical experts. The search filter embeds technical searching expertise into a search strategy link for clinicians to do a reliable real time search.*

*Search filters are embedded throughout the website in clinical evidence pages, as URLs to take clinicians directly into PubMed in hundreds of searches on topics of relevance to palliative care.*

**Keywords:** Librarians; Skills; Search filters; Information services; Palliative care; Cross functional teams

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## 1 INTRODUCTION

CareSearch palliative care knowledge network was launched in 2008, and has been funded by the Australian Government Department of Health since its inception. CareSearch aims to provide relevant and trustworthy information to clinicians, patients, carers and families about all aspects of palliative care. For consumers, it is a “safe place” to find information; for those whose work involves palliative care (nurses, doctors, allied health practitioners, service managers and policy makers), it is a source of high quality evidence to inform and support that work.

The subject of end of life care touches all members of the community at some point in their lives. The importance of palliative care within the health community is increasingly recognised in Australia, with an ageing population whose care requirements for chronic and progressive disease are growing. To meet this important need as effectively as possible, the information provided on CareSearch must be accurate, current, accessible and tailored to the needs of a varied group of users – potentially, every Australian citizen.

While the web offers a ready means of access to information, it is important to ensure that the resources provided via the web are appropriate to the needs of the users, are accessible, and can be trusted. CareSearch makes a wide range of tailored and organised resources and information available via its website and employs a knowledge translation framework. Knowledge translation frameworks provide a structure to ensure that issues around knowledge assembly and exchange are considered in the development of such resources (Tieman, 2012).

The CareSearch website is the platform from where the services are delivered; other services beyond the website include provision of print materials, research support, presentations at conferences and other educational services and contribution to national forums and projects, but the website is at the heart of the service. There are sections of the site designed specifically for health professionals and others for patients, carers, family and friends. All material in the website is subject to quality checking processes, including regular ongoing scrutiny by Australian health professionals. CareSearch complies with the HONcode standard for trustworthy health information and is aligned with Healthdirect Australia.

Information on CareSearch is open to all without the need to log on. In order to target it for each type of user, it is divided into sections. CareSearch contains four major sections for health practitioners known as Hubs: the Nurses Hub, the GP Hub for general practitioners, the Residential Aged Care Hub and the Allied Health Hub. There is also, chiefly for health practitioners, the section Clinical Evidence, containing content written for and by CareSearch

drawing together the most significant current evidence across all clinical areas of palliative care. Finally, for health practitioners there is a section called Finding and Using Evidence which focuses on the nature and importance of evidence, and how and where to find and apply it. There is a major section for consumers entitled For Patients, Carers and Families. Web metrics for usage of CareSearch are maintained and analysed and showed over 1 million visits in the year 2014. The diagram below (Figure 1) shows the complexity of the CareSearch structure. In this paper, we are going to focus on the areas within this project to which the librarians chiefly contribute (essentially the Finding Evidence and Clinical Evidence sections); however, it is important to understand the interrelatedness of the CareSearch components that make up this complex service and website.

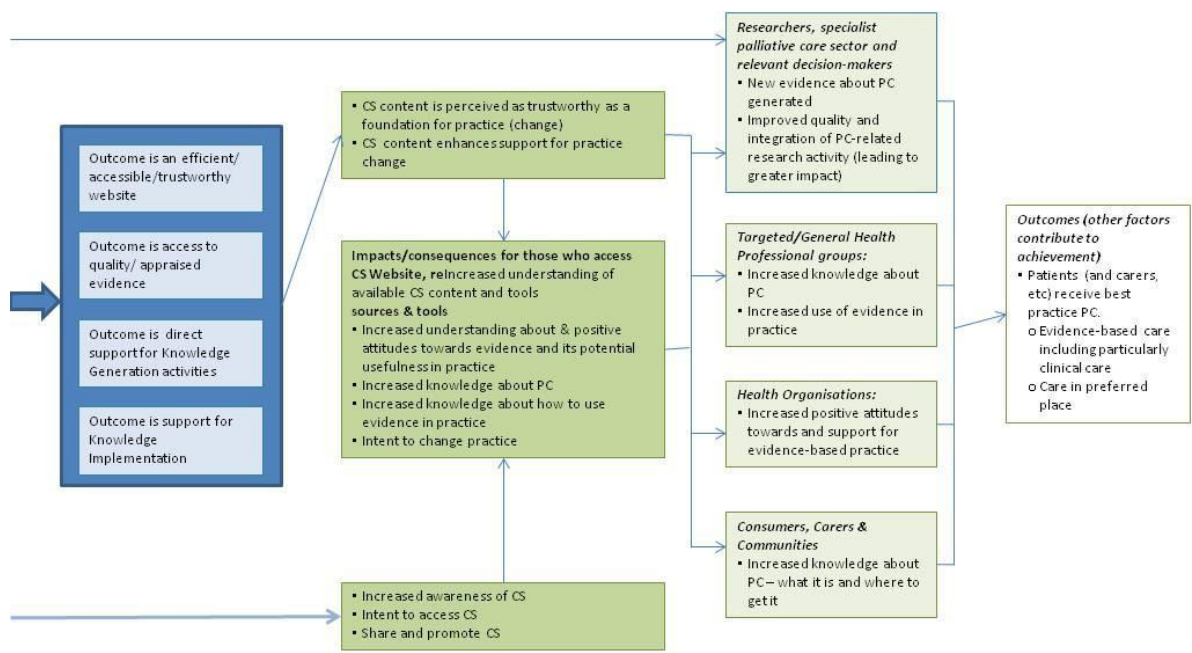
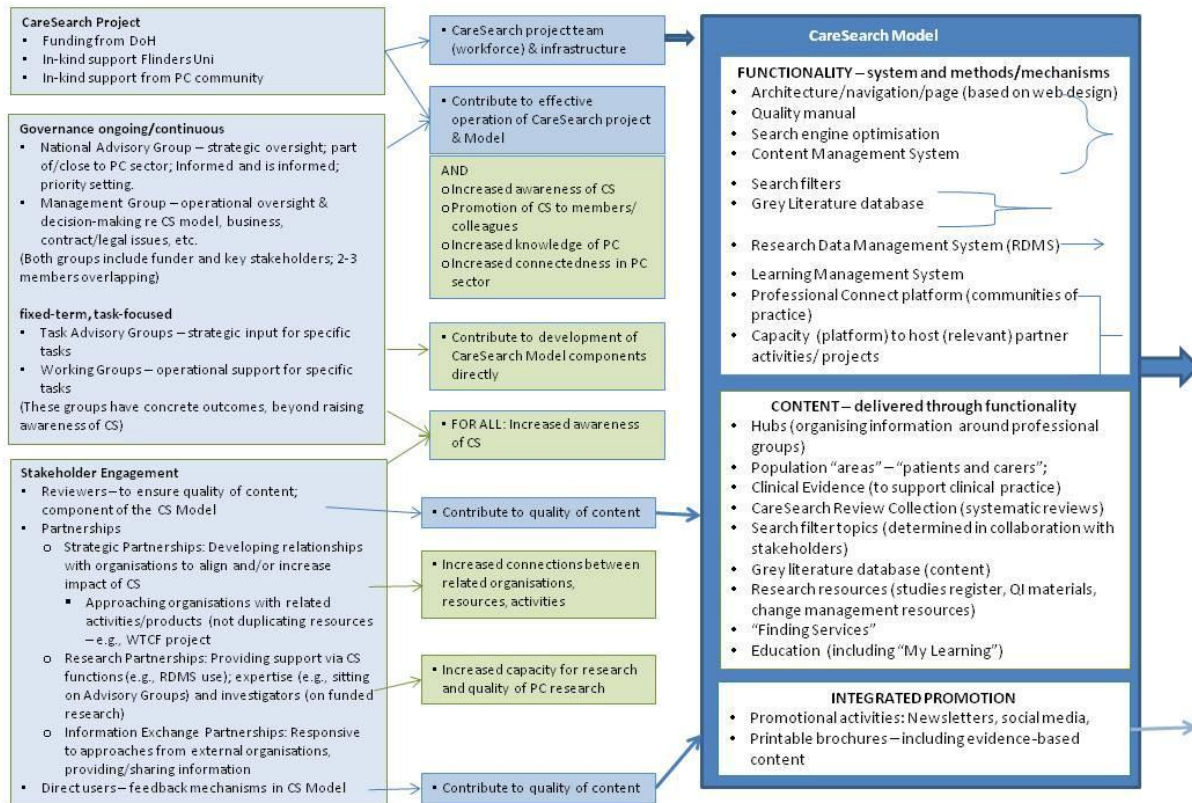


Figure 1: Program Logic representation of CareSearch including the CareSearch Model (Marsh and Lewis, 2014)

## 2 EVIDENCE-BASED INFORMATION AND CARESEARCH

CareSearch emphasises the importance of evidence-based information to support the best possible care for those at the end of life and their loved ones. As stated on the website, a series of concepts have driven the development of the CareSearch project:

- The role of evidence from creation to application, "the knowledge translation cycle"
- The multidisciplinary nature of palliative care
- The concept of a palliative care community, that is, both those providing palliative care and those affected by the need for palliative care
- Granularity, or the idea of the size and scale of components and their relationships within a system, that enables users to find specific information and enter at different points within the website
- Quality processes to ensure trustworthiness and relevance of content
- Currency of information being supported by processes that enable information to be regularly updated
- Relationship between the print and web page so they can function independently as sources of information.

The use of quality evidence and provision of reliable access to that evidence are at the heart of CareSearch. CareSearch identifies and enables access to evidence but also uses evidence-based approaches in designing and developing the service. CareSearch has developed structures and processes based on the Knowledge to Action Cycle (KTA) developed by Graham et al (2006) to draw together the evidence base for the users of the site (health professionals and consumers) and in addition to provide tools and resources to facilitate engagement with the evidence and between groups of those working in palliative care.

CareSearch supports people searching for evidence in palliative care, by providing shortcuts to aggregated evidence that is tailored and targeted to the different user groups. The evidence on CareSearch is provided in a number of different ways, some of which are:

- embedded links to real-time PubMed searches, using validated search filters and expert searches
- evidence summaries, written by external clinical experts
- curated collections of reviews and of grey literature
- self-paced learning modules
- guidelines and instructions for users to undertake their own searches
- guidelines and instructions for evaluating and applying evidence
- newsletters, conference presentations and ongoing social media communication with the palliative care community

The resources on CareSearch are provided in multimedia formats, online and in print. An evidence-based approach is used for the development and provision of the mechanisms by which the resources are made available. Quality assurance, based on research into best practice, is applied to accessibility, readability and navigability of the website. For example, different language reading levels are used in writing content for patients and their families from those used for the content intended for GPs and palliative care specialists. Research knowledge from informatics, education and psychology has been used to help design the page layouts and the information architecture. Taxonomies have been developed to ensure consistency throughout the website sections in categorisation and terms used for categories.

For example, in the GP Hub, articles will be found under a heading *Paediatrics*; in the Patients, Carers and Families section, information will be found under the heading *Children and Adolescents*.

The third way in which CareSearch relates to evidence is by contribution to the palliative care, health informatics and bibliometrics evidence bases through project research. CareSearch staff undertake and contribute to research projects and publications. In addition, CareSearch supports research in the Australian palliative care sector through the provision of a Research Data Management System. More detail about CareSearch and Evidence can be found on the website at <http://www.caresearch.com.au/caresearch/tabid/628/Default.aspx>.

Librarians in CareSearch contribute extensively to many of the aspects described above, and particularly in the identification and organisation of the evidence, together with creation of tools for accessing the evidence and development of guidelines for using it. We will look in more detail at the role of the librarians later in the paper.

### **3 TEAMWORK AND CARESEARCH**

The complex CareSearch knowledge network project employs a multidisciplinary skilled team, whose members have a broad range of expertise. The CareSearch director is a senior academic with qualifications in psychology, management and health informatics, and extensive high level experience in research, together with university administration and project management. Over the years, professionals employed in the project have included librarians, web technicians, research assistants with statistics expertise, a palliative care physician, former palliative care nurses, tertiary educators and academics, allied health specialists, an aged care service administrator, a pharmacist, marketing specialists and experienced finance and administrative officers.

The core team undertaking the work of CareSearch is not huge – as many of the staff are part-time, the full-time equivalent is approximately 6 people at any one time. Contract staff are used when needed to ensure the right mix of skills and knowledge. External partners and advisory groups are used extensively, to complement the internal skill base and to provide quality assurance of the content provided.

This is thus a small base of team members providing a complex and responsive information service for a large and varied audience, in an important and often challenging context. There is a strong need for good communication within the team, willingness to share skills, knowledge and information, maintenance of a shared vision, collegiate respect and provision of mutual support. Communication is managed through regular meetings, planning days, use of document management protocols, and a professional commitment by each team member to the goals of this important project.

A small team with diverse skills can be a very satisfying and stimulating environment; each team member learns from the expertise of the others, and in CareSearch there is a clear willingness to share information and learn together. The nature of the subject, palliative care, is one that touches all lives and every team member respects and understands the importance of providing information that will make a difference in this field.

For the librarians, as for other non-clinical team members, it is an opportunity to engage with the topic itself, to work with people who have cared for those at the end of life and their families, and to learn from their experiences. It enriches one's work in the information sphere to have direct contact with the experts in the field, and it greatly enhances the quality of the information management provided, to understand how it might be applied in a clinical context. For the former clinicians, it is an opportunity to understand how their individual clinical knowledge and expertise can be repackaged and made available to the wider palliative care community, and to learn about the principles of finding, using and applying evidence for practice.

#### **4 LIBRARIANS IN CARESEARCH**

Librarians bring information management expertise into the pool of skills in CareSearch, undertaking identification, classification and organisation of resources. The Finding and Using Evidence section of CareSearch is the area where the librarians are most closely involved. Their work supports the information provided for health professionals rather than that for patients, carers and families, but in an integrated service such as CareSearch all pieces of work ultimately inform others. The work librarians do in areas such as finding evidence and resources, providing assistance with developing taxonomies, and document management, supports the work of the entire project.

In summary, librarians undertake or contribute to the following tasks within CareSearch:

- Creation and maintenance of search filters and associated expert topic searches
- Writing reports and papers about evidence processes (including search filters)
- Conference presentations and training in the areas of search filters and finding and using evidence
- Maintenance and development of the Finding and using evidence pages (ensuring content and references are up to date)
- Development and maintenance of online learning materials relating to the use of the search filters
- Literature searches including for systematic reviews undertaken within CareSearch
- Collection and tracking of citations and web reports about CareSearch
- Review of quality processes and manual
- Monitoring of requirements in the area of copyright and IP
- Evaluation of systematic reviews for the review collection
- Assistance with taxonomies of categories throughout the website
- General assistance with information management tasks as required
- Provision of training and education sessions as required.

We will focus now on the core tasks, undertaken by librarians, relating to CareSearch's innovative use of subject-based search filters to target the best available evidence about palliative care (and related topics) in the published medical literature.

Search filters are defined search strategies designed to find certain types of articles in a particular database. They are tested and validated and are of known performance effectiveness. Many search filters are methodological, targeting certain published studies

which use certain designs, for example, randomised controlled trials or systematic reviews. Examples of these can be seen on PubMed Clinical Queries, where the options chosen will trigger PubMed to use search filters in the search it runs. The InterTASC website is a good source of information on methodological search filters. The search filters developed by CareSearch and Flinders Filters are the second type: subject based (or topical). These are far less common and target a particular subject field.

The Palliative Care Search Filter was developed in 2006 by informaticians and librarians at CareSearch to help people find relevant palliative care articles. There was an identified need for a means for clinicians and researchers to access the diffuse published literature in this field that crosses many disciplines in health care (Sladek et. al., 2006). The Palliative Care Search Filter was developed in Ovid Medline and translated for PubMed. As a PubMed search, it can be embedded in web pages and combined with topic searches for use by clinicians and researchers.

Since then, librarians at CareSearch have created the Heart Failure Search Filter, the Lung Cancer Search Filter, the Residential Aged Care Search Filter, Dementia Search Filter and the Bereavement Search Filter, for Ovid Medline and for PubMed. An associated project, Flinders Filters (<http://www.flinders.edu.au/clinical-change/research/flinders-filters/>) has arisen from the search filters work at CareSearch, and furthers the investigations into the methodology of searching effectively for published literature in health care and potentially other fields. Flinders Filters projects have included the development of search filters for Primary Health Care, Australian Indigenous Health Care and Contraception.

The librarians at CareSearch and Flinders Filters follow established methodology to create and test search strategies using a gold standard set of references, advised by external clinical experts. The search filter embeds technical searching expertise into a search strategy link for clinicians to follow for a reliable real time search in PubMed.

The creation of a search filter is a major project, taking several months, and is done in close collaboration with an expert advisory group of clinicians, researchers and decision makers, to help ensure that the search filter will be applicable in practice and to minimise bias.

The steps within the development of a subject-based search filter (built in Ovid Medline and translated for PubMed) are broadly as set out below. (In this paper we are not covering the full detail of the search filter creation methodology, but providing a general description of it to indicate the role of librarians in the CareSearch project. More detailed information about search filters and their development, including published papers, can be found via the CareSearch website at <http://www.caresearch.com.au/caresearch/tabid/371/Default.aspx> and on the Flinders Filters website at <http://www.flinders.edu.au/clinical-change/research/flinders-filters/publications.cfm> ).

#### **4.1 Steps in CareSearch Search Filter Development:**

1. Establish an Expert Advisory Group of clinicians, researchers and decision makers (EAG)
2. Determine the requirements, scope and boundaries of the search filter



3. Investigate the existing literature base and terminology of the topic
4. Create a gold standard set of representative and relevant references (ratified by the EAG)
5. Divide the gold standard set into three subsets: Term Identification, Filter Development and Filter Validation
6. Identify and test candidate search terms using the Term Identification set and other relevant sources
7. Build and test the search strategy iteratively in the Filter Development set
8. Validate the strategy's sensitivity in the Filter Validation set
9. Validate the strategy's sensitivity in an external validation set if available
10. Assess the search filter's precision through external expert post hoc relevance testing of sample retrievals from the open Medline database
11. Translate the search filter for the PubMed database and create a URL
12. Develop expert searches for topics identified by the EAG as significant in the field

When the expert searches are created, they are embedded as links within the CareSearch website, wherever they will be useful for the health professionals who use the site. This work that has been undertaken by the librarians, using their professional expertise, has been informed by collaboration with clinicians to ensure accuracy and relevance. Further collaboration with web specialists at CareSearch ensures that the links are housed on pages that are findable, navigable and compliant with current web accessibility standards. The work with palliative care clinical experts at CareSearch, internal and external, ensures that the content of the pages containing the links is of high quality and relevance to practice in palliative care. The librarians also work closely with the CareSearch marketing professionals to ensure that information about the service is promoted effectively.

The “anatomy of a CareSearch Hub” below illustrates how the tools contributed by the librarians, in the form of links to evidence, are used within a major CareSearch section.

## **5 ANATOMY OF A CARESEARCH HUB**

The image below shows a view of some elements within the Residential Aged Care (RAC) Hub in CareSearch, indicating how the work of the librarian has contributed to the collaborative whole. The Residential Aged Care Search filter was developed following the methodology outlined above. It has been deployed on the website as a basis for searches on palliative care in residential aged care (in combination with the Palliative Care Search filter), on dementia in residential aged care (in combination with the Dementia Search Filter) and in 38 expert topic searches where it is a basis for links to real time results in the PubMed database for searches on topics such as advance care planning in residential aged care or depression in residential aged care.

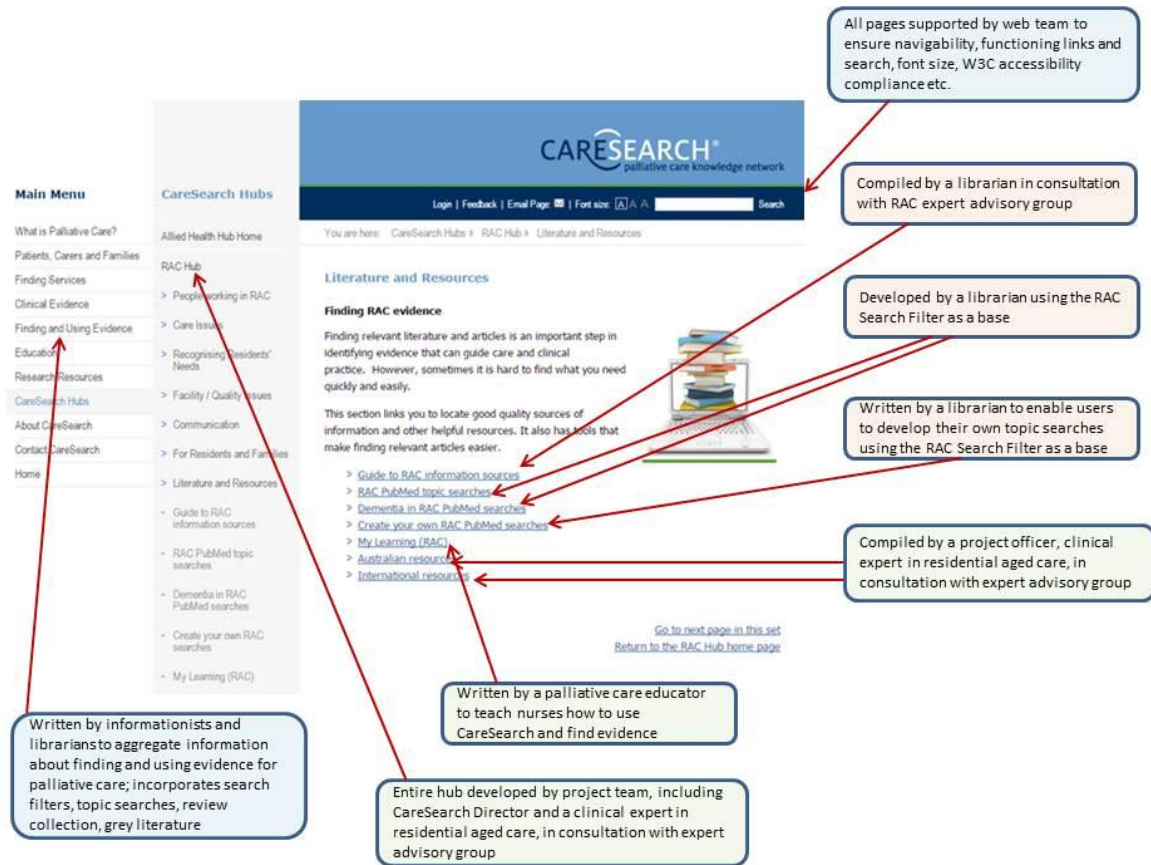


Figure 2: Anatomy of the CareSearch Residential Aged Care Hub

## 6 CONCLUDING THOUGHTS

CareSearch provides a national government-funded network in an important area of healthcare, employing a multidisciplinary team with a broad base of skills, including librarians who contribute information management expertise to the collaborative work of the team. The ability of the librarians to find, analyse and organise information is supplemented, strengthened and enriched by the experience and knowledge of the other professionals in the team: colleagues with clinical experience in palliative care; colleagues with technical web expertise and experience; marketing professionals; colleagues with experience in public administration and finance--within a supporting academic context in which education and research are integral to the programme. CareSearch is part of a triple strand of activity that supports and delivers palliative care: clinical practice, research and education. The work undertaken by the librarians contributes to all three elements of this strand.

This model enables the librarians to be an important part of the knowledge network of CareSearch. Beyond the traditional and discrete library-related activities of undertaking literature searches, or cataloguing and organising information, the work of the librarians within the CareSearch team has moved past the simple retrieval of the evidence to becoming a pivotal part of the knowledge to action process: supplying the best available evidence to inform best practice in palliative care. In the development of topical search filters, as outlined above, librarians have the opportunity to use and extend the highest levels of their expertise in understanding information structures and applying their technical knowledge and expertise within a collaborative project with clinicians and researchers, in a context of mutual respect.

It is a challenging and highly satisfying exercise, which results in a product of immediate use and importance. As soon as the links to the search filter and the associated topic searches are created, they can be published on a website and promoted to users. The links access the databases in real time so deliver current search results of known relevance.

The value of this work is in its outcomes for all those in the Australian community who are involved in palliative care, whether as providers, managers or researchers or as patients, families, carers and friends. The practice of palliative care will be better informed by the best available evidence, made accessible by a team of information and subject experts, in which librarians play a significant part.

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