LA TROBE UNIVERSITY

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AUSTRALIAN INSTITUTE FOR PRIMARY CARE & AGEING

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CareSearch 2015-2017

Evaluation Report
August 2017

ENQUIRIES
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Table of Contents

LIST OF TABLES

LIST OF FIGURES

1. Executive Summary

BACKGROUND

The Australian Palliative Care Knowledge Network, also known as CareSearch, located at www.caresearch.com.au, has created structures and processes that consolidate the evidence base and information relevant to palliative care for health professionals and consumers. It provides tools and resources to facilitate engagement within and between palliative care groups. It has created an infrastructure that can help improve practice by facilitating access to and encouraging the use and development of evidence as well as ensuring that patients, carers and families can find the information they need when it is needed.

CareSearch is funded by the Australian Government Department of Health under the "National Palliative Care Projects" initiative as part of the National Palliative Care Strategy, to support improvements in the quality of palliative care within Australia. CareSearch has been operating since 2006. CareSearch entered a new funding period in 2015, focused on maintaining the quality, currency and relevance of the existing CareSearch website, and building on it to ensure information remains relevant to support professional learning and practice, care delivery and consumer awareness.

CareSearch has adopted a strategic approach to evaluation, based on externally supported critical self-reflection. Working with an independent evaluator (The Australian Institute for Primary Care & Ageing, La Trobe University), CareSearch's monitoring and evaluation activities have been guided by a well-developed framework. The evaluation framework is based on a program logic that represents the intended consequences of CareSearch's range of activities in a coherent way, rather than treating each activity as separate and independent. Data are collected from different stakeholders using appropriate methods and, generally, with a focus on a particular element of CareSearch; but the data collected all relate back to the overarching evaluation framework and program logic.

This evaluation report explores and summarises evidence of the impact of the work that CareSearch undertakes, with a focus on activity and evaluation findings reported between January 2015 and July 2017. The CareSearch Model is not described in detail in this report; the 2014 Evaluation Report contains details about the processes, functionality and content of the CareSearch Model.[1]

It is important to recognise the different elements of knowledge translation when reviewing evidence to support the evaluation of the impacts of CareSearch. The Canadian Institutes of Health Research (CIHR) has defined "knowledge translation" as "a dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically-sound application of knowledge".[2] CareSearch recognises these components, and is clearly focused on building capacity for good quality palliative care through synthesising and disseminating evidence, with a view to it being applied. As CareSearch notes, "simply generating and disseminating new research evidence is rarely sufficient to successfully change practice".[3] CareSearch promotes evidence-based approaches to implementation of practice by organisations and individuals, but recognises that there are many factors that contribute to successful practice change.

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[1] Australian Institute for Primary Care and Ageing, CareSearch Evaluation Report, 2014

[2] McLean RK, Graham ID, et al. Understanding the performance and impact of public knowledge translation funding interventions: protocol for an evaluation of Canadian Institutes of Health Research knowledge translation funding programs. Implement Sci. 2012;7:57.

[3] CareSearch. Implementing Change https://www.caresearch.com.au/caresearch/tabid/335/Default.aspx, Cited 8 August 2017

Attribution of changes in the experiences of palliative care of patients and their families to CareSearch or any other single project or activity is not possible; however, gathering evidence that CareSearch contributes to changes at a system and community level that will lead to better quality palliative care in Australia is important. The primary impacts of CareSearch that the evaluation aims to capture and review are related to the accessibility of information through CareSearch, perceptions of its quality, and the impact this has on knowledge of, attitudes towards, and intentions to implement evidence-based palliative and end of life care in Australia.

SUMMARY OF RESULTS

The CareSearch Model

CareSearch has maintained the key activities and structures that support development and delivery of the CareSearch Model during 2015-2017. This has included: financial and in-kind resources; governance groups (CareSearch Management Group and National Advisory Group) that contribute to the strategic direction and quality of the work of CareSearch; engagement with stakeholders that contribute to development and quality of all aspects of CareSearch; processes and standards to maintain the currency and quality of content. These established systems and structures have supported the processes of reviewing and refreshing the website's functionality and content.

The workforce required to maintain and develop CareSearch during 2015-2017 included about 10-12FTE staff with a mix of skills and expertise. Sequential funding of CareSearch as a project introduces a degree of risk to retention of staff.

During 2015-2017, CareSearch undertook a major quality improvement project: a review of usability of the website, with a focus on improving the website navigation and user experience when accessing CareSearch on mobile devices. This major Refresh project led to revisions to a number of content areas. In addition, CareSearch developed new content areas including "costs of care" search filters, an Aboriginal and Torres Strait Island Hub, the Dying2Learn Massive Open Online Course (MOOC) and new web-based learning resources.

Reach and Trust

Routine monitoring of the overall web metrics of the CareSearch website continues to demonstrate a high level of engagement and ongoing accessing of the information, tools and resources that are part of the CareSearch Model. Data for 2015-2107 show an average of around 130,000 visits to the website per month, with a steady continual trend in increasing number of visits per month. There were 3,527 subscribers to the @CareSearch monthly newsletter by June 2017, and 1,852 people visited at least one of eight CareSearch My Learning Modules between April 2016 and January 2017. The data clearly demonstrate that CareSearch has been able to maintain and develop its model in a way that continues to attract people to use it.

In addition to its own website, CareSearch is able to extend its reach by engaging organisations with existing links to target audiences, such as health professional associations, health and aged care sector peak bodies, and patient and carers groups. For example, by the end of 2016, 14/31 Primary Health Network websites mentioned CareSearch. A CareSearch piece written for The Conversation had stimulated over 115 comments and had 27,650 views to July 2017. Through these links, CareSearch reaches new target audiences without incurring the costs of direct marketing and promotion. It is difficult to monitor the consequences of this kind of indirect reach; however, examples of feedback from key stakeholders included in this report indicate that CareSearch is seen as an authoritative source of evidence, and a producer of quality information that is appropriate for a range of target audiences. CareSearch is clearly established as a trusted source.

CareSearch has established itself as part of the infrastructure for evidence generation, synthesis and dissemination about Palliative Care in Australia. Evidence from formal and informal data gathering activities consistently indicate that CareSearch is highly regarded as a source of trustworthy information.

What CareSearch has achieved

Generation and synthesis of knowledge

CareSearch continues to support capacity in Australia through the Research Data Management System, and through established partnership agreements with organisations involved in palliative care research. The CareSearch Research Studies register provides a means of sharing information, developing linkages, preventing duplication and promoting awareness of current research activities. This register contains information about 30 current projects in the database and 146 completed projects. CareSearch's reputation in the sector is evidenced by the number of partnership collaborations it has with peak bodies, individuals, organisations, and others. Many of these relationships are generated by organisations approaching CareSearch to request their active engagement in projects, including providing specific technical support, access to CareSearch functionalities (such as the Learning Management System), expertise in the development of online content, and key personnel acting as an expert member of project advisory groups. These relationships help to consolidate CareSearch's position as a key strategic partner with stakeholders across the end of life, palliative care and broader health sectors.-

CareSearch's contribution to the body of evidence for palliative care through publication of relevant knowledge arising from their own activities, and in collaboration with partners, has increased in this funding period. CareSearch has authored or co-authored 14 peer-reviewed publications in the areas of e-learning, health literacy, literature searching methods, knowledge translation theory and health services research. Citations of CareSearch publications have remained consistently high since 2012 (40-50 citations each year).

CareSearch also has an active role providing advice to development of key resources and policies, including providing advice for the redevelopment of the Therapeutic Guidelines for Palliative Care, identifying tools and resources for the NSW Agency for Clinical Innovation, acting as a member of a service review group for Palliative Care Australia.

Impacts on Knowledge and Attitudes

There is evidence from a range of evaluation activities to indicate that CareSearch is changing the knowledge and attitudes of those who access information, resources, tools and training. While each individual study or evaluation report provides modest evidence, the consistency of findings from analyses of quantitative and qualitative data from multiple sources builds a convincing picture of increased knowledge of, and stronger positive attitudes towards, evidence about palliative care among health professionals, organisations and consumers.

Examples of evidence of knowledge change include reports from Allied Health Hub users about the way they use information for their, and colleagues' professional development, as well as unsolicited feedback from health professionals and consumers and carers.

Impacts on practice and organisational change

CareSearch collects data where possible to demonstrate changes to individual practice of health professionals, and to the way organisations deliver or participate in evidence-based palliative care. Some examples of evidence that has been reported include: 92% of respondents to a survey of users of My Learning modules said they would use the module information in practice, and 28% of Allied Health survey respondents said they had used information from the newsletters to change and assess practice with palliative care patients. As indicated above, CareSearch understands that organisations wanting to introduce changes in practice need to do more than provide education to staff; therefore, CareSearch has developed resources to support organisations and health professionals to bring about practice change. This includes resources such as the “End of Life Implementation Toolkit” (part of the End of life Essentials Project). Through this Toolkit, CareSearch contributes to changes in practice beyond those with whom they have direct contact.

CONCLUSION & FUTURE DIRECTIONS

During 2015-2017, CareSearch has built on the successes of past years. It is an established and unique part of the infrastructure for palliative care in Australia that not only delivers a wide range of high-quality resources, but also contributes to building links and cohesiveness across related programs and the sector generally. Through direct and indirect contact, CareSearch is contributing to increased knowledge of evidence about palliative care, and to implementation of quality practice that has the potential to improve the experiences at end of life for consumers and their families and carers.

2. Background

FOUNDATIONS

The Australian Palliative Care Knowledge Network, also known as CareSearch, located at www.caresearch.com.au aims to provide a “one stop shop of information and practical resources that serves the needs of those providing, or affected by, palliative care”.

Operating since 2006, CareSearch has created structures and processes that consolidate the evidence base and information relevant to palliative care for health professionals and consumers as well as providing tools and resources to facilitate engagement within and between palliative care groups. It has created an infrastructure that can help improve practice by facilitating access to and encouraging the use and development of evidence as well as ensuring that patients, carers and families can find the information they need when it is needed.

A number of concepts and principles have driven the development of CareSearch[4], including:

- 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.

CARESEARCH EVALUATION FRAMEWORK

Evaluation Framework, 2015-2017

CareSearch entered a new funding period in 2015, focused on maintaining the quality, currency and relevance of the existing CareSearch website, and building on it to ensure information remains relevant to support professional learning and practice, care delivery and consumer awareness.

The existing program logic-based evaluation framework was updated to describe the activities and structures that support the *CareSearch Model,* and the intended consequences for users of CareSearch resources and services, the palliative care sector in general, the health sector more broadly, and, ultimately, for health consumers (patients, carers and families).

Capturing all of the detail in the Program Logic provides a framework for evaluation. The Program Logic represents an in-depth description of implementation and an extensive set of intended impacts that could

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[4] CareSearch website, accessed April 2014

potentially be captured through the use of existing data or by implementing a targeted evaluation activity. The impacts described include immediate, short, medium and long-term intended consequences. Having a detailed Program Logic framework does not mean that all of the components described have to be, or necessarily should be included when evaluating or reporting on the CareSearch project. A program logic describes the intended causal pathways between the activities of a project and its ultimate goal, but there are often many other factors that contribute to goals.

The ultimate goal and outcomes to which CareSearch intends to contribute relate to the experience of consumers: patients (and carers, etc.) receive best practice palliative care (wherever they are), the care provided is evidence-based (particularly clinical care), and the palliative care occurs in the preferred location of the patient. The evaluation framework recognises that this ultimate consequence is influenced by CareSearch but also by other health sector and wider social contextual factors that cannot be meaningfully assessed or unreservedly attributed to CareSearch.

The evaluation framework also recognises and aims to capture the influence that CareSearch has through its strategic engagement with stakeholders and other organisations. Through this engagement, the relatively small project team employed by CareSearch is able to contribute to cohesive sector-wide capacity building to support improvements in care. The evaluation activities seek to gather evidence of these indirect consequences and represents them in the program logic.

Discussion and consultation through the governance groups determines which components of the program logic are most important to measure and report, based on the agreed priority of the potential evaluation questions. CareSearch has committed to prioritising and actively adopting an evaluation framework and process to identify the value and quality of activity and to help determine impacts for users, health services and the system. Through a partnership with and guidance from the independent evaluation team at La Trobe University, CareSearch has implemented an extensive set of self-evaluation activities and routine collection of data that is incorporated into the CareSearch Model and the roles of CareSearch workforce.

The summarised CareSearch evaluation framework is outlined in Figure 1: CareSearch Evaluation Program Logic with further detail provided in Appendix 1.

In addition to the CareSearch program, during 2016 CareSearch was approached to manage the PalliAGED program. A separate evaluation framework was developed for PalliAGED, with a focus on achieving the immediate outcome of developing and launching a high quality website by June 2017.

THIS REPORT

This evaluation report explores and summarises evidence of the impact of the work that CareSearch undertakes, with a focus on activity and evaluation findings reported between January 2015 and July 2017. The CareSearch Model is not described in detail in this report; the 2014 Evaluation Report contains details about the processes, functionality and content of the CareSearch Model.

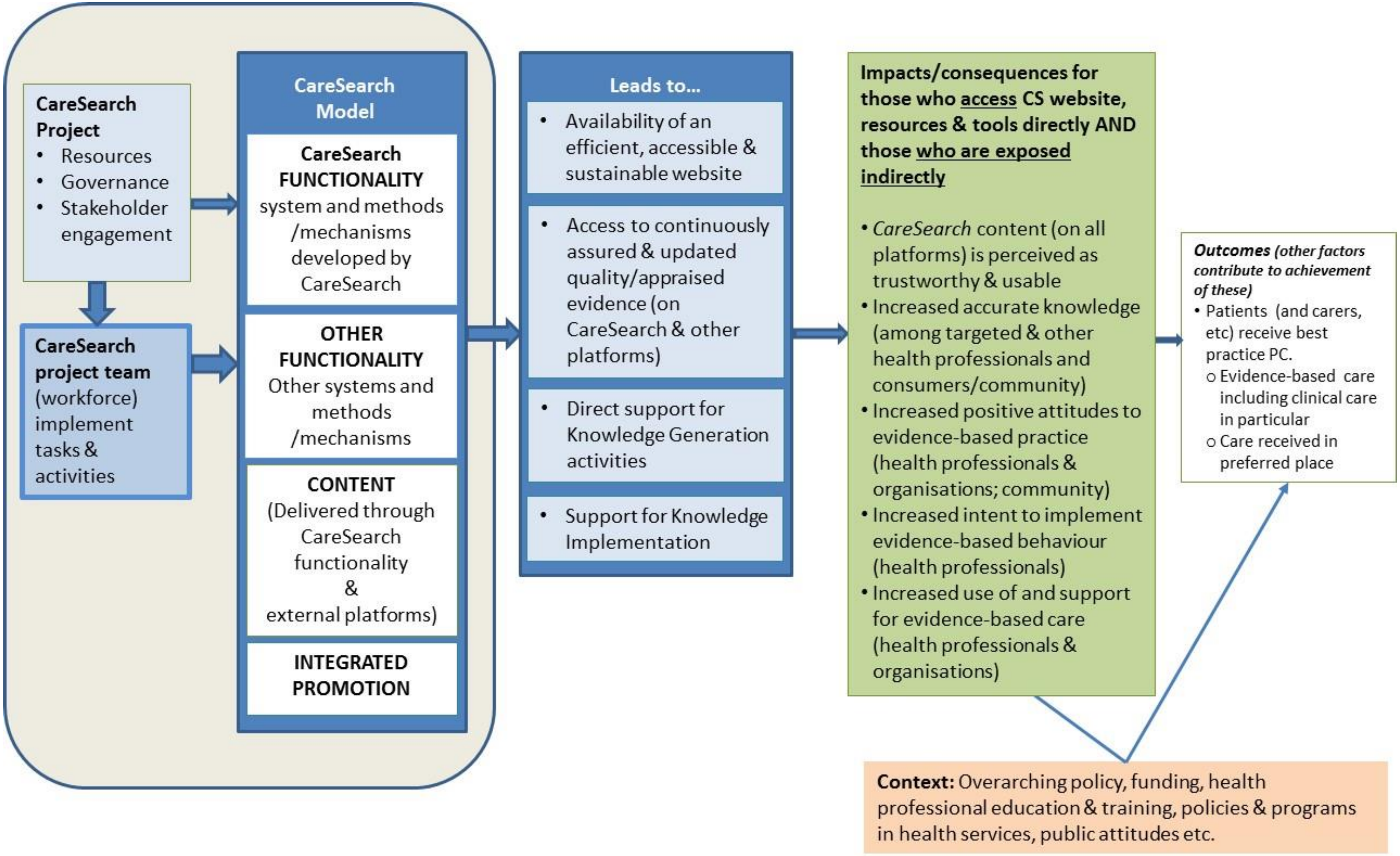

Figure 1: CareSearch Evaluation Program Logic

3. What is CareSearch?

THE CARESEARCH MODEL

The *CareSearch Model* that is delivered through the project has been developed and refined since its initial launch in 2008. The *CareSearch Model* is described as having three components:

1. Functionality – referring to the systems (including hardware, software and procedures) and the methods and mechanisms that provide the platform for delivering the CareSearch Content. In the 2015-2017 period, this extended to using other platforms and programs to deliver CareSearch Content.
2. Content – referring to the content pages, databases and resources available and delivered through the functional elements.
3. Integrated Promotion – referring to the resources and activities that promote awareness of the CareSearch Content and the underlying principles around the importance of evidence in palliative care.

Functionality

The key elements that contribute to functionality in the *CareSearch Model* are:

- Architecture of the website including the web design elements that enable effective navigation through content pages
- Quality Manual providing resources and guidance to support developing of trustworthy content
- Search engine optimisation
- Content Management System (CMS) including user registration
- User Management System (UMS)

These elements contribute in particular to an efficient, accessible and trustworthy website.

- Search Filters – providing PubMed literature search strategies that are saved as web links
- Grey Literature database – a searchable database of six sets of palliative care information that can be hard to find (see below for kinds of content searched). Material that is included is rated for quality

These elements ensure that users have access to evidence that is appraised for its quality.

- Research Data Management System (RDMS) – providing assistance in designing surveys and collecting data for research conducted at a single or multiple sites

This element provides direct support for knowledge generation through research activities.

- Learning Management System (LMS) – provides a platform for training and professional development
- In 2015-2017, the LMS supports continued professional development in palliative care
- Professional Connect Platform – provides a platform for linking end users of CareSearch who are interested in developing their knowledge further and implementing practice change. (e.g., support for discussion groups, communities of practice)

- A platform that can host relevant partner activities or project – CareSearch provides a platform to assist organisations with whom CareSearch has formed a relationship to deliver relevant activities
- Massive Open Online Course (MOOC) Platform – CareSearch will review and analyse existing options available to support MOOC
- Apps@caresearch (a CareSearch platform)

These elements support activities that lead to implementation of practice change based on knowledge of relevant evidence.

In 2015-2017, CareSearch upgraded and enhanced major systems (RDMS, CMS, UMS) through a process described as CareSearch Refresh.

Content

The content that is developed and delivered using the elements of functionality of the *CareSearch Model* is described under the following categories:

- *Hubs* – providing content relevant to different disciplines and professional groups involved in providing palliative care. In 2015-2017, development of an ATSI Hub was a focus
- *Population areas* – where content is presented in a way that is most appropriate for a particular target group, e.g., patients, carers and families
- *Clinical Evidence* – providing summaries of the state of evidence on a range of topics including providing access to relevant literature where possible in order to support clinical practice
- *CareSearch Review Collection* – identification and assessment of systematic reviews or structured literature reviews on topics relevant to palliative care
- *Search Filter topics* – providing a range of topics relevant to palliative care. Each link runs an immediate search in PubMed using the Search Filter
- *Grey literature database* – the content that results from the searches of conference abstracts, non-indexed journals, theses, materials from government and other organisations, links to project funded through the national palliative care program and research studies
    - The grey literature database was extended in 2015-2017 to include palliative care conference abstracts, non-indexed Australian palliative care journals, theses and treaties, government and organisational reports and other grey literature, research studies in progress and projects funded under the Australian Government National Palliative Care projects Programme and other national initiatives
- *Research resources* – providing a set of resources and tools designed to support researchers, including the RDMS, the Research Studies Register (a database of Australian research project and studies in palliative care based on information provided voluntarily by researchers and presented using different organisational structures), information for new researchers, links to grants and granting agencies, information about approaches to quality improvement and resources to support change management
    - In 2015-2017, the RDMS operated for use by palliative care researchers and others as negotiated, and RDMS modules and guides for users will be developed
- *Education* – providing content related to training and professional development. Targeted to health professionals, a number of different learning activities are available, including some that attract continuing professional development (CPD) points and modules made available using the CareSearch LMS.

- *"Finding Services"* – content about services and organisations that provide help to people who are ill or their carer

The intent is that the content developed and delivered through the *CareSearch Model* is perceived as trustworthy as a foundation for practice and enhances support for practice change.

Integrated Promotion

The final element of the Model is the promotion of CareSearch as a resource to support the use of evidence in practice and evidence-based content generated by CareSearch and others. The project uses a range of online and offline strategies. Through newsletters, social media, events, and a range of printable brochures, posters and factsheets awareness of the website and evidence about palliative care practice is promoted.

The intent of promoting awareness of CareSearch is to encourage people to access all of the functions and resources available on the website and to encourage them to share information and promote CareSearch more widely. In 2015-2017, a communication plan was developed to increase awareness of the CareSearch website and to promote new and existing resources and initiatives through publications and conference presentations, and through the release of resources during significant events such as the National Palliative Care Week, Carers Week and World Hospice and Palliative Care Day.

CareSearch uses its relationships with other stakeholders in the palliative care and related sectors to build awareness and increase the reach of the content. While this approach may dilute the identification of CareSearch itself (as a "brand"), it enables CareSearch to increase its reach in a cost effective way. It also reduces unnecessary duplication of subscription lists for users.

RESULTS: PERCEPTIONS OF CARESEARCH

Evaluation Question: Is CareSearch perceived to be a trustworthy, efficient, accessible website?

The previous evaluations of CareSearch have described in detail the processes and procedures used to develop content for the website, and the way in which they contribute to its quality and perceptions that the information can be trusted. Further evidence of CareSearch's reputation as a trustworthy, efficient and accessible website comes indirectly from the trends of increasing use (as outlined in the following sections) and its integration into a broad range of knowledge generation and dissemination activities across the sector (described later). Statements from CareSearch users, particularly those that are unsolicited, provide further evidence about the quality of the website, and its usefulness.

Direct feedback from users of CareSearch

Feedback from health professionals

Unsolicited feedback from health professionals illustrates the high-regard for CareSearch amongst those who use its resources, for example, this LinkedIn message from a palliative care clinical nurse specialist nurse

> *"…Just wanted to say thanks for the hard work at CareSearch. Such a wonderful resource for clinicians and patients!"*

Feedback from key stakeholders

Interviews with selected stakeholders from across Palliative Care organisations and the health sector included discussion of the perceived value of the CareSearch website.[5] Comments described CareSearch as "evidence-based" and "looking plausible" and that this was …"essential if senior doctors in particular are to become well informed… this is how to win the heart of doctors".

Feedback from health organisations

The following unsolicited comments from organisations highlight perceptions of the quality of CareSearch's approach, and the potential reach of CareSearch through other organisations' promotion of CareSearch.

Email received from Partner Manager, Healthdirect Australia (4/4/2017):

> *"I just happened across your new ATSI Hub:…It's excellent by the way. I want to link to all its resources from both healthdirect and Carer Gateway. In fact you may wish to link back to this page on the Hub somewhere: **https://www.carergateway.gov.au/resources-for-aboriginal-and-torres-strait-islander-carers "***

Email from Tracy Aylen, President, Australian Diabetes Educators Association (5/5/2015):

> *"I have left a message via phone today to seek further information regarding the creation, set up, costs and usage relating to Care Search. I'm impressed by the range of information available and the fact that consumers, health professionals and research are all 'co-located'. This may be a useful approach in diabetes as well."*

CareSearch continues to be approached to collaborate with organisations working across the health, end of life and palliative care sectors. This includes development of a number of partnerships and formal agreements related to building awareness of palliative care and palliative care approaches through linking organisations to CareSearch resources and materials. In collaborating with other organisations, CareSearch provides resources and supports awareness raising approaches that enhance their reach to the wider health community. For example, CareSearch provides content for newsletters for organisations (for Primary Health Networks, Allied Health Association) and has provided the content for websites which provide resources for health professionals (Advance Dementia Care project resources for general practitioners and practice nurses). Further details of the extent of CareSearch's partnerships are provided in Appendix E.

Feedback from health organisations provides a clear indication of the perceived value of CareSearch in supporting organisations to build the palliative care knowledge, capacity and skill of their work force. These examples reflect a high degree of respect for CareSearch, as well as a belief that there is potential for CareSearch to contribute to behaviour change.

An email request from a Queensland hospital Social Work Department:

> *"Queensland Health Social Work is creating an online Central Resource Directory that catalogues various educational material and resources into an accessible location for our Social Workers across the state to access. I am seeking permission to link to your website in this directory.*
>
> *I see your site as a valuable resource for our workers in Queensland Health that would aid in their education and professional development…."*

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[5] Australian Institute for Primary Care and Ageing, CareSearch; The future of palliative care in Australia; report on key Stakeholder Interviews, 2017

A Queensland primary care network:

> *"I am emailing on behalf of PHN darling downs and west Moreton to request if you would consider sharing your website resources with our organisation. PHN would like to copy the dementia information on your **www.palliaged.com** website to our PHN website which would assist our G.Ps in the treatment of patients with dementia….."*

Engagement from organisers of community events

Each year CareSearch supports "Dying to Know Day". This annual day is designed to encourage all Australians to develop new knowledge and attitudes about how to deal with death, dying and bereavement and support each other at the end of life. On the Dying to Know Day website people anywhere in Australia can register if they are hosting an event. CareSearch resources are promoted for organisers to hand out at their events. Feedback from people who organised an event and ordered materials in 2016 indicate the reasons they chose the resources:

- Because CareSearch's website is excellent and full of information
- Because they are "patient friendly" and clear and concise
- I like to promote Palliative Care + educate people about its benefits

This event has continued to grow. In 2017, CareSearch developed and sent out 895 "Dying2Learn Kits".[6]

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[6] Direct email Jennifer Tieman

4. What has CareSearch achieved?

BACKGROUND: WHAT CARESEARCH INTENDS TO ACHIEVE

The intended consequences or impacts for people who access the CareSearch website and use the information, resources and tools available, or have other forms of direct contact with CareSearch, include:

- Increased awareness of available CareSearch content and tools
- Increased understanding of available CareSearch content and tools
- Increased understanding about & positive attitudes towards evidence and its potential usefulness in practice (including increased support for evidence-based practice by relevant organisations)
- Increased knowledge about palliative care and related issues (including, for consumers in particular, but also health professionals and others, increased knowledge about PC – what it is and where to get it)
- Increased knowledge about how to use evidence in practice
- Intent to change practice (or implement a behaviour)
- Increased use of evidence in practice (where relevant)

There is also an intention that the effects go beyond immediate users of the CareSearch website and resources, particularly for targeted groups, including specific and general health professionals and sectors of the health system. These effects may occur because of a more widespread distribution of resources and information, and a change in the level of knowledge and evidence-based practice across the palliative care sector and general health sector.

CareSearch explicitly engages with peak bodies, leading researchers, stakeholders and organisations in order to amplify the effects of their activities without the direct investment of time and resources that would be required to achieve this reach directly. CareSearch does not require that its "brand" dominates in the context of these partnerships, and hence it is important to note the embedded impact and value of this work also becomes associated with these partner organisations.

This means there are additional consequences of CareSearch at the level of groups of stakeholders—including health professionals, researchers, and policy makers, regardless of whether they have direct contact with the CareSearch website—that are more difficult to demonstrate, but are recognised as part of the underlying logic of the Model.

- Impacts for palliative care researchers, specialist palliative care sector and relevant decision-makers to which CareSearch intends to contribute include:
  - New evidence about PC being generated
  - Improved quality and integration of PC-related research activity (leading to greater impact from several sources)

The ultimate goal and associated outcomes to which CareSearch intends to contribute relate to the experiences of consumers. These goals are shared widely, and a range of programs initiated at different levels of government and by other organisations seek to influence similar outcomes. Many factors influence the experiences of consumers; however, CareSearch aims to gather evidence where possible about its contribution to the following longer-term outcomes:

- Patients (and carers, etc.) receive best practice palliative care (wherever they are)

- Care provided is evidence-based (particularly clinical care)
- Palliative care occurs in the preferred location of the patient

RESULTS: EVIDENCE OF IMPACTS OF CARESEARCH

Evaluation Question: Is there evidence that CareSearch has contributed to the following impacts for individuals who have had direct or indirect contact with information, resources and activities?

- Increased understanding about and positive attitudes towards evidence and its potential usefulness in practice (including increased support for evidence-based practice by relevant organisations)
- Increased knowledge about palliative care and related issues (including, for consumers in particular, but also health professionals and others, increased knowledge about PC – what it is and where to get it)
- Increased knowledge about how to use evidence in practice
- Intent to change practice (or implement a behaviour)
- Increased use of evidence in practice (where relevant)

Evidence of reach and uptake

In order to demonstrate an impact of an activity, resource or project, it is necessary to demonstrate that the activity has reached the intended target individuals or groups.

CareSearch website utilisation

Routine monitoring of the overall web metrics of the CareSearch website continues to demonstrate a high level of engagement and ongoing accessing of the information, tools and resources that are part of the CareSearch Model. Figure 2 provides a representation of the website trends over 2015-2017, with further detail provided in Appendix D. This data shows an average of around 130,000 visits per month, with a steady continual trend in increasing number of visits per month.

It should be noted that during the period 2015-2017, CareSearch has undertaken work to improve the navigability and functionality of the site on mobile devices, reducing the number of steps required to access sub-menu items of the site. As a result the number of page views per visit has declined in 2017 in comparison to 2015. In addition, as part of the Refresh CareSearch project a number of highly accessed content pages (in particular the newsletter and blog) have been moved from within general content sections to sections that are counted independently for web statistics. CareSearch is also in the process of investigating options for tracking of page pathways to understand user movement through the site in more detail. The Refresh and website improvements are detailed further in the section on functionality, below.

While these data can only be considered an indirect indicator, they continue to provide a clear picture of a website that is being used and continuing to be used over a long period, demonstrating that CareSearch has been able to develop and sustain its model in a way that continues to attract people to use it.

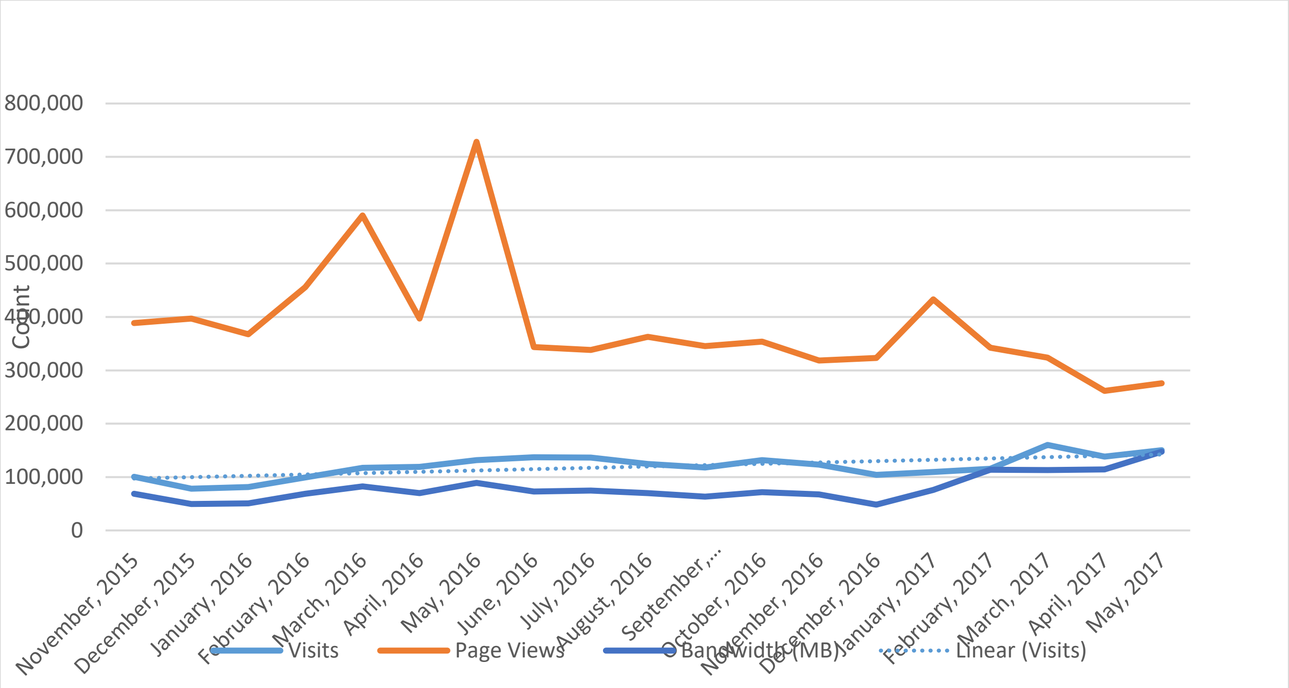

Figure 2: Visits, Page Views, Bandwidth and Visit Trend 2015-2017

In addition to the visitors to CareSearch website, CareSearch extends its reach by engaging users of CareSearch-developed content on external websites, and to CareSearch resources that are forwarded or distributed in hard copy. Data on the use of these external CareSearch-developed websites have not been accessed for the purposes of this report.

Palliative Perspectives blog

CareSearch established this to provide Australian health professionals posts from their peers across the research and health professions, particularly those with expertise and an interest in palliative care.[7]

There are generally around 500 views of a blog, with numbers as high as 3,655 views for the blogs recognising International Nurses Day with a series of biographic profiles. The number of views increase over time as the blogs and series remain available on the website.[8]

Social media

At July 2017 there were 1,660 CareSearch Twitter followers, with numbers steadily increasing. CareSearch also created a LinkedIn page in mid-2016 which, at July 2017, had 89 followers subscribed.

Allied Health Hub utilisation

In recognition of the importance of Allied Health professionals as palliative care team members, CareSearch's Allied Health 'Hub' (launched in 2013) contains information and resources specifically targeted at this group. Statistics on utilisation of the Allied Health Hub show (Table 1) a large number of page visits per section for the three most visited topics. The breadth of the topics is notable, including pages related to allied health professionals' role in palliative care, clinical considerations when providing care, and information about how to work with patients and carers.

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[7] CareSearch Performance Report for Department of Health 31 July 2016

[8] CareSearch Performance Report for Department of Health 31 July 2016

Table 1: Allied Health Hub Web stats, 12 Months to 30/09/2016

Year	Page visits
Allied health and palliative care (11 pages)	6,774
Clinical considerations (7 pages)	4,239
Working with patients and carers (8 pages)	3,142

During 2015 CareSearch undertook a survey of people registered to receive the Allied Health Hub Newsletter (approximately 1000 at the time of the survey).[9] Thirty-five respondents, distributed across six states, namely SA (n=8), Victoria (n=11), QLD (n=7), WA (n=1), NSW (n=3) and Tasmania (n=3) (one unspecified), completed the survey. Respondents represented a range of allied health disciplines, with a slightly older cohort than is represented in the AIHW figures of the Allied Health workforce. The majority worked outside specialist palliative care settings, reflecting the targeting of the Hub.

Responses from users of the Allied Health Hub showed strong support for, and strong engagement with the content.

- Of the 26 (72% of respondents) of the allied health professionals who had used the Hub, 39% used the Hub monthly or more frequently and 42% used the Hub every three to four months and 96% said they would (or do) recommend the Hub to others.
- Respondents' ratings of the usefulness of the Hub demonstrated the relevance of the content to those who are using it, with 85-100% of these allied health professionals rating each of the Hub sections as useful or very useful, and 100% indicating they would not change anything about the content of the Hub.

General practitioners

Fact sheets designed by CareSearch for general practitioners to use with for patients and family, are available on Health Share website www.healthshare.com.au. The factsheets were revised in September 2016. Data on the number of downloads since this time, represented in figures 3 and 4, show factsheet downloads have fluctuated with as many as 80 patient and carer fact sheet down loads per month and a trend to overall increasing use, showing increasing engagement with these resources as they become more widely known.[10] [11]

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[9] CareSearch Evaluation Program: Report No 222. Evaluating the Allied Health Hub: results of an online survey. October 2015

[10] CareSearch Update, National Advisory Group Meeting 24 & 25 November 2016

[11] Downloads of health share factsheets, Data downloaded 31 July 2017

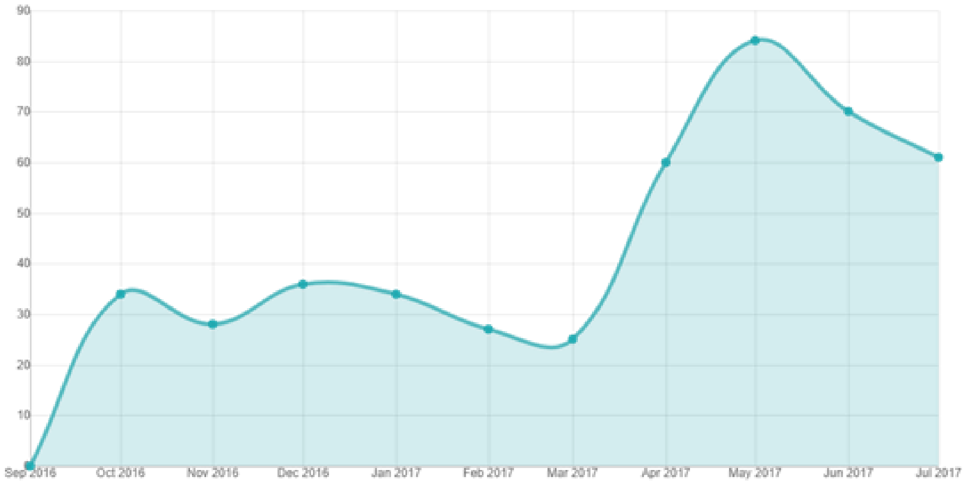

Figure 3: GP Engagement with Patient and Carer Factsheets, Per Month

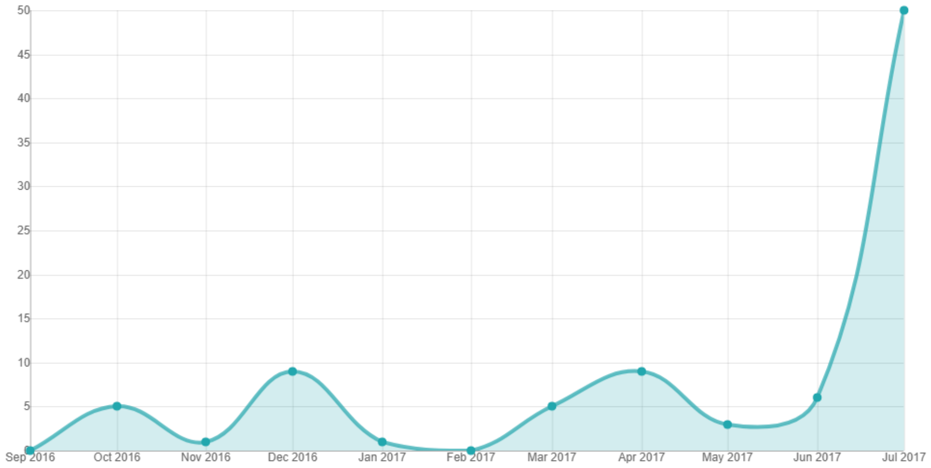

Figure 4: GP Engagement with Care Processes Factsheets, Per Month

My Learning utilisation

The CareSearch My Learning modules were designed to assist health professionals to build an understanding of applying evidence in practice (knowledge mobilisation).

These modules were evaluated through a survey of users prior to and post their completion of a module.[12] Data collected over the nine months to 4 Jan 2017 showed 1,852 learners visited one of the eight CareSearch My Learning modules landing pages.

- Of those, 1,137 opted in to take part in CareSearch's evaluation, with 92% completing the pre-module survey and 32% completing the post-module survey. Figure 5 demonstrates the geographic spread of this group of users of CareSearch resources.
- While these data can only be considered an indirect indicator, they continue to provide a clear picture of a website that is being used and continuing to be used over a long period, demonstrating that CareSearch has been able to develop and sustain its model in a way that continues to attract people to use it.
- The majority of learners were from postcodes in the third SEIFA IRSD quintile (27%), with around one-third of learners coming from postcodes with greater levels of disadvantage (32% SEIFA IRSD

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[12] CareSearch Evaluation Program: Report No 21. 'My Learning': Results of pre-test, post-test evaluation. March 2017

quintiles 1 and 2) and the remainder were from areas of least disadvantage (42% from SEIFA IRSD quintiles 4 and 5).

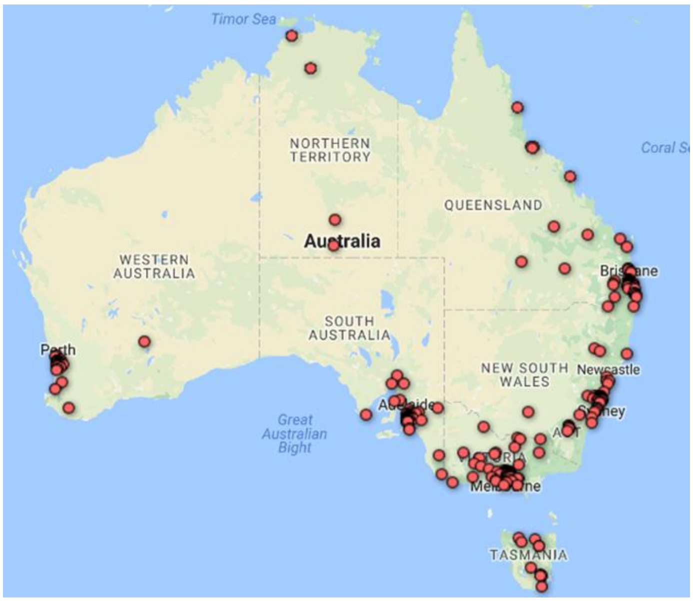

Figure 5: Access of CareSearch My Learning Modules across Australia

Newsletter subscriptions

Newsletter subscriptions have continued to grow over the period, exceeding subscription targets. Subscription statistics are provided in Table 2. CareSearch newsletter subscribers are located in all states and territories, including remote regions. Figure 6 shows the locations for a sample of subscribers who have provided data at July 2016.

Table 2: CareSearch Newsletter subscriptions

NEWSLETTER	EDITIONS TO DATE JAN 2015- 30 JUNE 2017	TARGET SUBSCRIPTION (PER EDITION)	SUBCRIBERS AT 30 JUNE 2017[13]
@CareSearch newsletters (monthly)	30	>3,200	3,552
Nurses News (quarterly)	10	>1,900	2,107
Residential Aged Care News (quarterly)	10	>1,110	1,223
Allied Health News (bi-monthly)	15	>860	1,225

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[13] CareSearch Report Feb-June 2017, CareSearch

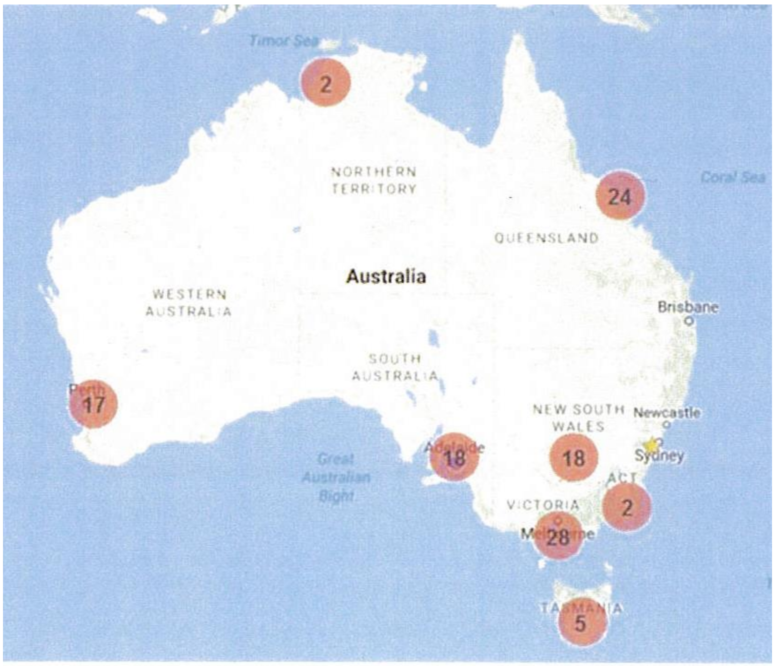

Figure 6: Distribution of newsletter subscribers
(sample of 520 at June 2016)

Organisational engagement

Primary Health Networks' uptake and promotion of CareSearch

The establishment of Primary Health Networks in 2015 created a new opportunity for CareSearch to provide palliative care information and education resources to the general public and primary care health professionals through PHN events, newsletters, websites and web portals. During 2016 CareSearch established a project to evaluate reach and effectiveness of CareSearch information provision to PHNs, and to establish contacts and opportunities for CareSearch palliative care information provision.

Despite the early stage in the establishment of these PHNs, the evaluation project[14] demonstrated that CareSearch has established effective engagement with some PHNs. The evaluation also highlighted opportunities for CareSearch to further strengthen its understanding of the training, information and communication needs of PHNs and their target users to focus and tailor information.

- In January 2016 seven of the 31 (23%) PHN web sites made mention of CareSearch or CareSearch resources, mostly in relation to advance care planning, palliative care or online training and 21 of the 31 sites contained some form of palliative care information
- During February 2016 contact was established with communication officers from 22 of the 31 PHNs and electronic or hardcopy information kits were distributed to these PHNs. CareSearch and palliative care information electronic materials were distributed to all PHNs at least monthly during February/March-November
- Six of these PHNs continued to mention CareSearch and to update with new material over the period from February-November, eight further PHN websites (a total of 14 out of 31) had added CareSearch-related content up to the November time point

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[14] CareSearch Evaluation Program: Report No 25. Evaluating the results of CareSearch engagement with Australian Primary Health Networks

- CareSearch was included in newsletters for 5 PHNs during the year, PHN websites linked to the CareSearch website whenever CareSearch was mentioned.

Table 3: Number of CareSearch mentions in PHN websites and e-newsletter, 2016

Date	At January 2016		At November 2016	
PHNs by state	Number of PHN websites mentioning CareSearch	Number of times mentioned, total	Number of PHN websites mentioning CareSearch	Number of times mentioned, total
ACT-1	1	5	1	1
NSW-10	1	1	4	6
NT-1	0	0	0	0
QLD-7	1	1	3	8
SA-2	0	0	2	2
TAS-1	1	2	0	0
VIC-6	3	3	4	12
WA-3	0	0	0	0
Total 31	**7**	**12**	**14**	**29**

Community engagement & reach

Dying2Learn MOOC

The Dying2Learn Massive Open Online Course (MOOC) in 2016 and 2017 was very well subscribed: 1,143 individuals enrolled in this course in 2016[15] and a further 1,944 in 2017.[16]

- 92.5% of these participants were located in Australia, with all state represented but the majority in the more populous states Victoria and NSW
- The majority of participants were female (92.5%) and while a broad range of ages were represented (from 16 to 84 years) the participants were generally older (78% per 40 and over, 20% were 60 and over)

Data from the 2016 MOOC showed that over 350 of these enrolments were not from the health professions, and so, given the promotional strategy of encouraging participation of the public, it is likely that many of the 350 were members of the public, carers or health care consumers.

Of those enrolled (overall), the level of engagement was strong, with 75% going on to complete learning modules and a high level of participation evidenced in commenting, completion of activities (4909 in total) and page views (9230 in total).[17]

Dying2Learn media and social media

In addition to course itself, the CareSearch team have successfully pursued secondary opportunities to use Dying2Learn materials in community engagement strategies including a D2L tweetchat and Dying to Know promotions in 2016 and 2017.

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[15] Lewis-Miller L, , CareSearch Dying2Learn MOOC progress report January-July 2016

[16] Tieman J, CareSearch Annual Presentation, May 2017

[17] Lewis-Miller L, CareSearch Dying2Learn MOOC progress report January-July 2016

A CareSearch piece, “Passed-away-kicked-the-bucket-pushing-up-daisies-the-many-ways-we-dont-talk-about-death”, summarising findings of participant contributions during the MOOC was originally published in the Conversation and then reproduced on the ABC news website and the Over60s website.[18] The Conversation article had been viewed 27,650 to date (at July 2017) and generated over 115 comments, demonstrating a strong level of interest in the material.

Postcards

To gather feedback from consumers and the public, CareSearch developed a set of reply paid postcards, encouraging individual consumers to comment on their experience with CareSearch and provide some insight into the use of CareSearch resources and palliative care knowledge in this group.

Sixty responses were received from the postcards given out at community events, amongst these five people indicated they had heard of CareSearch before the event, 59/60 thought online information was important and all 60 would go to CareSearch if they needed pall care info in the future.

Increased knowledge about palliative care and palliative care approaches

Evaluation question: Is there evidence that CareSearch has contributed to:

- Increased knowledge about palliative care and related issues
- (For consumers in particular, but also health professionals and others: Increased knowledge about palliative care – what it is and where to get it)

Health professionals

CareSearch Education Section users

The education section of CareSearch underwent a major review and reformat (completed May 2016) to accommodate the Whole of Workforce framework (and as part of the CareSearch Refresh process). This Framework was developed to provide guidance for individual health care providers, education providers, health service managers and policy makers to ensure all health care providers are equipped with capabilities relevant to their context to provide care for people who are dying. A group of health professionals who responded (n=16) to the invitation to provide feedback on the revised site were asked about their intended use of the information and its value in informing practice.[19]

- The most common reason for seeking palliative care education and training aligned with the goal of improving training in the sector. The most common reasons identified were role as a trainer, education or mentor (88%), personal education (56%), need for information to support own practice (44%), specific interest in condition symptom or therapy (44%),or researcher (44%).
- Respondents were positive about the applicability of the material in their own CPD or in training others, and provided comments on the value of such education in bringing about change in an organisation:

> *“Education is the catalyst for knowledge translation and subsequent practice change.”*

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[18] https://theconversation.com/passed-away-kicked-the-bucket-pushing-up-daisies-the-many-ways-we-dont-talk-about-death-77085

[19] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

> *"PA toolkit has changed practice in aged care facilities by promoting a framework of care and providing educational resources."*
>
> *"Plays a huge role. When it is embedded in professional development/registration/clinical care for health accreditation there is an external driver to attend which also supports clinical care. Vital to be up to date with best available evidence to inform practice. Vital for managers to know what is best practice, to inform development of teams/manage staffing issues.*
>
> *There are increasing numbers of people with palliative care needs in non-specialist palliative care services (and believe this number will only increase). Clinicians need to be upskilled in how to best meet their needs. It is not always covered off well in undergrad/generic discipline specific masters courses due to demands for competing content in curricula. Education must occur post grad for clinicians formally &/or informally. Uptake is often better when there is clinical application for what is learned."*

Allied Health professionals

In a survey of Allied Health newsletter subscribers undertaken in 2015, the majority (97%) of respondents found the Allied Health Hub newsletter informative, describing it as "useful", "relevant" "up to date", "varied" and "informative".[20] This support for the value of the newsletter was also evidenced from the way it was used, with 80% of respondents reporting they shared the newsletter with colleagues.

Specific comments included positive statements about the usefulness of the newsletter as an educational tool:

> *"New ideas and helps with education topics"*
>
> *"New research, ideas for practice, links to relevant articles without having to search!"*
>
> *"Generally learn something each time I read the newsletter"*
>
> *"The Caresearch Allied Health Hub is a great way for rural allied health professionals in Palliative Care to keep in touch and update their knowledge base"*

Another theme in the responses was reflecting on the usefulness of the Newsletter as a means of learning about palliative care more broadly:

> *"Learn about different professions, their roles in pall care and examples of clients/interventions"*
>
> *"Reading case studies is very helpful and knowing what PD (professional Development)/ conf (conferences) are coming up"*
>
> *"Limited other support services/resources for allied health professionals working in palliative care"*
>
> *"Good to get different perspectives and experiences of palliative care"*
>
> *"The multi-D aspect is great"*
>
> *"Great newsletter that really fills in a gap for people working in palliative care"*

In addition to a survey of subscribers to the Allied Health Hub, CareSearch undertook a second, general survey of Allied Health professionals' knowledge of palliative care, education and professional development,

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[20] CareSearch Evaluation Program: Report No 222. Evaluating the Allied Health Hub: results of an online survey. October 2015

practice and attitudes.[21] These individuals were recruited through a range of channels including industry associations, special interest groups and word of mouth during November 2015–April 2016.

- 217 professionals completed one or more items in the survey, of whom 94% were female, with a relatively even distribution across age groups (with the exception of the group aged greater than 60 years who were less represented at 6%) and most (31%) fell in the 30-39 age group. Respondents worked across each Australian state and territory, with the greatest proportion from the eastern states of Victoria, NSW and Queensland (28%, 24%, 22% respectively).
- Those who responded represented a range community socio-economic status, with 28% working postcodes in the lowest SEIFA IRSD quintiles (based on 2011 census data), 30% in the middle quintile and 42% in the highest quintiles.
- Overall eight disciplines were represented, with occupational therapists (28%), social workers (22%), physiotherapists (185) and dietitians (18%) the most common disciplines. The majority worked within the hospital setting (52%), followed by specialist palliative care service or hospice (33%), and community settings (32%)

This survey didn't assess use or familiarity with CareSearch (and hence doesn't provide direct evidence of CareSearch's impact) but does provide a snapshot on experience, attitudes and education needs for these professionals in relation to palliative care which may have been impacted by CareSearch.

When asked to describe what palliative care involves, these allied health professionals displayed a comprehensive knowledge of palliative care, which could be summarised in themes:

Palliative care…:

..involves treating, and actively managing the patient's medical symptoms

..requires a shift in perspective from a "Medical Model" to a focus on the person and their needs, wishes, prioritises, and quality of life

..provides support in other domains, rather than solely medical support

..involves working with a patient with a life limiting condition and consideration of death and dying

..involves multidisciplinary/interdisciplinary teams

..extends beyond the individual patient to the patient's family, carers, and the broader community

..requires healthcare professionals to have a specific set of skills/attributes

.. is proactive and is implemented from the point of diagnosis

.. is implemented in a range of settings and timeframes

- While those who had an interest in palliative care may have been more likely to opt-in to the complete survey, it is positive to see the favourable attitudes to palliative care. Sixty three percent stated they cared for 15 or more clients/families with palliative care needs in the past year, and 66% of respondents had been involved in a palliative care case conference at some point. Importantly, these professionals mostly reported they liked working with palliative patients (56% strongly agree, 26% agree) and many chose to work with palliative care patients (51% strongly agree, 19% agree). Those with greater duration of experience post-training were more likely to feel equipped, both professionally and personally, to provide palliative care.

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[21] Palliative care practice, experience and attitudes of allied health professionals in Australia. CareSearch draft report, 2016.

Dying2Learn MOOC

In 2016 and again in 2017 CareSearch ran a Massive Open Online Course (MOOC) Dying2Learn. This online course aimed to provide a community platform for social discussion and connection regarding death, dying, and palliative care. The objective was to foster community conversations and strengthen community awareness of palliative care and death as a normal process.[22] [23] Investigation of the impact of this MOOC demonstrated effectiveness in engaging people in these conversations and changing attitudes.

The course content was designed to be collaborative, community driven and participatory rather than directly instructive and approached death and dying through a social rather than medical or clinical lens. Facilitators, encouraged participants to get involved in discussion boards, create interest groups, share resources and complete activities including completing readings or watching selected videos. Module 1 focussed on how today's society engages with death and dying through the language we use, humour, public mourning and funerals. Module 2 focused on representations of death and how death is portrayed in history, art, film, TV, and other media. Module 3 focussed on the role of medicine in how we die. Module 4 addressed death and its meaning in the digital/internet age.

With the data collection embedded in the MOOC course website, the CareSearch team were able to examine the effect of the online course on attitudes to death and dying of the 895 individuals who completed the 2016 MOOC. At the commencement of the MOOC almost all of participants agreed that death is a normal part of life, most felt comfortable about talking about death, but felt that others do not feel comfortable about talking about death. This high level likely reflected the high proportion of individuals with health professional training who enrolled in the MOOC, however despite this high baseline those who completed the MOOC showed increased comfort in talking about death and dying (of those initially not comfortable 13/14 were reported they were comfortable the end of the course) and greater agreement with the idea that death is a normal part of life. A follow-up study of participants showed these changes appear to be sustainable, with many respondents indicating they had been involved in talking about death and dying since their participation.[24]

Importantly those changes applied to both health professionals and those who did-not identify as health professionals, show the content and approach was successful in engaging both groups as individuals. The engagement of both of these groups also demonstrates the course meets a need these individuals have identified to be able to more openly discuss dying.

Consumers and Carers

CareSearch is also in the process of undertaking an online survey of CareSearch consumers and the general public, with the project currently at ethics approval stage. Once complete, this survey aims to provide further insight on the users of the CareSearch website, their experience with the site and their level of knowledge of palliative care.[25]

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[22] Lewis-Miller L, Tieman J et al (Draft manuscript) Can exposure to online conversations about death and dying influence death competence? An exploratory study.

[23] Tieman J, Lewis-Miller L, et al (Submitted Manuscript) The contribution of a MOOC to community discussions around death and dying, 2017.

[24] Tieman J, What we've learned (presentation), Canberra, May 2017

[25] Application for ethical approval of behavioural research involving human participants, January 2017

Informal feedback

Unsolicited feedback from a consumer who has used the CareSearch site illustrates she found value not just in the presentation and functionality of the site, but was also able to apply the information sourced in caring for her parents:

Email from carer (27/8/2016)

> *"This is just a quick note to say thanks for an incredibly useful website - easy to navigate and packed with easy to read, relevant information. Not a single link broken! Stellar job!*
>
> *I have been trying to find how to best support my elderly parents, one of whom has pancreatic cancer and wants to die at home. I found so much of actual practical help on your website and feel more in control of the situation now.*
>
> *I am particularly grateful for the careful avoidance of "health speak" which so often equates to meaningless motherhood statements of no practical use.*
>
> *Profound thanks"*

Email from consumer representative

> *"I am very impressed with this website. The large volume of information is carefully/logically organised which made it easy to navigate. I didn't get 'lost' which is often a complaint I hear from consumer reps, i.e. they make 3 clicks on a website, go in deeper and deeper and give up at his point.*
>
> *I will share it with the rep team for their interest…"*

Increased support for and use of evidence

Evaluation question: Is there evidence that CareSearch has contributed to:

- Increased understanding about & positive attitudes towards evidence and its potential usefulness in practice (including increased support for evidence-based practice by relevant organisations)

Users of My Learning

The CareSearch My Learning modules were designed to assist health professionals to build an understanding of applying evidence in practice (knowledge mobilisation). The module design was informed by evidence about effective knowledge mobilisation and adult education strategies; aiming to prompt and remind clinicians about the role of evidence inn practice, to demonstrate how to find relevant evidence, and to show how to use the evidence resources in CareSearch to make a difference in clinical care. Each module includes a case study application of the information covered in the model.

CareSearch evaluated the use of these modules through a survey of users prior to and post completion of a module, with 1852 learners visiting one of the eight MyLearning modules landing pages during the evaluation period, 1137 opting to complete the evaluation, 92% completing pre-module evaluation and 32% completing post-module evaluation.26 Module access and evaluation completion rates are provided in Table 4.

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[26] CareSearch Evaluation Program: Report No 21. 'My Learning': Results of pre-test, post-test evaluation. March 2017

Table 4: Completion of MyLearning modules

CARESEARCH® MODULE	*MODULE VISITS*	*PRE-MODULE EVALUATION ONLY*	*PRE-POST-MODULE EVALUATION*	*TOTAL EVALUATION*	*TOTAL PRE-MODULE EVALUATION*
	n	***n (% visits)***	***n (% total eval)***	***n***	***n***
MyLearning 1: Finding Evidence (Published Literature)	364	196 (54)	78 (28)	274	267
MyLearning 2: Finding Evidence (Searching for Evidence)	181	71 (39)	44 (38)	115	113
MyLearning 3: Searching the Web	176	59 (34)	46 (44)	105	104
MyLearning 4: Residential Aged Care	190	69 (36)	45 (39)	114	114
MyLearning 5: Dementia	202	75 (37)	48 (39)	123	121
MyLearning 6: Carers	181	53 (29)	41 (44)	94	94
MyLearning 7: Knowledge Translation	441	145 (33)	58 (29)	203	203
MyLearning 8: Disseminating Research Findings	117	20 (17)	6 (23)	26	27
Total	1852	688 (37)	366 (35)	1054	1043

- The data showed that health professionals are accessing these resources, the majority of respondents were nurses (66%) with a smaller number working in aged care (8%), allied health professionals (6%), doctors (4%) and the remainder selected “other”.
- The modules on knowledge translation and finding evidence were the most frequently visited. The use of individual modules varied by discipline, suggesting differences in professional needs/interests. The proportion of nurses completing MyLearning module 4 (*Residential Aged Care*; 73%) was highest, lowest for module 8 *Disseminating Research Findings* (41%), while doctors (11%) and those who classified themselves as ‘other’ were most highly represented in module 8 (44%).
- Overall respondents found the modules easy to use (99%), would recommend the module to a colleagues (93%), would undertake another module (96%) and would visit CareSearch again in the next six months (93%). Importantly, a very high percentage also reported they would use the module information in practice (92%). These responses remained high when examined in relation to the individual module completed, with no modules rated poorly.
- The evaluation of the module 7 *knowledge translation* also assessed attitudes to practice change post completion of the module. 77% reported they felt more confident in participating in a knowledge translation project and all (100%) agreed that evidence should be an important part of change management.

Individual unsolicited feedback on the modules was also received via email:

> *"Accessed from ipad. Completed the 6 modules: very interesting and relevant information for my work practice. Enjoyable reading and learning. Learnt a lot"*

These results demonstrate a high number of health professionals with preparedness to complete these modules, and a high intent to apply knowledge from the modules in practice.

Allied Health professionals

Results from the Allied Health survey reflected knowledge mobilisation (i.e., moving available knowledge into active use) as a consequence of engaging with CareSearch, with 28% of respondents stating that they had used information from the newsletters to change and assess practice with palliative care patients.

Comments on useful aspects of CareSearch included:

> *"Affirmation really about what I thought I wanted to say/do, and actually doing it. E.g., I now have more confidence to have those open conversations with people who are at end of life (where appropriate), whereas I thinking I tended to find some conversations confronting"*
>
> *"References to new articles reviewing local practice"*
>
> *"Used some information re best practice ideas"*
>
> *"More to broaden service than to change practise, particularly remember pharmacy input and speech path input being helpful at the time"*
>
> *"Developing a more "slow stream rehab" approach to some of my patients; increased motivation to offer them more active intervention if appropriate to their goals. Confirmed my previous approach but increased my confidence to pursue it"*
>
> *"Clinical guidelines"*
>
> *"Approach to end of life in aged people"*

In relation to the application of information from the Allied Health Hub, 41% (9) of survey respondents indicated they had used the Hub to assist them to make changes in their practice with palliative care patients, including building general knowledge and understanding, increased knowledge and skill in specific areas (such as pain management and nutrition) and:

> *"Using best practice ideals"*
>
> *"Advanced care planning, talking to children"*
>
> *"Reinforcing need to avoid hospitalisation in patients with advanced dementia"*

Use of CareSearch to inform others – extending reach and impacts

Evidence that CareSearch reaches beyond those with whom they have direct contact is reflected in the responses of Allied Health newsletter survey respondents to questions about the use and usefulness of Hub content. The Hub content was considered very/somewhat useful for professional development and "personal education and study" by all respondents. Other uses of content that were rated highly as very/somewhat useful were in relation to providing the information to patients and family members, and sharing with colleagues.

Table 5: Ratings of Usefulness of Allied Health Hub Content

USE AND USEFULNESS OF HUB CONTENT					
How is content used	**Very Useful**	**Somewhat Useful**	**Not Useful**	**Not applicable**	**TOTAL**
For your own professional development	14 (74%)	5 (26%)			19
For personal education and study	13 (72%)	5 (28%)			18
To use with a patient or family member	7 (44%)	6 (37%)		3 (19%)	16
Provide handouts to patients, families	6 (37%)	3 (19%)		7 (44%)	16
To discuss with another health professional	6 (35%)	8 (47%)		3 (18%)	17
To support an idea or argument	6 (35%)	8 (47%)	1 (6%)	2 (12%)	17
Provide handouts to health professionals	5 (31%)	3 (19%)		8 (50%)	16
To disseminate to others	5 (29.5%)	7 (41%)		5 (29.5%)	17
Teaching others	5 (29%)	8 (47%)		4 (24%)	17
As a discussion point	4 (25%)	10 (62%)		2 (13%)	16
To change an area of practice	4 (22%)	8 (44%)		6 (33%)	18
To discuss with a manager	2 (13%)	6 (40%)		7 (47%)	15
Include in newsletters	1 (7%)	2 (13%)	1 (7%)	11 (73%)	15

CareSearch has also worked with and supported other organisations to promote the use of CareSearch in health professional training, including working with GP Partners to provide information and evidence for their SA-based training program, and linking to PEPA & PCC4U training through online links and including information from the website in newsletters. Through these relationships, CareSearch extends its reach in an effective and efficient way.

Use of CareSearch in organisations

An evaluation of the "End of Life Essentials" website and toolkit for hospital employees, provided evidence of the way in which CareSearch can have impacts for people and organisations who do not necessarily engage directly with the website. CareSearch recognises this and developed the "EoL Implementation Toolkit" as a way to support those working in hospitals in delivering end of life care.[27] Responses from an interview with a nurse who used the Toolkit highlight the potential reach of these kinds of resources and tools.

> *"We are not just going to push it [My Toolkit] through [the] emergency [department], we are going to push it through the hospital … [I have] managed to get people from a lot of different departments…interested in the topic at the moment….starting on the floor within an ED [Emergency Department] as a trial and filtering out into other departments. I'm excited to get working on the change that is going to happen...it is good to see the consultants jumping on board and it's not just the nurses." (Interview 9, Nurse, VIC)*

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[27] Hutchinson C 2017 End of Life Essentials Evaluation Report: Phase 2, My Toolkit Flinders University

Contribution to generation of new evidence

Evaluation question: Is there evidence of intended impacts for palliative care researchers, the specialist palliative care sector and relevant decision-makers with whom CareSearch engages?

- In what ways has CareSearch contributed to the generation of new evidence about palliative care?
- Has CareSearch contributed positively to the quality and integration of palliative care research activity in Australia?

CareSearch's contribution to the body of research for palliative care is evidenced both in work undertaken by, or in collaboration with, the CareSearch workforce, in addition to the use of CareSearch materials and resources in research generated by the wider palliative care and health sector.

Completed CareSearch-led Research Projects

- Economic Impact of Palliative Care: CareSearch created of a set of broad and specific search filters and recommendations to allow faster identify current high quality literature about economic aspects of palliative care.[28] Specific searches include cost of bereavement care, cost of lung cancer care, costs of dementia care and costs of primary health care. These search filters were released in October 2015, and in the following 6 months webpage view counts suggest a potential search initiation rate using these filters in the vicinity of up to 11 per day.[29]
- Investigation of telehealth as a means of offer new ways of managing load and care prioritisation for palliative care patients living in the community.[30]
- Evaluation of the effectiveness of online learning and contribution to community discussion of the Dying2Learn MOOC, including understanding community views of death and dying, informing research design for MOOCs, identifying euphemisms for death, coping with death research scales study, paradoxes around death.

CareSearch-led research currently underway:

- The project "How do people find and use online health information, and what are their views on death and dying, palliative care and CareSearch?"[31] is currently awaiting ethics approval and is expected to be completed in 2017.

Contribution to evidence dissemination

CareSearch research publications

CareSearch has authored or co-authored 14 peer-reviewed publications to date during 2015-2017. These publication have covered topics from across the breadth of CareSearch's work, contributing to knowledge in the areas of e-learning, health literacy, evidence based information and literature searching method,

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[28] Hayman, S. and J. Tieman (2017). "Finding evidence about the costs of palliative care: CareSearch's suite of search tools." Palliat Med **31**(4): 387-388.

[29] CareSearch data, CareSearch Update National Advisory Group Meeting: 17 March 2017

[30] Tieman JJ, Swetenham K, Morgan DD, To TH, Currow DC. **Using telehealth to support end of life care in the community: a feasibility study.** BMC Palliat Care. 2016 Nov 17;15(1):94.

[31] "How do people find and use online health information, and what are their views on death and dying, palliative care and CareSearch." Application for ethical approval of behavioural research involving human participants, January 2017

knowledge translation and health services research. Details of these publications are provided in Appendix B. A further three publications arising from the Dying 2Learn MOOC are in development.[32]

Table 6: Number of CareSearch Published Peer Reviewed Articles and Research

Year	Peer reviewed journal articles	Presentations at scientific meetings
2017 (to date)	5	4
2016	4	13
2015	5	4

CareSearch research presentations

CareSearch team members presented the results of CareSearch research in 19 presentations to date over the course of 2015-2017. Details of these presentations are provided in Appendix C.

CareSearch research promotion

CareSearch champions and promotes research and evidence within its promotional and educational activities. Where appropriate, CareSearch promotes knowledge generated by CareSearch, along with relevant Australian and international research, in newsletters, the website and other CareSearch promotion.

Research use: citation of CareSearch resources

A search of citations of CareSearch in published research to the end of 2016[33] shows that CareSearch is often cited in journal articles either as a reference or as a part of the research method or process (Figure 7). These publications provide evidence of CareSearch's recognition both for palliative care research and information, and for the significant contribution the project team has made to the field of literature search/search filter method.

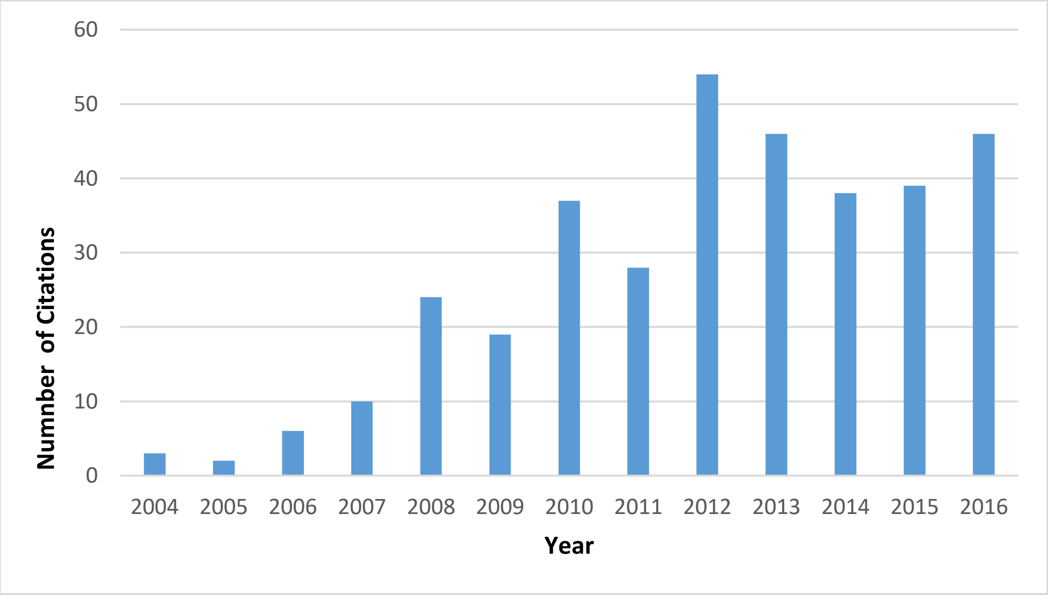

Figure 7: Number of Publications Citing CareSearch

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[32] Tieman J, What we've learned, Presentation to Department of Health May 2017

[33] CareSearch citations search, CareSearch February 2017

CareSearch research resources

The CareSearch Research Data Management System (RDMS)

The RDMS is used to facilitate research data collection and hence research activity in the sector. The previous AIPCA evaluation demonstrated that the RDMS has clear value in enabling research data to be collected in an ethical and cost effective way.[34] During 2015-2017 CareSearch established a further ten partnership agreements with organisations to use the RDMS in research and nine agreements with organisations undertaking service data collection, including the Palliative Care Australia's National Standards Assessment Program (NSAP) and The Australian Palliative Care Clinical Studies Collaborative (PaCCSC) multi-site phase III clinical trials.[35] Further details of data collection partnerships are provided in Appendix E.

The CareSearch Research Studies register

The research studies register is a database of Australian research projects and studies in palliative care. The database is actively used, with details for 30 current projects and 146 past projects entered in the register to date.[36] The register provides a means of sharing information, developing linkages, preventing duplication and promoting awareness of current research activities.

CareSearch information resources for researchers

In addition to providing access to existing research, the RDMS and the studies register, the CareSearch website provides resources for researchers, guides for new researchers, and links to grants and granting agencies.

CareSearch My Learning module

The CareSearch My Learning module *Disseminating Research Findings*, released in November 2016, provides training for uses on communicating research findings in a planned way.

Stakeholders' view of CareSearch as a research resource

Care Search is valued as a mark of authority in palliative care research, as evidenced by stakeholders interviewed regarding the future of palliative care in Australia:[37]

> *"I worry if systematic reviews don't say they have been through CareSearch"*
>
> *"Love it to bits- so phenomenally useful! If I need to look for something quickly, CareSearch will provide me either, for the researcher that wonderful broad net or for the clinician the wonderful narrow focus of what I need to know right now. I think CareSearch is absolutely invaluable and there is nothing like it around the world."*

CareSearch stakeholders were advocates for CareSearch being involved as a partner in research projects. CareSearch is also an important facilitator of conversations about research in the palliative care sector. As part of the interviews, stakeholders identified factors they considered important for improving the quality and relevance of palliative care research, including:

- The need for a consistent definition of palliative care and end of life, and for accurate recording of terminal prognosis or circumstances around death, recognising an end of life pathway, to improve

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[34] Australian Institute for Primary Care and Ageing, CareSearch Evaluation Report, 2014

[35] Agreement Summary: CareSearch and Agreement Partners as at June 2017

[36] CareSearch website, accessed July 2017

[37] Australian Institute for Primary Care and Ageing, CareSearch; The future of palliative care in Australia; report on key Stakeholder Interviews, 2017

the quality of research data
- More research that is focused on palliative care models and cost implications, patient needs and benefits from palliative care including diverse communities, appropriate care for specific diseases and multi-morbidities (e.g. dementia).

CareSearch research and research advisory partnerships

CareSearch has contributed to the quality and integration of research activity in the sector through acting as a trusted source for evidence and advice and collaborating partner for organisations in the palliative care and broader health sectors:

- Therapeutic Guidelines sought CareSearch advice on their comprehensive revision and update of the Palliative Care clinical practice guideline, 4th edition, cited CareSearch as a reference in the guideline and included links to the CareSearch website.[38] [39]
- CareSearch developed evidence sheets used in PCOC benchmarking workshops
- CareSearch co-investigators and individual management and advisory group members are also Investigators, through Flinders University/ their respective organisations, on the Centre of Research Excellence in End of Life Care (CRE EOLC). [40]
- This partnership led to the development of the My Learning modules *Knowledge Translation* and *Research Dissemination.* The modules provide guidance on applying research and information to improve patient outcomes and on strategies for disseminating research outcomes.
- NSW Agency for Clinical Innovation commissioned CareSearch to identify local, national and international tools and resources for the clinicians in palliative and end of life care[41]
- Partnership with Australian Centre for Grief and Bereavement in the project to identify bereavement costs of care.

CareSearch policy advisory activities

During 2015-17 CareSearch has been approached to contribute to Australian policy in Palliative Care, including:[42]

- Providing feedback as a key stakeholder for policy evaluation
- Member of service review group for Palliative Care Australia
- Involvement in economic impact project for Palliative Care Australia
- Informant for development of potential palliative care pages for use in the Aged Care Roadmap

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[38] Email feedback to CareSearch, September 2015

[39] Therapeutic Guidelines www.tg.org.au Palliative Care electronic guidelines, accessed 12/07/ 2017

[40] Centre of Research Excellence in End of Life Care (CRE-ELC) website http://www.creendoflife.edu.au/ 17/07/2017

[41] NSW Agency for Clinical Innovation Palliative and End of Life Care Resources sourced by CareSearch accessed 17/07/17

[42] Personal communication, Jennifer Tieman

5. How is CareSearch delivered?

IMPLEMENTATION OF THE CARESEARCH MODEL

This section of the report provides a brief summary of the activities and structures that support development and delivery of the *CareSearch Model*. In 2015-2017, there was a renewed focus on capturing the elements that contribute to long-term sustainability of the *CareSearch Model.*

Key inputs for CareSearch are the financial and in-kind resources that support the project, the governance arrangements for strategic and operational support and broad stakeholder engagement in a wide range of activities that support development and implementation of the *CareSearch Model*.

Governance Groups

The governance arrangements for CareSearch – as a project and a knowledge network model – involve multiple layers and a range of different relationships, including:

- Ongoing Governance through two key groups with some degree of overlapping membership (2-3 members including the funder):
- National Advisory Group (NAG) to provide strategic oversight and ensure that CareSearch remains closely linked to and part of the palliative care sector. This group informs and is informed by the work of the CareSearch project.
- Knowledge Network Management Group (KNMG) to provide operational oversight and make decisions in relation to the *CareSearch Model*, project-related business matters and contractual/legal issues.
- Fixed-term and task-focused groups, including:
- Advisory Groups to provide strategic input for specific tasks
- Working groups to provide operational support for specific tasks

Intended consequences of governance arrangements

The key intended consequence of the Governance arrangements is:

- To ensure the effective operation of CareSearch, including the day-to-day operations of the project and the knowledge network.

The governance groups also serve to contribute to other objectives of CareSearch.

Resources

Funding from the Department of Health

The majority of the funding from the Department of Health continues to be used to fund staff positions, with the remainder funding IT website hosting and system integration and for additional resources such as the Research Data Management and Learning Management system licences.[43]

In-kind support from Flinders University

Flinders University continues to provide substantial in-kind support to CareSearch. These supports include

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[43] CareSearch Performance Report 31 July 2016

- Access to bibliographic databases and support form health and medical librarians
- Legal support for contract with users and suppliers
- Support for marketing, promotion and events
- Systems and processes for management of project finances, human resources and occupational health and safety to ensure accountability for the project
- Access to a variety of content and methodological experts across the University who can inform direction and decision-making.

In-kind support from the palliative care and health sectors

CareSearch engages with an extensive network of individuals and organisations in the palliative care, health, research and general community, many of whom contribute in kind support to various degrees. This group included those involved in governance and advisory groups for CareSearch and its projects, detailed in the following section. This support includes:

- content review
- representation
- participation in workshops and other activities
- preparation of blogs
- promotion and dissemination of CareSearch information and resources through networks and associations

CareSearch project team (workforce)

Over the course of 2015-17, the CareSearch leadership team has continued to recognise and highlight the importance of the CareSearch workforce as an integral component of delivering the CareSearch Model. While the website maintains automated and interactive functionality, the development, updating, process and management of the components of the Model all require input from a skilled staff.

The CareSearch workforce undertakes a wide range of tasks and activities to:

- Maintain Functionality (website) including upgrades & enhancements as required; Provide support to website visitors; Support online interaction tools
- Develop and maintain Content
- Develop and implement Integrated Promotion (supported by Communication Plan)
- Engage stakeholders, including peak bodies (e.g., peak palliative care sector organisations, professional associations), health professionals, health service providers, consumers, carers, community, researchers, decision makers and policy advisors

Essential roles and responsibilities, skills and experience

During the period 15-17 the core CareSearch staff of 10-12 FTE has included the following roles and tasks:

- Marketing & Communication team: Online communication and marketing, database management, website design management, writing to meet accessibility and readability standards and to tailor to various target audiences, relationship development, administration
- Website Management team: information architecture, administration, user testing and review, user feedback, website standards (Hon code) data entry, Website information architecture, website statistics, user support for website, research and learning management software platforms

- Management: project oversight and management, contract management, partnership development
- Evidence and Research team: Research development and management, partnership management, literature searching, search filter development, ongoing search updates, literature synthesis, statistical analysis
- Online education: material development, management and delivery

In addition to the normal operational workload of managing CareSearch, new projects for CareSearch can place additional, sometimes unpredictable demand on staff time:

- The popularity of the Dying2Learn MOOCs created substantial additional workload to manage the participant platform and ensure a quality experience for participants.
- The agreement to commence the Enhanced Knowledge Base for Palliative Care in Aged Care (PCACE Project), alongside CareSearch has required restructuring of the CareSearch workforce and recruitment of additional staff to meet the needs of both Programs.[44]
- The development of the Aboriginal and Torres Strait Islander Hub evolved in concept, based on feedback from the Advisory Group, and additional staff time were dedicated to this project to meet the revised scope and timelines.
- CareSearch Refresh required input from staff with specific technical skills

Workforce development and retention

The nature of the Department of Health CareSearch funding agreements introduces some risks for the program, as staff are unable to be offered long-term role security, leading to increased difficulty in retaining skilled specialist staff as they leave to take up ongoing positions.[45]

Governance

The two key advisory groups, the CareSearch Management Group (CMG) and the National Advisory Group (NAG) provide strong ongoing input into shaping both the strategic direction and content of CareSearch, and in building engagement with the sector, as evidenced in the minutes of meetings assessed as part of this report, as well as in the hands on involvement in reviewing content and structure- for example the CareSearch refresh project.

CareSearch Management Group (CMG)

The CMG includes representatives from organisations from across palliative care:

- A representative with translational science skills
- A representative with skills and knowledge information retrieval and dissemination
- A representative with policy and systems knowledge
- Representatives from key academic institutions around Australia
- A representative from primary health care
- A representative for bereavement issues
- A representative from Palliative Care Australia
- A representative with IT experience
- A representative for Aboriginal and Torres Strait Islander issues
- A consumer representative
- A representative of Carers Australia
- A representative with legal and business skills
- A representative of the aged care sector

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[44] CareSearch Performance Report for Department of Health 31 July 2016

[45] CareSearch Performance Report 31 July 2016

National Advisory Group (NAG)

The NAG meetings occurred at or above the planned number of meetings for each year in 2015-2017.[46] Representatives or members of following groups and organisations form the basis for the National Advisory Group:

- Allied Health Professionals of Australia (AHPA)
- Australian & New Zealand Society Palliative Medicine (ANZSPM)
- Australian Centre for Grief and Bereavement
- Australian College of Rural and Remote Medicine (ACRRM)
- Australian Palliative Care Outcomes Collaboration (PCOC)
- Carers Australia
- Carer / Consumer Representative
- Consumer Health Forum
- Federation of the Ethnic Communities Council of Australia (FECCA)
- National Aboriginal Community Controlled health Organisation (NACCHO)
- National Rural Health Alliance
- Palliative Care Australia
- Palliative Care Nurses Australia (PCNA)
- Primary Health Care Research & Information Services (PHCRIS)
- Program of Experience in Palliative Care Approach (PEPA/PCC4U)
- Residential Aged Care Facilities
- Advance Care Planning Australia
- Royal Australian College of General Practitioners (RACGP)

The CMG and NMG meetings occurred at or above the planned number of meetings for each year in 2015-2017. [47]

Table 7. Governance meetings per year (Jan-Dec)

	Meeting dates		
Group	2015	2016	2017 to June 30
NAG	27 April teleconference 13 Oct teleconference 10 August f2f	16 March Teleconference 11 July f2f 18 Oct teleconference 19 December teleconference – joint with KNMG	17 March teleconference
CMG	19 May teleconference 8 Sept f2f 10 Nov teleconference	15 March F2F 19 May teleconference 10 Nov teleconference 19 December teleconference – joint with NAG	None to date

f2f= Face to face

Task Focused working and advisory groups

Specific time-limited and task-focused groups provide additional resource, strategic input and means of engaging with the palliative care, health and wider community.

- The Aboriginal and Torres Strait Islander Reference Group for the PEPA and PCC4U projects have acted as the advisory group for the development of the Aboriginal and Torres Strait Islander Hub.

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[46] CareSearch Performance Report 31 July 2016

[47] CareSearch Performance Report 31 July 2016

This group has been essential in providing extensive feedback, in particular in relation to the potential for the Hub to contribute to building cultural understanding. The group reviewed structure, content, images and was very influential in determining the direction of development of the Hub. CareSearch has paid careful attention to ensuring the reference groups perspectives were taken into account and accommodated these in a revised concept, while extending timelines to ensure sensitive and high-quality delivery of this section.

- *The Allied Health advisory group* includes representatives from the major allied health disciplines (dietetics, physiotherapy, occupational therapy, psychology, social work, speech pathology and music therapy) to advise on ongoing content review, newsletters, case studies and profiles of interest for the respective professions.[48]

Table 8 Task specific groups during 2015-2017.

Group	Focus
Allied Health Review Group	newsletter and Hub
PCACE Review Groups (4)	PCACE content
Nurses Review Group	Hub
Aboriginal and Torres Strait Islander Care Review Group	Hub

Stakeholder Engagement

In addition to formal governance groups, CareSearch undertakes a range of activities and tasks to engage stakeholders for a range of intended outcomes.

CareSearch has continued to actively maintain and develop new partnerships to contribute to the quality of content, to improve cohesiveness and reduce duplication in the sector, to contribute to information sharing and skill development across the sector and to support promotion of CareSearch resources.

Stakeholders are currently engaged through the following kinds of relationships and roles:

- *Reviewers* – relevant experts are engaged to ensure the quality of content provided through the *CareSearch Model.* They can also take on additional roles. For example, each member of the Allied Health Hub advisory group leads an edition of the bi-monthly newsletter.
- *Partnerships* – where the relationships range from information exchange through cooperation to collaboration. Partnerships have previously been described falling into four categories: functional, collaborative, commissioned, research, and community. Currently there are a range of different kinds of partnerships including:
    - *Strategic Partnerships*: These involve proactively developing relationships with organisations in order to align and/or increase the impact of CareSearch. Organisations with related activities/products are approached by CareSearch. These partnerships also contribute by providing strategic information and advice to shape the content and direction of CareSearch. In addition, and increasingly over time, CareSearch is approached by other organisations to act as an expert advisor to their projects and activities.

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[48] CareSearch Evaluation Program: Report No 222. Evaluating the Allied Health Hub: results of an online survey. October 2015

  - *Research Partnerships:* These involve CareSearch taking on different kinds of roles around research activities, including providing operational support to research via: the functions of CareSearch (e.g., using the Research Data Management System); offering expertise as part of in-kind support for projects (e.g., sitting on Advisory Groups); and acting as investigators to seek funding and deliver successful research project applications. Increasingly over time, CareSearch is being identified as a key organisation to engage to partner in research collaborations
  - *Information Exchange* Partnerships: CareSearch is responsive to approaches from external organisations, and will provide and share relevant information.
- *Direct Users of CareSearch* – those who use resources and material are also important stakeholders. CareSearch has a range of consultative and feedback mechanisms to enable the Model to be responsive to the needs of end users.

Strategic partnerships

As indicated, partnership and collaborations are an important aspect of CareSearch's work. The number of partnership collaborations, and ongoing approaches to be involved in new and evolving programs from a range of organisations across the sector, evidences CareSearch's strong reputation across different sectors.

Major strategic partnerships continued, completed or commenced in this period include those listed below, and detailed further in Appendix E.

Community engagement partnerships

- Carers Australia
- Groundswell
- Federation of Ethnic Communities' Councils of Australia

Health professional engagement partnerships

- Allied Health Professions Australia
- Palliative Care Australia
- Paediatrics Collaborative Clinical Indicators

Organisational Engagement

- Leading Age Services Australia -supporting development of Cert III modules
- Palliative Care Australia- service reviews
- South Australian Department of Health- contribution to End of Life Care Strategy
- Australian Commission on Safety and Quality in Health Care (ACSQHC): End of Life for GPs

Engagement to support health professional education and training content

- Queensland University of Technology (QUT) Whole of Workforce Framework
- Hammond Care- Advance
- Quality of Care Collaborative for Australia in Paediatric Palliative care (QuoCCA))
- Austin Health Decision Assist
- Centre of Research Excellence in End of Life Care
- EoL Essentials
- Queensland Health Best Practice
- Palliative Approach Toolkit guide to implementing a palliative approach in residential aged care facilities

THE CARESEARCH MODEL – PROCESSES

Functionality

Systems (hardware, software, procedures), methods and mechanisms

CareSearch has developed the website and associated platforms with integrated functions to deliver CareSearch functionality in a cost effective manner, with content pages continuing to be structured to function independently. CareSearch continues to work with Morton Blacketer and Genki Design as well as a new design company, Reward Design, to maintain online resources.

The key platforms and facilities used are:

- DNN Platform (formerlyDotNetNuke) open source content management system- web environment
- Research Data Management System (RDMS) licensed product, research database
- Learning Management System (LMS) (Mediasphere, Captivate),
- Mail Chimp
- Social media including Hootsuite, Twitter and LinkedIn

New and updated functionality

As the website has evolved with updates, additional projects and partnerships, and in response to user need, CareSearch has added additional functionally to the website. Some of these developments have also allowed and/or been designed to allow CareSearch to reach and communicate with a wider target group and to support a wider range of computer/smart phone devices (refer CareSearch Refresh below). These have included:

- *Dying2Learn MOOC* hosted and developed within the OpenLearning Platform (www.openlearning.com)
- Apps @CareSearch- smart phone apps
- You Tube, Vimeo integration to host video

CareSearch Refresh Review and update of functionality

CareSearch has undertaken a major quality improvement project- a review of usability of the website, with a focus on improving the website navigation and user experience when accessing CareSearch on mobile devices (smartphones, tablets). This review was in part also necessitated by the addition of PCACE/PalliAGED to the CareSearch web environment. The review examined:[49]

- Information architecture generally and within specific sections (for example, the Education section)
- Search optimization
- Responsiveness to device (i.e. mobile vs laptop, respective operating systems)
- Optimising user experience in a cost-effective manner bounded by the funding contract
- Currency of content
- Integration of videos, images and interactivity

As part of the refresh, CareSearch prioritised and progressively completed stages from November 2016 to May 2017, with priority given to the sections related to health professionals (previously known as Hubs) and the Patient & Carer section, and minimizing interference for users during the process:[50] [51]

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[49] Hall K CareSearch Refresh Project Plan August 2016

[50] National Advisory Group CareSearch Refresh Update March 2017

[51] Minutes of the KNMG Teleconference 14th July 2016

- Improved web architecture through revised layout and menus (to reduce number of steps required in navigating pages)
- A branding and design update
- An update to the content management system (CMS) to 'DNN7' to allow more responsive capabilities, along with opportunities to develop staff experience and expertise in responsive formats

In addition this major Refresh project, Project Team continues regular processes to:

- Update pages as new resources are released
- Check throughout the site to ensure links within and external to the site are current and functioning

Responding to user feedback regarding functionality

Usability testing

Usability testing was completed during 2016, as par the CareSearch Refresh process. This involved groups of consumers (2 individuals) and health professionals (3 individuals) completing a series of user experience exercises. Feedback from this exercise rated the ease/difficulty of navigating through the site and finding specific items.[52] The results of this exercise were positive, confirming the acceptability of the labelling and navigation structure the site has adopted.

Education Section - post implementation survey

An additional review assessed the navigability and layout of the Education Section, following on from implementation of the Whole of Work Force approach and initial iterations of CareSearch refresh. The Health professionals who completed the post implementation survey were in the majority positive or very positive in their ratings of the logic, navigability and language of the revised section.[53]

Key Stakeholder feedback

Interviews with key palliative care stakeholders also investigated perceptions of CareSearch's functionality.[54] The support for CareSearch was positive, but a few specific comments identified issues such as the site being sometimes 'clunky', resources sometime hard to find or locate with the site search engine or "a bit buried". This group also noted the difficulty some health care workers have in accessing computers in their workplaces. Addressing this type of functionality and usability on mobile devices has been a key focus of the CareSearch Refresh website improvements.

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[52] CareSearch Refresh. Usability Testing Results. January 2017.

[53] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

[54] Australian Institute for Primary Care and Ageing, CareSearch; The future of palliative care in Australia; report on key Stakeholder Interviews, 2017

Content

During the period 2015-2017 CareSearch continued to improve, update and expand the content on the CareSearch website.

New content areas

Additional content areas developed and added during the 2015-2017 period:[55]

- *My Learning 8: Disseminating Research Findings* CareSearch, in conjunction with the Centre for Research Excellence in End-of-Life Care, developed a new learning module about communicating research findings in a thoughtful, planned way. It offers ideas to researchers and higher degree students that go beyond traditional conference presentations and journal publications.
- *Carers: How to Find Trustworthy Health Information Online* This infographic was developed for National Carers Week 2016. The infographic presents tips on which websites or other online resources you can trust. It also explains how carers can trust the information and resources found on the CareSearch website**.**
- *Living and dying in pain - it doesn't* have *to happen* This poster was created for World Hospice Day 8 October 2016
- *Costs of Care* Broad 'costs of care' searches to facilitate retrieval of literature relevant to the cost and economics of palliative care were released in October 2015. Several additional 'costs of care' searches have been developed to assist health professionals find the relevant literature on costs and economics. They include:
    - Costs of Bereavement Care Searching
    - Costs of Lung Cancer Care Searching
    - Costs of Dementia Care Searching
    - Costs of Primary Health Care Searching
- *Aboriginal and Torres Strait Islander Hub* The Aboriginal and Torres Strait Islander Hub was finalised and released on 16th March 2017.
- *Dying2LearnMOOC:* The Dying2Learn 5-week course covered four topics:
    - How does today's society engage with death and dying? How do we use language to describe it?
    - What does death 'look' like? How is death and dying portrayed in the media?
    - If death is the problem, is medicine the answer?
    - Digital dying: What does death mean during the internet-age?
- *Web Based Learning Resources:* Added new resources
    - Initiative for Pediatric Palliative Care
    - Introduction to Paediatric Palliative Care

In addition to CareSearch's core content, the CareSearch team has contributed to the development of new websites and content on behalf of other organisations or in collaboration. During 2015-17 this included[56]:

- *Decision Assist:* as part of a formal agreement CareSearch created the Decision Assist advanced care planning website

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[55] CareSearch Update, National Advisory Group Meeting 17 March 2017

[56] Minutes of the NAG Teleconference 18th October 2016

- *Advance*: as part of a collaboration and formal agreement with HammondCare CareSearch developed the website and eLearning modules to assist GPs in initiating advance care plans.
- *End of Life Essentials* website for hospital employees

Maintenance of content and revised content areas

Existing content continued to be revised and updated as part of the Model, including a review of the a review of the Systematic Review collection in 2015, the Web based Learning section (education) in 2015,Deb the Research Studies Register in 2015, and annual content reviews (each page in each section).[57] [58] Key updates include:

- *Hubs and Population areas:* Content within the Hubs is regularly updated and reviewed. In addition the CareSearch Refresh process has led to updates in layout, format and types of content, each of the Population areas and Hubs have been updated during 2017.[59]
    - Patients Carers and Families
    - GPs
    - Allied health
    - Nurses
    - Residential Aged Care
    - Researchers
- Clinical Evidence: Updates to pages
    - Bereavement and grief (2016)
    - Abnormal grief (2016)
- *CareSearch review collection:* on average approximately 19 new reviews are identified and added monthly
- *Search Filter topics* Palliative Care PubMed Searches new topics during 201 5-2016:
    - Bereavement
    - Paediatrics
    - Perinatal
    - Self- Care
    - HIV/AIDS
    - COPD
    - Non-malignant
    - Adolescent and Young Adult
    - Ethics
    - Mouth Care
    - Spinal Cord Compression
- *Grey Literature items* The number of items in the Grey Literature Database as at 20 July 2017 is:
    - Conference proceedings: 4,163
    - Grey Other: 267
    - Theses: 211
    - Research Studies Register: 173
    - Non-indexed Journal Articles: 697
    - National Program: 86
- *Education* The CareSearch Education section has undergone a major redevelopment during 2016 and 2017 to align with the Whole of Workforce Framework. This Framework aims to provide guidance for individual health care providers, education providers, health service managers and

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[57] CareSearch Performance Report for Department of Health 31 July 2016

[58] Communication from CareSearch, August 2017

[59] CareSearch website, accessed 4 August 2017

policy makers to ensure all health care providers are equipped with capabilities relevant to their context to provide care for people who are dying.[60] The revised Education section, released on 6 May 2016, includes

  - Information on the Whole of Workforce Framework.
  - Quality-assessed palliative education initiatives including and learning resources relevant to health professionals, carers and volunteers
  - A section on supporting educators and service managers developed by QUT.
- *My Learning modules (8)* revised during 2016 with a focus on improving understanding of how to use CareSearch resources in practice.
- Web based learning resources added resources:
  - Initiative for Pediatric Palliative Care (IPPC)
  - Paediatric Palliative Care (WA Department of Health).
- *Blogs:* blogs for Australian health professionals are published on the CareSearch website approximately weekly. Blog titles are provided in Appendix F.

Assessing end user needs and quality of content areas

CareSearch has quality processes in place to guide the quality, usability and evidence base of all content. Ongoing evaluation and development of CareSearch included regular review of content sections within the website and a more substantive review of the overall site as part of the CareSearch Refresh

- *Hubs and population groups:* The Hubs and population group sections have an advisory group involved in selecting, reviewing, updating and contributing content.[61] In addition, specific evaluation of these sections have included:
- *Allied Health*: Survey of allied health professionals registered to receive the CareSearch allied health newsletter, which included requests for topic areas.
- *Allied Health*: CareSearch survey of allied health professionals generally[62], which explored level of understanding of palliative care, caseload, information sources and education, information and knowledge needs.
- *Patients, Carers and Families* For the public/ patients carers and families, the review process includes guideline for authors on readability and writing for the web, advisory group and review processes, layout and formatting, application of web standards for accessibility of information for people with disabilities (W3C and WCAG 2.0), navigability as well as user testing.[63]
- *Education:* As part of CareSearch's contractual requirements and participation in the Whole of Workforce Framework project, CareSearch has completed a review of the education section of the website and the needs of intended users. This included
  - Consultative workshop and feedback survey (December 2015)
  - Review of navigation and layout, within CareSearch Refresh
  - A survey of site users post implementation

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[60] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

[61] CareSearch Evaluation Program: Report No 22. Evaluating the Allied Health Hub: results of an online survey. October 2015

[62] Palliative care practice, experience and attitudes of allied health professionals in Australia. CareSearch draft report, 2016.

[63] Rawlings D, Tieman J. Patient and carer information: Can they read and understand it? An example from palliative care. Aust Nurs Midwifery J. 2015;23(5):26-9.

Gaps in content areas

Internal review processes for CareSearch have identified the need for further resources to support learning for the community generally and for patients, carers and families affected by palliative care (for example in a format such as that applied in My Learning). In particular, CareSearch identified the need to ensure that family and community carers have access to knowledge about how to care and community infrastructure to support preferences to be cared for at home. In response, resources on this topic have been identified as potential future priority for CareSearch.[64]

Responding to user feedback regarding content

CareSearch is active in its uptake of user suggestions, and many of these topics have been integrated into new and existing content.

Education section

The redesign of the education section to accommodate the Whole of Workforce framework and CareSearch Refresh principles was directly informed by consultation with a stakeholder group.[65] As well as collating comments during the workshop, CareSearch asked participants in a workshop completed a survey. Suggestions were and findings were incorporated into the website redesign. These included:

- Include information about actual educational offerings, including for volunteers and carers
- Incorporate a tool to help users select appropriate training
- Ensure resources in the section are evidence based with expert authors, free, and current
- Target the whole workforce

A further survey from a sample of invited users was completed post the release of the revised section.[66] The 16 respondents to this survey provided feedback on their needs in relation to palliative care training and the updated Education section felt the content was comprehensive, and with the majority agreeing/strongly agreeing that the content would be application in the own CPD, covers all of their individual learning needs, and could be used to plan education for their organisation.

Allied Health Professionals' suggestions for additional content areas for the Allied Health newsletter and Hub, provided feedback from the survey of Allied Health professionals subscribed to Allied Health news (see details in section 2, above) included:

- Information on the NDIS in relation to community palliative care, specific disease topics (for example, communication with motor neurone disease patients, osteosarcoma), mental health and palliative care models and services (and their interface with other services and programs).

As an example of CareSearch's response to this feedback: the May2016 newsletter was a special edition newsletter on motor neurone disease.[67]

LGTBI-inclusive language Carer Gateway arranged a review of sites linked to within the Carer Gateway to assesses for appropriateness of language for a lesbian, gay, bisexual, trans, and/or intersex people, and contacted CareSearch to provide suggestions to use gender neutral language (such as using s/he or you, they and the word gender rather than sex or male/female), to balance the gender of images. These issues were

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[64] CareSearch Performance Report for Department of Health 31 July 2016

[65] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

[66] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

[67] CareSearch website, accessed 12 July 2017

discussed at a National Advisory Group meeting, and CareSearch has noted its efforts to be empathetic and inclusive of a wide range of audiences, including aiming to use gender neutral language.[68]

Integrated promotion

Communication Plan

Communication is an integral component of CareSearch's growth and effectiveness. The communication plan developed for the 2015-207 period[69] is comprehensive. It outlines communication objectives and strategies informed by situational analysis and CareSearch's overarching objectives. The plan also sets out benchmarks and measures for assessing the success and progress of CareSearch's communication work.

Promotional activities and materials

Promotional activities include both general awareness raising and engagement for palliative care and CareSearch, and specific promotion for key functions and objectives.

- *Palliative Perspectives blog:* the blog continues to be regularly updated with blogs published weekly. A list of blogs is provided in Appendix F. Special blog series have been produces to recognise International Nurses Day and to promote the launch of palliAGEDnurse.
- *Dying2Learn MOOC* promotion was successful in drawing over 1156 enrolments including 300 enrolments from the target audience, the general public in 2016 and 1944 total enrolments in 2017. The large health professional uptake of the course also showed the success of the promotion and need outside the initial target audience for the course. Promotion included
    - Collaboration with Groundswell, a not for profit organisation known for using innovative arts and health programs to create social and cultural change about death and dying.[70]
    - A webpage with information about the course and capacity to express interest
    - Advertisements within OpenLearning and on the MOOC List directory
    - Social media (twitter, linked in, facebook ad)
    - Electronic announcements distributed to community organisations, palliative care and specific health organisations, universities,
    - Media release and related press, interview and blog.
- *CareSearch newsletters* are distributed to subscribers, with numbers for each newsletter exceeding targets (refer to further details in section 2 above).
- *Promotional materials:* available to order include printed factsheets, posters and bookmarks for health professionals; brochures and posters for patient, carers and families.
- *Promotional subscribers* As of March 2017 there are 1,179 subscribers who receive information on new promotional materials and 1,219 who wish to receive information on new pages or page updates. [71] Figure 8 shows the location of subscribers based on data available at June 30 2016.

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[68] Minutes of the NAG Teleconference 18th October 2016

[69] CareSearch Communication, Engagement, Partnerships: B.3 Communication Plan, 2015

[70] http://www.thegroundswellproject.com/

[71] CareSearch Update, National Advisory Group Meeting 17 March 2017

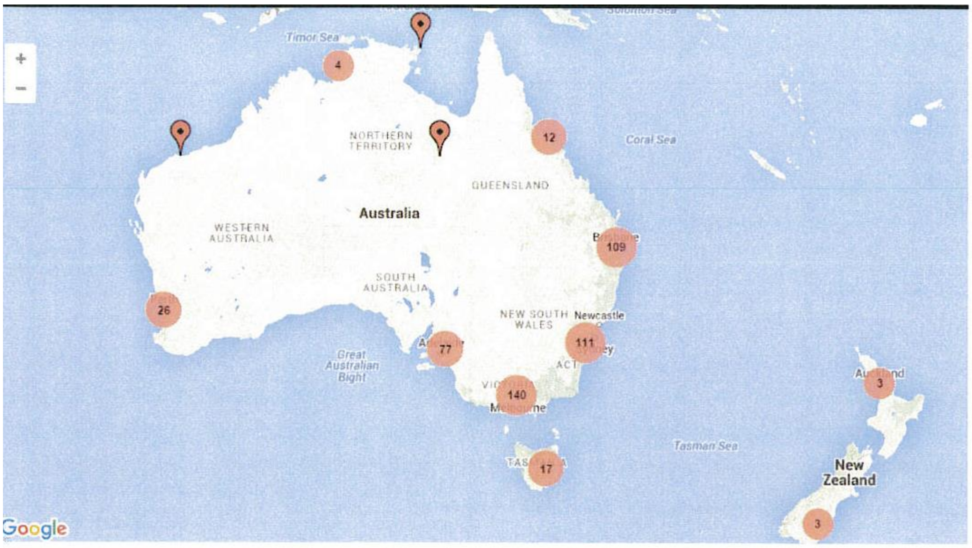

Figure 8: Location of groups placing orders for promotional materials 2015-2016

- *Social media:* The CareSearch twitter presence includes working collaboratively with others in the National Palliative Care Program to cross promote activities and resources and to build an understanding of palliative care.
- *External newsletters* CareSearch material was included in newsletters and websites from external organisations:
- *Awareness days and public events* In addition to presenting work at scientific conferences (refer Appendix C), CareSearch was involved in a number of community and health sector palliative care and end of life awareness-raising events. In addition to presenting original research, CareSearch distributed materials and resources at conferences.
  - *National Carers Week* promotion included a blog from Ara Creswell, the CEO of Carers Australia, Carers Week 2016 highlighting the contribution made by unpaid carers as well as a set of blogs published on palliative perspectives highlighted different aspects of caring. CareSearch also released an infographic to help carers finding trustworthy health information online. These resources were promoted through electronic alerts and emails and through social media
  - *World Hospice Day* CareSearch created a poster promoting evidence resources to help clinicians know how to update their knowledge. The poster was promoted through electronic alerts and emails and through social media
  - *Dying to Know Day* a series of resources intending to create community connection, based on the Dying2Know know MOOC, were released for the Dying to Know Day (8 August 2016)[72]
  - *Tasmania Palliative Care Dying to Talk Expo*: CareSearch participated in both expos in Tasmania to build community awareness about the CareSearch website and about palliative care information.

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[72] CareSearch Update, National Advisory Group Meeting 17 March 2017

Table 9: Promotional event activities

Satchel inserts	▪ 49th Australian Association of Gerontology Conference 2-4 November 2016 (CareSearch and PCACE) ▪ 2016 International Indigenous Allied Health Conference, 1-3 December 2016 (CareSearch Aboriginal and Torres Strait Islander Hub) ▪ Australian and New Zealand Society of Palliative Medicine, 8-11 September 2016 (CareSearch) ▪ General Practice Conference and Exhibition in Melbourne, 11-13 November 2016 (CareSearch Palliative Care and End-of-Life Care Resources for GPs)
workshops	▪ National Palliative Care Workshop: CareSearch participated in the National Palliative Care Grant Recipients' forum held in Canberra on 7 & 8 April 2016.
Conference Booth	▪ Transforming our Landscape Palliative Care NSW Biennial State Conference 2016 13-15 October 2016

Feedback on promotion and dissemination

CareSearch sought feedback from users of the Allied Health newsletters who suggested promotion of the Allied Health news and Hub through education events, professional associations, social media, clinical and health services.

Users of the revised Education Section who responded to the post implementation evaluation survey[73] provided suggestions for marketing approaches and reminders to encourage health professionals to access the available educational materials. CareSearch has integrated a number of these suggestions to help increase uptake of these resources.

Interviews with key palliative care stakeholders also investigated perceptions of CareSearch's promotion strategy.[74] In general these comments aligned with the strategy CareSearch has already implemented, or is currently working toward. The importance of CareSearch, and its products being well known across the sector was highlighted. Comments included positive support for the extent of CareSearch's promotion through events, organisational engagement and newsletter. Others suggested potential benefit in further integration with the information sources currently used by Health Professionals such as electronic medical records; more organisational partnerships and joint production of information resources to build the profile and advocacy for CareSearch and seeking international society or journal cross promotion.

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[73] CareSearch Evaluation Program: Report No 30. User Response to Revised Education Section, 2016, January 2017

[74] Australian Institute for Primary Care and Ageing, CareSearch; The future of palliative care in Australia; report on key Stakeholder Interviews, 2017

6. Conclusions and future directions

The CareSearch Model has been developed and implemented by the CareSearch Project. It has been funded by the Australian Government Department of Health and receives in-kind support from Flinders University and support from the palliative care sector more broadly. This results in an appropriately qualified project team members (workforce) and the necessary infrastructure being available to deliver the CareSearch Project, including developing and implementing the CareSearch Model of a palliative care knowledge network.

During 2015-2017, CareSearch has built on the successes of past years. It reviewed the CareSearch website and resources, and made significant improvements to the functionality and responsiveness of the design. It also revised existing, and developed new content. A Communication Strategy supported further engagement with the palliative care and broader health sectors to support greater reach. Partnerships with key stakeholders and organisations have contributed to further embedding CareSearch as an essential part of the infrastructure for capacity building in palliative and end of life care in Australia.