CARESEARCH: SUPPORTING KNOWLEDGE TRANSLATION IN PALLIATIVE CARE

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ABSTRACT

Knowledge Translation (KT) is a relatively new term encompassing evidence based practice. It is a complex concept, yet its purpose is tantalisingly simple - to accelerate the benefits of research into strengthening health systems and improving people's health (World Health Organization, 2005); or put more simply, moving knowledge to use (Sudsawad, 2007).

The CareSearch website is an online resource consolidating evidence based and quality information for various groups within the palliative care community. This includes patients and family, carers and health care professionals. Funded by the Australian Government as part of its National Palliative Care Program, it is an example of how KT processes can be embedded within a significant healthcare project. KT principles informed each component of the project's development, and are reflected in the content and structure of this unique website.

This presentation will provide an overview of KT, and will highlight core concepts using the CareSearch website as an example. The focus will be on key library-related research undertaken during the development of the website which was then utilised in both the content provided and the processes of content development. This provides an example of the significant contribution that librarianship has made in a large health informatics innovation.

INTRODUCTION

Research utilisation, evidence based medicine, evidence based practice, evidence based healthcare, diffusion of innovation, quality improvement, reducing evidence to practice gaps, evidence translation, knowledge transfer, knowledge brokering, evidence implementation … these terms have been used variously by many researchers, healthcare workers and policymakers over many years. All capture the concept of change and betterment through the use of knowledge, albeit with their slightly different emphases. Knowledge Translation (KT) is a term now being used that embraces many if not all of these concepts. KT includes "all steps between the creation of new knowledge and its application and use to yield beneficial outcomes for society" (Canadian Institutes for Health Research, 2004).

In healthcare, KT is integral to realising better health outcomes (Armstrong *et al*., 2006). There is an emerging understanding that the full public health benefits of research investments (that is, decreased mortality and morbidity) are not being realised because certain practices for which evidence has accumulated, have not been fully implemented

(Lenfant, 2003). Given that in Australia alone the annual federal government investment on health-related research through its National Health and Medical Research Council (NHMRC) for 2008 was announced as $560 million (Howard, 2007), this is not insignificant.

Effective KT depends on many players, and library and information workers are key to these processes in healthcare. We are knowledge creators, finders, organisers, purveyors, producers, facilitators, enablers, connectors. We are inextricably linked to KT processes. This paper will, using examples from a large health informatics project (CareSearch*palliative care knowledge network*), highlight how our professional expertise has contributed directly and indirectly to KT.

WHAT IS CARESEARCH?

When an illness cannot be cured, the focus of care changes to helping patients to have the best quality of life possible while managing their symptoms. This is known as palliative care, and encompasses emotional, spiritual and social needs associated with death and dying (World Health Organization, 2008). Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. Yet it has been as hard for those living with life-limiting illnesses to find reliable and trustworthy information about palliative care, as it has been difficult for health care professionals to find the underlying evidence. In effect, there has been a gap between the knowledge base for palliative care and its intended users and recipients.

In response to these needs, the Australian Government Department of Health and Ageing funded CareSearch, an online palliative care resource located at www.caresearch.com.au, and launched in May 2008. It is a website … but it is not just a website. It is a unique network of quality information and evidence, tools and resources aimed not only at a wide range of healthcare professionals, but at patients, families and friends. It is open to all, it is free, and it is regularly updated. Importantly, CareSearch was developed and reviewed by Australian health professionals to ensure its content is the highest quality and is relevant to the needs of those working in, and affected by, palliative care.

CareSearch is analogous to a KT project. It exists to consolidate, enable access to, and encourage use of, the evidence base in palliative care. It does this using a diverse and layered range of strategies.

KT AND CARESEARCH

Various examples provide insight into the depth and breadth of the KT strategies in CareSearch. The most obvious is the structure of the website. 'Finding Evidence' is one of the nine major sections, written specifically for healthcare professionals. This section uses the recognisable 'evidence based practice' terms based on the well known 5-step processes of evidence based practice: asking, finding, appraising, applying and evaluating the evidence (Strauss *et al*. 2005). Yet it also includes a more fulsome range of important KT processes, relating to generating, communicating and implementing evidence. For example, a section called Reducing Evidence-Practice Gaps covers issues relating to implementation of evidence. It includes subsections of Identifying the Need

to Change, Implementing Change and Measuring Change. All of these sections contextualise the relevance and usefulness of the information in palliative care. In total, this approach reflects an understanding that KT is a deliberate and active process, something increasingly understood by governments worldwide, that simply generating and disseminating evidence alone does not lead to its implementation.

KT involves multiple players and CareSearch pages are written specifically for different groups. In doing so, CareSearch acknowledges that the needs of particular groups differ, as does the information and evidence base. Presenting and tailoring information to specific needs increases the likelihood of its use.

Such tailored information, is in itself an expression of the commitment to different players in KT. Yet there is a deeper level at which this is demonstrated. The KT processes that underpin the construction of the Finding Evidence section were also considered for patients, carers, family and friends. Hence there are equivalent pages for these processes, albeit using different headings (or sometimes simply that the content is embedded within other pages), for both professional groups and patients, carers, family and friends. As an example, the Finding the Evidence Section/Appraising Evidence page written for health professionals, is matched by a consumer's page Finding out More/Is is Trustworthy? A Finding the Evidence Section/Databases and Resources page written for health professionals, is matched by a Finding out More/Sources page written for patients, carers, family and friends.

KT is considered to be both a strategy and a process. At the broadest level, the existence of the CareSearch website, as an online resource, represents an interventional strategy to improve palliative care. It does this by providing a diverse range of information, tools and resources for multiple users. Yet CareSearch does not simply provide access to the evidence; it has integrated evidence into its development processes, influencing the website's content, design and functionality.

For example, those responsible for writing clinical pages followed a described search method to find the strongest evidence relevant to that topic, with a specific focus on finding systematic reviews, considered by the NHMRC to be the highest level of research evidence to address many key questions of interest. Sources searched routinely included the bibliographic databases of Medline, CINAHL, EMBASE, PsycINFO, and others as relevant.

Research evidence from a multiplicity of disciplines was used to design the individual webpages: from informatics, education, psychology and information technology. For example, consider the positioning of information on a screen. We know that when people scan a webpage their eyes follow the lines of the letter F (Nielsen, 2006). This influenced the order of icons on the homepage, where the premium top three positions were allocated to help patients and families. For patients and families, research evidence from the field of education and information technology informed how the pages were worded and presented. As an example, all patients and family content pages were evaluated for acceptable readability levels using an established scale prior to inclusion to ensure pages would be readily understood by most of the population.

A range of original research activities was also undertaken to support development of the CareSearch resource. The focus of this paper now turns to outlining one CareSearch

feature that was developed directly as a result of this research, and of particular interest to library and information professionals: PubMed Topic Searches.

PUBMED TOPIC SEARCHES

Finding good quality information and evidence immediately when it is needed, is important. The National Library of Medicine's PubMed system offers a freely available and accessible research tool for clinicians and others, thus enabling dissemination of research evidence as it is required. CareSearch is therefore particularly committed to maximising access to this service.

CareSearch users are provided with a layered approach to accessing PubMed. Most basically, links are provided in the Finding Evidence/Database and Resources page to PubMed and PubMed Clinical Queries. Users can elect to search these databases directly themselves.

However, it was known that there were issues specific to palliative care that made searching difficult, such as its diffuse and multidisciplinary nature, and its recent emergence as a discipline. It was proposed that if a search strategy could be developed and validated, specifically to find palliative care literature, it could potentially help users. In other words, if it were developed using an appropriate research methodology, it would provide an evidence-based way to search for the evidence. Using an equivalent method more commonly used by those validating the performance of a new diagnostic test in healthcare, a 12 term search strategy, which we refer to as the Master Palliative Filter, was developed for use on OVID Medline (Sladek *et al.,* 2006). This research was presented at the most recent Health Libraries Australia (HLA) Professional Development Day preceding Dreaming 08, namely in Sydney, 2006.

The Master Palliative Filter is an evidence based search strategy. Evidence alone, however, regardless of how robust it is, is rarely in and of itself, useful. An evidence based vaccine, for example, does not decrease disease incidence if no-one is vaccinated. Similarly, an evidence-based search strategy does not lead to successful information retrieval if it isn't used. The key point is that implementation of evidence is as integral to evidence based practice as generating the research evidence (Grimshaw & Eccles, 2004). Evidence needs to be considered for its generalisability, and strategies developed to apply it 'in the real world'. Generalisability was the focus of our subsequent research attention, which is reported in detail elsewhere (Sladek & Tieman, 2008).

In the context of the current discussion, the strategies developed in response to both the original and subsequent research are of particular interest. These strategies are, in effect, implementation strategies. They are mechanisms for encouraging the use of the best available evidence about searching for palliative care literature. Importantly, a revised palliative care search strategy for use on PubMed (with justifiable modifications) was constructed. Several strategies were implemented to maximise the use of this filter. All involved embedding the URL for an individual PubMed search into the CareSearch website pages:

- Users can immediately run the palliative filter without needing to type its details, and variant searches are provided so that users can select, for example, all palliative literature, the last three months only, the last four weeks only or the last seven days only. In this way, users can keep up to date with the most recently published literature.
- Finding Evidence/Create Your Own PubMed Topic Search page provides users with specific details of how to combine the palliative filter search with their own search topic of interest. Using these instructions, for example, users can restrict a search on the use of narrative therapy to narrative therapy in palliative care.
- 50+ topic based searches known to commonly be of interest to palliative care were developed and combined with the palliative filter, and are listed on the PubMed Topic Search page so that users can select one of interest.
- Five variant searches for each of these 50+ topic based searches were created, so that those looking for higher levels of evidence could preferentially search for same. This further integrates the evidence about how to search most effectively for randomised controlled trials, as the methodological search filter used in the PubMed Clinical Queries pages was embedded into these searches. This means that users can run over 250 searches in real time, providing immediate and current PubMed search results.
- 'Postage stamps' icons, offering the full range of available PubMed topic search variants, are placed on corresponding clinical pages on the website. For example, a user can select a search for dyspnoea from the PubMed Topic Search page. Or upon reading the clinical page summarising the existing evidence about dyspnoea, a user can select a current PubMed search.
- A 'Technical Notes' page is included so that the search construction methodology is transparent and available to inform others.

To highlight the importance of these implementation strategies, consider the comparison with a clinical decision. Evidence based practice proposes that the best decisions are based on the best evidence, applied in combination with the clinician's expertise and experience, and the individual patient's unique circumstances. Evidence based library and information practice is no different. In CareSearch, the best evidence about searching, is combined with professional expertise and experience. A National Reference Group identified the relevant topics, a medical librarian constructed the subject searches in combination with the evidence, and the user can choose the particular variant search that they require. This could include, for example, restricting a search to the most recent literature only.

CARESEARCH AND LIBRARY AND INFORMATION PROFESSIONALS

Not surprisingly, there has been a very strong relationship between CareSearch and library information professionals. This has been at many levels, and has included:

- Participation in CareSearch's multidisciplinary National Advisory Group
- Engagement as CareSearch Project Team members – involving a diverse range of activities, such as informing search processes underpinning the writing of clinical pages, writing content pages such as those found in the Finding

Evidence section, and collaborating in original research – leading to three peer reviewed publications with a further two in progress, and involvement in performing searches for systematic reviews and establishing alerts

- Reviewers of individual pages or providing consultative advice
- Specialised library services of both the Daw Park Repatriation General Hospital (for example, co-funders of access to EMBASE) and Flinders University (for example, access to a wide range of online resources and document delivery).
- Publication of manuscripts in professional library journals (JMLA and HILJ) and an article in HLA News.
- Use of the published library and information professional literature relating to searching.
- Use of ALIAHealth to engage collaborators on "Finding Australian Content in Healthcare: A Select List of Websites", and the collaborators themselves.
- Countless library websites, both big (e.g., PubMed) and small (e.g., government library homepages) that were used to find relevant information, or else are linked within CareSearch pages.

There are invisible librarians behind many of the websites referred to, and used, in the development of CareSearch.

SO WHAT?

KT and the examples from CareSearch provide an opportunity to see how dynamic connections can be made between our profession and a large health informatics innovation. CILIP Chief Executive Bob McKee, said that a lot about research generation and dissemination relates to the …

" … vision of our profession and our place as individuals within that profession … we have got to see ourselves as part of a very big picture, and not part of a little box. There is a mind-set that says I do the work, I deliver my library service and I do a good operational job. A large number of our colleagues don't lift their sights above that and say, actually, I'm part of a very large profession that has a very fundamental impact on social, educational and economic processes, and I need to reengage with the whole of that." (Eve & Schenk, 2007)

Quite literally, our work, and the work of those before us, is so fundamentally integrated into the systems and knowledge of those around us, that the full impact of our profession in a project such as CareSearch will never be able to be assessed. However, KT does provides a framework to crystallize these important roles, not that we *can* play, but that we *do* play, in making a difference in healthcare. By seeing and appreciating a larger and more complex context, it may help us articulate the depth and breadth of our value. The roles outlined in regard to CareSearch are noteworthy because they relate to both the individual (e.g., employment of library and information workers and enhancement of individual career pathways) and our profession (e.g., peer review processes, involvement in research, publication in journals, professional communications, service provision, professional bodies and their services). Importantly,

it is the process of reflection that can bring these roles out of the shadows and into our full view.

DREAMING 08

This paper has highlighted aspects of KT using examples from CareSearch, a large scale health informatics project in healthcare that embeds KT principles in its development and content. The relationship between the CareSearch project and the library and information profession, in its different layers, punctuates our own intrinsic roles as players in KT in healthcare. Dreaming 08 now affords the opportunity to contemplate not only ourselves and our individual and collective futures, but the landscape around us. KT provides a framework to consider where we fit in this broader picture.

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BRIEF BIOGRAPHY OF PRESENTER

Ruth Sladek has a mixed academic background in librarianship, psychology, and public health. Most recently she finalised a PhD in which she investigated the relationship between thinking and behaviour among medical practitioners, and how this might influence the development of evidence implementation strategies. Her current research interests include individual differences and their impact on professional practice change, eHealth literacy and knowledge translation. She is currently a researcher in knowledge translation with the CareSearch project, funded by the Australian Department of Health and Ageing.