

An Australian Palliative Care Knowledge Network: A Review of the Literature

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1 Introduction

This literature review forms part of the preliminary investigation relating to the development of a concept option(s) for a Knowledge Network for palliative care in Australia. The review sought to identify the significant trends relating to the use of IT and the internet in health and palliative care, the key concepts relating to knowledge management and its application within palliative care, and the existing research and evidence relating to contents and functions that could potentially be included on a Knowledge Network.

The search strategy involved:

- General searching of electronic databases for articles dealing with internet, interventions, knowledge management, knowledge networks, communities of practice, website evaluation, technology, health informatics,
- Web based searches for additional materials. Location of relevant government and organisational reports and policies.
- handsearched to locate supplementary materials where necessary.

The searches were of necessity limited due to time constraints. They are not intended to be definitive and complete but to provide an overview of the issues and possibilities that have been identified in the literature. Where possible, refereed articles have been used. Some materials have come from the grey literature and the emerging electronic literature where authorship and review protocols are harder to establish.

2 Overview of knowledge themes

2.1 Knowledge Management

Since Drucker's analysis of the importance of knowledge workers to the economy, the importance of knowledge as an asset for organisations has been discussed. Knowledge is seen to be a broader concept than information or data. It incorporates aspects relating to context, experience, values and information (Hale, Kalucy, McIntyre and Thomas, 2002). Sookanan (2001) has postulated a value pyramid for organisations where with sequential steps there is a movement from data to information to knowledge to decisions to actions to outcomes.

Knowledge is increasingly being regarded as an asset not just of the individual but of the organisation. Knowledge is no longer equated with power and therefore hoarded and hidden. Increasingly, attention is being paid to the way in which knowledge is managed and the ways in which knowledge is created, identified, captured and shared. This is seen to be particularly important in healthcare where knowledge is such a large, critical and changing component of clinical practice and patient care.

2.2 Knowledge Networks

Knowledge Networks can be seen as mechanisms by which knowledge is captured, stored, shared and used by users. Networks are more than the ICT components.

Lonsdale (2002) compares knowledge networks to shopping malls with different offerings and different consumers coming through the door. She also describes the difficulties associated with terminology noting that the following terms are sometimes used interchangeably to describe the type of service that collects and catalogues resources for a particular audience:

Portal, gateway, subject gateway, Internet subject gateway, information gateway, subject-based information gateway, quality-controlled gateway, hub, network, directory, net directory, hybrid library, digital library, virtual library, clearinghouse, vortal, vertical portal, enterprise information portal, information portal, knowledge management portal, resource discovery network, grid, web, special interest network, knowledge network, information network, broker and Internet resource guide. p11

In business, knowledge networks have become an important mechanism to create new intellectual capital and to leverage the work of research areas. The decisions companies make regarding as to why, how and when to become a member of a knowledge network are starting to be researched (Pena, 2002; Hildren and Kimble, 2003).

2.3 Communities of Practice

Communities of practice (CoPs) are becoming an increasingly powerful conceptual structure to drive discussion about knowledge processes. CoPs exist to facilitate the fluid sharing of a collected knowledge (Information Outlook, 2003). Knowledge cannot be separated from the communities that create use and transform it.

Wenger (2004) sees communities of practice as social structures dealing with knowledge. They are

...groups of people who share a passion for something they know how to do, and who interact regularly in order to learn how to do it.

He has identified three dimensions of communities of practice

- Domain: the area of knowledge that brings the community together
- Community: the group of people for whom the domain is relevant
- Practice: the body of knowledge, methods, tools, stories, cases, documents which members share and develop together.

The importance of these elements is that it links purpose, with relationship and outcome or application. A CoP is functional not just interest based.

2.4 Health Informatics

Health informatics has been developing as an area of activity and study. The Health Informatics Society of Australia defines health informatics as a socio-technical and scientific discipline that deals with the collection, storage, retrieval, communication and optimal use of health related data, information and knowledge. (www.hisa.org.au/100101.php, accessed 18.03.04)

The International Medical Informatics Association has identified six proposed content areas for medical informatics: applied technology, information technology infrastructure, data-infrastructure related, applications and products, human-organisational, and education and knowledge. Health informatics as a field of enquiry has included knowledge management, knowledge bases, networks, knowledge-based systems within these content areas. (www.imia.org/2002_scientific_map.html, accessed 18.03.2004)

The possible applications of health and medical informatics on health has been discussed in numerous publications (Bakken, 2001; Ball, Douglas, & Lillis, 2001; Bakken, Cimino and Hripczak, 2004; Bury and Fox, 2000).

The work that has occurred within this field will inform the breadth of components and applications pursued within the design of a conceptual Knowledge Network for palliative care within Australia.

3 The Australian Healthcare Context

As with most developed countries, Australia faces a number of healthcare challenges. Alexander, Ramsay and Thomson (2004) have summarised the following workforce challenges affecting the healthcare sector:

- Demographic and social including ageing population, changing concept of a career for life, and competition for recruitment
- Professional requirements including more pre and post-training, more specialisation and safe practice
- Individual preferences including lifestyle options, retention and mobility, and pressure, scrutiny and burn-out
- Nature of work including specialisation, safe practice and audit
- Place of work which is increasingly towards community and home
- Who you work with including multidisciplinary teams, new roles and functions
- Machines and new technologies.

This analysis provides a context for the working conditions and issues confronting healthcare workers within Australia and which need to be recognised when developing a knowledge network.

There have been a number of initiatives within Australia regarding the development of knowledge systems for healthcare generally and palliative care

specifically. The NSW Government has supported the introduction of a website that uses the web as a platform to provide clinical decision-support information at the point of care for the state's health professionals (Ayers & Wensley, 1999). This project has included a significant and continuing evaluation program relating to its effectiveness in terms of use and improved patient outcomes.

Other local networks in healthcare and social care that have been established recently include the Primary Care Research and Information Service, enablenet, Primary Mental Health Care Australian Resource Centre (PARC) and Virtual Cancer Centre.

In the ministerial foreword to the report prepared for NOIE titled From Telehealth to E-health (Mitchell, 1999), Ministers Alston and Woolridge noted

The increasing use of information and telecommunications technologies including Internet technologies, has emerged as a key tool to drive efficiency and effectiveness in Australia's health system...Electronic health (e-Health) is much broader than telemedicine or telehealth. It covers the use of digital data transmitted electronically – for clinical, educational and administrative applications – both locally and at a distance.

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Yellowlees and Brooks (1999) argue that there is an urgent need to examine the processes of healthcare delivery and service models to accommodate the changing economic imperatives, technological advances and consumer focus.

Already various local businesses have put together administrative systems to support palliative services in managing their patient records, care planning and billing arrangements (Brisbane Palliative Care, 2000; eClinic, 2003).

It is within this Australian context that a Knowledge Network for palliative care will need to be developed: increasing evidence based practice, utilising current and emerging technologies, supporting consumer/patient and healthcare professional needs, being economically efficient and incorporating different localities and structures of healthcare delivery.

4 International Trends in healthcare knowledge systems

4.1 United Kingdom

The NHS in the United Kingdom has embarked on a major restructuring exercise with regard to the knowledge management. The principal focus is to create a learning organisation where the needs of professionals, patients and the public for up-to-date, cross-referenced evidence-based are met a by a National Knowledge Service. (NeLH, 2001). Knowledge management and its relationship to electronic systems and networks has also been linked directly with creating a learning organisation. (Nutley and Davies, 2001)

Gray (1999) reports on the change in direction by noting that the investment in computing is directed by benefit to the clinicians and the patient. The knowledge components in the National electronic Library for Health rely on the following principles:

- Quality not simply quantity of information
- Contains both “know how” and knowledge
- Open to both patients and clinicians, and to managers and the public
- Exists only in an electronic form
- Involves users in decision-making.

More specific initiatives have included approaches such as the NCI-Ireland Consortium, which has structured services, cancer registries and technological support system in single entity to improve services and outcomes for cancer patients (Johnston & Daly, 2001).

A similar approach is being taken within the UK generally where the NHS Cancer Plan (DoH 2000) describes the establishment of supportive care networks alongside cancer networks to improve coordination of care. These networks would comprise linked groups of professionals and organisations across primary, secondary and tertiary care (Travis and Hunt, 2001).

4.2 European Perspectives

The European Association for Palliative Care (EAPC) was created in 1991 by 42 founding members from nine European countries. It now maintains directories of people involved with and interested in palliative care and relevant organisations and associations. It organises conferences, manages a review journal and hosts developed networks in education, ethics and research functioning as a co-ordinating body for European practitioners (EAPC, 2002).

Tremblay (2000) outlines some of the implications for health policy for Europe of the fundamental restructuring of post-industrial economies with new media and technologies. He argues that not only will new technologies affect the delivery of health services they will also change the environment in which the policy debate about health services occurs.

Europe has commenced several projects investigating aspects associated with telematics including the Council of Europe’s Expert Committee on “the patient and the internet” and the European Commission’s TM Alliance Project – Telemedicine 2010: Visions for a personal medical network. (WHO, Regional Office, 2004)

4.3 Canadian Activities

Canada has been very active in developing a health, social and business approach to development that incorporates knowledge management concepts and communities of practice. Clark (1999) reports on twenty years of work with formal knowledge networks. The Canadian Institute for Advanced Research has

fostered eight networks with the intent of developing international excellence. This approach has aided not only the development and translation into application of knowledge but has created an environment in networks are being directed towards education, social and political issues. There is also active research on the function of communities of practice and healthcare decision-making in Canada (HealthOrganizationChange, 2004; iisd, 2003).

Two specific projects relating to palliative care are the Canadian Virtual Hospice and the Pallium project. On 6 February 2004, the Canadian Virtual Hospice opened for business. This platform provides a resource for practitioners, patients, carers and volunteers and the chance for interactive communication.

In December 2003, the Pallium Project received \$4.3million over 2½ years to develop stage 2. The project focuses on better team-based palliative care training for local physicians, registered nurses, pharmacists and other providers; better linkages between community –based professionals and palliative care experts in major centres; and strategic investments in information, teaching resources and professional development to be applied across Canada (University of Calgary, 2003).

Canada has also been active in the investigation and production of resources to support palliative care. These materials such as the Alberta Palliative Care Resource (Pereira, Otfinowski, Hagen et al, 2001) are available online.

4.4 USA

The USA has a broad range of networks supporting palliative care groups and professional activities. Many palliative specific resources are available online including ethical resources, educational packages and materials for families and carers (See listing from Centre to Advance Palliative Care, 2004).

The USA has invested in Quality and Safety research and has looked at how information can be disseminated through the web and networks and at the creation of clinical informatics that are electronically based. (Meyer, Battles, Hart and Tang, 2003)

There has also been substantial investment in national resources that support health such as the NLM.

5 Framing factors for a Knowledge Network

5.1 Purposes of a Knowledge Network

At the broadest level Pereira and Bruera (1998) wrote on the internet's resource possibilities for palliative care and hospice. They identified ten possible applications

- Promoting palliative care and hospice

- Electronic journals
- Teaching
- On-line conferencing
- Communication
- Database accessing
- Listing of services
- Promoting balanced clinical information
- Grief and bereavement services
- Posting of events, conferences and seminars.

The exploitation of IT by palliative care was seen to offer benefits in terms of more robust communication by Lynch (1998). He saw many potentially useful applications of IT to palliative care:

- National and international electronic networks offering efficient, effective and economical communication options for individuals and organisations.
- Expert (artificial intelligence) systems could support clinicians in making decisions about patient care base on evidence.
- Integrated health information systems enabling continuity of patient care.
- Capacity to disseminate more ephemeral information and knowledge through the World Wide Web.
- Capacity to develop a political forum for palliative care.
- Development and dissemination of IT health tools.

5.2 Potential users of a Knowledge Network

In developing a conceptual model of a Knowledge Network for palliative care, defining for whom the network is designed and whether particular groups will have particular needs will be crucial.

Palliative care services have primarily been established in urban and metropolitan areas. Rural areas typically have less well-organised services and it primary care professionals who undertake most of the palliative care. Primary care professionals have reported difficulties in obtaining training and in accessing specialist services and training. Developments in information technology have been identified as one possible solution to these problems. (Evans, Stone and Elwyn, 2003; Kuebler and Bruera, 2000)

There has been some work about using the internet and networks to deliver support groups and/or training to those with cancer or other life-limiting illnesses. One American study has found that an online support group for women with breast cancer reduced depression for the group (Lieberman, Golant, Giese-Davies, 2001). Other work has shown that internet access and training of community residents can lead to empowerment with regard health decision-making (Masi, Suarez-Balcazar, Cassey, Kinney and Piotrowski, 2003).

A web-based survey of Internet use by palliative care health professionals showed that 88% of respondents were searching the internet for clinical

information, 80% used emails, 69% were accessing online journals and 59% subscribed to listserv or update groups. (Pereira, Bruera and Quan, 2001)

The Australian Census Analytic Program Report (Lloyd and Bill, 2004) *Australia Online* reminds us that use of a network depends on access. In 2001 10.2 million or 54% of Australians did not use a personal computer at home and 11 million or 58% did not access the Internet in the week prior to the census. Those least likely to use the computer were over 65 years, Indigenous Australians, those with lower incomes and lower levels of education and those who do not speak English very well. In looking at community use of a Knowledge Network, access to resources will be an issue.

5.3 Principles relating to the integrity of web based information

Many concerns have been raised about the quality, reliability and consistency of information found on websites. If a Knowledge Network is to be of high quality it must develop mechanism that ensure the validity, reliability and integrity of the material that is generated for the site and the validity, reliability and integrity of information found on associated websites. There is a developing body of literature dealing with website evaluation (Martin-Facklam, Kostrzewa, Martin and Haefeli, 2004; Canadian Health Network, 2004).

Several reviews of Internet-based material available for patients have shown faults with the content reflecting its unregulated state (Harmon, Dudgeon and Flynn, 2000; Latthe, Latthe and Charlton, 2000; Tamm, Raval and Hunyh, 2000).

5.4 Ownership

Allied with ownership are concepts about teamwork and readiness to innovate that will guide success. Gosling, Westbrook and Braithwaite (2003) have suggested that clinical team functioning may be an important factor in the effective use of online evidence systems in improving patient care. The elements in team functioning were participative safety support for innovation, vision and task orientation. This work reinforces the need to emphasize an organisation and community of practice culture that supports change and application within practice.

5.5 IT and Knowledge Networks

Technology and the internet have become cornerstone elements of knowledge networks. Consumers and patients are increasingly taking advantage of the material available on the web. Such material could (but does not necessarily) promote self-care, enable informed decision-making, promote healthy behaviours and promote peer exchange (Houston and Ehrenberger 2001).

Baker, Wagner, Singer and Bundorf (2003) have recently reported on an American survey of internet usage for healthcare information. They found that approximately 40% of respondents with internet access had used the internet to

look for advice or information on health or healthcare. It is less clear whether internet access actually affects healthcare choice or utilisation.

5.6 Knowledge Networks and Evidence-Based Practice

Evidence based practice relies on clinicians and planners having access to appropriate information at the time that it is needed. Failure to access needed information has been reported as a barrier to EBP (Haynes and Haines, 1998; Briggs, 2004). Processes such as ACP Journal Club and Evidence Based Medicine have been designed to distill knowledge and evidence into manageable amounts. (Davidoff et al, 1995; Evans, 2001) Networks will provide a mechanism to enable the timely dissemination of materials relevant to evidence based practice.

Haynes, Hayward and Lomas (1995) have also noted the importance of solutions for evidence transfer and to ensure that informatics solutions tailor information to fit the circumstances of the patient and the setting. There must be awareness when developing systems, tools and resources of the end user and whether the materials developed meet their needs in a practical way.

The limitations of an individual having the time and skills to carry out searching, critical appraisal and assessment for generalisability and transferability have been documented in various studies (McColl, Smith, White and Field, 1998). A study of Australian GPs found that time was a critical barrier to EBM (Young and Ward, 2001)

Four preconditions for implementing new evidence were identified in an Australian review (Rubin, Frommer, Vincent, Phillips and Leeder, 2000). One of these was ready access to evidence. The availability of computerised databases and a working knowledge of how to use them are seen as important elements in translating evidence into practice. Jeannot, Scherer, Pittet et al (2003) found that while acceptance of clinical practice guidelines via the Web is high the main limits to acceptance seems to be lack of a computer in the doctor's room and fear that the use of guidelines would interfere with the physician-patient relationship.

Rodrigues (2000) has modeled the spectrum of information systems and technology applications that could support evidence-based practice. He has identified six areas:

- Reference databases
- Contextual and case specific information
- Clinical data repositories
- Administrative data repositories
- Decision support software
- Internet-based interactive health information.

The potential inclusion of such EBP support facilities will need to be considered in the development of a Knowledge Network for palliative care in Australia.

6 Informing particular functions of a Knowledge Network

6.1 Clinical Resources

As well as the classic sources of clinical information, knowledge network could include or provide access to other databases such as grey literature repositories and research directories. (Eysenbach, Tuische and Diepgen, 2001)

Ensuring that clinical resources not only contain quality information but can be easily and successfully searched for relevant literature is essential to the provision and use of resource and databases for clinical, education and research purposes (Kaufman, 2002; Keeling & Lambert, 2000). The development of strategies and search engines that can function within the formal databases and more generally on the web will enable more comprehensive search results to be achieved (Health on the Net Foundation, 2002)

6.2 Linkages to information

There are already substantial amounts of information relevant to palliative care available online within Australia and internationally. These repositories such as the NLM and Cochrane Collaborations exist electronically and can be linked given appropriate approvals being arranged.

6.3 Education and training

The availability of teaching materials and training packages in palliative care online is increasing. Some are formal tertiary studies using a web-based delivery system (e.g. Graduate Diploma in Palliative Care in Aged Care, Flinders University) while others are more specific training resources (Centre to Advance Palliative Care, 2004; Growth House, 2004; StopPain, 2000).

Some major centres have developed materials specifically for their community and have made these resources available online (Alberta Palliative Care Resource, 2004).

The Centre for Distance Learning in Palliative Care (2003) offers a range of online training courses for healthcare professionals specific offerings for rurally located practitioners.

There are opportunities for topics or specialist material to be successfully delivered online including research methods (Steckler, Ford, Bontempi et al, 2001). Some work has also been done on evaluating the Web as an active learning centre (Turchim and Lehmann, 2000).

6.4 Supporting patients and carers

The possibility of incorporating technologically based monitoring systems in community based care has started to be investigated with regard to the

management of chronic illness (Brooks, 2003; Celler, Lovell and Chan, 1999). There may be the opportunity to explore the application of such directions in the management of palliative patients in rural and community settings.

The Internet has also been used to deliver interventions and to undertake formal evaluations of these approaches. Christensen's work with regard to depression has shown that both cognitive behaviour therapy and psychoeducation delivered via the Internet were effective in reducing symptoms of depression (Christensen, Griffiths and Jorm, 2004).

A study of an internet support group for women with primary breast cancer showed that this intervention was effective in reducing participants' scores on depression, perceived stress and cancer related trauma measures (Winzelberg, Classen, Alpers et al, 2003).

A pilot study of cancer patients and family members who were trained in how to access web-based materials specific to their needs felt empowered by the knowledge they had gained (Edgar, Greenberg and Remmer, 2002). Although only a pilot study, the work supports the potential of knowledge networks in meeting the needs of patients for information with consequent benefits in terms of empowerment and well-being. A similar project undertaken in family residency clinics found benefits arising from assisted learning about the Internet (Helwig, Lovell, Guse and Gottlieb, 1999). Other studies have focused on working with seniors (Leaffer and Gonda, 2000) and as support for those awaiting cardiac surgery (Scherrer-Bannerman, Fotonoff, Minshall et al, 2000).

6.5 Safety and Quality Issues

Web-based systems within a particular discipline area offer particular opportunities to develop audit and benchmarking capacities. Tools are available to track benchmarking aspects such as key outcomes information, drug utilisation rates, comparative costings or resource utilisations (Korner, Oinonen and Browne, 2003).

The US has undertaken a major project on patient safety research. Part of this work related to Clinical Informatics to Promote Patient Safety (Meyer, Battles, Hart and Tang, 2003)

6.6 Clinical Databases and Point of Care systems

Black (1999) argues for the establishment of high quality databases that could be used in multiple ways by a community of practitioners. He suggests that the shared collection of these databases could be used not only for audit but to aid clinical practice, manage services and evaluate health technologies. There are many examples of particular tools designed for knowledge management and delivery of knowledge at the appropriate time. (Hanka and Fuka, 2000; Imhoff, Webb, Goldschmidt, 2001; Jadad, 2000)

There has been work in Australia on information technology use within palliative care particularly with regard to data management and electronic clinical information projects (Martin, Woods, Smith, Cavenagh and Whan, 2000). It is important that the work and lessons from these projects is utilised in developing a Knowledge Network.

Celler, Lovell and Basilakis (2003) have pointed out the applications of ICT in managing chronic illnesses through shared services (virtual health networks and electronic health records), knowledge management (care rules and protocols, scheduling and information directories) and consumer-based health education and evidence-based clinical protocols. Similar uses could be envisaged within palliative care.

6.7 Communication Forums

Electronic bulletins are a feature of many networks enabling the free exchange of information. While there is an argument for open and uncensored information exchange, Culver et al's (1997) study of an electronic bulletin board has shown that medical information posted in such a forum may come from nonprofessionals and be unconventional, based on limited information or incorrect. The results of such work will need to be examined when considering the management of such facilities and the legal ramifications of such advice on a network.

Eysenbach and Wyatt (2002) see the posting of such information in a more positive way. This material could help identify health beliefs, emotional or information needs of patients and needed areas of research. Osheroff (1997) also saw Culver's work in a broader context seeing online forums along with bulleting boards becoming an important resource for physicians and patients wanting education, guidance and interpersonal communication.

An analysis of bulletin board use by patients with implantable cardiovascular defibrillators characterised this type of patient activity as self-directed patient education and therapeutic connection (Dickerson, Flaig and Kennedy, 2000).

6.8 Research

A Knowledge Network offers the opportunity to support research activities directly and indirectly. The provision of tools and information will assist in building the capacity of the palliative care community to undertake research and to utilise resources that are of good quality and that do not require development (e.g. Evaluation tools developed for Caring Communities – Eager, Senior, Fildes et al, 2003).

The network could also be used to support collaborative medical research (Marshall and Haley, 2000).

The network itself could also offer opportunities to host interactive web experiments along the lines of the Sintchenko, Coiera, Iredell and Gilbert's (2004) work on the comparative impact of guidelines, clinical data and decision support on prescribing decisions.

7 Evidence Supporting Knowledge Network Concepts

There is evidence that technology for collecting from and disseminating to patients can be successfully applied in the clinical setting (Allenby, Matthews, J, Beresford and McLachlan, 2002).

Bero, Grilli, Grimshaw et al's (1998) overview on systematic reviews of interventions promoting the implementation of research findings suggest several possible roles for a Knowledge Network in translating research into practice – computerised reminders and audit and feedback loops. The more traditional aspects of dissemination and electronic publications were seen to be less effective as bringing about clinical change and may need to be reconceptualised in the concept development.

The results of an RCT dealing with teaching rural physicians to use on-line medical information showed that comfort and competence in using computers to address patient problems can be improved with individualised training (Kronick, Blake, Munoz, Heilbrunn, Dunikowski and Milne, 2003). Such work along with the findings of the ciap evaluation highlight the need for planned support and resourcing to ensure uptake of the technology.

8 Success Factors and Implementation Issues

8.1 Evaluation Aspects

Developing an evaluation strategy along with the implementation strategy will assist in defining the purposes of a network. The evaluation strategy will also ensure that measures for reporting and accountability can be built in at the design stage.

There have been a series of evaluation projects undertaken associated with various electronic libraries (D'Alessandro, D'Alessandro, Galvin and Erkonen, 1998) and with knowledge systems (Westbrook and Gosling, 2002; Collaborative Projects Planning Committee, 2001).

8.2 Successful implementation

Verna Allee (2000) writes of a variety of factors that are associated with successful knowledge management:

- Building the capacity for meaningful conversation
- Building supporting infrastructure
- Creating a culture that values learning and sharing

A collaborative culture has also been identified as a variable that influences the effectiveness of knowledge work (Sveiby and Simons, 2002; Hildreth and Kimble, 2003). This will also build on the importance of ownership by the palliative community.

Several authors have described the importance of researching the specific information needs of the intended users and the purpose of the system. (Henczel, 2001) Jadad (1999) identified bandwidth as one issue affecting transmission speed resulting in rates of transfer that are too slow to accommodate the fast receipt and delivery of large amounts of data. Equitable access to technology and information was also identified as another issue.

The experiences and learning from building a virtual network in Canada are summarised in ten key lessons dealing with role clarity, technology vision, implementation staging, protected time, training, ongoing facilitation, work integration, participatory design, relationship building and outcomes (Lau and Hayward, 2000). This work reinforces the need to see relationships and ownership as integral to the process not just the content and the IT infrastructure.

Access to computing resources and skills and confidence in using the technology will need to be considered in the implementation strategy. This can be a factor for patients and families (Mandl, Feit, Pena and Kohane, 2000), clinicians and organisations. A project in IOWA showed that training improved the information seeking skills of public health professionals (Walton, Hasson, Ross and Martin 2000). A similar project found benefits for rural physicians (Kronick, Blake, Munoz et al, 2003).

In implementing successful systems, consideration will need to be given to presentation issues relating to design, language level and navigation aspects (Payne, Large, Jarret and Turner, 2000).

Pereira and Bruera (1998) have identified a series of potential issues or barriers with regard to the internet or networks being a resource. These include:

- Uncontrolled and unmonitored publishing
- Legal liability and ethical dilemmas
- Requests for further information or resources
- Conflict of interest
- Lack of internet accessibility
- Language barriers
- “Cluttering” of information
- Evanescent nature of home pages.

Such concerns would need to be recognised and considered in implementation planning.

9 Summary and Recommendations

- There does appear to be an opportunity and advantages in creating a network of resources, tools and communication forums to support the work of palliative care professionals and to encourage the participation and exchange within this community.
- There does appear to be the opportunity and outcomes associated with developing resources, tools and communication forums for patients, carers, consumers, volunteers and the community generally.
- We need to recognise that Knowledge Networks are embedded with the people who use them and we need to ensure that the network promotes ownership and engagement by the healthcare professionals and the palliative community.
- There is a great deal of experience from other website developments and we should draw on this experience in the development of a Knowledge Network.
- The structure for a Knowledge Network should include the clinicians, researchers, educators, patients, carers, managers and planners, volunteers and the general community as end users.
- There is a need to clearly define the purposes of the knowledge network, its structure and its areas of responsibility.
- We need to ensure that the IT review investigates the directions of current and emerging delivery systems and technologies.
- The Knowledge Network will need to determine its position as a dissemination and communication vehicle but also with regard to the inclusion of technological tools such as clinical informatics that are relevant to palliative practice.
- We need to ensure that the resources and links available are reliable, valid and appropriate and that clinical materials should be based on the best available evidence.
- The system has the capacity to be more than an information dissemination site; it has the capacity to support communication and interaction, research activities and potentially interventions and patient resources.

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