

Knowledge Network: Tour Presentation Summary

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Knowledge Network Tour: Adelaide Meeting

Date: Wednesday 6 October 2004

State or Territory: South Australia

Venue: Institute Building, Daw House

Participants:

Twenty-three individuals registered for the workshop. Thirty-two attended the workshop.

The following organisations were represented:

- Cancer Council of SA
- Repatriation General Hospital
- DATIS
- Lyell McEwin Hospital
- Flinders University
- Queen Elizabeth Hospital
- Southern Adelaide Palliative Services
- RAH Cancer Centre
- Independent Homes
- Western Community Hospital
- Royal District Nursing Service
- Women's and Children's Hospital
- Flinders University
- Palliative Care Council of South Australia

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions.

The workshop participants were very supportive of the concept and benefits that a Knowledge Network could bring to palliative care. One participant commented that it would be a real resource gain bringing together existing resources, preventing duplication of effort and providing more resources for the community. The possibility of including protocols and equipment accreditation on the network was raised.

The need to ensure that the needs of those in rural or geographically or socially isolated work environment was raised.

The best way of supporting carers who may not have access to Internet resources was raised. This led to discussion around the importance of the network's resources to information and knowledge brokers such as other family members, councils and community centers, and GPs and community health professionals. These groups could have a significant role in not only letting people know about the network but by printing off resources for individuals who may not own a computer or may not be comfortable searching for information.

There was extended discussion on the role of chatrooms on the network and issues relating to – vulnerability of participants; predators, salespeople and charlatans; need for controlled access and monitoring; the right of individuals to participate freely; and providing privacy.

There was also discussion about the likelihood of the network being introduced.

The potential role of the Network in not only collating evidence but in also generating evidence was noted.

With regard to governance there was discussion about the options for location of the Network. Most felt that a national body would be useful. The options discussed were PCA, DHA, university consortium or an independent operator. Most saw PCA as the most appropriate option. The importance of the entity being able to ensure up to-date information and access to resources for those working on the Knowledge Network was seen as critical. The need for a strong supportive base was also emphasized.

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Perth Meeting

Date: Monday 12th July 2004

State or Territory: Western Australia

Venue: Lecture Theatre, Hollywood Private Hospital, Monash Avenue, Nedlands

Participants:

Thirteen individuals registered for the workshop. Around twenty attended the workshop. The following organisations were represented:

- Edith Cowan University
- University of WA, School of Social & Cultural Studies
- Cancer WA
- Palliative Care CNC
- Carers WA
- Silverchain
- Health WA

University of WA

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions. There was strong support for the concept of Knowledge Network and what it could ultimately achieve.

There was a lot of emphasis from the audience around service development. The ability to support services in enhancement bids and in initiating services was seen as a crucial role for the Knowledge Network.

There was a specific question about whether there would be “a shop front” for the Knowledge Network. The question was in the context of one street address per State or Territory where people especially from the broader community could access information about palliative care.

The breadth of literature that needed to be covered was also touched on. The question of non-refereed, more popular literature was certainly touched on in a question.

The role of a “one-stop shop” in the Knowledge Network was strongly supported although at the same time there was clear acknowledgement that this would be something that would require a staged process over many years.

The governance of it was proposed at 3 levels:

DHA

PCA

Specific consortium

The overwhelming response was in favor of PCA taking on this role although it was acknowledged that the structures and form of PCA may need to evolve in order to accommodate this change.

The issue of ensuring that just as within Australia we are not replicating resources, the need to avoid that internationally was highlighted.

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Sydney Meeting

Date: Thursday 15th July 2004

State or Territory: New South Wales

Venue: John Greenaway Seminar Room, Kerry Packer Education Centre, Royal Prince Alfred Hospital, Camperdown.

Participants:

Eight individuals registered for the workshop. Twelve attended the workshop.

The following organisations were represented:

- Cancer Voices NSW
- Dept of Health, NSW
- Prince of Wales Hospital
- CHERE Uni. of Technology, Sydney
- Royal Prince Alfred Hospital
- Cumberland Hospital
- University of Sydney – student
- Palliative Care Association of NSW

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions.

There was again strong support for the concept of a Knowledge Network, while acknowledging the enormous resource that would be required to develop and sustain such a process.

A great deal of the open discussion time was around the role of clinical trial data bases with a view that an International clinical trial data base is timely in palliative care and would sit well within the current Caresearch / future Knowledge Network framework. Given the fact that most of this research is not supported by pharmaceutical companies, there was a feeling that there was a great opportunity in achieving this.

The governance was again raised. PCA was the preferred option from the participants.

Research infrastructure and advice was also thought to be important including methodology. This sits well with current proposals.

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Brisbane Meeting

Date: Thursday 29th July 2004

State or Territory: Queensland

Venue: Wesley Research Institute, Wesley Hospital, Auchenflower, Qld.

Participants:

Seventeen individuals registered for the workshop. Over twenty people attended the workshop.

The following organisations were represented:

- Royal Brisbane & Women's Hospital
- Mater Health Services
- Mt Olivet Community Services
- University of Queensland
- School of Humanities & Human Services, Qld University of Technology
- Centre for Palliative Care. Qld University of Technology
- Royal Children's Hospital, Brisbane
- Wesley Research Institute

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions. It was an engaging and full two hours.

Issues raised included the challenge of getting websites to come up on common search engine such as Google and MSN because without that, the link to the community will be limited.

Concerned were raised about the ability to navigate within the site and to ensure that internal search engines had enough money and time invested in them to generate a genuinely useful website.

The way that links are created with other websites was seen as crucial. Evaluating those websites and whether they are up to date, and whether they are of use, will be an ongoing resource commitment.

The concept of virtual support groups for patients and caregivers by age, gender or diagnosis was strongly supported. It was felt that this would be a major catalyst to improving care around the country.

The issue of moderation of chat rooms was raised. Concepts of who would access them and whether they could be subverted was an issue. The issue of, in one place, reaching a vulnerable end-of-life population, was discussed at length. The ability to moderate a chat room around the clock was acknowledged as clearly limited and the question of user registration was debated actively. It was felt that the more open the chat rooms could be, the more likely they were to succeed.

International links were raised. Not reinventing the wheel was seen as tremendously important. Accessing the advice and experience of other overseas projects received good support.

In terms of justifying cost, the reduction in duplication was seen as a very real cost saving across the country.

Service templates and minimum resourcing levels were seen as crucial if the website was going to influence service development.

Ensuring guidelines are dynamic but at the same time reflect local issues is important. Ensuring that the guidelines has input on a wide enough level to ensure good outcomes was felt to be crucial. Just giving resources on the net was not going to engage the clinical community, and ensuring that engagement was felt to be crucial.

It was acknowledged that this is an enormous project and would need step wise development. It was agreed that local issues could still be dealt with within this broader context.

Two specific websites were mentioned including Romeo and the Gynaecological Oncology Cancer Society of Queensland website.

Questions were asked about the palm pilot downloads especially around clinical guidelines. The issue of Therapeutic Guidelines Limited and their usefulness was discussed.

Questions of the intellectual property contributed to reviews or the website was specifically raised.

Again PCA with its member organisations are identified as the preferable form of governance

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Canberra Meeting

Date: Wednesday 13th October 2004

State or Territory: Australian Capital Territory

Venue: The Function Room, Clare Holland House, Barton, ACT

Participants:

Twenty-four individuals registered for the workshop. Around thirty people attended the workshop.

The following organisations were represented:

- Upper Jindalee Nursing Home
- Dept of Health & Ageing
- Rural Palliative Care, Australian Division of General Practice
- Palliative Care Australia
- CNC Oncology Service
- Calvary Hospital
- Clare Holland House
- LCM Health Care
- Carers Australia
- Alzheimer's Australia
- Home Based Palliative Care

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions.

There was strong support for the Knowledge Network at the meeting in Canberra. Members of the Department of Health and Ageing Rural and Palliative Care Branch were present.

The need for virtual clinical communities, particularly for isolated practices was warmly received. The issue of discipline specific support group was also warmly received.

The ability to minimise duplication was seen as a major advantage of the project. There is a real sense that most services are duplicating identical resources and not working together in that regard.

Beyond this, the issues of governance were raised. It was again felt that PCA was probably the best body to auspice this. The Department of Health & Ageing was not felt to be the responsible body.

No one suggested that this was not a good idea. Even if there were limited national resources this was seen as a major priority.

Clinical Guidelines (as opposed to systematic reviews) were seen as a useful adjunct within this setting. This is clearly of importance as we think about the resources that have been outlined in the consultant plans presented to us. Guidelines around best practice are clearly going to be incredibly resource intensive and need to be considered carefully.

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Launceston Meeting

Date: Wednesday 3rd November 2004

State or Territory: Tasmania

Venue: Launceston Tram Shed, Inveresk Rail Yards, Mowbray

Participants:

Twenty-two individuals registered for the workshop. Nearly thirty people attended the workshop.

The following organisations were represented:

- Dept of Health and Human Services
- Aldersgate Village
- Palliative Care Services (North)
- Palliative Care Services (South)
- Palliative Care Services
- Rosary Gardens
- LGH Occupational Therapy
- Tasmanian Palliative Care Service

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions.

The workshop participants were very positive about the Knowledge Network project and the integrating benefits it could bring with regard to information.

There was some discussion on aged care needs for palliative care resources.

Participants were also invited to send any further thoughts or ideas to the project team.

Knowledge Network Tour: Melbourne Meeting

Date: Thursday 4th November 2004

State or Territory: Victoria

Venue: Education Department, Peter McCallum Cancer Centre

Participants:

Seventeen individuals registered for the workshop. Around twenty people attended the workshop.

The following organisations were represented:

- Department of Human Services
- Hume Regional Palliative Care
- National Institute of Clinical Studies
- Monash University
- Peter McCallum Cancer Centre
- Wahroonga Nursing Home
- South Eastern Palliative Care
- Melbourne City Mission Palliative Care
- Alfred Hospital
- Broadmeadows Health Service
- Very Special Kids
- Melbourne University

Summary of Key Points from Discussion

The Workshop was invited to comment on several topics specifically as well as provide any further general comments and opinions.

The workshop participants were very supportive of the concept and benefits that a Knowledge Network could bring to palliative care.

The possibility of resources for medical staff beginning in palliative care would be a great resource. There was also interest in the Network providing some case studies that people can work through. This could also relate to the Network having the role of providing continuous professional development points.

There was discussion on how the concept of academic detailing or educational outreach could be supported by the Network given its effectiveness as a dissemination and uptake strategy.

The group felt that a frequently asked questions page for people with life-limiting illnesses and their caregivers would be useful.

The possibility of a section for employers on how to support someone who you employ who is affected by a life-limiting illness directly or as a caregiver was also raised.

Participants were also invited to send any further thoughts or ideas to the project team.