THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA


THE DR DOROTHEA SANDARS AND IRENE LEE CHURCHILL FELLOWSHIP TO EXPLORE ADVANCE CARE PLANNING PROGRAMS WHICH RESPECT AND HONOUR PEOPLE’S WISHES FOR HEALTH CARE INCLUDING AT THE END OF LIFE CARE – CANADA, USA

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Signed J.R.Cocker Dated 17 December 2014
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I thank the sponsors of this Fellowship Dr Dorothea Sandars and Irene Lee (deceased) for their legacy and in their life’s work and friendship, inspiration for this fellowship.

I would like to thank ACT Health CEO Peggy Brown for her support in allowing me to undertake this fellowship. I would also like to thank my line managers Dr Deborah Brown, Heather McKay, Emma Awizen and colleagues including Julie Solway for all their support and encouragement.

My sincere appreciation goes to my husband, as always, for his practical and loving support and wisdom.

Lastly, but not least, I would to thank all the wonderful dedicated, committed and inspiring people I met and talked to on my Fellowship travels. I am grateful for the time they took to answer my emails, phone calls, and for coordinating meetings and site visits. I very much appreciate their generosity in sharing their knowledge, experiences, resources, stories and practice wisdom not to mention their warm hospitality.
Introduction

It has only been in the last 20 years or so that what is known as ‘advance care planning’ (ACP) has been conceptualised and programs systematically developed and implemented in health care settings. This development has been as a response to the increasing advances in medical technology and the corresponding complexity and choices people have to make in every sphere of their lives including health care. Coupled with this phenomena is the fact that people are living longer and, as the research informs us, are more likely towards the end of their lives to have repeated hospital admissions and to spend their last days in an acute hospital ward.

Advance care planning is recognised as a process that begins with ‘having the conversation’ about wishes and choices around health care for a time when/if you are unable to speak for yourself including at the end of life. Conversations about death and dying and the health care we would want including at the end of life is a very personal process that can happen anywhere including around the ‘kitchen table’ with those who are close to us like our family and friends. These same conversations happen with healthcare professionals in a health setting. However these conversations are not always easy either between people or between the heath care professional and the patient and family.

I undertook this Fellowship to explore advance care planning programs in Canada and the USA. My brief was broad to reflect the work that is undertaken by the Respecting Patient Choices program in the ACT. This exploration included: Community marketing and promotion campaigns, proven processes for engaging with and facilitating ACP; systems of ACP in the hospital that may prevent unwanted treatments and hospital admissions; quality measures that assess the impact of ACP on people’s experiences at the end of life and ACP facilitator training. It was my intention to bring back the findings, to share the information and knowledge with colleagues for the enhancement of advance care planning in the ACT and more broadly Australia.
Executive Summary

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Project description

The Dr Dorothea Sandars and Irene Lee Churchill Fellowship to explore Advance Care Planning (ACP) programs which respect and honour people’s wishes for health care including at the end of life – Canada, USA

Conclusion

For Advance care planning to be sustainable in the long term the community needs to have ownership of ‘having the conversation’. Individual ACP programs are best placed to support communities and individuals by: coordinating networks to share ideas, resources and local initiatives; provide ACP training; disseminate information and develop/provide resources. This approach is being used successfully in Canada and the USA by the ‘Speak Up’ campaign, ‘The Conversation Project’, ‘Honoring Choices’ and the California ‘coalitions’.

It is imperative that a variety of quality resources and in-service training workshops/eLearning modules are developed and shared to train healthcare professionals in ‘having the conversation’ with their patients. Pallium and the Canadian Hospice and Palliative Care Association are an example of a successful collaborative effort in the development and sharing of education resources across Canada.

The Gundersen 3 steps model of ACP in the hospital is a well-established and a proven model that encompass the whole of the ‘patient journey’ and ensures that the care a person receives matches their wishes and choices at every step on the patient journey including at the end of life.

Recommendations Summary

Local

1. Develop a ‘vision statement’ for the whole of the ‘patient journey’
2. Investigate using the whole ACP 3 step Gundersen model specifically:
3. Improve Education and awareness. Specifically:
4. Develop Resources. Specifically:
5. Investigate the use and satisfaction levels of current ACP amongst doctors and patients.
6. Investigate developing an ACP Communities of Practice Network

National

7. Establish an ACP program within a national body to create a national ACP campaign and/or coordinate ACP across the country including:

Dissemination and Implementation of Fellowship Findings

Local/interstate RPC programs; ACT health teams; ACP/palliative conferences/forums/networks; newsletter articles; national/local ACP websites; community events; universities; Austin Health, Victoria; Fellowship agencies visited. I will also utilise other avenues and forums as opportunity arises.
## Programme

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<tr>
<td>5th September</td>
<td>Ottawa, Ontario, CANADA</td>
<td>Canadian Hospice Palliative Care Association</td>
<td>Louise Hanvey, RN, BN, MHA, Director Advance Care Planning in Canada Speak UP Start the Conversation about End of Life Care</td>
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<tr>
<td>5th September</td>
<td>Ottawa, Ontario, CANADA</td>
<td>Pallium Canada; inter-professional education in palliative and end of life care</td>
<td>Nathalie Gravelle-Ray, Program Manager &amp; Kathryn Downer MSc, EdD, National Director</td>
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<td>9th-12th September</td>
<td>Montreal, Quebec, CANADA</td>
<td>20th International Congress on Palliative Care at the Palais des Congres</td>
<td>Congress presented by Palliative Care McGill University</td>
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<td>15th-19th September</td>
<td>Boston, Massachusetts, USA</td>
<td>Beth Israel Deaconess Medical Centre (BIDMC)</td>
<td>Dr Lauge Sokol-Hessner, MD, Attending Physician Hospital Medicine, Associate Director of Inpatient Quality, Instructor in Medicine Harvard Medical School, Project Leader Conversation Ready at BIDMC</td>
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<td>Dr Lachlan Forrow, MD, Director Ethics Programs, Director, Palliative Care Programs BIDMC</td>
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<td>Conversation team representatives</td>
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<td></td>
<td>Cambridge, Massachusetts USA</td>
<td>Institute of Healthcare Improvement</td>
<td>Mandy Ferguson Project Coordinator; Kelly McCutchuen, Director Conversation Ready</td>
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<td>19 September</td>
<td>Via phone Boston - New York USA</td>
<td></td>
<td>Eric Cassell, MD M.A.C.P. Emeritus Professor Public Health Weill Medical College of Cornell University, Adjunct Professor of Medicine Faculty of Medicine McGill University</td>
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<td>22nd September</td>
<td>Minneapolis, Minnesota USA</td>
<td>University of Minnesota, School of Public Health</td>
<td>Mary Butler, Assistant Professor Health Management and Policy</td>
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<td>23rd September</td>
<td>Minneapolis, Minnesota USA</td>
<td>Twin Cities Medical Society, Honoring Choices Minnesota</td>
<td>Sue Schettle, CEO Barbara Greene, Director Community Engagement Karen Peterson, Program Manager Education Network meeting representatives Bill Hanley, TPT Public TV Helen Jackson Lockett-El, Pastoral Care Community Engagement</td>
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<td>24th – 26th September</td>
<td>La Crosse, Wisconsin USA</td>
<td>Gundersen Health Facility. Respecting Choices</td>
<td>Danielle Rathke, Advance Care Planning Coordinator; Tami Ebner, Pastoral Care; Brett Welnetz, Business Development Consultant, Tomas Harter, PhD Clinical Ethicist, Dr Bud Hammes PhD Director of Respecting Choices</td>
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<tr>
<td>29th September – 3 October</td>
<td>San Jose/San Carlos, California USA</td>
<td>CODA Alliance</td>
<td>Cindy Safe, Founding Executive Director and Board member</td>
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<td>San Francisco, California USA</td>
<td>San Francisco Veterans Medical Centre</td>
<td>Dr Rebecca Sudore MD, Geriatrician, Associate Professor of Medicine, University of California</td>
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<td>Sacramento, California USA</td>
<td>Coalition of Compassionate Care</td>
<td>Judy Thomas, JD, Executive Director; Ellen Hickey, Program Manager</td>
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<td>Phone contacts</td>
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<td>Alberta Health Services and Alberta University</td>
<td>Charlotte Pooler</td>
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<td>University of California</td>
<td>Dr Wendy Anderson, MD, Assistant Professor, Division of Hospital Medicine and Palliative Care Program.</td>
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Setting the Scene: Issues around advance care planning in selected local media - Canada and the USA.

National Post (September 4) headline:
‘End of Life Choice not up to MDs: ruling: refused to revive’

Doctors at a major Toronto Hospital violated the law by unilaterally imposing a do-not-resuscitate order on an elderly patient without consulting the family or obtaining agreement from the substitute decision maker. The decision was against what the family and SDM would have wanted i.e to revive. Ruling: The doctors should have consulted and if they disagreed with the family on the matter should have gone to the Consent and Capacity Board.

Author’s reflections in an Australian context:
Australia state of play re: reimbursement of doctor’s time with patient and ‘having conversations’ esp. as this has long been identified as a barrier to ACP. How are people dying in Australia? Institutionalising of death similar to birthing - more are dying in the hospital; how we can better support people wishing to die at home – further investigation.

Check out Australia’s Grattan Institute’s report: Dying Well.

Author’s reflections in an Australian context:
Doctors education/training: knowing their legal responsibilities; development/awareness of ‘decisions making tools’ in the clinical arena e.g UK’s AMBERcarebundle health care decision making tool for patients with uncertain recovery – do we have same/ equivalent tools in Australia? Also refer signing off on a patient’s ‘capacity/non capacity’ i.e formal processes by 2 doctors as per Gundersen Health.


Major report by the Institute causing quite a stir in the media with the report’s damming account of how the health system in America is responding to meeting the needs of patients at the end of life as the current system is geared to more and more interventions with corresponding greater health care costs. The report recommends greater access to quality end of life care/palliative care and support for ‘conversations’ around advance care planning and physicians being reimbursed for ‘having the conversation’.
Author’s reflections in an Australian context:
Journalist/writers using opportunities of high profile personalities and people in the public eye like the death of Joan Rivers to spark reader’s interests in conversations about death and dying and planning ahead using ACP programs. Can we do more of this in Australia perhaps using media to support and grow an Australian *Dying to Know Day*?

*Forbes* (September): headline: ‘Joan Rivers can help with difficult end-of-life conversations’

Joan River’s well known personality open discussion and jokes about death and dying ‘I ain’t afraid of dying – I’m in show business. I died a million times...” Joan River’s death and the decision by her daughter to take her off life support was made because her daughter and Ms Rivers had made an ACP....

Author’s reflections in an Australian context:
There were similar stories in Canada where media pieces are focusing on PAS and little focus on palliative care. Canada’s study found less that 30% of Canadians have access to palliative care.

*Huffington Post* (11 September): ‘When the end is in sight: Handling the end of your life’

Controversial case of young woman 29 years, with terminal cancer, who opted to move to a state with legal ‘physician assisted suicide’ (PAS). The author of this piece calls for less energy on the controversial PAS and more on talking about end of life and advance care planning.

Snippets

- Social workers working for commercial enterprise undertaking Advance care planning by phone in a ‘call centre’.
- ACP facilitators working privately on a consult basis.
- United Airways ‘Hemisphere’ in-flight magazine:
  - Advertisement for free copies ‘What every healthcare professional should know’ - various topics including *Advance Healthcare Directives*
  - Dossier Massachusetts: Life Sciences ‘Research performed at universities and hospitals includes Beth Israel Deaconess Medical Centre, Harvard teaching affiliate ranks 3rd among independent hospitals for National Institute of Health funding.........at any one time more than 300 clinical trials are conducted there.
  - Advertisement: Commercial business ‘home care for the elderly’ described as an ‘exploding market’
Part 1

Community

and

‘Having the Conversation’
1.1 National Programs: Canada - ‘Having the Conversation’

1.1.1 The Canadian Hospice and Palliative Care Association

The Canadian Hospice and Palliative Care Association in Ottawa is a national agency working for quality end of life and palliative care in Canada. The Association’s work covers policy and public education and awareness.

In 2012 the Association published the *Advance Care Planning in Canada: National Framework* available at [http://www.chpca.net/](http://www.chpca.net/)

The Framework was developed and implemented by a project Task Group comprising representatives from provinces across Canada including from the health and NGO sectors and the Association.

The drivers for this work include an ageing population who are more likely than at any time in human history to reach old and extreme old age and to have multiple and complex chronic conditions towards the end of life. The likelihood for people to then to be hospitalised, to have more medical interventions and eventually to die in hospital also increases.

The Framework document covers: the importance and process of advance care planning (ACP); guiding principles and engaging the public and healthcare professionals as well as the legal and healthcare systems.

The long term goal of this project was to raise awareness of Canadians about advance care planning (ACP) and also to develop and provide access to tools to engage in the advance care planning process. The secondary goal was to prepare healthcare providers and professionals with tools to engage in the process with their clients and patients.

I met Louise Hanvey, Project Manager of Advance Care Planning in Canada and member of the Framework Task Group in Ottawa on September 5th.
At this meeting Louise related the work of the Association including the ‘Speak Up’ campaign.

Louise spoke with great clarity about the advance care planning process, and one I suspect is born out of being involved in a campaign from its inception through to its realisation. I was particularly struck by the way that the Canadians identified the evidence, were consultative in forming a national task force to develop a clear vision of what they wanted to achieve and how those goals were going to be realised.

According to a poll conducted in 2004 commissioned by the Association 70% of Canadians at that time had not prepared either a living will or Advance Directive and fewer than 44% had had a conversation with loved ones about end of life care. This was evidence enough that a major campaign had to be developed, implemented and evaluated to engage the public, health and legal sectors in the process of ACP. Hence the ‘Speak up’ campaign was born at http://www.advancecareplanning.ca/

The Speak Up campaign covers ‘having the conversation’ between the person(s) and their appointed attorneys and family in the community as well as with health care professionals.
1.1.1.1 The Campaign/national program

The emphasis in the advance care planning process is on ‘the conversation’. ACP programs can develop aids and tools to help the public and patients in this process including making decisions around appointing substitute decision makers for health care. ‘The Conversation’ plants the seed ‘irrespective of whether the actual physical written plan is completed then or at another time’. As research has shown that written documents alone i.e advance care plans or advance care directives do not necessarily mean that the person’s wishes will be carried out if these conversations have not happened and continue to happen between the person and their family, SDM and their health provider.

The Campaign’s website includes: Advance Care Planning Workbook; promotional materials – posters, Speak up campaign kit’ personal stories; videos; resources relevant to specific provinces’ blogs and news. These resources are also used and shared to support the National Advance Care Planning Day April 16th.

Louise described the advance care planning process as articulated in the ‘Framework’ document thus: the process of planning ahead for health care if one loses capacity to speak for oneself. Advance care plans which are a written document setting out a person’s wishes, values and beliefs and this plan will inform the substitute decision maker (SDM) or attorney in respect to care decisions if a person loses capacity. This information on values and choices may also be translated into an Advance Care Directive which will give direction as to the person’s wishes specifically for continuation or discontinuation of medical treatment. Louise explained that Advance Care Directive may be undertaken if the person is diagnosed with a chronic condition or life limiting illness and wants to be more prescriptive about treatment options and the conversation with health care professionals and SDM around ‘goals of care’.
Below is one example of promotional material developed by the Association:

1.1.1.2 ‘Having the conversation’ – Healthcare professionals

The project includes tools and resources for health professionals in ‘having the conversation.’ These include ‘conversation starters’ like the ‘Just Ask’ card. This card was developed after the Accept study which included a hospital audit. This audit study identified 80 year old+ who were admitted with a high risk of dying on that admission. The study found that less than a quarter where asked about ACP on admission by the treating team. And only 30% had had a conversation themselves with their doctor.

- The ‘Just Ask: Talking to patients and families about Advance Care Planning’ conversation card includes prompt questions for the treating team in sequence. For example what do you understand about your illness or what is happening to you? Do you have an ACP? Do you

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Got a Severe Case of Ostrich Syndrome?

of Canadians have never talked to family and friends about what they’d want if they were ill and couldn’t speak for themselves.

When it comes to talking about the end of life, most of us freak out and run for the hills. Nothing’s more uncomfortable than a conversation about dying.

But 100% of us will die. So what’s the use of avoiding the topic?

It’s time to take your head out of the sand and talk about your end-of-life wishes.

Learn more: www.advancecareplanning.ca

Speak Up
know what I mean by this? If no, then there is a prompt to ask “If we need to make decisions about your care and you were unable to speak for yourself, whom would you want me to speak to about your care? This resource is available at:


• The project has also developed new advance care planning tools specifically for cancer patients and their families/substitute decision makers as well as doctors.

The tool for oncologists was developed after a literature review and testing with professionals in the field. It consists of practical suggestions for when to have the conversation and specific conversation starters. ‘Cancer and advance care planning: Tips for oncology’ is available at http://www.advancecareplanning.ca/health-care-professionals.aspx

• The Association also coordinates an Advance Care Planning Educators’ Communities of Practice Network’ and hosts a meeting of network participants every two months to share practice wisdom, ideas and resources.

1.1.1.3 Palliative care – Advance care Planning

Louise also talked about the palliative care project ‘The Way Forward: An integrated Palliative Approach to Care’. Research had shown that palliative care is accessed by only 16-30% of people and in some areas palliative care is not always readily available. Louise also spoke about press coverage of physician assisted suicide versus palliative care. In Quebec the ‘Medical aid in dying’ Bill is currently before parliament.

The project aims to increase the access and uptake of palliative care for all Canadians.

‘The Way forward’s campaign slogan is ‘Let’s talk about palliative care first’. It aims to bring attention to palliative care so that all Canadian are aware of and can gain access to quality palliative care.

This project focuses on integrating a ‘palliative approach’ in health care for those people ageing and who have a chronic health condition. This integrated approach also encourages ‘the conversation’ early about health care choices i.e. when the person is healthy. The project includes ‘having the conversation’ and advance care planning.

1.1.1.4 Primary health sector: GP project

The Association’s current project the i-GAP project is focusing on the primary health sector and GPs. As our RPC program had just identified this as a project for next year I was interested to know how this project was being developed.

The i-GAP is a national study with the aim of improving advance care planning in GPs practices. Research had already shown that Canadians expected their health care provider to provide them
with information about advance care planning and 67% of primary care physicians had said that they needed more information and resources on this subject.

The study is currently looking for general practices across Canada to participate to assist in the development to tools and practices.

**Reflections in the Australian Context**

The Speak Up campaign is an example of a coherent national campaign and showcases what can be achieved by a broad based consultative process, a systematic gathering of national evidence, careful planning and a coordinated implementation involving the community, health and legal sectors.

**Lesson 1:** Good results for a national campaign or a state/regional campaign can best be achieved by: broad based consultation; sourcing/gathering the evidence; coordinating a response and implementation that involves all relevant sectors

**Lesson 2:** Build on the excellent work of the Australian national ACP website and the inaugural (Nov. 2014) national ACP conference by creating an ACP Community of Practice Network in Australia

**Lesson 3:** Use the National ACP Dying to Know Day to galvanise media attention and focus on ACP and to keep alive/revitalise interest in the community.

**Lesson 4:** Develop a variety of ACP Australian themed resources including posters, cards to promote ACP and to support the national ‘Dying to Know Day’.

**Investigate:**

What is the experience of doctors and patients ‘having the conversation’ in the Canberra Hospital at this time e.g. Oncology? The results of this investigation may be helpful in the development of training/education resources for healthcare professionals
1.1.2 Pallium: Interprofessional education in palliative and end-of-life care

Pallium is a national education community-of-practice created in 2009 to further the work of the original project Pallium Project Phases 1 and 11. Further funding has enabled the organisation to further its work in engaging and collaborating with a number of partners across Canada to develop professional resources and tools to healthcare providers.

I visited Pallium at the Bruyère’s health facility in Ottawa on 5th September and met with Nathalie Gravelle-Ray, Program Manager and Kathryn Downer, National Director.
The context of the education program being developed by Pallium is to build capacity for ‘change’ that is to move palliative care away from a perception that palliative care is for the last stage of a person’s illness towards an early introduction of palliation alongside active treatment including in oncology. ‘Change’ in the health setting also involves a reframing of ‘hope’ away from ‘curative treatment’ towards ‘goals of care’.

Nathalie is working on the LEAP program which is a continuing professional education for nurses and doctors, pharmacists and allied health to support competency based palliative care in a variety of settings.

Modules include: Advance Care Planning; Grief - what to say and do; Essential Conversations and Being Aware (early benefits to enable a person to remain in their chosen environment)
The curriculum of courseware packages including the design, content, testing and refinement is undertaken in consultation with key stakeholders e.g ambulance services, NGOs, consumers and aboriginal groups.

Pallium also provides training to facilitators of LEAP courses.

Decide to communicate is a tool developed to trigger doctors to make decisions to communicate with their patients regarding important issues.

Nathalie has developed an innovative suit of eLearning resources including just-in-time apps and videos. These include: Doodle – 1-3 minute videos which are designed to change misconceptions surrounding advance care planning; Snippets – 3-5 minutes education videos on specific subjects with one learning objective and courselets 20-30 minute interactive modules with several learning objectives.

For these resources plus the ACP ‘Parachuting’ video see http://pallium.ca/elearning/

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**Reflections in the Australian Context**

**Lesson 1:** Collaborative efforts to develop and share healthcare education/training resources saves reinventing the wheel’ and is prudent given the climate of government financial restraint/efficiencies.

**Further investigation questions:**

1: What is the scope and opportunity for ACT Health to create local innovative just in time apps and other resources in collaboration with other agencies including the higher education sector e.g ANU Medical School; ACU, UC and CIT?

2: How to change the popular perception and, in some cases ,the practical application that palliative care is at the last 12 months of life to one where palliative care begins much earlier in the person’s illness?

3. In addition to education/training how to affect the ‘change’ needed for healthcare professionals to reframe hope from ‘curative’ to ‘goals of care’? e.g. investigate what are the barriers and challenges including personal and professionals attitudes, system issues including institutional expectations and patient/family expectations of professionals.

4. ‘Decide to communicate’ tool may be useful especially as ‘timing’ for having the conversation continues to be a challenge.
1.2 National programs: USA – ‘Having the Conversation’

1.2.1 ‘Conversation Project’ – Institute of Healthcare Improvement (IHI)

I visited the Institute for healthcare Improvement on the 17th of September and met with Mandy Ferguson, Project Coordinator, Harriet Warshaw, Executive Director (by phone) and staff.

The Conversation project is a national campaign dedicated to assisting people in the community to talk about their wishes and choices for end-of-life care. The project was co-founded by Ellen Goodman, well known U.S. journalist and writer. The project aims to make a significant shift culturally from not talking about death and dying to talking about it and the kind of care we want and don’t want for ourselves including at the end of life. The project aims to begin these conversations around the ‘kitchen table’ rather than in hospital including the intensive care unit in the hospital.

The project’s website contains information under **What** – it’s all about; **Why** – it’s important and **How** – to get started (includes a ‘starter kit’). The site also includes ‘your stories’ videos and ‘news’.

The project provides a template for an advance care plan document as well as a template for a ‘letter’ to express wishes and choices. The Project does not promote any one ACP document or template as the emphasis is on ‘having the conversation’. The Project is available at: [http://theconversationproject.org/](http://theconversationproject.org/)
I was aware of this project before I left Australia but it was exciting that I should be in the office on a
day that coincided with a national meeting via WebEx of community project partners across
America. Community participants come from approximately 135 agencies in 30 states in America.

The meeting covered a number of topics and projects/initiatives that were innovative, exciting and
inspirational. The projects discussed included: the prison project – sharing information of conversations and advance care planning with prison inmates; bringing ‘the conversation’ to pastoral care students; primary care; death over dinner cookbook and the ‘volunteer training initiative’ with the aim of training volunteers to ‘have the conversation’ within their own communities e.g church, cultural and linguistically diverse communities (CALD); the ‘starter kit’ for parents with seriously ill children and the paramedic initiative (similar to the ACT’s newly released *Paramedics Extended Care* initiative).

The ‘Conversation project’ has also developed a number of facilitator resources e.g. ‘Coaching the Conversation: A guide to facilitating conversation groups’ which can be used by facilitators for group conversations. These are intended for people who have difficulty in having the conversation with family and who would like the support of a facilitated group to gain skills and confidence to have these conversations.

1.2.1.1 TedX talk in Boston on Thursday 2 October with Ellen Goodman – ‘A good death – or a hard one? – let’s talk’

TedX is a program designed to help communities spark conversations and connections. This is done via video talks and/or live presentations on the web. In this session in Boston Ellen Goodman talks about the Conversation Project bringing the ‘conversation to people ‘where they live, work, pray and eat. Conversations, Ellen said are about who do you want to make decisions for you, if you couldn’t speak for yourself, where would you want to die, do you want ‘the whole enchiladas of medical treatments’ or when would you want comfort care.

‘Conversations’ are about values......‘it’s what matters to you not what is the matter with you’.

Ellen Goodman
Reflections in the Australian Context

The Conversation Project started with one person having a conversation with other people around a table one night. It hasn’t stopped with that person or the original group but has mushroomed into a national campaign. This growth is due to ownership in the community where a large number of organization/agencies, individuals and groups have ‘taken up the baton’ and are running with it.

Lesson 1: National campaigns help create the cultural shift that is needed to ‘have that conversation’ about a socially ‘uncomfortable’ subject ie death, dying and end of life wishes that can then be recorded in an ACP.

Lesson 2: It’s extremely useful in our media driven and online world to have a high profile person or people to lead the community in having the conversation as people like Ellen Goodman have championed ACP in the States.

Lesson 3: It’s essential to have a national body that will promote ACP nationally in partnership with state/regional ACP programs.

Lesson 4: It’s essential for that body to then coordinate a network of state/regional/local ACP programs, communities and individuals . This approach: fosters the sharing of ideas, resources, initiatives; continually reinvigorates ACP programs and people working in the field and mitigates against people working in isolation.

Lesson 5: ‘Conversation groups’ can be a used in the RPC program as a natural progression for those who may find it difficult to ‘have the conversation’ and/or to complete ACP individually and who may like a group discussion. ‘Conversation groups’ may be added to our community education offerings specifically for any communities where group/family (collective) decision making is traditionally employed versus individual decision making and/or where this subject may be particularly sensitive e.g aboriginal and Torres Strait Islander and some CALD communities.

Lesson 6: ACP programs to use all means at their disposal to spread the word including those means not already employed e.g TEDx Canberra

Lesson 7: Networks of ACP practitioners across programs not just within programs can lead to cross fertilization of ideas and practices and aid in creating ‘best practice’ of ACP
1.2.2  ‘Honoring Choices’ - Wisconsin – Twin Cities Medical Society (TCMS)

The Respecting Choices program in La Crosse Wisconsin which began in the Gundersen Health facility by Dr Bud Hammes and colleagues (Refer Under ‘Hospitals’ section) has sprouted the “Honouring Choices” program. Essentially this is the community arm of the program much like the ‘Conversation project’ and ‘Conversation Ready’ are companion community/health programs.

The Twin Cities Medical Society has carriage of the Honoring Choices program in Minnesota. There are also sister programs in Wisconsin and Massachusetts.

I was particularly keen to visit the Twin Cities Medical Society as the program sounded similar in scope and staffing to the Respecting Patient Choices program here in the ACT, Australia. The Minnesota program was set up to provide a standardised approach to advance care planning in a metropolitan area i.e. the twin cities of Minneapolis and St Paul. The program in the ACT is similar serving the city of Canberra and suburbs.

The RPC model in the ACT is based on the model first developed by Gundersen Health and a modified version brought to Australia by Associate Professor Bill Silvester from Austin Health, Victoria. Both the ACT RPC and the ‘Honoring Choices’ program uses the same training, principles and overall methodology as devised at Gundersen Health.

I visited the Society on Tuesday 23 September and met with Sue Schettle, CEO, Karen Peterson, Program Manager and Barbara Greene, Director of Community Engagement.
The Honoring Choices place the emphasis on ‘the conversation’ and not merely the filling out of documents. It is viewed as a ‘thoughtful process’ as the sage leaf emblem of the RPC program symbolises – wisdom and contemplation. The model encourages the use of a trained facilitator to engage people in a contemplation and conversation about values, choices and wishes around health care.

The Program’s ethos, like the RPC program in the ACT, is one of collaboration and partnership with other agencies and individuals in the community and does not seek to compete. This is worth mentioning because American society in general is very competitive especially in like agencies competing for dollars and recognition. The Americans I met where very upfront about this significant cultural difference between America and Australia. The Honoring Choices sought to develop and provide resources to support ‘the conversation’ both in the community and the health sector. The program collaborates with the two big health facilities in Minneapolis and St Paul ‘HealthEast’ and ‘Alina Health’ who have trained facilitators and are using the Gundersen ACP model. The big difference between the Honoring Choices program and ACT RPC program is that the RPC program has a dual role and operates both within the hospital as well as the community.

The Society also fosters collaboration between other Honoring Choices programs in other states to share ideas, initiatives and practice wisdom.

1.2.2.1 Community Engagement

The program has developed a ‘Volunteer Ambassador’ program. These volunteers are chosen for their connections to their own communities. The aim is to increase community awareness of ACP.

Currently all the ‘low hanging fruit’ has been picked and they are looking for other communities that they have not previously targeted in the first rounds much like RPC in the ACT.

The Society has also developed an e-based toolkit for Ambassadors to help with raising awareness and education. The toolkit includes PowerPoint presentations, printed resources and an evaluation tool.

1.2.2.2 Developing resources and raising community awareness - TPT public TV project

I met Bill Hanley at TPT TV facility and discussed the background to this initiative between the TCMS and TPT to raise public awareness of advance care planning in the broader community. Funding had to be sourced for this project as TPT TV gets the majority of its funding from viewer subscriptions and corporations - only 10% of funding or so comes from government and TCMS itself did not have the funds to cover a public campaign of this nature. With the combined efforts and commitment of these two agencies over $500,000 was raised within three months and over a million was raised within the year.

The question that these two agencies faced, at the beginning of the project, was how to raise public awareness. The working group were keen to avoid any toxicity that had previously been generated by some sectors in the United States and the misconstruing of ACP with ‘death panels’. This was a
concern that was voiced by just about everyone I visited in both Canada and the U.S. The controversy and angst of this campaign was keenly felt by everyone in the field and the scarring effect on ACP programs was evident. For this project a decision was eventually made to couch this campaign in terms of allowing people the freedom of ‘having a conversation’. The emphasis was not to be on people having to fill out lengthy forms as this could be perceived as a ‘burden’. They also realised that ‘having the conversation’ is also about ‘cultural change’ and this always takes time hence the 7 year project commitment.

The project was centred around a number of documentaries populated by real human stories to build a ‘need for advance care planning’ in the community. It was also important that the ‘stories’ and documentaries demonstrated cultural and religious diversity.

The website now contains 800 (2-3 minute video clips), documentaries, resources, links and e-vite (video email invitation to your family). Various perspectives are covered e.g. humour, time to talk, let’s get together as well as FAQ.

http://www.honoringchoices.org/

Bill recounted that this has been the most successful program in the history of TPT and as the TV station has been on air for 57 years this was no small thing.

The current project within this broader project include a series of videos for people suffering chronic health conditions and ‘late life’. This series of videos is to be called ‘Lifecourse’.
1.2.2.3 Culturally and Linguistically diverse (CALD) communities

In her work with CALD communities Barbara Greene set up a Multicultural Board of representatives i.e. actual leaders who were able to work in their respective communities. The aim is for these ‘leaders’ is to raise the awareness of ACP in their own communities as well as training new ACP facilitators within their communities. Barbara encourages these communities to nominate or suggest ‘young leaders’ where/when possible. This is a deliberate move so that here is ‘sustainability’ built into the program. There is also an awareness that younger members of the community, once they are trained, are also then able to talk to their own parents and older members of their family about ACP.

1.2.2.4 Pastoral care

I met Helen Jackson Lockett-El who has been working with TCMS ‘Honoring Choices’ in the faith communities. Helen described a project that was begun several years ago called ‘graceful journey’. This project involved 90 minute presentations to congregations by a member of the church who has been trained as an ACP ambassador. The presentations encompassed the subject of aging, death and dying in a faith community and the importance of being prepared including advance care planning. The use of scriptures was used, as appropriate, to that particular group i.e. if they were scripturally
based. The TCMS staff were used for the medical perspective of ACP that is to talk briefly about CPR and life sustaining treatments.

‘Congregation of Care’ is a current project which aims to provide support to people with life limiting illness and facing grief and loss issues as well as general caregiver support. An expanded 36 hours of training is given to train facilitators in the faith communities to do this work. The ‘go wish’ cards are used and are found useful to expand the conversation about values i.e. to go beyond the medical.

So far there are 30 faith ambassadors who have all been trained in ACP. Their training includes role plays which aims to ensure that all ambassadors are comfortable talking about ACP. So far over 100 presentations have been given across 100 churches in the area.

Helen said that ACP programs working with faith communities needed to locate a contact in the church either via a spiritual leader or a pastoral care or parish nurse. The advantage is that these people know what will work in their own communities.

1.2.2.5  Health professional’s education

As I had originally earmarked health professionals education as one of my Fellowship interest areas Barbara kindly invited me to a network ACP academic preparation meeting on campus in the beautiful Bethel University.

At this meeting there were representatives from local education facilities including: Bethel University; St Cloud University and Minnesota University as well as HealthEast.

Participants discussed their specific initiatives and efforts to embed advance care planning in the curriculums in their respective institutions.
Megan Lifto from University of Minnesota has a working background in nursing in oncology. Megan recognised an opportunity of using her Graduate School Master’s of Nursing Degree coursework assignment to incorporate ACP in the nursing curriculum. She has developed face to face course for nurses including components ‘Conversation starters’ for nurses; completion of documents; a module working with CALD populations; role plays in triads including roles for client, facilitator and observer. This training is very similar to the RPC ‘train the trainer’ facilitators course work in Australia. Nurses completing their own ACP is also an important component of course. Megan has also developed a new voice thread narrative presentations on POLST for staff on the oncology wards at the local hospital.

The group agreed that it is preferable to incorporate ACP into other units of a course rather than as a discreet unit as the curriculum is already so full. The aim is to make ACP sustainable by embedding it permanently into the curriculum.

Patty Bresser from St Cloud State University targeted both nurses and social workers and has now successfully incorporated ACP into the curriculum of 7 schools. Examples include a ‘Nursing care of older adults’ unit incorporating ACP and an ‘ACP elective course’ which has been incorporated into an interdisciplinary course (allied health e.g. social workers, speech pathology).

Marge Schaffer from Bethel University has developed an ‘End of Life Nursing Care’ as an elective course for nursing seniors in their final academic year. Marge has also developed an ACP facilitator course (based on RPC facilitator training) as an elective 2 X 4 hr sessions. Content includes role plays; doing your own ACP and testing out’ skills on family and friends to gain confidence before working with patients.

Patty Kelly from HealthEast uses simulated learning’s with manikins/masks for ACP and end of life conversations.
**Reflections in the Australian Context**

**Lesson 1:** Identify and train leaders (including young leaders) in CALD communities as ‘ambassadors’ and ‘trainers of facilitators’. These ‘leaders’ know their own communities and what works best in those communities.

**Lesson 2:** Collaborate with CALD communities to develop specific resources for them.

**Lesson 3:** Public media campaigns make a huge impact and increase both the awareness of ACP in the community and potentially the number of ACP completed by the public.

**Lesson 4:** ACP program need to work closely with higher education facilities to incorporate ACP as a permanent element in the curricula. This will build ACP sustainability in healthcare professional education.

**RPC/NGO Further work:**

Population groups not previously targeted systematically e.g prisons, faith, disability and mental health; homeless

Continue to build on the BeMyVoice campaign and website in partnership with NGO and to encourage partnerships for further $ funding for continued development.

Develop a local network to develop local initiatives to support Australia’s national Dying to know Day

A more systematic sourcing and collection of ‘Stories’ to add to the BeMyVoice website.

**Investigate:** The use of manikins/masks for ACP facilitator training as well as healthcare professionals in ‘having the conversation’
1.3  State programs – California

1.3.1  Background to the community coalition movement and ACP in California

A 2009 survey confirmed that most Californians said that they would prefer to die at home yet only 32% of deaths occurred at home that year. A larger percentage of survey respondents said it was important to put their end of life care wishes in writing, yet only 23% said they had actually done so. To address this challenge in California regional coalitions – which included hospitals, skilled nursing facilities, emergency medical service providers, nursing homes, senior centres and consumer groups formed in the 1990s and 2000s to promote advance care planning through a community-based/grass roots approach. When Physical medical orders for life sustaining treatment (POLST) was introduced in 2007 it was easy for these community coalitions in promoting advance care planning to expand their focus to incorporate POLST by broadening their membership and amending their strategies.

In California Advance Care Planning is referred to a ‘continuum’ where the conversation and accompanying documents can happen over the course of a person’s life i.e. a person can complete an ACP any time 18 years or over and then update it periodically. If diagnosed with a serious or chronic progressive illness the ‘goals of care’ can be discussed and a POLST form may be completed.

The California Healthcare Foundation surveyed a number of Coalitions to identify best practice of ACP in the community. Components include individual and group conversations in the community to begin discussion about end-of-life wishes with a purpose to introduce the topic, resources and normalize the conversations. In the healthcare settings undertaking one-on-one conversations incorporating advance directives/real-time medical decisions and the completion of a POLST document. This document aims to make explicit specific decisions about treatment. The outcome of the sum of those conversations, in a health care setting, is that a person’s wishes are honoured. (Advance care planning takes roots: best practices from four California communities, California Healthcare Foundation, April 2014).
1.3.2 California Coalition of Compassionate Care (CCCC)

I visited the Coalition of Compassionate care on Thursday 2 October 2014 and met with Judy Thomas (nee Citko), Ellen Hickey and staff.

The Coalition has a team of six people in an office building just out of town in Sacramento.

The CCCC website is at: [http://coalitionccc.org/](http://coalitionccc.org/)

Judy Thomas Executive Director of the Coalition and is the Chair of the National POLST Paradigm Task Force which was originally set up to establish quality standards for the POLST Paradigm, forms and programs and to assist states to develop POLST programs. The Taskforce comprises cross sector representatives from hospital, nursing and doctor associations and residential aged care facilities. The Taskforce is responsible for the final review and signoff of any amendments to the POLST forms.
1.3.2.1 Community

The CCCC coordinates and supports a number of smaller coalitions throughout California. These smaller coalitions are largely voluntary and work within their own communities. Coalition leaders are given ACP training first before sourcing other ambassadors. Coalitions may be individual parsons or faith leaders, members of Alzheimer’s Association, physicians or standalone community organisations e.g a hospice or a Medical Association.

The CCCC Program includes development of resources including:

- A website with resources and tools for ‘having the conversation’ for both health professionals and the community.

- A work book for people with developmental delays has been developed by the Coalition. This resource is based on the groups’ reflections and output. The question posed in the focus groups included: What do you want for your health care?; the groups were also provided with information on making informed choice and how to receive the care that matches their wishes and choices. The resulting Booklet is called ‘Thinking Ahead: My Way, My Choice, My life at the End’. It includes information and step by step questions including personal requests as well as making medical treatment choices and choosing an advocate and ‘staying in control’. Forms are also included.

- CCCC has also developed a series of ‘decision aids’ on specific medical treatments e.g ‘What is a ventilator’; ‘What is artificial hydration?’ ‘What is CPR?’ ‘What is tube feeding?’ These are colourful, easy to read, question and answer format four page booklet. There is also the booklet ‘Finding your way: medical Decisions when they most count most.’ This booklet includes information on both the advance care planning process and the POLST. There is also the ‘Facing serious illness: making your wishes known: Your Guide to POLST” booklet.

1.3.2.1.1 Multicultural communities

For practitioners working with CALD communities it is important to know how culture affects both decision making and choices in end of life care. The CCCC have produced a statement on Cultural Issues at the End of Life including a clearly articulated multi-cultural philosophy encompassing a definition of diversity including race, ethnicity, religion/spirituality, gender, age, sexual orientation,

‘Cultural humility requires an open mind an awareness of one’s own biases, assumptions and culture so that we don’t inadvertently impose those on the patient or family member.”

California Coalition of Compassionate Care, 2014
mental disability and other factors.

The statement also includes a definition of ‘culture’ and a model of their multicultural approach. This model encompasses the understanding that in the healthcare setting all parties including the patient and the healthcare team members bring their own culture into the relationship/transaction.

The California Healthcare Foundation has also produced a report of research findings from interviews of patients and families from CALD communities. This research was conducted to provide insights into just how culture, including learning and decisions making, as well as values affects preferred end of life health care. (California Healthcare Foundation, 2014)

1.3.2.2 Facilitator training

CCCC also had developed and hosts Community Advance care Planning Train-the-Trainer courses. This course includes community engagement; advance care planning facilitation including facilitating conversations using value-based decisions, role plays, cultural humility and end of life planning. The objectives of the course are to describe key elements of ACP; differentiate between the ACD includes appointing a substitute decision maker, POLST forms and demonstrating beginning competency of facilitation ACP conversations.

1.3.2.3 Healthcare professionals and healthcare facilities

- CCCC provides a consultancy service to health care facilities to provide training and to assist a health facility in establishing POLST programs within their agency.

- The POLST forms are viewed by those in the health sector as the ‘best protection’ a person has that their wishes/treatment options will be honoured and followed through by the medical team. The POLST is the last step in the ACP process and can be quite specific in that the person by the last 12 months of a person’s life has experience of both the illness and the treatments to be specific in their healthcare decisions.
Reflections in the Australian Context

Lesson 1: A vision statement reflects the ACP process i.e. Advance care planning is a process and happens across the ‘continuum’ of a patient’s journey.

Lesson 2: A vision statement aids in providing a conceptual framework which is useful to guide decision making and to integrate all the parts i.e. ACP (RPC); specific treatment decisions; MOLST; Imminently dying guidance into the one coherent whole that is the ‘ACP patient journey’.

Lesson 3: ACP resources are needed to support people and health professionals to ‘have the conversation’ and undertake ACP.

Lesson 4: ACP resources are needed to support specific communities including population with developmental disabilities, CALD communities and disadvantaged groups.

Lesson 5: Evaluate a variety of ACP facilitator manuals to ensure we are capturing all relevant aspects of ACP facilitation training.

Lesson 6: ACP training and community education to include all elements of the ACP process including MOLST

Further investigation questions:

Research report: Snapshot Final Chapter: Californians attitudes and experiences with death and dying/ California Healthcare Foundation, February 2012. Could we conduct similar research in the ACT?
The CODA Alliance is one of the smaller Coalitions in the San Jose area of California. Cindy is a member of the Board, which oversees the alliance. Board members include Dr Elizabeth Menkin, Rev. Larry Wildemuth and Mr Kavinoky. Cindy was previously the Executive Director of CODA for five years. I had arranged to meet with CODA because I was intrigued and interested in the development of an innovative concept of a game to further enhance ‘having the conversation’. What I didn’t know, before I met Cindy, was the background to the development of the game.

I met Cindy safe in the lovely township of San Carlos midpoint between San Francisco and San Jose on the CALTRAIN route.

We talked about the most successful initiatives of the Alliance, the ‘Go Wish’ cards. These cards are still being purchased at the rate of 300-400 packs per month. This tool are helping both communities/individuals and health professionals in ‘having the conversation’.
1.3.3.1 ‘Go Wish’ card game – History and development

Over ten years ago the Alliance were promoting advance care planning in the community based on the Gundersen community outreach project. At this time the Alliance were training both professionals and volunteers in facilitating advance care planning conversations. This was found to be expensive and time consuming and people didn’t always have the confidence, even after training, to speak to others.

In 2004 CODA embarked on a project to promote a better understanding of ACP and end-of-life care discussion in assisted living facilities where Dr Menkin worked. This was a population facing challenges including cognition (impaired memory), language, vision and hearing impairment. Additionally some of the staff and aids had limited fluency in English as English was not their first language. There was an obvious need to develop a tool that would promote discovery and discussion of a patient’s values and goals. It was identified that the tool had to be inexpensive and requiring minimal training. Population based research had already shown that there are a number of ‘commonly cited statements’ about what is important when life is short as well as a list of potential topics that can be used in a values history. Knowing this research and in response to the needs of this population group Dr Menkin and the Alliance developed the Go Wish cards.

In the Journal of Palliative Medicine Dr Menkin cites a number of settings where the cards have been useful. Including in situations where people get stuck for an answer to the question that often arises in ACP discussions i.e. ‘What is important to you?’

Cindy went on to explain that the cards are now used not just in residential aged care facilities but in various settings throughout the community.

1.3.3.1.1 Multicultural

These cards have been translated into a number of other languages including Chinese and Spanish. Cindy explained how culture has played a part in how the games look and how they are used.

1.3.3.1.2 Translation process

The process of translations begins when the ethnic groups/communities leaders contact the Alliance. Sometimes when this doesn’t happen the Alliance then needs to identify a leader or champion within this community and to approach them to find out if there is interest in translating and using the cards in their community. This approach has been used for the Vietnamese community, which is the 3rd largest language spoken in California after English and Spanish.

The Alliance relies on the community itself to do its own research including organising focus groups in their own community to see how the cards may be utilised to start ‘the conversation’ and how they may be modified to suit the community.

“The cards provide important vocabulary to give voice to patient’s needs and concerns, and give opportunity to explain and personalise those ideas” E. Menkin, 2007
For example the Chinese End of Life Coalition approached the Alliance to use the games in their community and wanted the cards to look like a ‘normal’ pack of playing cards. This was deliberate as card games/gambling is perceived by this group as a traditional Chinese pastime. Accordingly the cards were required to number 52 and not 36 and to have suites of hearts, spades etc. The Chinese Coalition also decided to make the card game larger and incorporate other aspects of planning to include financial and broader palliative care elements.

This community has also used the cards so that 1st generation American Chinese can pass down to the 2nd and 3rd generation of their respective families aspects about death and dying rituals that are important to them e.g aspects around caring for the body and release of the soul immediately after death.

For this group the Chinese script was used with English translations underneath.

The Spanish community on the other hand with a strong Catholic influence did not want the game to look like a pack of playing cards and wanted to keep a distance from anything that resembled ‘gambling.’

1.3.3.1.3 Use of the cards

The cards can be used as a whole pack or selectively and are used in the Community including Individuals and faith communities, physicians and specialist also use the cards to assist them in ‘having the conversation’ with their patients. The Ohio physician education system has purchased multiple copies of the game for physician education and training.

1.3.3.1.4 Current projects:

- The cards are being translated into Japanese, French and Vietnamese.
- A paediatric version of the cards is being developed
- The Alliance is in conversation with a group of young people regarding the development of a card game ‘Gift of Grace’ that encompasses ACP conversations within the context of death and dying is part of life. This game will be framing the ‘conversation’ in the context of a whole of life ‘perspective’. The conversation can then develop into how do I live my life well and what is important to me in life.
Reflections in the Australian Context

Lesson 1: The Go Wish card game is a wonderful example of an innovative approach to aid people in having the conversation.

Lesson 2: Source and/or develop innovative approaches and tools to have ‘the conversation’ including with specific groups. As the RPC program has found, traditional presentations with the frail aged population is not always effective and as with other disadvantaged population groups other tools may need to be found eg homeless.

Lesson 3: The Younger population are a gap in our current program as we have focused our attentions on older adults. The RPC could potentially work with the Education Directorate for a school program that incorporates ACP. This program may work best potentially within a broader context i.e. getting ready for adulthood including getting ready to vote, alcohol use and grief regarding death of loved ones and friends eg in road trauma, suicide or accidental death. This will also have a flow on effect of younger people potentially talking with their parents and grandparents.

Lesson 4: Include the ‘Go Wish’ cards into facilitator training as a tool for participants to gain confidence in ‘having the conversation’. As RPC in the ACT have also found a lack of confidence in facilitating conversations is common even after formal training.

Investigate:

Add questions around the ‘confidence’ issue in future facilitator training evaluations.

Explore other ways to build ‘confidence’ in ‘having the conversation’ in RPC facilitator training.

Use Go Wish cards with residents in RACF and other group work.
Part 2

Hospital
2.1 Beth Israel Deaconess Medical Center (BIDMC)

I was particularly interested in visiting the BIDMC as it is partnering with the Institute of Healthcare Improvement (IHI) in the Conversation Ready project. This project was designed to complement the community Conversation Project. The intention of this project is for healthcare facilities to be ready to respond to the need/expectations in the community for ACP. The BIDMC is one of the pioneering health facilities to develop the prototype of ACP best methods and systems. Once the system is up and running the intention is to implement the system in other health facilities. I was also interested to see how the model under development differs from the Gunderson Respecting Choices model.

I visited the BIDMC on Tuesday 16th September and met with Dr Lauge Sokol-Hessner Associate Director of Inpatient Quality and Conversation Ready team leader as well as Dr Lachlan Forrow, Director of Ethics and Palliative Care programs. A return visit was made to BIDMC on the 18th for a Conversation Ready multidisciplinary team meeting. BIDMC is a large campus covering many blocks on a very busy Brookline Avenue, Boston.

2.1.1 The Vision for Conversation Ready at BIDMC

‘To ensure we reliably treat our patients – with serious illness or at the end of their lives – with respect, so that we prevent harm to their dignity, Since the end of life is often unpredictable, in order to ensure we are giving out patients all the feasible opportunities to complete their lives in the ways that matter most to them, we need to prepare in advance. The trigger for preparations is “serious illness” (defined by expert in each disease area and/or the “surprise question”), and the process is called advance care planning – the “four Rs”’
• **Reach out:** Asking every patient about their goals and preferences for treatment

• **Record:** Documenting the patient’s preferences

• **Retrieve:** Patient preferences are promptly available at any predictable future point of care

• **Respect:** A patient’s preferences are always respected

This looks relatively simple on the page but quite complex in the reality of a busy hospital. In our discussions and as per Lachlan’s post on the web, Sept. 30 2013 some of the questions and issues that need to be asked, canvassed and addressed in this project include:

• **Reach out:** What conversations should be expected for which patients? And for a patient with a serious illness who should be responsible the oncologist? The primary care physician or both?

• **Record:** Beyond documentation of the healthcare proxy (health attorney) what information and in what detail is it essential to record and where?

• **Retrieve:** In the standards for electronic health records what information should be instantly retrievable and by whom? who is responsible for ensuring this? How to link with the primary care physician’s record?

• **Respect:** since it is impossible for any plan to cover anticipate all decisions that may need to be made in an emergency when is it reasonable in an emergency for a doctor to ‘err on the side of life’.

It is interesting to note that these questions are very similar to the questions that have come up for the RPC program in the ACT and indeed for any health facility developing and/or implementing a model of ACP.

The BIDMC in association with the IHI have developed a “Champion Toolkit’ currently under development. This toolkit is designed to support ‘champions’ in their local environments. This toolkit covers the tools and actions that are needed to perform the four Rs. These include: engaging staff and providers in the change process; supporting these people with contacts to experts and local champions; articulating a clear vision and providing tools for continuous quality improvement and suggestions for removing obstacles.
2.1.2  The system (currently being finalised)

The implementation of the model is described in terms of the outcomes, primary and secondary drivers’ and measures/goals. The people who are responsible for these elements are also covered.

An example follows:

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Primary drivers</th>
<th>Secondary Drivers</th>
<th>Measures/goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved end of life care</td>
<td>Clinicians review ACP when forming a plan of care</td>
<td>Key clinical areas are ‘Conversation Ready’ and key staff are trained about healthcare proxy(s) ‘having the conversation and MOLST</td>
<td>Number of engaged champions; changes that have been implemented and number of providers trained.</td>
</tr>
</tbody>
</table>

The Massachusetts ‘Medical Orders for Life Sustaining Treatment’ (MOLST) form does not include, unlike other POLST and MOLST forms in the US, any reference to an Advance Care Plan or Directive. The form requires a signature by the person or person’s proxy and clinician that conversations have taken place.

An ‘Advance care planning’ flag in the electronic medical denotes ACP conversations and/or documents.

**Evaluation:** The database produces reports on how many patient admission assessment sheets have been completed as well as responses to specific questions e.g. Does the patient have a Substitute Decision Maker (SDM)? Was the information on SDM provided to the patient?

NB The data is used for learning and not a performance measure.

2.1.2.1  Conversations between doctor and patient:

Lauge described the different types of conversations that are being encouraged between patients and their families/proxies and the health care team.

1. Why it’s important to select a proxy and to have the conversation about preferred health care, choices and wishes.

2. An honest discussion of patient’s diagnosis, prognosis and treatment options

3. An understanding of the patient’s goals, values, wishes and preferences i.e what matters most to you?
4. Discussion of the role of life sustaining treatments with a goal of providing the patient treatments that make sense to them and none of the ones that don’t make sense.

2.1.2.2 Education and Training: Health professionals’ Having the conversation

Lauge described the healthcare professional ‘having the conversation’ in terms of the 4 Ws: Who, When, What, Why and How

The physician to think about:

**Who**: Is the best person in the team to have the conversation and thereafter is designated the person to have the conversation is it the social worker the doctor, the nurse or the specialist? Sometimes a person recognises that they are not the ‘best person’ and refers to another member of the team.

**When**: A new diagnosis of a chronic condition or life limiting illness

**What**: Is the nature of the conversation

**Why**: To give the pt/family an understanding of the illness and to find out what the patient understands about their illness

**How**: Find out how much or how little does the pt/family want about the prognosis/treatment options and what matters most the this person/family
Reflections in the Australian Context

Lesson 1: The implementing of any ACP model requires consideration of the specific patient population that is being targeted for ACP within the context of the facility’s available resources as few facilities will have enough resources to cover all adult patients.

Lesson 2: ACP programs and models, just like advance care plans themselves, are not fixed in cement and once implemented must also be reviewed, amended/adjusted over time as both internal and external need arises.

Lesson 3: ACP and communication skills need to be covered in both in-service education and training as well as become a permanent element in the curriculum for healthcare professionals.

Lesson 4: In-service training and education resources, tools and courses need to address all learning styles and clinical settings eg just-in-time apps, eLearning modules, conversation companion cards; face to face workshops with role plays etc.

Lesson 5: The 4 Ws are a good example of what needs to be considered in a hospital for healthcare professionals ‘having the conversation’.

Lesson 6: In the context of ACP a hospital’s reputation is based as much on the quality of the relationship between the patient and the healthcare team and on ‘care’ of the whole person versus ‘treatment/cure’ alone.

Lesson 7: The development and sustainability of ACP programs needs the ongoing commitment of all staff/stakeholders and support from senior management. Champions for ACP may come and go so the sourcing of more champions in all clinical areas as well as in policy and in senior management needs to be an ongoing process.

Lesson 8: Committees/teams implementing and monitoring ACP programs in the hospital, need to be regularly evaluated. This will allow for others to contribute to the program and for different perspectives and ‘voices’ to be heard. This will also allow for the ACP programs to grow and remain vibrant.

Lesson 9: Data on ACP is useful for staff leanings and is not necessarily useful as a performance measure. This is crucial as ACP data/information used for the latter may well result in undermining ACP in the hospital.

Investigate: Production of a ‘champion tool kit’
2.2  Professor Eric Cassell MD

I was particularly keen to speak with Dr Cassell having heard him speak in a plenary at last year’s 12th Palliative Care Conference in Canberra. I find Dr Cassell inspirational because he has kept the ‘person’ and the ‘relationship’ between the person and the doctor at the heart of his medical practice and teaching.

2.2.1 ‘Having the conversation’: healthcare professionals

Dr Cassell related that the fact is the ‘conversation’ is not about death and dying because dying and death is no surprise to anyone i.e we are all going to die sooner or later. Also when a person comes into a doctor’s surgery and they have been diagnosed with cancer it is no surprise that they would not be thinking about death and dying (even if this is not explicitly expressed i.e the elephant in the room.)

A conversation should happen at the beginning of a diagnosis. It is not that the doctor is ‘upbeat’ talking about treatment but ‘downbeat’ when talking about ‘you are going to die’. The focus should always be on the person’s goals and purposes and how they are going to live their life (with/without/decline or impairment of function). The question for the doctor to ask the patient is ‘What can I do in order for you to live your life the way you would want to live it? and how can I help in your well being?

Medical education has become so focused on the ‘science’ that it has lost sight of the person and the relationship between the person and the doctor. Doctors have been relegated to the ‘carriers of the science’. As such doctors focus on the disease and not the whole person. The assumption is that if you have been trained and carry the ‘science’ you can treat the patient. Whereas treating the patient (healing the sick) is more than the science it is in the relationship that matters.

Science does not deal with death and science does not deal with how you live your life or how you have sex or how you learn to live with a colostomy bag ,nor how you deal with domestic violence or family conflicts etc. Science is brilliant and technology is wonderful but they are tools only. MRI’s don’t treat people it is the doctors and nurses and social workers etc that treat the person.

The relationship between a doctor and patient is ‘about living your life well’ and life is ‘subjective’ and not ‘objective’ like a disease. In having the conversation we have to get back to what matters most the ‘relationship’ between the person and the doctor that is to be ‘person centred’ and ‘relationship based’.

‘What matters most when you are facing disease and illness, death and dying? It is people and emotional closeness.’

Eric Cassell, 2014
Reflections in the Australian Context

Lesson 1: Conversations between the healthcare professional and the patient can be natural and based on mutual trust and collaboration between the doctor and the person/patient.

Lesson 2: The focus is always on the ‘goals of care’ and how people want/can live their life given their functional ability

Lesson 3: The relationship between the doctor and the patient is as important today as it ever was

Lesson 4: Doctors and no different are no different from others in the community and face the same challenges in having conversation about perceived difficult subjects

Lesson 5: The fact that we are training doctors in ‘having a conversation’ is one of the indications that medical education has swung too far away from it’s healing and relationship roots towards science as object and the use of technology as cure all and at all costs.

Lesson 6: Science and technology are wonderful but it doesn’t teach us how to live our life. When we are suffering and/or dying it’s not the science or the machine that we cling to its warmth, love and human touch that we crave.

Lesson 7: We are all going to die – that no surprise to anyone!

Lesson 8: Seek out a variety of perspectives in developing healthcare training and education materials/ resources. Some health professionals, like social workers and psychologist with a social science perspective, are trained in communication skills and can prove useful in this role.
2.3  Gundersen Health System – ‘Respecting Choices’

On Wednesday 24th September I travelled by coach to the lovely town of La Crosse, Wisconsin situated on the confluence of three rivers The Black, La Crosse and Mississippi Rivers.

Gundersen Health in La Crosse was always going to be part of my Fellowship exploration and on the travel itinerary. Essentially in this small mid west town of approximately 50,000 people the “Respecting Choices” program was born and is the foundation model for the RPC program in the ACT.

On Thursday 25th and Friday 26th I met with Danielle Rathke program coordinator, Tami Bender, Pastoral care, Dr Bud Hammes Respecting Choices Director, Brett Welnetz, Business Development Consultant and Tomas Harter, Clinical Ethicist.
2.3.1 Social context

I was lucky in coming on a day the Gundersen’s CEO Jeffrey Thompson was giving an overview of Gundersen Health Strategic Plan 2012-2016 incorporating the Obama health reforms. From what I understand of the health reforms the health system will get $ for care of a disadvantaged population group under Medicaid. According to the Strategic Plan Gundersen’s Health emphasis will be a move away from more medical interventions and treatments to keeping people out of hospital with an emphasis on health care education, disease prevention and health promotion. This approach will support ACP and visa versa.

2.3.2 The 3 steps of Advance Care Planning

There are three steps to ACP under the Gundersen model and these steps and the ‘conversation’ were explained to me as below:

2.3.2.1 Step 1

This is the basic advance care plan and includes both appointment of a health attorney as well as statements of wishes and choices for healthcare. Similar to our program the emphasis is on hypothetical situation(s) i.e. a major accident or injury ‘if I had a serious injury or accident with significant neurological damage’ what would be my choices and wishes for health care.

The conversation: The question is: What is the functional loss threshold that would be tolerable to the person? e.g. ‘If after a major injury you didn’t know who you were, where you were or who you were with and this was permanent condition would this be tolerable to you? When thinking about functional loss - where is the tipping point for you? When would you want to change your goals of care for prolonging life to allowing death to occur?’
2.3.2.2 Next Steps

If a patient has been diagnosed with an advanced chronic condition (e.g. heart/lung) or a life limiting illness and starts to have more serious complications (e.g. repeated hospitalisations) then the ‘next step’ is to advance ‘the conversation’ and to complete as an ‘addendum’ to the original ACP. This is a more specific form that is called a ‘Statement of Treatment preferences’ (SOTP). There is a ‘general’ ‘Statement of Treatment Preferences’ and other forms that cover specific illnesses such as cancer, heart disease, lung disease and kidney disease. Specific forms for dementia and ALS are currently under development. The aim here is not to forego treatment but to determine when treatment would be considered a failure for the patient.

The conversation: On the new diagnosis of a chronic condition or life limiting illness there is a conversation comprising a series of questions and answers that explore a person’s understanding of their condition in the context of their life and to clarify their ‘goals of care’.

This is described in the health literature as a simple technique called ‘Ask-Tell-Ask’

- Ask what is the patients’ perspective of their illness
- Tell the patient about information that the health care professional needs to deliver
- Ask the patient to ensure they understand the information plus:
  - Provide the patient with recommendations for treatment/care.

Example:

- What is your understanding of your illness? ; What is your experience of your illness?
- This is what I can tell you about the illness/trajectory
- After hearing what I have just told you about your illness what have you learnt from that?

2.3.2.3 Last steps

The last steps occurs when clinician’s ‘would not be surprised’ if the patient died within the next 12 months. At this stage, the person has end-stage illness and the goal of planning is to develop a detailed plan expressed as’ medical orders’. ‘The conversation’ continues and the specific goals of treatment are captured in a Physician orders for Life Sustaining Treatment POLST document. This document is linked to the earlier ACP including any ‘Statement of Treatment Preferences’ (SOTC), as applicable. In the Wisconsin POLST document section F states:

‘I have given significant thought to life-sustaining treatment. I expressed by preferences to my physician and/or healthcare providers. This document reflects my treatment preferences. The following have further information regarding my preferences Advance Care Directive – yes or no.’
2.3.3 **The RC facilitator model**

The Program is based on what is called a facilitator model i.e facilitators at Gundersen are trained as facilitators and come from across the multidisciplinary spectrum. The Pastoral Care unit play a major part in triaging patients to appropriate facilitators. This ‘matching’ is deliberate as they try and match patients with an appropriate facilitator as per need and facilitator attributes.

2.3.3.1 **Facilitator Training**

The RC Coordinator Daniele in Gundersen facilitates conversations directly with patients, coordinates and provides training and support to facilitators within the hospital.

For Step 1 facilitators need not be health professionals but for the ‘Next steps’ and ‘Last steps’ they must be health professional’s e.g. nurses or allied health that have completed the training.

RC also host facilitator courses for other staff in regional areas outside La Crosse. This work is carried out by a separate Unit in the community.

2.3.3.2 **Consultations**

Bud Hammes, Linda Briggs and staff travel widely to discuss the model and potential implementation within other health facilities across the country.
Reflections in the Australian Context

‘From small things big things grow’ adage (or was it a song?) is true when you consider the birth and development of this model. One person’s idea inspired and galvanised colleagues to come together to discuss it further. From this small beginning the concept was fleshed out and a system took shape and was further developed, tested and implemented. This Respecting Choices’ is now in several states in America with versions of this model in Australia, Singapore and now Europe.

There will be more on the European model at the 2015 International Advance Care Planning Conference in Munich, Germany.

Lesson 1: The three steps model covers the whole of the patient journey including the continuum of ‘the conversation’ and the companion documentation.

Lesson 2: The Gundersen model’s ‘Next steps’ phase covers patients with chronic disease and/or life limiting illness. This is particularly important that any ACP model covers this patient populations (increasing prevalence and complexity) and the more critical phase of the patient journey.

Lesson 3: The ‘ask, tell, ask’ simple technique is extremely useful for healthcare professionals in ‘having the conversation’.

Lesson 4: It’s important for the sustainability for ACP programs to have champions throughout the hospital and solid leadership. Leaders need to develop, mentor and encourage other ‘leaders’ to ensure the continued viability and sustainability of ACP programs.

Lesson 5: A multidisciplinary team is important in ACP programs in the hospital. Specifically it is helpful to match patients with facilitators as per their qualifications, personality and skill sets as well as patient need.

Lesson 6: In the ‘Next Steps’ and ‘Last steps’ phases of the patient journey the emphasis should be on the ‘goals of care’

Lesson 7: Helping patients to make important health care decisions is very much part of the role of ACP programs and the development of decision aids is part of this role.

Lesson 8: All ACP programs face challenges as hospitals are complex systems. ACP programs need to be evaluated and improved in order for them to grow and meet a growing need for them in society and in the hospital

Lesson 9: We can all learn from each other
2.4 Dr Rebecca Sudore and ‘Having the Conversation’

I was very much interested in talking with Rebecca Sudore as a geriatrician at the San Francisco Veterans Affairs Medical Center and Associate Professor at the University of California – San Francisco. Rebecca was one of the researchers on the ‘Prepare’ website as well as researching and writing widely on ACP with vulnerable population groups including frail aged and those with low literacy and health literacy and culturally and linguistically diverse (CALD) groups.

I visited the SF Veterans Medical Center after a wild ride through downtown SF including a philosophical discussion on the ‘meaning of life’ with a very erudite taxi driver on Wednesday 1st October. Due to unavoidable circumstances that happen on Fellowships and indeed life! I subsequently spoke to Rebecca by phone.

Please note in the photo below the ‘golf buggy’ not for golf but for transporting patients around the facility. I also saw these within the hospital at Gundersen Health in La Crosse as well. They are brilliant! I saw many grateful patients who had mobility problems being taken for the appointments. As health facilities and hospitals become bigger these are indispensible aids for patients with mobility issues!
2.4.1 ‘Having the conversation’ in the community

2.4.1.1 Prepare website

This website was prepared by academic researchers at the University of California as a part of the Conversation Project to start ‘the conversation’ in the community. It was specifically researched and written at a fifth grade level as this was found to be the level of education of some vulnerable population groups and the target audience for this web site on ACP. It features large type, voice overs and how-to-videos with closed captioning to assist people in ‘how’ to have the conversations and to make medical decisions. It was designed to simplify what would otherwise have been a daunting process. The website was one of the website that was reviewed for the development of our local joint Medicare Local ACT and RPC project BeMyVoice ACP campaign and accompanying website.

Rebecca and I had a broad ranging and informative discussion including around ‘having the conversation’ early in the community and reaching carers, and frail aged as well as ‘healthy adults’. The ‘Prepare’ website was designed to raise awareness in the community and to raise health literacy, specifically decision making skills. The website was designed to be a ‘process’ to reflect the fact that advance care planning is a process.

Ultimately advance care planning is about people having the conversation so by the time they come into a health facility they are prepared and can have a ‘conversation’ with the healthcare professional and be in a better position to make decisions about their healthcare.
2.4.2 ‘Having the conversation’ in the hospital

The ‘conversation’ in the health facility needs also to be incorporated into a seamless ‘flow of care’. Otherwise it becomes an issue that patients then have to be ‘prepared’ to then have ‘the conversation’ as it is so daunting.

From a clinicians point of view conversations may be better to be incorporated into healthcare at the time of a flu shot or regular annual health check-up at 65 years and over. ACP can be covered each time a person comes in for a yearly check-up. This makes the whole exercise less confronting and/or less intimidating and/or shocking.

Up to this time there has been a continuing issue of payment for GPs and one of the main barriers to GPs undertaking ACP with their patients. In the USA a Bill has recently been introduced to reimburse physicians to have discussions about ACP. This appears to be only a minimal amount and may not cover actual consult time. Consequently this may not prove to be the incentive hoped for by ACP practitioners. In hospital ‘Conversations’ are better to be framed within the context of ‘medical decision making’ versus ‘end of life’ which for most people is just a real ‘turn off.’

Conversations can be framed in the context of people having to make decisions in life including at times making ‘hard’ decisions e.g looking after a frail aged parent, being a ‘carer’ for a family member, own health issues etc Conversations on ‘making decisions’ may be less confronting than around ‘end of life’ not only for the patient but also for the healthcare professional.

The doctor has knowledge about treatments and diagnosis and the person/patient knows much more about their own life. In social work terms, i.e coming from a bio psychosocial model the ‘person is the expert of their own lives’ as a professional we work alongside the person. The patient story needs to be captured by ACP.
Reflections in the Australian Context

Lesson 1: The patient’s health literacy is important in the completion of documents like POLST or MOLST i.e what do patients really understand about these decisions they are making? It’s important for healthcare professionals to check this out and pitch their conversations accordingly.

Lesson 2: Documents, like POLST and MOLST, alone do not capture the full patient story needed to inform complex ongoing decisions about care. The story is best captured by a fuller conversation and earlier ACP processes and documents.

Lesson 3: It is really important that the patient identifies his/her wishes with their surrogate/family and doctor and understands the choices they are making in ACP. This is all affected by the patient’s literacy/education level, language and culture. Healthcare facilities need advance care planning aids/tools/resources that that take these factors into consideration.

Lesson 4: Healthcare professionals also need training/awareness of how health literacy and cultural factors affect decision making and choices and to take these factors into account when ‘having the conversation’ with patients and their family.

Lesson 5: Incorporate ACP discussion into the regular health checks so as to be less threatening.

Lesson 6: ACP conversations can be couched in terms of normal medical decision making versus ‘end of life’ and decision making tools developed for patients.

Investigation:

Is ACP best done by a facilitator? Is ACP only as good as the facilitator? Each health facility needs to look at their own facilitators and their qualifications/training as well as agency expectations.

Local research needs to be conducted to garner satisfaction levels of doctors and patients with ACP so that this evidence can be gathered and utilised for improved ACP tools.

What are the current perceived and real barriers to GPs undertaking ACP?
Part 3

20th International Congress on Palliative Care: Summary & Emerging Issues in Advance Care Planning
3.1 20th International Congress on Palliative Care: Summary

The Congress on was held at the Palias des Congress in the heart of Montreal on September 9 - 12th. There were over 1,300 delegates attended the Congress from 58 countries.

This was a full program of plenary sessions, workshops, lectures, film screenings, group meetings, student sessions, exhibits and poster displays and network lunches. In the tradition and spirit of palliative care i.e care the whole person the program also incorporated delegate self-care sessions, the quiet room for meditation and reflection and musical interludes of top quality performers as well as a social program.

Palias des Congress, Vider St, Montreal

3.1.1 Summary and reflections

A stirring plenary was given on the Thursday which pretty much summed up the Congress. Palliative care is and has always been at the ‘heart of medicine’. It is a branch of medicine that is based on the power of the ‘relationship’ between people and in particular between the person and the health
professional. This is different from ‘medicine’ in general that has become increasingly dominated by a culture of performance, efficiency and evidence. While these things are in themselves important health care should always give priority to ‘the person’ and ‘the relationship’. (Chatel, T. 2014)

This theme of relationships, communication, treating the ‘whole person’ and education of healthcare professionals particularly interested me in relation to the work we are doing in advance care planning and training of healthcare professionals in ‘having the conversation’.

3.1.1.1 Education of healthcare professionals and ‘having the conversation’

There is a substantial body of research in the literature about the need for healthcare professionals to be adept at facilitating the conversation around ‘goals of care’ between the healthcare professional and the patient and their family and appointed attorney(s)/substitute decision maker (SDM). Presenters at the Congress as well as participants recognise that these conversations are crucial for care that is appropriate to the patient and their family and their end of life experiences. Finding and utilising a variety of formats and tools to educate healthcare professionals in having these conversations is at the forefront of efforts in healthcare facilities including our own in the ACT not only in palliative care but also in all areas of health.

Presenters included Pallium on their just-in-time online learning packages and the Canadian Hospice and Palliative Care Association on their ‘Speak Up campaign’ and the tools available to engage people in advance care planning.

Kate McNamee-Clark from Providence Health Care, Vancouver, British Columbia gave a presentation on the development and trial of a ‘Goals of Care Companion Card’ for use by health professionals in the hospital. This project began with the research question ‘To explore and evaluate the clinicians’ experience using the ‘goals of care companion card: Piecing together a preference for care’ – communication resource using Interpretive description methodology.’ The results were mixed and demonstrated that the wallet size card was a portable and an easy to use resource. The puzzle design was non sequential and allowed for healthcare professionals to be able to pick up and have a conversation at any time in the patient’s stay in the hospital. On the negative side there was a risk in over reliance on the resource and professionals avoiding the importance of the ‘relational encounter’. The ‘struggle’ remains when is the ‘best’ time or the most ‘appropriate’ time to have the conversation?

Alberta Health Services Amane Abdul-Rassak gave a presentation on a research project that looked at patient preferences for physician’s end-of-life communication behaviours. The findings revealed that patients preferred: expressions of personal connection and being present (Non verbal behaviours); acknowledging family roles and respecting one’s background (knowing me) and assessing the readiness of the patient and family to receive information, receiving an invitation and appropriate delivery of the information (conditional candour).

Associate Professor Elizabeth Clark gave a presentation on a Quality Improvement in Montefiore Medical Centre/Albert Einstein College of Medicine in New York. The project involved increasing advance care planning discussions in a clinical setting with education and training. The results
demonstrated that communication skills can be taught. The communication skills training including small group seminars, facilitated practice in using specific communication tasks with standardised patients e.g. ‘breaking bad news’, discussing prognosis and empathic listening. The communication skills curriculum for internal medicine residents included 2 learning sessions of 1.5 hours. These sessions included didactic learning, discussion, role plays and self study. Skills training included ‘active listening’ and ‘Ask-Tell-Ask’ conversation technique.

A presentation by End-of-Life Care Research Group, Ghent University highlighted the need for family physician/GPs to have training in having advance care planning conversations. This presentation also highlighted that GPs lose connections with their patient once their patients go into treatment with a specialist. Specific barriers of patients with heart failure and dementia revolved around less predictable disease courses and difficulty communicating diagnosis and prognosis. The author’s conclusions were that GPs needed more skills development and knowledge and there needs to be better communication/processes between the GP and the specialist in regards their ‘shared care’ of their patient.

Katherine Clark from Calvary Mater, Newcastle and Newcastle University gave a presentation on a web development initiative i.e. an online education for GPs called the Healthpathways’. This project was funded by the NSW Cancer institute. This education resource to be used by GPs and Residential aged care facilities (RACF). The project is a collaboration of professionals including GPs, nurse partitioners. The project partners develop and review material ensuring that the content is based on best practice and is evidence based. The Unit will also be developing content on ‘advance care planning’ and ‘bereavement.

Throughout the Conference there was a strong push for early palliative care that is palliative care that begins much earlier in a person’s illness and can coexist alongside active treatment. In this way the person/patient can receive a holistic care incorporating spiritual and psychosocial supports when they most need these supports. As Victor Cellarius in his presentation on “Palliative Care; History, Ethics and Practice” described the emphasis is on ‘quality of life and supportive care’. This approach is particularly important when you consider the aging population, disease co-morbidity and complexity of medical responses.
3.1.1.2 Paramedics

One of the complexities of Advance care planning is the fact that it can involve a number of different sectors including the ambulance services and residential aged care facilities. Anecdotally a question that clients often ask is ‘if I call the ambulance will they respect my advance care plan?’ The presentation by Charlotte Pooler from Alberta Health Services, University of Alberta, in Edmonton described an initiative that is currently being rolled out as a new service in collaboration with Emergency Medical Services in the community in Alberta. This initiative was in response to the recognition that people in palliative care can be unexpectedly transferred to hospitals in an emergency. This was found to not always be optimum from the patient’s point of view. There was also recognition that there were many community supports and services in place for people receiving palliative care at home.

As there was a high level of success and satisfaction with this initiative/ trial it was decided to establish a service. People are now able to phone a normal number and not the ‘emergency call number’. The paramedics can come to the person’s home to provide care including medications and equipment. Paramedics providing this type of care in the home first receive ‘Palliative’ education ‘ in-service training. It is also hoped that as a consequence of this service more people will be able to die at home, if this is their expressed wish (as per an advance care plan) rather than being ‘rushed’ to the emergency department of the hospital.
Reflections in the Australian Context

**Lesson 1:** Paramedics remain one of the key systems in the ACP process and should be a vital part of all discussions and development of ACP programs. Locally ‘Memorandums of Understanding’ may be useful plus representation on ACP Committees by the Ambulance services.

**Lesson 2:** Encourage palliative care at the beginning of a diagnosis not at the end. This will help draw funding to this area of health services as well as improving the care and experience of patients on their health journey.

**Lesson 3:** Encourage the ‘relationship’ and ‘good communication’ between doctor and patient in all areas of the clinical environment. This will also help determine when is the ‘best time’ for conversations between the healthcare professional(s) and the patient and their family.
3.2 Emerging Issues in Advance care Planning

3.2.1 Decisions aids

I visited Mary Butler at the School of Public Health, University of Minnesota, Mayo Building on Monday 22 September 2014. I was interested in meeting Mary as she had been an investigator on the Technical Brief, No. 16 “Decision Aids for Advance care Planning” prepared for the Agency for Healthcare Research and Quality. I was aware that this project was evaluating advance care ‘decision aids’ for specific medical decisions and focused more on advance care directives and or/MOLST and POLST documentation than on advance care plans. However the local RPC program had produced a ‘glossary of medical terms’ as an information /decision aid for our clients and patients and facilitators and I was interested to see if this document or anything we might produce in the future could be evaluated.

This ‘Brief’ reports on an evaluation of existing decision aids for advance care planning/advance care directives. It deliberately excludes the more general advance care plans i.e. the plans that are generated in an ACP program like the RPC here in the ACT. The ‘Statement of Choices’ are concerned more with values and wishes around ‘hypotheticals’ and not decision making around specific treatments.

It was interesting to note that, according to the criteria used in this evaluation, the tools we use in ACP are assessed as providing low or medium levels of education and decision structure but are high on communication and do not provide people with the means to deliberate on their decisions using a ‘structured process’. The notable exception to this is the ‘Prepare’ website mentioned elsewhere in this report under ‘Rebecca Sudore’.

The three criteria of the International Patient Decisions Aid Standards are:

1. An educational component
2. A structured approach to thinking about choices
3. A means of communicating those choices

The study looked at the ‘decision aids’ that were designed to meet individuals with life limiting illness where the illness trajectory is often more clearly defined. These tools usually focus on one topic. These tools are more precise and targeted at specific decisions.
Future directions for efforts/research recommended by this evaluations study included:

1. Well designed tools that are easily accessible, and understandable across health settings, and working with various facilitators (as per the facilitator’s background and experience); broad range of tools to meet the needs of a broad range of professionals in different settings and at various stages of illness/health e.g healthy adult versus adult with life limiting illness versus frail aged, acute need for clinical decisions versus hypotheticals for ‘healthy adults.

2. Research on patient and provider satisfaction and impact of preferences stated and efficiency of ACP processes.

3. Methods of evaluating decision aids within the context for which they are intended to be used. Especially as facilitators come from a wide variety of backgrounds e.g nurses, social workers, lawyers’ and pastoral care etc.

4. Research to be conducted to gain an understanding of how the background of the facilitator affects the decision making process of the client.

5. Create decision aids that provide personal narratives based on people experiences on various health conditions and after receiving life prolonging therapies. Using social media to democratise the process of sharing and collecting people’s experiences.

Reflections in the Australian Context

Lesson 1: Produce and make available a variety of ‘decision aids’ in the Australian context. This will be beneficial for patients when they are having to make specific medical/health decisions.

Lesson 2: It is useful for ‘decision aids’ to conform to the International Patient Decision Aid Standards so that they are able to be evaluated.

Lesson 3: Decision aids should be evaluated for effectiveness and usefulness to the patient in making healthcare decisions and to the healthcare professionals who are working with the patient in carrying out those decisions.

Lesson 4: Collect people’s stories (i.e. the ‘personal narrative’) so they can be used as a ‘decision aid’ (Refer: ‘Respecting Choices’ and ‘Conversation project’ websites)

Lesson 5: A range of ACP tools may be useful in different clinical settings and phases of the illness
‘Structured interviews’ – Wendy Anderson, University of California

Wendy has been given a grant for nurse education University of California. The project is focused on a collaboration with heart failure patients who are getting left-ventricular assist devices. The project aims to train nurses in having ‘structured advance care planning interviews’ with both patients and their care givers involving patients' prognosis and goals of care. Training includes education around ‘communication including role plays and practice of skills including ‘open ended question’; reflection statements; tell me more; empathic responses; ‘Ask-Tell-ask’/ hope /worry statements.

Reflections in the Australian Context

Investigation:

“Structured interviews” may be a useful approach in consideration of the use of MOLST in the hospital as well as development of ACP beyond the initial general conversation and ‘hypothetical’ phase i.e. specific diseases.
Conclusion & Recommendations and References/Reading Lists
Conclusions

This Fellowship exploration of ACP programs afforded me the opportunity to see that the Respecting Patient Choices model used in the ACT may be quite unique. During this Fellowship none of the places and programs I visited or heard about had an equivalent staffed ACP program that encompasses both ACP in the community and in the hospital. The fact that we are doing both is a testament to the energy, enthusiasm and commitment of the staff as well as their resilience.

A stand out message for me from this Fellowship is that no one program or agency can do ‘everything’ to raise awareness of ACP the community. For ACP to grow and be sustainable in the long term ACP needs to be ‘owned’ by the community and that ‘having the conversation’ is the responsibility of everyone with our without a facilitator. ACP programs with limited resources are best placed to: source provide ACP training to ‘ambassadors’ and ‘champions’ in the community and for them to raise awareness in their own communities. To support these communities the Program needs to be: conduits of information and research in best practice; collaborators/developers of resources including websites; enablers to create solutions to problems and importantly creators and facilitators of ‘networks’ of people and agencies to regularly connect to share ideas, resources, stories and innovative initiatives. It was evident that this approach is being used successfully by the Canadian Hospice and Palliative Care Association’s ‘Speak Up campaign and in the U.S ‘Conversation Project’ coordinated by the Institute of Healthcare Improvement, the ‘Honoring Choices’ program hosted by agencies like the Minneapolis Twin Cities Medical Society and state ‘Coalitions’ like the California Coalition of Compassionate Care in California.

In the hospital/health facilities healthcare professionals need to learn to ‘have the conversation’. It is imperative that a variety of quality online and print resources, tools and in-service training modules are developed and shared at the national, state/territory and/or local level. Agencies working in collaboration to produce and share resources like Pallium in Canada exemplify how this can be done.

In hospital advance care planning systems like the one being developed at the Beth Israel Deaconess Medical Centre for the ‘Conversation Ready’ project or the well established and evaluated Gundersen ‘3 steps’ advance care planning model are needed. Such systems need to be evaluated and adjusted to meet developing public as well as healthcare professionals growing awareness and expectations of ACP. The Gundersen model encompasses the whole of the ‘patient journey’ from healthy adult with episodic care to a person with a chronic condition or life limiting illness to end stage disease. Having a vision statement like the one developed by the Coalition of Compassionate Care makes a clear unequivocal statement that advance care planning is a process and a continuum where the conversation and the person’s story can be captured by appropriate tools at all stages on the patient journey to improve patient healthcare including at the end of life.
Recommendations

Local

1. Develop a ‘vision statement’ for the whole of the ‘patient journey’ incorporating ‘healthy’ adult, adult with chronic conditions/life limiting illness, end stage disease (MOLST) and final days

2. Investigate using the whole ACP 3 step Gundersen model Specifically: the ‘Next steps’ phase of the patient journey including the documentation i.e. the Statement of Treatment Preferences (specific diseases)

3. Improve Education and awareness. Specifically:
   a. Conduct information sessions for any vulnerable populations not covered by the community NGO under contract e.g. jails, mental health
   b. Conduct ‘brown bag’ lunchtime presentation on ACP to public servants.
   c. Encourage all employees to complete their EPA and an ACP
   d. Expand ACP facilitator training workshops to include half day modules on specific diseases and population groups e.g. dementia, CALD, aboriginal and Torres Strait Islander peoples, disabled, homeless
   e. Develop ‘facilitator guidelines’ for both in-house and external facilitators
   f. Include ‘conversation groups’ into the RPC’s suit of community education sessions specifically for groups where shared decision making is common or where people need extra support for ‘having the conversation’ e.g. some CALD communities and Aboriginal and Torres Strait Islander communities.
   g. Support Australia’s national day ‘Dying to Know Day’ by collaboration with other individuals/agencies on ACT specific activities.
   h. Investigate the incorporation of an EPA and an ACP session in a program for college student’s .e.g ‘coming of age’ or similar.

4. Develop Resources. Specifically:
   a. Develop specific ‘decision aids’ for CPR and Life prolonging treatments especially for our vulnerable and CALD communities.
   b. Investigate and develop resources, aids/tools as well as in-service workshops for health professional in ‘having the conversation’ . These to incorporate cultural and health literacy awareness.
   c. Investigate a more systematic collection of people’s stories for upload to the BeMyVoice website, use in facilitator training and as a potential decision aid
d. Purchase several packs of the ‘Go wish’ cards to be used in facilitator training plus conversation groups including specific population groups CALD and Aboriginal and Torres Strait Islander groups

5. Investigate the use and satisfaction levels of current ACP amongst doctors and patients.

6. Investigate developing inter-professional and cross sectoral ACP Communities of Practice Network locally/interstate.

**National**

7. Establish an ACP program within a national body that is independent of state and territory health bodies and not attached to any specific ACP programs. The program should work in concert with all ACP programs, individuals, agencies across Australia in a non bipartisan way. Specifically it should:

   a. Create, in partnership, a national ACP campaign and coordinate ACP across the country, including developing and sharing resources and information and coordinating the ‘Dying to Know Day’ as an annual national focus.

   b. Work with state governments to ensure populations in regional and remote areas in Australia have access to ACP resources and documentation
References


Minnesota Evidence-Based Practice Center (2014). Decision Aids for Advance Care Planning. s.l.: Agency for Healthcare Research and Quality.

Select Reading List


Web Resources

- National POLST
  http://www.polst.org
- Massachusetts MOLST
  http://www.molst-ma.org
- New York MOLST
  http://molst.net
- CODA Alliance – Go wish cards
  http://gowish.org/article.php/aboutcoda
- Speak Up
  http://www.advancecareplanning.ca/
- Conversation Project
  http://theconversationproject.org/
- Honoring Choices Minnesota
  http://www.honoringchoices.org/
- Pallium
  http://pallium.ca/