The Winston Churchill Memorial Trust of Australia

Report by Phillip Good - 2015 Churchill Fellow

The Dr Dorothea Sandars and Irene Lee Churchill Fellowship to Develop Academic Leadership in Palliative Care

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Signed: Phillip Good                                      Dated: 21/08/2016
# Table of Contents

1. **INTRODUCTION** ........................................................................................................................................... 3

2. **EXECUTIVE SUMMARY** .............................................................................................................................. 4
   2.1 **FELLOWSHIP DETAILS** ....................................................................................................................... 4
   2.2 **PROJECT DESCRIPTION** ....................................................................................................................... 4
   2.3 **HIGHLIGHTS** ....................................................................................................................................... 4
   2.4 **MAJOR LESSONS LEARNED** ............................................................................................................. 4
   2.5 **INFORMATION DISSEMINATION STRATEGY** .................................................................................... 4

3. **PROGRAM** ...................................................................................................................................................... 5

4. **OVERVIEW** .................................................................................................................................................. 8

5. **LEEDS** .......................................................................................................................................................... 9
   5.1 Lessons learned from Leeds: .................................................................................................................... 11

6. **DUBLIN** ...................................................................................................................................................... 14
   6.1 Lessons Learned from Dublin: ................................................................................................................. 15

7. **EDMONTON** ............................................................................................................................................... 17
   7.1 Lessons Learned from Edmonton: ............................................................................................................ 19

8. **CONCLUSIONS AND RECOMMENDATIONS** ............................................................................................ 20
   8.1 Conclusions .............................................................................................................................................. 20
   8.2 Recommendations .................................................................................................................................. 20

9. **REFERENCES** ............................................................................................................................................. 21
1. INTRODUCTION

Research in palliative care has been historically challenging. There has been a view from within palliative care that sick and vulnerable patients should not be subject to ‘experiments’. (1) The opposing view is that without research in this group of patients, everyday practice is in fact a series of ‘experiments’ on sick and vulnerable people. (2) It is because these patients are sick and vulnerable that they should be getting the best clinical care possible. The biggest challenge is to perform high quality research that is able to provide answers to important clinical questions.

When I was training in Palliative Medicine I was challenged to think about how much of my practice was based on evidence. This led me to investigating this question and writing my first ever research article. (3) More recently improving my own practice and as a result the clinical care of my patients and families has become the driving force of my work. Improvement comes from self-reflection and questioning of why things are done a certain way. Each day I ask – “Is there a better way to do this?” I have learnt that performing research helps not only to answer these questions, but improves my knowledge and care of all patients, whether enrolled in research trials or not.

Research is usually not a part of routine practice, but rather seen as an add-on, for those doctors interested or have the time (or more commonly, make the time). The impetus behind this Churchill Fellowship was to learn how to develop a culture of research within palliative care units. I was aiming to spend some time with experienced palliative care clinician researchers and learn from their career experience of undertaking research at the same time as continuing in clinical practice.

I wanted to say thank you to Dr Dorothea Sanders and Ms Irene Lee for the generosity of funding a fellowship for palliative care. I am extremely grateful to the Winston Churchill Memorial Trust for the opportunity to visit and learn from the many palliative care clinicians and researchers I met on this trip. I was very appreciative of the time I was given by every person I met, and especially Professor Mike Bennett and Professor Robin Fainsinger for their personal generosity.

Both my work places – Mater Health Service and St Vincent Private Hospital, Brisbane were very supportive of my time away, and I particularly thank my medical colleagues who covered all my clinical practice whilst I was away. Finally thank you to my wife and family for supporting and encouraging me to continue to improve.
2. EXECUTIVE SUMMARY

2.1 FELLOWSHIP DETAILS

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2.2 PROJECT DESCRIPTION
The aim of this project was to learn how to best integrate research and clinical practice in Palliative Care. I travelled to leading academic units in Canada and United Kingdom to observe their clinical and research practice and specifically learn how they successfully combine the two.

2.3 HIGHLIGHTS
These academic units provided me with insights on how research can be embedded in clinical practice, and how clinical practice can be changed by high quality research.

2.4 MAJOR LESSONS LEARNED

1. Always have a short and long term strategy  
2. Try to have a variety of projects at various stages  
3. The importance of patience and perseverance  
4. The need for collaboration within and outside the palliative care field  
5. The importance of collaborating with academics and others who are skilled at writing journal articles, project grants, and completing collaborative tasks.  
6. The need to be successful in finding money – through competitive grants or other sources  
7. Try and concentrate on a few themes of research, not be spread too thin  
8. The importance of involving the whole team, and ensuring everyone feels they have input and ownership over direction.  
9. The benefit of having dedicated time to plan, perform, publish and fund research

2.5 INFORMATION DISSEMINATION STRATEGY

1. Presentations at workplaces – St Vincent’s Private Hospital, Brisbane and Mater Health Services  
2. Presentation at Queensland Palliative Care Interest Group  
3. Dissemination of this report to my department research committees  
4. Distribution of this report to my state and national palliative care research collaboratives  
5. Publication of collaborative research project
### 3. PROGRAM

**Leeds, United Kingdom – 23rd May to 3rd June, and 13th June to 17th June, 2016**

<table>
<thead>
<tr>
<th>PERSON</th>
<th>ORGANISATION</th>
<th>POSITION and ROLE</th>
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<tbody>
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<td>Prof. Michael Bennett</td>
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<td>Head of the Academic Unit of Palliative Care</td>
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<td>Dr Lucy Ziegler</td>
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<td>Senior Research Fellow in the Academic Unit of Palliative Care</td>
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<td>Matthew Mulvey,</td>
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<td>Kathryn Black</td>
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<td>Julie Kaye</td>
<td>St Gemma’s Hospice</td>
<td>Community Nurse</td>
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**European Association of Palliative Care Research Network and European Palliative Care Research Centre Pre Congress Research Seminar – Dublin, Ireland, 5th-7th June, 2016**

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<tr>
<th>Facilitators</th>
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<tr>
<td>Stein Kaasa</td>
<td>Professor of Palliative Medicine at the Institute of Cancer Research</td>
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Camilla Zimmermann  
Professor of Medicine, University of Toronto. Head of Palliative Care for the University Health Network and Medical Director of the Harold and Shirley Lederman Palliative Care Centre at Princess Margaret Cancer Centre, Toronto.

Luc Deliens  
Professor and director of the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel

David Currow  
Professor of Palliative and Supportive Services at Flinders University

Cinzia Brunelli  
Palliative Care, Pain Therapy and Rehabilitation Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, Italy

Barry Laird  
Clinician Scientist in Palliative Medicine. Honorary Consultant at the Edinburgh Cancer Centre and at the Beatson West of Scotland Cancer Centre

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<tr>
<th>PERSON</th>
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<tbody>
<tr>
<td>Prof. Robin Fainsinger</td>
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<td>Dr. Sarah Burton MacLeod</td>
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<td>Dr. Vincent Thai</td>
<td>University of Alberta Hospital,</td>
<td>Palliative Medicine Specialist, Palliative Care Medicine Consult Program</td>
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<td>Professor Karen Forbes</td>
<td>University of Bristol</td>
<td>Professorial Teaching Fellow at the University of Bristol and a consultant in Palliative Medicine at the University Hospitals Bristol NHS Trust.</td>
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<tr>
<td>Dr Ingrid De Kock</td>
<td>Edmonton Zone Palliative Care Program</td>
<td>Community Palliative Medicine Specialist</td>
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<td>Dr Megan Sellick</td>
<td>Royal Alexandra</td>
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<tr>
<td>Name</td>
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<td>Care Medicine Consult Program</td>
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<td>Shelley Cloutier</td>
<td>Covenant Health Palliative Institute</td>
<td>Clinical Nurse Educator</td>
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<td>Dr Amanda Brisboeis</td>
<td>Grey Nuns Hospital</td>
<td>Facility Chief of Medicine</td>
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<tr>
<td>Prof Vicki Baracos</td>
<td>Department of Oncology University of Alberta</td>
<td>Professor, Palliative Care Medicine</td>
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<td>Prof Konrad Fassbender</td>
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<td>Cheryl Nekolaichuk</td>
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<td>Psychologist and Associate Professor, Palliative Care Medicine, Department of Oncology University of Alberta</td>
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4. OVERVIEW

The aims for my Churchill fellowship were:

1. To gain insights into clinical practice in UK and Canada
2. To gain insights into how to incorporate research into routine clinical practice, in sites of excellence in UK and Canada
3. Develop a collaborative project at each site
4. Observe how research activity is combined with clinical services and how research knowledge is fed back into clinical practice
5. Understand how to promote a research culture within clinical practice
6. Observe how they encourage junior staff to have an active role in research
7. Disseminate through further development of integrating research and clinical practice within the Palliative Care Services where I work
8. Presentation at national Palliative Care meetings/conferences
9. Sharing of knowledge within my research collaboratives
5. LEEDS

Part of my inspiration for applying for this Churchill Fellowship was when I met Professor Mike Bennett at the Australian and New Zealand Society of Palliative Medicine Conference at the Gold Coast in 2014. I had admired his research especially in cancer pain, and was really fascinated by his description of his Churchill Fellowship, where he went, who he met, and what he learnt.

I was so grateful when I was able to visit his Academic Unit at the University of Leeds, and spend time discussing his approach to research and clinical practice in Palliative Medicine.

One of the advantages of Leeds, was my shortest ever commute to work. Staying on campus and only having to walk across one road was fantastic and enabled me to make the most of my time in Leeds.

I shared an office with Prof Bennett, and was able to discuss research ideas, develop a collaborative project and talk to most of his research team.

Prof Bennett has developed the Academic Unit of Palliative Care as part of the Leeds Institute of Health Sciences.

Their website sets out their aims:

We aim to be recognised internationally as an outstanding model for improving care of those approaching the end of life through integrated research, teaching and clinical practice. Our work is guided by our values:

• Respect and value patients, carers, staff and all those we work with
• Innovate and integrate with local clinical practice
• Inspire and support continual development and sharing of knowledge
• Build capacity to ensure a sustainable academic unit
• Be responsible and accountable for the standard of our work

The Academic Unit of Palliative Care links academic and clinical partners and is physically located on two sites; Leeds Institute of Health Sciences and St Gemma’s Hospice. This underpins our commitment to integrated clinical academic practice.” (4)

The Academic Unit is on campus at the University of Leeds, but also has staff and space at St Gemma’s Hospice. Whilst lead by a Palliative Medicine Specialist, staff come from a wide range of backgrounds (but all with academic experience, and all having completed PhDs in various fields). There are clinical nurses on site at St Gemma’s Hospice and St James’s University Hospital (location of major oncology service in Leeds). At the Leeds Institute of Health Sciences staff are all working on major projects, performing research, writing papers, and grant applications to secure future funding.
One of the things that struck me was how all the research staff (except one) were on short term contracts (between 1-3 years). The longer term contracts such as 2-3 years were relatively unusual in the research field and were very sought after.

Spending some time talking to the members of the research team was very enlightening. Each had a real passion for the projects they were involved in and for developing these projects onto the ‘next step’.

Prof Bennett has developed an impressive academic unit, that has secured large grants, and produces high quality research. His particular research focus has been cancer pain, and he is seen as one of the world’s leading experts in the assessment and management of cancer pain. The program grants involve a lot of collaboration with other disciplines within the University of Leeds Collaboration. For example they have a research project – IMPACCT: Improving the management of pain from Advanced Cancer in the Community. With this project there are collaborations with health informatics, sociology, pharmacy, clinical trials unit and health economics. Senior academics in all these areas contributed to the grant proposal, and are involved in managing each of their ‘work streams’. Researchers in the Academic Unit are responsible for actually doing the research in these work streams overseen by Prof Bennett, and collaborative senior academics.

At the same time the researchers are encouraged to develop project ideas and apply for grants, to continue to be able to secure funding and perform further research. Results from this research are used as a platform for future projects, in hopefully a snowballing fashion. For the clinical research projects, palliative care research nurses are embedded within St Gemma’s Hospice, and the major cancer hospital. This ensures good linkages with oncology, and also helps to identify patients for recruitment to the research.

The individual researchers were really impressive, in their background, their motivation to perform and their enthusiasm for research in general. Whilst probably there is a large element of self selection in that to progress in their academic career they need those attributes, I was really interested in how they came to work on this team in particular. It was clear that the two things were important – picking the lead researcher of the team, and their ability to support and lead the team, and seeking out the right people for the research projects and team.

As well as having academic researchers as part of the unit, another important aspect is providing the opportunity to develop clinician researchers. There are two academic palliative care registrar positions attached to the academic unit. Doctors doing specialist training in Palliative Medicine are able to spend 25% of their time in research activities. During this time their aims are to learn about research, develop and finish a project, and try and secure a grant to complete a PhD.

I was fortunate to spend some time observing clinical care at St Gemma’s Hospice and their associated community service. St Gemma’s Hospice was opened in 1978 by the Sisters of the Cross & Passion, and is the biggest hospice in Yorkshire. It has 32 inpatients beds, all individually named after landmarks in Yorkshire, rather than the traditional method – which is by a number.
There were a lot of similarities to palliative care in Australia, although there are not many free standing palliative care inpatient units in Australia anymore. There are 2 wards of 16 beds. Consultants perform ward rounds twice per week. Before the ward round there is a mini team meeting with the doctors, nursing team leader and nurse looking after that group of patients, then the patients are visited in their room. Following this there is a post ward round handover with everyone to ensure everyone is on the same page in terms of plans of care. Once per week there is a full multidisciplinary team meeting where doctors, nurses and allied health meet and discuss each patient’s care. It was really impressive to see such a high level of team communication, as well as the excellent care of the patients.

The community team had one Palliative Medicine trainee doctor and one consultant, who was also involved the Day Hospice program. A big advantage the community team had, was their use of a computerized patient record system that also was used throughout Leeds, enabling access to a lot of background information. The nurses case managed a load of patients – all of whom they were able to get to know well, and developed links with local general practice surgeries. I was able to attend an outpatient clinic that took place in a GP surgery, and home visits – with lots of similarities to the approach in Australia.

5.1 Lessons learned from Leeds:

1. Importance of protected academic time – work practices have been set up, so there is clear delineation between clinical time and academic time. This needs cooperation and collaboration from all medical team members, and enables the clinician researchers to focus without distractions.

2. Benefit of computerized medical records – clinically this really helped in community. It also enable a focus of research – database registry research for projects such as referral to palliative care, number of palliative care visits, home deaths and other outcome measures that take a lot of time to find if attempted manually.

3. Building on an area of research focus – this was particularly evident on Leeds, where the central theme had been cancer pain.

4. Collaboration with academic researchers – in many ways these were the ‘engine room’ of the research output. They had particular expertise in performing the research, writing grant applications and publishing results – both at conferences and in journals.

5. Success in grant writing – the need for this skill, as well as using resources within the university to help to improve grant applications.

6. Having a short and long term strategy for research projects, and knowing what is the funding cycle.
St Gemma’s Hospice, Leeds.
Academic Unit of palliative Care – located at St Gemma’s Hospice, Leeds
6. DUBLIN

I attended a pre-congress seminar, conducted by European Association of Palliative Care Research Network and European Palliative Care Research Centre. It was facilitated by 6 experienced palliative care researchers – Stein Kaasa, Camilla Zimmerman, David Currow, Cinzia Brunelli, Luc Delians, and Barry Laird.

Each gave an interactive talk on topics including:
• Why do we need large enough clinical studies?
• Palliative care research involving registry/health administrative databases?
• Conducting RCTs with complex interventions: pitfalls and pearls
• Study design issues – dealing with Missing data, deaths in RCTs, deaths and withdrawals due to frailty,
• Results interpretation: clinical and statistical significance
• Palliative care population: how to define, identify and describe

During the rest of the seminar time was spent presenting research ideas and protocols and receiving feedback from the facilitators and other participants. This was valuable both in regards to individual feedback, and to observe how others were developing and participating in different types of research.

For me the most valuable aspect was to see the breadth of research that was occurring – there was qualitative research, quantitative (including RCTs and complex interventions), registry data research on a population level (including international collaborations) and translation research.

The next event was the European Association of Palliative Care Research Conference held at University of Dublin. This is the major research conference probably in the all of Palliative Care with over 1000 delegates from all over the world attending. There were plenary sessions, abstract presentations and lots of posters.

There were some really interesting sessions on the challenges of researching pain. There were several posters about registry data research, and that made me think a lot about whether this was an area that had been explored in palliative care in Australia. There was a lot of focus around early referral to and integration of palliative care in the broader medical specialities.
6.1 Lessons Learned from Dublin:

1. The importance of careful trial design.
2. Always focussing back on what is the question being asked in the research.
3. Thinking about the validity of the results – by defining the patient population well – clinicians can be clearer about whether these results are applicable to their patients.
4. The importance of qualitative and quantitative approaches in research.
5. How to improve uptake of new evidence – key opinion leaders, academic detailing, and use of audit and feedback loops.
Perhaps the most interesting (or least inspiring) poster was this one:

It had a connection with Australia (via Frank Hurley being the official photographer on the Imperial Trans-Antarctic Expedition) and made me think of what clinical research is all about. Yet, without it there would be so much less progress and innovation in health care.
7. EDMONTON

The Edmonton Zone Palliative Care Program (EZPCP) started in 1995 and provides a coordinated, integrated palliative care service to the Edmonton area in Canada. It aims to provide high quality, cost effective care to all patients irrespective of their site of care. Sites of care include community consultations, hospital consultations, inpatient care at hospices and inpatient care at the Grey Nuns Tertiary Palliative Care unit for complex symptom needs.

The service also has a strong track record of academic excellence through clinical research, links with basic science research, health economic research and a structured education and training program for doctors. I was fortunate to visit and observe all these aspects of the service.

**Grey Nuns Tertiary Palliative Care Unit (TPCU):**
This unit is situated within the Grey Nuns Hospital, and has 20 beds. Patients are admitted to the unit if they have complex physical and/or psychosocial needs. The service is consultant run, and involves daily morning handover meetings, daily ward round by the Palliative Medicine Specialist. One of the reasons for this is that junior medical staff have fairly frequent rotations through the service – between one and four weeks at a time, and so there needs to be a consistent medical presence and oversight of the clinical care. There is an intensive approach to data collection with many scores kept – including the use of the Edmonton Symptom Assessment System (ESAS – developed in Edmonton(5)), Performance scales, cognition assessments, constipation scoring and goals of care. This systematic collection of data has enabled the service to have a comprehensive overview of what their patient population is, and compare it to other areas within the same service. It also provides a rich source of data for research and audits. Professor Robin Fainsinger and research team has had a consistent theme of research around the Edmonton Classification System for Cancer Pain(6, 7). Currently they are involved in more qualitative research involving dignity therapy (8) being applied to palliative care inpatients. This research was having an immediate effect on patient care as well as providing data for the wider palliative care community.

**Education:**
There is a structured training and education program for doctors who are specialising in palliative care in the Edmonton region. There are protected education sessions for these doctors, twice per week in the first part of their year, followed by the expectation of a research project in the second six months. Each week there is a grand round lecture, video conferenced across all sites. Also weekly is a review, lead by the residency program director, of how each trainee is performing.

**Cross Cancer Institute:**
This is a hospital dedicated to care of patients with cancer. There are only 56 inpatient beds with a consultation liaison service provided by palliative care to both inpatients and in the clinic setting. There is a very comprehensive multidisciplinary clinic, and when patients attend it enable them to be seen by all relevant health personnel at the same visit. It was impressive to see how any member of the team was able to take the initial history, perform
cognition and pain assessments irrespective of their discipline.

**Academic:**
There is an Academic Director of Palliative Care that is responsible for education and research within the Palliative Medicine discipline of the University of Alberta. The education component is supervised by the residency program director (as above).

The research interests are spread across the service and include clinical research, basic science research around cachexia, and health economics. The doctors all have different employment conditions, but usually they include protected time for academic work – consisting of either education or research.

Professor Vickie Baracos is the Professor of Palliative Care Medicine, Department of Oncology, University of Alberta. She comes from a basic science background and is a world leader in cancer cachexia research. She has a strong belief in the importance of doctor/basic scientist collaboration, including benefits of different ideas, perspectives on questions, faster turnaround of outcomes, and the use of more methodologies. I was particularly interested in her comparison of how basic science researcher are trained. There are often different approaches to research training amongst basic science research careers and medical staff. In a basic science research career there is a very structured approach to learning about research. Early projects are very structured and ready to go for junior staff, with little choice about what areas to work on, and as the career progresses there is more of a collaborative input. This can be in contrast to clinical staff, who may have little training during their undergraduate days and then postgraduate days are required to complete a research project.

The Covenant Health Palliative Institute was established to enhance patient care and research in palliative care. Dr Konrad Fassbender is the scientific director, and is recognised as a world leader in the economic evaluation of palliative care services. The institute has developed a particular focus on research and implementation of advance care planning in the Alberta province of Canada. Dr Fassbender has been very successful in obtaining grant and other program funding, and crystallised for me what is needed to help obtain health services funding. He emphasised the need for triple aims – improved outcomes, increased satisfaction, and lower costs.

**University of Alberta/Royal Alexandra Hospital**

At both these hospitals, palliative care provides a multidisciplinary inpatient consultation liaison service. A really interesting innovation at the Royal Alexandra Hospital is the use of what are designated “Comfort Care beds” or “C” beds. These are for people at the end of life, and are staffed by trained, and dedicated nursing staff. The length of stay is usually only 1 to 2 days, and the care is maintained by the treating team, with input from palliative care.

**Community**

The community palliative care service operates as a consultative model. It is staffed by Palliative Medicine specialists, and nurses. Some of the nurses work in the rural areas
outside of Edmonton, and a nurse practitioner works within the community team, alongside the doctors. Referrals only come form family physicians (general practitioners). The patients are usually seen only once, and advice given for ongoing care by the family physician and community nursing team. If patients can’t swallow then medications are given by intermittent subcutaneous injections by the family, and sometimes if needed regularly it is up to the family to give these every 4 hours around the clock. This was an interesting cultural/service difference, as in Australia there is widespread use of devices (subcutaneous infusers) that provide an infusion of medication over 24 hours, with extra subcutaneous medications either given by nursing services or family members.

**Hospice**

There are five hospice facilities and approximately 90 beds in the Edmonton area.

Hospices are inpatient facilities for palliative care patients who can’t be cared for at home, and don’t need acute care in hospital. Care is provided by the family physician and nursing and allied health staff. Once a week a Palliative Medicine Specialist form the community part of the EZPCP attends a multidisciplinary team meeting. Whilst I was in Edmonton, I attended a meeting at one of the hospices for a discussion about Medical Assistance in Dying (MAID). Most of the hospices, the community service of the EZPCP and the TPCU is run by Covenant Health or other catholic organisations and they all have not agreed to participate in MAID. However some hospices run by the provincial health service are grappling with how to approach MAID within a palliative care hospice environment.

7.1 Lessons Learned from Edmonton:

1. Imbedding data collection (that could be used for research/audit) within clinical practice
2. Collaboration with basic scientists and health economists. The exposure to these different disciplines seemed very advantageous, especially to training doctors.
3. Benefit of having structured research projects available for training doctors
4. Developing a culture of research with clinician researchers from different disciplines – in Edmonton the clinical psychologist on the TPCU also had a strong interest in particularly qualitative research
5. Protected non clinical time for developing research ideas.
6. The benefit of research being driven by clinical practice, as well as the different methodology that may be used to answer a clinical question.
8. CONCLUSIONS AND RECOMMENDATIONS

8.1 Conclusions

Palliative care research is a challenging and rewarding area of work. It provides the opportunity to improve care for patients and families at a very difficult time in their lives. Research must remain focussed on these patients and families.

There were some common themes from the people and places I encountered on this fellowship:

1. Leadership – the importance of having a short and long term strategy, that starts with funding, involves supporting and developing researchers, and ends with publishing and disseminating the results. There is a need to involve the whole team, and ensure everyone feels they have input and ownership over direction.
2. Collaboration – within and outside palliative care field. It is important to have local and international collaborations. It is valuable to link with academics and others who are skilled at writing journal articles, project grants, and completing collaborative tasks.
3. Patience and perseverance – research in this field is challenging, but rewarding. Continuing to work in clinical practice enables focus on clinical problems, as well as the ability to directly implement research findings into improving patient and family care.

8.2 Recommendations

1. Support for research via dedicated, protected time within staff job descriptions.
2. Providing ‘academic’ registrar positions to enable motivated palliative medicine trainees to develop into clinician researchers.
3. Development of links outside palliative medicine research fields – eg. with basic science researchers, sociologists, health economists.
4. Identification of academic mentors within Australia who can act as a reference and resource for clinicians interested in research.
9. REFERENCES


