The Winston Churchill Memorial Trust of Australia

Report by

Professor Kate White – 2011 Churchill Fellow

Improving Sexual Function and Sexuality Outcomes in Cancer Survivors: Addressing the unmet needs of cancer survivors

I understand that the Churchill Trust may publish this Report, either in hard copy or on the Internet or both, and consent to such publication.

I indemnify the Churchill Trust against any loss, costs or damages it may suffer arising out of any claim or proceedings made against the Trust in respect of or arising out of the publication of any Report submitted to the Trust and which the Trust places on a website for access over the internet.

I also warrant that my Final report is the original and does not infringe the copyright of any person, or contain anything which is, or the incorporation of which into the Final Report is, actionable for defamation, a breach of any privacy law or obligation, breach of confidence, contempt of court, passing-off or contravention of any other private right or of any law.

Signed: ___________________  Dated: ______________
Table of Contents

Introduction .................................................................................................................... 4
Acknowledgements.......................................................................................................... 4

Executive Summary........................................................................................................ 5
Objectives of Scholarship ............................................................................................... 5
Key Highlights from the Fellowship ................................................................................ 5
Recommendations ............................................................................................................ 5
Dissemination and Implementation.................................................................................. 6

Fellowship Program ....................................................................................................... 7

Background ..................................................................................................................... 9
Sexual Concerns and Dysfunction Following Cancer ....................................................... 9
Barriers to Addressing Sexual Concerns with Cancer Survivors ...................................... 10
Nurse instigated psychosexual care ................................................................................. 10

Royal Marsden Hospital ................................................................................................. 12
Clinical and policy context .............................................................................................. 12
Addressing Sexual Dysfunction RMH ........................................................................... 13
The Psychosexual Clinic: Overview ................................................................................. 13
Policies and Processes of the Clinic ................................................................................. 14
  Referral Pathway to the Clinic: ............................................................................... 14
  Criteria For Referral ................................................................................................. 14
  Confidentiality, Privacy, Communication with Other Members of the Health Care Team
  ................................................................................................................................. 14
  Assessment and Screening Tools.............................................................................. 14
  Interventions ............................................................................................................ 14
Observations ................................................................................................................... 14
Key reflections from clinic observations:......................................................................... 15
Other Sexual Dysfunction Services................................................................................ 16
  Erectile Dysfunction (ED) Clinic: ........................................................................... 16
  Pelvic Radiation Disease - Cancer Late Effects Clinic .............................................. 17
  Survivorship Clinic Post Bone Marrow Transplant.................................................. 17
Nurse led care and expanded nursing roles in UK .......................................................... 18
  Nurse led services .................................................................................................. 19
  Reflections .............................................................................................................. 19
Approaches to improving cancer care delivery in the United Kingdom

External Drivers for Change

National benchmarks

Clinical Audit and Impact of Clinical Care

Rapid Access Clinics

Open Access Follow-up

Effective electronic medical record system

Kings College London

Multidisciplinary Care in Cancer

Survivorship Care

Professor Alex Molassiotis Manchester University

Professor Danny Kelly Cardiff University

CONCLUSIONS

Transferability of the RMH Model to the Australian Context

Potential Model for Australia

Recommendations
Introduction

Advances in cancer care have led to significant improvements in survival rates with more than 60% of Australian cancer patients surviving more than five years. Many individuals are left with physical and psychological needs that affect general health and well-being. These include fear of recurrence and uncertainty about the future; ongoing treatment effects including fatigue, infertility and loss of sexual function; and financial hardship. Although it is widely recognised that cancer treatments have a negative effect on sexuality and sexual function for cancer patients and partners, significantly affecting their quality of life, research and interventions in this area are limited. Studies on cancer survivors continue to identify significant information gaps and absent or limited support in this aspect of their recovery. Consequently, for the growing number of cancer survivors this remains a major neglected area of care.

The first nurse-led clinic for sexual dysfunction in cancer patients has been established at the Royal Marsden Hospital (UK). The aim of this fellowship was to examine the role of the specialist clinics, screening, interventions delivered for sexual dysfunction in cancer patients, & establish a research partnership in this area.

The second aspect of this fellowship was to examine nurse led models of care in cancer, including nurse practitioners. The overarching aim to establish the feasibility of adapting the nurse led model of care for implementation in Australian context, and establish a research partnership that tests new strategies for specific issues relating to sexual dysfunction in cancer survivors and their partners.

Acknowledgements

It has been an honour to be a recipient of the Winston Churchill Fellowship in 2012, and a highlight of my professional career. I would like to express my sincere gratitude to the Trust for the opportunity the fellowship afforded me, and to all the panel members who give generously of their time. The fellowship provided an opportunity to explore and build links with international peers, and to examine a neglected area of cancer care for implementation in Australia. It also introduced me to the broader Fellowship community, Australians from very different backgrounds, all with a passion for Australia and ongoing development.

I would like to thank Dr Isobel White for her enormous generosity in sharing her time, skills and knowledge with me, Professor Shelley Dolan and Dr Theresa Wiseman for the warm welcome to the Royal Marsden Hospital, and the staff I spent time with at the Royal Marsden Hospital who gave time within their busy clinical days to share their experiences. Similarly I thank Professor Emma Ream and all the staff at Kings College and Professor Alex Molasotisis from Manchester University, for their warm welcome and opportunity to share research and clinical experiences.

I would also like to sincerely thank my husband for his continued support and encouragement, for keeping the family on track, allowing me to travel worry free.
Executive Summary
Professor Kathryn White (Kate) (PhD, MN, Onc Cert, Pall Care Cert)
Chair Cancer Nursing, Sydney Cancer Centre, University of Sydney
Royal Prince Alfred Hospital, Missenden Road,
Camperdown, 2050   PH: 02 95156327

Objectives of Scholarship
The objectives of the Churchill Fellowship were to:

1. examine the role of the specialist clinics, screening, interventions delivered for sexual dysfunction in cancer patients, and establish a research partnership in this area;
2. examine nurse led models of care in cancer, including nurse practitioners;
3. examine the feasibility of adapting the nurse led model of care for implementation in Australian context, and
4. establish a research partnership that tests new strategies for specific issues relating to sexual dysfunction in cancer survivors and their partners.

Key Highlights from the Fellowship
- Observation of psychosexual counseling sessions, which provided clarification of role and role limitations.
- Opportunity to work with an experienced psychosexual therapist in cancer care.
- Opportunity to participate in debate about current practices in the management of sexual dysfunction.
- The Pelvic Radiotherapy and Late Effects Clinic and knowledge I gained from this clinical setting.

Recommendations
1. The impact of cancer treatments on sexual function requires a strategic focus by national cancer organisations to raise awareness and support the implementation of approaches to address these concerns.
2. Health professionals working in cancer need to be appropriately skilled to provide information on sexual impact, sexual assessment and have knowledge on appropriate interventions.
3. To address current gap in knowledge and skills, short education programs be developed for members of the cancer treatment team. The aim would be to raise awareness, address myths and misconceptions, and provide guidance on simple interventions. Communication skills would be an integral component.
4. That a framework for addressing sexual concerns in the cancer setting be developed that would provide guidance for cancer centres to establish assessment, information and referral pathways.
5. There is a role for cancer nurses to become more skilled in this area, and to play an active role in developing services and establishing the framework in consultation with all members of the multidisciplinary team.
**Dissemination and Implementation**

1. Report submitted to University of Sydney
2. Report submitted to Area Director and Senior Clinical Nurse Manager Cancer Services Sydney Local health District.
3. Report Submitted to the Chief Cancer Director, CINSW
4. Proposal for development of short education programs for cancer health professionals on sexual dysfunction and management in development.
5. Proposal to establish pilot study to test a model for implementing triage model is in development.
6. Following the fellowship, I have developed a research project with Dr White, that will investigate the role of culture in addressing sexual function concerns. This will be submitted for funding in September.
7. Series of presentations of outcomes from fellowship to clinical cancer settings within metropolitan Sydney is scheduled throughout late 2012.
Fellowship Program

The principle aim of the fellowship was to examine approaches to improve sexual outcomes for cancer patients, and specifically the role of nurse led specialist services. Therefore a significant proportion of my time was programmed to be at the Royal Marsden Hospital and within the clinics. A varied experience was provided, and opportunity to explore models of nurse led care across a range of clinical settings, age groups and stages of the cancer journey, at both clinical sites. Approaches to clinical assessment and service evaluation were also incorporated into the formal program.

An invitation to meet with colleagues in Switzerland to further examine this area was taken up at completion of the fellowship program.

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>14th – 18th May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>21st May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>22nd May 2012</td>
<td>Royal Marsden Hospital Sutton</td>
</tr>
<tr>
<td>23rd May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>24th May 2012</td>
<td>Kings College London</td>
</tr>
<tr>
<td>25th May 2012</td>
<td>Royal Marsden Hospital Sutton</td>
</tr>
<tr>
<td>28th May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>29th May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>30th May 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>31st May 2012</td>
<td>Kings College London</td>
</tr>
<tr>
<td>1st June 2012</td>
<td>Royal Marsden Hospital Sutton</td>
</tr>
<tr>
<td>2nd – 3rd June 2012</td>
<td>Professor Alex Molastiosis Manchester University</td>
</tr>
<tr>
<td>4-5th June 2012</td>
<td>Queens Jubilee Public Holiday</td>
</tr>
<tr>
<td>6th June 2012</td>
<td>Royal Marsden Hospital Chelsea</td>
</tr>
<tr>
<td>7th June 2012</td>
<td>Kings College London</td>
</tr>
<tr>
<td>8th June 2012</td>
<td>Royal Marsden Hospital Sutton</td>
</tr>
<tr>
<td>10th – 12th June 2012</td>
<td>Frieberg University Switzerland</td>
</tr>
</tbody>
</table>

Clinic Attendance
Psychosexual Clinic                Dr Isobel White
Urology Clinic                      Urology Team
ED Clinic                            Amanda Baxter CNS
Pelvic Radiation Disease Clinic      Dr Jervoise Andreyev
Head and Neck Clinics               Sutton and Chelsea Campus
Bone Marrow Transplantation Late Effects Clinic                          Dr Bronwen Shaw
Adolescents and Young Adults Unit                                      Sutton
Palliative care clinic AYA                                             Sutton

Meetings:

Advanced Nurse Practitioners:
- Jon Knox                        Plastic and Reconstructive Surgery
- Jorn Rixen-Osterbro            Head and Neck Unit
- Louise Soanes                   AYA
- Anne McLoughlin                 Open Access Breast Nurse
- Natalie Doyle                  Living with and Beyond Cancer
- Ann Muls                       Cancer Late effects

Senior Clinical Staff:
- Nicola Tinne                   Head and Neck
- Andreia Fernandes              Gyaneoncology
- Maria Crisford                 Colorectal
- Amanda Baxter                  ED CNS
- Sonja Hoy                      Thyroid/Head and neck
- Jervoise Andreyev              Bowel dysfunction after treatment

Education Team
Chief Nurse: Professor Shelley Dolan

Researchers:
Professor Alex Molassiotis                                         Manchester University
Professor Danny Kelly                                                 Cardiff University
Professor Emma Ream                                                   Professor of Supportive Care Kings College
Vicki Tsianakas                                                        Research Fellow Kings College
Dr Theresa Wiseman                                                     Strategic Lead Health Service Research RMH
Rebecca Verity                                                         NIHR Doctoral Research Fellow Kings College
Cath Taylor                                                            Research Fellow MDT in Cancer Kings College
Sylvia Tan                                                            Director Clinical Audit Royal Marsden Hospital

Invited presentations:
Royal Marsden Hospital Research Forum                                Cancer Nursing Research in Australia
Kings College London                                                   Research down under
Background
The 2008 Australian Institute of Health and Welfare Report on Cancer Survivors identified over 655,000 Australians who had been diagnosed with cancer in the previous 23 years and were alive at end of 2004. The number of cancer survivors continues to grow, with increasing five year survival rates reported over the past decade. This is in part due to improved screening leading to early diagnosis, and new and improved treatments for cancer. Even when cure may not be achieved, cancer can be managed as a chronic illness, with individuals living with their illness and continuing to maintain their day to day lives.

As the number of cancer survivors grow, so does our understanding of the medium and long term consequences of cancer and its treatment for the individual and their family. Few cancer survivors are left untouched by the experience, and many live with complex, debilitating side effects from the multi-modal therapies or disease-related problems. These can include, but are not limited to, fatigue, pain, lymphoedema, bowel dysfunction, and sexual concerns or dysfunction.

Sexual Concerns and Dysfunction Following Cancer
The impact of cancer treatments on sexuality and sexual function can vary between individuals. In addition to the physiological and anatomical changes that may occur with cancer treatment, co-morbidities, psychosocial concerns can also contribute to problems in this area. While widely recognised that any cancer treatment can negatively impact sexual function, the majority of research has focused in individuals where the cancer has an impact on areas involved in sexual functioning. Recent surveys by NSW Health identified information of the impact of cancer on sexual function a high area of unmet need in the NSW Cancer Patient Survey.

Cancer related sexual dysfunction can result from the direct effects of surgery, radiation therapy, chemotherapy, hormone therapy, changes in serum levels of testosterone, lowered physical functionality and an increase in symptoms of depression or anxiety. Studies have highlighted the range of problems and concerns include poor self-image, loss of libido, delay in arousal, erectile dysfunction, consequences of premature menopause to name but a few.

Research suggests that 20-90% of women treated for gynaecological cancer experience significant sexual difficulties, 30% of women with gynaecological cancers will experience sexual dysfunction, with 50 per cent experiencing dyspareunia (painful sex), and only 50 per cent of women remain sexually active after treatment. Treatment for gynaecological cancer typically involves a combination of surgery, radiotherapy, chemotherapy and hormonal therapy. These invasive and often aggressive treatments are associated with significant side effects and long-term sequelae, including effects on body image, sexuality, sexual function, menopause status and fertility.

Similar negative sexual function outcomes are reported in males treated for prostate cancer, between 60-90% report sexual dysfunction post radical prostatectomy, and up to 85% following radiotherapy. Despite the number of studies that have reported sexual function outcomes post treatment in these core three groups of survivors (prostate, breast and
very few studies have invested interventions to ameliorate the impact.

A recent Cochrane Review found only 11 RCT of interventions to address sexual dysfunction in cancer survivors. Ten of the eleven were on male survivors only, and overall quality of the trials was considered poor by the reviewers. Clearly there is a significant gap in the research and knowledge in relation to managing the impact of cancer treatments on sexual function. However for many individuals tailored information, delivered at the appropriate time could assist to reduce the severity of the sexual dysfunction, and improve quality of life in this area.

**Barriers to Addressing Sexual Concerns with Cancer Survivors**

There are a number of barriers to assessment and management of sexual dysfunction following cancer. A major barrier to the identification of psychosexual issues is the reluctance of patients to raise their concerns, combined with a reluctance of health professionals to discuss the issue with their patients. In a survey of Gynaecologic Oncologists, Wiggens and colleagues (2007) found that less than 50% routinely took a sexual history, and 80% of respondents did not address this topic at follow up. Horden and Street (2007) found different perspectives among cancer patients and health care professionals, in the type of communication that was desired, highlighting the role these divergent perspectives had on reducing access to effective psychosexual support. A number of small studies have highlighted a lack of clarity within the multidisciplinary team regarding who had responsibility for addressing this concern, fear of embarrassment, and not feeling confident with the topic area as compounding the invisibility of this issue in cancer setting.

Arming health professionals at all levels with appropriate skills and tools to open discussion of sexuality and relationships with patients would mark an important step in improving support for cancer patients and their partners. More recent small studies have identified that tailored information and symptom management can lead to significant improvements in individual’s sexual function, reduce the negative consequences of treatment and improve overall quality of life for individual’s following treatment.

In developing the fellowship program, three factors have been central:

1. Identifying appropriate interventions to address sexual dysfunction and concerns experienced by cancer survivors;
2. Reviewing and identifying sustainable service delivery approaches to facilitate sexual function concerns be addressed in a timely manner within cancer services;
3. Developing a tiered curriculum to support the cancer multidisciplinary team (MDT) to develop strategies and process for managing sexual dysfunction within their clinical setting.

**Nurse instigated psychosexual care**
As highlighted earlier, there exists a lack of clarity of ownership amongst MDT for addressing sexual function concerns. Cancer nurses are the ideal clinicians to address these needs due to their breadth of knowledge of cancer treatment and its side effects, good communication skills (as required by the nature of their role) and skills and experience in intimate care and discussing and providing information about sensitive topics. Furthermore, nurse-led clinics in other aspects of cancer care have been shown to be cost-effective methods for improving clinical and quality of life outcomes for cancer patients. Thus, establishing a nurse-led clinic for sexual concerns in cancer patients has the potential to meet the needs and improve the quality of life of cancer survivors and their partners.

A review of the effectiveness and cost effectiveness of nurse-led versus conventional physician-led follow-up for patients with cancer confirmed the safety and feasibility of nurse-led care, with no statistically significant differences found on any of the core outcomes of survival, recurrence or psychological morbidity when compared with standard medical follow up. Descriptive studies reporting on nurse-led care indicate that:

- Nurse-led clinics demonstrate greater patient satisfaction with the care provided, and that nurse-led interventions are effective in managing treatment related side effects
- Nurse-led clinics result in a reduction in patient levels of stress and anxiety compared with patients who receive traditional medical follow-up
- Nurse-led clinics demonstrate positive clinical outcomes in relation to symptom management

While this model is still evolving and further research is required, the gap in current services and evidence of unmet need among cancer survivors, supports further investigation of the potential for nurse led psychosexual service is needed.
The Royal Marsden Hospital (RMH) is an internationally renowned centre of excellence in cancer care and research. Established in 1851, the RMH provides specialist cancer services at two locations in greater London area; Chelsea and Sutton. The RMH partners with the Institute of Cancer Research (ICR), with research formally imbedded within all aspects of cancer treatment.

The hospitals provide specialist cancer services to the local area, and are a major tertiary cancer referral centre for specialised cancer services, rare cancers, access to Phase 1 and 2 clinical trials and patients from outside of the UK. Paediatric, and Adolescent and Young Adults (AYA) services are located at the Sutton Site. In line with trends in cancer care in developed countries, the majority of cancer treatments are delivered on an outpatient basis. The average length of stay for surgical patients is declining, however remain considerably longer then equivalent surgeries in Australia.

The RMH has been an international leader in many areas of cancer research and care, including the integration of psychological supportive care services, establishing rehabilitation services, and integrating complementary therapies into cancer care. The RMH education centre in conjunction with academic partners offers number of cancer specific postgraduate programs for nurses, research opportunities through Honours and Masters Nursing Science degrees, and continuing education programs.

Clinical and policy context

In 2010 the National Cancer Survivorship Initiative was established in response to a rapidly growing recognition of significant gaps in the care for cancer survivors. This was one element of Cancer Reform Strategy established in 2007 to address variable outcomes in cancer care and survival in the UK.

A major focus of the National Cancer Survivorship Initiative, co-led by the Health Department and Macmillan Cancer Support Services, was to stimulate research and build an
evidence base for interventions and models of delivery to meet the needs of cancer survivors. This has stimulated a large program of work in survivorship care, with an emphasis on a triaged model, incorporating self-managed care, primary health care and specialist services.

**Addressing Sexual Dysfunction RMH**

The evolution of specialist services for sexual dysfunction at RMH has occurred over time, largely led by individual clinicians, until the recent focus on cancer survivorship. The establishment of the psychosexual clinic was in response to the RMH Patient and Carers Advisory Group feedback regarding high unmet need and lack of services in this area. Recognition of the benefit in developing a broader strategic approach to addressing sexual dysfunction among men and women, and the need for comprehensive service the Psychosexual Clinic was established, with Dr Isobel White, a psychosexual therapist and experienced cancer nurse appointed.

Formal assessment and focus on sexual dysfunction is undertaken within several clinical settings; Urology Clinic (all team members), Gynaeoncology Clinic (CNS); Pelvic Radiotherapy Clinic (all team members).

Specialist services are provided through the Erectile Dysfunction Clinic (CNS led); and the Psychosexual Clinic. Both clinics are heavily booked, with waiting period for the ED clinic extending to several months. Referral to expertise in managing areas such as menopause symptoms, fertility concerns is primarily on an individual basis.

With the establishment of the psychosexual clinic, the expertise of Dr White, the RMH is establishing a strategic direction for the management of sexual dysfunction services at RMH. To date this has been focused on:

1. Developing guidance of assessment and management of ED, including multidisciplinary review of evidence. A key aim is to establish standardised baseline interventions for men.
2. Assessment and management of menopause following cancer

**The Psychosexual Clinic: Overview**

The psychosexual clinic was established in 2010 and based at both Chelsea and Sutton sites. The clinic runs one day a week, with some flexibility around follow up appointments for individuals whose work commitments can make attendance difficult. On occasion follow up sessions have been undertaken over the phone, for individuals who are outside of London and are unable to travel. The clinic is staffed by an experienced sexual therapist and cancer nurse, who is an active researcher in this area, Dr Isobel White. The clinic is funded currently by the RMH, and patients access these at no charge.

At the time of my visit, a significant number of individuals referred were greater than five years since diagnosis, and had experienced considerable frustration in accessing support and guidance.
Policies and Processes of the Clinic

Referral Pathway to the Clinic:
Any member of medical, nursing or allied health staff at RMH can refer a patient to the service. The majority of referrals to date have come from senior medical and nursing clinicians. Cancer survivors are able to self-refer, and have done so. Primary health care practitioners can refer patients who have been treated at RMH previously also.

Criteria For Referral
The criteria for referral to the clinic include any sexual concern or dysfunction post cancer treatment. There is no time limit applied for when the cancer was treated. Both individual and couple therapy is provided. However as the prime focus is the cancer patient, partners are included if the cancer survivors agrees.

Confidentiality, Privacy, Communication with Other Members of the Health Care Team
An individual’s right to privacy and confidentiality is critical in addressing sensitive areas such as sexual function, intimacy and relationships. All patient care as RMH is documented in a highly effective electronic medical record (EMR) system, however any member of the treating team can access these records. In line with other confidential or sensitive areas such as the Counselling and Psycho-oncology Service, any documentation of clinic attendance is held separately to other medical records to ensure confidentiality. No notation of the reason for attending clinic, outcomes, or follow up visits are included in the EMR.

Any correspondence arising from the clinic to GPs, specialists and other members of the health care team are shown to the patient in advance to ensure they agree to the specific personal details being included.

The steps to ensure confidentiality and privacy are explained by the therapist at the commencement of the first consultation. Reasons where the therapist may be required by law to breach confidentiality are also clarified.

Assessment and Screening Tools
In addition to the detail clinical and sexual history, sexual function tools are used to guide discussion and as a baseline to assess change over time. Tools selected are determined by the nature of physical problems, gender and consistency within the RMH.

Interventions
Interventions to address areas of concern include counselling based therapies (couple therapy, sensate therapy), provision of tailored information including practical recommendations (interventions for erectile dysfunction), referral to specialist services if required (fertility specialist), testosterone and menopause therapy. As the causes of sexual dysfunction post cancer can be multifactorial, and multidisciplinary approach to addressing this is critical. Given the complex nature of the problems cancer survivors can experience, and multifactorial aspects, it was noted that it may take several visit before all of the concerns are disclosed. Similarly some individuals will only attend on one occasion, having obtained the information or support required.

Attendance is limited to 10 sessions, with option of additional 5. The number of sessions vary among individuals. Patients are discharged from the service when therapy has been completed.

Observations
I was able to observe individual and couple sessions on each clinic day. While there was hesitancy on our part regarding approaching patients to seek permission for me to observe, and great care was taken to emphasise the right of refusal, only one person declined
permission. The speed at which I became invisible in the room, and the focus remaining between Isobel and the individual/couple was in some ways a reflection of the path these individuals had taken to get to this point in the cancer experience. It was also a reflection of the skills of therapist. I am indebted to these cancer survivors for the generosity.

It is not pertinent to the purpose of this report to provide detailed description of the clinical interventions provided. The opportunity to share experiences of different approaches and interventions to support patients return to sexual function was extremely useful. While the interventions of themselves do not differ greatly, the commitment to providing a service and building an evidence base to guide practice, and grow our knowledge in this area was.

Key reflections from clinic observations:

- For nearly all of the individuals/couples accessing the support for this aspect of their recovery had been arduous and frustrating. It was of note that many commented – “you are our last hope”.
- A significant number of those seen were greater than five years since treatment completion. It is known the duration of sexual dysfunction can impact on the degree of recovery that is able to be achieved. It also reflects barriers that exist for patients in accessing support in this area.
- The importance of establishing both individual/partner goals, and assisting is setting realistic goals for the therapeutic interventions was evident.
- The opportunity to be able to talk about their concerns, the impact on their lives and relationships was of itself therapeutic. To feel heard, have their concerns validated and not dismissed was a clearly valued experience.
- A common theme expressed by those attending the clinic was that they recognised they should be grateful to be alive, and not let the loss of the sexual aspect of their lives concern them, but it did.
- Difficulties in maintaining sexual function post cancer were compounded by complicated chronic conditions that develop as a consequence of treatment. This was particularly evident in patients who had received pelvic/rectal radiotherapy.
- Early intervention would have made a substantial difference to these individual’s quality of life.
- I was struck by the depth of support that was provided by partners. However, these partners identified feeling helpless in knowing how to best help the cancer survivor and were actively seeking guidance.

There was clear benefit described by cancer survivors, partners and health care professionals in the breadth of expertise and skill Dr White brings to the clinic, combining cancer specific knowledge as well as being an experienced psychosexual therapist. Dr White is a bridge between these two often disparate clinical environments, in some ways a unique situation. For the medical staff there was a sense of relief in having someone they could refer patients to, and address an area they felt neither skilled nor comfortable in. The third aspect however, was her background in and commitment to research. There remain substantive gaps in the evidence on approaches to reduce the impact/improve psychosexual outcomes for cancer survivors, and the need to develop and test interventions. A strength of this clinic is that it is positioned within a cancer clinical setting with a strong focus on research, that is integrated all clinical areas.
As outlined earlier, Dr White is working with colleagues to establish clinical guidance for management of sexual dysfunction, with the aim to standardised assessment and care, to enable better evaluation of the different treatment modalities.

Other Sexual Dysfunction Services

**Erectile Dysfunction (ED) Clinic:**

The ED clinic was run by the Urology clinical nurse specialist, and was schedule parallel to the urology clinic. The ED clinic provided expert assessment of erectile dysfunction concerns, information and management, and supported trial of interventions. Specialists from the penile pump companies attend each clinic, and were available to provide education to patients on the products they were trialing. Interventions primarily included use of oral medication, pumps, and intra-penile injections.

Assessment is a critical element, and the ED and Urology clinic used a patient self-reported assessment tool on ED, in conjunction with other quality of life surveys. This is completed by patients on each occasion prior to seeing the CNS, and used to guide the consultation. The CNS was skilled in discussing all aspects of erectile dysfunction with sensitivity and reducing the patient’s embarrassment.

The advent of pharmaceutical intervention has led to some improvements in sexual outcomes for men following cancer treatment, with the use of external pumps declining. It was rare patients went on to have permanent internal prosthesis. Despite this a number of men do not experience a benefit from any of the treatments. It was apparent that this had a significant emotional impact for these men.

The CNS has access to the full urological team if patient requires medical review. While the ED clinic had been running for some time, and was integrated into the outpatient clinic setting, this was not always appropriate for male patients. Initial testing of intra-penile injections must be carried out in the clinical environment. Following injection, and education of the patient in how to do this, the patient needs to wait a period of up to 30 minutes to assess response (developing erection) and if dosage needs to be altered. Accessing private space for the men to learn technique and then wait for both response, and return to normal was a significant challenge in the limited clinic space. The demand for clinical rooms, running along-side the urology clinic, was constant, and this was a major limiting factor in the number of men able to be seen in the ED clinic, contributing to the long waiting list for appointments. The space pressures also impacted on the time the CNS had with the men to provide support.

Clinical debate: As with other areas in the management of prostate cancer, there was extensive discussion and debate regarding the use of robotic surgical techniques and the reported reduce impact on sexual function within the clinic and team meetings. Of note a significant number of men seen during the fellowship had had robotic surgery, and had significant impact on sexual function, which did not respond to any of the interventions. In some cases these men had opted to travel, or paid privately for surgery on the basis of recommendations that they had a higher chance of maintaining sexual function. The men reported frustrated and anger as from their perspective they had been given false hope and reassurances.

The second area of debate and much discussion was the role of penile training to prevent or reduce the impact on erectile function post treatment. Studies are being undertaken in the
USA using PDS pre-operatively and postoperatively to stimulate nerve pathways. There were mixed views regarding the potential benefits expressed by the team.

**Pelvic Radiation Disease - Cancer Late Effects Clinic**

This clinic is unique within the cancer setting, as it primarily focuses on the long term consequences of pelvic radiotherapy on the bowel. Led by Dr Jervoise Andreyev, a gastroenterologist, the multidisciplinary team includes Clinical Nurse Consultant, Dieticians, Physiotherapist and Researchers. The longterm impact of radiation and chemotherapeutic treatments to the gut is substantive. Many patients will experience lifelong bowel dysfunction that impacts every aspect of their daily life. Research led by this team has highlighted that the underlying causes of these symptoms are often amenable to simple interventions, that can significantly reduce and in some cases stop the symptoms. The research team have identified a number of causative factors including pancreatic insufficiency, small bowel bacterial overgrowth, bile salt malabsorption as common problems post pelvic radiotherapy. When appropriate diagnosis and treatment is instigated the symptoms resolve.

It was a significant clinical experience to observe patients who had experienced 15 years of chronic diarrhea have their condition resolved and be able to return to a normal life. Treatments include pharmaceutical approaches, but dietary control is a critical elements. The clinic has 3 dieticians as well as 2 research dieticians. As with other clinics, patients complete a self-report assessment tool prior to their appointment, and this guides the consultation. It is recognised that some of the dietary changes are not easy for patients to make (no alcohol, no sugars), and to assist the team they have all undertaken motivational interviewing training. This has led to better uptake of the treatment recommendations, and help the treating team to work with patients to make the necessary lifestyle changes. This clinic was pertinent to my visit, as many of the patients I met in the psychosexual clinic, I also came across here. For some patients managing the bowel symptoms was a key factor to assisting return of sexual function. There was significant cross referral between this clinic and Dr White’.

**Survivorship Clinic Post Bone Marrow Transplant**

Located at Sutton site, the survivorship clinic was established to provide focus on addressing the range of medium and long term consequences post bone marrow transplant. This clinic is staffed by one Haematologist, who works very closely with other specialist services. As noted earlier there was a close collaboration between this service and the Psychosexual Clinic. Patients who are one year or more post bone marrow transplant can be seen at this clinic. It is held away from the busy haematology clinics, and runs at a slower pace. The focus is on returning to normal life and addressing concerns or barriers. The initial appointment is detailed holistic assessment, includes vitamin and hormone levels, physical function, sexual function. Appropriate referrals are made where required.
Nurse led care and expanded nursing roles in UK

The opportunity to examine advanced practice and nurse led care in cancer was incorporated into the fellowship. I spent time with advanced practice nurses in acute and rehabilitation settings, that were tumour specific, age specific or the role focused on a specific stage of the cancer journey.

**Titles:** It is a little confusing at first to work through the different position titles, and what they represent. **Clinical nurse specialist (CNS)** is a senior clinical nurse, holds a Master degree, or be working towards this. These nurses work in sub-specialty areas and play a significant role in the overall delivering of cancer care, and coordination of this care, for example the Breast Cancer CNS and Urology CNS. **Advanced Nurse Practitioner** is the next senior clinical level, these nurses should already have a Masters of Nursing Science, but do not always. They have completed the prescribers program and to the most part are perceived to be equivalent of a Nurse Practitioner in Australia. The final senior clinical level is **Clinical Nurse Consultant**, who is an advanced practice nurse, able to function autonomously but remains very much a member of the multidisciplinary team.

**Advanced Nurse Practitioner Positions**

The opportunity to meet with and observe a number of the advance nurse practitioners and two CNCs, was afforded to me during my visit. Mostly, these were senior clinical nurses, with a long track record of working in cancer care. Several were establishing new sub-specialty areas as well as a new advanced nurse role. Specialty areas covered included: Adolescent and Young Adults, Head and Neck Cancer, Urology, Reconstruction Surgery, Open access follow up, Rehabilitation and Intravenous Access. Other roles included critical care advanced practice nurse who provides support to ward areas overnight.

There have been a number of drivers in the evolution of these roles.

1. **EU ruling that junior medical staff cannot work over 38 hour week**, reducing shift hours, overtime and oncall for this group. To address the impact this has had within the health system, alternatives were sought. This led to the establishment of the critical care advanced nurse practice on night duty, who provides rapid assessment of any patient of concern, is able to instigate treatments and investigations in response to changes in patients condition. Of note the same work restrictions on number of hours worked does not apply to nurses. Several of those I met were working well over a 38 hour week.

2. **Clinical Challenge:** a common consequence of cancer treatment, is over time it becomes harder for staff to find venous access for intravenous infusions and taking blood. Less experience staff, such as junior medical staff can find this more challenging, and have multiple attempts, leading to increase patient distress and delay in therapy. Following a review an advanced nurse practitioner IV team was established that provides 24 hour coverage. The number of complications including infection rate, have declined since the service was established. In addition, the proportion of patients who experience more than one attempt at canulation has declined significantly.

3. **Change of model of delivering routine follow up post breast cancer.** A component of the National Cancer Survivorship Strategy was to examine the role of routine follow up in cancers with high cure rates. The RMH have pilot tested and established “open
access” follow up for women following treatment for breast cancer. To support this initiative an advanced nurse practitioner was established to support the women and guide implementation.

4. **Areas of Unmet Need:** Similar to Australia, there has been a national recognition of the special needs and gaps in service provision for young people diagnosed with cancer. Often too old for paediatric services, and too young for adult settings, the age group 15-24 has been identified as having unique needs. The establishment of AYA cancer units has been rolled out across the UK, with the new unit recently opened at RMH Sutton. Clinical nurse consultant in AYA position has been established to guide development of clinical nursing practice this area.

5. **Cost saving:** Reduction in health care funding has led to organisation looking for alternative approaches, including less expensive staff, to carry out some of the roles.

6. **Addressing identified gaps in cancer care:** As cancer survivors grow in numbers, the rehabilitation and recovery needs of this group have become better known. The establishment of the rehabilitation role has led to a pro-active approach to optimizing recovery, support return to normal lifestyle and address consequences of cancer treatment.

**Nurse led services**

In addition to advanced nurse practitioner roles, I was able to explore a number of nurse led services and models for delivering cancer care. It should be noted that while this may mean a nurse was running a specialist clinic or service, all of these services remained imbedded within a broader multidisciplinary team. The collaborative working relationship between the different members of the teams where these roles existed was a consistent feature, with clarity around expectations and value of different roles. Of note there was difference between advanced nurse practitioner roles and nurse led delivery of services.

**Reflections**

Unlike the Australian setting, Advanced Nurse Practitioners are not nationally regulated, but determined at a local level. It is a requirement that Advanced Practice Nurses have completed an additional Prescribers Program. While many have completed a Masters of Nursing Science, there is no requirement to have done so. All nurses in the UK are able to prescribe from the nurses’ formulary.

Time was spent with advanced practice/clinical nurse consultants in a number of settings. Few had been in post longer than 12 months, and there was general agreement that these positions were evolving. They all carried a sizable case load, and to the most part patient centred in their focus.

Surprisingly, there was a lack of clarity around the expectations of how this role differed from other clinical roles, and significant variability in nature of activities of the position. Without a clear national approach to regulate the education preparation, expectations, skills and competency of the advanced roles, local factors became the drivers for the position. In the short term this may appear advantageous, however is unlikely to contribute to system wide reforms that benefit patients, or the discipline. This is in no way a reflection of the practice of the individuals I met, or the work they undertook.
Approaches to improving cancer care delivery in the United Kingdom

Outside of the core aims of the fellowship I observed a number of aspects that contributed to an improved delivery of cancer services. I could see how they supported and enable change to occur within a complex health system, increased accountability and transparency and facilitated knowledge translation within the clinical environment. I have included these in the report as they were important learning from the fellowship.

External Drivers for Change

The overarching policy context in relation to cancer service delivery in the UK has been an important factor in development of in cancer survivorship research and practice. As the government has moved to implement increased accountability for care, evidence based benchmarks, agreed targets that must be met they have also provided a framework for this to be undertaken, and resourced the “Trusts” (Local Health Networks) to be able to provide captured and report on key outcomes. There is a strategic national approach to identify where there are gaps in services, areas of unmet need, and how to address these areas. This is then followed up with ongoing review to identify if change has occurred. For example a national audit on access to breast reconstruction following mastectomy identified significant gaps. Recommendations have been widely distributed, and repeat audits have been held on 3 occasions, finding improvements across all sectors, and highlighting areas for development.

National benchmarks

For all cancer services there is set benchmarks that must be met. Failure to meet these impacts on funding to the organization, and each “breach” requires an explanation. These benchmarks have been established from a review by the National Institute of Clinical Excellence (NICE) and are informed by the NICS Guidelines. The selected areas are based on addressing barriers to improving patient outcomes, impact on admissions, increase cost of care. In addition patient surveys are undertaken quarterly using the Picker Survey.

Some examples include:

- Individuals identified by a GP as having a high suspicion of having cancer must be seen within a two week period by a specialist service.
- Discharge letters from acute setting must be completed and sent within 24 hours mid-week, 48 hours if on a Friday.
- Non-attendance at clinic appointments and follow up

Clinical Audit and Impact of Clinical Care

At a local level the drivers for the benchmarking and reporting is high quality data collection and analysis. In addition to the national indicators, each Trust establishing additional clinical indicators for the 12 month period. These are included into the report and publically available. Staff can also identify clinical areas or aspects of care for audit at a local level.
Audits are conducted quarterly, with the annual report required to be publically available. To meet the requirements a substantive unit within all trusts is the Clinical Audit Unit. The units are staffed at a significantly higher level than found in Australia, and are able to produce detailed reports and information on services, patient outcomes, investigate discrepancies in a way that can be fed directly into change or improving clinical care. The unit has extensive input from clinicians and patient consumers.

It was evident that this is a powerful resource to have to implement and guide improvements in patient care.

Rapid Access Clinics

The rapid access clinic was established to provide a one stop, easily identified referral pathway for GPs to refer individuals with suspected cancer. All referred patients are provided with an initial appointment within two weeks of referral. Based on an initial assessment of the referral information, the CNS will commence scheduling investigations and appointments for relevant medical clinics. This service enables quick diagnosis and commencement of treatment, but also provided significant reassurances to individuals and their family. Clinical nurses within the unit are skilled at providing psychological support and facilitate referral to specialist nurses, that will support and follow the patient through their cancer treatment. This led to seamless introduction to what can be a complicated and confusing clinical environment at a time of stress. This service has reduced waiting periods to see a specialist, reduced the time period from suspected cancer to treatment instigation.

Open Access Follow-up

As the incidence of cancer continues to rise, all cancer services are struggling to meet demand and examining ways to improve the service. On area of focus in the UK has been routine follow up post treatment for patients who are well and have highly curative cancers. The RMH has led a project instigating and evaluating a new model of follow up for women post treatment for early breast cancer. Currently women return initially 3 monthly, 6 monthly then annually for follow up. The purpose of this follow up is to screen for recurrent disease. However a number of studies have shown recurrent disease is rarely diagnosed at routine follow up, and that women find the period before the appointment stressful.

The open access clinic is used in place of scheduled follow up appointments. Woman who are identified by the team as appropriate for open access follow up met by the Open Access Advanced Nurse Practitioner on completion of treatment. They are provided with information to support their recovery, educated regarding signs of recurrence and given information on how to access the clinic. No scheduled follow up appointments are made, if women have a concern they can call and will be given an appointment within 5 working days. Routine mammograms are continued for five years and this is managed with their GP.

Effective electronic medical record system

The RMH has an effective electronic medical record system. This is sued by all staff, and additional administrative support is provided in the clinics so any paper documents are
scanned into the patient’s electronic record immediately. Letters back to referring clinicians, general practitioners are dictated onto a digital system and typed within 6 hours.

The EMR was a far more user friendly version than I have experienced locally. Of note much of the information is able to accessed in de-identified grouped categories allowing for interrogation by clinicians and the clinical audit unit. It provided a seamless single point for all information on the patient. The only information not included were details from the psychological counselling and psychosexual clinics.
Kings College London is a leading UK university, with a long tradition of research and education in health care. The School of Nursing leads a large program of cancer research, led by Professor Emma Ream. Below is brief overview of some of the areas explored as potential for collaboration.

**Multidisciplinary Care in Cancer**
As is evident throughout this report multidisciplinary care is critical to the delivery of cancer services. It has been identified that cancer patients who are cared for by a multidisciplinary team (MDT) do better. However, not all teams work well, and it is unclear what are the attributes of well performing MDT. Dr Cath Taylor Senior Research Fellow is leading a large program of work funded by the National Cancer action Team to develop MDT practice.

**Survivorship Care**
The National Cancer Survivorship Initiative has been a major program that is leading to the testing of a number of models for providing survivorship care. Three of these models have incorporated primary health care into the model. The team at King’s have a suite of studies underway in this space, and there are opportunities for collaboration.

**Professor Alex Molassiotis Manchester University**
The schedule visit to Manchester University to meet with Professor Alex Molassiotis occurred in London due to Professor Alex Molassiotis’ altered travel plans. Professor Molassiotis has led a number of projects looking at nurse led models of cancer care. In meeting with Alex the focus was primarily around the research and evaluation of these roles, instruments and nurse sensitive outcomes. Professor Molassiotis has recently accepted a post as Dean Hong Kong University, and will be visiting Australia. This opens up further opportunities for collaboration.

**Professor Danny Kelly Cardiff University**
Professor Kelly is a recipient of UK Churchill Fellowship who will be spending three months with me in 2013 to investigate approaches to provide support to young adults with cancer. Professor Kelly travel to London and we used this opportunity to plan for his visit in 2013.
CONCLUSIONS

Transferability of the RMH Model to the Australian Context
There is a need among Australian cancer survivors to be able to access services that assist them in managing sexual dysfunction following treatment for cancer. To date, available services focus on a single aspect of sexual dysfunction; for example erectile dysfunction or menopause after cancer. Access to these services is often opportunistic, and not integrated into standard cancer care pathways.

The cancer centre based clinic model has a number of strengths; including building clinical expertise, establishing clear referral pathways, integrating research into sexual function into cancer centres, early access to the service to name a few. There are limitations to this model. Evident among a number of staff, was the perspective that they had “handed over” responsibility for this aspect of patient care to the “expert”. This is counter to the aims of increasing the skills of all members of the cancer team in raising and addressing sexual function concerns.

To adopt this model broadly within Australian cancer centres is not feasible for a number of reasons. Having appropriate skilled and qualified psychosexual therapists to fill positions, obtaining funding, meeting needs of regional and rural Australia are significant challenges to overcome in the short to medium term. In addition, this model remains acute cancer setting focused, and to date there has been review of the potential role of primary health care. However there are a number of aspects that could be readily adapted and implemented within the Australian cancer setting.

Potential Model for Australia
It is apparent from the research, clinical experience and observations during the fellowship that there is variability across individual and patient groups in the degree to which they experience sexual dysfunction, or have concerns about this aspect of their life. All cancer patients need to be informed about the potential impact on sexual function, however not all patients will need or wish to see a psychosexual therapists. As there are different levels of needs, there can be different levels of service. This would require integration of a triaged model into existing cancer services, incorporating assessment for all individuals and triaging cancer survivors as appropriate/preferred to relevant services. Underlying this model is the recognition that all members of the health care team have a responsibility to inform cancer patients regarding consequences of cancer treatments on sexual function. Therefore, all members of the cancer team need skills in communication. Within this model all patients were be assessed by the cancer team, those who require more specialised expertise would be referred following an established referral pathway.

Key Principles:
1. That sexual function and sexual health is a core component of an individual’ quality of life.
2. All cancer patients should be informed of the potential impact of cancer treatment on sexual function, and given the opportunity to discuss their concerns.
3. Patients should have timely access to tailored information on how to reduce the impact of treatment on sexual function.
4. Patients should be provided with information on how to access additional resources in this area if required.
5. Cancer clinicians should explored the impact of treatment on sexual function at follow up.
6. All health professionals have a responsibility to assess the impact of treatments on sexual function and to develop interpersonal skills to undertake this in a sensitive manner.

**Figure 1. Triaged Model for Assessment and Management of Sexual Function Post Cancer**

The model would need to be underpinned by increased education and skill development for all members of the cancer team in assessing sexual concerns, expanding knowledge of practical interventions.

**Recommendations**

1. The impact of cancer treatments on sexual function requires a strategic focus by national cancer organisations to raise awareness and support the implementation of approaches to address these concerns.
2. Health professionals working in cancer need to be appropriately skilled to provide information on sexual impact, sexual assessment and have knowledge on appropriate interventions.
3. To address current gap in knowledge and skills, short education programs be developed for members of the cancer treatment team. The aim would be to raise awareness, address myths and misconceptions, and provide guidance on simple interventions. Communication skills would be an integral component.

4. That a framework for addressing sexual concerns in the cancer setting be developed that would provide guidance for cancer centres to establish assessment, information and referral pathways.

5. There is a role for cancer nurses to become more skilled in this area, and to play an active role in developing services and establishing the framework in consultation with all members of the multidisciplinary team.