

## **EONS Research Travel Grant Report 2017**

**Dr Jane Winter**

### **Rationale for the visit**

I have a joint appointment as Consultant Nurse for Gastrointestinal Cancer at University Hospitals Southampton NHS Foundation Trust and as a Senior Research Fellow at the University of Southampton, in the Macmillan Survivorship Research Unit.



My day-to-day clinical practice is based in Colorectal Cancer, which is the second leading cause of cancer-related mortality across the world, with an estimated 1.3 million cases diagnosed in 2012. With improvements in early diagnosis and treatment, 76% of people in England diagnosed with colorectal cancer now survive a year and 57% survive for five years. As a result of these improvements, survivors of colorectal cancer form the largest group of cancer survivors affecting both men and women. Literature suggests that most colorectal cancer patients experience reasonable to good quality of life after their cancer diagnosis. The CREW (ColoRECTal Well being) study was established to systematically follow a cohort of patients from diagnosis using a framework of recovery of health and wellbeing to explore the multiple factors that might affect recovery over time. With an estimated two million people living with or beyond cancer in the UK and this figure rising by more than 3% per year.

I have been working with the Macmillan Survivorship Research Group at the University of Southampton since the inception of the CREW study in 2012. The experience has opened up the opportunity for me to be immersed in a large multi- centre research study, from the original design to the publications which we are now producing. Currently my role is as a postdoctoral research fellow working one day per week with the team with the remainder of my time in clinical practice with patients with colorectal cancer as a Consultant Nurse.

Findings from the first two years data from the CREW study show psychosocial factors including self-efficacy and depression before surgery predict recovery trajectories in Quality of life, health status and wellbeing following colorectal cancer treatment independent of treatment or disease characteristics;

(<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0155434>)

This has significant implications for colorectal cancer management as appropriate support may be improved by early intervention resulting in more positive recovery experiences. Currently these factors are not routinely assessed. I am proposing the design of an exploratory study to develop and test the predictive validity and acceptability of a screening tool to identify individuals at risk of

poorer health and wellbeing following surgery for colorectal cancer and use this information to intervene to support them at an early stage in their pathway.

I saw the research travel grant opportunity as offering the potential to really contribute significantly to my development as a researcher. Not only did I gain new knowledge and insights from working with such experienced teams but they have both implemented similar screening approaches and pathway development initiatives which would be hugely beneficial to observe and contribute to informing my own research project in the UK. I think the visit will be inspirational in relation to working with such renowned researchers in the field, building collaborative relationships for the future and to develop my own confidence as an oncology researcher.

My application for the grant involved the opportunity to visit two centres in Australia who have made significant developments in cancer survivorship and psycho-social oncology. I approached them to ask if they would host my visit and received enthusiastic support from them and was made to feel incredibly welcome by both them and their colleagues.

Both Professors Butow and Krishnasamy have developed, adapted and implemented clinical pathways to screen for anxiety, depression and unmet psychosocial needs. They have also been integral to the living with and beyond cancer work in the country and this was an incredible opportunity both as a developing researcher and in relation to promoting the synergy between research and practice.

#### **Objectives for the visit**

- Inform my own research study by observing similar work in a large oncology centre which is translated into an established clinical pathway and collaborate on the design and implementation of a feasibility study within the UK.
- Develop international links with expert researchers in the field of psycho-oncology to develop innovative approaches to care in the UK.
- work alongside expert researchers in colorectal cancer to understand the development of screening tools which can inform prehabilitation of health and well being and early intervention approaches to supportive care.

#### **Proposed outcomes for the visit.**

- To design a robust feasibility study which could lead to developing a clinical pathway in the UK and ultimately Europe.
- To demonstrate strong links forged with international units.
- To grow as a researcher and lead on my own research project.
- Develop novel approaches to care which are informed by the emerging evidence base from the CREW study and the wider health and wellbeing work in Europe.
- Disseminate the research work across a wide audience through presentations and publications.

#### **Overview of the visit.**

The visit comprised two weeks at separate centres in Australia. I chose the centres to really understand and see first-hand the survivorship work which was being undertaken and gain insight into the challenges and opportunities they had experienced. I was fortunate to be hosted by

Academics who were really keen to both share their work and understand the work we were undertaking in the UK.

## **Week 1**

### **Melbourne**

#### **The Peter MacCallum Cancer Centre**



#### **Professor Meinir Krishnasamy**

This visit was hosted by Professor Meinir Krishnasamy, where she holds the Chair in Cancer Nursing at the Peter MacCallum Cancer Centre in Melbourne. The centre is the only public Hospital in Australia which is solely there to provide cancer services and is housed in a purpose built centre. Services are also delivered at the Royal Melbourne and The Women's Hospital. The Hospital Houses over 500 researchers alongside its clinical activity and the sense of integration between the two is strong. Of particular interest for me was the work that Professor Krishnasamy was involved with in the Australian Cancer Survivorship Centre and their research programme, which is aimed at improving the lives of people following treatment.

My timetable was full and included many meetings and observational experiences, which the size of this report won't allow. I have therefore included those where I felt had greatest impact and had the potential to transform care back at home to the UK. I also had the opportunity to present twice in the first week and once in the second week to groups of researchers and clinicians around the findings of the CREW study.

The first morning was spent with Professor Krishnasamy exploring her work within the centre. Her research portfolio is vast as is her experience as a cancer nurse. She holds the inaugural Chair in Cancer Nursing at the University of Melbourne. Her research interests include the development and evaluation of nurse-led interventions targeted at improving patient and carer experiences of living with a diagnosis of cancer, demands of treatment and symptom profiles. She is particularly interested in the development and evaluation of nursing and allied health-led services. The focus of her work has been on the best ways of meaningfully translating new and existing evidence into clinical practice. The centre has a strong focus on psychological care and I was particularly interested to meet the teams providing this.

## **Professor Steve Ellen**

Professor Steve Ellen is the Director of the Psychosocial Oncology Programme and the Department of Cancer Experiences Research. He is also Professor of Psychiatry at Melbourne University. I was fortunate to have the opportunity to discuss his work. Prior to working at Peter Mac he was the Lead for emergency and Liaison psychiatry at the Alfred Centre. He has done extensive work in HIV and it was a great opportunity to discuss his extensive experience in managing anxiety and depression and his interest in developing the liaison psychiatry services in a cancer setting. He discussed the transferability of the fundamental principles of managing mental health in any setting and the similarities and differences he had found in cancer. At the time we met he was in post as the Director of Psycho-social Oncology and has since become Director of Cancer Experiences Research. He introduced me to Joy Forster who is the Consultant Psychiatric Liaison Nurse at the centre.

## **Joy Forster - Consultant Psychiatric Liaison Nurse**

I had a fascinating afternoon with Joy and learnt so much. Her role encompasses clinical practice and staff support / clinical supervision. She accepts referrals from all areas of the Centre and her role is essentially to 'provide psychiatric nursing consultation to non-psychiatric nurses and other health care professionals working within cancer services in order to achieve more integrated and holistic care to all patients'.

Her role encompasses:

- Assessment & monitoring of the mental health needs of patients.
- Assist with care planning in relation to patients with mental health problems.
- Assist with issues related to the need for or use of 1:1 psychiatric nursing care.
- Assist with issues related to the transfer and/ or discharge of individuals with acute mental health needs.
- Provide assistance in the management of difficult behaviours.
- Provide assessment and planning in the management of patient with comorbid Drug and Alcohol issues.
- Provide clinical education on psychiatric nursing/mental health issues.
- Act as a resource on psychiatric nursing/mental health issues.
- Assist with the development of standards & policies in relation to mental health care of patients.
- Facilitate Discipline specific Clinical Supervision groups within nursing teams.
- Provide group and / or individual Critical Incident Stress Debriefing

An afternoon wasn't enough to spend with her really as her work was so diverse. However I was able to observe her in clinic with patients with severe anxiety and really understand what 'holding' measures she was able to put in place to support the patients before they had access to appointments for counselling and I was also able to attend a group supervision meeting with newly qualified nurses who had been in post for 6 months and were in their preceptorship phase. A particular issue was the recent lymphoma diagnosis of one of the group and Joy provided a masterclass in supervision. Her skills were quite remarkable and she was able within that hour to provide structured and meaningful support for those nurses.

Her role was one of the key areas I felt we could develop more strongly here at home. It's a role I have reflected on at length since meeting her and really feel there is a place for similar roles in the

UK. She also introduced me to CALM (Cancer and Living Meaningfully) therapy. An approach which has been pioneered in Toronto by Professor Gary Rodin. He and his team describe the approach as: 'Managing cancer and living meaningfully (CALM) is a brief, semi-structured individual intervention designed to alleviate distress and to promote psychological growth in individuals with advanced disease. This intervention emerged from a longitudinal program of research and from the theoretical traditions of relational, attachment, and existential theory. Through a process that supports affect regulation, attachment security, and reflective functioning, CALM focuses on four content domains: (1) symptom management and communication with healthcare providers; (2) changes in self and relations with close others; (3) sense of meaning and purpose; and (4) the future and mortality. Qualitative research has shown that cancer patients experience the structure of CALM as a safe place to explore fears, to be seen in human terms, and to face the challenges of advancing disease. Quantitative studies have shown that CALM leads to a reduction in depressive symptoms and death anxiety and an increase in spiritual well-being' (<http://oxfordmedicine.com/view/10.1093/med/9780199363315.001.0001/med-9780199363315-chapter-62>). Since the visit I have been able to visit Gary and his team in Toronto and plan on implementing the approach in my clinical practice in the UK.

### **The Specialist Cancer Nursing Teams**

The following day I was able to spend time with the lower GI Nurse specialist team and attend the Lower GI MDT meeting. The meeting is quite different from the meetings in the UK and the presentation of patients, the role of the nurse specialists and the forum for discussion was very different. Each patient is presented by the registrars, in the theatre layout with them at the lectern. Discussion was quite limited and the nursing voice not strong. Their specialist nursing role was quite different. A dominant part of their role was to coordinate the care of the patient's pathway. They were a young team and really felt like they were establishing themselves. They were integrated with the stomal therapy nurses and were starting to map out their service specifications and integrate their service into the wider patient's experience. This was quite a different experience to the late effects MDT and clinic which I was able to attend. These patients return to the Hospital for follow up, many who were treated for childhood malignancy and were now adult and moved away, but the long term consequences of their treatment and the late effects in relation to health issues, further cancers and cardiac morbidity are often managed by the team (or at least coordinated through) who treated them originally and understand the nature of those conditions. The nursing voice in this team was strong and the multi professional sense of contribution of all members of the team was effective.

Equally this was evident with the role of the Consultant nurse for Melanoma and skin cancer (Donna Milne) who is clearly well established in her role. She has a clinical academic role in the cancer patients experience department and her PhD investigated the perceptions of palliative care services held by patients with cancer. She has a role in the delivery of immunotherapy and her research interests were around the experiences and expectations of patients receiving treatment. She has a broad portfolio as a member of the board of the Australian and New Zealand melanoma Trials Group. She has been actively involved in the development of the survivorship care plan work. Being able to see these and the resources she shared proved so useful and have been invaluable since returning to the UK in relation to developing our own care plans and survivorship tools. The focus of the tools are to detail:

- the survivor's cancer type and treatments
- potential short- and long-term effects of treatment

- what the survivor should look for (including psychosocial effects) and how frequently they should visit the doctor for check-ups and screening
- screening guidelines and symptoms of cancer recurrence, including second primaries
- how the survivor's follow-up care will be coordinated between the oncology specialist, GP, nurses and allied health professionals, and who to contact between appointments
- lifestyle changes to reduce the risk and severity of treatment side effects, prevent comorbid conditions and promote better health
- useful community resources on employment and insurance issues arising from cancer and its treatment
- fertility planning for patients of reproductive age
- the survivor's values and preferences regarding their care

(<https://www.petermac.org/research/clinical-research-trials/clinical-research/australian-cancer-survivorship-centre-research-2>)

There is an effective treatment summary and survivorship care plan process which they have implemented with great success and really reflects the recovery package work which is being laid out in the UK.

## **Week 2**

### **Sydney**

#### **Prince Alfred Hospital – Chris O'Brien Lifehouse.**



The Lifehouse describes itself as

‘an integrated and focused centre of excellence, offering everything a cancer patient needs in one place, including advanced onco-surgery, chemotherapy, radiation therapy, clinical trials, research, education, complementary therapies and psychosocial support.’

#### **Professor Phyllis Butow**

I was hosted by Professor Phyllis Butow who has a vast research portfolio in health psychology with a particular focus on the impact of disease in relation to adjusting and coping. She is co-director of CeMPED (The centre for medical psychology and evidence based decision making). Working with her is Dr Haryana Dhillon who orientated me to the centre and arranged visits to the concord centre and for me to meet many members of the Lifehouse staff, spend time in the centre and see the vast range

of facilities and services they had to offer. She also introduced me to the PoCoG team ( Psycho-oncology Co-operative research group) where I was based for most of my stay. Dr Dillons work has predominantly focussed around colorectal patients and was such a good opportunity to discuss her work and think about how that related to my own work in the UK. She has been doing some fascinating work around cognitive decline – particularly following chemotherapy. Their work suggests this can persist up to 2 years after treatment and can persist for up to 10 years. She is working around mechanisms for undertaking cognitive rehabilitation exercises and assessing the impact these may have.

She also has been working extensively around cancer related fatigue and her research has pointed towards a number of practice changes which could support our work in the UK, Particularly around undertaking assessments at diagnosis. She is especially interested in the link between anxiety, depression and fatigue.

### **Adapt Programme**

Dr Heather Sheppard is a senior research fellow at the University of Sydney and heads up the work where they have a five year government funded programme grant to undertake the translational work of the Adapt programme (Anxiety and Depression Pathway Programme). The programme ‘aims to facilitate the integration of a newly developed clinical pathway for anxiety and depression in cancer patients into routine care, as well as to develop and evaluate implementation strategies to promote the uptake of the pathway in the Australian health care context’ (<http://www.pocog.org.au/content.aspx?page=adaptprogram>) I was there at the time of roll out of the programme which was envisaged will inform suture implementation strategies for a National rollout of the clinical pathway. The pathway is designed to provide guidelines for best practice in identifying anxiety and depression. On line tools are included and the assessment tools to undertake the formal screening process (ESAS-r or Distress thermometer) are their preferred tools. The software they have developed is in interactive programme, which allows assessment at varying time points.

### **The Exenteration service**

As we had just embarked on establishing the exenteration service at Southampton and been the first Hospital in the UK to offer IORT – visiting the centre was really informative. They have 20 years of experience and a well-established multi professional team. I was able to meet with professor Mike Soloman (Consultant Surgeon) and Sarah O’Shannasey (Programme Nurse Manager) They have their own research department called SOURCE which records all of the clinical outcome data and have a data base which had at the time just over 4 years of comprehensive data collection.

Sarah was also in the process of establishing a training package for nurses who could join the service for an 18 month programme of work, rotating through a number of specialities to develop a specialist nursing workforce to understand the needs of these patients and the complexity of their care.

### **Dr Janette Vardy Medical Oncologist.**

The Sydney Cancer Survivorship Centre at the Concord Hospital, offers a multi-professional survivorship clinic to any patient recovering from treatment with curative intent. I was able to attend the Multiprofessional meeting prior to the clinic and then spend the afternoon with a patient as they attended the clinic. The patient was a breast cancer patient who had undergone a complex pathway,

neoadjuvant chemotherapy, three operations (culminating in a bilateral mastectomy) plastic / reconstructive surgery and radiotherapy. All with a young family and a long way from her friends and family in Korea. She had been previously working as an accountant in a large multi-national accounting firm in the business district in Sydney, where her husband still worked and had also recently had her mother in law move to her home as she was unwell. The afternoon was spaced into 5 x 20 minutes sessions – the first session was with the Breast CNS, who hadn't had the opportunity to meet the patient prior to this encounter for a variety of reasons, but it was, an observer, clearly a support that would have been beneficial earlier in her pathway. She then met the Exercise physiologist who gave her information relating to a programme of exercise for her recovery. She then met the psychologist. She quickly picked up on her need for further sessions and ensured they were planned before the end of the slot. In the region they are funded through medicare to have 6 sessions of mental health support / counselling following a cancer diagnosis – which she so obviously would benefit from in the future. She then met Professor Vardy (Medical Oncologist) who bought the whole consultation together. As an experience it was quite a 'whirlwind' for the patient who managed to accumulate a large amount of information and I suspect would really benefit from a CNS follow up call to help in processing it all. However as a venue for survivorship support it was innovative and informative for patients and a novel way of supporting them post treatment. The project is being evaluated by Dr Haryana Dhillon who co-established the Survivorship Research Group with her at the University of Sydney in 2007. She established the survivorship centre at the Concord Cancer Centre in 2013. The research they undertake is focussed around quality of life, symptom management, lifestyle characteristics and needs assessment. They seek to explore changes over time in these issues and determine risk factors that may affect outcome, such as weight, activity levels and nutritional status. They are also evaluating the impact of their services on patient and carer experience and the synergy that the multiprofessional clinics may bring to the survivorship trajectory.

Within the grounds of the Centre is the cottage, a centre for courses for cancer survivors – similar to our own Macmillan centres, where courses such as nutrition, exercise, mindfulness, acupuncture, art therapy and yoga classes are held.

### **Conclusion**

This is just a glimpse of the opportunities the grant afforded me during my visit. The travel grant gave me the opportunity to explore so much in the 2 weeks I had available. The timetables in both centres were comprehensive and extensive. I met many more individuals than I have been able to include for the purposes of this report. The visit has been profoundly influential in relation to both my research experience and my clinical practice. I have learnt a huge amount about the implementation of the survivorship agenda stratified pathways of care, psychological approaches to care and the impact of being introduced the CALM therapy has been profound.

The visit will allow me to evaluate the broader contextual elements, such as the infrastructure and resources involved and also meet patients who are part of the current programme to really understand the impact that an effective, stepped approach to care can have for individuals and their carers. I am so grateful to the EONS for affording me this exceptional opportunity.