

European Oncology Nursing Society Travel Grant: 15th to 25th January 2018

Children's National Medical Centre, Washington

Dana-Farber Cancer Institute, Boston

Helen Pearson, Clinical Nurse Specialist Solid Tumours Children and Young People,

The Royal Marsden NHS Foundation Trust

Research teams chosen:

The Children's Research Institute, Children's National Medical Centre, Washington led by Dr Hinds is internationally known for research into parent/child experiences of paediatric cancer focusing on decisions making in treatment and end of life. Various publications have looked at parental experiences relating to hope, quality of life and the development of a conceptual model of how parents of children with serious illness change medical care goals.

The Dana-Farber Cancer Institute, Boston led by Dr Wolfe is internationally known for research into parent/child experiences initially researching the needs of children with a life-limiting cancer diagnosis and how to support these families. Research has continued to focus on parental experiences via various methodologies including surveys, interviews and focus groups.

My research study:

The aim of my research is to understand the process parents go through to make treatment decisions when their child has relapse neuroblastoma. At the time of relapse there are many treatment options available with no standard protocol and the long-term cure poor. The objectives of the study are to explore factors which are important to parents when considering treatment options, understand factors which contribute to decision making (influences, impacts) and how parents process these decisions based on their own values.

Objectives for the visit:

- Observe and learn from experienced researchers within the paediatric oncology field to gain insight into approaches and methods used to obtain data (particularly methodologies and

analysis), ideas on dissemination of findings (outside of publications and conference presentations) and limitations and barriers to researching this population.

- Establish a network with experienced researchers to learn, examine and discuss approaches to further research developments within the paediatric oncology field with particular reference to gaps in research.
- Develop knowledge and expertise in research approaches and methods to obtaining data which takes into account the sensitivity of researching parents of children with a life-limiting illness

Main outcomes of the visit:

- Design and development my own research proposal
- Further enhance my understanding, knowledge and own pathway for a clinical academic career
- Potentially establish collaborations for further international research into parental decision making

The visits:

I commenced my experience at Children's National Medical Centre with Dr Hinds and her research team. This is a nursing research faculty with multiple research studies being undertaken including an extension to the original work on the conceptual model of 'The good parent'. Dr Hinds has the responsibility of overseeing all nursing research within Children's National which nurses are undertaking and it was evident from my time there that the support network for researchers is exemplary and the passion for research to improve the patient experience is outstanding.

I saw many research students present their studies or research ideas and how the faculty support clinical nurses in pursuing either quality improvement projects or research. Children's National is one of the top ten institutes in America which combines both research with quality improvement and there are various routes nurses can take to be involved. The Conway research scholars are allocated a percentage of time to their research study and meet monthly to update on progress and discuss ideas of developments/gain feedback from the group. Each month one of the scholars presents at The Conway Chair meeting on their research which is attended by nursing directors, management, nurses and researchers. This discussion allows for the student to present where they are with their research with an open discussion on specific questions. On completion on the meeting, the Conway research scholars come together as a group again to discuss what went well

with the presentation, what did not and how to improve for future meetings. This monthly event enables nurses who are interested in research to come together with a good support network, engaging stakeholders in the research which is happening within the hospital and creates an environment which is supportive and nurturing.

I learnt about the importance of legacy mapping. This is establishing the main aim of your career, what you need to do to work towards this outcome mapped with what you are currently doing. This map allows for discussions and revisiting your current work commitments to ensure you are working towards your main aim. It is an ongoing developing piece of work but provides a focus on how to structure your career to enable you to meet your goals. This session was extremely useful to enhance my understanding on my own clinical academic career and factors to consider to meet my goals. Dr Hinds *et al* have published a paper of legacy mapping: Hinds, P. *et al* (2015) 'Creating a legacy map to help assure meaningful work in nursing', *Nurse Outlook*, 63, pp. 211-218.

I attended an ethics committee which approved new studies and amendments to current studies with representation from various healthcare professionals including doctors, nurses and psychologists. This enabled me to think broadly in terms of how ethics committees review research proposals and areas where clarification could be required ie: number of participants, minimising harm and benefit to participants versus risk. Various individual meetings with researchers within the team allowed for discussions on their own research studies as well as my proposed research. These meetings provided broader thinking to my research – data collection methods, how to analyse the data and discussions on various other published research which I had not found through my own literature search as well as linking me in with other researchers.

The good parent study is due to open at a second site and I attended the session where this was presented to the team. The discussion was with the co-investigators introducing the study, purpose of the study, how to screen potential participants, how to keep track of refusals/acceptance into the study, how to approach parents to ask for their participation and consent process. Participating in this discussion allowed for further thinking in how to manage my research which has the potential for interviewing parents at different time point and what obstacles this could entail. It also gave me additional ideas on how to present the study at my patient public involvement meeting in February.

Throughout the week I had plenty of 1:1 time with Dr Hinds to discuss my career development, opportunities and concerns I have towards my research study and how the week had development my thinking. I came away from the week feeling passionate about my research, how important it is and how I need to engage stakeholders within my own hospital to support me in the research developments.

The second week I spent with Dr Wolfe and her research team at Dana Farber Cancer Institute, Boston. Dr Wolfe leads pediatric palliative care research department which is physician lead with no distinct nursing research team. This is due to the fact that the hospital is aligned with Harvard University where there is no nursing school. There are three areas of research: psycho-social, oncology and palliative care.

Various 1:1 meetings gave me the opportunity to explore decision making from the psycho-social, oncology and palliative care perspective. It was interesting to discuss how from a clinical perspective information regarding relapse is communicated to families and the similarities/differences in information giving and how parents make decisions from the healthcare professional perspective. These meetings also allowed for discussions of appropriate data collection methods and data analysis relating to my research study and the pros and cons of mixed methods, specific interview time points, participant requirements, ethical considerations and realistic sample size due to the rare disease type within the timeframe for the study. Speaking with experienced researchers I was able to gain insight into potential pitfalls within research ie: what happens if you do not meet your expected participant numbers and incorporating adequate write up time for the study. The researchers were all able to reflect on their research career from novice to expert and how this developed giving me good advice particularly when it came to asking a specific research question which is manageable within the timeframe of the study.

As a potential outcome to my research there could be the possibility of developing a decision-making tool/aid for parents. One of the researchers has developed their own online programme for parents and teenage young adults in relation to treatment decision making which reflects seven different criteria to consider when making a treatment decision considering different trade offs in terms of type of treatment, quality of life, hospital visits and length of potential extension of life. I was also pointed in the direction of a decision making aids website which incorporates various decision making tools which have been created and implemented in practice: <https://decisionaid.ohri.ca/resources.html>

I attended the second day of the response team training for a research study which is about to open at four different sites following a successful pilot study at Dana Farber. The session was attended by the medical team who would be caring for these patients and delivering the implementation. The participant and consent discussion are done by the research team and requires participants (parents and children over 8 years old) to answer weekly online questions relating to four specific domains: health, social, school and emotional for 16 weeks. The aim is to identify whether involvement of the

palliative care team earlier improves symptom management in patients with advanced cancer. This session as well as the session I attended at Children's National gave me further thoughts in how to engage key healthcare professionals at different sites in my research study – how to deliver the purpose/aims of the study and ways of communicating and engaging those that would be involved in the recruitment process mindful of the additional burden this could bring to their clinical workload. Some of the research undertaken has incentives for both participants and those recruiting to the studies which is something I had not considered for my research study but is something which needs some discussion and thought.

Dr Wolfe meets with the research team weekly to update, feedback and discuss important topics ie: study amendments, site recruitment, communication to stakeholders on research studies which are about to open and topics which may need clarifications or plans to be made. This is a great opportunity for the team to come together and clarify information as required. As the meeting was after the training session this meeting focused on feedback received, areas for improvement with the training sessions at the remaining study sites and areas which still required clarification. It was good to observe the different roles within the team and how a research team is structured to be able to deliver an effective research study.

The post-doctoral research students meet weekly to discuss their projects and gain feedback from other students. This week one student spoke about implementation of focus groups for healthcare professionals who are providing care to international adult patients. The meeting was used to discuss how to structure the focus group and provide feedback on the interview guide. Discussions around wording of introducing the study and ensuring the words used did not bring bias towards a particular viewpoint was also considered and the importance of capturing data within a short timeframe (1 hour) in a group setting. The focus group was going to be piloted with the paediatric healthcare professionals before being undertaken with the intended healthcare professional group.

This week really helped with the developments of writing my research proposal which I started during this week. It was valuable to gain different ideas on data collection and analysis methods with a prospective longitudinal study which will follow a cohort of patients and how this could be approached to gain rich data.

Summary:

The EONS research travel grant has enabled me an opportunity which I would never had had otherwise. It has been a fantastic experience seeing two different research institutions and how

they work in conjunction with the clinical teams to enhance patient experience, care and satisfaction through research and quality improvement. The benefit of researchers being based at the hospital certainly makes the difference in how research is generated and designed as well as supporting junior researchers in their own developments.

I would highly recommend applying for the research travel grant if you are thinking of developing your own research study. Spending time with research teams who have experience of research in your area to gain new knowledge, learn from experts and create collaborations which can enable development of your own research topic is invaluable. From these visits I have been able to start writing my research proposal and broaden my thinking as well as collaborate with researchers internationally. The EONS research travel grant is a wonderful way of making this happen and I am so grateful for the opportunity and experience this has given me.