

“Don’t tell me I have  
a life threatening  
disease and then  
make me wait for  
care”

- Anon

## THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

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2017 CHURCHILL FELLOW*

*The Jack Brockhoff Foundation Churchill Fellowship to  
investigate the role of patient navigation in cancer care and  
determine the feasibility of implementing a volunteer model of  
patient navigation of cancer care in Australia*



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# Acknowledgement

I would like to acknowledge the Jack Brockhoff Foundation and the Churchill Trust for the privilege of being awarded this Fellowship. I will endeavour to ensure my valuable learnings are translated to the Australian community to improve the cancer experience of those undergoing cancer care. The opportunity afforded to me has been a deeply enriching personal and professional experience, providing me with opportunities to meet leading international cancer care experts working to ensure that the patient is central to everything we do. Travelling under this fellowship has not only assisted in the development of extensive new connections and opportunities, but allowed the privilege to take time out of a very busy role and focus on one thing, improving the patient experience, which is central to providing world's best cancer care.

I express my sincere thanks to the Chief Executive of Peter MacCallum Cancer Care, Professor Dale Fisher, for supporting my application and encouraging me to immerse myself in the Churchill experience. I thank the Board of Peter Mac for recognising the importance of the Churchill and supporting my application. I would like to acknowledge the Prevention & Wellbeing team whose everyday work is all about navigating patient needs and ensuring that the wellbeing needs of our patients are being met.

I am deeply indebted to the many people that took time out of their busy schedules to welcome me to their organisations and spend time explaining and championing their work. There are many people working hard to ensure the delivery of high quality cancer care around the world, listening to our patients and hearing them is what we must endeavour to always do. In the words of Winston Churchill:

***“Courage is what it takes to stand up and speak. Courage is also what it takes to sit down and listen”***

Finally to my partner Bruce and children Finn and Milla, I thank you for your constant support, love and understanding and for ensuring I really could immerse myself in this wonderful experience.

# Executive Summary

The purpose of this Churchill Fellowship is to examine the role of patient navigation in cancer care. With an ageing population, improved treatments such as personalised medicine and immunotherapy, Australians are living longer than they ever have before. Access to health care is complex, and for those that are less able to navigate the complexities of the system there is a risk that their cancer outcomes will be poorer.

This Churchill Fellowship has allowed me the privilege to consider how our current system of cancer care can better adapt to the system challenges arising from our ageing population and stretched health system. The patient navigation model of care offers opportunities to truly consider patient centred and relationship based care.

Whilst my travels focussed on the United States (US) and United Kingdom (UK) both have different health ecology to our system of universal health care. There are lessons for us to consider and opportunities to leverage of the mature models of patient navigation practiced in the US and the UK.

The need to consider alternate workforce models and to leverage off “physician extender models” of workforce such as physician assistants has not proven sustainable to date in Australia. The nurse practitioner model of workforce experienced much opposition from the medical fraternity when first established in Australia and is now well integrated and supported in our health system. The drivers for change in the US are clearly different, the health disparities experienced by marginalised populations is extreme; adopting workforce models that are less reliant on employing doctors and nurses has enabled the system to focus on engaging and supporting marginalised groups to access health care.

The Patient Navigation movement in the US has adapted to the needs of diverse populations. Nurse navigators, patient navigators and lay navigators all act to improve the patient experience and ensure barriers to health care are addressed before, during and after cancer care. The patient experience movement is increasingly emerging as a credible mechanism for measuring patient navigation success. The focus on prevention and wellbeing gives permission to consider the holistic needs of a person undergoing cancer care. Coupled with good quality cancer information at a time when the patient wants it and in a form that the patient needs can dramatically impact on cancer outcomes.

Our health system has long focussed on supporting those with chronic disease; cancer lags behind other chronic diseases where the focus on self-management and wellbeing provides the individual with the opportunity to live and participate well in the community. Embedding self-management principles into cancer care will enable those living with cancer, the opportunity to be active participants in their health care. Rural communities, Aboriginal and Torres Strait Islanders, those experiencing homelessness, and refugees have poorer access to health services. As a group, they experience poorer health than the urban population<sup>1</sup>.

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<sup>1</sup> Peter MacCallum Cancer Centre Draft Prevention & Wellbeing Strategy 2016

Patient navigation has been defined as a community-based service delivery intervention. It is designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care. Patient navigation is widely used in the US and the UK.

Cancer care has become more specialised, technology has evolved and the advent of personalised medicine has resulted in multiple care pathways with no one cancer treatment experience being the same. Survival rates are dramatically different to ten years ago but treatment is often more complex. While this complexity has resulted in better health outcomes overall, our health system has become fragmented and siloed. It often requires someone from within the system to provide guidance to patients<sup>2</sup>.

The US models of patient navigation whilst more mature than the UK are driven by legislation; the concept of patient navigation was established by renowned breast surgeon Dr Harold Freeman in 1990. This was in response to the low breast cancer survival rates for African American women from low socioeconomic areas in Harlem. Dr Freeman developed The Harlem Patient Navigation Program to address disparities in access to health care. The navigators were community members or culturally similar to the population they worked with.

The program increased the five year breast cancer survival rates from 39 percent to 70 percent. The success of this program was the impetus for the *Patient Navigation, Chronic Disease and Prevention Act* which was passed in 2005 by President GW Bush; the act included \$25 million for demonstration programs<sup>3</sup>. One of the many highlights of this Fellowship was attending the Harold Freeman patient Navigation Training Program in New York and meeting Dr Freeman now retired from clinical care but actively involved patient navigation training.

This Churchill Fellowship has enabled an in depth review of patient navigation and an opportunity to consider how lay and volunteer patient navigation may be embedded into cancer care in Australia. I have examined and conducted an analysis into the critical success factors required to ensure a return on investment, and how patient navigation can not only improve patient experience, but ultimately improve cancer outcomes for Australians.

My conclusions and recommendations focus on establishing navigation services that address a particular barrier to care or support a discreet population experiencing poor cancer outcomes related to their capacity to navigate the system.

*“No patient should spend more time fighting the health care system than they do fighting their disease”*

*Freeman*

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<sup>2</sup> Tho PC & Ang E. The effectiveness of patient navigation programs for adult cancer patients undergoing treatment: a systematic review. 2016;14 (2): 295-321, JBI Database of Systematic Reviews & Implementation Reports

<sup>3</sup> Freeman H & Rodriguez R. The History & Principles of Patient Navigation. Cancer. 2011 Aug; 117(15 0): 3539–3542

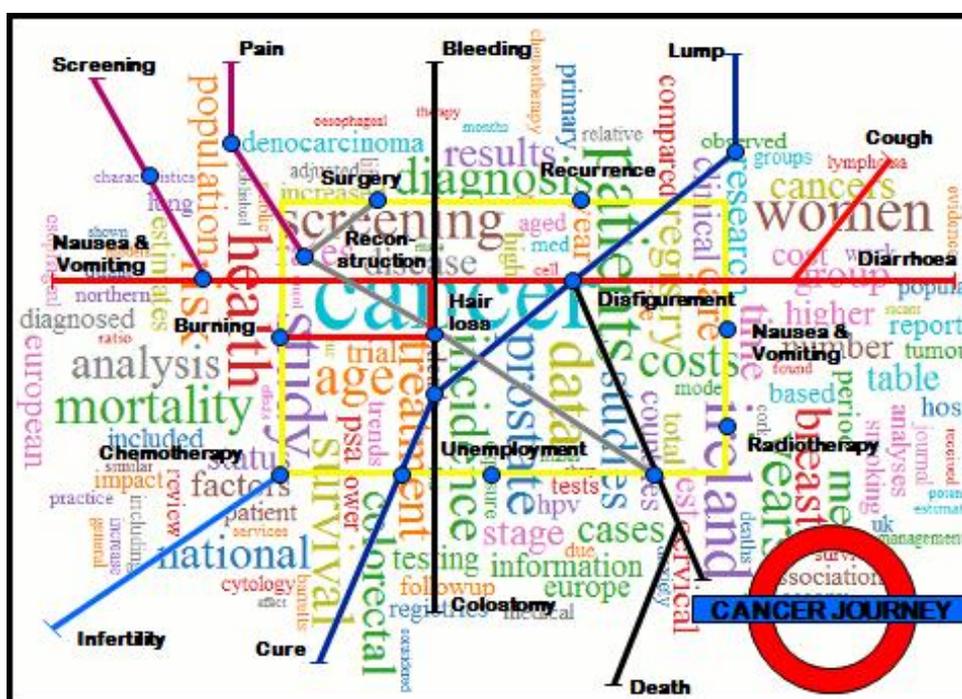
## Program

City	Host	Activity
Chicago	The Beryl Institute	Conference
	University of Chicago Medicine	Hospital Tour
Denver	University of Colorado	Meetings and Presentation
Houston:	MD Anderson Cancer Center	Meetings and Tours
Boston	Dr Mardge Cohen and Dr Gordon Schiff	Meeting
	Paul Levy and Farzana Mohamed	Meeting
	American Oncology Nurse and Patient Navigator Conference (AONN)	Conference
	The Schwartz Center for Compassionate Healthcare	Meeting
	Dana–Farber Cancer Institute	Meetings and Tours
New Haven	Yale School of Public Health & Yale Cancer Centre	Meetings
New York	Memorial Sloan Kettering Cancer Centre	Meeting
	American Cancer Society	Training program & Meeting
	Harold P. Freeman Patient Navigation Training	Training Program
London	University College Hospital Macmillan Cancer Centre - UCLH	Meeting
	Charing Cross Hospital – Imperial College	Meeting and Tour
Manchester	Maggies Centre	Meeting and Tour
Manchester	The Christie Hospital	Meeting
London	Maggies Centre	Meeting and Tour

## State of the Problem

Cancer care is complex, confusing and frightening. Our patients describe feeling disempowered, and having no control, which has been likened to being on a speeding train without a ticket, and not knowing how or where to get off.

### This is what cancer feels like



Cancer is a complex disease. It is not one single disease; it is the name for a whole family of diseases that all share a common characteristic - the uncontrolled growth of abnormal cells. The word "Cancer" was coined by Hippocrates, who gave us the "Hippocratic Oath", it comes from the Greek word, "karcinos", which means "crab". The analogy refers to the vice-like painful grip of the crab's claws being like the infiltrating filaments that some cancers have - and of course, the terrible pain<sup>4</sup>.

Cancer is a leading cause of morbidity and mortality in Australia and has a substantial social and economic impact on individuals, families and the community. In 2017, it was estimated that 134,174 Australians would be diagnosed with cancer and 47,753 people will die from cancer<sup>5</sup>.

The cancer landscape is rapidly evolving; Precision medicine (PM) is now becoming usual care. This is a medical model that proposes the customization of healthcare, with medical decisions, treatments, practices, or products being tailored to the individual patient based

<sup>4</sup> Kruszelnicki K. Cancer, one single disease? June 2005  
<http://www.abc.net.au/science/articles/2005/06/09/1387330.htm> accessed 07/05/18

<sup>5</sup> Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW

on the medical teams genetic understanding of their cancer<sup>6</sup>. Five-year survival rates have dramatically increased over the last ten years. Between 1984–1988 and 2009–2013, five-year relative survival for all cancers combined increased from 48 percent to 68 percent<sup>7</sup>. Whilst the survivorship story is positive it is important to also understand that survivorship may come with its own challenges both medical and psychological.

Fear of recurrence, as well as living with the often debilitating side effects of cancer treatment, which also require expertise and support, is a common story. The cancer experience in many people never really ends. The system can be just as complex in the survivorship phase as the diagnosis and treatment phases. If we are to impact on improving the patient experience, wellbeing and prevention in cancer care deserves the same attention that survivorship has seen over the last ten years if we are to truly improve the patient experience.

## What's missing from the system?

Our health systems are complex, as treatment options improve and personalised medicine impacts on care, the system becomes more difficult to navigate. Our health budgets are stretched, our staff are working past capacity and we cannot keep up with demand. Innovation becomes ever important as we search for answers to provided best possible cancer care.

Our patients need compassion and empathy from their health care providers and in order to foster an environment that supports compassionate care we need to examine the environment our staff are working in. As identified by Lown B (2014) *“the fragmentation, discontinuity of care, technology that both hinder communication and relationship building, burgeoning operational and administrative requirements, inadequate communication skills, alarming rates of burnout and increased costs and market pressures”* all impact on our ability to provide compassionate care<sup>8</sup>.

The Schwartz Center for Compassionate Healthcare was established in 1995 by Ken Schwartz shortly before his death. Its mission is simple but compelling: to promote compassionate care so that patients and their caregivers relate to one another in a way that provides hope to the patient, support to caregivers and sustenance to the healing process<sup>9</sup>. The work of the Schwartz Center has grown to an international movement of committed health professionals that are committed to simple acts of kindness and compassion in care, understanding that this results in better health outcomes for our patients.

Dr Lown's paper (2014) outlining the seven guiding commitments for supporting a more compassionate system was the result of a roundtable hosting healthcare professionals,

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<sup>6</sup> National Cancer Institute 2017 Precision Medicine in Cancer Treatment. <https://www.cancer.gov/about-cancer/treatment/types/precision-medicine> accessed 07/05/18

<sup>7</sup> Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW PG 40

<sup>8</sup> Lown BA. 2014 Seven guiding commitments: Making the US. Healthcare system more compassionate. Journal of Patient Experience Issue Issue 2/Vol 1. 2014

<sup>9</sup> The Schwartz Center for Compassionate Care “About Us” <http://www.theschwartzcenter.org/about-us/story-mission/> accessed 09/05/18

educators, researchers, administrators, health evaluators, and family and patient advocates. From this consultation the seven guiding principles were developed to inform health services to ensure more compassionate and empathetic care. There is emerging research correlating empathy and compassion with healthcare quality and patient outcomes<sup>10</sup>. Further to this, investigations show that building compassionate systems into a healthcare system is an important step to supporting a truly patient-centred system, and one where the return on investment is proven.

The guiding principles developed in 2014 remain relevant today and provide a platform for health services when developing their patient experiences strategies. They ensure compassion and empathy are not lost in the complex systems our patients are forced to navigate.

**Figure 1. Seven Guiding Commitments for a Compassionate Healthcare System (adapted from Beth Lown paper referenced above)**



<sup>10</sup> Mohammadreza Hojat, Daniel Z. Louis, Fred W. Markham, Richard Wender, Carol Rabinowitz, and Joseph S. Gonnella, Physicians' empathy and clinical outcomes for diabetic patients. Acad Med 86 (2011): 359-64

## Recommendations to create a more compassionate health system (adapted from Beth Lown)

Commitment	Goal	Recommendations
Commitment to Compassionate Healthcare Leadership	Healthcare leaders within and across organisations and systems reinforce compassionate care as a leadership priority	<ul style="list-style-type: none"> <li>• Leaders share and disseminate exemplary compassionate care leadership practices, tools and quality standards to implement and assess organisational climate and capacity for compassionate healthcare.</li> <li>• Leaders implement these strategies and assess their impact on patients' experience and satisfaction, population health, and costs of care.</li> </ul>
Commitment to Teach Compassion	Health professional students, trainees, and practising clinicians continuously improve their competence in the knowledge, skills and attitudes required to provide, teach, and model compassionate care.	<ul style="list-style-type: none"> <li>• Educators integrate, teach and assess the knowledge, skills and attitudes required to provide compassionate care across all years of education, training, and practice, and provide faculty development in these domains.</li> <li>• Regulators include the knowledge and skills required to provide compassionate care in licensure examinations and accreditation requirements.</li> <li>• Education leaders develop interventions and strategies to eliminate mistreatment of students and trainees, track reported incidents, and set standards for faculty remediation.</li> </ul>
Commitment to Value and Reward Compassion	Healthcare institutions value, support and reward the cognitive, emotional, and collaborative work and time required for caregivers to provide compassionate care.	<ul style="list-style-type: none"> <li>• Stakeholders ensure that financial and nonfinancial incentives emerge from collaborative processes aimed at the shared purpose of providing compassionate, patient- and family-centred care.</li> <li>• Stakeholders make public the processes used to develop, implement, evaluate and revise financial and other incentives.</li> <li>• Stakeholders provide incentives for care that improves patients' quality of life, wellbeing, and experiences of compassionate care as well as health outcomes.</li> <li>• Valid and reliable measures of compassionate care are included in publicly reported surveys of patients' experiences of care and linked incentives.</li> </ul>
Commitment to Support Caregivers	Healthcare organisations and systems support the wellness and resilience of healthcare professionals and address systematic factors that contribute to burnout.	<ul style="list-style-type: none"> <li>• Leaders and employers offer and incentivise wellness initiatives that support emotional and psychological health.</li> <li>• Organisations provide opportunities for caregivers to share stories and to reflect on the emotional and social aspects of clinical care, and what sustains them.</li> <li>• Organisational leaders and employers measure and track burnout and assess the impact and outcome of programs designed to enhance resilience and wellness.</li> </ul>

# What does Patient-Centred Cancer Care look like?

In 2015 there were 17.5 million cancer cases reported across the world; a 33 percent increase in less than a decade<sup>11</sup>. The Institute of Medicine identified critical components to transform cancer care in the USA (see figure 3.).

Equity of access is central to a high quality cancer system. In 2015 Peter MacCallum Cancer Centre (Peter Mac) adopted a Wellbeing Model of cancer care based on the social determinants of health. The Wellbeing Model is based on a fundamental belief that best practice cancer care addresses, not only the treatment of the disease but the social, emotional, cultural and spiritual issues associated with being a cancer patient. Access and equity are important components of the principles of wellbeing, not only in cancer care, but more broadly when accessing all health care. Identifying the cultural, social, emotional and spiritual issues that impact on an individual's ability, capacity and motivation in accessing health care is central to best practice cancer care.

As a state-wide cancer service, the needs of our consumers and community are complex and ever-changing. We recognise that each person is unique and one person's cancer experience is not the same as another's. Knowing who our consumers are and what is important to them is essential to our model of success.

In 2017 Peter Mac conducted a series of consultations around Victoria with patients, families, carers, and health care providers to inform the development of our community compass; guiding principles in how we, as a lead cancer care provider, engage with and deliver cancer services. We asked patients what was important to them and what they needed from us to partner better in cancer care. Four key areas for investment were identified as areas for focus over the next three years, these include:

## **INVESTMENT ONE: INFORMATION AND COMMUNICATION**

Universally, participants reported a need for a more comprehensive understanding of the cancer information and treatment options available to them. Communication regarding correct timing of the provision of information was also important.

*"My mind could not take in all of the information at the beginning- I was still in a state of shock"  
Shepparton participant*

We recognise that timely and accessible information is essential in order to understand a diagnosis and support choices regarding treatment options. We are committed to improving the provision of accessible information to patients, at a time when they feel ready to absorb it. Our communication approaches regarding the provision of information will reflect our commitment to empathy for the patient, their carers and their individual circumstances.

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<sup>11</sup> L.D. Shockney (ed), Team Based Oncology Care: The Pivotal Role of Oncology navigation, [https://doi/10.1007/978-3-319-69038-4\\_3](https://doi/10.1007/978-3-319-69038-4_3)

## **INVESTMENT TWO: NAVIGATING YOUR CANCER EXPERIENCE**

Participants expressed a need for better mapping of the cancer pathway and an understanding of the steps which are expected to occur along the way. Having a general idea of the path they are on can build patient resilience by placing milestones and triggers that promote success.

*“It’s a bit like falling off a cliff” Bendigo participant*

We recognise that having a navigation path through the cancer experience can be empowering and provide comfort and security by allowing the patient to take more control of their circumstances.

## **INVESTMENT THREE: BUILDING CAPACITY**

Participants expressed a desire to be informed and active partners in their care and for staff to consult with them regarding decisions about their care and services provided.

*“We need to be able to advocate for ourselves” Traralgon participant*

We acknowledge that a cancer diagnosis has a major impact on all aspects of life, including family, work and finances. We are committed to building individual and collective capacity so that the patient’s confidence in both self and the hospital is enhanced and they feel equipped to advocate for themselves.

## **INVESTMENT FOUR: SUPPORT NETWORKS**

Acknowledgement was given to the important role of family, friends and carers. More emphasis on nurturing this group was widely supported.

*“Some of the best support we got came from someone we had never met, but they had been through the same thing and understood what we were going through” Traralgon participant*

We understand how crucial support networks can be to support physical, emotional and spiritual wellbeing. We are committed to strengthening the network of care to build resilience and enhance wellbeing. Best practice cancer care includes building the patient's capacity to self-manage and advocate for themselves and when this is not possible, as is the case in people experiencing high health disparities, providing a navigation process to better support these patients is a truly patient-centred model of care. Patient navigation is a widely applied intervention that has, since its inception in 1990, “*expanded across the continuum of care to include prevention, detection, diagnosis, treatment and post treatment quality of life support*”; it is an evaluated model of providing patient-centred cancer care.

Patient-centred care most importantly provides a platform for recognising that a patient’s cultural, spiritual, psychological and social needs are central to how a person will

experiences cancer or ill health. The Victorian Cancer Plan 2016-2020 recognises the need to move not only to person-centred care but to also encompass person-directed care<sup>12</sup>.

Patient navigation recognises that all of these paradigms must be acknowledged and understood by the healthcare team. It is essential that the role a navigator plays in supporting the team to develop a care plan that speaks to the individual's needs, is recognised. It enables a compassionate and empathetic health system to flourish and be responsive to individual patient needs. The principles of patient-centred care underpin the Victorian Cancer Plan 2016-2020 by "providing culturally responsive, competent, respectful and accessible services is core to improving cancer outcomes for all Victorians"<sup>13</sup>. The report also acknowledges the importance of building a culturally responsive cancer care workforce including the need to ensure more Aboriginal health workers are supported in our system to work against the inequities and poor cancer outcomes experienced by Aboriginal Victorians.

Patient-centred care involves respectful and responsive communication to individual patient preferences, evidence-based information to educate, not only the patient, but also the multidisciplinary team about treatment options and shared decision-making processes. The Victorian Cancer Plan 2016-2020 identified the following principles to ensure improved cancer experiences *"To ensure the best experience of the cancer treatment and care system, people need to be supported as partners to navigate the steps in the care pathway and to make decisions about what care they receive, when and where. A focus on understanding the outcomes of care most important to cancer patients will facilitate shared decision making about treatment and promote recovery"*<sup>14</sup>.

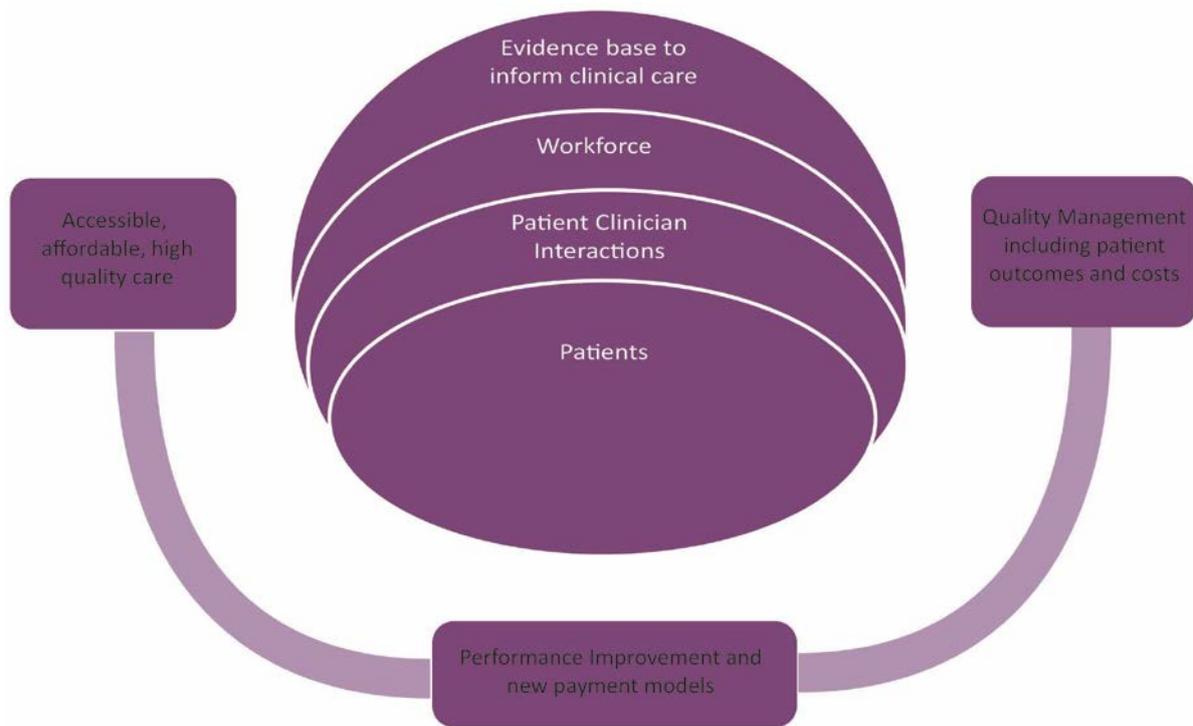
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<sup>12</sup> Freeman H. Patient Navigation as a Targeted Intervention: For Patients at High Risk for Delays in Cancer Care. Cancer 2015 3930-3932

<sup>13</sup> Victorian Cancer Plan 2016-2020: improving cancer outcomes for all Victorians accessed online 25/05/18 at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)

<sup>14</sup> Victorian Cancer Plan 2016-2020: Improving cancer outcomes for all Victorians accessed online 25/05/18 at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer) pg 10

## A high quality cancer care delivery service.



## Relationship Based Care

Relationship-based care (RBC) refers to a model of care co-opted by healthcare professionals working in psychosocial care. It has predominantly been led by the nursing and social work profession in recognition of the lack of compassion and kindness in healthcare and the constant pressures of an under-resourced health system, which results in high burn out. The central characteristic of relationship-based practice in healthcare is the emphasis it places on the professional relationship as the medium through which the practitioner can engage with and intervene in the complexity of an individual's environment<sup>15</sup>.

Relationship-based care has three core components with the patient and family at the centre of all the components:

1. Care providers' relationship with patient and families
2. Care providers' relationship with self
3. Care providers' relationship with colleagues<sup>16</sup>.

The patient navigation system is an excellent example of how relationship-based care places the patient at the centre of care, not only focussing on the individual patient and family needs but also on the development of a relationship between the patient navigator and the patient. Too often health professionals refer to scope of practice and professional

<sup>15</sup> Wilson K., Ruch G., Lymbery M. and Cooper, A. (2011) (eds) *Social Work: An introduction to contemporary practice*, Pearson, Harlow, pp. 7–8

<sup>16</sup> Falter Betty. *Relationship-Based Care: A Model for Transforming Practice*. *Nursing Administration Quarterly* June 2006- Volume 30 Issue 2- pg 182

boundaries as reasoning for not fully engaging with the patient, as a person. The patient navigation role gives permission for deep engagement and understanding of the barriers and obstacles for accessing care.

## Cultural Patient Navigation

A major tenet of high quality cancer care is equitable access for all. This notion seems in itself simple, it is highly complex. It must consider the implications of discrimination based on race, ethnicity, sex, gender identity, religion, socioeconomic status and nationality<sup>17</sup>. The health disparities identified in the US between black and white Americans can be likened to the disparities that our Aboriginal and Torres Strait Islander Australians (Aboriginal and Torres Strait Islander) experience; lower screening rates, later diagnosis and inequitable access to clinical trials.

There is much to learn from our American colleagues. This was particularly highlighted when visiting the *Patient Navigation Training Collaborative* at the University of Colorado. This academic group situated in the Colorado School of Public Health, Center for Public Health Practice at University of Colorado have a long history of developing and evaluating patient navigation programs for diverse cultural groups, particularly the Native American population that experience high levels of health disparities.

The Native American population experience is very similar to the Aboriginal and Torres Strait Islander health experience. Shaped by historical trauma defined by Harjo et al. (2014) as:

1. Issues of trust due to prior history of mistreatment and its impact on health care access
2. Communication unique to culturally specific tribal populations (e.g., Muscogee (Creek) Nation versus Dakota Nation)
3. Cultural perceptions common to a specific tribal nation, band, or clan
4. Spirituality (traditional Indian medicine versus modern Western medicine and/or complementary medicines unique to specific tribal nations or geographic regions)
5. Logistical issues unique to Indian Health Services Contracts<sup>18</sup>.

Among Native American women with breast cancer, the average time from initial biopsy to initiation of treatment is six months. However, when a native patient navigator is involved the time to treatment is shortened to less than two months. Native Patient Navigators can bridge the unique and complex cultural issues, practices and barriers that Native Americans face when diagnosed with cancer<sup>19</sup>.

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<sup>17</sup> Pratt-Chapman M. Quality Cancer Care Chpt 3 in Team based Oncology Care: The pivotal role of oncology navigation L.D Shockney 2018

<sup>18</sup> Harjo LD, Burhansstipanov L, Lindstrom D. Rationale for "Cultural" Native Patient Navigators in Indian Country. *Journal of cancer education : the official journal of the American Association for Cancer Education*. 2014;29(3):414-419. doi:10.1007/s13187-014-0684-0

<sup>19</sup> Burhansstipanov L. Navigating unique populations: Native American Patient Navigators. *Journal of Oncology Navigation & Survivorship* 2017 Vol 8, No.1

A recent Australian publication from Reilly et al (2018) examined Aboriginal experiences of cancer and care coordination, focussing on care coordination and its impact on the cancer experience. The authors found that when care coordination needs were being met the impact was highest on continuity of care and as such may potentially improve cancer outcomes<sup>20</sup>. Whilst Aboriginal Health Liaison Officers (AHLO) have been in place in Australian hospitals since the late 1990s hospitals continue to face difficulties in recruitment and retention. This role has expanded to *be something for everyone* resulting in high rates of burn-out, without these services health services potentially face lack of culturally safe services, limited understanding of the complexity of accessing care for Aboriginal people, and reduced numbers of Aboriginal people accessing and continuing cancer care.

A DHHS report (2016) examining the role of the AHLO found that:

*The role of the AHLO is deemed critical to enhancing culturally responsive care and ensuring the cultural safety of patients. As critical roles within the hospital experience and as bearers of important knowledge and expertise, AHLOs mostly feel undervalued and neglected. AHLOs are the subject and object of community trauma and as such their roles are highly stressful and stress leave was common. Without sufficient support, legitimacy and acknowledgement of these roles, culturally responsive care and cultural safety become highly vulnerable for Aboriginal patients<sup>21</sup>.*

## Workforce shortage

Workforce shortages in oncology care are a recognised phenomenon internationally, with many countries identifying an aging workforce where oncology care demand is outstripping supply as the leading cause of workforce shortage. The need to consider alternate models was another driver behind the development of patient navigation models of care. In the USA in response to workforce challenges the American Society of Clinical Oncology (ASCO) commissioned research into the workforce issues in oncology care. The study found that an ageing and growing population, increasing numbers of cancer survivors, and slower growth in the supply of oncologists will result in a reduction of 2,550 oncologists, reducing the number of working oncologists down to 4,080 by 2020<sup>22</sup>.

In response to this research ASCO developed a workforce strategy, among the recommendations was the need to work better in collaborative multidisciplinary models that utilised other “non-oncologist physician extender” roles such as physician assistants and nurse and patient navigators. Physician assistants are the fastest growing medical professional group in the American health care system.

Australia experimented with physician assistants but this is yet to gain traction in this field. Physician assistants are not eligible for a Medicare provider number, which significantly increases the cost to either the patient or their employer, and the profession is not registered by the Australian Health Practitioner Regulation Agency (AHPRA). They also faced fierce opposition from the Australian Medical Association and the Nurses Union. There is

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<sup>20</sup> Reilly R et al. Aboriginal experiences of cancer and care coordination: Lessons from the Cancer Data & Aboriginal Disparities (CanDAD) narratives. Health Expectations. 2018:1-10

<sup>21</sup> DHHS 2016: Cultural Responsiveness in Victorian Hospitals: Final Report 2016

<sup>22</sup> ASCO 2007 Forecasting the supply and demand for Oncologists: A report for ASCO from AAMC

now only one university offering this degree, but with limited employment opportunities it is likely this will not be continued<sup>23</sup>.

There is a need to consider how the Australian health care workforce could be leveraged to develop a role that supports patient navigation. In the US and the UK patient navigators often have a health sciences background, such as health promotion or a Masters of Public Health. Typically these qualifications provide an in depth understanding of the interdependencies of low socio-economic status and poor health outcomes. There is an opportunity to consider the development of a patient navigation model in Australia that focuses on populations experiencing high health disparities, such as our Aboriginal and Torres Strait Islander populations.

## Multidisciplinary Cancer Care

The term interdisciplinary, transdisciplinary or multidisciplinary refer to the multiple professional groups working together in a care team, in this case cancer care<sup>24</sup>. The Venn diagram below has been adapted for the Australian environment from Franklin et al. description of members of a multidisciplinary cancer team.

Members of the patients' multidisciplinary team.



<sup>23</sup> ABC news 2018. Why have a course where there is no outcome: James Cook University under fire for health care degree Feb 2018 accessed 24/05/18 <http://www.abc.net.au/news/2018-02-08/james-cook-university-under-fire-for-physician-assistant-course/9376342>

<sup>24</sup> L.D. Shockney (Ed.), Team Based Oncology Care: The Pivotal Role of Oncology navigation. Chapter 13 Understanding Role Delineation of the Multidisciplinary Team Members [https://doi/10.1007/978-3-319-69038-4\\_3](https://doi/10.1007/978-3-319-69038-4_3)

The American experience of developing models of patient navigation, as described earlier in this report, provides Australia with evidenced-based, evaluated models of navigation that have improved access to care and cancer outcomes in populations experiencing high health disparities. Introducing new roles into a craft group that has historically had “ownership” has its difficulties.

We have seen this in other areas of health when new roles have been introduced. The importance in understanding and developing clear scope of practice should not be underestimated. Duplicating roles serves no purpose to the patient or the multidisciplinary team. The aim of considering patient navigation in cancer care is to address the barriers to accessing and continuing cancer care. A patient navigator should be part of a team and work closely with the social workers and nurse navigators in identifying the individual barriers and unmet needs experienced by patients.

One patient navigation program in Washington, USA focussed on patient experience and patient satisfaction data, as well as patient complaints, to develop the areas of focus for the patient navigation team and grouped them into the following themes:

1. Care management and coordination
2. Social and psychosocial support
3. Financial support and counselling
4. Nutritional support and education.

Each theme had multiple needs and issues within each of these four categories. These fundamental patient needs drove the decision to create a multidisciplinary Navigation Team, versus the traditional pool of case managers. By leveraging the focused skills of each individual on the team, they believed that cancer patients would be better supported and that team members would be more satisfied with their work<sup>25</sup>.

The team established a baseline survey that captured satisfaction with care pre-navigation and then repeated the survey post-navigation. The results were significant enough for the hospital executive to double the staff numbers in the navigation. The satisfaction survey was an important tool used to further establish the return on investment of the program.

The model included a nurse navigator, a social work navigator and a patient representative that acted as a financial advice navigator. The team was further increased to include disease specific navigators. The disease-site-specific navigators were expected to work, not only with the patient and family, but also to serve as a direct liaison between the cancer program and referring physicians and surgeons. This multidisciplinary model was found to be more cost-effective than just employing nurse navigators.

The authors noted if the team consisted only of social workers or volunteers, there would be an absence of qualified expertise to work through the complex medical issues associated with cancer care. A critical component of developing the model was to define boundaries and scope of practice for each navigator; the issue of role delineation and “scope creep” has been identified across Europe and the US and should be included as a critical success factor for a multidisciplinary model of patient navigation.

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<sup>25</sup> Nicewonger D. Patient Navigation. A multidisciplinary team approach. 2009 Association of Community Cancer Care: A Call to Action

The following was identified by the author as useful tips when establishing a navigation team<sup>25</sup>.

#### Practical Tips for Developing and Growing a Patient Navigation Team

■ **Start small.** Although your needs may be great, consider implementing a smaller navigation program with defined boundaries and objectives that can then be used as benchmarks for success and justification for program expansion. It's better to do a few program elements successfully and use that success to validate expansion than to allow the program to struggle with measurable outcomes due to "scope creep."

■ **Use a multidisciplinary model.** Bringing together RNs, social workers, nutritionists, financial counsellors, and other professionals can provide a depth of expertise in a cost-effective manner. Clearly define roles for each discipline on the team.

■ **Survey your cancer patients.** Conduct a baseline survey of patient satisfaction administered prior to initiation of the navigation program so that success can be measured and reported to leadership.

■ **Listen to your cancer patients.** Keep a log of patient success stories. These anecdotal accounts provide faces, emotions, and reality to patient navigation benefits that are not easily quantified. These human interest success stories help gain and sustain support for navigation programs and services.

■ **Control program growth.** Evolving the program structure and scope in small intervals with demonstrated successes through each stage can garner confidence and support for continued expansion.

■ **Expand the navigator role.** Asking patient navigators to liaise with your community referral base—patients and referring physicians—can help increase patient volumes and grow your navigation program.

■ **Establish an advisory council.** An advisory council of providers, patients, and family members can help direct the goals and work of your Navigation Team.

■ **Set up a foundation to help fund the program.** A foundation can accept community donations and other funds to pay for supplies, materials, and programs associated with the work of your navigation team.

## Fragmentation of Care

The complex systems and processes established as our health system does not automatically translate to efficient equitable care. A fragmented health system has been ranked as the highest among system barriers. However, external factors such as poor access to transport have also been identified as one of the main barriers to accessing care particularly for those that are travelling long distances or those that cannot afford transportation.

An Institute of Medicine (IOMM) report (1999) stated *“that the cancer care system does not ensure access to care, lacks coordination, and is inefficient in its use of resources<sup>26</sup>”* the later IOMM report (2013) again noted that even with electronic medical records and multidisciplinary team care the system still remains fragmented and patient-centred care remains the exception not the rule<sup>27</sup>.

The importance of better care coordination cannot be underestimated; the increasing numbers of survivors and the ageing population have placed pressure on an already fragmented system. It is worth noting that the US experience has identified the two members of the multidisciplinary oncology care who are ever constant is the **navigator and the patient**. Members of the team change as treatment change; the navigator provides the patient a more seamless experience by remaining constant through care transition<sup>28</sup>.

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<sup>26</sup> Institute of Medicine. Ensuring quality cancer care. Chicago: National Academy Press; 1999

<sup>27</sup> Institute of Medicine. Delivering high quality cancer care: charting a new course for a system in crisis. Washington DC: National Academy Press; 2013

<sup>28</sup> L.D. Shockney (ed) & Burhansstipanov. Team Based Oncology Care: The Pivotal Role of Oncology navigation. Chapter 1. Team based Oncology Care. [https://doi/10.1007/978-3-319-69038-4\\_3](https://doi/10.1007/978-3-319-69038-4_3)

# Developing a Framework for Patient Navigation in Australia

Whilst patient navigation is firmly embedded in the cancer care system in the US, and to some extent in the UK, the concept is less well utilised and embedded in Australia. Patient navigation has predominantly been performed by nurses in Australia; this has led to highly qualified nurses being subsumed by administrative work that could easily be passed to an administrative patient navigator.

Much confusion exists around patient navigator roles and responsibilities. Community health workers (CHWs), patient navigators, and clinically licensed navigators (i.e. nurse and social work navigators) are three professional types that have overlapping yet distinct roles and responsibilities<sup>29</sup>. Most navigators do provide some form of education to patients but the level and depth of this information is determined by the qualifications of the navigator.

For instance, nurse navigators are well qualified to provide in depth medical information about cancer and treatment. An administrative patient navigator often referred to as “lay navigators” will be able to provide education about the process and pathway; lay navigators are often unlicensed i.e. they may have an undergraduate health qualification such as public health or health promotion but do not hold a clinical qualification. A community navigator may be better versed in prevention, screening and transition to tertiary care for treatment.

There appeared to be a lack of clarity around role delineation and types of navigation in many of the services I visited. Patient navigation appeared to have its own ecosystem in each organisation visited and roles were developed based on the needs of the health system. This method of responding to the needs of the health system by determining what model of navigation best suited patients needs is a tenet of patient-centred health care and allows services to focus on the environmental drivers and health disparities of the local population. Whilst this is the purpose of patient navigation it also contributes to confusion around what a patient navigator role is, and what qualifications, expertise or experience is required to fulfil the role of patient navigation in a cancer centre.

The GW Cancer Centre in Washington has developed frameworks and toolkits to support the development of patient navigation programs acknowledging that one model does not fit all and that a clear understanding of the challenges you are trying to address will determine the type of program that best suits<sup>30</sup>.

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<sup>29</sup> Willis A et al. Development of a Framework for Patient Navigation: Delineating Roles Across Navigator Types. *Journal of Oncology Navigation & Survivorship* Dec 2013 Vol 4, No 6

<sup>30</sup> Willis, A., Hoffler, E., Villalobos, A., Pratt-Chapman, M. (2016). *Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals*. The George Washington University Cancer Institute. Washington, DC

## Types of Navigators and Areas of Focus<sup>30</sup>

Type of Navigator	Professional Summary
<p><b>Nurse Navigator</b></p> <ul style="list-style-type: none"> <li>· Hold a clinical license</li> <li>· Unique focus on clinical decision making, symptom management and care coordination</li> <li>· Unique understanding of oncology, medical and health information</li> </ul>	<p>Nurse navigators are professional nurses trained to specialize in working with oncology patients. This requires a nursing degree and a clinical license. Nurse navigators focus primarily on the patient’s clinical needs and care coordination, and have advanced understanding of medical, oncology and health information. Nurse navigators refer patients to social workers for psychosocial and/or social service needs as well as patient navigators or peer navigators to address non-clinical barriers</p>
<p><b>Social Workers</b></p> <ul style="list-style-type: none"> <li>· Hold a clinical license</li> <li>· Unique focus on psychosocial support, counselling and social services</li> <li>· Unique understanding of psychosocial information and social service resources</li> </ul>	<p>Social workers are trained to work with oncology patients. This may require a Master’s Degree in Social Work and a clinical license. In addition to addressing barriers facing patients, social workers also have advanced understanding of psychosocial issues including appropriate mental and behavioural health interventions. They are also fluent in available social service resources and assist patients in obtaining the resources and services they need to address their concerns. Social workers refer to nurse navigators for clinical concerns as well as patient navigators or peer navigators to address non-clinical barriers</p>
<p><b>Patient Navigators</b></p> <ul style="list-style-type: none"> <li>· Do not hold a clinical license</li> <li>· Unique focus on helping to address practical barriers for patients</li> <li>· Unique understanding of resources available to solve non-clinical barriers</li> </ul>	<p>Patient navigators come from a variety of professional backgrounds. They specialize in addressing non-clinical barriers facing patients such as:</p> <ul style="list-style-type: none"> <li>· Logistical issues</li> <li>· Insurance and financial challenges</li> <li>· Education and employment issues</li> <li>· Communication challenges</li> <li>· Cultural, religious or spiritual concerns</li> </ul> <p>Patient navigators adhere to strict boundaries and refer to nurse navigators for medical concerns and treatment decision assistance and to social workers for patients’ psychosocial care needs.</p>
<p><b>Peer Navigators</b></p> <ul style="list-style-type: none"> <li>· Do not hold a clinical license</li> <li>· Volunteers who focus on nonclinical challenges facing patients</li> </ul>	<p>Peer navigators are volunteers and are often cancer survivors and/or live in the communities they serve. They have a unique understanding of the challenges facing the patients they serve. Peer navigators must adhere to strict boundaries referring to nurse navigators for clinical needs, social workers for psychosocial and social service needs and patient navigators for additional assistance with practical challenges.</p>

As the patient navigation profession grows there has been a realisation that the development of metrics and core competencies is essential to evaluating their navigation services. A focus on what is the measure of success and what does return on investment look like, is imperative in building the business case for a patient navigation program. The

Academy of Oncology Nurse and Patient Navigators are in the process of developing metrics for evaluating patient navigation programs.

One study by Treiman et al. (2015), addressed the psychosocial needs of cancer patients from diagnosis through post treatment survivorship and the implications of patient navigation services outside the traditional clinical setting. The authors found that the level of emotional distress decreased from study intake and six weeks after intake, patients who experienced the provision of emotional support from their navigator had a significant reduction in cancer-related concerns. Further, participants who had an emotional support navigator reported greater confidence in their ability to access emotional support, to talk with their healthcare team about personal problems related to their diagnosis, and to take action to make themselves feel better<sup>31</sup>.

The Australian health system, whilst often referred to as one of the best universal health care systems in the OECD, faces challenges. These challenges are due to changes in health care needs, demand for improved health outcomes, increasing health care costs associated with expensive treatments and a move towards precision-based medical care, as well as an aging population leading to many living with complex comorbid conditions.

There is pressure on policymakers to address care coordination, patients' needs and experience, patients' engagement in healthcare delivery and the redesign of funding mechanisms. Workforce demands in Australia are at critical points and require rethinking; patient navigators have operated successfully in the US and UK for many years. The patient navigation model works well in oncology care and is easily transferable to the chronic disease system. Utilising the GW Cancer Centres definition of *types of navigators* provides health services an opportunity to invest in demonstration projects that address particular issues.

In Victoria there is widespread recognition that our approach to delivering best practice cancer care requires rethinking. Peter Mac has recently implemented a patient navigation model in each tumor stream. The following outlines the patient navigator position.

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<sup>31</sup> Treiman K, Bann C, Squiers L, et al. Cancer support services outside of clinical settings: an evaluation of LIVESTRONG Foundation's Cancer Navigation Program. *Journal of Oncology Navigation & Survivorship*. 2015;6(3):8-17

## Patient Navigation at Peter MacCallum Cancer Centre

At Peter Mac our patient care is delivered via a tumour stream model. This means that a patients' care is coordinated and provided by a multidisciplinary team of people who have specialist knowledge of a specific type of cancer.

The Patient Navigator is an integral member of this team, playing an important role in providing the first line response to incoming calls from patients, carers and referrers in the community needing assistance. The Patient Navigator resolves questions and concerns about how to organise appointments, change appointments or clarify appointment instructions. If the caller needs clinician input the Patient Navigator transfers the call to the most appropriate clinical staff member or service. They are an expert in supporting patient flow through the cancer care system and play an important role in facilitating timely patient access.

Patient Navigators are responsible for ensuring the patient's diagnostic, treatment and clinic review appointments are appropriately timed, sequenced and coordinated. This includes ensuring, where clinically appropriate, that multiple appointments are booked on the same day and or/ face to face consultation are replaced with video/telehealth consultations, to reduce the patients' travel burden.

The Patient Navigator works closely with the tumour stream specialist nurses and doctors who will provide support and direction regarding daily work priorities. This includes attending tumour stream based clinics to support the multi-disciplinary team to ensure the clinics run smoothly. In addition, the Patient Navigator provides administrative support for the weekly Multidisciplinary Meetings (MDMs) by ensuring all required patient diagnostic and pre-treatment assessment data is prepared and available for the meeting to facilitate timely treatment planning and recording of MDM outcomes.

The Patient Navigator also works closely with the Registrations and Referrals team to ensure that urgent patients are identified and prioritised quickly for Registration and first appointments<sup>32</sup>.

## Opportunities for improvement

Whilst the above model of patient navigation is focussed on administration there is an opportunity to implement a peer/volunteer model of patient navigation. Health services visited in the US had mature models of volunteering where volunteers were recruited for particular purposes and with particular skill sets. MD Anderson in Houston utilise *myCancerConnection*; a cancer support community of trained volunteers that may be survivors or caregivers that have a cancer experience. A database matches volunteers with people requesting peer support. The *myCancerConnection* cancer support community provides opportunities for patients, survivors, and caregivers to connect in person or by phone.

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<sup>32</sup> Patient Navigator Position Description: Peter MacCallum Cancer Centre 2018

## Peer Navigation

The development of a well governed peer support program whose purpose is to provide peer navigation for particular purposes provided in conjunction with high quality patient information that is targeted to individual needs should be considered. A demonstration project that works with the clinical team and supports the nurse consultants and patient navigators, represents an opportunity to showcase how patient-centred relationship-based care is responding to the complex needs of patients, particularly those experiencing health inequity.

Peer support is defined as people who are living with the same or similar illnesses share their time and experience with each other, to offer hope, encouragement and a positive role model.

The word 'peer' is important. It means one of equals. It is different yet complementary to the vital care provided by doctors, nurses and allied health professionals. Research shows talking with someone who has shared a similar experience can make a significant difference by:

- Offering strategies for better self-management
- Providing an avenue for people to express their feelings with people who are 'in the same boat'
- Enabling greater confidence and a sense of hope into the future
- Reducing feelings of isolation especially for those who may not have family or friends, or who cannot voice their concerns to them.

Peer support can be especially useful for people who are newly diagnosed and/or coming to terms with a life-long condition. It can also be as vital for partners, caregivers, friends, families or siblings. Development of a peer navigation program in partnership with the community sector will enable Peter Mac to leverage off the high quality work that is offered by the community sector. This model also addresses the disconnect with the primary and tertiary health sector supporting a better integrated care system.

## Financial Aid Navigation

The term 'financial toxicity' is broadly used to describe the distress or hardship arising from the financial burden of cancer treatment. In much the same way as physical side-effects of treatment like fatigue, nausea or blood toxicities, financial problems after cancer diagnosis are a major contributor to poorer quality of life, treatment non-adherence and delayed medical care<sup>33</sup>.

A number of studies demonstrate that individuals with cancer are at higher risk of experiencing financial difficulty than are individuals without cancer. Historically, cancer has been one of the most costly medical conditions to treat in Australia. For patients and their families with cancer, the financial impact of this disease can be devastating. Although this may also be a problem for patients with other serious diseases, patients with cancer are

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<sup>33</sup> Gordon.L et al. Financial Toxicity- What is it and how to measure it. Cancer Forum Vol 41, N 2. July 2017

particularly vulnerable, in part due to the high costs associated with multiple components of care, advancements in technologies, new oncology pharmacotherapies and surgical techniques, increased use of imaging, and genetic testing<sup>34</sup>. In addition, ancillary costs such as travel, parking, accommodation, medical aids and equipment, home help and child care also contribute to the financial toxicity a person may experience. Health systems are consistently challenged by constrained budgets resulting in a reliance on patients to make larger co-payments and financial contributions to their healthcare<sup>35</sup>.

Patients with cancer often believe they are sufficiently protected from high medical costs through their public health system or their private health insurance, only to discover inadequate coverage and subsequent ‘bill shock’ as invoices arrive<sup>36</sup>. Whilst the Australian health system claims ‘universal health care’, in practice this may not be truly universal. Additional patient out-of-pocket expenses are common even in countries where there is universal health care or when individuals purchase private health insurance. High out-of-pocket healthcare costs have led to the recent conceptualisation of ‘financial toxicity’.

Whilst Australian health outcomes rank well internationally, Australia’s out-of-pocket costs for health care are sixth highest among Organisation for Economic Cooperation and Development countries, despite universal health insurance. Out-of-pocket expenses accounted for 57 percent of non-government health expenditure in 2011-12, or over 17 percent of all health care expenditure. Health care costs in Australia continue to rise well above the consumer price index. The net burden of costs are reported by clinicians to influence some decisions that patients make, with the potential for detrimental health outcomes for individuals, and for Australia’s health as a whole<sup>37</sup>.

A large degree of Patient Navigation programs run internationally focus on the development of financial advocacy and navigation for patients undergoing cancer care. Of the 12 health services visited during the Churchill Fellowship, all had a well-established financial advocacy service that worked to address the financial barriers to accessing health care. The Maggie’s Centres in the UK, whose purpose is to provide free practical, emotional and social support to people with cancer, their families and their friends have financial aid services in all of their Centres and provide an invaluable service for visitors.

Consideration should be given to the development of a financial navigation service that provides individual financial advice and information to patients and families accessing cancer care addressing the following:

- Carers payments
- Budgeting and advice on managing costs of daily living
- Centrelink payments; advice and support to complete required documentation
- Debt management

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<sup>34</sup> e Souza JA, Wong YN. Financial Distress in Cancer Patients. *J Med Person*. 2013;11(2).doi:10.1007/s12682-013-0152-3

<sup>35</sup> Gordon LG, Walker SM, Mervin MC, et al. Financial toxicity: a potential side effect of prostate cancer treatment among Australian men. *Eur J Cancer Care (Engl)*. 2017;26(1).doi:10.1111/ecc.12392. Epub 2015

<sup>36</sup> Laba TL, Essue BM, Jan S. Financing options to sustain Medicare: are we committed to universalism? *Med J Aust*. 2015;203:244-5.e1

<sup>37</sup> Currow D. & Aranda S. 2016 Financial Toxicity in clinical care today: a “menu without prices”. *Medical Journal of Australia* 204 (11) June 2016

- Transition to retirement strategies
- Advice on accessing superannuation and support in facilitating discussions with superannuation companies

## Legal Navigation: Health Justice Partnership

In Australia one in five people have three or more legal needs in any given year, many of these Australians are those experiencing higher health disparities and are the most marginalised and vulnerable in the community. These people are more likely to raise these problems with a trusted healthcare professional<sup>38</sup>.

In Australia, over recent years there has been a rapid growth of Health Justice Partnerships (HJP) in healthcare settings. Psychosocial obstacles are common barriers of low-income individuals facing a cancer diagnosis. Legal solutions can help to minimize these obstacles, yet patients rarely have access to these services. The goals of patient navigation being to eliminate barriers to care: be they psychological, financial or logistical. Incorporating legal services into the patient navigation model for cancer and other serious illnesses will further this goal by eliminating a substantial barrier to care, assist with unresolved legal issues, and enable patients to fully focus on treatment and survivorship<sup>39</sup>.

The Law and Justice Foundation (NSW) research indicated that people with chronic illness or disability are more likely to experience disadvantage and social exclusion. They are vulnerable to a wide range of legal problems, with lower rates of resolution. This suggests a bi-directional association and the benefit of an integrated service model like a Health Justice Partnership where health, welfare and legal services work together to improve the health, social and justice outcomes of people with chronic illness or disability<sup>40</sup>.

### What is a Health Justice Partnership?

Although Health Justice Partnerships (HJPs) take many forms, essentially they are a partnership between members of the legal, health and welfare professions. They are intended to create a more integrated approach to problem solving for patients/client groups facing immediate health, legal and social issues. Issues can range from outstanding fines, problems with paying the rent, appointing powers of attorney and family law matters (e.g. divorce, child protection).

Beyond service provision, HJPs also see it as their role to advocate on issues that have noticeable impact on patient/client groups and can offer community legal education to patient/client groups and staff.

All of the health services visited provided a patient legal advice or navigation service. Many were pro bono services established by large law firms as part of their corporate social responsibility. Many Victorian health services run very busy HJPs. Consideration will be

<sup>38</sup> Health Justice Australia website accessed 08/09/18 <https://www.healthjustice.org.au/hjp/health-justice-partnerships-in-australia/>

<sup>39</sup> Retkin R et al 2013 Legal Services: A Necessary Component of Patient Navigation. Seminars in Oncology Nursing Vol 29 ,issue 2 May 2013

<sup>40</sup> McDonald, HM & Wei, Z 2015, How people solve legal problems:level of disadvantage and legal capability. Justice issues paper 23, Law & Justice Foundation of NSW Sydney

given to establishing this service at Peter Mac, in partnership with other health services situated in the Parkville precinct.

## End of Life Care Navigation

There is a broad cultural unwillingness to acknowledge and talk about death. Not enough attention is given to death in our healthcare system. Effective end-of-life care (EoL) is based on the understanding that death is inevitable, and a natural part of life. A focus on comfort and dignity can often be difficult to achieve in an overstretched busy hospital. Providing patients an opportunity to consider how they want their EoL to be supported would be considerably simpler if it was removed from the medical model and considered in the social model of health.

Consider the other end of the spectrum, “birth”. Much time and thought is invested into how a woman would like to give birth, the system adjusted accordingly, birth centres were developed, birth doulas invented and a non-interventionists philosophy has been espoused and championed. If we were to take the same philosophy with EoL there would be far fewer people dying in hospital undergoing futile treatments.

Supporting patients and healthcare professionals to talk about death, become more death-aware, and learn how to accompany a person through EoL is a challenge. As a leading cancer research, education and treatment centre globally and in Australia, and with a vision to provide the world’s best cancer care, Peter Mac has a vital role to play. This includes ensuring that the best supports are in place for staff, patients, families and carers irrespective of where they are in their cancer journey. Making decisions around planning for future health care and end-of-life decisions are also part of providing these supports. Peter Mac’s Prevention and Wellbeing Model recognises that care involves consideration of the whole person across the lifespan, including at EoL.

Delivering patient-centred care at the EoL phase supports positive experiences beyond the individual to family circles, community networks and healthcare professionals. Providing a forum for our patients, their families and healthcare teams to tell us what matters to them, reduces the risk of patient choices not being heard resulting in sub-optimal EoL experiences, complicated grief and extended bereavement.

Developing an EoL navigation service that complements the work of our palliative care team provides an opportunity to embed wellbeing principles and practices to promote better and informed EoL experiences. Hosting this service in a non-clinical space such as the Wellbeing Centre, where the principles of self determination and patient choice have more room for consideration and are integral to our service. Whilst these principles underpin all care at Peter Mac the reality of workforce pressures and increasing demand impact on the time available in a busy clinic or ward to spend an hour with a patient to talk about EoL.

The development of a service will provide tailored practical advice on EoL; provide education to families and friends and information based on relevant legislation such as the Victorian Government’s Medical Treatment Planning and Decisions Act 2016 that came into effect earlier this year. This Act creates clear obligations for health practitioners caring for

people who do not have decision making capacity. It also gives statutory recognition to advance care directives, which will allow Victorians to:

- Make an instructional directive (which will provide specific directives about treatment a person consents to or refuses)
- Make a values directive (which will describe a person's view and values. A medical treatment decision maker and health practitioner will be required to give effect to a values directive)
- Appoint a medical treatment decision maker (who will make decisions on behalf of a person when they no longer have decision making capacity)
- Appoint a support person (who will assist a person to make decisions for themselves, by collecting and interpreting information or assisting the person to communicate their decisions).

In addition, Voluntary Assisted Dying (VAD) legislation comes into effect in June 2019. As a leading Victorian Cancer service it is likely a number of our patients will be considering VAD; an EoL navigation service seeks to support our work in EoL to ensure we are ready for the new legislation and have the best resources available to support our patients with planning for EoL. It is timely and crucial for health professionals to implement initiatives that are designed to raise awareness and build the capacity of patients, carers and health professionals to do dying better. By doing so, we will contribute to the overall wellbeing of our patients in the final stage of life, and their family and friends, allowing them to feel more empowered and supported to make their own treatment decisions.

## Aboriginal and Torres Strait Islander Cancer Navigation

Members of the Aboriginal and Torres Strait Islander population have poorer health outcomes compared to the broader Australian population, with higher rates of mortality, illness and disability from many major disease, in particular cancer. As identified earlier in this report the Native American population has experienced similar historical traumas and discrimination to our Aboriginal and Torres Strait Islander population. When visiting the University of Colorado Patient Navigation Training Collaborative their development of Native American patient navigation ensures a model of care that better supports marginalised groups has better cancer outcomes.

A recent cultural safety audit at Peter Mac identified a number opportunities to improve cancer care for our Aboriginal and Torres Strait Islander population. Development of a Aboriginal and Torres Strait Islander cancer navigation service that places significant attention on, not only the cultural safety, but care coordination and navigation of the cancer system. There are workforce shortage considerations that will impact on our ability to implement a sustainable model of Aboriginal and Torres Strait Islander cancer navigation.

This navigation path will require further investment and support from our health system than currently available. However, the return on investment in improving cancer outcomes for our first nation people should be of the highest priority. Recently published work in South Australia<sup>41</sup> provides evidence that the practice of cancer care, navigation and

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<sup>41</sup> Reilly R et al. Aboriginal experiences of cancer and care coordination: Lessons from the Cancer Data & Aboriginal Disparities (CanDAD) narratives. Health Expectations. 2018:1-10

coordination delivers potentially better cancer outcomes for Aboriginal & Torres Strait Islanders by improving access and equity of care.

# Conclusion & Recommendations

This Fellowship has highlighted the need for Australia to consider alternate models of care that better address those experiencing health disparities. The patient navigation model of care enables the patient to be an active participant in their care. It also acknowledges that barriers to care can be identified by ensuring the social model of health is the principal tenet of cancer care. Addressing and reducing barriers, access to screening, diagnosis and treatment, supportive care and survivorship are part of the experience of a cancer patient. Whilst there is no single model that can address all these issues simultaneously, identifying where in the continuum of cancer care the patient experiences the most challenges, should be the driver for establishing a patient navigation program.

The patient experience movement is increasingly emerging as a credible mechanism for measuring patient navigation success. Research and evidence must underpin the establishment of the patient navigation program ensuring the metrics for measuring success are validated tools that capture what you are trying to address in order to demonstrate return on investment.

Every health service or organisation I visited were implementing patient navigation models that addressed the particular needs of their patients. Identifying the problem you are trying to address is tantamount to success. I will utilise the following principles to support the development of patient navigation:

1. Understand the problem you are endeavouring to address
2. Ensure the development of a patient navigation program is developed utilising principles of co-design with the patient as a partner
3. Ensure the model is part of the multidisciplinary team
4. Ensure clear scope of practice and role delineation
5. Implement a rigorous program evaluation.

The development of the specific patient navigation services that are focussed on particular barriers or cohorts would support the current model of cancer care at Peter Mac. The scoping of these navigation services to ensure they compliment and support current service delivery is a priority outcome of this Churchill Fellowship.

- Financial Aid Navigation
- Health Justice Partnership
- End of Life care Navigation
- Peer Navigation
- Aboriginal and Torres Strait Islander Cancer Navigation.

## Appendix A - Itinerary

Date	Meeting	Activity
April 16-18	<b>The Beryl Institute Conference</b> “The Patient Experience” (Chicago)	Conference
April 18	<b>University of Chicago Medicine</b> (Chicago)	Hospital Tour
April 23	Professor Betsy Risendale School of Public Health & Founder patient Navigation Training Collaborative <b>University of Colorado</b> (Denver)	Meeting
April 24	Patricia A. Valverde PhD MPH Director, Patient Navigator Training Collaborative (PNTC) & Erin Martinez Program Manager ,Patient Navigation Training Collaborative <b>University of Colorado</b> (Denver)	Meeting
April 24	School of Public Health Leadership <b>University of Colorado</b> (Denver)	Meeting and Presentation
April 26	Elizabeth Garcia, MPA BSN Executive Director, Patient Experience Office of Process Improvement & Quality Education <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Paula Lewis Patterson, DNP, MSN. Executive Director, Cancer Survivorship Office of Cancer Survivorship <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Toni Abbasi, MBA, DNP Executive Director, Projects & Operations <b>MD Anderson Cancer Network</b> (Houston)	Meeting
	Larkin Strong, PhD Assistant Professor Health Disparities Research <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Elizabeth Frenzel, MD Professor Employee Health Services – Patient Care <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Melissa S. Lopez, MS Program Manager Cancer Prevention & Control Platform <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Therese B. Bevers, MD Medical Director, Cancer Prevention Clinical Cancer Prevention <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
	Cindy Shursen, MA Program Manager Office of Health Policy <b>MD Anderson Cancer Centre</b> (Houston)	Facility tour
	Qian Lu, PhD Associate Professor Health Disparities Research <b>MD Anderson Cancer Centre</b> (Houston)	Meeting
Susan P. French Associate VP, Volunteer Services & Merchandising <b>MD Anderson Cancer Centre</b> (Houston)	Meeting	
May 1	Dr Mardge Cohen and Dr Gordon Schiff (Boston)	Meeting

May 2	Paul Levy* and Farzana Mohamed (Boston) * author of Goal Play “Lessons in Health Leadership from the soccer field”	Meeting
May 3-6	American Oncology Nurse and Patient Navigator Conference (AONN) (Boston)	Conference
May 7	Dr Beth Lown <b>The Schwartz Center for Compassionate Healthcare (Boston)</b>	Meeting
May 9	Nancy A. Borstelmann, LICSW Director, Patient/Family Support Services <b>Dana-Farber Cancer Centre (Boston)</b>	Meeting
	Ann Partridge, MD Director, Adult Survivorship Program <b>Dana-Farber Cancer Centre (Boston)</b>	Meeting
	Edward J. Benz, Jr, MD President and CEO Emeritus <b>Dana-Farber Cancer Centre (Boston)</b>	Meeting
	Craig A. Bunnell, MD Chief Medical Officer <b>Dana-Farber Cancer Centre (Boston)</b>	
	Jennifer Ligibel, MD, MPH Director, <b>Zakim Center for Integrative Therapies Dana-Farber Cancer Centre (Boston)</b>	
	Anne H. Gross, PhD, RN, FAAN Vice President, Adult Nursing & Clinical Services <b>Dana-Farber Cancer Centre (Boston)</b>	
Jennifer Ligibel, MD, MPH Director, Zakim Center for Integrative Therapies <b>Dana-Farber Cancer Centre (Boston)</b>	Meeting	
Zakim Center for Integrative Therapies <b>Dana-Farber Cancer Centre (Boston)</b>	Tour	
May 10	Edward J. Benz, Jr., MD President and CEO Emeritus <b>Zakim Center for Integrative Therapies Dana-Farber Cancer Centre (Boston)</b>	Meeting
	Suzanne Fountain Director, The Jimmy Fund <b>Zakim Center for Integrative Therapies Dana-Farber Cancer Centre (Boston)</b>	
	Krietta Jones Associate General Counsel <b>Zakim Center for Integrative Therapies Dana-Farber Cancer Centre (Boston)</b>	
	Terry Mazeika, MSN, RN, OCN Adult Ambulatory Services <b>Dana-Farber Cancer Centre (Boston)</b>	Meeting
	Laura Ma, RN, BSN, OCN Adult Ambulatory Services <b>Dana-Farber Cancer Centre (Boston)</b>	

May 10	Anne L. Levine, MBA, MEd Vice President, External Affairs <b>Dana-Farber Cancer Centre</b> (Boston)	Meetings
	Magnolia Contreras, MSW, MBA Director, Community Benefits <b>Dana-Farber Cancer Centre</b> (Boston)	
	Hannah Green Ambulatory Practice Management Director, Disease Center Operations <b>Dana-Farber Cancer Centre</b> (Boston)	Meeting
	Deborah Toffler, MSW, SCSW Director, Patient and Family Programs and Services <b>Dana-Farber Cancer Centre</b> (Boston)	Meeting
	Maritza Nassif, Program Coordinator Patient & Family Programs & Services <b>Dana-Farber Cancer Centre</b> (Boston)	Meeting
	Patricia Stahl Senior Manager, Volunteer Services and Programs <b>Dana-Farber Cancer Centre</b> (Boston)	
	James Tulskey, MD Chair, Department of Psychosocial Oncology and Palliative Care <b>Dana-Farber Cancer Centre</b> (Boston)	Meeting
May 14	Professor Beth Jones Assistant Director for Diversity and Health Equity Yale Cancer Center Program Director <b>Smilow Cancer Screening and Prevention Program</b> <b>Center for Cancer Epidemiology &amp; Prevention</b> <b>Yale School of Public Health &amp; Yale Cancer Centre</b> (New Haven)	Meeting
May 15	Julia Ramirez Patient Navigator <b>Memorial Sloan Kettering</b> (New York)	Meeting
May 16-18	Ms Wandina Pilarte Patient Navigation Training session <b>American Cancer Society</b> (New York)	Training program
May 23	Dr Lallita Carballo and Dr Hilary Plant Joint Clinical Leads for Supportive Cancer Care & Heads of the Macmillan Support and Information Service <b>Cancer Academy</b> (London)	Meeting
May 24	Diane Dunne and Claire Barry <b>Imperial College</b> (London)	Meeting
May 29	<b>Maggies Centre</b> (Manchester)	Tour and Meetings
May 29	Meeting Patient Advice & Liaison Service <b>The Christie Hospital</b> (Manchester)	Meeting
May 31	Sarah Beard <b>Maggies Centre</b> (London)	Tour & meetings