FINAL REPORT

Perceptions of the Role of the Primary Care Generalist within Multidisciplinary Cancer Care Team

[PCGen-Cancer]

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BACKGROUND

The Victorian Cancer Action Plan (2008-2011) advocates a multidisciplinary team care approach for all people with cancer from diagnosis through to palliative care. Evidence exists that generalist primary care providers (e.g., General Practitioners) are suited to managing patients with chronic and complex conditions, as generalists can provide whole-person, continuous and coordinated care over the patient's life course. Limited information exists about what people with cancer want from or value about their generalist primary care providers. This study investigated the perceptions, experiences and expectations of people with cancer, cancer specialists, general practitioners and members of Victorian cancer support organisations about the role of GPs within multidisciplinary cancer care teams.

KEY FINDINGS

- People with cancer and GPs do not use the term 'team' to refer to the health care professionals involved in their cancer care nor recognise GPs as being part of a team, when discussing current cancer care arrangements. This finding potentially highlights the dominance of professional autonomy and independence within professions involved in providing cancer care. The lack of recognition by people with cancer of their care being delivered by a cancer care team is likely to be a constraint on the multidisciplinary cancer care team approach.
- The existence, and need for, 'relationships' and 'communication' between all cancer care professionals, GPs and people with cancer is viewed by all as critical to ensure quality cancer care. Despite the existence of Patient Management Frameworks for cancer care within Victoria, and rebates from Medicare for case conferencing, these systems as currently functioning may not be effective for supporting (administratively nor financially) ongoing information sharing and communication between GPs and cancer specialists.
- Many people with cancer viewed their GPs as having a central role in their overall health care and this includes their overall health throughout their cancer care journey. However, there is a lack of clinician role clarity among people with cancer, GPs and cancer specialists, about GP roles within multidisciplinary cancer care teams.
- The type and quality of GP roles throughout a person's cancer care journey and the overall care provided is influenced by GP attributes (e.g., attitudes, experiences, skills; networks), and their practice context (e.g., patient workload; time constraints), the type of cancer, whether the person with cancer has co-morbidities, and importantly the strength and longevity of the GP's relationships with the person with cancer.
- Cancer specialists view GP roles within cancer care as positive, and as a link between tertiary care and the person with cancer. However, GPs are not routinely included in current team-based structures (e.g., multidisciplinary cancer team meetings) and only kept informed via letters/emails, leading to information sharing generally being one-way (cancer specialist to GPs) and sometimes being delayed. This potentially limits the GPs capacity to provide input into whole-person care decision-making throughout a person's cancer care journey.
- Members of Victorian cancer support organisations confirmed that the main role of GPs is to support the person with cancer across their cancer care journey, that GPs have a pivotal role in multidisciplinary cancer care teams; and noted that there is currently a lack of effective communication between cancer specialist and GPs.
- The role of GPs across the cancer trajectory changes from during the pre-diagnosis/diagnosis phase (*advocate*, communicator, investigator*, interpreter*, and supporter providing psychosocial support to the person and their family and advising about cancer care) to different roles during treatment (*intermediary*, communicator, investigator, a *sounding board*, *supporter*, manager) and to post-treatment roles (generalist, communicator, *observer*, *coordinator* of care and in palliation).

- People with cancer valued and confirmed the theorised dimensions of 'generalists' – *ways of being* (GPs as the trusted interpreter), *ways of knowing* (GPs use of bio-technical and biographical information) and *ways of doing* (GPs as the first point of call, as gatekeeper, as care-coordinator who deals with uncertainty and unexpected consequences). Ideally people with cancer want their GPs to interact and communicate with them, their family and their cancer specialists, to be a navigator, to be available, knowledgeable, genuine, to check things and follow through with investigations. However, people with cancer do not want their GP to be a surrogate cancer specialist

APPROACH

This study had two phases. A literature review to explore perceptions and understandings of the role of GPs in multidisciplinary cancer care teams. This was followed by a qualitative research study using semi-structured individual face-to-face, telephone or focus group interviews based on an evidence-based conceptual model to obtain the views, experiences and expectations on the role of the generalist primary care provider (i.e., GPs) in the cancer care team. Forty-two participants were involved, including: 21 people with cancer; seven GPs; six cancer specialists; and eight members of Victorian cancer support organisations. Ethics approval was obtained from the Cancer Council Victoria's Human Research Ethics Committee and The University of Melbourne Human Research Ethics Committee.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

The study has provided rich practice-based evidence about the myriad of dynamic and interdependent roles that GPs have and potentially can have within multidisciplinary cancer care team approaches. The current Victorian Cancer Action Plan and accompanying cancer care policy guides (e.g., Achieving Best Practice Cancer Care: a guide for implementing multidisciplinary care) demonstrates its commitment to high quality evidence informed multidisciplinary cancer care, as exemplified by the key principle below:

> *The key principle of multidisciplinary care is that all cancer patients will have the opportunity to have prospective treatment and care planning by an appropriate multidisciplinary team…The patients' general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.*
>
> *Key Principles for Multidisciplinary Care (1, p. 13).*

Our study findings can inform the development and implementation of the above principles. As a way of concluding this study we outline implications for policy, practice and research below.

Policy Implications

- **Enhanced clarity about team concepts**: With the current Victorian cancer care policy documents (e.g., Victorian Cancer Action Plan, Integrated Cancer Initiative, Patient Management Framework) advocating 'team-based' multidisciplinary cancer care, and identifying GPs as part of the cancer care team, work could be done with all cancer care policy makers and professionals about what the term 'team' and 'teamwork' means for the delivery of care, for health professionals and for people with cancer. Furthermore, current evidence reinforces that 'teams' or 'teamwork' is a '*means to an end, and not an end in itself* thus, the impact or outcomes of such models of care for people with cancer needs to be evaluated to inform future cancer care policy decision-making.
- **Enhanced role of existing multidisciplinary cancer care treatment plans:** While there was consensus among cancer specialists and GPs, that GPs have a role in cancer care teams, there was also a lack of clarity regarding GP roles in these care teams. Cancer care treatment plans could be a mechanism to formally identify and recognise GPs roles and promote shared working relationships with cancer specialists

- **Improved business models** New financial arrangements are required to fund ongoing information sharing and communication between the GP and the cancer specialist, and between all health professionals and people with cancer. The current Enhanced Primary Care Medicare items for Case Conferencing, Care Planning and Team Care Arrangements are not remunerating GPs nor cancer specialists for lengthy consultations, non-direct patient care activities (e.g., phone consultations or information provision to people with cancer) thus not facilitating multidisciplinary cancer care team approaches nor shared ways of working together. As there is a lack of evidence about how to incentivise and reward team work where there is both specialist and general practitioner care, research is needed in this area

Practice and Research Implications

- **Improved infrastructure and new integrative processes:** Formal and funded information sharing and communication processes need to be developed between GPs, cancer specialists and people with cancer. Current work on the development of an 'electronic shared health record' may support communication between GPs and cancer specialists and people with cancer. These 'electronic shared health records' could include information about cancer types; the treatment team; treatment plan and side-effects; guidance on management of anticipated toxicities associated co-morbidities and supporting care options within a multidisciplinary cancer care team approaches.
- **Enhanced role of Generalist in Cancer Care teams:** Many people with cancer valued and confirmed the essential skills, elements and dimensions that underpin the role of the primary care generalist (e.g., GPs). However, people with cancer did not want their GPs to be surrogate cancer specialists, but to remain as their generalist (i.e., GP). Further research is required to examine how generalists can form part of the multidisciplinary cancer care team.
- **Enhanced workforce role delineation:** People with cancer especially those with co-morbid conditions state the importance of having their cancer care and overall care coordinated. Whether this role is to be only in the domain of GP may need further exploration.
- **Enhanced cancer education and inter-professional training opportunities:** GPs require easy access to education to gain skills in cancer care that complements their generalist's skills. Given the dominance of a culture of professional autonomy and independence and absence of a culture of team-based care (i.e. shared decision making and responsibility, mutual respect), inter-professional education could provide the framework and opportunities for knowledge transfer and exchange between GPs and cancer specialists in a mutually respectful and on-going learning context.
- **Relationships and accessing quality cancer care:** This study highlights that the strength of the relationship between a GP and a person with cancer can influence the level of active involvement the GP takes in cancer care. Whether this is related to a possible bias from participants, or a reflection of practice, this notion of relationships influencing cancer care requires further investigation. Such an influence (i.e. strength of the relationship) could impact on the consistency of care across a person's cancer trajectory, and hence efforts to avoid this from happening need to be in place. Furthermore, given that the strength of relationships is so important, we need systems in place to ensure consistency of care across a persons' cancer care trajectory.

- **Building the evidence base that strengthens GP roles in multidisciplinary cancer care:** This study has reinforced that there is a need for further research evaluating the implementation of different models of multidisciplinary cancer care involving generalist primary care providers throughout the cancer care journey. Research is also required to establish if multidisciplinary team care approaches improves the quality, coordination, continuity and health outcomes of people with cancer. These research directions align with the recent literature review on the various types of multidisciplinary cancer care team structures and their impact on the quality of cancer care, published as part of a series of papers on 'Towards Improving the Quality of Cancer Care: addressing the Interfaces of Primary and Oncology related Subspecialty Care' in *The Journal of the National Cancer Institute Monograph* 2010 (2). Our study's findings will also be used to inform the development of a module to assess the perceptions of people with cancer regarding their GP's involvement in their cancer care for Cancer Council Victoria's PROSPECT surveys. The aim of questions in this module will be to quantify the findings reported from the current qualitative study.

1. INTRODUCTION

> *…The GP had to deal with all the side effects, try and work out what had caused them, try and refer me onto the appropriate Specialist to deal with them and then write scripts for all the drugs needed to manage the side effects. (Person with Cancer 14)*

The above quote illustrates the array of roles and tasks that GPs are involved in providing care for the whole person throughout their cancer care journey, and that people with cancer require knowledge, expertise and skills beyond any one profession – indicating a need for multidisciplinary cancer care team approaches.

A multidisciplinary team approach to cancer care is widely endorsed in clinical practice guidelines for cancer (3) and such models of care are linked to improved quality of life and reduced mortality (4). The importance of the general practitioner (GP) as part of the multidisciplinary care team is particularly emphasised in the Psychosocial Guidelines for Adults with Cancer (5). Evidence suggests that generalist primary care providers (e.g., GPs) are suited to managing patients with chronic and complex conditions, as generalists can provide whole-person, continuous and coordinated care over the patient's life course (6-8). As the population ages, a greater proportion of people diagnosed with cancer will be living with multiple co-morbidities (9), thus a greater need for generalists to be involved in their cancer care.

Despite recommendations for the involvement of GPs in cancer care, a recent study of family physicians in the USA concluded that 'we do not know what the optimal role of generalist physicians in caring for their patients with an active diagnosis of cancer is' (10, p. 31). While there is limited Australian research on this topic, one study indicated that in contrast to multidisciplinary care (MDC) recommendations (3), most breast surgeons do not consider the GP or the patient to be part of the multidisciplinary team (11). Other studies show that GPs value detailed and specific information from the multidisciplinary team on their patients' cancer treatment (12) and psychosocial information (13). Enhancement of the role of the GP as part of the multidisciplinary team may enable better integration between primary care and other specialist services needed to optimise the overall physical health and psychosocial well being of patients (14, 15). Within the broader literature, patients report valuing interpersonal skills and communication, technical competence, accessible services, continuity of care and information provision in primary care services (16, 17).

The current cancer policy context (e.g., Victorian Cancer Action Plan 2008-2011 (18), Integrated Cancer Initiative, Patient Management Frameworks (19)) also advocate for multidisciplinary team care approaches involving GPs for all people with cancer from diagnosis through to palliative care, as seen below:

> *The patients' GP is regarded as a team member and processes to ensure effective communication with GPs are implemented* (Appendix 1: Key Principles for Multidisciplinary Care (1, p 13-14)).

More broadly, the Australian government is increasingly encouraging linkages, collaboration and specifically teamwork within primary health care for patients with complex and chronic conditions (20). This is in response to concerns about quality, coordination and continuity of care; increasing burden of long-term, chronic, complex and multi-morbidity; workforce shortages, mal-distribution and a variable skill mix; and increasing focus on role expansion with the need to expand the scope of practice. In fact a key objective of the National PHC Strategy is to support team-based approaches within primary health care (PHC) as can be seen below:

Primary health care professionals work in environments which support a team-based approach and a work/life balance, with conditions that attract, support and retain a strong local workforce.

(20, p. 112)

Despite, the positive-developing evidence base and positive-policy context, there is a paucity of evidence concerning people with cancer's views about the role of GPs in their cancer care. With patient centred care defined as care that is responsive to patients' needs, values, and preferences (21), the patient perspective is critical to identifying how GPs are currently perceived to be involved in cancer care, and to inform the development of new models of care.

This study aimed to address current gaps by investigating the perceptions, experiences and expectations of people with cancer, cancer specialists, general practitioners and professional members of Victorian organisations that support people with cancer and their families along across the cancer trajectory, about the role of GPs within multidisciplinary cancer care teams.

2. APPROACH

This study had two phases: Phase 1 was a purposive literature review to explore perceptions and understandings of the role of GPs in multidisciplinary cancer care – its findings are available as a separate report. Phase 2 was a qualitative research study using semi-structured individual face-to-face or telephone interviews and focus groups based on a an evidence-based conceptual model to obtain the views, experiences and expectations on the role of the generalist primary care provider (GPs) in cancer. Forty-two participants were involved, including: 21 people with cancer; seven GPs; 6 cancer specialists; and eight members of Victorian cancer support organisations. Ethics approval was obtained from the Cancer Council Victoria's Human Research Ethics Committee and The University of Melbourne Human Research Ethics Committee. This next section presents the: recruitment strategy and outcomes; data analysis and interpretation processes.

2.1 Recruitment Strategy and Outcomes.

Recruitment strategies varied according to the participant group. For example strategies included advertisements on cancer support groups' websites for people with cancer; contact with managers of medical clinics across Victoria and recommendations by members of the advisory board for GPs; advisory board contacts for cancer specialists; and personal contact with cancer support organisations for professional members such as support group facilitators and counsellors. Further details are in Appendix A.

All participants were provided with participant information sheets and consent forms (Appendix B), and given the opportunity to have queries about the project answered. Consent was obtained prior to the interviews either by signing the consent form and returning to this researcher, or recording consent at the interview commencement. Participants, cancer support organisations and key recruiting personnel were sent summaries of the findings. General practitioners received a $50 book voucher in recognition of their time in telephone interviews. People with cancer who attended focus groups were offered reimbursement for their travelling costs and all declined.

The interview guidelines were based on the conceptual model of generalism developed as part of the APHCRI literature review of the role of generalism the 2020 primary care team (22). Each participant group had specific questions related to their category. Copies are in Appendix C. General practitioners and cancer specialists participated in telephone interviews at mutually convenient dates and times. People with cancer and professional members of cancer support organisations, participation options were telephone, in-person or in focus group interviews. Details are in Appendix D, Table 1. In-person and telephone interviews ranged from 25 to 35 minutes and focus group interviews were approximately 90 minutes. All interviews were audio recorded and transcribed.

2.2 Data Analysis and Interpretation Processes

Data comprised transcribed interviews and managed using the software package QSR NVivo 8 for qualitative analysis. Analysis followed an interpretive approach using a deductive process to divide the data under broad categories or 'nodes' of information with 'broad-brush coding', then 'coded on' to form information categories. Using an inductive process categories of information were developed into themes and themes. For example 'broad brush' coding of chunks of information from the interviews about similar topics were coded into a node of information such as information about the roles of GPs across the cancer trajectory were grouped under 'cancer trajectory'. This data were reviewed for the different phases of the trajectory then 'coded on' to nodes labeled 'pre-diagnosis and diagnosis', 'during treatment', 'after treatment' and 'palliative care'. The data in these phase 'nodes' or 'categories' were further coded on to 'child nodes' labeled with the various roles identified by participants such as an *advocate*, *a resource* and *investigator*. Themes evolved through an inductive process by identifying the common threads of similarities and differences in the analysis. For example: a thread of similar concepts that emerged was the GP as the *link*, *defense* or buffer between PwC and other health professionals and medical facilities. Modelling (23) was used to conceptualise the findings. Data analysis exemplars are in Appendix F

3. RESULTS

3.1 Participant profiles

Overall 42 participants were recruited for study (Table 1) and contributed to 34 transcribed interviews. The findings provide a snapshot of perceptions and experiences of people with cancer, general practitioners, cancer specialists and professional members of cancer support organisations and thus cannot be generalized to all groups in Victoria.

Table 1: Overall participant group

Participant category	No	Male	Female	Urban	Rural	Both
Person with cancer (PwC)	21	6	15	18	3	-
General Practitioner (GP)	7	4	3	5	2	-
Cancer specialist (CS)	6	3	3	6	-	-
Professional member of cancer support organisation (PMSO)	8	3	5	5	-	3
Totals	**42**	**16**	**26**	**34**	**5**	**3**

People with Cancer

Twenty one people with cancer were interviewed including eight people who participated in two focus groups. The majority of participants were female (*n*=15) with 18 of the 21 living in the metropolitan area. Participant ages ranged from 35 to over 80 years with seven each in the 45-54 year range and greater than 65 years.

The majority of people with cancer were diagnosed between 45 and 54 years (*n*=9) and eight participants are currently receiving treatment. The cancer treatments reported were surgery, chemotherapy, hormonal and radiotherapy. Other treatments included stem cell transplantation and elective removal of ovaries. The main other medical conditions were cardiovascular and/or musculoskeletal. Pernicious anaemia and osteoporosis were reported as a result of chemotherapy.

All people with cancer in the study had a GP and regularly attended the same clinic to visit their GP. Ten participants visit their GP less than five times a year and seven visited five to nine times a year.

General practitioners

Seven general practitioners participated in telephone interviews: four GPs were male; ages ranged from 35 to 64 years with four GPs in the 45 to 54 age group; and four GPs practiced in the metropolitan area. Five GPs had practiced more than 20 years as a general practitioner. Three GPs indicated they had on their client list more than 50 patients who had had a cancer diagnosis; two GPs indicated they had between 25-50 patients who had had a cancer diagnosis and two GPs reported less than 25 patients.

All GPs saw patients covering a range of cancer illnesses with skin/melanoma (*n*=7), haematological (*n*=7) and urological (*n*=7) cancers being the most common. The GPs interviewed indicated they saw patients mainly during diagnosis, recovery (after treatments) and in follow-up (surveillance) (*n*=7) phases of the cancer trajectory. Other phases reported were during treatment (*n*=6), in palliative care (*n*=6) and providing psychosocial support for families (*n*=5). These results represent the sample of GPs who participated in the study and cannot be generalised to the GP population in Victoria.

Cancer specialists

Six cancer specialists participated in the study. There were equal numbers of males and females, and ages ranged from 25 to 64 years with the majority between 35 and 45 years. Three cancer specialist had worked in oncology for between 5 to 9 years, and in their current discipline between 5 to 9 years (*n*=4). Cancer specialist oncology disciplines were haematology (*n*=2), medical oncology (*n*=2), palliative care (n=1) and clinical genetics (*n*=1).

The cancer specialists treated a range of cancers including haematological (*n*=3) and colorectal (*n*=3) using various treatments: radiotherapy, chemotherapy and immunological therapy, and bone marrow transplants. Cancer specialists indicated they were involved with people with cancer across the cancer trajectory including genetic pre-diagnostic screening and oncology palliation. All cancer specialists practiced in the public health care system only.

Professional members of cancer support organisations

Eight members of cancer support organisations were interviewed via the telephone. The majority were female (*n*=5). Ages ranged from 23 years to greater than 65 years with the majority in the 45-54 age bracket (*n*=5). The organisations were mainly in the metropolitan area with two organisations covering the rural area as well. Four cancer support organisations support people with cancer across all cancer types, three organisations support men with prostate cancer and one organisation specifically supported women with ovarian cancer as well as other gynaecological cancers.

3.2 How people with cancer view the GP role in their cancer care

When asked, most people with cancer were unaware of their general practitioner being a member of a 'team'. The term was reframed into 'the group of people who look after you in regard to your cancer – the multidisciplinary team'. The GP roles identified during the cancer trajectory are summarised in Table 2. The role common across the trajectory was 'communicator'. The generalist role involved *holistic care*, *prescribing medications*, *putting me back together* and communicating and working with specialists. People with cancer talked about the tasks of GPs as though the tasks were the role of the GP without understanding the medical background behind them. Tasks included *organising blood tests*, referrals and *prescribing and writing scripts*. Further explanation of the GP roles is in Appendix F.

The GP roles across the trajectory as perceived by people with cancer

The role of the GP began very actively with investigating, testing and referral to specialist care. Depending on the cancer type, a patient could be referred on quickly or after a period of testing

> *So he was on the phone straight away and I went down the next day and when I came back they took blood tests and all that sort of thing and arranged for me to see the Specialist. PwC02*

During treatment the role could be active or less active depending on co-morbid conditions and cancer treatment as with haematological cancers. Managing side-effects and supporting patients and families through the treatment phase were the main activities for GPs.

> *[The GP] was involved quite a bit after surgery because I had several incidences of breast infection and a couple of times I went back into [hospital]; they were able to address it immediately but other times I actually went to him and he was able to address the situation and fit me in with antibiotics or whatever. So he's been involved there.... I've had an ongoing relationship with the GP, he's been my GP for 20 years.... It's a psychological support in some ways, because I know that there'res things that probably I would be more prepared to go and discuss with him being in that relationship. PwC21*

Table 2: Summary of GP roles across the cancer trajectory (no ranking)

Pre diagnosis and diagnosis	Treatment	After treatment
advocate	*intermediary*	generalist
communicator	communicator	communicator
Investigator	investigator	Observer/monitor
supporter	supporter	*On-going role*
interpreter	*sounding board*	Co-ordinator of care
	manager	palliation

The role is most active if the patient has existing co-morbidities that the GP is already managing. Some people with cancer prefer their GP to co-ordinate their medications to ensure pharmaceutical interactions are minimised while others preferred the GP to be the GP and the cancer care team to look after everything to do with their cancer.

> *I know [the GP] could have given me any moral support if I wanted to, but it wasn't relevant to me at that stage ... Certainly [the surgical oncologist] has always been supportive and I saw him a lot of times for follow up appointments and he was excellent. PwC19*
>
> *I'm still on hormonal treatment and I'm seeing my breast surgeon and oncologist three monthly turn about. So any issues I have I usually discuss with them. PwC 17*

After treatment, the GP role became more active in getting the person with cancer back to their normal routines. For some PwC, the GP role was about *picking up the pieces* and setting them *back on the right track*. The *on-going role* was monitoring for re-occurrences or secondary presentations of cancer. Depending on the level of patient unmet needs, the GPs' role could involve further referrals for psychological support. Two people with cancer reported they expected their GPs to be there for them during end-of-life care and to manage palliation.

Some PwC changed GPs because they were not happy with the role of the GP in the cancer care and the way they had been treated. In this scenario the person with cancer had an active role in finding another GP and interviewed GPs. The role of the new GP was very active in picking up from specialist reports and developing a working relationship with the person with cancer.

> *There is a lot more people seem to be seeing Specialists but there is no aftercare so the GPs is[sic] always picking up the bits. So I think there is probably a growing trend. PwC 14*

Influences on the GP role

Aspects that impacted the GP role can be categorised into three types of influences: GP attributes, environments and the GP/patient relationship. These are listed in Table 3.

GP attributes were based on qualities valued by people with cancer. These qualities included *'compassion, kindness, considerate'*, honesty, trust, thoroughness, being the person's' *mainstay'* and giving *'peace of mind'*.

Environments included the GP being in the cancer care team: *communicating with specialists*, *reassuring patients* and *receiving reports.* The environment of medical centres promoted friendliness and confidence in the GP team and encouraged PwC to remain with the same GP and medical centre and continuity of care.

Table 3: Three influences with criteria, on and to the GP role (no ranking).

GP Attributes	Environments	GP/PwC relationship
GP attitude	Communication: *with specialists*, *reassuring patients* and *receiving reports*	Length of time with the same GP
Dedication	Being included in cancer care team	The patient's attitude
Follows-up	*Having community links*	Patient preparedness
Cultural background	Medical centre environment	GP relationship with PwC
GP experience of cancer care; own illness experience	Time	PwC assertiveness
Being well informed	*Networks*	
Shows human side		
Being available		

The GP/PwC relationship impacted on the level of involvement of GPs in the cancer care for the person with cancer. The strength of the relationship seemed to be bounded by rapport, person with cancer's level of assertiveness in the relationship, length of time the person with cancer has been seeing the GP, how prepared the person with cancer is for consultations, and if the GP manages any co-morbid conditions.

Overall view of the GP role by people with cancer

PwC's overall view of the role of the GP in the cancer care team can be divided into three areas - (1) PwC see the GP role as being *active* , (2) the GP being *the defense between the patient and other medical establishment* as in being the buffer or invisible barrier protecting the PwC from the medical jargon, medical facilities and other health professionals; and (3) the GP being in the background of cancer care.

(1) The active role included tasks of *regular consultations during treatment* for other conditions and for preventative health care - the generalist role. After treatment the GP was seen to actively *'put pieces back together'*. For one male PwC this was his GP's key role because his body and life had been disrupted through extensive hospital care for infections post surgery. This role enhanced rapport and the relationship between the GP and the patient.

The on-going roles for GPs related to advocacy and to communication. GPs acting as advocates were variable according to the relationship and interest of the GP and whether the GP had time to advocate. These GP attributes influenced the relationships between GPs and patients and their trust in the health care system, as these PwC explain.

> *I've learnt to be strong enough to stand up for myself but there are times when I am so sick that I can't do that either, so I really need advocates ... most of the time [my GP] does, ... that's why I've continued to go to her. PwC11*
>
> *I felt very confident that I had this young man advocating on my behalf, he did, it made me feel very confident indeed in the whole system PwC16*

In some instances, relationships with GPs were tense, PwC *lost faith* in the health care system and would actively seek out and change GPs.

2) 'The defence between the patient and other medical establishment'.

Although only five PwCs contributed to the notion and suggestion of GPs role as being a barrier or buffer between the patient and other medical establishment - protecting them though advocacy and navigating the system for them, the significance was evident when combined with views of the cancer specialists who see the role of the GP as the 'link' in the community. Roles associated with this notion were *interpreter and friend*, *navigator*, researcher, advisor, *co-case manager* and *central focal point* in the cancer care for patients.

> *In my opinion the GP has the opportunity to run defence between the patient and the rest of the medical establishment. ... His role is almost one of interpreter and friend. PwC08*
>
> *Keeping all of the strings tied together from all the different specialists that I see has been absolutely crucial all along ... she's really been that central focal point, particularly with having multiple illnesses PwC11*
>
> *I feel I'm to the point now where I'm virtually as well educated in my specific circumstance as [GP] might be in a way, apart from the drugs of course, and so I guess is sort of a co-case manager. PwC12*

3) The GP being in the background of cancer care was a key role particular for people with cancer who had no co-morbidities. This was the role the GP sometimes took on when the cancer diagnosis was the result of routine health care check organized through another organization (eg screening mammography through 'BreastScreen'). In these situations the person was often linked to a cancer care team without returning to a GP.

> *[The GP] wasn't involved at all with the diagnosis because mine came through the free breast screen and I went straight through [surgical oncologist]... So the only time I saw my GP at that time, was I was going for a flu injection ... PwC19*
>
> *I think I have more of a relationship with my oncologist really. He's wonderful, I can ask him anything. I can ring him between visits he doesn't care. He's great, so I suppose he is the GP substitute really. PwC17*

For some people with cancer, the cancer care team were the health professionals they returned to for any problems or concerns with their cancer care. They did not return to the GP.

> *If I had a problem I always just thought of going straight back to my oncologist or the breast surgeon or whoever I was seeing. It wouldn't occur to me to go and see my GP because I have that direct link to that team. They made it very clear, made me very aware that they were there for you and any time you call. So I didn't really feel the need to go to my GP in those circumstances, because I had the support from the team PwC17*

3.3 How GPs view their role in the cancer care team.

Seven GPs contributed to understanding the role of the GP in the cancer care team. They understood their role as the generalist with many other potential roles. Table 4 lists the different roles identified by GPs.

Across the trajectory

Overall GPs see their roles through the cancer trajectory as providing generalist care, educating, providing psychosocial support to the person and their family, having a monitoring role for side effects of chemotherapy or re-occurrence of the cancer and providing holistic care.

It seems the GP's role does change from being active in the pre-diagnosis and diagnosis phase, to not so active during the treatment phase and then after treatment is completed, the role becomes active again with surveillance and monitoring the patient. This activity pattern reflects the experiences as reported by the people with cancer in section 3.2.

Table 4: GP roles in the cancer care team as viewed by GPs across the cancer trajectory (no ranking).

Pre diagnosis and diagnosis	Treatment	After treatment
generalist	generalist	*generalist*
educator	educator	educator
informant	*Sounding post*	Co-ordinator of routine cancer check reminders
investigator	Surveillance and monitoring role	Surveillance and monitoring
Psychosocial support	Psychosocial support	Psychosocial support
Co-decision-maker	Advocate	Palliative role
	navigator	
	Co-ordinator	

For GPs the activity level related to the 'severity' of the disease, the relationship with the patient, and the communication between the specialists and the GP. Sometimes cancer care is totally managed by cancer specialists and other times the GP is involved because of treatment side-effects. If the GP and PwC have a strong relationship and/or the GP is involved in the cancer management because person with cancer has been proactive in sustaining the GP in 'the team', the GPs role is actively ongoing. Similarly if the GP and PwC do not have a relationship based on reciprocity, trust and co-morbid care, the GP's role is less involved with their cancer care – less active. Further if timely and reciprocal communication occurs between the CS and GP, the GP will feel like being in the cancer care team and thus be more actively involved in the cancer care. The reverse was also evident and the GP role has less involvement and activity. GP's can have a role in learning to adapt to the needs of PwC and the environment in which the needs are met.

> *It depends on the severity of the disease. If I don't have really much input, the patient is completely followed up by that specialist through the period without really linking with me, until the patient finishes the chemotherapy. Then, I don't have much role until they come back when they are completely better. But if the patient is unwell then certainly I am involved with it. So it depends on if the specialist will get me involved from the beginning, or he's happy to follow-up with everything. Sometimes the patients have their phone number and they can ring the oncologist and everything is done through that, and sometimes it's straight away with me and I link with the specialist in between the oncologist GP03*
>
> *My role it's not one hard and fast role. It tends to be just adapted according to the needs of the person at the time and the level of other resources that they have and finally the ability of the other people in the supposed team to communicate with me GP06*

The consistent roles across the trajectory are of being the educator and informing patients, answering their questions, and empowering them with knowledge; and providing psychosocial *support* for the person with cancer and the family by being there to listen, be a *sounding board* in decision-making, refer on for psychological support and supporting them through palliation.

The GP and the team

GPs' views about being in a cancer care team are variable. Some GPs do view themselves as part of the team but others feel they are *invisible* and are left *out of the loop*. They acknowledge a lack of timely communication from cancer specialists and sometimes needing to rely on their patients to give them information. Patients sometimes return to GPs between cancer treatments because of side-effects. The GP role is to manage the side effects either by contacting cancer specialists about the side-effects or use the management plan sent by them to make decisions about treatments and severity of effects. At times GPs and cancer specialists have an existing professional relationship thus the GP can be seen as being in 'the team' caring for the person with cancer.

Factors identified by the seven GPs that impacted on being in the team included communication, appropriate remuneration, having enough time available for patient consultations and/or home visits, geographical distance for people with cancer to attend services in Melbourne and patients' perceptions about the realities of having 'cancer'.

Five GPs discussed remuneration for services as both a barrier and facilitator to involvement in 'the team'. Remuneration was suggested for items such as phone calls from GP liaisons, home visits, and long consultations during busy times. The lack of funding meant GPs were reluctant to be involved in 'the team' . Yet some GPs noted they were included in team meetings through teleconferencing that was remunerated as explained by one GP:

> *I have recently been in the last 12 months involved in, and I thought it was really good ... a Care Planning Meeting. I was able to join by phone and GPs were able to claim an Item Number which was very helpful.... Because often you end up doing things for nothing. That was really helpful joined by phone to their group meeting about a particular person because you have known people for a long time. That is one of the big things you contribute. Understanding the person as a person and background information, you have looked after people for 10 sometimes 20 years. Now for myself you get to know them well, that is what we can offer. We can also offer an understanding of their physical condition - Is there background medical issues? Psychological ... The Division or the Network have [sic] been working with to improve that side of things. GP4*

This contrary view suggests that either there are differing levels of awareness regarding remuneration options for GPs, or that options for remuneration for services vary across s across Victoria due to the work of Victorian Divisions of General Practice.

3.4 How cancer specialists view the role of the GP in the cancer care team

Six cancer specialists (CS) from various oncology disciplines contributed to these findings, thus their experiences and opinions provide a snapshot of cancer specialists' views about the GP in the cancer care team. Overall, CSs do view the GP as being a valued member of the cancer care team, particularly in the role of generalist, surveillance, monitoring, managing side effects and communication with CS about the PwC's progress. The roles GPs play in the cancer care team as viewed by cancer specialists are listed below (Table 5)

Table 5: Summary of GP roles across the cancer trajectory as viewed by CS (no ranking)

Pre-diagnosis & diagnosis	Treatment	Post treatment
	On-going	*On-going*
Screen	Generalist	*Generalist*
Monitor	*Monitor*	*Monitor*
	Link/middle person	*Transition*
Surveillance		*Surveillance*
Investigator	Management of co-morbidities	*Troubleshoot*
Communicator	Communicator	Communicator
Refer on	Constant/consistency in community	*Refer on*
Psychosocial support	Psychosocial support	Psychosocial support
	Management of side effects	*Management*
		Palliative care

The GP role across the trajectory as viewed by cancer specialists

As with people with cancer and the GPs, cancer specialists also view the GP role as changing across the cancer trajectory, from being very active, to taking *a step back* and either returning to usual care or *actively involved* in the palliative setting if they can.

> *When someone has a diagnosis of cancer, they need to be referred to a specialist centre and so sometimes the GP will feel almost obliged I guess to take a bit of a step back in terms of the actual management, but hopefully they will still be there as an emotional and physical source of care for the patient even though they have to refer on for the management side of things. CS2*
>
> *I think their role, usually it diminishes. They're very actively involved in diagnosis, and then during active treatment it's usually the oncologist, the surgeon or the radiation oncologist. Then during palliation, if they want to be, then some are very actively involved but the overall majority just don't have the time. CS5*

Cancer specialists identify GPs having roles to play in cancer care from surveillance and in diagnosis/investigation to psychosocial support during treatment and at end-of-life in palliative care. CSs view the role as *ongoing* and as a consistent *link* with PwC and their families in the community across the cancer trajectory. Cancer specialists view the GP role as crucial in monitoring and managing side-effects and in communicating PwCs' changes in cancer healing/curing, back to them. Cancer specialists value the role of the GP in the cancer care team.

In the beginning the GP role is active with investigating, screening, monitoring, referring on and providing psychosocial support for people who have suspected cancer. After treatment, the level of GP involvement or activity varies. Activity increases as PwC transition from specialist care back to GP care. Some cancer types require a greater involvement of CSs so the transition process remains open with the GP and CS collaborating in the care of the PwC. Involvement of GPs in palliation also varies depending on the GP's desire to be involved and/or relationship with the person with cancer and family, and time constraints for home visits.

The common GP roles identified across the trajectory are *monitor*, *communicator* and providing psychosocial *support*. Further, being a *consistent* health provider in the community reflects the idea of the GP playing a role across all phases of the cancer trajectory although the role changes over time.

> *[The GP role] I think probably as a link … between the patient and the specialist. Really to troubleshoot and make sure that everything's going smoothly. I guess it depends on which stage the disease or cancer patient's going through. Often let's say in the curable cancer as in breast cancer, they've had chemotherapy and then they have to put up with all the ongoing long term side effects of chemotherapy which the GP will have to deal with those problems. Or perhaps menopausal symptoms and things like that, which the GP often has to deal with.*
>
> *They're not equipped to deal with those sometimes because they can be quite hard to treat. Then to know who to refer on to or to ring, the relevant oncologist and ask an opinion. I view their role to be more important in patients whose disease are assumed to be cured and they will live for a long time. These patients we see every three months to start with and then we see them every six months. So we don't really see them that often. A GP will be the one in the community that is dealing with these patients. CS1*

Role of the GP in the cancer care team

Cancer specialists acknowledge that GP membership in the cancer care team varies. The perception of the GP in 'the team' can depend on their relationship with the PwC; the cancer type and timely, open communication between the GP, CS and PwC.

> *I do think the GP is an important member of the team but we need to make sure that they feel valued as a member of the team as well. CS2*

Most cancer specialists in this study agreed the GP role in the cancer care team is positive for different reasons such as monitoring people with cancer in the community and being more readily available to them than the cancer specialists through the cancer trajectory. GPs are viewed as important for continuity of care, although some cancer specialists report GPs do not feel included in the team and one of the main reasons was a lack of communication from the team. Similarly, the cancer specialists in this study related that some GPs cannot be involved because of the cancer type and treatment.

> *If the communication channel is open I think it's a very positive one CS1.*
>
> *I just think it's important to maintain some kind of continuity of care in the community CS2*
>
> *the role in haematology is a bit limited just because of what they can physically do. CS5*

This last extract is in contrast to the GP profile in this study in which the GP participants identified being involved in the care of people with haematological cancers (Section 3.1)

Sometimes conflicts of opinions exist in the team. In palliation, sometimes GPs are not included because their views about end-of-life care are different to those of the palliative care team. Sometimes the cancer specialists in the hospitals are too busy to involve them, or because of the age of the person with cancer and the condition, the GP has had no connection with the family. Oncology palliative care specialists, palliative care teams and hospitals will step in and the GP is not involved.

> *Occasionally we've had GPs who say the weirdest things to patients. Occasionally they're really opiate-phobic. … normally you'd try and involve the GP but usually everyone's so busy and you're in your pretty enclosed world of the hospital or the community palliative care service…. In paediatrics often it's the end of a prolonged illness and the kids have had such complicated illnesses that they don't really see the GP, they just see the hospital all the time. So come end of life, the family or child often don't feel attached to a particular GP. CS4*

Cancer specialists made suggestions of how to involve GPs in the cancer care team. These include:

- clarity of roles, expectations, communications and responsibilities of the team members at the beginning of the illness;
- for CS to keep GPs informed about a patient's cancer management and remind them how important they are in the cancer care team and for the patient;
- for CS to develop relationships with GPs and include them in education sessions about new developments in cancer treatments and management of side effects;
- to improve communication suggesting patients to remind cancer specialists to send information to their GP and ask patients to relay questions from the GP to the CS; and
- improvement in reciprocal communication across disciplines; for GPs to respect the need for CSs to be kept up to date with the condition of patients.

Summary

Cancer specialists in this study provide a snapshot of the GP role in cancer care and in the cancer care team. Communication between the multidisciplinary team members and the GP needs to be established and maintained for GPs to be involved in the team and feel like they are members. Relationships between PwC can facilitate or hinder GP involvement in their cancer care. Cancer specialists identified strategies to involve GPs in the team and suggested changes to support GPs particularly in communication, education and financial rewards

3.5 How professional members of cancer support organisations views of GPs role in cancer care teams

Eight professional members of cancer support organisations participated in one-off telephone interviews. Some organisations were for specific cancer groups as in ovarian and prostate cancers, and other organisations provided support for all cancer groups. Some views come from being a palliative care nurse, an oncology nurse, continence care nurse and facilitators of cancer support groups. The views are varied and rich and provide a snapshot of PMSOs opinions and experiences. The GP roles identified across the cancer trajectory are listed in Table 6.

The common roles of the GP across the trajectory were generalist, symptom management, referring patients on including cancer support services and providing psychosocial support to the patient and their family.

> *if the GP has the knowledge and understanding of maybe survivorship issues and just as a sounding board and a support person because the patient is always going to have cancer in the back of their mind and to varying degrees the person is going to be more vigilant about every little symptom that crops up.... So again if they trust their GP I think the GP can have a really strong role there in reassuring them and supporting them through that understandable process but some GPs are better than others at that emotional support. PMSO03*

From the support organisation perspective the GP was viewed as having a gate-keeping role in limiting requests for diagnostic test for all patients who requested them. Some support people relayed that people with cancer felt demoralised because the GP questioned them about the request or their request was denied and then down the track they were diagnosed with cancer. This tension exists because of the costs associated with the diagnostic tests that patients request as a part of their ongoing personal health care. Further, proactive personal cancer health care is widely publicised and some cancer screening tests are widely promoted although some lack evidence to support their impact on survival, (eg PSA testing for prostate cancer survival rates (24)).

Table 6: Summary of GP roles across the cancer trajectory and ideal roles as viewed by PMSO (no ranking)

Pre-diagnosis & diagnosis	Treatment	Post treatment
Generalist	Generalist	Generalist
Investigator	*Link in community*	*surveillance*
Recognising symptoms	*Symptom management*	*Symptom management*
Organising tests	negotiator	*Authorise support funding*
diagnostician		*monitor*
Referral point		
Refer on	*Refer on*	*Refer on*
communicator	Maintain relationship with PwC	Re-establish relationship with PwC
advocate		*Survivorship role*
Psychosocial support	*Support role*	Psychosocial support
Gate keeping		Palliative care role

Members of support groups also identify different roles to those identified by the GP and CS groups. Relationships were identified as important and the need for GPs to maintain a working relationship with PwC. The survivorship role entails supporting PwC after treatment and getting them back to normal.

Survivorship includes surveillance and monitoring for mental health issues and allaying of fears of the cancer returning. This group of participants promoted a different view for the model of care in the community for PwC and identified other members of the cancer care team such as the palliative care nurse, oncology nurse, and occupational therapists.

> *[GPs] are expected to look after people with really complex needs that are at home whereas 30 years ago [they] would have still been in hospital… so Practice Nurses that have got expertise in particular areas as well with the Chronic Illnesses. Also given the number of people that get treated for cancer … it probably wouldn't hurt to have an Oncology experienced Nurse. PMSO02*

A key role for the GP is defined by Department of Human Services for a co-ordinated and consistent approach to integrate support services in the community through general practice (25). That is, the GP has the role of being the one health professional to authorize support services for patients, for example continence care products and services, as identified in the post treatment phase.

3.6 Barriers to the Role of the GP in the 'team'.

GPs, cancer specialist and professional members of the cancer support organisations were asked about the barriers to the involvement of GPs in the cancer care team. These are listed in Table 7.

Geographical distance and patients' perceptions can be a barrier to accessing cancer care and the cancer care team thus cancer care is undertaken by the GP without the support of a cancer care team because 'the team' is in Melbourne.

Rurally geographic distance, which is not a big distance from Melbourne, but the culture of our community, a lot of patients in our community, especially the elderly, they don't go to the next town let alone into Melbourne, so to get them to access the right sort of services can be a real barrier, both into the transport and their own fear of the big city. That's not universal but there's certainly patients that find that; we're not having an argument but we're debating the merits of going into the city versus, "you just do all this sort of thing doctor".

I think the patient's perceptions of cancer and what it means within their cultural and family settings is important... sometimes that can be a barrier to getting them to access the appropriate care in the right manner. Some will ignore things and some will panic and do more than they need to. So patient's perceptions can be difficult. GP7

Table 7: Summary of barriers to involvement in the cancer care team (no ranking)

GPs	CS	PMSO
Remuneration (5 GPs)	*Patients gravitate to specialists* (3 CSs)	Impaired communication (3 PMSO)
Communication (4 GPs)	CS patient workload – challenging communicating with each GP for each patient (2 CSs)	Differing philosophies about care (1 CS)
Time (3 GPs)	*Rapid decision making* in some cancers, excludes GP (1 CS)	Lack of time (1 CS)
Not invited into team (1 GP)	Teleconferencing is time consuming (1 CS)	System errors eg test results inconclusive (1 CS)
Geographical distance for patients to go for team care (1 GP).	Communication systems between specialist and hospital specialists cut out GP (1 CS)	Lack of knowledge (1 CS)
Complex referral system (1 GP)	Everyone is too busy don't want to overload GPs (1 GP)	
GP not interested (1 GP)	CS doesn't interact with GPs (1 CS)	
No barriers (1 GP)		

Distance and access to closer cancer care services is an issue that is beyond the scope of the current project but is worthy of further exploration in the future.

Cancer specialists noted that often patients gravitate to specialists during treatment and that often the patients will request specialists to write out repeat prescriptions for them instead of returning to the GP for co-morbid care. These views are reflected in GP roles in supporting the transition of people with cancer away from specialist care back to the GP (Section 3.4, Table 5).

they tend to gravitate to the Specialists - The older ones maybe not but the young ones definitely CS5

Further CS report writing the prescriptions so the patient did not have to arrange another medical appointment but they reinforce to Pwc the need to return to the GP for future scripts.

Because they see the oncologist or whoever it is a lot, if they're having treatment they're seeing us every two weeks whereas they might see their GP once a year, so they come to rely on us in getting scripts for their blood pressure medications and things like that. So sometimes that does happen which would suggest that perhaps they're not going to their GP for their other health problems. CS2

3.7 Ideal GP role as viewed by all participants

Ideal role of the GP in the cancer care team

The ideal roles identified by the four participant groups are listed below (Table 8). There is no ranking in the table. The common role across all groups was for the GP to be a generalist and provide psychosocial support. The perceived ideal GP roles by each group do vary according to the needs of the group participants.

Table 8: Summary of the ideal GP role in the cancer care team by all groups (no ranking)

PwC expectations	GP	CS	PMSO	Common roles across groups
GP not surrogate specialist	generalist	*Generalist*	*Generalist:* *Holistic view* *Triage patient*	Generalist
co-case manager (patient and GP)	Co-ordinator	*Co-ordinator*	*Manager of medications*	
	Being pivotal, being central	*Management of side effects*	*Symptom management*	
	A role in follow-up	The link in the community	*A team member*	
navigator role	Being a resource	*Surveillance*	*Knowledgeable about cancers*	
role adequate	Being remunerated	On-going	*Refer on*	
closer communication with specialists	Having communication	*Communicator*		
		Build relationships	*Relationship builder*	
more GP interaction with the family	Providing psychosocial support	*Psychosocial support*	*Psychosocial support*	Psychosocial support
			Palliative role	

The expectations people with cancer have of their GP focus on what the GP can do to resolve their health issues. GPs' views are about their professional role and how they would like to enact their role in the cancer care team. The roles reflect their values as a GP in the cancer care team. Cancer specialists view the GP role as one that supports their work in treating the person with cancer, thus see the GP as the link to the community sector and PwC. They view the GP as having the relationship and knowledge of the PwC and thus rapport and someone for the PwC to return to for support. CS view themselves as being a resource for the GPs in managing side effects and reporting back to them about any issues for the PwC. The PMSO group view the GP role differently in viewing the role as a clinician caring for a PwC from a different discipline perspective or model of care such as a community health care model.

Ideal role of the GP by GPs

The GPs see the ideal role as *being pivotal* in the care of a person with cancer, *being central, having communication* with and in receiving information from specialists and passing it on to patients, and being the *co-ordinator* of care. The *co-ordinator* role includes cancer care as well as co-morbid and overall holistic care.

> *to be really the co-coordinator. So everyone needs to relay back to me and tell me what's happening, because everything will come back to me at the end, even when [the patient] recovers so I'm the one who's looking after his kidney functions and liver functions and all of that. So it's important that everyone comes back to [me] and I usually write very good letters as well for referrals so the communication will be very good. GP3*
>
> *I still see GPs as being ideally based to coordinate care, as we do with anything that involves other health care professionals ... we have the medical records, we have the medication, we have the past history of the patient, we know the patients, so we're ideally placed that's just the way it is ... and we accept that we need the help of nurses, of allied health, of whatever it is to ensure the patient gets the best care, GP5*
>
> *I think the most important thing actually is a co-ordinator of their care, and not necessarily the administrator of their care, if that makes sense. GP7*

The ideal role would see them being the 'generalist', the *support* person, a *resource* for patients and having a particular role in *follow-up*. In addition the GPs would like to be respected for their contribution to cancer care and team, and be remunerated for their involvement in the team. The need to be remunerated for GP involvement was a topic identified by other participant groups.

> *we should ask that we have a teleconference ... I'd be happy to talk when there's a team approach which we get paid for it, and otherwise if we're just talking one-on-one we're not getting paid, and so if we're getting paid and you've got more of the team discussing the complexity of the care then it seems like a better idea. GP2*
>
> *They also need to have the Medicare Rebate so that if they go to do a home visit they get paid for it because often they don't. PMSO04*

These 'ideal' roles identified by GPs are in contrast to those previously revealed across the trajectory in section 3.3.

Ideal role of GPs by CS

From the perspective of cancer specialists, the ideal role for the GP is that of the generalist and being the *link* in the community to manage side effects and *all other health issues that arise or that are chronic and longstanding during their cancer treatment* (CS2). The surveillance role encompasses developing relationships with PwC and their family members to track down family members with a predisposition to particular cancers from genetic profiles and to then refer them on to specialists, as well as surveillance and monitoring for side effects and cancer re-occurrences for cancer survivors. The following statement epitomizes the views of cancer specialists and their views of the GP role in the cancer care team.

> *An integrated, valued, respected member of the multidisciplinary care team CS3.*

In contrast, the findings in this study do not reflect how GPs view their role in the cancer care team. Appendix G has a summary of the views of all participants.

3.8 Overarching Themes

From this snapshot of participant experiences and opinions there are emerging themes of 'communication' and 'relationships' that enabled a cancer care team to work effectively for the person with cancer, and an emerging notion of the GP as the link and buffer between people with cancer and other members in medical establishments. The notion for this latter theme was identified by people with cancer, and cancer specialists in their words.

[The GP] is an important link between the tertiary centre and the patient. CS1

[The GP] in the community port of call in between appointments for the patient CS2.

my GP acted as an intermediary between myself, the General Surgeon PwC09

An alternate view to the cancer care team is a network of relationships and communications binding health professionals to enable them to be fully involved in the care of the person with cancer.

Communication

Communication is an issue for GPs who want *timely* information from specialists about their patients and cancer specialists would appreciate information from GPs when a patient has any medical issues.

I find there isn't as much good communication with the GP in terms of really active communication. There's certainly letters that go back and forth, mainly in terms of written correspondence informing everyone of what they're doing but certainly not in terms of a team plan and working collaboratively. GP7

Delayed communications about patients are challenging particularly when a patient sees the GP and their GP has not been informed of their current cancer treatment. People with cancer can facilitate written correspondence or electronic communication between GPs and specialists by asking the specialists to send copies of results to GPs. In contrast the specialists explained that they dictate the letters and send them off. They seem to be satisfied they have sent the letters and unaware if the GP receives them. GPs and CS both indentified the primary issue as the time it takes for transcription of the dictated letter, subsequent signing and sending to the GP.

most of my information about the care of my patients comes from talking to the patients directly rather than any really reliable communication from the team GP6

Patients more often than not will say "Let my GP know about this", "Can you make sure my GP gets a copy of this letter". So they're very much pro the involvement of the GP in the whole process. CS1

the patients are usually the drivers from that perspective in that when they go to see their Oncologist if they are a fan of their GPs they will say, "Look I go and see my Doctor you know will you be talking to him about what is happening?"GP1

GPs and CS reported that electronic communication is gradually being incorporated into the health care system. Divisions of General Practice have instigated strategies to support GPs in their division. Strategies are enabling GPs to view radiological results in a timely manner via computer systems. Also reported was teleconferencing with a Medicare rebate is another communication method being trailed to involve GPs in a team of health professionals caring for people with cancer in a rural area.

Communications improve between the specialist and GPs when specialists provide details of treatments for people with cancer that include treatment side-effects so problems can be acted on quickly. Sometimes a collaborative interaction between specialists and GPs enables a successful process for working out care regimes in the post treatment phase. Rapport between GPs and PwC evolves as a result of the strength and depth of their relationship and sometimes includes cancer specialists. Strength in the GP relationship with the person with cancer is based on the length of time with the same GP, mutual respect, and management of co-morbidities if they are present.

Relationships

The patient relationship with the GP is influential in the relationship across the cancer trajectory. GPs usually see patients who have consistently seen them and attended the same the medical centre. The strength of relationship appears to influence the level of GP participation in cancer care for the person. The relationship may extend though to palliation depending on the strength and depth of the relationship.

> *I think as a practice we have quite high patient loyalty, and so generally patients don't go wandering off to other GPs that often, they may see other GPs occasionally for minor ailments, but anything of any consequence. We would generally see them and follow through ... If complications come to light ... the specialists will actually refer back to us if there's some other unrelated issue ... for further management, and of course if things aren't working out well then we get involved in the palliative care side of things. GP5*

> *it was interesting the appointment I had with my GP with the other day he actually said to me at the end, you know if you have any concerns or if you want to just come and talk, you don't have to be sick, you just come and talk to me. Now that's the first time that he's said anything like that to me since I was diagnosed. So if he'd said something like that to me in the beginning I probably would have used him more. But so yes, it's definitely that you do need to involve yourself but yes, I think it's the kind of relationship you have. PwC21*

Sometimes the GP acts as a *defence*, or barrier, attempting to protect the PwC from the other medical establishments such as the specialists and hospital system, and will negotiate the health care system for them. GPs will act as intermediaries between health professionals and the PwC. Sometimes the person with cancer mediates communication channels between the specialists and the GP, so the GP is not left *out of the loop*.

The strongest relationships reported were those between GPs and PwC when longevity and continuity with the same GP occurred or if the GP had personal experiences with cancer. Sometimes there was a co-case manager relationship with sharing decision-making with the patient in treatment and care. Reciprocal respect, assertiveness and rapport support the relationship between people with cancer and their GP. The level of involvement is dependent on the relationship:

> *the patient's relationship with the GP. I have some patients who continue to see their GP very, very regularly and really appreciate their involvement and then there's others that, before they have cancer they've never had an illness before and so once they're in the hospital system, because they don't often see their GP beforehand, they wouldn't feel the need to see their GP because they're in the hospital system. So that by itself is more frequent doctor reviews than they would have otherwise. So it depends on the patient really. CS2*

A summary of participant views is provided in Appendix G

4. DISCUSSION

Our study has provided rich evidence about the myriad of dynamic and interdependent roles that GPs have and potentially can have within multidisciplinary cancer care team approaches. Key findings include:

- People with cancer and GPs do not use the term 'team' to refer to the health care professionals involved in their cancer care nor recognise GPs as being part of a team, when discussing current cancer care arrangements. This finding potentially highlights the dominance of professional autonomy and independence within professions involved in providing cancer care. The lack of recognition by people with cancer of their care being delivered by a cancer care team is likely to be a constraint on the multidisciplinary cancer care team approach.
- The existence, and need for, 'relationships' and 'communication' between all cancer care professionals, GPs and people with cancer is viewed by all as critical to ensure quality cancer care. Despite the existence of Patient Management Frameworks for cancer care within Victoria, and rebates from Medicare for case conferencing, these systems as currently functioning may not be effective for supporting (administratively nor financially) ongoing information sharing and communication between GPs and cancer specialists.
- Many people with cancer viewed their GPs as having a central role in their overall health care and this includes their overall health throughout their cancer care journey. However, there is a lack of clinician role clarity among people with cancer, GPs and cancer specialists, about GP roles within multidisciplinary cancer care teams.
- The type and quality of GP roles throughout a person's cancer care journey and the overall care provided is influenced by GP attributes (e.g., attitudes, experiences, skills; networks), and their practice context (e.g., patient workload; time constraints), the type of cancer, whether the person with cancer has co-morbidities, and importantly the strength and longevity of the GP's relationships with the person with cancer.
- Cancer specialists view GP roles within cancer care as positive, and as a link between tertiary care and the person with cancer. However, GPs are not routinely included in current team-based structures (e.g., multidisciplinary cancer team meetings) and only kept informed via letters/emails, leading to information sharing generally being one-way (cancer specialist to GPs) and sometimes being delayed. This potentially limits the GPs capacity to provide input into whole-person care decision-making throughout a person's cancer care journey.
- Members of Victorian cancer support organisations confirmed that the main role of GPs is to support the person with cancer across their cancer care journey, that GPs have a pivotal role in multidisciplinary cancer care teams; and noted that there is currently a lack of effective communication between cancer specialist and GPs.
- The role of GPs across the cancer trajectory changes from during the pre-diagnosis/diagnosis phase (*advocate*, communicator, investigator*, interpreter*, and supporter providing psychosocial support to the person and their family and advising about cancer care) to different roles during treatment (*intermediary*, communicator, investigator, a *sounding board*, *supporter*, manager) and to post-treatment roles (generalist, communicator, *observer*, *coordinator* of care and in palliation).
- People with cancer valued and confirmed the theorised dimensions of 'generalists' – *ways of being* (GPs as the trusted interpreter), *ways of knowing* (GPs use of bio-technical and biographical information) and *ways of doing* (GPs as the first point of call, as gatekeeper, as care-coordinator who deals with uncertainty and unexpected consequences). Ideally people with cancer want their GPs to interact and communicate with them, their family and their cancer specialists, to be a navigator, to be available, knowledgeable, genuine, to check things and follow through with investigations. However, people with cancer do not want their GP to be a surrogate cancer specialist

The above key findings can be further categorized into four key emergent themes, including:

- Team/teamwork in cancer care– rhetoric or reality;
- System alignment to support multidisciplinary cancer care teams;
- GP role clarity and delineation in cancer care teams; and
- Generalist primary care role in cancer care.

Overall these four emerging themes resonate with the findings of the rapid literature review conducted as part of Phase One of this study (see Appendix E Summary of Literature Review). Briefly our literature review revealed that:

- Primary care generalists (GPs) have a central role in providing care for the whole person throughout a person's cancer care journey;
- A lack of clarity exists about the role of the primary care generalist (GPs) in cancer care;
- Primary care generalists (GPs) are well placed and have the capacity to understand the impact of cancer and to provide whole person medical care; and
- A lack of funding, investment, infrastructure, resources, support, expertise and continuing educational opportunities exist for GPs in cancer care.

The four qualitative study emergent themes will now be discussed with regard to the current evidence base and policy context. Our observations of the study limitations and rigor of the research are also discussed.

4.1 Team/teamwork in cancer care – rhetoric or reality

Our study revealed that people with cancer and GPs do not use the term 'team' nor recognise GPs as being part of a team, when discussing current cancer care arrangements. This is likely to constrain multidisciplinary cancer care team approaches. This finding resonates with current research that explored the future health care needs of patients' with complex and multiple conditions, regarding multidisciplinary team care arrangements, and to identify if the features of generalism were relevant for the development of multidisciplinary team care in the Australian primary care setting (26). Specifically Palmer et al found that primary care professionals did not use a single definition of the term 'team'.

More broadly this finding aligns with the findings of a narrative systematic literature review of Incentives for Primary Health Care Team Service Provision by (27) that found there was no agreed definition nor understanding of the concept of a 'team' in primary health care. This review by Naccarella et al also highlighted that teamwork was not an end, but a means, to achieving better quality, coordination and continuity of care, particularly for patients with complex and chronic conditions'

Our study also found that the existence, and need for, 'relationships' and 'communication' between all cancer care professionals and people with cancer were viewed as critical to ensure quality cancer care. This finding concurs with work commissioned by Cancer Australia (28) to identify role design options that support greater engagement of primary health care providers in cancer treatment and surveillance post treatment. The report specifically recommended that *'timely and systematic communication (that includes role clarity) between all shared care team members and which involves the person with cancer'* is required'.

These findings may also be a reflection of the fact that teams or teamwork are a complex phenomenon which is influenced by an array of factors at the micro (individual), meso (organisational) and macro (systems) level. These include:

Micro: the types and levels of leadership available to the team such as the GP acting as the advocate for the person; the team composition including the mix of skills, knowledge and experience; the extent to which members have shared objectives, communicate, make decisions jointly, support innovation and review working progress; the extent to which team members have had inter-professional education, learning and training opportunities.

In this study often the person with cancer was included in the team through communication between GPs and cancer specialist by acting as messengers and as drivers for GP team membership.

Meso: the extent to which organisational contexts support team work; the available practice infrastructure and support; the attitudes to teams/team work within the team.

These aspects were recognized in this study in the way GPs were seen as valued members of the team and how hospital staff are educated regarding their importance.

> *to keep the GP informed and if the team is aware that this is important and actually values that, that's obviously a facilitator and I think that's been something that's been assisted by the increased recognised importance of multidisciplinary team care. CS1*

Extended information technology has enabled the inclusion of GPs in cancer care team case conferencing within Victoria through teleconferencing. Although this has a Medicare rebate, the teleconferencing is only accessible in specific areas. There is a proposal for the integration of the electronic health records to support timely communication of care. Within the health care system other health professionals support GPs – for example GP liaisons in hospitals, and practice nurses in medical centres.

Macro: the extent to which funding arrangements reward teamwork; the extent to which regulatory mechanisms support/value/reward teamwork.

Improved remuneration for services such as home visits and lengthy telephone conversations, was a theme through the current study identified by GPs, cancer specialists and professional members of cancer support teams. Medicare rebates are available now for support services for people with cancer such as mental health care but GPs have requested that the process be simpler. Health professional participants suggested moving to different models of care such as having oncology care only in the public health care system and integrating the GP into a community health care model (27, 29-31).

4.2. System alignment to support cancer care teams

Our study revealed that GPs are not routinely included in current team-based structures (e.g., multidisciplinary cancer team meetings) but only kept informed via letter/emails, leading to information sharing being one-way (cancer specialist to GPs) thus potentially limiting GPs capacity to provide input into whole-person care decision-making throughout people's cancer care journey. The feasibility of including GPs in multidisciplinary cancer team meetings needs exploring. This finding also concurs with the review of incentives for PHC team service by Naccarella et al (27) that found: 'Practice level support and e-health infrastructure systems can support team work for patients with chronic and complex illness (32-35). This finding also aligns with the Palmer et al (26) work as they found that at the organisational level, there is a need for the provision of physical and technological infrastructure support to facilitate team care. A greater need is present for developing shared ways of working together across different professions and the development of information sharing systems and processes. Despite the existence of Patient Management Frameworks for cancer care, no system currently exist for supporting effectively (administratively nor financially) ongoing information sharing and communication between GPs and cancer specialists

4.3 GP role clarity and delineation in cancer care teams

While there was consensus that GPs have a role in cancer care teams, there was also a lack of clarity regarding GP roles in these care teams. The roles of GPs across the cancer trajectory were found to change from within the pre-diagnosis/diagnosis phase (as a advocate, communicator, investigator, *interpreter*, and supporter providing psychosocial support to the person and their family and advising about cancer care) to roles during treatment (as a *intermediary*, communicator, investigator, a *sounding board*, supporter, manager) and to post-treatment (as a *generalist*, communicator, observer, coordinator of care and in palliation). This wide array of roles could be clustered into three main categories: 'knowledge broker'; 'advocate' and 'coordinator of care'. Despite a lack of GP role clarity, people with cancer commented that they did not want their GP to be *a surrogate specialist*.

The need for greater role clarity resonates with the Cancer Australia commissioned report that recommended greater role clarity as key in any role design options that support greater engagement of PHC providers in cancer care. This finding may also be illustrating that GP roles are in a state of dynamic change due to workforce supply (shortages) and workforce demands (changing workforce and consumer expectations, and increasing burden of complex and chronic conditions) (27). Such workforce pressures are leading to the creation of new roles and /or realignment of existing roles to make better use of the existing workforce (36).

The Palmer *et al* (26) study also confirms this finding as they found that patients that had between four and ten health care providers still viewed the GP as the central coordinator of their care and that patients value their longitudinal relationship with their GP.

From a policy context, the Victorian Government's commitment to high quality multidisciplinary cancer care via policy directions i.e., Clinical Excellence in Cancer Care (37); Achieving Best Practice Cancer Care: a guide for implementing multidisciplinary care (38); Linking Cancer Care (39); and Patient Management Frameworks (19), may provide a basis for 'Cancer Care Treatment Plans' to be a mechanism to formally identify and recognise GPs' roles and promote shared working relationships with cancer specialists. Under the Victorian Government Integrated Cancer Initiative, Patient Management Frameworks (19) were developed for 14 tumor streams to promote/guide consistent cancer care across Victoria. The frameworks provide clear steps in the process for treating cancer from diagnosis to end of treatment and palliation if required. GPs have a prominent position in the cancer care team, but in this study GPs often felt '*out of the loop'*. Similarly people with cancer and professional members of cancer support organisations highlighted the lack of effective communication between specialists and GPs.

4.4 Generalist primary care roles in cancer care

People with cancer valued and confirmed the essential skills, elements and dimensions that underpin the role of the primary care generalist (e.g., GPs). Specifically the study revealed that people with cancer perceived their GPs as central in their overall (medical & non-medical care) care - their *'point of reference',* who listens, observes, discusses, interprets and conveys information to and for them in a trustworthy manner, and who is person not disease oriented across their cancer care journey. These findings add weight to the building evidence that theorised dimensions of 'generalists' (7, 22, 40) – *ways of being* (GPs as the trusted interpreter), *ways of knowing* (GPs use of bio-technical and biographical information) and *ways of doing* (GPs as the first point of call, as gatekeeper, as care-coordinator who deals with uncertainty and unexpected consequences).

Despite this evidence, further research is required as to how to ensure these generalist skills and dimensions are strengthened and embedded in ongoing multidisciplinary cancer care team approaches. Furthermore, given that GP roles throughout people's cancer care journey and overall care was influenced by the extent to which people with cancer advocated for GP involvement and the longevity of their relationships with their GP, these primary care generalist roles need to be supported independent of these contextual factors.

People with cancer valued the generalist features underpinning GP work, and commented that they did not want their GP to be a *surrogate specialist*, but at the same time wanted the GP to be knowledgeable about cancer care, treatments and side effects, this raises the issue about how generalists can remain generalists, while gaining advanced skills in cancer care. This issue was also highlighted in the Cancer Australia report, as they recommended that education and training is required and needs to be is easy to access to encourage PHC clinicians (including general practitioners, all primary health care nurses, allied health providers, Indigenous health workers and physician assistants) to gain advanced skills (28).

4.5 Study limitations and rigour

From the outset we acknowledge that our study has limitations which may have implications for the application of the study's findings. We recognize that our study sample was small and not representative, but designed to be illustrative of people with cancer receiving care; GPs involved in providing care; cancer specialists; and members of Victorian cancer support organizations – a snapshot.

Despite having a sampling framework and criteria, we recognize that our participants may be biased. For example, we have recruited many people with cancer who had long term relationships with their GPs, thus potentially biasing their perceptions and experiences. We also did not recruit any surgeons in the cancer specialist group. As surgeons are often the first cancer specialists people would be referred to – the omission of this group of cancer specialists may have biased our findings regarding communication between GPs and cancer specialists. In addition cancer specialists recruited were from the public hospital system. Thus we have not been able to capture the experience of cancer specialists working in the private system. If cancer specialists from the private system have different ways of interacting with GPs we are not able to report on this. We also recognise that cancer care is a complex phenomenon with many contributing factors, and that in sampling participants we needed to be cognisant to the type and stage of cancer, experiences of cancer care, and access to specialist and community support. Given the scale of study this sampling framework for people with cancer was not possible.

In order to increase the strength of our study's findings and usefulness for informing future policy and research, we committed to a rigorous research study design, data collection, analysis and interpretation phases as discussed below:

- **Research study design**: The research questions were based on an evidence based conceptual model of generalism that was developed as part of a systematic narrative literature of the role of Generalism in the 2020 primary care team. The research underwent a rigorous ethics approval process through the Cancer Council Victoria's Human Research Ethics Committee and The University of Melbourne Human Research Ethics Committee. The research was also informed by an advisory group comprising of primary care and cancer specialist academics, practitioners and consumers

- **Research study data collection, analysis and interpretation**: The data collection tools were developed in conjunction with the advisory group; the data collection was undertaken by one researcher thus enabling reliability. All interviews and focus groups were recorded and transcribed by an independent transcriber, and then entered into QSR Nvivo 8 which allowed coding using a thematic data analysis approach. All emergent themes were discussed within the research team and advisory group for clarity and strategic relevance. We do recognize that no validation study was conducted, to verify our interpretations of the study findings. However, interview transcripts were also read by the principal researcher. Furthermore, given that the Advisory Group comprised of primary care and cancer specialist academics, practitioners and consumers we are confident that our findings are verifiable.

5. Implication for Policy, Practice and Research

The study has provided rich practice-based evidence about the myriad of dynamic and interdependent roles that GPs have and potentially can have within multidisciplinary cancer care team approaches. The current Victorian Cancer Action Plan and accompanying cancer care policy guides (e.g., Achieving Best Practice Cancer Care: a guide for implementing multidisciplinary care) demonstrates its commitment to high quality evidence informed multidisciplinary cancer care, as exemplified by the key principle below:

> *The key principle of multidisciplinary care is that all cancer patients will have the opportunity to have prospective treatment and care planning by an appropriate multidisciplinary team…The patients' general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.*
>
> *Key Principles for Multidisciplinary Care (1, p. 13).*

Our study findings can inform the development and implementation of the above principles. As a way of concluding this study we outline implications for policy, practice and research below.

Policy Implications

- **Enhanced clarity about team concepts**: With the current Victorian cancer care policy documents (e.g., Victorian Cancer Action Plan, Integrated Cancer Initiative, Patient Management Framework) advocating 'team-based' multidisciplinary cancer care, and identifying GPs as part of the cancer care team, work could be done with all cancer care policy makers and professionals about what the term 'team' and 'teamwork' means for the delivery of care, for health professionals and for people with cancer. Furthermore, current evidence reinforces that 'teams' or 'teamwork' is a '*means to an end, and not an end in itself*' thus, the impact or outcomes of such models of care for people with cancer needs to be evaluated to inform future cancer care policy decision-making.
- **Enhanced role of existing multidisciplinary cancer care treatment plans:** While there was consensus among cancer specialists and GPs, that GPs have a role in cancer care teams, there was also a lack of clarity regarding GP roles in these care teams. Cancer care treatment plans could be a mechanism to formally identify and recognise GPs roles and promote shared working relationships with cancer specialists
- **Improved business models** New financial arrangements are required to fund ongoing information sharing and communication between the GP and the cancer specialist, and between all health professionals and people with cancer. The current Enhanced Primary Care Medicare items for Case Conferencing, Care Planning and Team Care Arrangements are not remunerating GPs nor cancer specialists for lengthy consultations, non-direct patient care activities (e.g., phone consultations or information provision to people with cancer) thus not facilitating multidisciplinary cancer care team approaches nor shared ways of working together. As there is a lack of evidence about how to incentivise and reward team work where there is both specialist and general practitioner care, research is needed in this area

Practice and Research Implications

- **Improved infrastructure and new integrative processes:** Formal and funded information sharing and communication processes need to be developed between GPs, cancer specialists and people with cancer. Current work on the development of an 'electronic shared health record' may support communication between GPs and cancer specialists and people with cancer. These 'electronic shared health records' could include information about cancer types; the treatment team; treatment plan and side-effects; guidance on management of anticipated toxicities associated co-morbidities and supporting care options within a multidisciplinary cancer care team approaches.

- **Enhanced role of Generalist in Cancer Care teams:** Many people with cancer valued and confirmed the essential skills, elements and dimensions that underpin the role of the primary care generalist (e.g., GPs). However, people with cancer did not want their GPs to be surrogate cancer specialists, but to remain as their generalist (i.e., GP). Further research is required to examine how generalists can form part of the multidisciplinary cancer care team.
- **Enhanced workforce role delineation:** People with cancer especially those with co-morbid conditions state the importance of having their cancer care and overall care coordinated. Whether this role is to be only in the domain of GP may need further exploration.
- **Enhanced cancer education and inter-professional training opportunities:** GPs require easy access to education to gain skills in cancer care that complements their generalist's skills. Given the dominance of a culture of professional autonomy and independence and absence of a culture of team-based care (i.e. shared decision making and responsibility, mutual respect), inter-professional education could provide the framework and opportunities for knowledge transfer and exchange between GPs and cancer specialists in a mutually respectful and on-going learning context.
- **Relationships and accessing quality cancer care:** This study highlights that the strength of the relationship between a GP and a person with cancer can influence the level of active involvement the GP takes in cancer care. Whether this is related to a possible bias from participants, or a reflection of practice, this notion of relationships influencing cancer care requires further investigation. Such an influence (i.e. strength of the relationship) could impact on the consistency of care across a person's cancer trajectory, and hence efforts to avoid this from happening need to be in place. Furthermore, given that the strength of relationships is so important, we need systems in place to ensure consistency of care across a persons' cancer care trajectory.
- **Building the evidence base that strengthens GP roles in multidisciplinary cancer care:** This study has reinforced that there is a need for further research evaluating the implementation of different models of multidisciplinary cancer care involving generalist primary care providers throughout the cancer care journey. Research is also required to establish if multidisciplinary team care approaches improves the quality, coordination, continuity and health outcomes of people with cancer. These research directions align with the recent literature review on the various types of multidisciplinary cancer care team structures and their impact on the quality of cancer care, published as part of a series of papers on 'Towards Improving the Quality of Cancer Care: addressing the Interfaces of Primary and Oncology related Subspecialty Care' in *The Journal of the National Cancer Institute Monograph* 2010 (2). Our study's findings will also be used to inform the development of a module to assess the perceptions of people with cancer regarding their GP's involvement in their cancer care for Cancer Council Victoria's PROSPECT surveys. The aim of questions in this module will be to quantify the findings reported from the current qualitative study.

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Appendices

Appendix A: Recruitment strategies for each participant group

Participant group	Recruitment strategies
People with cancer (PwC)	Advertisement in cancer support group websites including NEMICS, Ovarian Cancer site, Breast Cancer Network Australia
	Personal contact with a retirement village
	Snowball recruitment
General practitioners (GPs)	Contact with managers of medical centres across Victoria
	Advertisements via Divisions of General Practitioners in Melbourne
	Recommendations from Advisory Board members
	VicRen
	CanNet
	Contacts via Department of General Practice, University of Melbourne
Cancer specialists (CS)	Recommendations by advisory board members
	Contact with managers of cancer centres in rural Victoria
	Contact with managers of oncology radiology services in rural Victoria
Professional members of cancer support organisations (PMSO)	Contacts via cancer support organisations and snowball contacts
	Contacts via Cancer Care Victoria
	'Cold call' contacts from the NEMICS Supportive Care book (2009)

Appendix B: Participant information sheet and consent form for PwC

PARTICIPANT INFORMATION SHEET AND CONSENT FORM (People with Cancer)

Site: Cancer Council Victoria

Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations

Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

Your Consent

You are invited to take part in this research project because you have received a cancer diagnosis. Focus groups will be used to explore the experiences of cancer patients and similar groups will be provided for professionals involved in cancer support organisations. Cancer specialists and general practitioners will be invited to contribute by semi-structured telephone interviews

This participant information sheet contains information about the research project.

Please read this participant information sheet carefully. Ask questions about anything that may require clarification or that you wish to know more about. Before deciding whether or not to take part, you may also wish to discuss the project with a relative or friend.

If you decide you want to take part in the research project, you will be asked to sign the consent form. By signing it you are telling us that you:

- Have read and understood the information that is provided in this information sheet
- Consent to take part in the research project
- Understand that relevant information collected as part of this research (i.e. the personal and health information that you choose to disclose), may be used over the course of the project, as described in the information sheet.

Please retain this participant information sheet and the copy of the consent form that has been provided for you to keep as a record.

1 Purpose and Background

For people with cancer, healthcare usually involves a range of different health care providers. These people are often referred to as the multidisciplinary care team. For multidisciplinary care to function most effectively, continuity and coordination of care across the professions is required. The Victorian Government's Cancer Services Framework recognises the general practitioner as an important member of the cancer care team[1]. However, limited information exists about the experience of general practitioner roles within the cancer care team.

The aim of the study is to explore the roles of general practitioners within the cancer care team as experienced by people with cancer, cancer support professionals, general practitioners, and cancer specialists. We will be seeking information on both your experience of the role of the general practitioner as well as your views on what the potential role could be.

This study is being carried out by the Australian Health Workforce Institute (The University of Melbourne) and the Cancer Council of Victoria.

[1] http://www.health.vic.gov.au/cancer/framework/pmfsnew.htm

2 Procedure

We are inviting you to take part in a focus group discussion to explore these ideas. The group will involve about 5 other participants who are also cancer patients and together you will be asked to talk about the role(s) of GPs within cancer care teams. We value everyone's opinion, so the facilitator will make sure that everyone in the group has a chance to talk and share their thoughts. There are no right or wrong responses.

The focus group will take place at the Cancer Council Victoria in Carlton and is expected to run for approximately 90 minutes. You will be reimbursed for your travel expenses in the form of a voucher. On site parking can be arranged if required.

Where it may not be practical for you to attend a focus group (e.g. if you live in a rural/regional location), you may still wish to participate in this research by completing an individual interview via telephone during or outside of regular office hours.

With your consent the focus groups or interviews will be audio-taped and then transcribed verbatim. All information provided as part of the focus group or individual interview will remain strictly confidential subject to legal requirements.

To participate, please return the expression of interest / permission to contact form in the self-addressed reply-paid envelope provided, so that a researcher involved with this study can call you to discuss the study with you further and if you are interested arrange for you to attend a focus group. Prior to your participation in the focus group you will be asked to complete the consent form attached to this document.

3 Possible Outcomes/Potential Benefits

While there may not be any direct benefit obtained from your involvement in this project, it is anticipated that patients who may have a cancer diagnosis in the future may benefit from knowledge obtained from your participation in this research.

4 Possible Risks

In the unlikely event that you experience discomfort when sharing your views, you will be referred either back to your health care provider for consultation or to a trained external counsellor.

5 Privacy, Confidentiality and Disclosure of Information

The researchers will ask you to provide some background information at the beginning of the focus group or individual interview by asking you to complete a brief questionnaire about you, your condition(s) and the care you are receiving, which will be used to complement the interview that you will participate in.

You will not be asked for your GP's or cancer specialist's name at any stage throughout the project and your participation or non-participation in this research will not affect the usual clinical care that is provided by your GP or cancer specialist.

All information you provide as part of the study will remain private and confidential. It will be stored securely (via locked filing cabinets and password protected electronic files, with controlled access). Only authorised persons involved with the study, who understand this information must be kept confidential, will have access to it. In any report of the research made available to the public, you will not be referred to by name and within research records your name will be replaced by a number so that your identity will not be apparent. No personal information will be provided to any person, except as described above, or as allowed or required by law. At the end of the research all audio-recordings will be destroyed, and de-identified transcripts and other data will be archived in The Australian Health Workforce Institute at The University of Melbourne for five years after the last publication of the project. Then all project data will be destroyed**.**

6 Results of Project

You have the option of receiving a summary of the results via email/mail upon completion of the study.

7 Contact Information

If you have any questions or would like to know more about this research project please contact Dr Lucio Naccarella (Tel: 03 8344 4535).

If you have any complaints or concerns about the manner in which this research is being conducted, please contact Ms Woody Macpherson, Head, Research Management Unit, Cancer Council Victoria (telephone: (03) 9635 5100), who will raise your concerns with the Chair of Cancer Council Victoria's Human Research Ethics Committee.

8 Participation is Voluntary

You are not obliged to participate in this project and should you choose to participate you have the right to withdraw from the project at any time. If you want to withdraw your information from the study as well you can do this by contacting the Project Coordinator. Withdrawing will not affect clinical care provided by your GP or cancer specialist.

9 Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to take part in research.

All aspects of this research project have been approved by the Cancer Council Victoria Human Research Ethics Committee and The University of Melbourne, Human Research Ethics Committee.

CONSENT FORM

Site: Cancer Council Victoria

Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations
Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

I have read the Participant Information Sheet Version 1: dated 11/03/2010
I understand the purposes, procedures and risks of this research project as described in the participant information sheet. I freely agree to participate in this project according to the conditions in the participant information sheet.
I have a copy of the participant information sheet and consent form to keep. I understand that I can leave the research project at any time
I understand that the researchers will not reveal my identity or personal details. If information about this project is published or presented in any public form, there will be no information revealing my identity or personal details.

Participant's Name (printed)…….

Signature……**Date**……...

☐ **I would like to receive a summary of the results upon completion of the study. Please send this summary to the following email / mail address:**

……

PLEASE BRING THIS FORM WITH YOU TO THE FOCUS GROUP.
THANK YOU

CONSENT FORM

Site: Cancer Council Victoria

Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations **Principal Researcher (s):** Lucio Naccarella, PhD; Vicki White, PhD.

I have read the Participant Information Sheet Version 1: dated 11/03/2010.
I understand the purposes, procedures and risks of this research project as described in the participant information sheet. I freely agree to participate in this project according to the conditions in the participant information sheet.
I have a copy of the participant information sheet and consent form to keep. I understand that I can leave the research project at any time
I understand that the researchers will not reveal my identity or personal details. If information about this project is published or presented in any public form, there will be no information revealing my identity or personal details.

Participant's Name (printed)…….

Signature……**Date**……...

☐ **I would like to receive a summary of the results upon completion of the study. Please send this summary to the following email / mail address:**

……

PLEASE BRING THIS FORM WITH YOU TO THE FOCUS GROUP.
THANK YOU

Appendix C: Questions for each participant group

Focus Group Discussion or Individual Interview Outline

(People with Cancer)

Project: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations
Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

The focus groups will take place at the Cancer Council Victoria in Carlton and will be expected to run for approximately 90 minutes. Alternatively, individual interviews will run for approximately 25 mins. The focus groups/interviews will be conducted in two parts;

- **Part 1: Background information** will be collected at the beginning of the focus groups or individual interviews via a brief questionnaire (see below)
- **Part 2: Experiential information** will be collected to identify patients' experiences of general practitioners' roles within the cancer care team.

Part 1: **Background Information**

This part is designed to obtain information on you, your condition(s) and the care you are receiving and will be used to complement the interviews that will be conducted with you.

Gender (Please tick): Female Male

Age Group (Please tick): 25-34 35-44 45-54 55-64 >65

Location (Please tick): Rural Metropolitan

Age at time of initial diagnosis (Please tick):

25-34 35-44 45-54 55-64 >65

Are you currently receiving treatment (Please tick): Yes No

What types of treatment have you received? (Please tick all that apply)

Radiation Chemotherapy Surgery Hormonal Other *(please specify)*_____

Do you have other medical issues? (Please describe)

_____

Do you have a regular GP? (Please tick) Yes No

On average, how often would you visit the GP each year? (Please tick)

<5 5-9 10-14 15-19 >20

Do you regularly attend the same medical centre? (Please tick) Yes No

Part 2: **Experiential Information**

This part is designed to identify patients' experiences of general practitioners' roles within the cancer care team (as explored by the interviewer).

1. Thinking about the time(s)/period(s) when you are being or have been treated for cancer, can you please share with us what your general practitioner's role has been within your cancer care team at this time?

Prompts

- What roles did they have (e.g., in making cancer diagnosis for example)?
- Why or why not involved in care?
- What role did they have in getting cancer specialist involved in patient care

2. Thinking about the time(s)/period(s) following your treatment for cancer, can you please share with us what your general practitioner's role has been within your cancer care team at this time?

Prompts

- What roles did they have?
- Why or why not involved in care?
- If GP involved in care at either stage—How did the GP get to be involved?—i.e. did you (or someone acting on your behalf) ask for their involvement? Did the GP pursue their own involvement? Did the clinician encourage their involvement?

3. Can you please share with us what your experiences of being cared for by your general practitioner within your cancer care team have been like?

Prompts

- What qualities do you value about your GP?
- What influences the role of your GP?
- What difference has your GP made to your care?
- What qualities did you not find helpful / could be improved?

4. Can you share with us what you expect from your general practitioner with regard to your cancer care?

5. What role(s) would you prefer your GP to have within your cancer care team?

6. What changes need to occur to support your GPs role within your cancer care team?

Semi-structured Telephone Interview Outline (GPs)

Full Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations
Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

The semi-structured interviews will take place via telephone and will be expected to run for approximately 25 minutes. The interviews will be conducted in two parts:

- **Part 1**: **Background information** will be collected at the beginning of the individual interviews via a brief questionnaire (see below)
- **Part 2**: **Experiential information** will be collected to identify GPs' experiences of general practitioners' roles within the cancer care team.

Part 1: **Background** Information

This part is designed to obtain information on you, your work practices and the care you provide and will be used to complement the interview that will be conducted with you.

Gender (Please tick): Female Male

Age Group (Please tick): 25-34 35-44 45-54 55-64 >65

Location of practice (Please tick): Rural Metropolitan

Length of time practicing medicine (Please tick):

<5 5-9 10-14 15-19 >20

On average how many people with cancer would you see per year? (Please tick)

<25 25-50 >50

What types of cancer have you been involved with? (Please tick all that apply)

Urological Head/neck Thoracic Colorectal Upper GI Breast

Gynaecological Haematological Central nervous system Skin /melanoma

Musculoskeletal Paediatric Other *(please specify)*_____

What stage of cancer trajectory have you most commonly been involved with? (Please tick all that apply)

Diagnosis Treatment Follow-up Recovery Palliative care Other *(please specify)*_____

Part 2: **Experiential Information**

This part is designed to identify GPs' experiences of general practitioners' roles within the cancer care team (as explored by the interviewer).

1. Can you please share with us what you understand to be the role of general practitioners within cancer team care, during treatment?

Prompts

- What roles do GPs have?
- Do GP's roles change/vary? If so, why?
- What role do GPs have when a cancer is suspected?

2. Can you please share with us what you understand to be the role of general practitioners within cancer team care for people with cancer, after treatment?

Prompts

- What roles do GPs have?
- Has the role of GPs changed/varied? If so, why?

3. What has been your experience of being involved in a cancer care team?

Prompts

- Did you view this as a positive role?
- Did the patient view this as a positive role?
- Did the specialist involved view it as a positive role?
- Did other team members involved view it as a positive role?

4. Can you please share with us what aspects you may have found to be barriers and/or facilitators to the role(s) of general practitioners within cancer team care?

Prompts

- Is there anything GPs can do to become more involved?
- Are there things other clinicians do which may help/hinder the involvement of GPs?
- What about patients, do they help or hinder GP involvement? How?

5. What would be the ideal role of general practitioners, within cancer team care?
6. What changes need to occur to support these GP roles within a cancer care team?

Focus Group Discussion Outline
(Professional members of support organisations)

Site: Cancer Council Victoria

Full Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations

Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

The focus groups will take place at the Cancer Council Victoria in Carlton and will be expected to run for approximately 90 minutes.

The focus group will be conducted in two parts.

- **Part 1**: **Background information** will be collected at the beginning of the focus groups via a brief questionnaire (see below)
- **Part 2**: **Experiential information** will be collected to identify support workers' experiences of general practitioners' roles within the cancer care team.

Part 1: Background Information

This part is designed to obtain information on you, your work practices and the support you provide and will be used to complement the interviews that will be conducted with you.

Gender (Please tick): Female Male

Age Group (Please tick): 25-34 35-44 45-54 55-64 >65

Location of service (Please tick): Rural Metropolitan

What types of cancer has your organisation been involved with? (Please tick all that apply)

Urological Head/neck Thoracic Colorectal Upper GI

Breast Gynaecological Haematological Central nervous system Skin /melanoma Musculoskeletal Paediatric Other *(please specify)*_____

Part 2: **Experiential Information**

This part is designed to identify support workers' experiences of general practitioners' roles within the cancer care team (as explored by the interviewer).

1. Can you please share with us what you understand to be the role of general practitioners within cancer team care, during treatment?

Prompts

- What roles do GPs have?
- Does the GP's role change/vary? If so, why?
- What role do GPs have when a cancer is suspected?

2. Can you please share with us what you understand to be the role of general practitioners within cancer team care for people with cancer, after treatment?

Prompts

- What roles do GPs have?
- Has the role of GPs changed/varied? If so, why?

3. What has been your experience of being involved in a cancer care team?

Prompts

- Did you view this as a positive role?
- Did the patient view this as a positive role?
- Did the specialist involved view it as a positive role?
- Did other team members involved view it as a positive role?

4. Can you please share with us what aspects you may have found to be barriers and/or facilitators to the role(s) of general practitioners within cancer team care?

Prompts

- Is there anything GPs can do to become more involved?
- Are there things other clinicians do which may help/hinder the involvement of GPs?
- What about patients, do they help or hinder GP involvement? How?

5. What would be the ideal role of general practitioners, within cancer team care?
6. What changes need to occur to support these GP roles within a cancer care team?

THE AUSTRALIAN HEALTH WORKFORCE INSTITUTE

Semi-structured Telephone Interview Outline

(Cancer Specialists)

Full Project Title: What role do general practitioners play in the cancer care team? A qualitative study of experiences of patients, specialists, general practitioners and professional members of cancer support organisations

Principal Researcher (s): Lucio Naccarella, PhD; Vicki White, PhD; Susan King, PhD.

The semi-structured interviews will take place via telephone and will be expected to run for approximately 25 minutes.
The interview will be conducted in two parts.

- **Part 1**: **Background information** will be collected at the beginning of the individual interview via a brief questionnaire (see below)
- **Part 2**: **Experiential information** will be collected to identify specialists' experiences of general practitioners' roles within the cancer care team.

Part 1: **Background Information**

This part is designed to obtain information on you, your work practices and the care you provide and will be used to complement the interviews that will be conducted with you.

Gender (Please tick): Female Male

Age Group (Please tick): 25-34 35-44 45-54 55-64 >65

Location of practice (Please tick): Rural Metropolitan

Length of time working in oncology (Please tick):

<5 5-9 10-14 15-19 >20

On average how many people with cancer would you see per year? (Please tick)

<25 25-50 >50

What is your discipline? (Please tick) Medical oncology Radiation oncology
Surgery Haematology Palliative care

Other, please specify_____

How many years have you practised in your current discipline? (Please tick)

less than 5 5-10 10-15 15-20 more than 20

Do you specialise in any of the following types of cancer? (please select all that apply)
Urological Head/neck Thoracic Colorectal Upper GI

Breast Gynaecological Haematological Central nervous system
Skin /melanoma Musculoskeletal Paediatric No speciality

What types of cancer have you treated? Please specify: _____ _____ _____

What types of cancer treatment have you been involved with? (Please tick all that apply)

Radiation Chemotherapy Other *(please specify)*_____

What stage of cancer trajectory have you worked in? (Please tick all that apply)

Diagnosis Treatment Follow-up Recovery Palliative care Other *(please specify)*_____

What is your estimated percentage of time currently spent in/occupied in:

____% Private practice _____% Public practice ____% Other

Part 2: **Experiential Information**

This part is designed to identify cancer specialists' experiences of general practitioners' roles within the cancer care team (as explored by the interviewer).

1. Can you please share with us what you understand to be the role of general practitioners within cancer team care, during treatment?

Prompts

- What roles do GPs have?
- Does the GP's role change/vary? If so, why?
- What role do GPs have when a cancer is suspected?

2. Can you please share with us what you understand to be the role of general practitioners within a cancer team care for people with cancer, after treatment?

Prompts

- What roles do GPs have?
- Has the role of GPs changed/vary? If so, why?

3. What has been your experience of being involved in a cancer care team?

Prompts

- Did you view this as a positive role?
- Did the patient view this as a positive role?
- Did the specialist involved view it as a positive role?
- Did other team members involved view it as a positive role?

4. Can you please share with us what aspects you may have found to be barriers and/or facilitators to the role(s) of general practitioners within cancer team care?

Prompts

- Is there anything GPs can do to become more involved?
- Are there things other clinicians do which may help/hinder the involvement of GPs?
- What about patients, do they help or hinder GP involvement? How?

5. What would be the ideal role of general practitioners, within cancer team care?
6. What changes need to occur to support these GP roles within a cancer care team?

Appendix D: Participant demographics

Table 1: participant groups and interview type and numbers

Group	Interview type	Number interviewed
CS	telephone	6
GP	telephone	7
PcW	Focus groups	8
	In person	2
	telephone	11
PMSO	telephone	8
Total		**42**

Appendix E: Summary of Key Emergent Themes from Literature Review

Box 1 Summary of Key Emergent Themes from Literature Review

Perceptions of people with cancer:

- People with cancer viewed the role of their GPs as an informed overseer and personalised support for all health-related and psychosocial issues, throughout all stages of disease.
- Consensus existed about the expectancy for GPs to be involved in aspects of cancer care related to prevention, recognition / screening, diagnosis and referral, follow- up after treatment in survivorship or palliation and bereavement.
- GPs can offer holistic and personalised care for the provision of information, practical and psychosocial support
- Concerns exist regarding the ensuring accessibility, ability to coordinate and communicate efficiently with other team members in and across different settings, and willingness to investigate symptoms, side effects and concomitant problems with appropriate support and teamwork, and refer on if needed

Perceived Roles of Primary Care Generalists

- The exact role of generalists is still poorly defined and very variable and there is a need for a definition and enactment of roles for primary and specialist care, information sharing / effective communication between primary and secondary care, and involvement of GP in multidisciplinary team.
- GPs are well-placed to have a role as have capacity for continuing, personalised and multidimensional care, however, their role should span the full spectrum of cancer (including treatment, the transition to survivorship or pall care, and psychosocial support of patients and their family/carers), as part of integrated multidisciplinary team, supported by a network of services.

Qualities of successful generalist roles

- can address the totality of a patient's experience and are in an ideal position to understand the impact of a cancer diagnosis on a patient's family
- are concerned with the comprehensive, coordinated, and continuous care of individuals, families, and increasingly, populations
- have the ability and willingness to perform care in cooperation with other health professionals, and act as the central coordinator of care/diagnostic pathway
- have the capacity for patient-centred/personalised care (tailored/individualised approach)

Factors Influencing Generalist Roles

- patient's desire for GP involvement at various stages of cancer care
- credibility with colleagues in primary care and counterparts in the acute sector
- uncertainty about respective roles of GP and specialists
- lack of evidence that multidisciplinary teams improve outcomes for patients in Australian context
- lack of funding, investment, infrastructure, resources, support, expertise and continuing
- educational input

Appendix F: Data analysis exemplars

Pre-diagnosis and Diagnosis

In the beginning before and during the diagnosis phase, GP roles indentified were being an advocate, communicator, investigator, interpreter, and supporter providing psychosocial support to the person and their family and advising about cancer care.

GPs were advocates for PwC care negotiating with other health professionals so the PwC's voice could be heard.

> *I've learnt to be strong enough to stand up for myself but there are times when I am so sick that I can't do that either, so I really need advocates ... most of the time [my GP] does PwC11*
>
> *I felt very confident that I had this young man advocating on my behalf, he did, it made me feel very confident indeed in the whole system PwC16*

In the communicator role GPs were available to the PwC and families, to explain about diagnoses, treatments and options; and available to give the results of tests and interpret they meant.

The GPs in the investigator and interpreter roles - recognised signs and symptoms, arranged diagnostic tests, received information and interpreted them for patients; follow up the test results; and referred patients on for specialised diagnosis and treatments.

> *when the PSA first began to appear on the horizon ... [the GP] moved when there was such an aberration, ... so just to be on the safe side he moved the annual blood test up to nine months and then when the same aberration continued but had doubled in its size, he moved that to six months and then as it still continued down to three months and then it was time to visit the Urologist. PwC08*

For some PwC, the investigator role did not eventuate until the PwC found a GP who could recognise symptoms.

> *March my breast changed shape and that then got me going, ... saw one doctor, and he said to me I should check my breasts more carefully, even though there was an obvious change in the shape of the breast because the breast went concave, which I have found in the literature, and it looked like the peel of an orange, and so look I didn't pursue the issue with that doctor ... booked in to see the female doctor ... this female GP immediately referred me for a scan. PwC12*

In the navigator role, GPs had knowledge about where to contact the hospital and ask about what was happening for the PwC. Knowing how to navigate around the health care system and organisations was valued by PwC

> *I realised the next day that I didn't really understand how it all fitted together, because I knew that I was going to a hospital the following week. He'd made this appointment ... I called him back about something and he contacted the hospital again. He was good at that because I didn't really know what to, where to go. And he always, he was very helpful. PwC16*

Psychosocial support extended to the family particularly when the possible diagnosis of cancer was given to the PwC.

> *He made himself available if I had any more questions, he seemed to understand the gravity of it. He asked who I had at home, who my family was ... well he was thinking I suppose of them and also what sort of support I had. PwC16*

Treatment

During the treatment phase some PwC were not clear about the role of the GP in cancer care. Some PwCs saw the GP role as not an active role as in the diagnosing stage. Other PwCs viewed the role during treatment as being vital. One person viewed the GP role as an *intermediary* between the patient and the cancer specialist.

> *my GP acted as an intermediary between myself, the General Surgeon who once the lump had been excised was no longer part of my treatment. PwC09*

The communicator role was one of receiving and following up letters from specialists about treatments and results of tests for the PwC. Often the PwC had an active role in negotiating communication between specialists and GP's keeping GPs *in the loop* of the PwC cancer care.

In the investigator role, GPs researched on the internet and in books to find answers to PwC queries, for example *alternative treatments* which were more about being complimentary to treatments in progress, or treatments for side effects such as in constipation and diarrhoea. The GPs actively involved during treatment, researched and managed side effects as they occurred.

> *The GP had to deal with all the side effects, try and work out what had caused them, try and refer me onto the appropriate Specialist to deal with them and then write scripts for all the drugs needed to manage the side effects. PwC14*

As *a sounding board* PwC could go to their GP and discuss treatment options, and be guided by suggestions from GPs. As a *sounding board* GPs supported the decisions of PwC.

> *He said to me, "This is really tough and if you are going to do this, you know it is a big operation." But he was also supportive when I said to him, "Look I have got a really strong feeling that it was a good idea to have both these breasts removed. I don't want to go through all this twice." So he was supportive in that regard PwC09*

In the supporter role, GPs provided psychosocial support for the person and their family members.

> *I guess that she was just a very good support system for me... yeah very good support ... I do have family, a husband and children and what not. My husband knows my GP very well, as it turns out ... and she was a good support to him PwC0*

One PwC viewed the role of the GP as being the manager of writing prescriptions. This occurred particular when the PwC had co-morbidities and to minimise pharmaceutical interactions.

> *I have insisted that all medication that I get ends up being prescribed by my GP rather than the Specialist. So that my GP is involved and knows - all medication is prescribed by the one person ... the number of cases my Specialists have offered to write me out scripts for stuff and I have said, "No, that is the GPs role and they are the person who has to manage everything." PwC05*

After treatment

After treatment the GP role reverted to a generalist role involving the provision of holistic care, and putting the pieces back together:

> *Basically getting me to put the pieces back together PwC08*
>
> *There is a lot more people seem to be seeing Specialists but there is no aftercare so the GPs is[sic] always picking up the bits. So I think there is probably a growing trend. PwC 14*

Most PwC relayed that GPs as researchers assisted them with understanding what the cancer specialist had said and finding out answers to queries.

> *I'm a very controlling type person and I need to know all the ins and outs of everything. She's been prepared to look up ... the medical things on the internet and what not, while I've been there if I'm asking questions. If she doesn't know the question she'll always find out and then let me know. PwC07*

Some PwC viewed the GP in a co-ordinator role in managing side effects and wound care along with observing and monitoring of their condition.

> *I had my surgery and went back because he did the follow care of my wound and so I saw him a few times. PwC16*
>
> *As the cancer had been successfully halted his[GP] role returned again to being one of maintenance to make sure that regular testing was reintroduced in consultation with the Urologist because of course there were ongoing back up visits to both. ... Just to monitor the situation and that period has now passed it was five years in May. The regular blood tests having continued and showing a negative result in the PSA area. PwC08*

GP attributes and qualities valued by PwCs.

- Communication with the GP: gets on the phone to talk, spend time with PwC in the clinic, having rapport with PwC , has got time to talk with and recognising a need to be heard. The rapport developed between the PwC and the GP is sometimes based on the length of time the patient has been seeing the GP and is greatly valued.
- PwC value GPs' expertise, cancer awareness knowledge and having a network of health professionals to access appropriate care for the person. Navigating the health care system and referring on.
- PwC value GPs who *concerned*, take time in the consultation, is interested, is *available*, is *supportive*, *doing their job* and going *the extra mile*.

> *she is concerned and I feel she is enlightened. She is not 'just take two Panadol and see you in the morning'. She always tries to try and find out what is going on. ... and you feel like ... you have her undivided attention. PwC12*
>
> *Well it certainly helps your state of mind to know that you have got a Doctor who cares - who has got the time, "It is not oh your time is up now off you go," sort of thing so it gives you a lot of confidence that you are getting the best that you can and that is I believe fairly necessary for somebody who has got a life threatening condition. PwC02*

- The qualities valued are 'compassion, kindness, considerate' ,good interpersonal skills, honesty, trust, thoroughness, being a 'good sounding board', prepared to listen; being the person's' mainstay' and giving 'peace of mind'.

> *Probably my GP has been the mainstay, look he can't do everything for me but he has certainly be able to direct me quite efficiently PwC09*

Influences that impact the GP role in the cancer care team.

Aspects that impacted the role of the GP can be categorised into three types of influences: GP attributes, environments and the GP/patient relationship. These are listed in Table 6.

Table 6: Three influences with criteria, on and to the GP role (no ranking).

GP Attributes	Environments	GP/PwC relationship
GP attitude	**Communication**	Length of time with the same GP
Dedication	Being included in cancer care team	**The patient's attitude**
Follows-up	Being available	**Patient preparedness**
Cultural background	Having community links	GP relationship with PwC
GP experience of cancer care; own illness experience	Medical centre environment	
Networks	Time	
Shows human side		
Being well informed		

GP attitude

> *So when it's necessary and it's urgent she will go that extra mile. I don't think she would like herself if she didn't. She's that kind of person who wants to do the right thing. PwC11*
>
> *so really comes back to their values doesn't it, and their priorities in a way PwC12*

Communication

Communication aspects included 'communicating with specialists', 'reassuring patients' and 'receiving reports'.

Medical centre environment

PwC viewed the medical centre environment as being influential on the role of the GP. This participant liked the feeling in the medical centre and how the GPs worked to bring about the '*climate within the four walls'*.

Patient attitude and preparedness

> I was armed with a series of questions too by that stage because I linked up with BRECAN *PwC12*
>
> I don't know whether I am better than anyone else but I do know that if something is wrong I will ask a specific question. Looking for some support, some help. And as I say him and I have known each other for a lot of years, and he knows if I ask a question there is normally something behind it. I am not just making conversation. So if I ask something he does normally gets right onto it. And he then probes deeper to find out exactly what is wrong with me or what I am thinking. And that is the relationship we have - if there is nothing wrong I don't have to discuss it, but if I have got a problem I ask him straight and I have normally thought about it and I do ask what I want to find out. If he doesn't answer it the first time I ask again. *PwC01*

Appendix G: Summary of Views

People with Cancer (PwC) key views (n=21)

- In general PwC value the role and contribution of GPs in to their cancer care, in particular in being available and supportive through the journey.
- PwC recognise and want their GP to provide ongoing medical care, independent of their cancer care providing a more generic role; and be their *point of call*/reference; their *interpreter and friend.*
- PwC who have strong relationships with their GPs are more likely to want, expect and advocate for their GP to be included in reciprocal communications with their cancer care team. Relationship strength is based on length of time with GP, level of reciprocal rapport, reciprocal respect between PwC and GP, management of co-morbidities and generational concepts about the GP role in health care.
- PwC are confused about GPs roles in their cancer care as the GP role changes. In the beginning, the GPs' role is active in investigating, interpreting, referring on to specialists, and being an advocate. During treatment the roles change depending on the cancer type and stage, specialists' role in cancer treatment, and the information, support, management of side effects and co-morbidities as required by PwC. After treatment the GP role is viewed as more active in programming surveillance measures, monitoring, supporting, continuing with co-morbidity management and *putting back together* the PwC for normal generalist care. Also GPs may refer PwC on to palliation and a palliative care team.
- In general, across the cancer journey, PwC expect GPs to be proactive in their overall health care; to be a *sounding board* in decision-making; be an investigator in problem identification and resolutions; an observer, a manager and navigator in the health services for them.
- PwC view the ideal GP role to include being a *co-case manager* of their cancer care with the PwC; the GP having more *interaction with the family* and GPs not be *surrogate specialists* but mainly PwC viewed the role as being *adequate* and happy with *the navigator role*

General Practitioners (GPs) key views (n=7)

- GP roles vary across the cancer trajectory. Most GPs have no perception of being in a team.
- GPs are not always included in multidisciplinary discussions or decision making about care for their patients. and often even if kept informed are not involved in decision-making
- GP work involves tasks and roles, tasks include timely investigations, writing prescriptions, referring on, and managing side effects.
- GP roles in cancer care incorporate the generalist, educator, navigator, advocate, manager of co-morbidity care, psychosocial support and informer across the cancer trajectory GPs act as care-coordinators and interpreters for PwC to understand disease orientated language.
- GP roles change depending on the type of cancer, treatments, severity and level of involvement the GP desires and the PwC desires.
- Level of GP involvement is also influenced by the level of existing co-morbidities the PwC may have and requirement for on-going care for those co-morbidities.
- In palliation, GPs work with a range of cancer care team members in addition to specialists e.g., district nurses and palliative care nurses; GP involvement varies.
- Reciprocal communication with cancer specialists and hospital staff is an issue for most GPs.
- Most GPs rely on PwC to request and advocate for GPs' inclusion in 'team' by asking for GPs to receive result copies and letters about progress from members of the multidisciplinary team caring for the PwC.
- GPs report communication with specialists is better in the private system than in the public system.
- GPs report a lack of communication from hospital staff via discharge summaries.
- Remuneration is one key barrier for communication between GPs and CCT (esp specialists). The issue of remuneration influences the overall role of GPs in cancer care.
- GPs roles in CCT could be supported using: electronic and patient held records to improve communication between GPs and specialists; communication with GP liaison officers within hospital cancer unit (in hospital outpatient clinics); timely focused education on cancer treatments; and appropriate medicare rebates for teleconferencing and home visits.

Cancer Specialist key views (n=6)

- GP roles viewed as positive and as providing link between tertiary cancer care and PwC.
- GP roles change across the cancer trajectory: during pre-diagnosis and diagnosis as the *first port of call* (surveillance, investigator, work up, communicator), during treatment (psychosocial support, managing side-effects, consistency in community; monitoring –managing co-morbidities) and post-treatment (transition, monitor, communicator, palliation).
- Not all GPs are involved in palliative care mainly because of time constraints and sometimes their philosophy about end-of-life care differs to those of the palliative care team.
- GPs inclusion in the cancer care team depends on cancer type and treatment (ie., chronic cancer like myeloma lots contact vs large cell lymphoma limited GP contact); GP relationship with PwC and management of co-morbid conditions, and open communication within the team.
- GPs have important role in pre-diagnostic surveillance and family mapping in familial cancers.
- GPs need to be valued as cancer team members and CSs have a role in reminding GPs of their importance.
- GPs need clarity about their role and domains of responsibility in the cancer care team.
- GPs not routinely included in multidisciplinary cancer team meetings but are kept informed via letters, electronic communications and phone calls from CS if urgent.
- GP training curriculum requires more information about cancer awareness including genetic profiling, consequences and effects of cancer treatments, long term follow-up and surveillance.
- CSs suggest they need to develop relationships with GPs and provide education sessions about cancer treatments and side effects and relative importance of the side effects.
- CS suggest that clarity of roles and responsibilities in a cancer care team will support the involvement of GPs in cancer care teams.

Cancer Support Organisation Member key views (n=8)

- The main role for GPs is to support the person with cancer across the trajectory.
- GP roles include: generalist, investigator, diagnostician; refer on; authorises support funding; relationship builder, survivorship role and providing psychosocial support.
- GPs recognised as having a *pivotal* role in palliation; a *referral point*, recognise symptoms; *first port of call*
- GP roles change over the trajectory from the actively investigator role, to a lesser role during treatment when relationship with PwC can be lost, and a more active role in re-establishing a relationship with the PwC, managing side effects, monitoring for reoccurrences and mental health issues and sometimes referring on to palliative care.
- PSMO identify GP relationships as being important in cancer care; relationships with PwCs, the palliative care team; and with cancer specialists.
- PMSO describe the ideal role for the GP is to be a team member, triaging patients; being knowledgeable about cancers; manager of medications as well as the generalist.
- The ideal GP role in palliative care is the point of entry, have joint home visits, have basic expertise about symptom management and access to hospital regimes to prevent side effects of medications.
- GPs identify with services (Palliative care service) not professionals (e.g., palliative care nurse)
- GP liaison officer within hospital cancer outpatient clinics really useful to keep GPs involved as does discharge planning
- GPs role in CCT hindered by fact that virtual (not physical) teams exist, thus GPs hidden, lack visibility and hence credibility
- PwC often advocate for GPs roles in CCTs
- GPs need Medicare rebate to assist ongoing communication with CCTs and not rely on GPs goodwill

Grouped ideal role of GP in the cancer care team

- generalist role having access to resources, have holistic view of patient, access to electronic medical records; able to manage medication adjustment
- GP in the team of being in the loop and being able to triage patient for symptom management and having mutual recognition of expertise in the team members
- Have knowledge about cancers
- refer on to support options including support organisations
- psychosocial support role for pat and family
- a positive relationship with patient
- in palliative care: point of entry into palliative care; joint visits(home visits) with palliative care team ; have clarity about the roles in the team; have basic expertise in symptom management; have knowledge of hospital regimes