

Bridging *the* Gaps

Multidisciplinary Cancer Care:
The views of General Practitioners



This project is a collaboration between the Discipline of General Practice, School of Medicine, The University of Queensland and Queensland Health and is supported by Cancer Australia.

Acknowledgements

This project is a collaborative effort, involving the following people as well as those who played a supportive role in the development, implementation, analysis and report-writing phases of the study.

A/Prof Geoffrey Mitchell MBBS, PhD, Senior Research Fellow, University of Queensland.

Ms Shoni Colquist, Manager, Queensland Cancer Control Analysis Team

Ms Hazel Harden, Research and Evaluation, Queensland Cancer Control Analysis Team

Ms Alison Love, Principal Project Officer, Queensland Cancer Control Analysis Team

Ms Letitia Burridge, BN, MPH, University of Queensland, Project Officer.

The management team are very grateful to Anne Isdale, a Registered Professional Reporter, who provided us with prompt verbatim transcripts of the focus group and interview discussions. We also wish to thank the participating GPs, whose willingness to give their time and insights enabled this important topic to be explored.

Contact us:

**Queensland Cancer Control
Analysis Team (QCCAT)**

GPO Box 48

Brisbane 4001

Ph: +61 7 323 90886

Fax: +61 7 323 90930

<https://qccat.health.qld.gov.au>

ISBN: 987-1-921447-84-6

Published by Queensland Health
September 2009

© The State of Queensland,
Queensland Health 2009

Copyright protects this publication.
However, Queensland Health has no
objection to this material being reproduced
with acknowledgement, except for
commercial purposes.

Permission to reproduce for commercial
purposes should be sought from:
The Manager
Qld Cancer Control Analysis Team
Queensland Health
GPO Box 48 Brisbane 4001



Table of contents

| | |
|----|---|
| 4 | Executive summary Summary of themes and recommendations Communication Difficulties Roles for GPs in cancer care Recommendations and guidance for the development of online communications tools |
| 7 | Introduction Project aims |
| 7 | Literature review Background Search strategy Summary of findings |
| 9 | Method Project design Sample and recruitment Data collection Instruments Data analysis |
| 10 | Results Sample characteristics Qualitative themes Part A – Concerns regarding the GP role in facilitating cancer care Part B – Perceptions of the role of GPs in cancer care Part C – Potential solutions to concerns regarding GPs' involvement in cancer care |
| 19 | Recommendations |
| 19 | Limitations |
| 19 | Conclusion |
| 20 | References |
| 21 | Appendix 1 Summary of literature |
| 26 | Appendix 2 Focus group questions |

List of tables

| | |
|----|--|
| 6 | Table 1: GPs suggestions to improve communications between themselves and specialist services |
| 10 | Table 2: Participant demographics (n=12) |
| 11 | Table 3: Transcription key for interview quotations |
| 16 | Table 4: Desirable components of GP referrals to specialists |
| 17 | Table 5: Desirable components of specialist feedback to GPs |
| 18 | Table 6: GPs' suggested solutions to concerns regarding their role in cancer care |

Executive summary

General Practitioners (GPs) are well-placed to be more active in the detection, referral and co-ordination of ongoing care. Cancer patients and their treating team can benefit from GPs' prompt access to relevant and adequate information regarding available services, referral pathways and better communication with other health professionals.

This project explored GPs' views regarding:

- The quality of cancer care from a primary care perspective
- The practicality and benefits of integrated cancer care using web-based communication
- GPs' potential role in their cancer patients' care and factors affecting such a role
- The key components of an online referral and communication system
- Factors affecting GPs' use of such a system.

Using a qualitative approach and open-ended questions, focus groups and one interview were conducted with 12 GPs from urban, regional and rural practices in Queensland. The transcripts were analysed to identify key themes relevant to the current position of GPs in cancer care.

These findings fell into three categories:

- Current concerns regarding the involvement of GPs in facilitating cancer care
- Potential solutions to these concerns
- Perceptions of potential roles of GPs in cancer care.

The concerns identified were:

- Communication between general practice and specialist oncology services
- Difficulties encountered in the referral process
- Pre-treatment delays
- Inadequate feedback from specialist services
- Increased workload for GPs.

Several factors contributed to this scenario, including various communication channels to be negotiated to reduce the impact of delays on quality of care, and the lack of regional access to specialists. Timely referral

was also influenced by GPs' familiarity with the system and their ability to liaise with individual specialists, which was usually more achievable within the private system. The GPs felt they had a unique role in cancer care, which includes establishing the diagnosis, providing follow-up and being responsible for palliative care. It is probable that GPs and specialists have a limited understanding of each other's role.

Many GPs were motivated to provide long-term care to their cancer patients. Both GPs and their cancer patients would benefit from initiatives to streamline the process which governs communication, referral, access to services and service capacity. They suggested several specific strategies to improve communication and enhance their role in cancer care.

In addition they proposed several recommendations for overcoming their concerns, which are:

- Referral coordination (assign the receipt of referrals to personnel with the clinical capacity to triage to minimise re-referring)
- Referral acknowledgment (send a receipt of every GP referral and provide a timeframe for response)
- Information access (streamline GPs' access to essential information regarding their patient)
- Instigation of change (articulate responses to these findings in accordance with existing initiatives)
- Provide adequate travel support for non-metropolitan patients and carers.

These findings provide guidance for the content and functionality of the online communication and referral systems currently being developed by Queensland Health. They also provide guidance for further service development to enhance GP participation in cancer care.

SUMMARY OF THEMES AND RECOMMENDATIONS

The project sought to identify the barriers to the provision of cancer care by GPs. The major themes identified were:

- Variability in communication between GPs and specialist oncology services
- Difficulties encountered in the referral process.

This section will provide a précis of these themes and the recommendations that flow from them.

COMMUNICATION

At present, timely referral for cancer care is more often accomplished in the private health care system as GPs contact specialists directly via phone or e-mail. The public referral process is generally to fax or phone a general number where patients are triaged. The options are also influenced by patients' preferences regarding the geographical location of their treatment, by the nature of local resources and the extent to which GPs have knowledge of and the preparedness to liaise with the system to achieve the best outcome. GPs prefer personal interaction with hospital specialists, rather than one-way communication, e.g. using faxed referrals. Negotiating the various communication pathways within the public system causes delays in achieving a timely specialist consultation. These constraints influence the roles GPs have in cancer management.

GPs provided detailed comments about the appropriate information to be included in a GP referral to an oncology service (Table 4, page 16). Similar comments were provided about appropriate content of feedback from specialist services to GPs (Table 5, page 17).

REFERRAL DIFFICULTIES

Timely access to diagnosis or treatment

Public hospital referral procedures differ between hospitals. However, notification from the hospital that the referral is being dealt with in a timely manner is not always forthcoming. Confirmation that a referral has been received and processed often has to be sought by practice staff. In addition, some GPs will try to bypass the uncertainty of the referral pathway by initiating direct communication with the specialist. This can only be done if there are existing relationships between the GP and specialist staff. The more established and experienced the GP, the more likely those relationships exist and the more effective the GP becomes.

Uncertainty about what investigations will facilitate the care of patients

GPs questioned whether it was wasted effort to conduct diagnostic investigations as many tests appear to be repeated by the hospital staff.

Limited access to specialist services in regional areas

Local access to appropriate public specialists is limited or possibly non-existent outside major metropolitan areas. GPs find alternative pathways to specialists to ensure their patients are seen promptly when the need is urgent. This may involve contacting a specialist directly, or referring a patient privately in the first instance, where access to specialists is easier to arrange and more timely for patients. The contrast between

the apparent simplicity of private referrals and the complexity of public referrals was a recurring theme.

Inadequate feedback from public specialist services

Initial referrals to local public hospitals can reduce delays but generate other problems. For example, GPs may be asked by registrars to fax the details to the hospital, but not provide feedback to the GP that the referral was being progressed. GPs are often not kept up to date regarding the patient's condition or treatment regimens. There are considerable differences in the speed and comprehensiveness of communication with GPs between private and public specialists. GPs frequently use email to refer to private specialists and receive a rapid response. By contrast there is no electronic access to public specialists.

Economic disadvantages when travelling to public specialist services

The inconvenience and expense of ongoing visits to specialists in a major centre deters many cancer patients living in non-metropolitan areas, who prefer to receive their care locally. This problem is compounded by the inflexibility of protocols within major hospitals when patients need to travel for appointments. For example, patients dependent on train travel find their appointment requires them to present to a clinic earlier than their train arrives - and/or they may miss the return train due to delayed or late appointments. This forces patients, who frequently have low incomes, to stay in Brisbane overnight, on top of train and cab fares. Additionally, the travel subsidy available from the Government falls considerably short of the actual travel costs.

Sometimes patients are referred to Brisbane centres for tasks that could easily be done at the GP surgery. Specialist clinic staff should consider whether the task for which the patient is being referred can be accomplished locally.

Doctors' lack of experience with the local health system

GPs were also concerned about the capacity of inexperienced or internationally-trained doctors working both as GPs and within the hospital system to provide adequate care, because of their unfamiliarity with the complexities of the local health system. Without that knowledge, their cancer patients could be placed at a disadvantage at the point of referral, or where internal referrals within the public system are required. Inexperienced hospital based staff may not be aware of the importance of liaison with community health practitioners.

Attitudes to multidisciplinary teams

There was a concern that some specialists and GPs may be unwilling to work with a multidisciplinary team. This may constrain the availability of effective team based care of cancer patients.

ROLES FOR GPs IN CANCER CARE

GPs see their principal roles as making the diagnosis of cancer, facilitating timely referral for confirmation of the diagnosis and commencing treatment. They may have roles in treatment which are not routine at present.

These include:

- Pre-treatment testing
- First clinical assessment of potential treatment complications
- In limited cases, administration of chemotherapy.

The latter would require the development of appropriate protocols, communication channels between the GP and the specialist services, and ensuring the clinic had appropriate physical infrastructure.

Post treatment surveillance could be conducted with adequate guidelines and communication strategies in place. The current role of GPs is to provide support to patients and their carers. GPs have a major role to play in the delivery of palliative care. They should be the primary physicians involved in palliative care, with specialist support providing backup care.

RECOMMENDATIONS AND GUIDANCE FOR THE DEVELOPMENT OF ONLINE COMMUNICATIONS TOOLS

| AT THE GENERAL PRACTICE LEVEL | |
|---|---|
| 1 | Improve content of GP referrals to specialists |
| 2 | Undertake GP training in cancer treatment and palliative skills |
| AT THE SPECIALIST LEVEL | |
| 3 | Improve content of feedback to GPs |
| 4 | Improve speed of feedback to GPs |
| AT A STRUCTURAL LEVEL, LOCALLY | |
| 5 | Replace paper messaging with reliable e-communication |
| 6 | Enable GPs to have easier access to relevant information |
| 7 | Improve infrastructure to support GP oversight of cancer treatment |
| 8 | Enable GP access to cancer co-ordinators pre-diagnosis |
| AT A STRUCTURAL LEVEL, LOCALLY AND SYSTEM-WIDE COMBINED | |
| 9 | Provide/improve patients' local access to specialists (reduce need to travel) |
| 10 | Clarify GP role and expectations in cancer care |
| AT A STRUCTURAL LEVEL, SYSTEM-WIDE | |
| 11 | Promote [a definitive] GP role in cancer/palliative care |
| 12 | Reduce professional sensitivity to discussing and planning palliative care |
| 13 | Establish College recognition of GP role in cancer care |
| 14 | Improve remuneration to match intensity of GP-based palliative care |

Table 1: GPs' suggestions to improve communications between themselves and specialist services

In addition, GPs suggested several overarching principles for overcoming their concerns, which are summarised in the following recommendations:

- Referral coordination (assign the receipt of referrals to personnel with the clinical capacity to triage to minimise re-referring)
- Referral acknowledgment (receipt of every GP referral and provide a timeframe for response)
- Information access (streamline GPs' access to essential information regarding their patient)
- Instigate change (articulate responses to these findings in accordance with existing initiatives)
- Provide adequate travel support for non metropolitan patients and carers.

The specific objectives of the project were to:

- Explore GPs' perceptions of their potential role in the journey of their cancer patients
- Identify the factors which would help or hinder GPs' engagement with an enhanced role in the care of cancer patients
- Identify the key components of a co-ordinated online referral and communication system which would be relevant and useful to GPs
- Identify positive and negative factors which would influence the use of such a system in the general practice setting.

Introduction

PROJECT AIMS

Managing the complexity of cancer care requires ongoing communication between health professionals from different disciplines. General Practitioners (GPs) are well-placed to be more active in the detection of cancer, timely referral for treatment and the co-ordination of ongoing care. The role of GPs in multidisciplinary communication regarding cancer care requires access to relevant and adequate information regarding available services and referral pathways. Improving GPs' access to current and accurate web based information and better communication with other health professionals can benefit cancer patients and their treating team by reducing delays in the care pathway.

The twofold purpose of this project was to explore:

- GPs' perceptions of the quality of cancer care in the community and in general practice
- GPs' views regarding the practicability and potential benefits of their involvement in the integration of cancer care services using web-based communication strategies.

The project was funded by Queensland Health and administered by The University of Queensland. This report was prepared by The University of Queensland Discipline of General Practice.

Literature review

BACKGROUND

Multidisciplinary care in cancer

Cancer is a major burden on our community - 1 in 3 men and 1 in 4 women in Australia will be directly affected by cancer in the first 75 years of life. It is estimated that in 2006 there were 106,000 new cases of cancer diagnosed in Australia¹. The complexity of this chronic life-limiting illness generates an array of challenges for cancer patients and their caregivers, which requires the involvement of a range of health professionals in the ongoing management of the illness¹⁻³. Multidisciplinary care is recognized as the cornerstone of good cancer care⁴⁻⁵. This model aims to put the patient at the centre of their care, and its effectiveness depends on health professionals' accessing current information regarding the patient's progress and treatment. Early diagnosis and the commencement of treatment without undue delay are critical to better outcomes for the patient, and hinge upon good communication⁶⁻⁸. This requires an unimpeded and continuous flow of relevant communication between patients, community and hospital based cancer care providers. Communication and patient involvement are two key principles of multidisciplinary care. Service providers in hospitals and the community are currently under enormous pressure dealing with the volume of cancer patients in their care⁹. This pressure could potentially be minimised by reducing barriers to effective communication between health professionals. The quality of referral letters is an under-researched but highly relevant aspect of this issue¹⁰.

The involvement of General Practitioners in cancer care

GPs play a significant role in the care of cancer patients. They are usually familiar with their patients, and are potentially more accessible to patients than hospital specialists. Further, the bulk of ongoing care occurs in the community and, by contrast, patients contact with hospitals, specialists and other health professionals is often only episodic. GPs are in a unique position to encourage their patients to seek early attention for potential cancer symptoms¹¹. GPs with the appropriate skills are also well-positioned to arrange and co-ordinate initial pre-diagnostic investigations, post-treatment management¹², and provide important aspects of their patients' medical history in a hospital specialist referral. The potential for GPs to be involved in the ongoing care of cancer patients is limited by the quality of information from hospital specialists regarding the patient's current status and treatment regimens. Insufficient detail or delays in the provision of information can present a dilemma for GPs who may then be called upon by the patient to deal with acute problems, often after-hours.

Communication between GPs and specialists regarding cancer care

Communication gaps need to be bridged in order to reduce the stress which delays can generate for patients, their caregivers and their GPs. Improving access to relevant clinical information for GPs and other multidisciplinary health professionals involved in the care of cancer patients can help to improve the quality of cancer care. An important step in achieving this is to explore GPs' perceptions of the factors which hinder or help them communicate with hospital specialists.

SEARCH STRATEGY

A literature review was conducted to determine what is known about the involvement of GPs in ongoing multidisciplinary care of cancer patients, and to identify factors which may enhance or hinder their role. Searches were carried out in the Cinahl, Pre-Cinahl and Medline databases since 1995, using combinations of the following terms: cancer OR oncol* OR palliat*, GP* OR general practi* OR family physician* OR primary care, specialist OR consultant OR oncolog* OR hospital OR tertiary care, communicat* OR referral OR feedback OR follow-up OR co-ord* OR continuity AND barrier* OR hinder OR prevent* OR help* OR facilitate. A total of 318 results were returned from this search. Of these, 32 potentially relevant articles were reviewed in full-text. Articles were excluded if they represented expert opinion rather than research.

Those which met the following criteria were included:

- Qualitative or quantitative design
- Articles published in English
- Article addresses at least 1 of the 3 primary themes:
 - Concerns about GPs' involvement in cancer care
 - Perceptions of the role of GPs in cancer care
 - Potential solutions to concerns about GPs' involvement in cancer care.

This enabled the review to remain focused on the key areas of interest to the project.

SUMMARY OF FINDINGS

The relevant findings from these articles are presented in Appendix 1, listed alphabetically by primary author. The findings are summarised here.

Most of the studies were conducted in Great Britain (n=10), eight took place in North America, five were Australian, and one each were conducted in the Netherlands and Belgium. GPs' concerns about being involved in cancer care initially stemmed from factors which caused delay between presentation with symptoms to diagnosis and treatment, such as lack of access to investigations and hospital services, the unsuitability of guidelines, communication difficulties, and the complexity of referring patients onto the appropriate pathway in secondary care. Tardy feedback after referral was a commonly reported problem, and both GPs and specialists felt there was room for improvement in the content of written communications which they received.

During the active treatment phase, GPs often lost touch with their patients and their progress and, as most follow-up and surveillance remained in the hands of specialists, GPs tended to be less familiar with current practice in cancer care. The role of GPs is not consistent across the cancer trajectory. While some GPs want to be involved in cancer care, others may be unwilling because of the professional and personal challenges that come with the role. Although cancer patients usually turn to their GP for moral support or ease of access to medical care, the role of GPs (and specialists) in shared care is not clear. Solutions to GPs' concerns have been identified and some have been tested, with modest results.

The complexity of change needed to improve the sharing of cancer care suggests that GPs' involvement will be achieved slowly and some may remain unwilling until the role is attractive as well as feasible.

The Australian articles explored attitudes and concerns of GPs in rural as well as metropolitan settings, and identified similar concerns to their overseas counterparts. None of the papers investigated the advantages and disadvantages of electronic communication as a means to overcome the need for prompt access to appropriate information, although some expressed reservations about using non-personal modes of communication to deal with the complexities of cancer care in general practice.

The views of Queensland GPs in metropolitan and rural practices need to be explored to provide insights which can inform the development and implementation of strategies to improve the referral and feedback process between primary and secondary care.

Method

PROJECT DESIGN

In consultation with the project team, a focus group approach was selected to explore GPs' perceptions of the quality of cancer care in the community and in general practice, and also to explore their views regarding the practicability and potential benefits of their involvement in the integration of cancer care services using web-based communication strategies. The core benefit of the focus group method is that, unlike surveys, it enables participants' opinions to be tapped through their interaction with peers¹³. Krueger identifies several advantages in the use of focus groups¹³. For example, it enables data to be collected in a natural environment which fosters openness and interaction in participants. It also provides the flexibility for interesting or unclear comments to be probed. These features of focus group research are particularly useful when investigating a topic which participants may find sensitive. Focus group discussions also have high face validity. The link between data collection and the results is more comprehensible and therefore more believable.

SAMPLE AND RECRUITMENT

Understanding the perspectives of Queensland GPs practising in a range of geographical locations was a primary consideration in the sampling procedure. Urban, regional and rural settings were selected to compare the participants' views and experiences related to their distance from larger centres where cancer and palliative services are available. Practising GPs with an interest in multidisciplinary cancer care were recruited by advertising through Divisions of General Practice representing these areas. The participants were self-selected by responding to the advertisements or by snowballing among their colleagues. GPs were offered reimbursement at the hourly rate usually offered by their local Divisions of General Practice. It is customary to do this when involving GPs in developmental research, because they are not salaried but rely on a fee-for-service for their income.

Ethical clearance for the study was obtained from a human research ethics committee at The University of Queensland. Participants provided voluntary informed consent in writing, and standard data confidentiality and security was assured.

DATA COLLECTION

The focus group interviews were directed by a series of questions related to the four topics of interest, and it was anticipated that each group would complete their discussion of the questions within two hours. An experienced moderator conducted each session, and interrupted the discussion only to clarify or redirect discussion to the topic at hand. An assistant moderator co-ordinated the logistics for each meeting, and took field notes to record important non-verbal communications and interactions, as well as overall impressions. The focus groups were video- and audio-recorded, with real-time verbatim transcription carried out by a professional stenographer. The stenographer also provided a summary of the comments made in each focus group, within 3-5 days. A telephone interview was conducted with one GP instead of a focus group, as no other GPs in that geographical area had expressed interest. This interview was audio-recorded and transcribed by the stenographer.

INSTRUMENTS

Open-ended questions were developed to generate dialogue around the four key areas of interest:

- Referral pathways
- Care co-ordination
- Enhancing communication
- Developing partnerships.

Supplementary questions were developed to explore the responses of participants regarding these four areas as needed during discussion. The questions (Appendix 2) were incorporated into an interview guide which also included a preamble, statements to introduce and link the questions and to close the discussion at the completion of each event. Using the interview guide with all groups helped to ensure that a consistent approach was used. In each focus group, participants were given an opportunity to clarify their points and to provide additional insights on the topics of interest. Participants provided standard demographic details and professional background details.

DATA ANALYSIS

The data analysis comprised of the following steps:

- The transcripts were read several times to develop a familiarity with the content. Units of data were identified and sorted into descriptive categories to correspond with the four key topics of interest, as well as any newly emerging categories.
- The categories were clustered by similarity of meanings to develop themes
- Quotations were extracted from the transcripts to illustrate the themes and provide a common thread to the results
- The emerging themes were refined in consultation with the assistant moderator, whose field notes were used to enhance the underlying meanings
- The themes were then analysed to identify converging and diverging views.

Results

SAMPLE CHARACTERISTICS

The demographic characteristics of the participating GPs are shown in Table 2. Three-quarters of the participants were Queensland-trained, and the remainder had trained overseas. A large minority (42%) held fellowships with the RACGP, and most (75%) had vocational registration. It is possible that the remaining 25% were GP registrars. The majority (75%) were interested in palliative care, one was not, and two were unsure.

| CHARACTERISTIC | SAMPLE |
|-----------------------|-------------|
| AGE GROUPS | % (ROUNDED) |
| Younger than 50 years | 50% |
| 50-59 years | 25% |
| 60-69 years | 25% |
| GENDER | % (ROUNDED) |
| Male | 25% |
| Female | 75% |
| PRACTICE LOCATION | % (ROUNDED) |
| Inner or outer urban | 42% |
| Rural or semi-rural | 42% |
| Other | 17% |
| PRACTICE SIZE | % (ROUNDED) |
| 2-4 GPs | 25% |
| More than 4 GPs | 75% |
| HOURS PER WEEK | % (ROUNDED) |
| 1-3 sessions | 8% |
| 4-7 sessions | 42% |
| More than 7 sessions | 50% |

Table 2: Participant demographics (n=12)

QUALITATIVE THEMES

Suboptimal communication between GPs and others in the multidisciplinary team was a common element in all dimensions, which led to delays and loss of continuity in cancer care, and influenced GPs' attitude toward providing palliative care. GPs were concerned about the impact this had on their cancer patients' quality of care. The participants provided insights regarding what GPs are able to achieve, and other potential solutions.

These form the three overarching components of this report:

- Part A:** Current concerns regarding the involvement of GPs in facilitating cancer care.
- Part B:** Perceptions of the role of GPs in cancer care.
- Part C:** Potential solutions to concerns regarding the involvement of GPs in cancer care.

The themes are presented in three sections to correspond with these components.

The abbreviations and notations used in the transcriptions are as shown in Table 3:

| | |
|---|---|
| Ex. | Extract |
| [] | Editorial comments |
| ... | Words omitted |
| M1 | Metropolitan group and participant number |
| 1N1–3N1 | Non-metropolitan group and participant number |
| : | Page number in transcript |
| For example, [1N1:1] after a quotation signifies a quotation from the first non-metropolitan focus group, made by participant 1, and extracted from page 1 of the transcript. Brief quotations are left within the text of the paragraph and placed in quotation marks to distinguish them from the text. All other quotations are indented and italicised. | |

Table 3: Transcription key for interview quotations

PART A – CONCERNS REGARDING THE GP ROLE IN FACILITATING CANCER CARE

GPs voiced their concerns about delays between referral and reaching the point of diagnosis and treatment, delayed or non-existent feedback to GPs after referral, and the increased workload they incurred as a result of these delays. Several factors contribute to delays in the referral process.

Ensuring timely access to diagnosis or treatment

Public hospital referral procedures differ between hospitals. Additional steps may be necessary to ensure a faxed referral is received, as they are not routinely acknowledged and 'you are operating on your own wits' [1N3:6].

For example:

Ex. 1

Public hospitals have their own setup. Some hospitals, they have outpatients coordinator. [In] some hospitals, nurses triage separate to clinic. The clinic specialist, they usually have a once a week meeting to set up triage - which one first [2N5:4].

To counteract their concern about undue delay, GPs may:

Ex. 2

...send a fax to them and a phone number to make sure they received the fax. Sometimes they don't receive the fax... each hospital individually can be completely different [2N5:5].

Without follow-up from their practice, GPs often have little assurance that a faxed referral is progressing in a timely manner. In the meantime, GPs feel responsible for their patients. This is consistent with the experience of others^{14, 15}. Without a common frame of reference, there is no recognised mechanism for ensuring that all patients have prompt access to the appropriate specialist.

Finally, the problem is further complicated when investigations initiated by the GP do not result in a conclusive diagnosis. Delays occur as non-metropolitan GPs try to determine, 'Where do I send you now?' [1N1:1], or 'Where do you start? Where do you go?' [2N1:4]. Metropolitan referrals face a similar challenge regarding faxed referrals as, 'who knows what happens to it' [M4:5].

Lack of regional access to specialist services

Local access to appropriate public specialists is limited or non-existent outside major metropolitan areas. GPs find alternative pathways to specialists to ensure their patients are seen promptly when the need is urgent. This may involve contacting a specialist directly, 'a specific person... who we know' ^[1N3:3].

It may entail referring a patient privately in the first instance, where:

Ex. 3

...of course, it is a lot easier. You choose someone who is suitable and phone them. They usually realise the clinical urgency and make an immediate arrangement for them to be seen, usually within a week, if it is that sort of cancer ^[2N2:3].

The contrast between the apparent simplicity of private referrals and the complexity of public referrals was a recurring theme. Knowing the advantages and disadvantages of each enabled GPs to fine-tune the management of their cancer patients, although this comes at a cost to the GP:

Ex. 4

You have to be personable and persistent in a way... make a personal contact. I have got a guy who has terrible mediastinal malignancy recurrence so I spent three quarters of an hour chasing around to the [cancer specialist] at the [major metropolitan hospital], eventually got her on the phone, spoke to her. She said "Send him in tomorrow." Stuff happens. It is actually trying to choose the right level to pitch your appeal for assistance ^[2N6:3].

This illustrates the extent to which progressing a referral may impose upon GPs' time and/or their willingness to provide care to their cancer patients. It also indicates the importance of personal relationships that the GP develops with specialists. The implication is that GPs who are new to an area, especially overseas-trained doctors, are likely to be significantly disadvantaged by their lack of familiarity with the local health system.

Lack of feedback from specialist services

Initial referrals to local public specialists can reduce delays but generate other problems. In the public system, for example:

Ex. 5

... it is frustrating because typically what you will get is a registrar for a particular area who will give you very non-committal kind of directions like "Type it into a fax, into a letter, fax it down, we will discuss it at our next multidisciplinary meeting and then we will contact the patient and get back to you." There is very little communication in the whole process. They don't usually get back to the doctor. We usually do find that they get back to the patient but you are never particularly sure ^[2N2:3].

Once a patient is referred to a local public hospital surgeon, GPs are often not kept up to date regarding the patient's condition or treatment regimens. Delays in communication are reported by other Australian GPs ^{16, 17}. It is frustrating for GPs who can email referrals to private specialists and receive the specialist's emailed 'letter back straight in as I can get path results in the morning' ^[3N1:4], but the provider is unable to link with public electronic systems. Emailed referrals work well for private patients, but many cancer patients have limited means and their first preference is to be referred for specialist care within the public system. The option of emailed referrals is unsuitable for these patients because this mode of rapid two-way communication is not available in the public system.

Economic disadvantages of travelling to tertiary specialist services

The inconvenience and expense of ongoing visits to specialists in a major centre deters many cancer patients living in non-metropolitan areas, who prefer to receive their care locally. This problem is compounded by the inflexibility of protocols within major hospitals when patients need to travel for appointments.

For example:

Ex. 6

Public transport out of [regional city] is the train, unless you are driving. If you are driving, to get there before 9, you have to get up at 3:30, 4 o'clock in the morning... [By train,] You can't get there before 10:30. The minute they book an appointment, 9 o'clock, the person has to go down the day before ^[1N3:13].

Also too they get the appointments at 3 o'clock in the afternoon ^[1N4:13].

The doctor is running late and they miss the train... you do have a round trip for a train service. Yes, it is a long day but people are prepared to do it because it is their home and they don't have to be stuck in Brisbane with accommodation and feeling lost and unsupported, whatever reason, and yet the appointment system won't facilitate that, no matter ^[1N3:13].

This is really a low socioeconomic area. It breaks the bank if they have to stay overnight ^[1N4:13].

The [Patient Transport System] will pay their train fare from here to Roma Street but it doesn't pay their cab fare from Roma Street to wherever they are going to and there and back. What's that, \$15 there and \$15 back, \$30? It does add up. People won't go to the appointments, they come to us ^[1N3:13].

The large proportion of cancer patients who have no alternative to the public system place referring GPs and their practices under additional pressure to ensure that ongoing care progresses appropriately and in a timely manner. This comment also highlights the need for a clear understanding of the purpose of the appointment and the opportunity to consider whether the task can be accomplished locally.

Doctors' lack of experience with the system

GPs were also concerned about the capacity of inexperienced or internationally trained doctors who are unfamiliar with the complexities of the referral and feedback system.

For example:

Ex. 7

...if you are a young doctor in town, say a GP registrar... or say for example you are an international medical graduate in [location suppressed] and you didn't have that experience and weren't aware of how the system worked, their patients can get very lost... some of those patients do have some waits because they don't know the way to get the patient through the system ^[1N3:10].

This suggests that practising GPs do not necessarily share a common baseline of knowledge and skills regarding the referral process, which may place their cancer patients at a disadvantage at the point of referral. The situation is similar in regional hospitals, where doctors are unfamiliar with the system and make no 'attempt to liaise with us in the community' ^[1N2:6]. The same can be said for these doctors' knowledge of the internal public hospital referral system.

Attitudes to multidisciplinary teams

There was a concern that, despite GPs' recognition of the benefits for the patient, some specialists may be unwilling to work with a multidisciplinary team. For example:

Ex. 8

If I come in and say "The multidisciplinary team at [referring hospital] said...", and the surgeon is not on board with that, then it is very difficult to change that outcome... If we are all part of the team and our treating physicians and surgeons in the same community were involved it would be great. The younger ones come looking for it because that's what they have been brought up on. The older ones feel inhibited. They have been in solo practice for a long time. It is very threatening for them to join the teams ^[1N3:8].

While attitudes to multidisciplinary teams remain mixed among doctors with varying levels of experience, the benefits of their combined knowledge and experience to patients, health professionals and the functioning of the system are limited.

Part A – Summary

At present, timely referral for cancer care is more often accomplished in the private health care system. The options are also influenced by patients' preferences regarding the geographical location of their treatment, by the nature of local resources and the extent to which GPs have knowledge of and the preparedness to liaise with the system to achieve the best outcome. GPs find that two-way communication, preferably with personal interaction, with hospital specialists is infinitely superior to one-way communication with a fax machine. The impact on quality of care is measured in terms of the delays resulting from the various communication filters which have to be negotiated. The constraints of the cancer patient referral and management process have a direct bearing on the role which is required of GPs.

PART B – PERCEPTIONS OF THE ROLE OF GPs IN CANCER CARE

GPs fill a unique role across the stages of the cancer trajectory, from diagnosis to follow-up to palliative care. This is particularly the case in non-metropolitan areas, where GPs tend to be more involved in diagnosis and support.

Managing the diagnosis

The role of GPs in the pre-diagnostic phase is to carry out investigations, reach an initial diagnosis and prepare the patient for the implications, particularly in non-urban practices.

Their intention is that:

Ex. 9

...each step [is] done in a good timeframe to ensure that the impact, when they finally get to the chemo, is going to be as good as possible ^[1N2:1].

This often means the GP has to manoeuvre around the system, finding and implementing the most propitious means of getting the required assessments done:

Ex. 10

It's a personal thing. You make the effort to push as hard as you can with the people who you know to get their best ^[1N2:10].

This effort translates into co-ordinating the process from investigations to referral letters to arranging appointments within the appropriate sector/s and using a recall mechanism to check that the patient is not unduly delayed before treatment.

For example:

Ex. 11

Often there is a delay in ultrasound... if [the patient says] "I am not able to afford any private care", you will still organise most [investigations] in the private sector. Then you are back to where we started from. Then we have got the diagnosis, then it will be referral on ^[1N3:10].

The role is one of liaison and co-ordinating where 'the diagnosis is our territory... [and specialists have] the expertise in management' ^[1N3:26]. Non-metropolitan GPs find that it is 'all part and parcel' ^[1N2:25] of their role to ensure, for example, that pathology tests have been completed locally before hospital appointments, although:

Ex. 12

People are busy and pushed for time and it is cheaper to organise more tests rather than track down the GP [who ran similar tests]... What usually happens... is that you get no feedback. You don't know whether you are wasting everyone's time by doing a lot of tests in general practice when they are just going to be repeated ^[2N6:17].

This duplication can result in unnecessary expense and effort, as well as role confusion. For example:

Ex. 13

I had one person who kept on coming to me and saying "It is difficult for me to get down to Brisbane. Should I go to this next appointment?" I said "Well, yes, you had better go." She went down and a nurse took her stitches out. That was six hours in the car. Then the next time she came and said "Should I go down?" I called up the registrar. He said "I don't know." It is a consultant clinic. I said to her "You had better go. I don't know what they are going to do but you had better go." They had planned radiotherapy that time which previously hadn't been discussed. I think, if they were a bit clearer about what is happening, when it is happening, what each visit is for, would be really good and I guess a coordinator could coordinate that, if there is such a person. A lot of time there is no cancer coordinator ^[2N2:5].

Dissecting the role of GPs and specialists can be difficult due to different expectations and geographical constraints. Further, hospital doctors may misconstrue the capacity of GPs because 'they see the two percent who we can't manage' ^[1N3:26]. Taken together, these comments illustrate the complexity of GPs' role during the diagnostic process.

Managing active treatment

The prospect of overseeing chemotherapy in a non-metropolitan location is daunting to many GP registrars 'without having a real big system and a lot of specialist support' ^[1N3:21]. More experienced GPs also tend to feel hesitant about overseeing chemotherapy treatment. This may reflect trends in general practice and cancer clinics which make the latter more suitable, such as access to support services and the opportunity for social contact with other cancer patients in dedicated clinics. GPs could organise pre-treatment assessment during

treatment phases, and it may also be feasible for them to administer chemotherapy. If the specialist supplied a protocol, if the practice was resourced to comply with standard guidelines, and if an appropriately skilled nurse could be involved, GP-based chemotherapy would be 'one chance to reduce public hospital bedding' ^[2N5:18]. This highlights the multifaceted and multidisciplinary nature of cancer care across the trajectory. Unless other human and material resources are able to supplement GPs' own commitment to cancer care, it may be difficult for the GPs to view cancer care as part of their role, particularly as cancer progresses and patients need more support more frequently.

Managing follow-up

GPs roles continue after referral and treatment, however, with a focus on supporting the patient and extended family, providing information 'in common language' ^[2N3:18] and negotiating appropriate action with their cancer patients, so that they 'feel supported through the journey' ^[2N6:21].

This includes managing issues such as:

Ex. 14

Surveillance. The follow up we often will do without anybody [supervising]. For example, I have some patients who don't get back to see their treating surgeon for their breast cancer follow up. They just come to see me. I didn't ask them. I can't say that. I encourage them to see the surgeon. [The patient replies,] "But I am not going to see him." ^[1N3:20]

[The patient says,] "Can't understand [the specialist]." ^[1N2:20]

"Leaving here at a quarter past five on the Tilt Train, doesn't get down until a quarter to ten." ^[1N1:21]

[The patient's] husband is demented and there is nobody to look after him. ^[1N3:21]

[The carer says,] "I am getting old and frail myself. I don't want to do it." ^[1N1:21]

This sequence of comments suggests that, in non-metropolitan areas, the respective roles of the GP and specialists could be constrained by the patient's choice to rely on the GP rather than travel to see specialists. It culminates in added responsibilities for the GP and the need for current specialized skills, and for clarification of the relationship between specialists and GPs and their respective roles. Rural GPs may not readily admit to a lack of skills or to the usefulness of training to equip them for following up their cancer patients ¹⁸. Regional GPs find that metastatic cancers with a long trajectory need to be managed as a chronic disease.

Patients who are more familiar with their illness readily request surveillance by their GP, and such a role could be enhanced if the multidisciplinary team were to:

Ex. 15

...engender confidence for the patient to return to us (local GPs) for follow-up... [which] we can certainly do and save that 30th trip down ^[1N3:23]

This is easier to achieve with the visiting specialist who 'gets to know our capacity' ^[1N3:18]. Having an established relationship with a specialist is effective when the cancer recurs, and GPs continue to liaise with specialists according to need, because:

Ex. 16

You get the best outcome for your patient. I had a lady with double breast cancer so I just bypassed [the local hospital] and sent her straight to Brisbane. She had it all done there, all done very quickly. She got a year from that. When she got sick again, I just rang the oncologist. She said "Send her down." She got down and unfortunately passed away within two days ^[1N2:16]

GP-based follow up of cancer patients during the span of their illness enables them to receive appropriate care in their preferred location for much of the time.

For example:

Ex. 17

...We can co-ordinate the local services as needed and we would also perhaps be the person that would ring the tertiary institution and say that this is what is happening on the ground... Maybe we could be seen as the key person to know what is happening at home in our local community ^[2N1:21]

This active role does not necessarily have a negative impact on relations between GPs and specialists, although it may be perceived by specialists as 'a threat to their area of practice' ^[1N3:26]. On the other hand, it is problematic for GPs to be left 'out of the picture altogether... [and treated like unpaid] referral and script writing services' ^[M4:2,12]. This under-recognition devalues their role and is a disincentive for involvement in palliative care.

The attitude of referring GPs is crucial to their involvement because:

Ex. 18

...the GP must be prepared to help... [and] be available to be of assistance, especially in the ongoing treatment... at home, in old age homes or retirement [settings] and also the hospital ^[3N1:5].

Motivation for the role is influenced by hurdles which accumulate within the system:

Ex. 19

...You try and find ways around things and you just seem to meet more and more barriers. I guess the issue will be whether I am allowed within the system to do things that may be appropriate and actually make a difference ^[1N1:30].

These comments highlight a tension for GPs between recognising the value of their role in cancer care and being willing to overcome the difficulties which militate against it.

Managing palliative care

The transition to palliative care signals further changes to the GP role in the cancer trajectory. In the palliative phase, GPs are able to play a co-ordinating role by activating support resources, but many patients and their family carers 'are not aware of all these things' ^[3N1:5]. Particularly in non-metropolitan locations, GPs see this aspect of their role as being their patient's 'go-to person' ^[2N6:2] with around-the-clock personal availability. In locations where specialist and palliative services are limited or absent, GPs are likely to be more heavily involved in both the diagnostic process and palliative support.

This extends their role beyond surgery hours, because:

Ex. 20

...with cancer care... people need your assistance now, so you have got to stop what you are doing and do it ^[2N6:19].

Involvement in palliative care is unattractive in the sense that:

Ex. 21

...if the GP is entirely responsible for the palliative care, it can be extremely time consuming and, if you have got a surgery full of patients and you know you can't just get away to go and see them every other day, it can become very burdensome ^[M4:2].

It seems that the more patients rely on GPs, the greater is the GP's need to be equipped for the demands of this role. Not all are able to maintain their palliative care skills ¹⁹. Metropolitan GPs are more likely to have a choice to relinquish palliative care because other providers such as specialists are geographically accessible to their cancer patients. Palliative care has a significant impact on GPs and general practices, although some non-metropolitan GPs are able to sustain the commitment to their cancer patients.

Perceptions of quality in GP referrals

Communication is a key aspect between those who provide care to cancer patients. While GPs rely on prompt feedback from specialists regarding key events such as diagnosis, treatment plans and any significant changes, GPs also acknowledge their responsibility to provide relevant and helpful information in their referral letters which can help to avoid delays in treatment.

The study participants identified key components of effective referrals between GPs and specialists, and these are categorised and listed in Table 4:

| DIAGNOSIS | |
|-----------|---|
| 1 | Diagnosis to this point |
| 2 | Histology/tests |
| HISTORY | |
| 3 | Medical history |
| 4 | Family history |
| 5 | Allergies |
| 6 | Current medications |
| 7 | Psychosocial risks, e.g. depression, poor family support, family violence |
| OTHER | |
| 8 | Current legal status, e.g. wills, power of attorney |
| 9 | Any relevant oddities about the patient |
| 10 | A typed referral |

Table 4: Desirable components of GP referrals to specialists

The GPs were aware of some referrals from GPs which were too brief to be helpful to the specialist, but thought that an adequate referral was essentially ‘a good summary’ [1N2:15].

Perceptions of quality in specialist feedback

There was high convergence among GPs regarding their expectations of specialist feedback. Specialist services and specialist information can be provided in different forms, and does not necessarily need to come from the specialist him/herself. The characteristics of adequate feedback which were identified by the GPs are presented in Table 5:

| DIAGNOSIS AND INITIAL MANAGEMENT | |
|----------------------------------|---|
| 1 | A clear description of the type and staging of the cancer |
| 2 | How the cancer was/is being treated |
| 3 | The next step |
| EARLY FOLLOW-UP | |
| 4 | A very clear description of the type and dose of chemotherapy |
| 5 | When the next dose is due |
| 6 | A profile of the side effects of the drugs |
| 7 | How to respond to side effects |
| 8 | Recommended websites for details regarding common events and timeframes |
| 9 | A statement regarding the current approach to care, e.g. surveillance or palliative |
| 10 | What the specialist has told the patient |
| 11 | A timeframe for review appointments, including which specialist and when |
| 12 | Expectations regarding who is to follow-up on minor events |
| 13 | Events to be referred back to the specialist |
| 14 | Which of concurrent specialists to refer back to, e.g. oncologist, radiologist, surgeon |
| 15 | Which tests have been carried out by the specialist |
| 16 | Which tests are required before the patient's next visit to the specialist |
| 17 | An invitation to contact the specialist regarding problems in the meantime |
| 18 | Readable format |
| 19 | A synoptic style of report, for reference |
| EARLY FOLLOW-UP | |
| 20 | The long-term plan |
| 21 | What to expect |
| 22 | Possible complications |
| 23 | What the specialist expects of the GP |
| 24 | What the GP can expect from the specialist |
| 25 | Palliative options |

Table 5: Desirable components of specialist feedback to GPs

Many GPs are already involved in the ongoing care of their cancer patients, across the illness trajectory. Specific feedback from specialists can be crucial during a patient consultation with the GP.

For example:

Ex. 22

...if you are going to be honest and open and their specialist hasn't been, then that becomes difficult
[M1:10]

Some of the GPs' comments reflect not only lack of familiarity with specialised knowledge and skills, but also imply that, in busy general practices, easier and timely access to information which is integral to the care of their cancer patients can help to reduce the pressure of providing appropriate and sensitive cancer care from this setting.

Part B – Summary

The GPs in this study believed they have a role in cancer care. There were notes of caution, however, as the demands of the role could be seen as excessive and unsustainable without the GPs' willingness to go the extra mile to achieve satisfactory outcomes for their patients. The components of a satisfactory GP referral and a satisfactory specialist reply were identified by the GPs, but the focus group comments were testimony to the probability that neither GPs nor specialists had an understanding of what was important to each other. The reasons for this are beyond the scope of this study, but it seems likely that the undercurrents of GPs' professional workload and lack of in-person communication with specialists are contributing factors.

PART C – POTENTIAL SOLUTIONS TO CONCERNS REGARDING GPs' INVOLVEMENT IN CANCER CARE

A range of suggestions emerged from the focus groups regarding strategies to overcome the concerns which work against GPs' involvement in cancer care. These suggestions incorporate changes among GPs, at the specialist level, and structural strategies which are sensitive to the differences between metropolitan and non-metropolitan areas.

The suggestions are categorised in Table 6:

| AT THE GENERAL PRACTICE LEVEL | |
|---|---|
| 1 | Improve content of GP referrals to specialists |
| 2 | Undertake GP training in cancer treatment and palliative skills |
| AT THE SPECIALIST LEVEL | |
| 3 | Improve content of feedback to GPs |
| 4 | Improve speed of feedback to GPs |
| AT A STRUCTURAL LEVEL, LOCALLY | |
| 5 | Replace paper messaging with reliable e-communication |
| 6 | Enable GPs to have easier access to relevant information |
| 7 | Improve infrastructure to support GP oversight of cancer treatment |
| 8 | Enable GP access to cancer co-ordinators pre-diagnosis |
| AT A STRUCTURAL LEVEL, LOCALLY AND SYSTEM-WIDE COMBINED | |
| 9 | Provide/improve patients' local access to specialists (reduce need to travel) |
| 10 | Clarify GP role and expectations in cancer care |
| AT A STRUCTURAL LEVEL, SYSTEM-WIDE | |
| 11 | Promote [a definitive] GP role in cancer/palliative care |
| 12 | Reduce professional sensitivity to discussing and planning palliative care |
| 13 | Establish College recognition of GP role in cancer care |
| 14 | Improve remuneration to match intensity of GP-based palliative care |

Table 6: GPs' suggested solutions to concerns regarding their role in cancer care

Most of the suggestions are supported by the literature, which was summarised in Appendix 1. Some seemed to be framed in terms of needs rather than solutions, however. For example, specifically how might the content and speed of specialist feedback be improved? It is also difficult to determine from these insights where the priority should lie. Delays in cancer care could be reduced by better communication, for example, but which mode/s of communication should take precedence? Most of the ideas involve change at a broader level, which may be more complex to implement. As suggested in the literature¹⁷, it will take substantially more work to develop solutions from these suggestions than to the point of action which can be implemented, but the points raised by GPs provide direction.

GPs' comments highlighted an overarching need for:

Ex. 23

...clearly articulated roles: what is our role, what are the expectations of other people around us, and some very clear information about their expectations of what is involved in the treatment for the patient, and that other knowledge or information, the tasks that other people would like us to do ^[M1:10].

Addressing this need would be beneficial to a range of key players and make the role more attractive to GPs because:

Ex. 24

No-one wants to work in a system that doesn't work. It leads to frustration, going through four hands, being transferred around hospitals and trying to follow up ^[2N2:21].

This comment highlights a core issue which affects all concerned. Although streamlining the underlying processes may be a complex task¹⁷, the stakes are high for those who will ultimately benefit; the patients.

In view of the multifaceted nature of the issues which GPs described, it is apparent that solutions will need to be found at different levels of health care. Underpinning this is the workforce issue and GPs' lack of control over workforce pressures. Innovative strategies are needed to address or adapt the system to workforce realities. Information management and, in particular, the use of internet technology are critical.

Recommendations

To complement the GPs' suggestions in Table 6, further comments are added here for consideration.

Assign the receipt of referrals to personnel with the clinical capacity to triage rather than re-refer them

The person taking referrals to the specialist services should be as senior as possible, and able to make decisions on behalf of the team. If junior personnel refer to multidisciplinary team meetings where diagnosis and treatment decisions are made, this sets up the risk of failure for the communication loop to be completed.

Acknowledge receipt of every GP referral, and provide a timeframe for response

It is essential to ensure that referrals are replied to so that the GP knows what is happening. The content of the letter should state when a decision is to be made regarding referral, and the nature of the decision that will be made.

Streamline GPs' access to essential information regarding their patient

The GP suggestion regarding improved infrastructure is broad and non-specific. The most important contribution would be access to information regarding the proposed treatments, e.g. link to a website with this information provided in any correspondence. Information regarding the reason for upcoming hospital visits would be helpful when rural patients ask their GP to advise whether the trip is essential.

Articulate responses to these findings with existing initiatives

Cancer Australia has developed the Cancer Service Networks National Demonstration Program, (CanNET) to better link regional and metropolitan cancer services. CanNET will improve access to quality, clinically-effective cancer services throughout Australia, particularly for specific population groups that may currently have poorer cancer outcomes, including Aboriginal and Torres Strait Islander peoples and people living in rural and regional areas.

Articulating these recommendations with ongoing work will enable the study findings to interface with the work of CanNET.

In addition to the above recommendations which relate to communication between GPs, the project provides a recommendation relating to the needs of regional and rural cancer patients.

Provide adequate travel support for non-metropolitan patients and carers

For regional and rural patients, it is important to ensure that travel arrangements are sensitive to their needs. This should involve flexibility of appointments to accommodate arrival and departure times, as well as adequate financial support for travel, including travel from major transport hubs to the hospital.

Limitations

While the focus groups were able to explore the views of metropolitan and non-metropolitan GPs, the perspectives of GPs practising in rural and remote areas of this decentralised State may be different. Those who chose not to participate have not been heard, and their experiences and observations may be different from those who attended the groups. Nonetheless, the convergence of themes with publications suggests that the key issues have been identified.

Conclusion

Providing care to cancer patients across the trajectory is challenging for GPs and other health professionals. These challenges are felt in busy metropolitan practices, but are multiplied in non-metropolitan settings where resources are less accessible to GPs, their patients and their families, and where distance affects communication with specialists and others on the multidisciplinary team. Non-metropolitan GPs learn from experience how to overcome the challenges of referral delays and inadequate communication. This influences the GP role in cancer care and, while GPs readily identify both their concerns and potential solutions, the role itself can be daunting and unattractive in the realities of general practice. However, both the literature and the findings of this study have shown that GPs are interested and motivated to provide long-term care for their cancer patients. This needs to be acknowledged and supported by strategies developed from the insights which they have shared.

References

1. Australian Government. CanNET Information Bulletin No. 2. Needs based approach to cancer. Canberra: Australian Government, 2007:8 pages.
2. Hutchison G, Mansi J. Cancer care in the community: a collaborative approach. *Journal of Cancer Care* 1996;5(3):93-95.
3. Dahele M, Ung Y, Meharchand J, Shulman H, Zeldin R, Behzadi A, et al. Integrating regional and community lung cancer services to improve patient care. *Current Oncology (Toronto, Ont.)* 2007;14(6):234-237.
4. Lapid M, Rummans T, Brown P, Frost M, Johnson M, Huschka M, et al. Improving the quality of life of geriatric cancer patients with a structured multidisciplinary intervention: a randomized controlled trial. *Palliative & Supportive Care* 2007;5(2):107-14.
5. Munday D, Mahmood K, Dale J, King N. Facilitating good process in primary palliative care: does the Gold Standards Framework enable quality performance? . *Family Practice* 2007;24(5):486-494.
6. Cornford C, Harley J, Oswald N. The '2-week rule' for suspected breast carcinoma: a qualitative study of the views of patients and professionals. *British Journal of General Practice* 2004;August:584-588.
7. Jiwa M, Skinner P, Coker A, Shaw L, Campbell M, Thompson J. Implementing referral guidelines: lessons from a negative outcome cluster randomised factorial trial in general practice. *BMC Family Practice* 2006;7(65):11 pages.
8. Jiwa M, Halkett G, Aoun S, Arnet H, Smith M, Pilkington M, et al. Factors influencing the speed of cancer diagnosis in rural Western Australia: a General Practice perspective. *BMC Family Practice* 2007;8(27):11 pages.
9. Biggs A. Background Note: hospital waiting lists explained. Canberra: Parliamentary Library, Parliament of Australia, 2008.
10. Jiwa M. Quality of referral letters. *British Journal of General Practice* 2003;May:406.
11. Summerton N. Cancer recognition and primary care. *British Journal of General Practice* 2002;52(474):5-6.
12. Brennan M, Spillane A. The breast physician: an example of specialisation in general practice. *MJA* 2007;187(2):111-114.
13. Krueger RA. *Focus Groups: A Practical Guide for Applied Research*. 2nd ed. Thousand Oaks, California: Sage Publications, 1994.
14. Jiwa M, Reid J, Handley C, Grimwood J, Ward S, Turner K, et al. Less haste more speed: factors that prolong the interval from presentation to diagnosis in some cancers. *Family Practice* 2004;21(3):299-303.
15. Norman A, Sisler J, Hack T, Harlos M. Family physicians and cancer care. *Palliative care patients' perspectives*. *Canadian Family Physician* 2001;47(10):2015-2016.
16. McConnell D, Butow P. Improving the letters we write: an exploration of doctor-doctor communication in cancer care. . *British Journal of Cancer* 1999;80(3-4):427-437.
17. Reinbrecht S. What do General Practitioners want from metropolitan hospital cancer services and what can be done about it? *Clinical Oncological Society of Australia 34th Annual Scientific Meeting*. Adelaide, Australia: Clinical Oncological Society of Australia, 2007.
18. O'Connor M, Lee-Steere R. General Practitioners' Attitudes to Palliative Care: A Western Australian Rural Perspective. . *Journal of Palliative Medicine* 2006;9(6):1271-1281.
19. Seamark D, Lawrence C, Gilbert J. Characteristics of referrals to an inpatient hospice & a survey of general practitioner perceptions of palliative care. *Journal of the Royal Society of Medicine* 1996;89(2):79-84.
20. Barnes E, Fan G, K H, Doyle M, Librach L, Chow E, et al. Involvement of family physicians in the care of cancer patients seen in the palliative Rapid Response Radiotherapy Program. *Journal of Clinical Oncology* 2007;25(36):5758-5762.

21. Chait I, Glynn-Jones R, Thomas S. A pilot study exploring the effect of discharging cancer survivors from hospital follow-up on the workload of general practitioners. *Journal of the Royal College of General Practitioners* 1998;48(430):1241-1243.
22. Cornbleet M, Campbell P, Murray S, Stevenson M BS. Patient-held records in cancer and palliative care: a randomized, prospective trial. *Palliative Medicine* 2002;16:205-212.
23. Daly H, Collins C. Barriers to early diagnosis of cancer in primary care: a needs assessment of GPs. *Irish medical Journal* 2007;100(10):624-626.
24. Dworkind M, Towers A, Murnaghan D, Guibert R, Iverson D. Communication between family physicians & oncologists: qualitative results of an exploratory study. *Cancer Prevention and Control* 1999;3(2):137-144.
25. Eccersley A, Wilson E, Makris A, Novell J. Referral guidelines for colorectal cancer--do they work? *Annals Of The Royal College Of Surgeons Of England* 2003;85(2):107-110.
26. Farquhar M, Barclay S, Earl H, Grande G, Emery J, Crawford R. Barriers to effective communication across the primary/secondary interface: examples from the ovarian cancer patient journey (a qualitative study). *European Journal of Cancer Care* 2005;14:359-366.
27. Gorman D, Mackinnon H, Storrie M, Wilson G, Parker S. The general practice perspective on cancer services in Lothian. *Family Practice* 2000;17(4):323-328.
28. Grunfeld E, Levine M, Julian J, Coyle D, Szechtman B, Mirsky D, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *Journal of Clinical Oncology* 2006;24(6):848-855.
29. Hewitt M, Bamundo A, Day R. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, & physicians. *Journal of Clinical Oncology* 2007;25(16):2270-2273.
30. Jefford M, Baravelli C, Dudgeon P, Dabscheck A, Evans M, Moloney M, et al. Tailored Chemotherapy Information Faxed to General Practitioners Improves Confidence in Managing Adverse Effects and Satisfaction With Shared Care: Results From a Randomized Controlled Trial. *Journal of Clinical Oncology* 2008;26:2272-2277.
31. Michiels E, Deschepper R, Van Der Kelen G, Bernheim J, Mortier F, Stichele R, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliative Medicine* 2007;21(5):409-415.
32. Papagrigoriadis S, Koreli A. The needs of general practitioners in the follow-up of patients with colorectal cancer. *European Journal Of Surgical Oncology* 2001;27(6):541-544.
33. Sisler J, Brown J, Stewart M. Family physicians' roles lin cancer care: survey of patients on a provincial cancer registry. *Canadian Family Physician* 2004;50:889-896.
34. Smith S, Allwright S, O'Dowd T. Effectiveness of shared care across the interface between primary and speciality care in chronic disease management. *Cochrane Database of Systematic Reviews* 2007(3):Art. No. CD004910.
35. van der Kam WJ BP, van Bommel JH, Meyboom-de Jong B,. Communication between physicians & with patients suffering from breast cancer. *Family Practice* 1998;15(5):415-419.
36. Webb J, Khanna A. Can we rely on a general practitioner's referral letter to a skin lesion clinic to prioritize appointments and does it make a difference to the patient's prognosis? *Annals Of The Royal College Of Surgeons Of England* 2006;88(1):40-45.
37. Wood M, McWilliam C. Cancer in remission. Challenge in collaboration for family physicians & oncologists. *Canadian Family Physician* 1996;42:899-904; 907-910.
38. Worster A, Bass M, Wood M. Willingness to follow breast cancer. Survey of family physicians. *Canadian Family Physician* 1996;42:263-268.

Appendix 1

SUMMARY OF LITERATURE

GPs' concerns about cancer care in general practice; perceptions of their role in cancer care; and potential solutions to concerns about their involvement in the cancer care.

| AUTHORS / YEAR | STUDY DESIGN / AIM | SAMPLE / SETTING | FINDINGS |
|---|---|---|--|
| Barnes et al. ²⁰ 2007 | Cross-sectional survey. To determine cancer patients' perceptions of family physician (FP) involvement in their care. | 365 consecutive cancer patients under palliative Rapid Response Radiotherapy Program. Toronto Sunnybrook Regional Cancer centre, Canada. | GP role: Commonest reason for limited FP involvement: oncologist attending to all cancer needs. Solutions: Greater FP involvement associated with: patient satisfaction with overall care, more recent visit to FP, seeing FP since cancer diagnosis, FP available on-call for emergencies. |
| Chait et al. ²¹ 2008 | Pilot study. To identify consequences for GPs of discharging long-term cancer patients from a hospital outpatient follow-up clinic. | Consecutive sample of 41/65 patients under annual review in hospital oncology clinic who accepted a planned discharge. Barnett General Hospital oncology clinic, UK. | Solutions: GPs felt more specialist Macmillan nurses were needed in community, highlighted importance of fast-track specialist referral, needed further training re routine follow up of cancer patients. |
| Cornbleet et al. ²² 2002 | a) Prospective, parallel group RCT; b) postal survey. To establish if a patient held record (PHR) could be used with different patients and in a different geographical area. | 231 staff-referred adult cancer patients with >6 months prognosis, attending oncology clinics or receiving hospice home/day care. Oncology outpatient centres in Edinburgh & Glasgow; hospice home-care, central Scotland. | Solutions: The PHR made no difference to information exchange between health professionals; success most likely if introduced early in patient's illness, but duplicated record keeping is still likely to hinder widespread adoption. |
| Daly & Collins. ²³ 2007 | a) Focus groups; b) national survey. To assess GPs' needs re early detection of cancer. Qualitative design, focus groups. To explore factors that may influence family physician involvement in cancer care. | a) Convenience sample of 47 GPs; b) 929 GPs (38% of all practising GPs). Republic of Ireland. | Concerns: The main barriers to diagnosis at any stage were: delayed presentation, lack of direct GP access to investigations, difficulty with hospital referral, inequitable access to hospital services, need for further education and clinical practice guidelines. |
| Dworkind et al. ²⁴ 1999 (Abstr.) | Prospective audit. To determine effect of urgent referral guide-lines for suspected colorectal cancer. | 14 focus groups, followed by structured phone interviews with 116 FPs. 6 Canadian provinces. | GP role: FPs deal with complex psychosocial and biomedical factors in cancer care, so written communication alone is inadequate. FPs wanted to be more involved in all stages of cancer care. Solutions: FPs need face-to-face and/or phone communication with oncologists to negotiate their respective roles, discuss patient's prognosis and effectiveness of proposed treatments. |
| Eccersley et al. ²⁵ 2003 | In-depth interviews. To explore GPs' views of communication across primary/ secondary interface. | 180 urgent referrals to a district general hospital. Unspecified setting in UK. | Solutions: Improved guidelines, as many patients do not have features which fit published referral criteria; improved GP support and better access to specialist services will reduce delays. |

| AUTHORS / YEAR | STUDY DESIGN / AIM | SAMPLE / SETTING | FINDINGS |
|--|--|--|---|
| Farquhar, et al. ²⁶ 2005 | Part of a multi-method study to enable earlier diagnosis of ovarian cancer and enhance primary/secondary partnership in ovarian cancer care. | Purposive sample of GPs with experience of caring for an ovarian cancer patient through to end of life in past 6 months. n=12. Cambridge Gynaecological Oncology Centre, West Anglia Cancer Network, UK. | Concerns: Tardy communications was commonest concern (up to 35+ days). Other issues: a) content (too much/little detail; treatment-focused; excluded patient coping, what was discussed with patient, problems, management plan, advice re inpatient admissions, prompt advice re death in hospital) and b) format of communications. GP role: During active treatment, GPs lost touch with their patients but could provide moral support and to manage crises; during the terminal phase GPs' role is to oversee care. Solutions: At diagnostic stage, GPs needed prompt information re test results, diagnosis; clearer guidance re-use of tests and fast-track referrals; during active treatment, GPs needed effective communication; in terminal phase, GPs needed information. |
| Gorman et al. ²⁷ 2000 | Questionnaire study. To obtain GPs' views about current services and potential improvements for patients with suspected lung, large bowel, nonmelanoma skin and breast cancers. | 79/134 general practices. Lothian Health Board area, Scotland. | Concerns: Hospital referral depended on knowledge of local services, practices sometimes unaware of hospital's post-diagnosis plan, communication was often too slow, practices often received poor advice re symptom control. GP role: 80% thought hospital follow-up for breast, colorectal and lung cancer should be routine; 20% thought likewise for non-melanoma skin cancer. Solutions: A minority of practices wanted referral guidelines. |
| Grunfeld et al. ²⁸ 2006 | Multi-centre RCT. To determine if family physician (FP) vs. specialist follow-up is safe and acceptable. | 968 breast cancer patients, 9-15 months after diagnosis/treatment at 6/9 regional cancer centres, and disease free. Canada. | GP role: Breast cancer patients can be offered follow-up by their FP without concern for adverse effects. |
| Hewitt et al. ²⁹ 2007 | a) Focus groups, b) qualitative interviews. To assess how a survivorship care plan prepared by oncologists could improve quality of survivorship care. | a) Older and younger, male and female cancer survivors, post treatment and 5 years of follow-up; 10-12 in each of 3 groups; 34 nurses with a range of oncology experience. b) 20 medical/radiation/ gynaecological oncologists and urologists. Fairfax, Virginia, USA. | GP role: Primary care physicians felt they had an important post-treatment role. Solutions: Primary care physicians felt a written care plan for follow-up would help them improve survivorship practices. Physicians providing oncology care acknowledged value of plans, but felt disinclined because the plans would not reduce other reporting and communication requirements, and would be an additional burden. |
| Jefford et al. ³⁰ 2008 | RCT. To examine whether tailored chemotherapy (CT) information faxed to GPs improves their knowledge, confidence and satisfaction with information and perceived shared care. | Convenience sample of GPs of patients receiving CT, randomly allocated to receive faxed letter and information re their patient's CT. n=81/113 (78%). Peter MacCallum Cancer Centre, Melbourne, Australia. | Solutions: GPs receiving CT sheet found it significantly more useful ($p<0.001$) and instructive ($p<0.001$) than standard correspondence alone. |
| Jiwa et al. 2007 ⁸ | Focus group discussion of <8 specific cases. To explore GPs' views of factors affecting speed of cancer diagnosis. | 42 GPs practising in 2 rural locations invited, 25% attended a group, 100% responded to summary. Western Australia. | Concerns: Speed of diagnosis hindered by: frailer and older population, presenting with multiple and complex diseases; procrastination in presentation due to seasonal and demanding work patterns; unhelpful scheduling of specialist appointments; variable impact of GPs' informal networks and social relationships. |

| AUTHORS / YEAR | STUDY DESIGN / AIM | SAMPLE / SETTING | FINDINGS |
|--|--|--|---|
| Jiwa et al. ¹⁴ 2004 | Structured investigation of clinical records in 1 practice. To explore general practice factors which delay cancer diagnosis. | 54 cases 1990-94. 1 urban group practice using computerised appointment system and serving deprived and affluent communities. UK. | Concerns: Patient reticence to seek expedited specialist appointments, communication failures, patients presenting multiple problems in short GP consultations, some delays result from avoidable errors before and after referral, especially by patient entering secondary care on wrong pathway, primary care influences and is influenced by policies in other parts of health care system. |
| McConnell et al. ¹⁶ 1999 | Semi-structured interviews. To explore views re improvements to referral letters, based on letters to and from 6 oncologists relating to 20 consecutive new patients. | 7 oncologists from 3 Sydney hospitals, 10 surgeons, 11 GPs practising in the Sydney metropolitan area, 2 rural GPs (n=28). Australia. | Concerns: Referring surgeons and GPs were concerned most about delays in consultant's reply; insufficient detail was a common problem; and replies included too much detail re patient's history/background. Solutions: Oncologists want information re patient's medical status, involvement of other doctors, and any special considerations. Referring surgeons and GPs want information re proposed treatment, expected outcomes, any psychosocial concerns. |
| Michiels et al. ³¹ 2007 | Qualitative interviews. To explore terminal patients' perceptions of GPs' role in delivering continuous end-of-life care, and barriers. | 17 terminally ill cancer patients informed about diagnosis and prognosis. Primary care, Belgium. | Concerns: Barriers to continuity: lack of time, lack of initiative. GP role: Terminal patients attribute a pivotal role to GPs: relational and informational continuity. |
| Norman et al. ¹⁵ 2001 | Qualitative interviews. To explore factors affecting patient-family physician relationship, and perceptions of FP's roles in their care. | Purposive sample of 11 male and 14 female palliative cancer patients. 2 palliative care hospital wards in Winnipeg, Manitoba, Canada. | Concerns: Factors affecting delay: patients or FPs relocate; distrust over delays in diagnosis; failure to perceive a need for FPs; poor communication between FPs and specialists; lack of FP involvement in the hospital. GP role: Patients value prompt access to GP appointments, phone contact, emotional and family support, referral, triage, general medical care. |
| O'Connor & Lee-Steere ¹⁸ . 2006 | Qualitative design. To identify: a) rural GP attitudes to palliative care; b) factors affecting GP attitudes; c) barriers to palliative care in a rural centre. | 10 GPs. Greater Bunbury Division of General Practice, Western Australia. | Concerns: Emotional impact of palliative care on rural GPs where other support not available, acknowledging need for education and training, dealing with wider context. GP role: To maintain patients' quality of life, support family. Solutions: Continuity of relationship with the patient care, having a multidisciplinary team to collaborate with, locally relevant education and training. |
| Papagrigoriadis & Koreli ³² . 2001 | Postal survey. To investigate what GPs need in order to follow up patients with colorectal cancer. | 164/278 (59%) GPs in 83 practices under Tees Health Authority, UK. | Concerns: Workload (60%), lack of guidelines (59%), lack of specialised knowledge (51%), re-referral specialist delays (41%). GP role: 43% saw role as a natural part of their work, 37% thought it was unrealistic, 8% thought it was wrong. Solutions: Guidelines (77%), fast routes of re-referral to specialists (72%), seminars to update (50%), open access to investigations such as colonoscopy (45%). |
| Reinbrecht ¹⁷ 2007 | Focus group. To standardise and improve communication with GPs at key points in patient journey. | 4 GPs practising in southern Adelaide, plus a cancer clinic practice manager, oncology nurse practitioner, redesigning care facilitators, project manager, Onkaparinga cancer support and a colorectal surgery consultant. South Australia. | Concerns: GPs not advised re receipt or processing of referrals, not informed re outcomes of multidisciplinary meetings, need more information re treatment and side effects; lack of formal role for GPs within the treatment plan, discharge summaries are not synchronised with pharmacy or GP availability (4 days' supply of drugs but unable to see GP within week); lack of handover re GP's role at discharge; lack of clarity re central person for GPs to obtain information from; all want information but no one has time to read it or respond to it. Solutions: Standardisation of complex processes is not easy. Embedding processes into current systems will help sustain change. |

| AUTHORS / YEAR | STUDY DESIGN / AIM | SAMPLE / SETTING | FINDINGS |
|--|--|--|--|
| Seamark et al. ¹⁹ 1996 | a) Retrospective chart audit; b) phone survey. To identify symptoms, prescribing and physical problems of patients referred to an inpatient hospice. | 130 consecutive first admissions (95 GP and 35 consultant referrals). 79 referring GPs surveyed. Exeter and District Hospice (12 beds) in grounds of District General Hospital (854 beds), UK. | Concerns: 37% of GPs had not attended palliative training/lecture in past 3 years, GPs had difficulties frequently/always in managing pain (n=8), or other symptoms (n=25), helping patients and relatives re emotional distress (n=18), managing own emotional responses to death/dying (n=5). |
| Sisler et al. ³³ 2004 | Mail survey. To describe cancer patients' experience of the role of family physicians (FPs) in their care | Stratified random sample of adults diagnosed with first cancer in last 6-12 months and with a mailing address, equal numbers from Winnipeg or elsewhere in Manitoba, Canada. (n=202=(56%). | GP role: 91% had a FP involved, which decreased after diagnosis. 40% received shared and parallel care between specialist and FP. Those with mainly specialist care more likely to prefer greater FP involvement than those with shared or parallel care (p<0.01). Most common needs were well provided for: general medical problems, quick referrals, taking extra time, quick appointments. Family support and house calls less well provided for. |
| Smith et al. ³⁴ 2007 | Systematic review (Cochrane Database). To determine effectiveness of shared-care in chronic disease. | 20 studies of shared care interventions (19 RCTs) | Solutions: Most studies were brief but examined complex interventions; no consistent improvements in health and well-being outcomes, admissions, risk factors, satisfaction with treatment; clear improvements in prescribing in studies which assessed this; variable methodological quality, and only a minority of high quality; insufficient evidence to support widespread use of shared care. |
| Van der Kam et al. ³⁵ 1998 | Questionnaire survey. To investigate: a) speed and type of communication between GPs, specialists and patients; and b) communication problems between GPs and specialists. | 150/246 GPs of patients with breast cancer. Zwolle region, Netherlands. | Concerns: GPs found communications too slow (49%) or infrequent (25%). GP role: 25% felt task distribution between |
| Webb & Khanna ³⁶ . 2006 | Prospective audit survey, retrospective review of chart, histology. To determine: if priority of GP referral letters adhered to guidelines; process outcomes; if new 2-week rule improved prognosis of melanoma at diagnosis. | 202 referral letters to skin cancer clinics. Plastic surgery department and outpatient clinics in a district hospital, England. | Concerns: 29% were referred as 2-week cancer referrals, of which 22% did not fall within guidelines, and 11 gave no diagnosis; 42% had no indication of priority, although it may have been implied. |
| Wood & McWilliam ³⁷ . 1996 (Abstr.) | Qualitative in-depth interviews. To explore oncologists' views on cancer follow up process, and what they need from FPs during remission. | Purposive sample of 9 medical or radiation oncologists with >2 years' experience. Regional cancer centre, Canada. | Concerns: collaboration with family physicians in remission inhibited by variable and unpredictable interest, poor communication with family physicians, and patients' own preferences for follow-up. Oncologist role: reassure patients, detect recurrence, monitor toxicity of treatment, gather data for clinical trials; Solutions: Oncologists wanted more understanding and support from family physicians through sharing follow-up care. |
| Worster et al. ³⁸ 1996 (Abstr.) | Mailed questionnaire. To explore experiences and willingness of FPs to follow-up stage 1 breast cancer patients. | 154/189 FPs, with oversampling of female physicians and those >20km from a cancer clinic. SW Ontario, Canada. | GP role: 53% had been involved in 5-year follow-up care of breast cancer patient, 77% believed it was an appropriate role for most patients, 90% would accept responsibility if asked. Willingness associated with previous experience. |

Appendix 2

FOCUS GROUP QUESTIONS

- What factors do you think have an impact on the quality of outcomes for cancer patients?
- What are the steps necessary for you to get a patient from one point of service to another?
- How do you feel the referral process could be improved to ensure timely access to multidisciplinary teams?
- In your experience, what stages of the cancer journey could be improved with better co-ordination?
- In your experience, what are the key components of good communication between cancer services and GPs?
- Tell me about your current experience of communicating with cancer services in rural or metropolitan hospitals in Queensland.
- What are your thoughts as to how well a co-ordinated online referral and communication system could work for GPs?
- What experience have you had with using internet-based links to other health professionals?
- Can you tell us about any issues that come to mind regarding electronic communications between GPs and other service providers?
- In your view, what role could GPs play in the ongoing management of people throughout their cancer experience?
- In what ways do you think these roles could be of benefit to patient care and planned outcomes?
- What do you think might enhance GPs' involvement in roles such as these?
- In your opinion, what factors might impede GPs' involvement in cancer care?
- Have we missed anything important about GPs' involvement in ongoing cancer care?

