

The impact of knowledge, attitudes and beliefs on the engagement of primary and community-based healthcare professionals in cancer care: a rapid review

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An **Evidence Check** review brokered by the Sax Institute
for the Cancer Institute NSW

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This rapid review was brokered by the Sax Institute.

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Contents

Glossary	4
1 EXECUTIVE SUMMARY.....	5
1.1 Conclusions and recommendations	6
1.2 Knowledge.....	7
1.3 Attitudes	8
1.4 Beliefs	8
2 Introduction and background	9
2.1 Primary care in Australia.....	10
2.2 Primary care in the developed world.....	11
2.3 Cancer.....	11
3 Method	13
4 Analysis	14
4.1 Hierarchy of evidence	14
5 Review Question 1	16
5.1 Referral and early diagnosis.....	16
5.2 Treatment.....	18
5.3 Follow-up care	20
5.4 Attitudes	21
6 Review Question 2	25
7 Review Question 3.	27
8 Conclusions and recommendations	29
8.1 Knowledge.....	29
8.2 Attitudes	29
8.3 Beliefs	30
9 References	31
10 Appendices.....	39
Appendix 1. Search methodology in detail.....	40
Appendix 2. Summary of literature reviewed	44

Glossary

Attitude

*"Attitudes are usually defined as a disposition or tendency to respond positively or negatively towards a certain thing (idea, object, person, situation). They encompass, or are closely related to, our opinions and beliefs and are based upon our experiences. Since attitudes often relate in some way to interaction with others, they represent an important link between cognitive and social psychology."*¹

Belief

*"Assent to a proposition or affirmation, or the acceptance of a fact, opinion, or assertion as real or true, without immediate personal knowledge"*²

Community-based health professional

Health professionals include medical practitioners, nurses, and miscellaneous health professionals. These professionals *"diagnose and treat physical and mental illnesses and conditions and recommend, administer, dispense and develop medications and treatment to promote or restore good health."*

Most occupations in this sub-major group have a level of skill commensurate with a bachelor degree or higher qualification. In some instances relevant experience is required in addition to the formal qualification.

*Tasks performed by health professionals typically include examining patients to establish the nature of their complaint and performing or ordering diagnostic procedures; selecting and administering appropriate treatment, medication and therapy; prescribing prosthetic or corrective devices; providing nursing care for patients; and conducting research to improve diagnosis and treatment.*³

Engagement

"Engagement means being motivated and committed, taking an interest in the way the whole organisation operates rather than working down a narrow furrow of your own, and discretionary effort." (Thomson cited in⁴)

Knowledge

*"Accumulated external and explicit information belonging to the community, being leveraged by tacit intrinsic insights which originate within individuals who then may act alone or cooperatively in order to control or integrate with their environment."*⁵

Patient

*"A person receiving or registered to receive medical treatment."*⁶

Primary care practitioners

Suitably trained practitioners that represent multiple disciplines and provide *"socially appropriate, universally accessible, scientifically sound, first level care"* (ADGP, 7)– *this encompasses health promotion, illness prevention, treatment and care of the sick, community development, and advocacy and rehabilitation.*

*'The role of the general practitioner gives an indication of the breadth of the primary care services provided and the degree of uniformity in the services. In industrialised countries, the GP is the only clinician who operates in the nine levels of care: prevention, pre-symptomatic detection of disease, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, terminal care and counselling.'*⁸

Prostate Specific Antigen (PSA)

Prostate-specific antigen (PSA) is secreted by the epithelial cells of the prostate gland. PSA is produced for the ejaculate, where it liquefies semen in the seminal coagulum and allows sperm to swim freely. It is also believed to be instrumental in dissolving cervical mucus, allowing the entry of sperm into the uterus. PSA is present in small quantities in the serum of men with healthy prostates, but is often elevated in the presence of prostate cancer or other prostate disorders.

1 EXECUTIVE SUMMARY

Cancer is the leading cause of illness in Australia⁹ and represents a national health priority.¹⁰ In addition to the personal effects for patients and those who care for them, cancer is associated with considerable organisational and, related to these, economic costs. Estimates suggest:

The total expected lifetime economic cost of cancer for people diagnosed in 2005 in NSW is around \$32.5 billion... In Australia the total expected lifetime economic cost of cancer for people diagnosed in 2005 is around \$94.6 billion and the total financial cost is around \$11.2 billion.¹¹

As the linchpin of the Australian health system primary care is well-positioned to support individuals diagnosed with cancer as well as those who care for them. However, the knowledge, attitudes and beliefs of health professionals and patients shape, and can potentially thwart the way they engage in cancer care. To understand these dynamics a rapid review of extant research was conducted to identify:

1. The knowledge, attitudes and beliefs held by health professionals and patients which can impact on the engagement of primary and community-based health professionals with early detection of cancer and follow-up care
2. The evidence that attitudes and beliefs can be modified with measureable impact on the engagement of primary and community-based professionals with cancer care
3. The attitudes and beliefs which are likely to be relevant to the New South Wales (NSW) context as potential drivers for engagement of primary and community-based professionals in cancer care, and the potential targets for intervention.

A search strategy was devised and deployed within six academic databases. This was complemented with a search of grey literature. Of the 4212 publications that were identified, 162 met the inclusion criteria and were included in this review.

Reviewed publications collectively suggest the following:

1. Cancer literacy among health professionals and patients – that is the knowledge and skills required to understand and use cancer-related information (adapted from Australian Bureau of Statistics¹²) – is largely limited. Health professionals have limited knowledge of evidence-based practices in the early detection of cancer, its treatment and follow-up care. This is associated with missed opportunities for patient consultation as well as delayed or premature referral to specialist care. For instance a study on referral for scrotal ultrasound scans found that 80% of patients were referred more urgently than the opinion of the specialist.¹³ Limited familiarity with and use of evidence-based cancer care practices might be partly explained by systematic issues¹⁴; the gatekeeper role held by some primary and community-based health professionals – as is the case with Australian general practitioners (GPs); the limited availability of clinical practice guidelines – as is the case for endometrial cancer in Australia; the ambiguity that surrounds some cancer symptoms¹⁵; ill-defined role delineation between health professionals¹⁶; and the unease of cancer care among some health professionals¹⁷

Among health professionals clinical practice is influenced by attitudes and beliefs about cancer. The application of the evidence gives rise to clinical experience which in turn impacts on the patient experience.¹⁸ Conversely beliefs about particular patient cohorts – like those based on age¹⁹ – and the skills of fellow health professionals²⁰ can thwart the delivery of evidence-based cancer care

Cancer literacy among some patients (and potential patients) is also limited. This is especially the case among minority groups²¹ including Aboriginal Australians.²²⁻²⁴ Lack of knowledge at one end of the spectrum, as well as influenced by myths and misconceptions about cancer at the other end of this spectrum, can affect help-seeking behaviour, access to services and cancer care. This affirms the interrelatedness of knowledge, attitudes and beliefs, whereby addressing one component is likely to affect the others

2. Irrefutable evidence to identify the attitudes and beliefs that can be modified with measureable impact is limited. However, inferences may be drawn from the some of the research on the attitudes and beliefs of health professionals and patients that can influence the engagement of primary and community-based health professionals in cancer care. For instance clear guidance – as provided by clinical practice guidelines²⁵, additional training²⁶, cancer care review protocols²⁷, and survivorship or shared care plans²⁸ – may increase self-efficacy in the delivery of cancer care
3. Irrefutable evidence to identify potential targets for intervention in NSW is limited. However, inferences may be drawn from the some of the research on the attitudes and beliefs of health professionals and patients that can influence the engagement of primary and community-based health professionals in cancer care, particularly research from comparable contexts. For instance research from Western Australian and Queensland suggests that enhanced cancer literacy among primary care practitioners and patients coupled with organisational support may enhance the engagement of primary and community-based professionals in cancer care.

Despite the potential value of these findings four key limitations deserve mention. Principally they were not identified through a systematic review of available literature. This would require ‘a disentangling of the variation in the characteristics of the targeted professionals, the interventions studied, the targeted behaviours and the study designs’.²⁹ Second, given the absence of well-accepted definitions of the key terms – including knowledge, attitudes, beliefs and engagement – the indexing systems used by databases to code publications may have obscured all relevant publications. Third, the review is limited by the paucity of robust research in this area – particularly those that offer level I and level II evidence. Finally the findings represent the authors’ understanding and interpretation of the identified publications, rather than a valid reliability check. Although the extracted information was substantiated through regular discussion, it does not constitute a valid reliability check. This might have been achieved through the use of inter-rater reliability measures.³⁰ Notwithstanding these limitations the following two lessons from this rapid review should be noted. First, there appeared to be **no** studies that suggest that the knowledge, attitudes and beliefs of health professionals and patients **do not** influence cancer care; this reaffirms the important role of knowledge, attitudes and beliefs among **both** health professionals and patients. Second, there is limited level I and level II evidence to definitively identify the attitudes and beliefs that can be modified with **measureable** impact—this is particularly the case in NSW; this suggests a need for further empirical research in this state to confidently identify targets for intervention.

1.1 Conclusions and recommendations

There is a significant body of literature reporting directly or indirectly on the impact of knowledge, attitudes and beliefs on the engagement of primary care practitioners (PCPs) and GPs in cancer care. However, this literature reports on studies done in very different health systems and therefore must be interpreted with caution. The vast majority of the publications reviewed were qualitative and observational studies with modest numbers. Even those publications that report Australian research are local and cannot be considered to represent the views of all Australian health professionals. Also knowledge, attitudes and beliefs may not translate into action if it is not

possible to assimilate these into workflow patterns in primary care. The following general recommendations are made with reference to the three constructs considered in this review:

1.2 Knowledge

1. Evidence-based guidelines to help identify patients with 'red flag' symptoms presenting to primary care are required. However, it cannot be assumed that GPs and PCPs act on research evidence or evidence-based guidelines to establish an early diagnosis. This is especially true of Prostate Specific Antigen (PSA) testing, but also the diagnosis of some of the commonest cancers presenting to Australian health practitioners. Therefore a key recommendation is to support research on innovations to implement guidelines. The most promising interventions in this regard are decision support tools that offer guidance at the point at which they are required in practice. For example, the 'Referral Writer' currently being tested in a randomised trial (http://www.anzctr.org.au/trial_view.aspx?ID=343136). Similarly an approach that includes the extraction of data from clinical systems in primary care and the development of decision support aids to complement this data may prove helpful. A number of such data extraction-decision support tools have been developed in Western Australia. Guidelines already exist for PSA testing and are the subject of a National Health and Medical Research Council expert panel review (PSA Testing Expert Advisory Group <http://tinyurl.com/a8rdsxn>). An important and somewhat overlooked issue is the role of other health care professionals in early diagnosis. A number of studies are currently underway to help triage patients presenting 'red flag' symptoms at pharmacies, including the *Jodi Lee Test* for lower bowel symptoms being tested by Sriram – PhD candidate, Curtin Health Innovation Research Institute (CHIRI) and the *Pharmacy Cough Assessment Tool* (PCAT) developed and awaiting evaluation at CHIRI
2. Knowledge of the help-seeking behaviour and presentation of 'alert' symptoms by some groups of patients, notably young people and patients from culturally and linguistically diverse (CALD) backgrounds is not clear. Access to and transfer of knowledge within these subgroups should be investigated and education resources developed as required. A good example is the deployment of video vignettes to explore men's help-seeking behaviours for bowel symptoms by Oberoi – PhD candidate, CHIRI
3. The support of patients treated for cancer offers the greatest opportunities for the engagement of PCPs; however, practitioners report that they do not have clear guidelines on their role in this context. The provision of shared care plans may be helpful especially for colorectal and prostate cancer. At the time of patient discharge additional information about common medical and psychosocial issues in this patient population would be useful to PCPs. An intervention to assist GPs to advise patients treated for colorectal cancer – the *Symptom Assessment Test for Patients* or *SAT-P* is currently being developed by Ngune, PhD candidate, CHIRI
4. There is evidence that GPs are not able to identify patients with advanced cancer who may benefit from some treatment modalities especially radiotherapy. We recommend the development of evidence-based guidelines but also the development of innovations to implement guidelines in practice
5. Rural and remote patients may benefit from receiving their treatment closer to home. However, there is insufficient evidence that PCPs or specialists would be willing to accommodate requests for chemotherapy to be delivered in a community setting or that it is technically safe to deliver this treatment other than in a hospital environment. However, there are pilot studies developing innovations to support GPs who may be consulted by a patient in the treatment phase (Jiwa et al. <http://tinyurl.com/az7pcqb>)

1.3 Attitudes

1. GPs should be encouraged to engage patients and significant others in cancer care. This is consistent with the philosophy of primary care which espouses continuity of care and a holistic perspective
2. GPs should be made aware that older patients may benefit from active treatment and that Aboriginal Australians and patients from culturally and linguistically diverse (CALD) backgrounds may have difficulty presenting symptoms or seeking appropriate help during their cancer journey. Such patients may be reticent to seek help or may experience avoidable poor outcomes because practitioners are not implementing evidence-based guidelines at point of referral and/or treatment
3. Patients may be reticent to accept GP follow-up care after cancer treatment unless there is a clear protocol to indicate that the GP was guided by a specialist. Development of protocols that include education resources for patients outlining the role of key health professionals in cancer care should be considered.

1.4 Beliefs

1. There is international evidence that the 'gatekeeper' role of the GP may inhibit some patients from presenting their symptoms sooner rather than later. This issue warrants further research in the context of NSW and Australia generally
2. Some specialists and patients believe that GPs lack the knowledge and skills to be more involved in cancer care. These beliefs need to be challenged as GPs are often well-placed to support patients if it were possible to facilitate a greater role for primary care. It is important that specialist groups endorse the role of GPs and that patient support groups similarly encourage people with cancer to access their GP whenever possible. There is no published evidence for the impact of specific recommendations however a key component of any intervention aimed at increasing the role of the GP should include endorsement by cancer specialists and active promotion of the GP's role by consumer groups.

2 Introduction and background

This rapid review focuses on clinical engagement in cancer care. It is framed within Glasziou and Haynes³¹ guidance on the factors that influence clinical practice. The framework proposes that the extent to which research evidence is translated into practice (clinical engagement) is directly proportional to a number of factors including but not limited to the extent to which practitioners are aware of the evidence (knowledge), accept the findings of the research or guidelines (beliefs and attitudes), and have the capacity to translate that evidence into practice. This rapid review synthesises findings from research involving general practitioners (GPs) and primary care practitioners (PCPs) in activity that could become an integral and a standardised part of their role in Australia and by corollary NSW. This review focuses specifically on the early diagnosis, screening, treatment and follow-up care of cancer.

The issues can be summarised as follows: $K + A + B + P = CE$. K represents knowledge; A represents attitudes; B represents beliefs; P encompasses processes, financial incentives and other factors that are beyond the immediate scope of this rapid review including models of care; and CE represents clinical engagement. Therefore K, A, and B are necessary but not sufficient for clinical engagement. Additionally the K, A and B of the patient, their family, and specialists can influence whether the GP or PCP will be involved in the care of the person with cancer or their family. These issues are depicted in Figure 1 below. The key stakeholders in clinical engagement are presented in Figure 2.

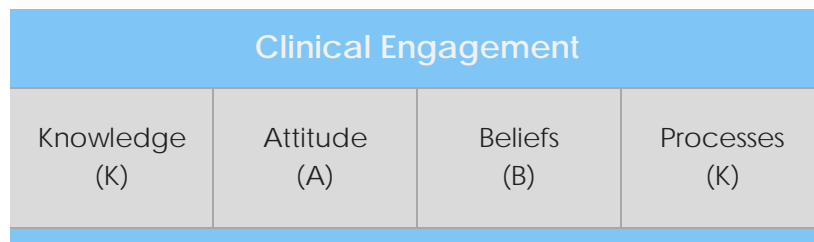


Figure 1: Foundations of clinical engagement in primary care

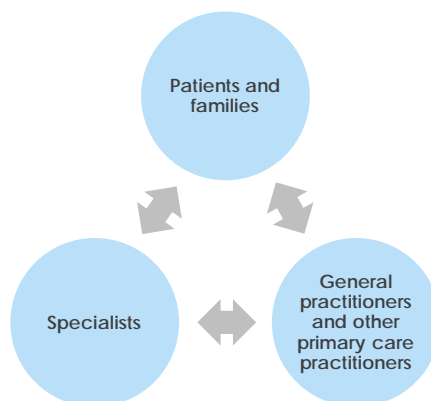


Figure 2: Key Stakeholders in Cancer Care

2.1 Primary care in Australia

Primary care in Australia is often considered synonymous with general practice; this is despite the fact that many other health disciplines are also directly accessible to the public and, in many cases are the first point of contact for a patient with cancer or symptoms suggestive of cancer (e.g. community pharmacists, physiotherapists, podiatrists, psychologists, nurse practitioners and occupational therapists). However, to contextualise this rapid review of the literature on cancer care, we will outline the organisation of primary care within Australia and briefly across other parts of the developed world. Australia's primary care system is characterised by:

- Universal medical and pharmaceutical insurance (Medicare and PBS) – although Medicare was introduced in 1984 to provide 'fair and affordable' healthcare to all Australians, many are now faced with extra costs for doctor visits, filling prescriptions, and diagnostic referrals such as blood tests and x-rays. Recent research suggests that Australians are paying more than \$1 billion each year for out-of-pocket medical expenses.³² One in five visits to the doctor now results in gap fees not covered by Medicare and almost a quarter of Australians had postponed or avoided having a prescription for medication filled due to cost. Young women are more likely to pay GP gap fees; furthermore two out of every ten Health Care Card holders and almost as many Pensioner Concession Card holders have paid to visit their doctor. This is despite concession card holders being entitled to bulk billing
- An established general practice sector – however many Australians experience access problems and GPs are not always supported to provide multidisciplinary care for complex health problems, such as cancer.

There are several areas in which the Australian primary care sector may fail to meet the needs of people with cancer and where the knowledge, attitudes and/or beliefs of healthcare professionals may be critical in developing and delivering an effective service.³³ Issues that tend to impact adversely on clinical practice include:

- **A fragmented and uncoordinated primary care system with** consumers treated in both public and private centres. This increases direct costs to consumers, reduces overall efficiency, and creates greater potential for errors and duplication. It also increases delay in providing treatment which can result in the preventable progression of cancer. Often valuable clinical data can be lost when treatment is provided in multiple locations which can also adversely impact on the quality and efficiency of care provided
- **An uneven imposition of healthcare costs on consumers.** People with chronic illnesses such as cancer can struggle to afford the cost of healthcare even when they have middle or high incomes. Healthcare costs can also differ according to condition with little fairness or rationality in how these costs are imposed; for example those conditions which require allied healthcare, like occupational therapy after cancer treatment, generally result in more out-of-pocket costs than conditions treated mainly by GPs
- **GP shortages in some areas**, particularly in regional, rural, remote and some outer-metropolitan areas such as Greater Western Sydney
- **Poor access to GP services for some groups** in the community including communities in rural, remote, or outer-metropolitan areas; Aboriginal communities; homeless people; and people from CALD backgrounds
- **High out-of-pocket expenses** for many allied health services and some pharmaceuticals
- **Limited consumer input** into primary care policy, planning, resource allocation and service delivery
- **Limited coordination between the primary, secondary, tertiary care sectors** and within the primary care sector itself, however some efforts have been made to address this

through Enhanced Primary Care item numbers, such as case conferencing, telehealth and care planning

- **Insufficient focus on prevention and population health**, however some progress has been made on this through programs such as the Immunisation Incentives Scheme and other activities of organised primary care structures, like the establishment of Medicare Locals
- **An inflexible funding system** (almost exclusively limited to services provided by medical practitioners) that does not always allow consumers to gain access to the most suitable form of care for their condition or permit consumer choice of treatment modality – however some efforts have been made to address this through Medicare funding for allied healthcare.

2.2 Primary care in the developed world

In developed countries, three models of primary care organisation have been identified: the hierarchical normative model in which the health system is organised around primary care and regulated by the State (e.g. Spain/Catalonia, Finland and Sweden); the hierarchical professional model where the GP is the cornerstone of the health system (e.g. Australia, New Zealand, the Netherlands, and the United Kingdom [UK]); and the non-hierarchical professional model in which the organisation of primary care is left to the initiative of healthcare professionals (e.g. Germany and Canada³⁴).

The United States (US) workforce of PCPs includes the specialties of family practice, general practice, general internal medicine, and general paediatrics and, for female patients, obstetricians and gynaecologists who provide 'primary care'. The specialty training and work role of family practitioners most closely resembles that of British GPs. The term GP in the US refers to doctors who did not complete a residency in a specialty. Unlike the situation in Britain, North American general internists and paediatricians mostly work in offices situated in the community. PCPs in the US have historically provided some inpatient care while few provide home visits, most are in private practice and about a third practice singlehandedly.³⁵

2.3 Cancer

According to Australian national research:

By the age of 85 years, 1 in 2 males and 1 in 3 females will have been diagnosed with cancer at some stage in their life. Cancer is estimated to be the leading cause of the burden of disease in Australia in 2010, accounting for 19% of the total burden.⁹

Overall, five-year survival is 65% for males and 67% for females³⁶; however, Australians fear cancer more than any other nation on earth.³⁷ The term cancer encompasses a great variety of conditions with a relatively benign course, such as most skin cancers, as well as those that have a very poor prognosis including pancreatic cancer.

Australian research suggests that, proportionately, GP consultations increase with age.³⁸ From April 2009 to March 2010 inclusive, "patients aged less than 25 years accounted for 21% of encounters, those aged 25–44 years for 23%, 45–64 years for 28%, and 65 years and over for 28%".³⁸ Although cancer is a relatively rare diagnosis in primary care, symptoms that may be suggestive of cancer are very common. The proportion of people presenting with symptoms that cannot be given a specific diagnosis is relatively high. For example, it is reported that 2.1 of every 100 encounters in general practice is for abdominal pain, a rate that varies with age. In more

than two-thirds of cases, the GP does not prescribe, supply or advise any medication; however, 40% of patients with abdominal pain will be offered some sort of investigation or test and in 25% of cases the practitioner will not be able to make a diagnosis.³⁹ Conversely gastrointestinal malignancies present at a rate of 0.2 per 100 encounters and the most common reason for contact with these patients is a request for a prescription.⁴⁰ In Australia, the average practitioner will encounter about four new patients each year that will be diagnosed with a potentially fatal cancer, and have about 16 patients at any one time with a diagnosed cancer under their care.

Cancer survivors experience significant physical and psychological morbidity which makes minimising their burden of disability and distress an important priority. Survivors require ongoing care that is well coordinated, focuses on prevention, and provides continued surveillance, all while minimising and managing the long-term effects of treatment and other comorbidities.⁴¹ The potential role of PCPs in cancer care is outlined in Figure 3.

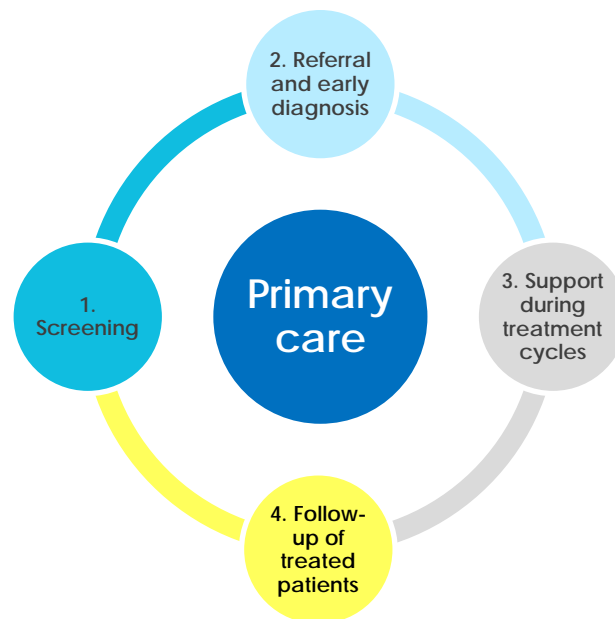


Figure 3: Role of primary care in cancer care

Following this overview of the primary care sector and cancer, the subsequent sections present the method used to identify publications relevant to the scope of this rapid review and the analysis of identified publications, with particular focus on three areas in Figure 2; namely, early diagnosis, support during treatment cycles and follow-up care. The report then concludes with key recommendations.

3 Method

The aim of this rapid review was to identify the impact of knowledge, attitudes and beliefs on the engagement of primary and community-based healthcare professionals with patients in the delivery of cancer care. A search strategy was developed to source articles published in English over the last ten years in the PubMed database, supplemented with a search of additional online abstracting and indexing databases, including CINAHL, Cochrane, Embase, PsycInfo and Informat. A limited search for additional grey literature was also performed. Additional references were added from the citations of relevant articles. All references were added to an EndNote library for review. The search strategy was informed by the key terms within the aim of this study and their euphemisms; an examination of keywords used by PubMed and additional abstracting and indexing databases; as well as keywords associated with known articles that are relevant to this review.

Details of the methods are provided in Appendix 1.

4 Analysis

4.1 Hierarchy of evidence

According to the National Health and Medical Research Council⁴², there are six primary levels of research evidence. These include:

- I Evidence obtained from a systematic review of all relevant randomised controlled trials
- II Evidence obtained from at least one properly-designed randomised controlled trial
- III-1 Evidence obtained from well-designed pseudorandomised controlled trials (alternate allocation or some other method)
- III-2 Evidence obtained from comparative studies (including systematic reviews of such studies) with concurrent controls and allocation not randomised, cohort studies, case-control studies, or interrupted time series with a control group
- III-3 Evidence obtained from comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group
- IV Evidence obtained from case series, either post-test or pretest/post-test.

Levels I to III-3 are largely situated within the paradigm of objectivism⁴³ and are guided by the scientific method – a body of techniques to gather discernible, empirical and quantifiable evidence, subject to specific principles of reasoning.⁴⁴ It involves a search for general laws, formal and a priori hypotheses, neutrality with regard to moral issues, standardised assessment devices, reduction of the observed reality into constituent parts, and the establishment of distance and non-intervention between the researcher and the researched.^{45,46} Although other research methods are also guided by standards⁴⁷⁻⁵⁰, the scientific method largely assumes that human behaviour is predictable, and thus can be treated in the same ways that physical entities are in the natural world.⁵¹ However, like other social phenomena that elude scientific prediction⁵², primary care represents a complex entity with multiple factors operating at different levels that influence effectiveness. For this reason alternative paradigms – like constructivism and subjectivism⁵³ – may be more appropriate.

Constructivism and subjectivism (and their variants) recognise varied ways of understanding the world.⁵³ Experience is assumed to be shaped by a myriad of interrelated and at times uncontrollable factors.⁵⁴ This is revealed by their respective methodologies and research methods. For instance, cross-sectional qualitative research methods (Level IV evidence) can help to breathe life into the lived experience.⁵⁵⁻⁵⁷ As such qualitative research methods can be particularly appropriate to capture and understand the knowledge, attitudes and beliefs that influence behaviour – including professional engagement with cancer care. As Dean has noted:

The tenets and beliefs of the biomedical model have seriously constrained the knowledge available for promoting and protecting human health... The dysfunctional dichotomies arising from classical empiricism hang on in the form of false dichotomies that pit nature against nurture or posit micro over macro influences, or the reverse, on behavioral, health, or other types of outcomes. Contemporary life exposes people to interactions among an increasingly complex array of biological and psychosocial influences that can damage health. A biological model that concentrates on biological markers or single components of the causal processes that influence disease

will unavoidably misguide health policy and practice... Qualitative researchers have long decried the neglect of a deeper and more complex causal understanding in much quantitative research.⁵⁸

It is important to understand the fundamental tenets of qualitative research in order to interpret findings appropriately and use this valuable research method effectively in the provision of optimum care along the continuum of cancer prevention, treatment and management.⁵⁹ While qualitative research may lack the 'traditional' methodological precision of quantitative research, it provides richness and depth of understanding around specific issues.^{60,61} In the context of this review it offers opportunities to explore in some detail: how and why particular levels or aspects of knowledge, attitudes, and beliefs impact on professional engagement; and identifies attitudes and beliefs of both patients and practitioners that could be modified in cancer care. For example, quantitative data can tell us how many patients don't receive optimal care while qualitative data will tell us why they don't. Both data sources are equally important in planning models of cancer care that can work effectively in practice.

5 Review Question 1

Identify the knowledge, attitudes and beliefs held by health professionals and patients which can impact on the engagement of primary and community-based health professionals with early detection of cancer and follow-up care

5.1 Referral and early diagnosis

Knowledge

Several studies report the predictive value of signs and symptoms in cancer diagnosis within primary care. These publications were not the subject of this rapid review, which focused primarily on engagement in cancer care. Available literature reports that the evidence (i.e. knowledge) is not consistently reflected in practice and thus there may be lost opportunities for early diagnosis and/or reassuring patients who request inappropriate tests for early diagnosis. For example, a recent publication suggests there is significant variation in referral practices among GPs and this is greater for endometrial cancer, for which there are currently no clinical practice guidelines in Australia.⁶² The most consistently reported evidence for lack of knowledge across many primary care systems pertains to Prostate Specific Antigen (PSA) testing.

Prostate Specific Antigen

A survey of 1,067 GPs in Northern Ireland suggests that lack of knowledge about the appropriateness of PSA testing is a significant issue.⁶³ The authors conclude there are complex influences on the PSA testing behaviour of GPs; addressing these could contribute to the rationalisation of testing. A low awareness of national guidelines indicated a need for new strategies to disseminate and implement guidelines. Another UK study similarly concluded that factors specific to PSA testing, which appeared to influence GP discussions, were the GP opinion of the PSA test and the need to counter men's primarily positive views of the benefits of PSA testing.⁶⁴ Awareness of the impact of their views on consultations may help GPs give men a more balanced presentation of the benefits and limitations of the PSA test.

Another UK study showed that the majority of doctors know the definition of PSA and its role in prostate cancer.⁶⁵ Although PSA has a higher positive predictive value than Digital Rectal Examination (DRE) for prostate cancer, the use of PSA without DRE is not recommended because 25% of men with prostate cancers have a normal PSA. Furthermore detection rates of prostate cancer are highest with a combination of two tests. In this study, more than half of the hospital doctors did not perform DRE, but a better combination of PSA and DRE was performed by GPs. Similar issues were reported in a study of referral for scrotal ultrasound scans in the UK.¹³ Overall 80% of patients were referred more urgently than the opinion of the specialist. Scrotal examination in primary care setting appears to be of variable accuracy. Many patients referred with a high suspicion of cancer are found to have benign pathology. Disagreements exist in the referral priority of patients.

Breast cancer

Breast cancer contributes the largest burden of cancer-related disease in Australian women.⁷¹ Early detection is considered an important part of GP work, with clinical audit recommended to help improve the quality of such work (Royal Australian College of General Practitioners Clinical

Indicators project (www.racgp.org.au). A clinical database was analysed for newly diagnosed breast cancer patients of one GP for the years 1986–2006.⁶⁶ Thirty new cases of breast cancer were diagnosed with 87% in the 'early' stages. Apparent false-negative investigations occurred in 33% of cases. The mean time interval between women noting symptoms and consulting the GP was 84 days and the mean time interval from first presentation to final diagnosis was 54 days. The diagnosis of breast cancer in this series was relatively infrequent, and prior apparent false-negative investigations were not uncommon. Many women who were diagnosed were outside the usual mammography screening age range of 50–69 years. Therefore, the authors recommend a need for a high index of suspicion for the possibility of breast cancer in all female patients. In another study on breast cancer, physicians more consistently provided moderate-risk standardised patients with reassurance and support compared with the high-risk cases.¹⁷ The authors posit that PCPs may be more unprepared or uneasy when addressing the issues associated with more complex scenarios and may benefit from training in the assessment and communication of breast cancer risk.

Atypical presentations

Atypical presentations of cancer lead to a delayed diagnosis and poor outcomes. Early referral of symptomatic cancer is important in a health system that is dependent on the gatekeeper role of the GP. In a UK study of adolescent consultations, alert symptoms were uncommon (reported in 4% of all consultations; 276 alert symptoms in 179 patients) and were not associated with age or gender.⁶⁷ The most common alert symptoms were unexplained pain (34.8%), unexplained fatigue (14.5%) and lumps (13.4%). In this study two benign tumours were detected. A high proportion of people consult their GP. Alert symptoms are uncommon and generally occur in isolation. More research is required to confirm these findings in a larger cohort and to examine how GPs respond to such alert symptoms.

Attitudes and beliefs

GPs consult patients with undifferentiated conditions. In practice symptoms suggestive of cancer are common whereas the diagnosis of cancer is uncommon. Therefore the ability to identify people who require specialist investigation has received greater attention. The ability to make a timely diagnosis of a life limiting condition in these circumstances depends on the attitude to managing undifferentiated conditions and the beliefs about the role of the GP. Norwegian GPs are reported to be able to recognise cancer symptoms in a variety of ways, including through awareness of the guidelines for urgent referral, awareness of deviations in clinical conditions and intuitive knowledge based on experience.¹⁸ Having a high index of suspicion (attitude and beliefs) for cancer was also reported as helpful. The authors conclude that cancer entered the differential diagnosis in the context of a long-term relationship between doctor and patient. The quality of their interaction and the doctor's accuracy in perceiving and interpreting cues were decisive.

A recent Dutch study indicates that the GP gatekeeper role in such health systems in Europe may delay diagnosis.⁶⁸ The article raises two hypotheses on the relationship between structural elements of a health system and people's reflections on seeking healthcare: (1) gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting care-seeking (attitude of patient); and (2) continuity in the doctor-patient relationship may negatively influence patient reflections on access to healthcare, as the focus shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which she/he is situated.

Colorectal cancer

The diagnosis of some cancers, especially those that present with vague symptoms, is especially challenging in primary care. In this regard a number of publications focus on colorectal cancer. One study has implications for how physicians and patients communicate about medical

problems during a consultation.¹⁵ Physician-patient discussions about gastrointestinal (GI) symptoms were described as challenging in primary care practice due to commonality of the symptoms. Patients sometimes presented with new, vague GI symptoms, some of which may mirror symptoms of existing chronic illness. Thus careful patient questioning is needed to distinguish existing and similar GI symptoms from newer ones. Furthermore physicians were urged to be mindful that the first problem the patient discusses may not be the most urgent. Multiple problems presented in a consultation may lead to increased cognitive load (i.e. physicians' efforts to collect relevant information, maintain the information in working memory and integrate the information to reach a decision) and ultimately faulty decision-making.

Attitudes are also important in relation to family history discussions, especially with young people. In a recent US study, the perception that physicians are responsible for initiating family health history discussions was associated with being non-white and less than completely knowledgeable about cancer.⁶⁹ Having a discussion with a physician was associated with being female, having a regular physician, perceiving genetics as a risk for developing cancer, and having a family member diagnosed with cancer.

Age

Several publications have reported age-related differences in the management of people with cancer. Most data have been derived retrospectively from hospital or cancer-centre databases. One study identified key non-organisational factors that influenced GP clinical management of prostate and breast cancer.¹⁹ Age was more important among GPs in deciding how to manage cancer patients than performance status and comorbidity. This is reported to be a common prejudice and in some cases reflects an ageist attitude towards older people. Nevertheless, GPs are inclined to refer people with cancer to oncologists independently of patient age.

Ethnicity

Awareness of the warning signs of cancer was reported to be low across all ethnic groups in a UK interview-based study, with lowest awareness in the African group.²¹ In other words knowledge of signs and symptoms of cancer was lower in these groups. Women identified relatively more emotional barriers and men, more practical barriers to help-seeking, with considerable ethnic variation. These may be related to stigma and misconceptions about cancer. Anticipated delay in help-seeking was higher among individuals who identified fewer warning signs and more barriers.

5.2 Treatment

Knowledge

An Australian publication on colorectal cancer reported poor patient experiences in primary care.⁷⁰ These were largely location-related. Several rural participants indicated that high staff turnover in their area hindered the continuity of care, with at least one participant attributing this to a significant delay between the first report of symptoms and referral. A lack of knowledge about local clientele, effective clinical networks and referral pathways appropriate to the locale in which practices operate, may impact adversely on continuity of patient care particularly in regional and rural communities. Furthermore some urban participants reported that waiting times to see a GP caused them to seek care elsewhere, including the increasingly popular use of the internet as a source of knowledge for 'self diagnosis'. There were some concerns about the knowledge base expected of GPs by participants with some relying on their GPs to have the appropriate knowledge to 'fill in the gaps' with extra information or clarify specialist advice. Participants also perceived the GP as a counsellor when they were struggling primarily because

of their longstanding relationship with their GP. Some relied on the GP to assist with decisions about treatment alternatives.

Attitudes

It is well documented that the attitudes and beliefs of families, both positive and negative, have a strong influence on the health and wellbeing of people undergoing treatment for chronic conditions (including cancer). However, literature from the UK suggests the needs and concerns of the partners of cancer survivors in caring for patients are seldom addressed.⁷¹ There is scope for primary care to elicit these needs and provide greater support. A proactive approach to patients, their partners and/or other family members at the time of diagnosis through an offer of support and their inclusion during treatment reviews would be useful. The role of PCPs in cancer care and especially during treatment has been reviewed in a US study.⁷² The authors concluded that PCPs assumed an active behind-the-scenes role to support patients with treatment decisions and processes. Three themes emerged from the interview data: (1) knowing the patient; (2) walking through treatment with the patient; and (3) sending them off or losing the patient to the system. The authors recommended that the mechanisms to support this role should be implemented in practice settings. The authors make the following recommendations:

The findings have implications for the educational needs of rural providers, such as access to up-to-date cancer care information and guidelines for establishing effective referral linkages with tertiary providers. Additionally, providers perceived their 'behind-the-scenes' role as trusted expert as critical to patient outcomes. These descriptions of the integration of professional and personal qualities may differ from traditional training curricula, and they should be emphasized for those new to regional or rural practice. To further extend the knowledge base regarding the experience of rural breast cancer patients and their providers, future studies should include the perspectives of both regional and rural breast cancer patients, and specialty providers from urban treatment centers. Integration of these perspectives can lead to creative solutions for management of breast cancer care for women living outside of large urban areas, and it may spur the development and testing of various practice models that will meet the needs of patients and both regional or rural primary care and urban specialty providers.

A study of women with gynaecological cancer highlights the problems associated with cancer in a rural community.⁷³ Problems may be solved by receiving care closer to home. Navigating the health system and accessing specialist care were identified as of particular importance. Travelling considerable distances to receive treatment meant leaving home for unspecified lengths of time, which lead to the associated difficulties of family upheaval and financial strains. All of the women interviewed in this study described the burden this placed on them and their families. Furthermore the need to leave home for treatment meant disclosure of their diagnosis was often broader than they would have preferred. Although this might also be relevant in more heavily populated areas, it is again much more difficult to remain low-key within a smaller population. To some degree this upheaval invaded personal privacy– privacy that was highly valued by at least two participants. These women also explained isolation and lack of support as key issues faced in their journey with the illness.

Clinicians and healthcare professionals need to be aware of factors that can impact on adherence to treatment schedules and endeavour to accommodate where possible. There is an opportunity for GPs and specialists to articulate their understanding of the problems faced by some patients in accessing and attending treatments. Understanding the role of carers in assisting patients to adherence to treatment regimes should also be part of practice models.

Beliefs

A study from the UK reported on beliefs about the site of chemotherapy for cancer care.⁷⁴ There was no agreement on the best location for chemotherapy (local or central). The only large difference of opinion between participants based in primary and secondary care concerned chemotherapy provision at local community hospitals (primary care was in favour, hospital practitioners against, $p < 0.001$). In making their decisions, participants considered access issues, but were also concerned with quality of care and feasibility in the current health service. The findings suggest more evidence is needed regarding the balance of risks and benefits of local chemotherapy provision.

5.3 Follow-up care

Knowledge

There is some evidence that survivorship or shared care plans (SCPs) may be helpful to facilitate access to knowledge in primary care and therefore improved prognosis. In a US study PCPs were asked to comment on the value of SCPs.⁷⁵ It found SCPs to be highly valued, increasing PCP knowledge about survivors' cancer history and recommended surveillance care and influencing patient care. A US study focused on prostate cancer further concluded that when SCPs were not instigated practitioners were not confident about their ability to provide appropriate care.²⁸ PCPs reported that prostate cancer survivorship care is prevalent in their practice yet few felt very comfortable managing the associated side-effects. To improve the quality of care implementing prostate cancer survivorship care plans across specialties, or transferring primary responsibility to PCPs through survivorship guidelines should be considered. Similarly, another team concluded that integrated systems that use electronic health records are likely to facilitate shared cancer care by improving PCP-oncologist communication.⁷⁶ However, strategies to promote a more active role for PCPs in managing comorbidities, psychological distress and behaviour modification, as well as strategies to overcome communication challenges between physicians who do not practice within the same integrated system, are still needed to improve shared cancer care. An example from a study conducted in Western Australia included screening of patients with unmet psychosocial needs in the specialist setting and subsequent referral of such patients to their general practitioners with recommendations for care plans that could allow Medicare funded access to allied health practitioners.⁷⁷ These issues are further highlighted by Norwegian GPs who reported at interview that plans for the follow-up care of patients could in many cases improve care and cooperation.⁷⁸ Such plans could be made preferably before discharge from inpatient care by a team consisting of the patient, a carer, a hospital specialist and a GP. Patients and GPs call on hospital doctors to initiate such collaboration.

Return to work

British researchers concluded that the type of work-related information given to patients by providers is not systematic.⁷⁹ Advice on return to work could be delivered in primary care in Australia. The UK team suggest it is necessary to develop a better knowledge-base about the impact of cancer and its treatment on work ability, sustainability and return to work; this would help providers to consistently offer tailored advice to patients. Therefore, it is appropriate to recommend formal training for providers.

5.4 Attitudes

Hospital follow-up care

In a survey of cancer survivors aged 18–45 years, 59% reported one or more cancer-related health problems.⁸⁰ Survivors rated clinical reasons for attending follow-up care more highly than supportive reasons ($p < 0.001$), although nutritional advice and counselling were also considered useful (60 and 47%, respectively). Those still receiving follow-up care did not discuss the range of issues intended, with 'late effects' and 'fertility' not satisfactorily addressed. Hospital rather than GP follow-up care was more highly rated. An observational study from Western Australia demonstrated that in 68% of cases women with breast cancer did not consult their GP about breast cancer-related symptoms in the six months prior to their appointment at a specialist clinic, choosing instead to present to a Breast Care Nurse.⁸¹ In a related survey patients preferred their GP if they needed a physical examination ($p = 0.007$) or referral to a specialist ($p < 0.001$). However, in practice patients tended to avoid consulting the GP; reasons for this were not explored in the study. Yet this contrasts with a study from the UK which reports that GPs have an increasing role in their care.⁸² A general practice research database was used to compare consultation rates between cancer survivors and controls. Breast and colorectal cancer survivors had one more consultation per year compared with controls up to five years after diagnosis; rates then converged at ten years post-diagnosis. Prostate cancer survivors consistently consulted up to three more times per year than controls. Increased consultation rates impact on service capacity. However, it is possible that frequent consultations do not pertain to cancer or related problems.

Unmet need

US researchers facilitated focus group discussions with three groups of women who had been treated for breast cancer.⁸³ According to all participants continuity of care is the continuous care over time; it involves the relationship between the healthcare provider and the patient. It is not just a follow-up review. The relationship is built on trust, loyalty and constancy. The perception is that the providers of care know you, know your case history and your future care is agreed on. Three categories of continuity of care were identified; but there were differences as to their perceived significance. Continuity of care was provided to most participants; however, deficiencies in the service were identified. Similarly women in rural Australia have identified limited psychosocial support and resources for breast cancer survivors in their areas.⁸⁴ Canadians with lung cancer indicated that although the oncology team is primarily responsible for follow-up care they also wished their family physicians to be involved.⁸⁵ Similarly interviews with UK patients revealed shortcomings in the content and organisation of follow-up care; these included system failings causing patients to fall through the cracks of follow-up care as well as unmet psychosexual needs.⁸⁶ Patients were mainly positive about the prospect of receiving follow-up care outside of the hospital setting. However, some were concerned about current follow-up practices and suggested improvements if primary care were to assume a greater role. In a survey of Canadian patients with advanced lung cancer, their specialists and PCPs, most specialists expected a major role for PCPs in all aspects of care; patients and PCPs agreed, mainly for emotional support and information.⁸⁷ In another Canadian survey PCPs were willing to assume exclusive responsibility for the follow-up care of adult cancer survivors given appropriate information and support.⁸⁸ In an US study, patients and physicians were noted to have discordant expectations with respect to the roles of PCPs and oncologists in cancer survivorship care.¹⁶ Uncertainties around physician roles and responsibilities were reported to potentially diminish the quality of care – this suggests the importance of survivorship care planning in cancer management. In the UK centres with higher case-loads (more than 200 per year) were more likely to discharge women treated for breast cancer earlier.⁸⁹ Reduced workload was perceived to be the main benefit of discharge, while lack of GP oncological experience and loss of outcome data were concerns. Specialists were said to favour a risk-adjusted discharge strategy and increased oncology infrastructure in primary care. In another UK survey the authors indicated that

learning more about late effects and checking for cancer recurrence were the key reasons for follow-up care by cancer experts and GPs.⁹⁰ Cancer experts agreed that follow-up care delivered by the primary care sector would increase their availability for acute oncological care, but reduce information on late effects. The most important resource to provide a quality follow-up service was specialist nursing support (91%).

Ambivalent attitudes

Results from a randomised controlled trial of primary care versus specialist follow-up care of patients with advanced cancer supported the involvement of PCPs and demonstrate variable perspectives on PCP involvement.⁹¹ Matching patient preferences and practices may improve satisfaction. Clarification on elements in the partnership between patients, PCPs and oncologists will inform efforts to optimally care for older patients with advanced cancer. An Australian study concludes there is strong support for the development and use of SCPs for bowel cancer survivors.⁹² However, there was varied opinion about the ideal content, who might prepare it, as well as how it might be discussed and used. All participants including patients, PCPs and specialists endorsed the core elements of the SCP, including information about diagnosis, diagnostic tests, a summary of treatments received, surveillance plan, and information regarding potential late and long-term effects. However, some of the most positive statements by survivors about the SCP involved the 'novel' components. These included lifestyle changes, plus psychosocial and practical issues. While nurses also strongly supported the inclusion of these components, hospital-based doctors were less supportive. There was no clear consensus amongst hospital-based healthcare professionals regarding who should write and deliver the SCP. Similarly a Dutch study suggests that a significant number of GPs are ready to participate in the long-term follow-up care of adult childhood cancer survivors if adequate medical information is provided and communication lines are clear.⁹³ On the other hand US researchers concluded that approximately 82% of PCPs believed that primary care guidelines for adult cancer survivors are not well-defined, and 47% of PCPs cited inadequate preparation and lack of formal training in cancer survivorship as a problem when delivering care to long-term survivors.²⁵ Although PCPs provide the bulk of care for long-term survivors within the survivorship phase of the cancer trajectory, only a small subset provide multidimensional survivorship care. A Canadian team identified gaps in the delivery of psychosocial and informational care to patients with cancer that may result in unmet needs.⁹⁴ In general GPs did not consider themselves as primarily responsible for coordinating supportive cancer care and do not wish to assume this role. In a longitudinal qualitative study some British patients were reported to enjoy straightforward recoveries from surgery, others experienced longer-term implications from their disease and treatment, particularly bowel-function issues, fatigue, anxiety and sexual problems.⁹⁵ The potential for primary care to contribute more to the ongoing care of colorectal cancer patients was identified. A US survey of specialists found approximately half thought specialists were more efficient at providing follow-up care than PCPs, but these same physicians recommended significantly longer and more expensive follow-up routines on average than others.⁹⁶ PCPs were said to be important allies, especially in managing the psychosocial concerns of patients. Most specialists indicated they should remain involved in follow-up care but this may result in increased resource use.

Beliefs

Women with breast cancer and their families in Australia believed their primary sources of support should be medical practitioners (e.g. surgeons, oncologists and GPs), with very few women or family members accessing mental health professionals.⁹⁷ Given the importance of adequate support when diagnosed and treated for breast cancer, the authors concluded that urgent attention needs to be paid to training medical professionals in providing appropriate support and referrals to their patients. Patients and primary care teams in England believe primary care has an important role in supporting people with cancer following treatment.²⁷ However, cancer care reviews in the UK since 2003, the Quality and Outcomes Framework (QOF) of the General

Medical Services Contract for Primary Care has provided an incentive for practices to establish a cancer register and to conduct a 'review' with new patients with cancer within six months of diagnosis (a 'cancer care review'). In their current format these were not regarded as helpful, with considerable scope for improving practice in this area. Patients did express some uncertainty over the role that primary care could play in their clinical cancer care. They were unsure whether their primary care team would have the necessary expertise. However, most patients also saw it as important that their GP acknowledged their cancer diagnosis and treatment, which could be part of a cancer care review. This would give reassurance that their primary care team knew of and cared about what this meant to the patient. The majority of patients felt that a designated appointment to discuss their cancer care would be useful as it could provide a legitimate context for reviewing their experience and raising any concerns. The vast majority of patients, even those who had regular contact with the practice, would have welcomed a call or other proactive contact from the practice at the time of diagnosis or initial treatment. The team made the following recommendation:

GP practices may want to consider routinely contacting newly diagnosed cancer patients (either by letter or phone) at the time of diagnosis, inviting further contact if needed. This would address patients' desire for acknowledgment of their diagnosis. An invitation to a specific review appointment following completion of active treatment would promote continuity of care and legitimise the raising of any concerns. This invitation could be extended to include close family members. Primary healthcare professionals need to be supported in their role by having access to clear and up-to-date information, and rapid access to specialists if required.

A key aspect of caring for people who have been treated for cancer includes attention to the psychological and social sequelae. A US study reports that some healthcare providers are not involved in psychosocial care and that oncologists and PCPs differ in their beliefs regarding who provides specific aspects of care – this underscores the need for better care coordination informed by the respective skills and desires of physicians to ensure needs are met.⁹⁸ Interventions targeting physician confidence, beliefs about who is able to provide psychosocial support and preferred models for survivorship care may improve psychosocial care delivery. Such interventions have not been tested. Other studies similarly conclude that patients do not believe GPs have the training or skills to monitor the physical or psychological sequelae of cancer.²⁶ However, many would be willing to have GPs share their follow-up care with the caveat that they receive extra training and were appropriately supported by secondary care specialists. In this study GPs felt that their own clinical skills were enhanced by attending the training seminars and shadowing at clinics. This also benefited their own patients in their own general practices and also improved communication with secondary care. Patients attending shared care clinics appreciated a local service and longer appointment times. GPs stress the importance of maintaining their own clinical skills and receiving reliable clinical and administrative support from secondary care.

A US survey concluded that compared with PCPs, oncologists were less likely to believe PCPs had the skills to conduct appropriate testing for breast cancer recurrence (59% vs. 23%, $p < 0.001$) or to care for late effects of breast cancer (75% vs. 38%, $p < 0.001$).²⁰ Only 40% of PCPs were very confident in their own knowledge of testing for recurrence. PCPs were more likely than oncologists to endorse the routine use of non-recommended blood and imaging tests for detecting cancer recurrence, with both groups departing substantially from guideline recommendations. In contrast Canadian researchers found PCPs who provide follow-up care to survivors of breast cancer are confident in managing care and satisfied with discharge letters containing a diagnosis and treatment summary, as well as recommendations for surveillance and endocrine treatment.⁹⁹ At the time of patient discharge additional information about common medical and psychosocial issues in this patient population would be useful to PCPs.

Men with prostate cancer, even the very elderly, have psychosexual issues for variable times after diagnosis. Patients in one study reported that these are not always addressed at the appropriate time.¹⁰⁰ The authors suggest that assessments of psychosexual problems should be conducted throughout the follow-up period and not only at the time of initial treatment. They further conclude that there may be a role for the GP in assessing wider psychosexual needs and signposting where to get help if needed. However, it has been reported that physicians while perceiving exploration of patients' psychosexual needs as part of their role may feel unprepared to identify and address these appropriately. GPs may also be particularly well placed to offer partners encouragement to consider their health and psychological needs at a time when care is largely focused around the patient. Research clearly showed that the role of partners in supporting patients was often neglected yet acting as a carer often impacted adversely on their health and wellbeing, and ultimately on their ability to provide optimum care to patients.

6 Review Question 2

What is the evidence that attitudes and beliefs can be modified with measureable impact on the engagement of primary and community-based professionals with cancer care?

Many of the knowledge, beliefs and attitudes discussed earlier may be modified. To avoid repetition they will not be discussed again. With specific reference to Australia it is noteworthy that a key feature of general practice is an emphasis on the continuity of care. This affords a longitudinal perspective of the individual in the context of their community (or communities) – this encompasses their partner and extended family, their peers, employer, colleagues and other individuals who may influence their health and wellbeing. It also includes supporting the patient to manage their comorbidities while they are treated for cancer. Within the context of cancer – a chronic and complex condition – focussing on the continuity of care has been shown to be important. For instance, research involving Scandinavian GPs suggests three key aspects of general practice.¹⁰¹ GPs represent a flexible mediator, negotiating the dynamic between the patient and the clinic; an efficient problem-solver, as well as a personal companion for the patient throughout their illness. In contrast, a US study found significant differences between the knowledge, attitudes and practices of PCPs and oncologists with respect to the care of people with cancer.²⁰ Regarding engagement in cancer care it is therefore important that a commitment to the continuity of care is emphasised by PCPs and specialists. However, continuity of care can be provided across the primary, secondary and tertiary settings with appropriate mechanisms for communication, handover and ongoing consultation. As has been emphasised in an article in the British Medical Journal continuity of care is defined in three different ways¹⁰²:

- Informational continuity – The use of information on past events and personal circumstances to make current care appropriate for each individual
- Management continuity – A consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs
- Relational continuity – An ongoing therapeutic relationship between a patient and one or more providers.

This offers the scope to offer informational continuity of care where patients move from one health sector to another.

Improving the care of people with cancer is also likely to require role clarity and effective communication between medical professionals, particularly GPs and oncologists, to increase confidence in their own and the other's capacities. Potentially modifiable factors were reviewed in a monograph – although its focus was US healthcare, these are summarised for completeness, given their relevance to the scope of this rapid review¹⁰³:

Table 1: Multilevel Factors Affecting Quality (adapted from Zapka et al. 2012¹⁰³)

Risk assessment	Safety may be measured by the use of counselling to explain risks to patients in a way that minimises emotional and psychological harm. Patient-centeredness may focus on ensuring patients are informed of their risk status and engaged to participate in prevention decisions and behaviours.
Primary prevention	Effectiveness and equity may take the form of multilevel promotion efforts and the availability of primary care services, as opposed to emergency medical care, for all individuals.
Detection	An intervention aimed at equity could promote screening for low-income individuals and those who face geographic and financial obstacles to screening. Timeliness might minimise the time between when a patient informs a provider of a symptom and when diagnostic tests are performed. There are specific areas in which knowledge, attitudes and beliefs may be modifiable. For example, clinicians in one study correctly identified prostate cancer risk factors, but were less knowledgeable about prostate cancer screening tests and overall prostate cancer risk. ¹⁰⁴ Therefore increasing knowledge about PSA testing may have a positive impact on engagement with male patients who may be symptomatic or present with concern about their risk of prostate cancer. However, there is a need for further research into understanding the basis of differences in referral patterns for at-risk patients, including a review of the existing guidelines for ovarian and cervical cancer and the development of guidelines for endometrial cancer. ⁶²
Diagnosis	Timeliness may be increased with the use of electronic health records to coordinate care quickly across medical specialties. Efficiency may focus on the most cost-efficient use of diagnostic tools for the patient and health system. As discussed an increase in knowledge without supporting processes to assimilate this knowledge cannot be assumed to facilitate effective engagement in cancer care.
Treatment	Safety may be considered when the physician uses a genetic test to estimate tumour recurrence risk in an effort to avoid unnecessary and potentially harmful treatments. Patient-centeredness may involve providers explaining the diagnosis, efficacy and potential side-effects of treatments, and encouraging patient participation in treatment decisions. To achieve these goals, it is important to ensure that PCPs are up to date in their knowledge of the local treatment options for the common cancers. ⁷²
Survivorship	Safety measures may include the application of tested interventions for reducing the long-term side-effects of treatment, while a patient-centred aim may be to provide psychosocial support for the patient and family. Australian researchers concluded that the GP role is influenced by GP-specialist communication, practice location as well as patient and GP factors. ¹⁰⁵ There is a potential to increase the role in survivorship especially in providing psychosocial support and counselling to both the patient and their family.
End-of-life care	A patient-centred approach would consider the patient's quality of life preferences in decision making. Efficiency and effectiveness aims might provide access to palliative care and hospice resources, which in turn reduce use of futile treatments. In a small study from Perth, Western Australia, GPs were invited to consult standardised patients presenting symptoms that might benefit from radiotherapy. ¹⁰⁶ There were significant differences in the management of the case with prostate cancer ($p=0.005$) and data suggested that GPs' clinical management varied widely. These data are consistent with other literature which suggests that in practice not all cancer patients are appropriately advised or referred. In some cases this lack of knowledge could result in adverse outcomes. Canadian researchers have reported similar findings. ¹⁰⁷ Many of the GPs surveyed were unaware of the effectiveness of radiotherapy in a variety of common palliative situations, and radiotherapy referral was correlated with knowledge about the indications for palliative radiotherapy. The authors suggest this was not surprising given their limited education in this area and their limited contact with radiation oncologists.
Transitions	Patient-centeredness, timeliness, and efficiency may be addressed by using patient navigators or designing information systems to help individuals negotiate the transitions between steps of care. In one study role clarification was a key requirement for engagement, together with greater mutual trust between GPs and specialists. ¹⁴ Key needs included accessible competency training and mentoring for doctors unfamiliar with the health system.

7 Review Question 3.

Which attitudes and beliefs are most likely to be relevant to the NSW context as potential drivers for engagement of primary and community-based professionals in cancer care? What are the potential targets for intervention?

Many of the knowledge, beliefs and attitudes mentioned are also applicable to NSW. Cancer is a leading cause of death in this state, although an increasingly higher proportion of people with cancer will survive the diagnosis in the coming decades. Cancer is primarily a disease of older people; as such those diagnosed with cancer are likely to be living with other comorbidities including (but not limited to) cardiovascular disease, diabetes, dementia and other psychiatric illnesses. The diagnosis of cancer is relatively uncommon among those who present to a GP with cancer symptoms. It is therefore important to help the GP decide which symptomatic people should be referred for further assessment, which may include invasive, risky and expensive tests. It is possible that other PCPs are involved in triaging or supporting people with symptoms and referring them to GPs for further investigation. It is also possible that Australian GPs will advise, advocate for and be involved in the treatment of patients prior to and immediately following the diagnosis of cancer. This role will greatly enhance the potential for providing timely support and empowering people to make appropriate choices. Patient ability to cope with the sequelae of cancer and its impact on significant others will require healthcare provided by PCPs that is focused on practical and psychological support throughout the cancer journey. The extent to which all people will benefit from effective primary care in NSW will also depend on systems to ensure that no groups are disadvantaged by virtue of culture or other differences. Many of the knowledge, attitudes and beliefs reported earlier are relevant to most, if not all Australian healthcare settings.

In 2005, an Australian study reported that the personal, confiding relationship between the GP and cancer patient might be better exploited by specialists.¹⁰⁸ Patients could feel more empowered in relation to their condition if provided with information by their GP that is more relevant and explicit. For this to occur specialists directly involved in the patients care must first provide GPs with timely and pertinent information about cancer management. In a recent small qualitative study Queensland GPs were interviewed about their perceived role in cancer care.¹⁴ Not all GPs wanted an enhanced role in cancer care. Existing system barriers and workforce pressures in general practice were perceived as barriers to shared cancer care. Notwithstanding methodological limitations the data suggest that knowledge, attitude and beliefs will have a limited impact on GP engagement in cancer care if the processes for translating those helpful aspects do not also facilitate GP engagement in the context of Australian primary care. In other words, knowledge, beliefs, and attitudes are necessary **but not sufficient to clinical engagement**. This research also suggests that the knowledge, beliefs and attitudes of patients and specialists are also likely to impact on clinical engagement among GPs.

Similar interviews with Norwegian GPs concluded they are close to patients, family, and the community, and as such are well-positioned to translate the impact of disease and its treatment into the lived experience.¹⁰¹ Having both biographical and biological knowledge of patients, and belonging to both the local community and the healthcare system, the GP position is an 'in-between' one. The knowledge, attitude and beliefs of patients may exert a negative influence on GP engagement. In a survey of Dutch patients one-third evaluated the cooperation between hospitals and primary care as suboptimal.¹⁰⁹ Younger patients were most dissatisfied. A third had needed GP support and 41% of these patients had not had their needs fulfilled. Older patients, patients in Stage 1 and patients from surgical departments were least likely to have needed GP

support. Patients described support from the GP as including 'empathic behaviour' and coordination of health services. A particularly relevant issue for NSW is the care of Aboriginal Australians where the patients relationship with their care provider closest to home has a very important impact on patients subsequent care trajectory.

Aboriginal Australians

Research from Western Australia suggests that misunderstanding, a fear of death, fatalism, shame, a preference for traditional healing, beliefs like cancer is contagious and other spiritual issues affected access to services among Aboriginal Australians.²²⁻²⁴ The authors suggest that these underlying beliefs must be specifically addressed to develop appropriate educational, screening, and treatment approaches including models of care and support that facilitate better patient engagement. Models of care and support that are more culturally-friendly where health professionals consider both Aboriginal and Western health beliefs and the relationship between these, and which engage and include Aboriginal people need to be developed. Cultural security, removing system barriers, and technical/scientific excellence are all important to ensure Aboriginal people use healthcare services to realise the benefits of modern cancer treatments. The holistic approach (physical, mental, emotional, and spiritual) to healing and wellbeing, and the concept that individual, family and community are inseparable, underpin Aboriginal care-seeking behaviour. One way of ensuring this could involve better coordination between diagnostic and treatment services and primary care services. In Western Australia this has been achieved in part by employing cancer care coordinators nurses and Breast Care Nurses as a liaison between specialists and GPs. It is clear from the experience with Breast Care Nurses that their involvement is often very helpful at the interface with care providers.⁸²

A summary table of all studies reviewed is provided in Appendix 2 (Table 2).

8 Conclusions and recommendations

There is a significant body of literature reporting directly or indirectly on the impact of knowledge, attitudes and beliefs on the engagement of PCPs and GPs in cancer care. However, this literature reports on studies done in very different health systems and therefore must be interpreted with caution. The vast majority of the publications here reviewed are qualitative and observational studies in design with relatively modest numbers. Even those publications that report Australian research are local and cannot be considered to represent the views of all Australian health professionals. Also knowledge, attitudes and beliefs may not translate into action if it is not possible to assimilate these into workflow patterns in primary care. The following general recommendations are made with reference to the three constructs considered in this review:

8.1 Knowledge

1. Evidence-based guidelines to help identify patients with 'red flag' symptoms presenting to primary care are required. However, it cannot be assumed that GPs and PCPs act on research evidence or evidence-based guidelines to establish an early diagnosis. This is especially true of PSA testing, but also the diagnosis of some of the commonest cancers presenting to Australian health practitioners.
2. Knowledge of the help-seeking behaviour and presentation of 'alert' symptoms by some groups of patients, notably young people and patients from CALD backgrounds is not clear. Access to and transfer of knowledge within these subgroups should be investigated and education resources developed as required.
3. The support of patients treated for cancer offers the greatest opportunities for the engagement of PCPs; however, practitioners report that they do not have clear guidelines on their role in this context. The provision of shared care plans may be helpful, especially for colorectal and prostate cancer. A suitable starting point may be to develop processes that encourage practitioners to share care through a care plan. This would need to include instruments to screen patients for unmet need. Such a demonstration project is underway in Western Australia (Irene Ngune- PhD thesis).
4. There is insufficient evidence that GPs are able to identify patients with advanced cancer who may benefit from some treatment modalities especially radiotherapy. This has the potential for adverse outcomes. It is imperative that this aspect of care be investigated to assess if GPs require information to maintain continuity of care for cancer patients across the health care spectrum.
5. Rural and remote patients may benefit from receiving their treatment closer to home. However there is insufficient evidence that PCPs or specialists would be willing to accommodate requests for chemotherapy to be delivered in a community setting or that it is technically safe to deliver this treatment other than in a hospital environment.

8.2 Attitudes

1. GPs should be encouraged to engage patients and significant others in cancer care. This is consistent with the philosophy of primary care, which espouses continuity of care and a holistic perspective. Key partners in this respect include the Cancer Institute, the Royal Australian College of General Practitioners, Medicare Locals and at a local level specialists

2. involved in cancer care. Encouragement could include the development of processes that allow practitioners to easily identify patients, carers and families of people with cancer. Developing a Community of Practice to improve the care of patients might offer a suitable approach to quality improvement in primary care.
3. GPs should be made aware that older patients may benefit from active treatment and that patients from CALD backgrounds may have difficulty presenting symptoms or seeking appropriate help during their cancer journey. Differences in cultural values are particularly relevant to Aboriginal Australians.
4. Patients may be reticent to accept GP follow-up care after cancer treatment unless there is a clear protocol to indicate that the GP was guided by a specialist. Development of protocols that include education resources for patients outlining the role of key health professionals in cancer care should be considered.

8.3 Beliefs

1. There is some evidence that the 'gatekeeper' role of the GP may inhibit some patients from presenting their symptoms sooner rather than later. This issue warrants further research.
2. Some specialists and patients believe that GPs lack the knowledge and skills to be more involved in cancer care. These beliefs need to be challenged as GPs are often well-placed to support patients if it were possible to facilitate a greater role for primary care.

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10 Appendices

- Appendix 1. Search methodology in detail
- Appendix 2. Summary of literature reviewed

Appendix 1. Search methodology in detail

PubMed (National Library of Medicine)

PubMed was searched in September 2012 using the following MeSH search strategy:

1. (cancer care facilities [mh] OR neoplasms [mh] OR early detection of cancer [mh])
2. (Health Knowledge, Attitudes, Practice [mh] OR Attitude to Health [mh] OR Attitude of Health Personnel [mh] OR Consumer Participation [mh])
3. (primary health care OR physicians, primary care [mh] OR primary care nursing [mh] OR general practitioners [mh] OR physicians, family [mh] OR pharmacists [mh] OR community networks [mh] OR community health services [mh:noexp] OR Community-Institutional Relations [mh] OR community health planning [mh] OR community medicine [mh])
4. #1 AND #2 AND #3
5. #4 NOT Skin Neoplasms [mh] AND english [la] Filters: published in the last 10 years.

A total of 1,766 references were found using this strategy.

A broader search was also performed to identify articles pertaining to Aboriginal and other ethnic groups – this was performed using the following search strategy:

1. Oceanic Ancestry Group [mh] AND Neoplasms [mh] AND Health Knowledge, Attitudes, Practice [mh] Filters: published in the last 10 years
2. Indians, North American [mh] AND Neoplasms [mh] AND Health Knowledge, Attitudes, Practice [mh] Filters: published in the last 10 years
3. Minority Groups [mh] AND Neoplasms [mh] AND Health Knowledge, Attitudes, Practice [mh] Filters: published in the last 10 years
4. Neoplasms [mh] AND (Health Knowledge, Attitudes, Practice [mh] OR Communication Barriers [mh]) AND Physician-Patient Relations [mh] Filters: published in the last 10 years.

A further 198 indexed PubMed citations were retrieved, bringing the total number of indexed citations to 1,964.

The PubMed search was supplemented by a text search for unindexed citations using various combinations of keywords and search terms relevant to the review – this was performed using the following search strategy:

1. (knowledge OR attitudes OR beliefs) cancer (in process [sb] OR publisher [sb]) (primary OR community OR engagement) Filters: published in the last 10 years; English.

132 citations were selected as being potentially relevant from the 541 citations retrieved.

Informit health databases

The full text Health Collection, Australasian Medical Index, Australian Public Affairs Information Service – Health, Aboriginal and Torres Strait Islander Health Bibliography, Health & Society Database, as well as the Rural and Remote Health Database subsets were searched using the following strategy:

1. (((MH=("Pharmacists")) OR (MH=("Community Medicine")) OR (MH=("Community Networks")) OR (MH=("Primary Nursing Care")) OR (MH=("Physicians, Family")) OR

2. (MH=(general practice)) OR (MH=(Primary Health Care))) AND (MHJ=(neoplasms)) Limits: 2002-2012
3. ((MHJ=("patient Participation")) OR (MHJ=("Attitude of Health Personnel")) OR (MHJ=("Attitude to Health")) OR (MHJ=("Health Knowledge, Attitudes, Practice")) OR (MH=("Patient Acceptance of Health Care")) AND (MHJ=(neoplasms)) Limits: 2002-2012
4. ((MH=(cooperative behavior)) OR (MH=("communication")) OR (MH=("interdisciplinary communication")) OR (MH=("interprofessional relations")) OR (MH=("referral and consultation"))) AND (MHJ=(neoplasms)) Limits: 2002-2012
5. ((MHJ=("skin neoplasms"))) Limits: 2002-2012
6. (#1 OR #2 OR #3)
7. (#5 NOT #4).

211 citations were retrieved from the search (198 after duplicate records were removed).

Cumulative Index to Nursing & Allied Health Literature (CINAHL) – Ebsco

The CINAHL database was searched using the following search strategy:

1. (MH "Health Knowledge") OR (MH "Health Knowledge (Iowa NOC) (Non-Cinahl)+") OR (MH "Health Knowledge and Behavior (Iowa NOC) (Non-Cinahl)+") OR (MH "Professional Knowledge+") OR (MH "Attitude to Health+") OR (MH "Attitude of Health Personnel+") OR (MH "Attitude to Illness+") OR (MH "Health Belief Model") OR (MH "Consumer Participation")
2. (MH "Cancer Care Facilities") OR (MH "Neoplasms+") OR (MH "Early Detection of Cancer") OR (MH "Oncologic Care")
3. (MH "Primary Health Care") OR (MH "Multidisciplinary Care Team+") OR (MH "Physicians, Family") OR (MH "Total Patient Care Nursing") OR (MH "Pharmacists") OR (MH "Community Networks") OR (MH "Community Health Services") OR (MH "Community-Institutional Relations") OR (MH "Community Health Nursing+") OR (MH "Health and Welfare Planning+") OR (MH "Community Medicine")
4. S1 AND S2 AND S3 AND Limiters - Published Date from: 20020101-20121231; Language: English
5. S4 NOT (MH "Skin Neoplasms+") OR (MH "Melanoma+") AND Limiters - Published Date from: 20020101-20121231; Language: English.

798 citations were retrieved (606 citations after PubMed duplicates were removed).

Cochrane Library (Wiley)

A new search interface, which became available on September 16, 2012, proved particularly challenging to search. Consequently, results of a previous search that had been performed using the previous platform on September 15, 2012, were used instead. On the old platform, it was possible to restrict the search to the Cochrane Database of Systematic Reviews. Unfortunately, the exact search strategy had not been fully documented but included the following MESH terms:

1. Explode [Neoplasms] NOT [Skin Neoplasms]
2. Explode [Attitude to Health]
3. [Primary Health Care] OR [Physicians, Primary Care] OR [General Practitioners] OR [Physicians, Family] OR explode [Professional-Patient Relations]
4. #1 AND #2 AND #3.

Approximately 140 citations were retrieved in this search and these were refined to exclude material that was not considered relevant and/or had been published more than ten years previously.

Sixty citations were retrieved for review.

Embase (Ovid)

A search was performed in the Embase database using the following search strategy:

1. exp *Neoplasms/ NOT (exp melanoma/ OR exp skin cancer/)
2. exp attitude to health/ OR exp attitude to illness/ OR exp patient attitude/ OR exp doctor patient relation/ OR exp health personnel attitude/
3. exp primary health care/ OR exp general practitioner/ OR exp consultation/ OR exp community care/ OR exp community medicine/
4. 1 AND 2 AND 3 limit to (english language and last 10 years).

1,046 citations were retrieved (227 citations after PubMed duplicates were removed).

PsycInfo (Ovid) 2002-2012 subset

The search was performed in the 2002-2012 subset of the PsycInfo database using the following search strategy:

1. exp *Neoplasms/ NOT (melanoma* or skin cancer*).mp.
2. exp health attitudes/ or exp health behavior/ or health knowledge/ OR participation/ or exp involvement/ or exp health personnel attitudes/
3. 1 and 2 Limit to (english language).

1,041 citations were retrieved (982 citations after PubMed duplicates were removed).

Grey literature

Due to time and funding constraints, limited attention was allocated to searching the grey literature for relevant material. The Trove database (<http://www.trove.nla.gov.au/>) maintained by the National Library of Australia facilitates access to a range of Australian resources, including selected digitised material freely available online. A search of this database yielded a number of theses and reports. Additional material was also found by searching Scirus (<http://www.scirus.com/>), Google, and Google Scholar. These searches retrieved a total of 55 additional citations. Twenty-two references were found incidentally in two Oncology journals (Current Oncology and Supportive Care in Cancer).

After removal of duplicate citations, a total of 4,212 citations were added to the EndNote library for review by the research team.

Review process

The 4212 articles were divided between three of the authors (MJ, AM, AD ~1330 each) and independently reviewed the abstract in the first instance using the following inclusion criteria:

1. Article represents a research article (rather than a letter or commentary) to ensure the inclusion of empirical research
2. Scope of the study includes involvement of GPs (including registrars and GPs with special interests) in cancer care

3. Published from 2000 onwards (inclusive) to optimise the currency and potential relevance of key findings in light of recent healthcare reforms (DH, 110, DHA, 111)
4. Study was conducted in the UK, Australia or New Zealand—this is because of the similar role of GPs in these countries as the conduit between primary and secondary care (112-114).

Articles selected by individual authors as possible inclusions were then reviewed again by one of the other authors as a measure of inter-rater reliability. Following this process, articles that were selected by at least two authors were further reviewed by all authors resulting in a total of 176 articles. Full text was then sourced and reviewed to determine inclusion employing the same process.

From the identified articles, the following information was extracted and tabulated for synthesis: health issue of interest; specialty of interest; methodology; primary intervention(s); comparative intervention(s); author-identified key finding(s); impact on patient care, prognosis and/or clinical outcomes; author-identified limitations; and author-identified opportunities for future research. Only the influence of primary care on patient outcomes is presented in this report. This rigorous process resulted in a total of 162 articles were included in this review.

To understand the quality of the evidence presented in this report, a table of relevant references is included in this report including an assessment of the level of evidence associated with each study. The 'hierarchy of evidence' measure used in report review is briefly described below. Following this, findings from an analysis of the identified publications are presented, with reference to the three questions that guided this rapid review.

Appendix 2. Summary of literature reviewed

Relevant publications	Sample/Method	Locale	Summary of findings	Evidence* (I -IV)	Key parameters	K=Knowledge A=Attitudes B=Beliefs	Recommendations
Absalom et al. ⁸⁰	Self administered questionnaire (SAQ), 207 cancer survivors aged 18–45 yrs, health status and quality of life (QOL) measures	UK	Some GPs not familiar enough with hospital based cancer treatments. Psychosocial needs unmet. Re-establishment of the contact between patient and GP was in this study dependent on a proactive attitude by the GP. Survivors value the clinical reassurance currently provided by consultant-led follow-up care, nutritional advice and counselling was well rated. Supportive needs such as late effects of treatment and fertility were not systematically addressed.	IV	Follow-up care	K	Due to some patients' barriers special attention is needed to guarantee the switch over from the cancer treatment centre to home-based end of life care. Multi-disciplinary services are recommended to meet supportive needs in addition to clinical care.
Adams et al. ¹¹⁵	Systematic review	Worldwide	Thirty-two publications were included in the review. Eleven categories of information need were identified. There was a predominant focus on breast or prostate cancer, leaving a knowledge gap in relation to other cancers. Few publications moved beyond the diagnosis and initial treatment phase, and most did not distinguish between met and unmet needs. Those that did indicated that partners/family members are more likely to have unmet needs for information about supportive care than for medical information. The concept of 'information need' was generally poorly developed and theorised in the publications.	I	Partners and family	K	Establishing the information needs of partners and family members of cancer patients is an important, but as yet neglected area of research. In order to develop our understanding of this more empirical research, with sound conceptual and theoretical foundations is required.
Adams et al. ²⁷	Qualitative semi-structured interviews (QI-SSI), 38 adults with 12 different cancer types at least six months post-treatment; and focus groups 71 primary care team members	UK	All felt primary care was important in cancer care. There was considerable scope for improving practice.	IV	Follow-up care	K, A	A GP consultation immediately following the end of active treatment may help transition and improve satisfaction with follow-up care.
Adams et al. ⁷¹	QI-SSI, 22 partners of cancer survivors	UK	Issues of concern were providing practical and emotional support while managing their own health and well-being. Partner concerns were often not addressed.	IV	Role of partners follow-up care	K, A, B	The role of partners of cancer survivors in follow-up care plans should be formally acknowledge and their health and well-being considered to maximise patient outcomes Support of partners of cancer survivors may improve the outcomes of patients. The health and well-being of partners should also be considered in cancer care follow-up to improve patient outcomes.

Relevant publications	Sample/Method	Locale	Summary of findings	Evidence* (I -IV)	Key parameters	K=Knowledge A=Attitudes B=Beliefs	Recommendations
Andersen et al. ⁶⁸	QI-SSI, 30 cancer patients and their families	Denmark	Delays in care-seeking could be due to a real or perceived power imbalance between GPs and patients, GPs are powerful gatekeepers within the health system. Patients often feel bound to accept the judgement of GPs and are reluctant to question them. Once referred for specialist care the GP-patient relationship can change.	III	Health system	K, A, B	<ol style="list-style-type: none"> 1. Gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting care-seeking 2. Continuity in the doctor-patient relationship may negatively influence patient reflections on access to healthcare, as the focus shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which she/he is situated.
Anvik et al. ⁷⁸	Focus group, six GPs; QI-SSI, 17 GPs; SAQ ,91 patients	Norway	The role of the GP in follow-up of patients with recently treated cancer is discussed under five main headings: patient involvement, treating the cancer and treating the patient, time and accessibility, limits to competence, and the GP and the hospital should work together.	III	Follow-up care	K, A, B	The GP has a place in the follow-up of many patients with cancer, also in the initial phase after treatment. Patients trust their GP to provide competent care especially when they have more complex healthcare needs on top of their cancer. GPs agree to take a more prominent role for cancer patients provided there is good access to specialist advice. Plans for follow-up of individual patients could in many cases improve care and cooperation. Such plans could be made preferably before discharge from inpatient care by a team consisting of the patient, a carer, a hospital specialist and a GP. Patients and GPs call on hospital doctors to initiate such collaboration.
Arora et al. ¹¹⁶	Time series, 623 survivors 2–5 years post diagnosis. 10 scales assessed survivor perception of care in the last 12 months; one scale measured rating of care	US	On nine of the 11 scales, mean scores ranged from 88 to 97 on a 0 to 100 response format, indicating very positive experiences. The two areas where quality perceptions were lower were discussions about health promotion and the physician's knowledge of the whole patient. In adjusted analyses those without private health insurance (p=0.02) and Hispanic and Asian survivors compared with whites (p<0.001) reported worse timeliness of care. Survivors who had multiple comorbidities	III	Follow-up care	K, A, B	Delivery of quality follow-up care to cancer survivors may require efforts to improve patient-centred communication and coordination. Special emphasis may need to be placed on health promotion discussions and adoption of a whole-person.

Relevant publications	Sample/Method	Locale	Summary of findings	Evidence* (I -IV)	Key parameters	K=Knowledge A=Attitudes B=Beliefs	Recommendations
			reported better scores on timeliness of care ($p<0.01$) and physicians' knowledge ($p=0.05$) than survivors without any comorbidity. Length of the patient-physician relationship was the variable most consistently found to be significantly associated with survivors' quality assessments. Physicians' information exchange had the strongest relationship with overall ratings of care, followed by physicians' affective behaviour, their knowledge of the survivor and survivors' perceptions of coordination of care ($p<0.001$ for all).				
Aubin et al. ⁸⁵	Five hospitals, 395 patients with recent diagnosis of lung cancer surveyed every 3–6 months, whether they had metastasis or not, for a maximum of 18 months, to assess family physician involvement in cancer care. 10 scales assessed survivor perception of care in the last 12 months; one scale measured rating	Canada	Of the 395 participating patients, 92% had a regular family physician but only 60% had been referred to a specialist by him/her or a colleague for the diagnosis of their lung cancer. A majority of patients identified the oncology team or oncologists as mainly responsible for their cancer care throughout their cancer journey, except at the advanced phase, where a majority attributed this role to their family physician. At baseline, only 16% of patients perceived a shared care pattern between their family physician and oncologists, but this proportion increased with cancer progression. Most patients would have liked their family physician to be more involved in all aspects of cancer care.	III	Follow-up care	K, A	Although patients perceive that the oncology team is the main party responsible for the follow-up of their lung cancer, they also wish their family physicians to be involved. Better communication and collaboration between family physicians and the oncology team are needed to facilitate shared care in cancer follow-up.
Aubin et al. ⁸⁷	395 patients surveyed on expectation regarding PCP participation in care at different phases of their cancer. Forty-five specialists and 232 community-based PCP involved in patient care were surveyed on same aspects	Canada	Most specialists did not expect participation of the PCP in coordination of care in the diagnosis and treatment phases (65% and 78% respectively), in contrast with patients (83% and 85%) and PCPs (80% and 59%) ($p<0.0001$). At these same phases, the best agreement among the 3 groups was around PCP role in emotional support: 84% and more of all groups had this expectation. PCP participation in symptom relief was another shared expectation, but more unanimously at the treatment phase ($p=0.85$). In the advanced phase, most specialists expect a major role of PCP in all aspects of care (from 81% to 97%). Patients and PCP agree with them mainly for emotional support and information transmission.	III	Follow-up care	K, A, B	Lung cancer patient, PCP and specialist expectations regarding PCP role differ with the phase of cancer and the specific aspect of cancer care. There is a need to reach a better agreement among them and to better define PCP role, in order to achieve more collaborative and integrated cancer care.
Baay et al. ¹¹⁷	SAQ of 20 risk factors for cervical cancer, 60 GPs, 28 trainees	Belgium	The five most important risk factors in the perception of the respondents were, in order of decreasing importance: viral infection, number of sex partners, sexual behaviour of the partner, unsafe sex, and early start of sexual activity. Fifty-six percent of the GPs expected the chance of survival to be between 80 and 100%, compared to only 31% of the trainees.	IV	Diagnosis and follow-up care	K, A, B	Most GPs are well aware of sexual habits as risk factors for cervical cancer development, including the role of Human Papilloma Virus as the viral agent in the etiology. However, they seem to underestimate the role of smoking and are

Relevant publications	Sample/Method	Locale	Summary of findings	Evidence* (I -IV)	Key parameters	K=Knowledge A=Attitudes B=Beliefs	Recommendations
							unable to identify the correct chance of survival for women in whom cervical cancer is detected within the frame of the cervical smear program. Attention should be given to education of medical students and practitioners, in order to allow them to supply patients with sufficient background information to make an informed choice on participating in cervical cancer screening.
Bains et al. ⁷⁹	QI-SSI, 18 health professionals from oncology, occupational health and general practice	UK	Health professionals provide conflicting and limited information to patients regarding ability to work during treatment or when to return to work thereafter. Lack of knowledge about impacts of treatment and symptoms on work ability and sustainability, particularly in relation to different occupations and work tasks resulted in providers offering minimal guidance to patients. Current practices relied on providers' previous experiences with employed patients rather than a sound evidence-base.	IV	From diagnosis to survival	K, A	The type of work-related information given to patients by providers is not systematic. It is necessary to develop a better knowledge-base about the impacts of cancer and its treatment on work ability, sustainability and return to work that would help providers to offer more tailored advice to patients, consistently. Therefore it is appropriate to recommend that formal training for providers is necessary. Enhancing the quality of information and training for health professionals to provide better work-related support to patients during the early stages of treatment could enable individuals to manage their work more effectively and facilitate a successful transition from patient to survivors.
Baldwin et al. ⁷³	QI-SSI, seven women with cancer in a rural area	Australia	The three themes presented regarding the particular experience of living in a rural or remote part of Australia are: seeking answers at a distance, sharing information in a small community and experiences of navigating the health system. These themes support the findings of previous researchers and illustrate the magnification of the female cancer experience related to rural or remote residence. Our findings also further illustrate the need for urgent intervention.	IV	Equity of access	K, A	Equity in healthcare access remains a difficult problem for authorities and service providers to address. The current initiatives for women with cancer in Australia are not sufficient to reduce the stresses on the rural women and their families. Models of service delivery tailored to the strengths of rural and remote people are needed. Self-care does

Relevant publications	Sample/Method	Locale	Summary of findings	Evidence* (I-IV)	Key parameters	K=Knowledge A=Attitudes B=Beliefs	Recommendations
							not mean no care it means different care and support. Research is needed to develop and test new modalities. The experiences of these women could be incorporated into strategic planning of services for rural communities to ensure that their needs as identified by them are being met.
Baravelli et al. ⁹²	SAQ, 20 cancer survivors, 95 health professionals; QI-SSI, 12 survivors, 14 health professionals	Australia	In study 1, cancer survivors completed a questionnaire regarding their follow-up and experiences during survivorship. Participants' PCPs completed a phone interview regarding proposed SCP elements. A subgroup of survivors reviewed a sample SCP and participated in a phone interview regarding this. In study 2, healthcare professionals working with colorectal cancer patients completed a questionnaire regarding follow-up and proposed elements of a SCP.	IV	Survivor care plans	K, A, B	There was strong support for core elements of the SCP. Additionally, nurses and survivors expressed support for supportive care and psychosocial elements. There was lack of consensus regarding who should prepare and discuss the SCP. There is strong support for the development and use of SCPs for bowel cancer survivors. There is some variation in opinion regarding ideal content of the SCP, who might prepare it, and how it might be discussed and utilised. Overcoming identified barriers to implementing SCPs for bowel cancer survivors is necessary for high quality cancer care.
Barton et al. ¹¹⁸	SAQ, 224 GPs	Australia	Of the registrars 86% rated highly their ability in performing cervical smears. Registrars reported examining more patients with breast cancer, lung cancer, or melanoma than rectal cancer, cancer of mouth/tongue, or lymphoma. More registrars rated the quality of their training as reasonable or better in assisting patients to stop smoking or modify alcohol intake than in cancer-related tasks. One third rated their teaching on management of curable/incurable cancer and care of the dying as poor and/or very poor, and over half had never examined prostate or rectal cancers.	IV	Diagnosis and follow-up care	K	GP registrars generally have good knowledge of cancer. Their exposure to cases of cancer is low, and it is of concern that many have never examined common tumours in our community.
Beattie ⁶⁶	Clinical database analysed for newly diagnosed breast cancer patients of one GP, 1986–2006	Australia	Thirty new cases of breast cancer were diagnosed, with 87% in the 'early' stages. Fifty-seven percent were outside the target age of 50–69 years used by BreastScreen to recruit women for screening. Apparent false-negative investigations occurred in 33% of cases. The mean time interval	III	Diagnosis	K, A, B	The diagnosis of breast cancer in this series was relatively infrequent and prior apparent false-negative investigations were not uncommon. As many women

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			between women noting symptoms and consulting the GP was 84 days and the mean time interval from first presentation to final diagnosis was 54 days.				diagnosed were outside the usual mammography screening age range of 50–69 years, there is a need for constant awareness of the possibility of breast cancer in all female patients. Encouraging women to present early with breast symptoms and adherence to the 'triple test' recommendation of clinical breast examination, imaging and biopsy for women with breast symptoms is important to minimise the risk of diagnostic delay.
Bethea et al. ¹¹⁹	SAQ, GP and Practice Nurses in four areas surveyed on confidence and competence in dealing with familial cancers. In two areas, genetic educational outreach was provided to 10 randomly selected practices and a matched analysis of questionnaire responses before and after intervention was done to determine impact of intervention.	England	Respondents were more confident in dealing with patient queries around familial breast cancer risk than those around bowel cancer. This was inconsistent with the ability to correctly assign familial risk, with 48% incorrectly assigning a high-risk categorisation to a low-risk breast cancer scenario. Respondents who had taken part in the intervention reported more confidence in dealing with issues related to the management of patient queries around bowel cancer. Following intervention, participants were more likely to report feeling confident in knowing the relevant family history to collect (72.4% of respondents from participating practices compared to 56.1% from non-participating practices; OR 2.39, p=0.02, 95% CI 1.14-5.00) and in making a basic assessment of risk (72.4% compared to 38.9%; OR 3.65, p=0.01, 95% CI 1.38-9.61).	II	Genetics	K	Providing genetic educational outreach has a positive impact upon how confident primary care staff feel in dealing with patient queries over familial cancers, particularly in relation to bowel cancer. Further research is needed to explore the impact of providing this service on other relevant outcomes such as appropriateness of referrals to genetic services.
Bickell et al. ¹²⁰	Randomised controlled trial (RCT), 374 women with breast cancer	US	Of the 374 new patients with early-stage breast cancer enrolled onto the RCT, only a slight majority of women (55%) perceived their quality of care as excellent; 88% actually received good quality, guideline concordant care. Excellent perceived quality (p<0.001) was significantly associated with patients' perception of the quality of the process of getting care (adjusted relative risk RR, 1.78; 95% CI, 1.65 to 1.87). Also associated with perceived quality—and mediated by race—were trust in one's physician (adjusted RR, 1.43; 95% CI, 1.16 to 1.64) and perceived racism which affected black women more than women of other races/ethnicities (black race-adjusted RR for perceived racism, 0.33 [95% CI, 0.10 to 0.87]; black race-adjusted RR for trust, 1.61 [95% CI, 0.97 to 1.90]; c=0.82 for the model; p<0.001). Actual quality of care provided did not affect perceived	II	Diagnosis to follow-up care	K, A, B	Patients' perceived quality of care differs from their receipt of high quality care. Mutable targets to improve perceived quality of care include the processes of getting care and trusting their physician.

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			quality of care received.				
Blaauwbroek et al. ⁹³	Postgraduate course, 358 GPs	Netherlands	We investigated the willingness of GPs who had followed a postgraduate course on late effects of cancer treatment, to participate in a shared care model for follow-up of adult childhood cancer survivors as well as what their requirements would be in case of participation. From the Northern Netherlands, 358 GPs participated in a postgraduate course on late effects in paediatric cancer survivors. After the course, they were asked to complete a 10-item questionnaire on motivation to participate in the regular follow-up of adult childhood cancer survivors as well as their conditions to participate. The response rate was 65%. Of the responders, 97% were willing to participate in a shared care model for follow-up and 64% felt that it was their responsibility to be in charge of childhood cancer survivors. The main requirements for participation were the availability of guidelines (64%), sufficient information about the patient's medical history (37%) and short communication lines (45%). The main barriers to participate were workload (16%), lack of knowledge (15%) and lack of communication (13%).	III	Training	K, A, B	Significant number of GPs are ready to participate in the long-term follow-up of adult childhood cancer survivors if adequate guidelines and medical information is provided and communication lines are clear.
Bober et al. ²⁵	SAQ, 227 GPs	US	Reported care patterns were assessed to create a multidimensional care score reflecting levels of attention to four areas of survivorship care: monitoring for cancer recurrence, management of late effects, sexual functioning, and mental health. Only 24% of PCPs met criteria for routinely providing more multidimensional survivorship care. More recent medical school graduates reported providing less multidimensional survivorship care when compared with their more experienced colleagues. Approximately 82% of PCPs believed that primary care guidelines for adult cancer survivors are not well defined, and 47% of PCPs cited inadequate preparation and lack of formal training in cancer survivorship as a problem when delivering care to long-term survivors.	IV	Long-term care	K, A	Although PCPs provide the bulk of care for long-term survivors within the survivorship phase of the cancer trajectory, only a small subset have reported providing multi-dimensional survivorship care. Results underscore a need for substantially increased training in survivorship care to support the delivery of multidimensional primary care for long-term survivors.
Braithwaite et al. ¹²¹	SAQ via internet, 268 GPs; QI-SSI, 72 GPs	UK	Ninety-two percent of respondents in the electronic survey and 68% in the telephone survey stated that they would be either extremely or fairly likely to use Genetic Risk Assessment on the Internet and Decision Support (GRAIDS). Intentions were associated with positive attitudes toward GRAIDS, beliefs that colleagues and patients would find the tool acceptable, perceived control and perceived confidence about conducting risk assessment and making appropriate decisions about patient management. Key attributes for the implementation of GRAIDS in practice were the authoritativeness of the guideline, easy user interface, the	IV	Training and support	K	Ninety-two percent of respondents in the electronic survey and 68% in the telephone survey stated that they would be either extremely or fairly likely to use GRAIDS. Intentions were associated with positive attitudes toward GRAIDS, beliefs that colleagues and patients would find the tool acceptable, perceived control and perceived confidence about conducting

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			validity and reliability of risk estimation and specific advice about patient management.				risk assessment and making appropriate decisions about patient management. Key attributes for the implementation of GRAIDS in practice were the authoritativeness of the guideline, easy user interface, the validity and reliability of risk estimation and specific advice about patient management.
Brazil et al. ⁹⁴	Eighty-four GPs	Canada	Most practitioners reported providing for their patients' various Supportive Cancer Care (SCC) needs. However, clear gaps were demonstrated in psychosocial and nutritional counselling and in providing information about SCC services. GPs were satisfied with their current role reported in SCC coordination, although the type of role varied; GPs who were asked about their end of life patients tended to see themselves as part of coordinating teams, whereas GPs asked about their recently diagnosed patients were more likely to defer this responsibly to a third party.	IV	Follow-up and long-term care	K, A, B	This study identified gaps in the provision of psychosocial and informational care to patients with cancer that may result in unmet needs. In general GPs do not see themselves as primarily responsible for coordinating patients' SCC and do not wish to assume this role. Accordingly models that involve GPs as team members in SCC coordination are more feasible for reducing patient need.
Browne et al. ⁹⁵	QI-SSI, 24 adults newly diagnosed with colorectal cancer and 12 month follow-up	Scotland	Participants' needs following a diagnosis for colorectal cancer included physical, psychological and social issues. GPs played a key role in diagnosis after which they were less involved. Participants valued GPs making unsolicited contact and offering support. Participants described being well supported by clinical nurse specialists who are expert in the illness, and who provide continuity of care and psychological support. A year after diagnosis when there was less contact with GPs and clinical nurse specialists, participants still faced challenges associated with the ongoing impact of colorectal cancer.	III	Follow-up and long-term care	K	While some patients enjoyed straight-forward recoveries from surgery, others experienced longer-term implications from their disease and treatment, particularly bowel-function issues, fatigue, anxiety and sexual problems. The potential for primary care to contribute more to the ongoing care of colorectal cancer patients was identified.
Bulsara et al. ¹⁰⁸	QI-SSI, 13 patients, long-term follow-up	Australia	Many patients had a long-term relationship with an individual GP. They perceived GPs as providing a primarily supportive rather than treatment role outside of the hospital setting, and relied on them for clarification and reassurance.	IV	Patient experience long-term care	K	The personal, confiding relationship between the GP and cancer patient might be better exploited by specialists. Patients could feel more empowered in relation to their condition if provided with information by their GP that is more relevant and explicit. For this to occur, specialists must first provide GPs with timely and pertinent information about their cancer management.

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Butow et al. ¹²²	Brief intervention Cancer Consultation Preparation Package (CCPP), 164 cancer patients	Australia	One hundred and sixty four cancer patients (67% response rate) were randomly assigned to receive the CCPP or a control booklet at least 48 hours before their first oncology appointment. The CCPP included a question prompt sheet, booklets on clinical decision-making and patient rights, and an introduction to the clinic. The control booklet contained only the introduction to the clinic. Physicians were blinded to which intervention patients received. Patients completed questionnaires immediately after the consultation and 1 month later. Consultations were audio-taped, transcribed verbatim, and coded. Results: All but one patient read the information. Before the consultation, intervention patients were significantly more anxious than were controls (mean, 42 v 38; p=0.04); however anxiety was equivalent at follow-up. The CCPP was reported as being significantly more useful to family members than the control booklet (p=0.004). Patients receiving the intervention asked significantly more questions (11 v 7 questions; p=0.005), tended to interrupt the physician more (1.01 v 0.71 interruptions; P=0.08), and challenged information significantly more often (twice v once; p=0.05). Patients receiving the CCPP were less likely to achieve their preferred decision making style (22%) than were controls (35%; p=0.06).	IV	Continuity of care	K, A, B	The finding that strong doctor-patient fit is linked to higher patient satisfaction is unexpected and differs from the results of other studies from the US. Further studies are required in order to examine how this may be influenced by differences in socio-cultural norms and expectations.
Chan et al. ¹²³	SAQ Patient Satisfaction Questionnaire, 80 cancer patients; SAQ Patient-Practitioner Orientation Scale, 80 cancer patients, 12 physicians from academic medical centre	Southeast Asia	Participants were 80 cancer patients and 12 physicians from a single academic medical centre. All participants completed the Patient-Practitioner Orientation Scale, while only the patient participants completed the self-administered Patient Satisfaction Questionnaire.	IV	Continuity of care	K, A, B	The finding that strong doctor-patient fit is linked to higher patient satisfaction is unexpected and differs from the results of other studies from the US. Further studies are required in order to examine how this may be influenced by differences in socio-cultural norms and expectations.
Cheung et al. ¹⁶	SAQ, 535 cancer survivors, 378 medical practitioners	US	Among physician respondents, 255 (67%) were PCPs and 123 (33%) were oncologists. Comparing patients with their oncologists, expectations were highly discrepant for screening for cancers other than the index one (agreement rate, 29%), with patients anticipating significantly more oncologist involvement. Between patients and their PCPs, expectations were most incongruent for primary cancer follow-up (agreement rate, 35%), with PCPs indicating they should contribute a much greater part to this aspect of care. Expectations between patients and their PCPs were generally more concordant than between patients and their oncologists. PCPs and oncologists showed high discordances in perceptions of their own roles for primary cancer follow-up, cancer screening and general	IV	Follow-up	K, A, B	Patients and physicians have discordant expectations with respect to the roles of PCPs and oncologists in cancer survivorship care. Uncertainties around physician roles and responsibilities can lead to deficiencies in care, supporting the need to make survivorship care planning a standard component in cancer management.

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			preventive health (agreement rates of 3%, 44% and 51%, respectively). In the case of primary cancer follow-up, both PCPs and oncologists indicated they should carry substantial responsibility for this task.				
Consedine et al. ¹²⁴	Stratified cluster-sampling to recruit 533 men (45–70 years) from four ethnic groups: African-American; European-American; immigrant Jamaican; and immigrants from Trinidad and Tobago	US	Multinomial logistic regression showed that minority men were less likely to report either never screening or yearly screening, while younger men were more likely. Lack of a regular physician (OR=2.87, 95% CI 1.39–5.84), an annual exam (OR=1.73, 95% CI 0.91–3.28), and low recommendation (OR=3.76, 95% CI 2.13–6.66) were associated with being categorised as a never (vs. partially adherent) screener, but only annual exam (OR=0.26, 95% CI 0.10–0.63) was associated with yearly screening. Lower cancer worry was marginally associated with never screening (OR=0.59, 95% CI 0.38–1.04), while knowledge was associated with screening yearly over time (OR=0.46, 95% CI 0.28–0.77).	III	Early diagnosis	K, A	Demographic, physician and psychological variables are differentially associated with never, less than yearly and yearly screening classifications. Minority men were unlikely to have never screened, but were also less likely to screen yearly. Physician variables were associated with the difference between not screening and partially adherent, but not between partially adherent and yearly screening suggesting that the role of physicians in PSA behaviour over time would benefit from further study.
Culver et al. ¹⁷	Patient simulation–led intervention with 86 PCPs randomly assigned to: 1. Moderate-risk case (n=25), presenting with a breast lump and mother with postmenopausal breast cancer 2. High-risk (maternal side) case (n=28), presenting with concern about breast cancer risk 3. High-risk (paternal side) case (n=33), presenting with an unrelated problem	US	Mean satisfaction with physician communication was higher for the moderate-risk case (2.92) than for the high-risk paternal case (2.25) or high-risk maternal case (2.42) (p<0.0001). The score was not influenced by session length, medical specialty or physician gender.	III	Simulated patient intervention	K, A, B	Physicians more consistently provided the moderate-risk standardised patients with reassurance and support compared with the high-risk cases. PCPs may be more unprepared or uneasy addressing the issues raised by more complex scenarios and may benefit from training in the assessment and communication of breast cancer risk.
Curtis et al. ¹²⁵	Longitudinal study with 55 patients, 36 family members, 31 physicians, and 25 nurses (220 hours interviews)	US	Asking patients directly 'how much information' they wanted was, by itself, not useful for identifying information needs, but in-depth questioning identified variability in patients' and family members' desires for explicit prognostic information. All but two patients endorsed at least one of the diagrams concerning the interaction of hope and prognostic information and some patients described moving from one diagram to	III	Prognosis	K, A, B	This study found important variability in the ways different patients with life-limiting illnesses approach the interaction of wanting support for hope and prognostic information from their clinicians. The four diagram approach may

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			another over the course of their illness. Respondents also described two different approaches to communication about prognosis based on the diagram selected: two of the four diagrams suggested a direct approach and the other two suggested a cautious, indirect approach.				help clinicians understand individual patients and families, but further research is needed to determine the utility of these diagrams for improving communication about end of life care.
Davis et al. ⁹⁷	Computer-assisted telephone interview (CATI) survey, randomly selected 544 women with cancer	US	Sixteen percent of women reported not receiving enough support during their diagnosis and treatment and only 65% of these women reported that their families received enough support. The primary sources of support for women and their families were medical practitioners (e.g. surgeons, oncologists and GPs) with very few women or family members utilising mental health professionals.	IV	Diagnosis and treatment	K	Given the importance of adequate support when being diagnosed and treated for breast cancer, urgent attention needs to be paid to training medical professionals in providing appropriate support and referrals for their patients.
Davison and Breckon ¹²⁶	SAQ, 180 adult males on active surveillance (AS) for less than 10 years post diagnosis	Canada	Thirty-five percent of patients reported assuming an active role in treatment decision making (TDM), 38% a collaborative role and 27% a passive role. Results suggest that patients less than 60 years prefer to play an active role in TDM whereas, men more than 70 years prefer to play a passive role. Available treatment options, eating a 'prostate friendly' diet, and non-traditional therapies were identified as the top three information preferences. Patients with higher levels of anxiety wanted access to more information compared to those with lower levels of anxiety. The urologists' recommendation was rated the most important factor influencing patients' decisions to go on active surveillance.	IV	Follow-up, long-term	K	The urologist's recommendation for treatment continues to have the most influence on the decision to go on AS. Our results suggest that age has an impact on the role patients wish to assume in TDM. Assessments of patients' information and decision preferences, and levels of anxiety are suggested for all prostate cancer patients considering AS.
Del Giudice et al. ⁸⁸	SAQ, random sample of 330 PCPs to examine views on routine follow-up of adult cancer survivors and modalities to facilitate PCPs in providing this care	Canada	A total of 330 PCPs responded (adjusted response rate, 51.7%). After completion of active treatment, PCPs were willing to assume exclusive responsibility for routine follow-up care after 2.4 +/- 2.3 years had elapsed for prostate cancer, 2.6 +/- 2.6 years for colorectal cancer, 2.8 +/- 2.5 years for breast cancer, and 3.2 +/- 2.7 years for lymphoma. PCPs already providing this care were willing to provide exclusive care sooner. The most useful modalities PCPs felt would assist them in assuming exclusive responsibility for follow-up cancer care were : 1. A patient-specific letter from the specialist 2. Printed guidelines 3. Expedited routes of re-referral and (4) expedited access to investigations for suspected recurrence.	III	Follow-up	K	With appropriate information and support in place, PCPs reported being willing to assume exclusive responsibility for the follow-up care of adult cancer survivors. Insights gained from this survey may ultimately help guide strategies in providing optimal care to these patients.
Dillard et al. ¹²⁷	Randomised CATI survey, 1729 adults (≥40 years) who reported making a cancer	US	As perceived risk for cancer increased, patients were more likely to seek information about screening on their own (e.g. 35% of participants who perceived a high risk of cancer searched the internet compared with 18%	III	Diagnosis - decisions	K, A, B	Higher perceived risk was associated with greater patient participation, as shown by more information seeking and greater

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	screening decision		for those who perceived a low risk ($p < 0.001$) and in interactions with their physicians. As perceived risk increased, patients were also more likely to consult with more than one provider. Gender moderated the shared decision making preference such that men with high perceived risks were more likely than women with high perceived risks to report they would have preferred more involvement in the decision (35% v. 9%, $p = 0.001$). Limitations: Cross-sectional data limit causal inferences.				desire for decisional involvement (moderated by gender). The results suggest that perceived risk of cancer could influence patient behaviour when deciding about screening.
Docherty et al. ¹²⁸	QI-SSI, 12 prostate cancer patients and partners	UK	The findings of this study show that inadequacies in patient and spouse knowledge and awareness of prostate cancer contributed to delayed contact, shock at diagnosis, preferences regarding decision-making, health judgments, including the use of the PSA test and physical wellbeing as accurate health indicators, and patient coping, incorporating the use of comparison with other patients.	IV	Treatment	K	Hospital staff, in particular the consultant and cancer nurse specialist, must be aware of the potential for inadequacy in patient and spouse knowledge and counter this through the provision of accurate and relevant information and support throughout the medical process. A series of recommendations have been generated.
Donnelly et al. ⁸⁹	562 specialists surveyed on case-load, follow-up, local policy and primary care involvement	US	Most commonly acknowledged purpose of follow-up was detection of treatment-related morbidity. Eighty four percent of respondents adhered to a locally developed protocol with only 9% conforming to NICE guidelines. The median follow-up was five years. Significant factors predicting delayed discharge were younger age ($p < 0.0001$); poorer Nottingham Prognostic Index ($p = 0.003$); treatment factors ($p = 0.002$); and patient risk factors ($p = 0.003$). Centres with higher case-loads (more than 200 per year) were more likely to discharge earlier. Reduced workload was perceived as the main benefit of discharge, while lack of GP oncological experience and loss of outcome data were concerns.	III	Follow-up	K, A	Specialists favour a risk adjusted discharge strategy and increased oncology infrastructure in primary care.
Drury and Inma ¹²⁹	QI-SSI, 11 patients, three cancer support workers in rural area	Australia	Patients who had the involvement of a cancer nurse coordinator and cancer support workers had better experiences and more streamlined care than did those who had to navigate the journey alone.	IV	Hospital based and follow-up care	K, A, B	This study endorses the function of cancer nurse coordinators and cancer support workers in providing better coordination of care in rural and regional cancer patients.
Earle et al. ⁹⁶	SAQ, 160 radiation oncologists, medical oncologists and surgical specialists in colorectal cancer to assess	Canada	Most recommended clinical assessments every 3–4 months in the first two years including carcino-embryonic antigen testing, gradually decreasing in frequency over five years. Ninety percent recommend a surveillance colonoscopy in the first year. The majority felt that specialist involvement in follow-up was important because of the increased	III	Follow-up care	K, A, B	Surveillance practices are generally in keeping with published recommendations. Most specialists feel that they should remain involved in follow-up, but this may result in increased resource utilisation.

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	recommendations for follow-up after potentially curative treatment, beliefs and attitudes and cost implications of follow-up strategies		opportunities for patients to contribute to research (76%) and teaching (73%). About half felt that specialists were more efficient at providing follow-up than PCPs, but these same physicians recommended significantly longer and more expensive follow-up routines on average than others. PCPs were felt to be important allies, especially in managing the psychosocial concerns of patients.				
Farquhar et al. ¹³⁰	QI-SSI, nine GPs	UK	This study describes GP views of the communication issues across the primary/secondary interface in relation to ovarian cancer patients using purposively sampled GPs and an audit of hospital medical records of 30 deceased ovarian cancer patients. Three stages in the patient journey were characterised by particular issues: <ol style="list-style-type: none"> 1. In the pre-diagnostic and diagnostic stage was a need for prompt information regarding the results of tests and diagnoses, and clearer guidance on the use of tests and fast-track referrals 2. In the active treatment phase, when GPs could lose touch with their patients, they needed effective communication in order to provide moral support and crisis management 3. When oncology withdrew and the focus of care switched back to the community for the terminal phase, GPs needed information to enable them to pick up the baton of care. 	IV	Continuity of care	K	There is a need to develop and evaluate interventions aimed at improving the content and speed of communications between secondary and primary care. Such interventions are likely to be complex and might include the greater use of telephone or fax for more selected communications, a review of secretarial support, the use of email, the development of GP designed pro-formas, the feasibility of patient/carer letter delivery options, nurse-led communication, universal electronic patient records, or a revisiting of the patient-held record.
Fern et al. ⁶⁷	Review medical records of 1650 young people	Scotland	One thousand six hundred and fifty nine teenagers and young adults (71.3% of registered patients) attended their GP at least once. Alert symptoms were uncommon, (reported in 4.0% of all consultations; 276 alert symptoms in 179 patients) and were not associated with age or sex. The most common alert symptoms were unexplained pain (34.8%), unexplained fatigue (14.5%) and lumps (13.4%). Two benign tumours were detected.	I	Consultation behaviours of youth	K	High proportion of teenagers and young adults consult their GP. Alert symptoms are uncommon and generally occur in isolation. More research is required to confirm these findings in a larger cohort and to examine how GPs respond to such alert symptoms.
Forsythe et al. ⁹⁸	Representative sample of medical oncologists (n=1,130) and PCPs (n=1,021) surveyed re: follow-up care of breast and colon cancer survivors	US	Approximately half of oncologists and PCPs (52%) reported broad involvement in psychosocial care. Oncologist and PCP confidence, beliefs about who is able to provide psychosocial support, and preferences for shared responsibility for care predicted broad involvement. However, oncologists' and PCPs' perceptions of who provides specific aspects of psychosocial care differed (p<0.001); both groups saw themselves as the main providers. Oncologists' confidence, PCPs' beliefs about who is able to provide psychosocial support, and oncologist and PCP preference for	II	Follow-up care	K, A, B	Findings that some providers are not broadly involved in psychosocial care and that oncologists and PCPs differ in their beliefs regarding who provides specific aspects of care underscore the need for better care coordination, informed by the respective skills and desires of physicians, to ensure needs are met. Interventions

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			models other than shared care were inversely associated with a shared approach to care.				targeting physician confidence, beliefs about who is able to provide psychosocial support and preferred models for survivorship care may improve psychosocial care delivery.
Frojd et al. ¹³¹	QI-SSI, 19 doctors re: 29 patients within endocrine oncology and haematology care	Sweden	Doctors considered the patients' verbal expressions, verbal behaviours, questions, body language, and facial expressions together with their own professional knowledge and experience when estimating the patients' worry and desire for information. The doctors also considered contextual factors, patients' demographical factors, and medical situation when estimating the patients' worry, and also when estimating the patients' desire for information. The findings illustrate that estimating patients' worry and desire for information is a multifaceted and complex task, and that doctors consider not only the patients' verbal and nonverbal cues, but also factors such as their own professional knowledge and experience, contextual factors and patients' demographical variables.	IV	Treatment, follow-up care	K, A, B	The findings should be communicated to doctors who meet cancer patients in medical consultations in order to illuminate the complexity of the medical consultation. The awareness of potentially important patient cues and other factors may aid doctors in their efforts to gain insight about their patients' emotions and informational needs.
Fumis et al. ¹³²	SAQ, 202 oncology physicians, 150 outpatients, 150 family members	Brazil	The majority of patients (92%) believe they should know about their terminal stage compared with 79.2% of physicians and 74.7% of families (p=0.0003). Cancer patients were most likely to support disclosure of diagnosis and terminality (p=0.001), to consider that this disclosure was not stressful (p<0.0001) and that this knowledge would improve their quality of life (p<0.0001).	III	Ethics – disclosure of diagnosis	K,B	Cancer patients seen in these centres in South-eastern Brazil prefer to know the truth about their poor prognosis more than their physicians and families think. Further studies with larger samples of patients and physicians are necessary to show if our results are representative of all Brazilian situations.
Gallagher et al. ¹³³	SAQ, 393 PCPs	US	Nearly all (98%) reported their organisations value good patient-provider communication, and 95% agreed that they communicate effectively with cancer patients. However, only 62% agreed that they knew when their cancer patients had unanswered concerns or questions, and 67% agreed that they were aware of most of the serious communication breakdowns that occurred in their patients' care. Almost all (99%) agreed that their organisation should encourage patients to alert the system when there has been a serious care breakdown and 88% agreed these reports would provide actionable information. Providers found some communication situations especially difficult. A majority (61%) found it extremely/very difficult to respond to patients' unrealistic beliefs about prognosis, 55% found it extremely/very difficult to respond to patients' concerns about delayed diagnosis. In response to a hypothetical patient who experienced	III	Communication between medical practitioners and patients	K, A, B	Cancer care providers value patient-provider communication but find discussions of prognosis, as well as disclosure regarding care breakdowns and delayed diagnosis, especially challenging. Providers support mechanisms to solicit cancer patients' concerns about their care. Health systems should explore how to create care delivery environments that improve patient-provider communication.

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			a delayed breast cancer diagnosis, 55% would provide very limited information to the patient, not explicitly mentioning the error causing the delay.				
Gibson et al. ¹³⁴	Two workshops to define preferred competencies of professionals in teenage and young adult cancer care	UK	The workshops generated three diamonds, which exhibited agreement of 13 principle skills, knowledge and attitudes. The top two being: 'expertise in treating paediatric and adult cancers' and 'understanding cancer'.	IV	Communication	K	The data from the education day suggested communication, technical knowledge and teamwork as being core role features for professionals who care for young people with cancer.
Greenfield et al. ⁹⁰	421 cancer experts (36% haematologists, 33% oncologists, 18% surgeons, 10% nurses, 2% other) and 54 GPs surveyed	UK	Clinicians valued clinical reasons for follow-up more highly than supportive reasons (p<0.001). Learning more about late effects and checking for cancer recurrence were rated as the most important reasons for follow-up by cancer experts and GPs. A total of 85% of cancer specialists hold follow-up consultations alongside patients on active treatment. Cancer experts agreed that primary care follow-up would increase their availability for acute oncological care, but reduce information on late effects. The most important resource to provide a quality follow-up service was specialist nursing support (91%).	IV	Follow-up guidelines	K	Follow-up guidelines that include late effects surveillance are needed. Where and who should deliver this care requires further debate.
Halkett et al. ¹⁰⁶	Six GPs consulted six standardised patients with indications for radiotherapy or with side-effects of radiotherapy	Australia	These data are consistent with the published literature which suggests that in practice not all patients are appropriately advised or referred.	IV	Standardised GP consultations – follow-up care	K	There is a need for innovations to support GPs to manage patients who would benefit from radiotherapy.
Hall et al. ²⁶	CATI survey, QI-SSI, 18 patients, six GPs. Modelling exercise completed by six GPs and five patients	UK	Many rural patients, and some urban patients, would appreciate follow-up being available nearer to home with the associated benefits of time saved and easier parking and continuity of care. Patients have concerns related to the level of extra training received by the GP and loss of contact with their consultant. GPs have concerns about gaining and maintaining the clinical skills needed to conduct follow-up, especially if the numbers of patients seen are small. They also have concerns about lack of support from other GPs and some administrative and organisational issues.	IV	Shared care	K, A	Many patients would be willing to have GPs share their cancer follow-up with the caveat that they had received extra training and were appropriately supported by secondary care specialists. Patients attending shared care clinics appreciated a local service and longer appointment times. GPs stress the importance of maintaining their own clinical skills and reliable clinical and administrative support from secondary care.
Hanks et al. ¹⁰⁵	Systematic review re: GP role in colorectal cancer (CRC)	Australia	The role of the GP in CRC management varies. Some GPs play many roles such as advocate, facilitator, supporter, educator and counsellor. The role	II	Review	K	There is a potential to increase this role, especially in providing psychosocial

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	management		of the GP is influenced by GP-specialist communication, practice location, and patient and GP factors.				support and counselling for both the patient and their family.
Holge-Hazelton et al. ¹³⁵	QI-SSI, 10 GPs re: role of in cancer care for young adults	Denmark	The GPs tended to make general statements, using everyday language, they experience that their patients disappear, they are seldom involved and they lack knowledge.	IV	Communication	K	GPs have few experiences with young adult cancer patients, but they have a potentially unique role in general primary cancer care if they develop their vocational vocabulary, relate more to relevant theory, and get a clearer vision of the content of the professional aspects of their work.
Hordern et al. ¹³⁶	Three stage reflexive inquiry using semi-structured interviews (n=82), textual analysis of 33 national and international clinical practice guidelines and participant feedback at 15 forums with patients and health professionals	Australia	This was in stark contrast to the expectations of patients. Cancer had interrupted their sense of self, including how they experienced changes to intimate and sexual aspects of their lives, irrespective of their age, gender, culture, type of cancer or partnership status. Key findings from this project reveal incongruence between the way patients and health professionals constructed sexuality and intimacy. Structures which govern cancer and palliative care settings perpetrated the disparity and made it difficult for health professionals to regard patients as people with sexual and intimate needs or to express their own vulnerability when communicating about these issues in the clinical practice setting.	IV	Communication – follow-up care	K	A degree of reflexivity about personal and professional constructions of sexuality and intimacy was required for health professionals to confidently challenge these dominant forces and engage in the type of communication patients were seeking.
Hudson et al. ¹³⁷	QI-SSI, 42 cancer survivors 47–80 years at least two years post treatment re: care preference	US	Forty-two survivors participated in the study. Most participants expressed strong preferences to receive follow-up care from their cancer specialists (52%). They described the following barriers to PCP engagement in follow-up care: <ol style="list-style-type: none"> 1. Lack of cancer expertise 2. Limited or no involvement with original cancer care 3. Lack of care continuity. Only one-third of participants (38%) believed there was a role for primary care in cancer follow-up care and suggested the following opportunities: <ol style="list-style-type: none"> 1. Performing routine cancer-screening tests 2. Supplementing cancer and cancer-related specialist care 3. Providing follow-up medical care when ‘enough time has passed’ or the survivors felt that they could reintegrate into the non cancer population. 	IV	Follow-up	K	Survivors have concerns about seeing their PCP for cancer-related follow-up care. Research interventions to address these issues are necessary to enhance the quality of care received by cancer survivors.
Jiwa et al. ⁸¹	SAQ, 101 breast cancer patients baseline, 60 follow-	Australia	In 68% of cases women reported that they did not consult their GP about breast cancer related symptoms prior to their appointment at the clinic,	III	Follow-up care preferences	K, A, B	Patients prefer their GP overall, but we observed that the majority of women did

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	up survey re: care preference		choosing instead to present to a Breast Care Nurse (BCN). In the survey patients preferred their GP if they needed a physical examination (p=0.007) or referral to a specialist (p<0.001). Older patients were more likely to choose a BCN if they wanted a mammogram and a GP if they wanted a physical exam or emotional support. The Patient Enablement Index (PEI) scores after follow-up with the BCNs were equivalent to those reported following GP consultations.				not consult their GP when they had scheduled appointments with a BCN at a hospital clinic.
Jiwa et al. ¹³⁸	Review 100 hospital records re: primary breast cancer	UK	The most frequently recorded problems in 702 patient years of follow-up were anxiety, unrelated medical problems and joint pain. Anxiety and depression tend to present relatively soon and are often enduring whereas concomitant medical problems also present later. Healthcare professionals considered patients difficult to manage because symptoms of recurrence require investigation for absolute reassurance of the symptomatic patient. However, investigations other than mammograms were seldom necessary.	III	Review	K, A	Patients and their partners are preoccupied with a fear of recurrence. This may manifest in a variety of guises including mental health problems. These can be addressed in primary care especially with the support of counsellors, with teamwork and agreed protocols for referral back to specialists when indicated.
Johansen et al. ¹⁰¹	QL-SSI – 14 GPs, 18 patients re: GP role in cancer care	Norway	The GPs claimed to have an important role in cancer care. In our analysis, three main aspects of GPs' work emerged: first, as a flexible mediator, e.g. first between the patient and the clinic, interpreting and translating; second, as an efficient 'handyman', solving practical problems locally; and third, as a personal companion for the patient throughout the illness.	IV	GP role cancer care	K, A	The interviewed GPs see their place in cancer care as being close to their patients. In their many tasks we found three main aspects: the mediating, the practical and the personal.
Johansen et al. ¹⁸	QL-SSI – 11 GPs re: clinical encounters	Norway	Awareness of cancer could arise in several contexts of attention: 1. Practising basic knowledge: explicit rules and skills, such as alarm symptoms, epidemiology and clinical know-how 2. Interpersonal awareness: being alert to changes in patients' appearance or behaviour and to cues in their choice of words, on a background of basic knowledge and experience 3. Intuitive knowing: a tacit feeling of alarm which could be difficult to verbalise, but nevertheless was helpful. Intuition built on the earlier mentioned contexts: basic knowledge, experience and interpersonal awareness 4. Fear of cancer: the existential context of awareness could affect the thoughts of both doctor and patient. The challenge could be how not to think about cancer all the time and to find ways to live with insecurity without becoming over-precautious.	IV	GP role cancer care	K, A	The thought of cancer arose in the relationship between doctor and patient. The quality of their interaction and the doctor's accuracy in perceiving and interpreting cues were decisive.
Katsiper et al. ¹³⁹	Five focus groups 21 survivors two focus groups 15 PCPs,	US	Survivors form intense relationships with specialists for reassurance and expertise. Many believed PCPs lacked necessary oncology expertise.	IV	Follow-up care	K, A, B	Breast cancer patients may experience difficulties transitioning to survivorship

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	two focus groups specialists. Groups explored transitions to follow-up, communication, patient needs, and provider roles		Survivors reported psychosocial and communication issues. African-Americans cited concerns about access to care and clinical trials as well as taboos to discussing cancer. Specialists reported that they struggle with discharging survivors due to protective relationships. PCPs were concerned about time and training to provide survivorship care and communication problems with oncologists. Written survivorship care plans were regarded by all groups as possibly helpful, but insufficient to ease the transition.				including ongoing psychosocial issues. African-American patients may face additional and unique barriers to successful survivorship. Oncology specialists may have concerns about discharging cherished patients. These findings suggest a psychological component that may influence the use of written survivorship care plans. PCPs may need additional training and greater access to specialists in order to care for survivors.
Kendall et al. ¹⁴⁰	Two focus groups, 18 patients or carers – monthly meetings over one year	Scotland	Patients with cancer and their carers identified five key times in the cancer journey as being especially significant from their perspective: around diagnosis, during treatment, after discharge, at recurrence and the final weeks. At each key time, there were five major issues of concern: information, communication, equity, a holistic approach and patient-centred care. Using these, the group members developed a checklist of recommended interventions for each stage in the illness trajectory and suggested how they might be implemented in primary care. Proactive and ongoing contact, if wished by the patient, was considered the central plank of cancer care in the community.	IV	Continuity of care	K, A, B	Patients with cancer and their carers believe that there is an important and unique role for primary care in offering continuity of care and information that is patient-centred and holistic, throughout the cancer trajectory, from first presentation. This study successfully brought patient, carer and professional perspectives to the development of a care framework for primary care.
Kew et al. ¹⁴¹	SAQ, 92 women with cancer re: views of routine follow-up	UK	A total of 54% (48/89) reported increased anxiety prior to their appointment, and 10% (9/90) still felt more anxious afterwards. Most women (82/92, 89%) preferred to see a hospital doctor and preferred this to a review by a specialist nurse or GP (p<0.001). Women thought the examination was the most important part of the visit (p<0.0001). Women viewed the specialist nurse's role as listening to concerns and taking blood, rather than detecting recurrence (p<0.0001). Women ranked detection of recurrence as the most important reason for attending for follow-up (p<0.0001).	IV	Follow-up care	K, A, B	Overall women think that detection of recurrence is the primary rationale for routine follow-up. Their views need to be taken into consideration when considering changes in the provision of follow-up care.
Khan et al. ¹⁴²	Systematic review re: long-term care of adult cancer survivors	US	Ten eligible publications in four categories: consultation rates in primary care, cancer screening, use of preventative services and chronic disease management. There was no conclusive evidence that cancer survivors have increased rates of consultation in primary care. The studies reported that cancer screening is well managed in survivors. Preventative and chronic care is worse in long-term colorectal cancer survivors compared	I	Review – long-term care	K	We found little research, especially outside the US, relating to the care of long-term cancer survivors in primary care. Future work should examine screening for treatment-specific sequelae and the quality of care for comorbid disease.

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			with long-term breast cancer survivors and controls.				
Khan et al. ⁸²	Database review. Worldwide		The population of cancer survivors is growing, and GPs have an increasing role in their care. The General Practice Research Database was used to compare consultation rates between cancer survivors and controls. Breast and colorectal cancer survivors had one more consultation per year compared with controls up to five years after diagnosis; rates then converged at 10 years post-diagnosis. Prostate cancer survivors consistently consulted up to three more times per year than controls.	III	Use of health system	K	These increased consultation rates are leading to an impact on service capacity.
Klabunde et al. ¹⁴³	National survey of physicians caring for cancer patients, 1694 PCPs, 1621 oncologists	US	Over 90% of PCPs fulfilled general medical care roles for patients with cancer such as managing comorbid conditions, chronic pain, or depression; establishing do-not-resuscitate status; and referring patients to hospice. Oncologists were less involved in these roles. Determining the treatment preferences of individual patients and deciding on the use of surgery were the only cancer care roles in which ≥ 50% of PCPs participated. Twenty-two percent of PCPs reported no direct involvement in cancer care roles while 19% reported heavy involvement. PCPs who were aged ≥ 50 years, were internists or geriatricians, taught medical students, saw more cancer patients, or experienced referral barriers fulfilled more roles. Rural practice location was not associated with greater PCP involvement in cancer care.	III	Review – GP in cancer care	K, A, B	PCPs across the US have an active role in cancer patient management. Determining the optimal interface between PCPs and oncologists in delivering and coordinating cancer care is an important area for future research.
Lafferty et al. ⁸³	Eight focus groups, 47 women diagnosed with breast cancer; SAQ, 33 carers and 44 healthcare professionals, analysed re: continuity of care; relational, informational and managerial	Scotland	According to the patients: 'Continuity of Care' is the continuous care over time; it involves the relationship between the healthcare professional and the patient. It is not just a follow-up review. The relationship is built on trust, loyalty and constancy. The perception is that the providers of care know you, know your case history and your future care is agreed on. Continuity of care was reported to be achieved for the majority of the respondents across all three samples however deficiencies in the service were identified.	IV	Continuity of care	K	The results provide an opportunity to improve service; recommendations have been made and steps to implementation taken.
Lawler et al. ⁸⁴	QI-SSI, 25 women with breast cancer re: follow-up care	Australia	Themes that emerged from the interviews centred on patient experiences and perceptions of follow-up service provision and provider interactions related to medical, psychosocial and lifestyle (e.g. diet, physical activity) care. Many women perceived a marked decline in the quality and duration of follow-up consultations with clinicians in comparison to their initial treatment experiences. Several women experienced considerable overlap in follow-up care when multiple providers were involved resulting in 'unnecessary' time and travel costs. Generally women experienced	IV	Follow-up care	K, A, B	Breast cancer survivors living outside major Australian cities have limited access to medical follow-up care, and psychosocial and lifestyle support programs. There is a need for greater coordination of care between health professionals to improve communication and reduce patient and medical system

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			limited availability of medical providers in rural areas resulting in a lack of continuity in care, exacerbated by limited communication and coordination between treating health professionals. Lastly women perceived a lack of available psychosocial support and resources for rural breast cancer survivors in their areas.				burden. Finding solutions (such as eHealth options) could help to alleviate these barriers and improve follow-up care for rural breast cancer survivors.
Lewis et al. ¹⁴⁴	Systematic review re: qualitative studies of follow-up care	UK	Nineteen studies were included; seven were linked to randomised controlled trials. Eight studies examined the views of healthcare professionals (four of which included GPs) and 16 examined the views of patients. Twelve descriptive themes were identified, from which 12 perceived implications for practice were derived. Most themes related to conventional follow-up in secondary care. Some views concerning other models of care were based on participants' ideas, rather than experiences.	I	Follow-up care	K, A, B	Patients' main concern is recurrent disease, and they find regular follow-up, expertise of specialists and quick access to tests reassuring. Information regarding the effectiveness of follow-up is not given to patients who also have unmet information needs which would help them to cope and be more involved. Continuity of care, unhurried consultations and psychosocial support are important, but sometimes lacking in secondary care. GPs are thought to be unwilling and to have insufficient time and expertise to conduct follow-up.
Lewis et al. ¹⁴⁵	Systematic review follow-up care. Worldwide	UK	There was no statistically significant difference for patient wellbeing, recurrence rate, survival, recurrence-related serious clinical events, diagnostic delay, or patient satisfaction. GP-led breast cancer follow-up was cheaper than hospital follow-up. Intensified primary care resulted in increased home-care nurse contact, and improved discharge summary led to increased GP contact. Evaluation of patient-initiated or minimal follow-up found no statistically significant impact on the number of GP consultations or cancer-related referrals.	I	Primary versus secondary follow-up care	K, A, B	Weak evidence suggests that breast cancer follow-up in primary care is effective. Interventions improving communication between primary and secondary care could lead to greater GP involvement. Discontinuation of formal follow-up may not increase GP workload. However, the quality of the data in general was poor and no firm conclusions can be reached.
Li et al. ¹⁴⁶	SAQ, 888 lung cancer patients from nine major public cancer treatment centres, Supportive Care Needs Study	Australia	The mean number of unmet needs (out of a maximum of 59) reported by lung cancer patients was 15.6 (95% CI 12.1–19.1), compared to 10.9 (95% CI 10.0–11.8) in other cancer patients. The differences were mainly due to the fact that lung cancer patients reported a higher mean number of unmet psychological needs (7.6 versus 5.0) and physical and daily living unmet needs (2.8 versus 1.4), compared to the other cancer patients. Having a lung cancer diagnosis was an independent predictor of having a high level of psychological need (RR 2.00, 95%CI 1.13–3.56) and daily living need (RR 2.81, 95%CI 1.60–4.95), together with not being in	III	Continuity of care – unmet needs	K, A, B	The results suggest that priority needs to be given to addressing the specific needs of this subgroup of cancer survivors.

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			remission and receiving the cancer diagnosis more than two years previously.				
Lundstrom et al. ¹⁰⁹	SAQ, cancer 1490 patients re: experience	Denmark	One-third of the patients evaluated the cooperation between hospitals and primary care as suboptimal. Younger patients and patients from the capital Copenhagen were most dissatisfied. A third had needed support from their GP, and 41% of these patients had not fully received what they needed. Older patients, patients in Stage 1 and patients from surgical departments were least likely to have needed their GP's support. Patients described support from the GP as empathic behaviour and help with coordinating health services.	III	Patient experiences of care	K, A, B	A substantial number of cancer patients experienced suboptimal cross-sector cooperation and supportive care. Efforts to improve cancer care cooperation may focus on the possible supportive role of the GP as it seems that there is an untapped potential in primary care.
Mahboubi et al. ¹⁴⁷	Medical records, 389 cancer patients re: GP involvement	France	A substantial number of cancer patients experienced suboptimal cross-sectorial cooperation and supportive care. Efforts to improve cancer care cooperation may focus on the possible supportive role of the GP as it seems that there is an untapped potential in primary care. GPs detected significantly more recurrences than specialists in patients over 75 and in those presenting symptoms.	III	GP involvement in care	K	GPs detected significantly more recurrences than specialists in patients over 75 and in those presenting symptoms. French GPs are widely involved in the surveillance of patients with early-stage colorectal cancer, without any unfavourable impact on the patient's survival. Some suggestions exist that continuing education in oncology may increase the implication of GPs in colorectal cancer surveillance.
Mainous et al. ¹⁴⁸	QL-SSI, 119 newly diagnosed cancer patients re: GP continuity of care	US	Half of the patients reported that their cancer was found through screening. Continuity of care prior to diagnosis was related to receiving mammography. Continuity of care was not, however, significantly related to earlier detection. Trust in PCP was related to earlier detection among both the entire sample of patients with colon and breast cancer and among a subsample of women with breast cancer. In a multivariate model, only detection through screening and trust predicted stage of diagnosis.	III	GP involvement in care	K,A,B	Continuity of care is not related to earlier detection of cancer, while trust with a regular physician was associated with earlier detection of cancer.
Maly et al. ¹⁴⁹	Medical records and SAQ, 222 breast cancer patients aged ≥ 55 years patients-physician interaction	US	In multiple logistic regression models, only physician interactive informational support had significant relationships with all three dependent variables, controlling for a wide range of patient socio-demographic and case-mix characteristics, visit length, number of physicians seen, social support, and physician socio-demographic and practice characteristics. Specifically informational support positively predicted patient breast cancer knowledge (adjusted odds ratio	III	Continuity of care	K, A, B	One specific domain of the patient-physician interaction, interactive informational support, may provide an avenue to ensure adequate breast cancer knowledge for patient treatment decision making, decrease treatment delay and increase rates of BCS for older breast

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			(AOR)=1.18, 95% confidence interval (CI)=1.00–1.38), negatively predicted treatment delays (AOR=0.80, 95% CI=0.67–0.94), and positively predicted receipt of BCS (AOR=1.29, 95% CI=1.07–1.56). Age and ethnicity were not significant predictors in these models.				cancer patients, thereby potentially mitigating known healthcare disparities in this vulnerable population of breast cancer patients.
Mao et al. ¹⁵⁰	SAQ, 300 breast cancer survivors (BCS) re: care delivery	US	Overall, BCSs rated PCP-related survivorship care as 65 out of 100 (SD=17). The areas of PCP-related care most strongly endorsed were general care (78%), psychosocial support (73%) and health promotion (73%). Fewer BCSs perceived their PCPs as knowledgeable about cancer follow-up (50%), late effects of cancer therapies (59%), or treating symptoms related to cancer or cancer therapies (41%). Only 28% felt that their PCPs and oncologists communicated well. In a multivariate regression analysis, non-white race and level of trust in the PCP were significantly associated with higher perceived level of PCP-related survivorship care (p=0.001 for both).	III	Continuity of care	K, A, B	Although BCSs perceived high quality of general care provided by their PCPs, they were not as confident with their PCPs' ability to deliver cancer-specific survivorship care. Interventions need to be tested to improve oncology-primary care communication and PCP knowledge of cancer-specific survivorship care.
Matejic et al. ¹⁵¹	QL-SSI, 22 women with cervical cancer; SAQ, 776 women	Serbia	Our findings indicate that there is poor communication between women and gynaecologists and an absence of proper counselling. Women's lack of knowledge about reproductive health issues, poor attitudes of gynaecologists, and personal barriers that women experience in accessing healthcare render preventive practices a low priority both for women and gynaecologists.	III	Health system - access	K	We recommend different educational and organisational strategies that may improve the counselling skills of gynaecologists and ultimately reduce the prevalence of cervical cancer in Serbia.
Meacham et al. ¹⁵²	QI-SSI, 14 healthcare providers re: best practice follow-up	US	Healthcare providers (HCP) described moderate to very low familiarity with survivor care, but high interest in online continuing education (CE) learning. Thirty-one lectures were given to HCP groups to increase awareness. Preferred types of ongoing CE were: lectures, online text, and video modules. CE material was developed based on feedback from HCPs and website utilisations and includes 19 QuickFacts and five CE modules. During the first year, the website had 471 unique visitors and 1,129 total visits. QuickFacts received 345 views with Neurocognitive, Survivor Care 101, and Endocrine being most visited, and 49 CME modules have been completed.	III	Follow-up – best practice	K	PCPs are interested in partnering in models of shared care for paediatric cancer survivors. Effective educational initiatives include lectures within HCP's professional education constructs and web-based CE opportunities. PCP involvement in survivor care alleviates some barriers to care such as geographic distance to the cancer centre and ensures that more paediatric cancer survivors receive recommended coordinated surveillance for late effects of cancer therapy.
Miedema et al. ¹⁵³	SAQ, 183 patients re: follow-up care GPs	Canada	Patients' perceptions of cancer follow-up care. Results: More than a third of participants (36%) were not sure which physician was in charge of their cancer follow-up care. As part of follow-up care 80% of participants	IV	GP involvement – follow-up care	K	Cancer follow-up care is increasingly becoming part of family physicians' practices. Family physicians need to

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			wanted counselling from their family physicians, but only 20% received it. About a third of participants (32%) were not satisfied with the follow-up care provided by their family physicians. In contrast only 18% of participants were dissatisfied with the follow-up care provided by specialists. Older participants were more satisfied with cancer follow-up care than younger participants.				develop an approach that addresses patients' needs, particularly in the area of emotional support.
Mitchell et al. ¹⁴	QI-SSI, 12 GPs re: role in cancer care	Australia	GPs' role in cancer care fluctuates between active advocacy during diagnosis and palliation, and ambivalent redundancy in between. The role is influenced by socioeconomic, clinical and geographical factors, patients' expectations and GPs' motivation. Not all participants wanted an enhanced role in cancer care, but all valued better specialist-GP communication. Role clarification is needed, together with greater mutual trust between GPs and specialists. Key needs included accessible competency training and mentoring for doctors unfamiliar with the system. Existing system barriers and workforce pressures in general practice must be addressed to improve the sharing of cancer care. Only one metropolitan focus group was conducted, so saturation of themes may not have been reached. The challenges of providing cancer care in busy metropolitan practices are multiplied in non-metropolitan settings with less accessible resources and where distance affects specialist communication. Non-metropolitan GPs learn from experience how to overcome referral and communication challenges.	IV	GP role in cancer care	K, A, B	While the GPs identified solutions to their concerns, the role can be daunting. GPs are motivated to provide long-term care for their patients, but need to be acknowledged and supported by the health system.
Neilsen et al. ¹⁵⁴	RCT, 248 cancer patients re: shared care program	Denmark	The shared care program had a positive effect on patient evaluation of cooperation between the primary and secondary healthcare sectors. The effect was particularly significant in men and in younger patients (18–49 years) who felt they received more care from the GP and were left less in limbo. Young patients in the intervention group rated the GP's knowledge of disease and treatment significantly higher than young patients in the control group. The number of contacts with the GP was significantly higher in the intervention group. The EORTC quality of life questionnaire and performance status showed no significant differences between the two groups.	I	Shared care program	K,A,B	An intersectoral shared care program in which GPs and patients are actively involved has a positive influence on patients' attitudes towards the healthcare system. Young patients and men particularly benefit from the program.
Nissen et al. ¹⁵⁵	SAQ, 132 medical practitioners re: involvement in cancer care	US	Overall 52% were comfortable having responsibility for surveillance of cancer recurrence, and 43% were confident they are following standard guidelines for cancer recurrence. Both of the aforementioned measures increased with years of practice. More than half rated the current transfer of care from oncologist to PCP as fair or poor. The most common	III	GP involvement in care	K, A	Levels of comfort, confidence, and satisfaction were generally low. PCPs need more specific guidance regarding surveillance for cancer recurrence.

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			problems identified were uncertainty regarding the type (62.6% for breast, 56.5% for colorectal), frequency (72.5%, 66.4%), and duration (74.8%, 67.2%) of surveillance testing.				
O'Brien et al. ¹⁰⁰ O'Brien et al. ⁸⁶	QI-SSI, 35 patients 59–82 years re: follow-up care prostate cancer	UK	<ol style="list-style-type: none"> 1. Psychosexual problems gained importance over time 2. Men felt they were rarely invited to discuss psychosexual side-effects within follow-up appointments and lack of rapport with healthcare professionals made it difficult to raise problems themselves 3. Problems were sometimes concealed or accepted and professionals' attempts to explore potential difficulties were resisted by some 4. Older patients were too embarrassed to raise psychosexual concerns as they felt they would be considered 'too old' to be worried about the loss of sexual function. 	III	GP involvement in follow-up care	K, A, B	Men with prostate cancer, even the very elderly, have psychosexual issues for variable times after diagnosis. These are not currently always addressed at the appropriate time for the patient. Practice implications: Assessments of psychosexual problems should take place throughout the follow-up period and not only at the time of initial treatment. Further research examining greater willingness or reluctance to engage with psychosexual interventions may be particularly helpful in designing future interventions.
O'Toole et al. ⁹¹	RCT, 357 late-stage cancer patients re: involvement of PCPs	US	Older patients (≥65 years) were more likely to have a PCP (p=0.02). Patients reported a broad range of perceived PCP involvement and satisfaction with that involvement. Greater involvement was associated with greater satisfaction (p<.001). Half of oncologists reported themselves as PCP for more than 25% of their patients. Approximately half of oncologists reported that more older than younger patients had PCPs, yet only 20% reported differences in PCP involvement or in their communication with PCPs for older late-stage patients.	I	GP involvement in cancer care	K, A, B	Results support involvement of PCPs in advanced cancer care and demonstrate variable perspectives on PCP involvement. Matching patient preferences and practices may improve satisfaction. Clarification of elements in the partnership between patients, PCPs and oncologists will inform efforts to optimally care for older patients with advanced cancer.
Oskay-Ozcelik et al. ¹⁵⁶	SAQ, 617 breast cancer patients re: information needs and preferences	England	A total of 617 patients responded, 552 on line and 65 via the hard copy questionnaire. The median age of the on-line group was 47 years (21–85) and 55 years (40–92) in the hard copy group. Sixty-five percent of the patients were treated with the intention of achieving a cure and 35% of the patients had metastatic disease. The median length of the consultation communicating the information 'You have breast cancer' was 15 min (0–300). The most effective and patient-relevant source of information about the disease and the treatment options was consultation with the physician (84%). When asked to suggest areas for improvement, patients' most common answers were: more complementary therapies should be offered by the physician (54%); physicians should take more time to explain things (51%); and	III	Patient information needs and preferences	K	This study underlines the need to give patients with breast cancer the full details on treatment options and cancer management. The results provide a suitable basis for a broader interdisciplinary discussion of the patient-physician relationship and should be useful in generating hypotheses for subsequent prospective studies.

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			cooperation between the physicians involved in the patient's care should be improved (39%). The questions most relevant to patients were: 'Am I getting the right therapy?' (89%); 'How many patients with my condition does my doctor treat?' (46%) and 'Can I be enrolled into a trial?' (46%). An independent second opinion centre was desired by 94% of the respondents but only 20% knew of any such resource.				
Phillips et al. ⁴¹	Review of long-term management of cancer patients	Australia	Cancer survivors require ongoing support in four key areas: prevention; surveillance; intervention for consequences of cancer and its treatment; and coordination between specialist and generalist providers.	III	Review of long-term care issues	K	Cancer survivors experience significant physical and psychological morbidity which makes minimising their burden of disability and distress an important priority. Survivors require ongoing care that is well coordinated, focuses on prevention, provides going surveillance whilst minimising and managing the long-term effects of treatment and other comorbidities.
Potosky et al. ²⁰	SAQ, 1072 GPs and 1130 oncologists, knowledge, attitudes, practices to follow-up care	US	Compared with PCPs, oncologists were less likely to believe PCPs had the skills to conduct appropriate testing for breast cancer recurrence (59% vs. 23%, p<0.001) or to care for late effects of breast cancer (75% vs. 38%, p<0.001). Only 40% of PCPs were very confident of their own knowledge of testing for recurrence. PCPs were more likely than oncologists to endorse routine use of non-recommended blood and imaging tests for detecting cancer recurrence, with both groups departing substantially from guideline recommendations.	III	Differences in care across healthcare professionals	K	There are significant differences in PCPs' and oncologists' knowledge, attitudes and practices with respect to care of cancer survivors. Improving cancer survivors' care may require more effective communication between these two groups to increase PCPs' confidence in their knowledge, and must also address oncologists' attitudes regarding PCPs' ability to care for cancer survivors.
Quinn et al. ¹⁵⁷	QI-SSI, 16 physicians in a cancer centre re: fertility preservation (FP)	US	While most physicians discussed potential fertility loss as a side-effect of cancer treatment, few provided information to patients about preserving fertility. Patient characteristics such as gender and cancer site may impact the discussion as well as system factors such as costs of procedures and access to FP resources. Education and training for physicians about FP options for cancer patients, particularly females, may promote discussion of FP. In addition, system barriers related to availability and affordability of FP resources must also be addressed.	III	Communication of fertility issues pre-treatment for cancer	K	Physicians should consider providing patients with timely, understandable information related to their FP options, prior to the administration of treatment. Such discussions may lead to improved quality of life for individuals as they transition from patients to survivors.
Rayman et al. ⁷²	Focus groups, 11 physicians, 14 nurse practitioners, one	US	Provider relationships were characterised as being with women with cancer and comprised an active behind-the-scenes role in supporting their	IV	Continuity of care	K, A, B	These findings should be a part of professional education for rural

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	clinical psychologist re continuity of care for breast cancer care in rural areas		patients through treatment decisions and processes. Three themes emerged from the interview data: knowing the patient, walking through treatment with the patient, and sending them off or losing the patient to the system.				practitioners, and mechanisms to support this role should be implemented in practice settings.
Richardson et al. ¹⁵⁸	Focus groups, 22 nurses, two social workers, one occupational therapist, one welfare officer	UK	The principal finding was the extent to which staff experience difficulties in caring for patients from black and ethnic minority groups. Entailing serious challenges to their own professional practice, these were found to arise at all stages of patients' experience of cancer, including at diagnosis, during treatment and at the palliative phase. Staff were concerned that their inability to communicate with some patients meant that they were not able to provide them a good service, as they could not develop an easy relationship and talk around issues. Yet it could be difficult to work with interpreters as well as family members, both of who could be reluctant to translate important information. They were also conscious of not being fully sensitive to patients' differing cultures, while noting the importance of not making assumptions about particular beliefs or behaviour.	IV	Training, knowledge – cancer care	K	Staff would welcome training to help them to explore their attitudes and assumptions in working with black and ethnic minority patients, but did not seek induction into the detailed practices of different cultures. Some staff felt they would benefit from training in working with interpreters.
Rozmovits et al. ¹⁵⁹	Review, 35 hospital follow-up care regimes	UK	Thirty-five (70%) hospitals supplied details of their follow-up regime. There was a wide variation: only three hospitals specifically stated that patients were given a choice about the type of follow-up. The patients' interviews highlighted their need for a responsive GP and realistic information about recovery, resources and diet. Choice is particularly important because patients differ in their views of the benefits of hospital follow-up.	III	Follow-up care regimes	K	The absence of evidence about what constitutes ideal clinical follow-up for colorectal cancer is reflected in current hospital practice. In such circumstances the preferences of individual patients are particularly important. Not all patients want repeated specialist investigations but those without stomas, and therefore no access to a stoma nurse, need another source of advice about recovery and long-term practical help. Follow-up care organised by GPs may be acceptable to many patients. We suggest a list of topics for GPs to discuss with their patients about follow-up. The needs described by patients are not extensive and could often be met by existing resources.
Sada et al. ⁷⁶	QI-SSI – 10 patients, 14 oncologists/ PCPs, shared	US	Physicians reported that electronic health records improved communication within integrated systems but that communication with physicians outside of their system was still difficult. PCPs expressed	IV	Shared care models	K,A,B	Integrated systems that use electronic health records likely facilitate shared cancer care through improved PCP-

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			uncertainty about their role during cancer care, although medical oncologists emphasised the importance of comorbidity control during cancer treatment. Patients and physicians described additional roles for PCPs, including psychological distress support and behaviour modification counselling.				oncologist communication. However, strategies to promote a more active role for PCPs in managing comorbidities, psychological distress, and behaviour modification, as well as to overcome communication challenges between physicians not practicing within the same integrated system, are still needed to improve shared cancer care.
Santoso et al. ¹⁶⁰	SAQ – 284 cancer patients during outpatient chemotherapy	US	Study participants included 284 patients (38% male, 62% female) (56% African American, 42% Caucasian, 3% others) with a median age of 62 years. Patients correctly answered in regards to their diagnosis (98%), cancer location (91%), and name of their doctor (99%). However, only 23% scored correctly when asked the stage of their cancer. In univariate analysis younger age (p=0.006) was the only significant variable in answering the question correctly, while higher income (p=0.065) and female gender (p=0.092) approached statistical significance. In multivariate analysis all three variables were shown to be significant (p values of 0.016, 0.028, and 0.041, respectively). Increasing age resulted in a reduction of 2.5% per year, higher income resulted in an increase of 1.3% per 1000 dollars, and females were 49% more accurate, in the ability to correctly identify the cancer stage.	IV	Patient knowledge of cancer care	K	Although patients seem to know their condition well, many of them do not understand the stage of their cancer. Older patients, patients with lower income, and male patients seem to have less understanding of the stage of their cancer.
Shahid et al. ¹⁶¹	QI-SSI – 31 Aboriginal people with cancer, 20 healthcare providers, re: experience	Australia	Key issues specific to Aboriginal research include the need for the research process to be relationship-based, respectful, culturally appropriate and inclusive of Aboriginal people. Researchers are accountable to both participants and the wider community for reporting their findings and for research translation so that the research outcomes benefit the Aboriginal community.	IV	Continuity of care	K	There are a number of factors that influence whether the desired level of engagement can be achieved in practice. These include the level of resourcing for the project and the researchers' efforts to ensure dissemination and research translation; and the capacity of the Aboriginal community to engage with research given other demands upon their time.
Shahid et al. ²²	QI-SSI – 37 Aboriginal people with direct or indirect experience with cancer	Australia	Outcomes indicated that misunderstanding, fear of death, fatalism, shame, preference for traditional healing, beliefs such as cancer is contagious and other spiritual issues affected their decisions around accessing services. These findings provide important information for health providers who are involved in cancer-related service delivery.	IV	Continuity of care	K	These underlying beliefs must be specifically addressed to develop appropriate educational, screening and treatment approaches including models of care and support that facilitate better

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							engagement of Aboriginal people. Models of care and support that are more culturally-friendly, where health professionals take account of both Aboriginal and Western beliefs about health and the relationship between these, and which engage and include Aboriginal people need to be developed. Cultural security, removing system barriers and technical/scientific excellence are all important to ensure Aboriginal people utilise healthcare to realise the benefits of modern cancer treatments.
Shahid and Thompson ²⁴	Review	Australia, Canada, New Zealand	Cancer in Indigenous populations in these four countries is characterised by high incidence and mortality rates for specific cancers and lower survival rates as a result of late diagnosis, lower participation and poorer compliance with treatment. A higher prevalence of many cancer risk factors occurs across these populations. Fear of death, fatalism, payback, shame and other spiritual and cultural issues are reported in the few qualitative studies examining Indigenous beliefs and understanding of cancer which undoubtedly influences participation in cancer screening and treatment.	IV	Review cancer care – Indigenous peoples	K	The holistic approach (physical, mental, emotional and spiritual) to healing and wellbeing, and the concept that individual, family and community are inseparable underpin Indigenous care-seeking behaviour. Further community-based research is needed to increase understanding of the needs of Indigenous people with cancer, and to guide policy and practice towards more supportive and effective care.
Shalom et al. ⁷⁵	QI-SSI, 15 PCPs, cancer survivor care	US	Ten indicated reading the SCPs before being contacted for the interview. All 10 PCPs indicated that the SCP provided additional information about the patient's cancer history and/or recommendations for follow-up care, and eight reported a resulting change in patient care. PCPs identified useful elements of the SCP that assisted them with patient care, and they valued the comprehensive format of the SCP. PCPs indicated that after reading the SCPs they felt more confident and better prepared to care for the cancer survivor.	IV	Survivorship care	K	SCPs were highly valued by these PCPs, increasing their knowledge about survivors' cancer history and recommended surveillance care and influencing patient care.
Siminoff et al. ¹⁵	QI-SSI, 242 recently diagnosed cancer patients	US	Factors associated with diagnosis delay (DD) more than 2 months included lower income (OR=0.56, p=0.03), having regular physician prior to receiving a cancer diagnosis (OR=2.52, p=0.03), having a physician who used temporising communication strategies during the consultation (OR=2.41, p=0.02), receiving an initial alternate diagnosis (OR=3.36,	IV	Delayed diagnosis	K, A, B	Excellent communication skills that appropriately probe for relevant social and economic patient information, assist patients in distinguishing and elaborating on symptoms, and provide clear rationale

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			p=0.02), experiencing referral delay (OR=3.61, p<0.001), and experiencing follow-up delay of any kind (OR=3.32, p=0.01).				and instructions for future steps, will speed along the diagnosis process and could be the difference between early and late stage CRC. Practice implications: Increased understanding of physician communication and practice styles that contribute to DD could have a positive impact on decreasing the morbidity and mortality from this disease.
Skolarus et al. ²⁸	SAQ, 902 PCPs, prostate cancer care	US	Two-thirds (67.6%) of providers cared for men during and after prostate cancer treatment. Providers routinely inquired about incontinence, impotence and bowel problems (83.3%), with a few (14.2%) using surveys to measure symptoms. However, only a minority felt 'very comfortable' managing the side-effects of prostate cancer treatment. Clear plans (76.1%) and details regarding management of treatment complications (65.2%) from treating specialists were suboptimal. Nearly one-half (45.1%) of providers felt it was equally appropriate for them and treating specialists to provide prostate cancer survivorship care.	III	GP involvement in cancer care		PCPs reported that prostate cancer survivorship care is prevalent in their practice, yet few felt very comfortable managing side-effects of prostate cancer treatment. To improve quality of care, implementing prostate cancer survivorship care plans across specialties, or transferring primary responsibility to PCPs through survivorship guidelines should be considered.
Smith et al. ⁹⁹	SAQ, 509 PCPs, care of breast cancer survivors	Canada	PCPs reported being most confident in screening for recurrence and managing patient anxiety; they were least confident in managing lymphedema and providing psychosocial counselling. Compared with physicians following fewer survivors of breast cancer, those who followed more breast cancer survivors had higher confidence in managing the biomedical aspects of follow-up and in providing counselling about nutrition and exercise. Most physicians found discharge letters from oncologists to be useful. Point-form discharge information was preferred by 43%; detailed description by 19%; and both formats by 38%. The most useful information items identified for inclusion in a discharge letter were a diagnosis and treatment summary and the recommended surveillance and endocrine therapy. Continuing medical education events and online resources were the means most commonly used to obtain knowledge about breast cancer.	III	Survivor care	K	PCPs who provide follow-up for survivors of breast cancer report that they are confident in managing care and satisfied with discharge letters containing a diagnosis and treatment summary, and recommendations for surveillance and endocrine treatment. At the time of patient discharge, additional information about common medical and psychosocial issues in this patient population would be useful to PCPs. Preferred means to access current breast cancer information include continuing medical education events and online resources.
Smith-McLallen et al.	SAQ, 1641 cancer patients, information seeking behaviour	US	Within one year of diagnosis with colon, breast, or prostate cancer, 1,641 patients responded to a mailed questionnaire assessing intentions to seek cancer-related information from a source other than their doctor, as well as their attitudes, perceived normative pressure, and perceived	III	Information seeking behaviour – people with cancer	K,A,B	Intentions to seek information, perceived normative pressure regarding information seeking, baseline information-seeking behaviour, and being diagnosed with stage

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			behavioural control with respect to this behaviour. In addition the survey assessed their cancer-related information seeking. One year later 1,049 of these patients responded to a follow-up survey assessing cancer-related information seeking during the previous year. Attitudes, perceived normative pressure, and perceived behavioural control were predictive of information-seeking intentions, although attitudes emerged as the primary predictor.				4 cancer were predictive of actual information-seeking behaviour at follow-up.
Stevenson et al. ⁷⁴	Delphi process, 62 health professionals, cancer care rural patients	UK	Of 49 items suggested, there was agreement on 26 (53%), encompassing fast access to diagnosis, high-quality specialist treatment, and well-coordinated delivery of care with good and fast communication and effective team working between all health professionals involved. Specialist oncology nurses in local hospitals were considered a priority along with good facilities, accommodation, and transport for patients. There was no agreement on the best location for chemotherapy (local or central). The only large difference of opinion between participants based in primary and secondary care concerned chemotherapy provision at local community hospitals (primary care was in favour, hospital practitioners against, p<0.001). In making their decisions, participants took problems of access into account, but were also concerned with quality of care and feasibility in the current health service.	III	Practice guidelines for rural based cancer care	K	Our findings show that more evidence is needed regarding the balance of risks and benefits of local chemotherapy provision. Overall however, there is agreement on many principles for cancer care that could be translated into practice.
Tariman et al. ¹⁶³	Review factors that impact diagnosis of cancer in older adults	Worldwide	A diverse group of factors were identified, which are likely to form a unique framework to understand clinical decision making and plan future investigations in older adult patient populations. Using longitudinal and prospective designs to examine the real-time interplay of patient, physician and contextual factors will enable a better understanding of how those divergent factors influence actual treatment decisions.	I	Nurse involvement in cancer care	K	Oncology nurses can advocate autonomous (patient-driven), shared or family-controlled treatment decisions, depending on an older patient's decisional role preference. Nurses can support patient autonomy during treatment decision making by coaching patients to engage in discussion of various evidence-based treatment options and a comprehensive discussion of the probability of success for each option with specialist providers. Oncology nurses may be able to promote treatment decisions that are consistent with a patient's personal preferences and values, with strong consideration of the patient's personal contexts.

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Thompson et al. ¹⁶⁴	Systematic review, Aboriginal people's beliefs around cancer	Australia	Includes information on what the research was about, how the research was conducted, what was found as a result of the research project and what recommendations have been made based on the research findings. The report also outlines how the research has been disseminated and the associated outcomes that have been achieved since the project's completion.	I	Practice implications Aboriginal people with cancer	K, A, B	Community education – getting more information in the community about preventing cancer and early diagnosis and sharing more positive stories about treatment and recovery. Support systems such as transport, accommodation and hospital liaison services. The health system including transfer of care from the community to the hospital and back to the community, training doctors and other health staff to be more sensitive and responsive to Aboriginal needs.
Veitch et al. ⁷⁰	QI-SSI, focus groups, 18 people with colorectal cancer (CRC); QI-SSI, 18 people with CRC; SAQ, 69 people with CRC	Australia	Participants had very little knowledge of CRC signs and symptoms pre-diagnosis, which sometimes led to delays in diagnosis. The speed of diagnosis was dependent on several practitioner-related factors. Treatment-related issues included coming to grips with the diagnosis and preparedness for treatment and side-effects. Personal beliefs and attitudes influenced treatment and follow-up decisions. Rural participants encountered travel related difficulties particularly during treatment as outpatients. There was a strong belief in the need for more public education about CRC in general, warning signs and symptoms and familial risk factors.	IV	Experiences of CRC	K, A, B	Good understanding of people's knowledge of CRC, their attitudes towards screening, diagnosis, treatment and follow-up, will enable health and cancer services provide focused and relevant support to people with CRC, their families and carers. This is especially important in non-metropolitan areas where the full range of specialist services is not locally available.
Votron et al. ¹⁹	SAQ – 678 GPs, two randomly selected simulated patient cases	Belgium	Elderly patients were more likely to be referred for non-curative treatment (OR 13.71; 95% CI 5.67–33.12; p<0.0001 for prostate cancer and OR 17.67; 95% CI 4.04–77.31; p<0.0001 for breast cancer). The other variables (performance status and medical history) did not affect treatment orientation. However, GPs were prepared to seek assistance from oncologists in both cases, irrespective of the patient's age.	III	Simulated patient case review	K	Age seems to be more important among GPs in deciding how to manage cancer patients than performance status and comorbidity. This is a very common prejudice. They are nevertheless inclined to refer people with cancer to oncologists independently of the patient's age.