The role of primary and community-based healthcare professionals in early detection and follow-up in cancer care: a rapid review of best practice models

Jon Emery
Lyndal Trevena
Danielle Mazza
Julia Fallon-Ferguson
Katie Shaw
Briony Williams
Megan Varlow

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.

This report was prepared by:
Jon Emery, Lyndal Trevena, Danielle Mazza, Julia Fallon-Ferguson, Katie Shaw, Briony Williams and Megan Varlow

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Enquiries regarding this report may be directed to the:
Manager
Knowledge Exchange Program
Sax Institute
www.saxinstitute.org.au
knowledge.exchange@saxinstitute.org.au
Phone: +61 2 95145950
Fax: +61 2 95145951

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EXECUTIVE SUMMARY

The role of primary care in cancer control is increasingly recognised as a vital component of cancer services in Australia. Effective healthcare relies on the delivery of appropriate care by the right team at the right time. Healthcare systems with a strong primary care component have been demonstrated to be more cost-effective than those without, which are predominantly led by hospital specialists. Primary care plays an important role across the cancer continuum: in primary cancer prevention, discussing and delivering cancer screening tests, accurately diagnosing people with cancer when they present in the community, providing supportive care during and after treatment, and at the end-of-life. This commissioned rapid review considers the evidence relating to the role of primary care in early detection, including cancer screening, and in follow-up care of cancer patients.

Traditionally, general practitioners (GPs) are considered as 'gatekeepers' to hospital services, limiting the flow of patients from primary into hospital-based care and contributing to more cost-effective overall care. As cancer prevalence rises as a consequence of improvements in survival and the ageing population, primary care will need to play a growing role in managing survivorship to ensure cancer care is sustainable. Ensuring safe and cost-effective care is delivered across the healthcare system depends on the ability to correctly classify patients according to the likelihood of a significant clinical outcome (e.g. cancer diagnosis, cancer recurrence, unmet clinical need). This depends on the following:

a. The ability to assess risk of an underlying cancer diagnosis to reduce diagnostic delay, and to minimise the harms and costs associated with over-investigation of people at low risk of a cancer diagnosis

b. The ability to identify cancer survivors who can safely and effectively be followed up in primary care. This might be determined by risk of recurrence, survivorship care needs, patient and provider preference or a combination of these factors.

Primary care needs to be more explicit, rather than implicit, in considering risk assessment and risk stratification as important in determining who receives optimum care in a timely and safe manner.

This rapid review focuses on early detection and follow-up of the high incidence cancers experienced in New South Wales (NSW): breast, colorectal, prostate and lung. The key questions were:

1. What are the current best practice models for cancer care that include a role for health professionals in the primary and community sectors? What is the evidence that these models are effective?

2. What are the key drivers for implementation of the models with respect to the evidence of effectiveness?

We applied rapid review methods to identify the key evidence relating to these questions, focusing on systematic reviews and randomised controlled trials (RCTs), and large observational studies where this was the most relevant study design. We identified 18 relevant systematic reviews and include a total of 166 papers in this rapid review. The review is broken down into the following sections:

1. The role of primary care in cancer detection
    a. The role of primary care in cancer screening
    b. The role of primary care in symptomatic diagnosis of cancer

i. How well do symptoms in primary care predict common cancers
ii. Models of care to improve diagnosis of cancer in primary care

2. The role of primary care in cancer follow-up.

Primary care can make important contributions to the effective delivery of cancer screening programs. The majority of studies we examined measured participation rates in cancer screening and showed that higher uptake rates are associated with greater involvement by primary care. In particular, GP endorsement of invitations, recall and reminder systems and audit and feedback on screening all lead to higher participation rates. Whether participation rates are the most appropriate measure of success in cancer screening is much debated, informed decision making is increasingly recognised internationally as a more relevant outcome in cancer screening. The role of primary care in assisting patients to make informed decisions about cancer screening, through the use of tools such as decision aids, was beyond the scope of this review but is an important area to consider in the context of cancer screening in primary care.

In the last ten years there has been a significant advance in our understanding of the epidemiology of cancer symptoms in primary care. Due to the low prevalence of cancer in primary care populations even so-called 'red flag' symptoms are not highly predictive of cancer. This is the significant challenge for primary care in detecting cancer early while not over-investigating or referring patients who are very unlikely to have cancer. Hamilton's CAPER studies and Hippisley-Cox's QCancer work have used slightly different methodological approaches to examine large general practice datasets but both have made important contributions to the understanding of the epidemiology of cancer symptoms in primary care. Potentially useful cancer risk models have arisen from this work that require further research in Australia and internationally on how best to translate them into clinical practice to potentially improve cancer detection in primary care.

Fast track cancer referral routes are another key potential strategy to improve early detection of cancer. Multiple large audits of the English Two-Week Wait referral system suggest they may be useful in reducing diagnostic delay for a large number of cases in health systems that have long waiting times for outpatient diagnostic services. However, they are no panacea: there is still significant variation between GPs' use of fast track referral routes and the associated conversion and detection rates. Moreover, fast track referral routes can only ever detect a moderate proportion of cancers because symptoms in primary care are not strongly predictive and some cancers present with nonspecific symptoms.

A number of RCTs have assessed primary care-led and shared care for cancer follow-up, finding them to be broadly equivalent to hospital specialist care. The strongest evidence for this is among patients with earlier stage breast and colorectal cancers. Patient and provider preferences for primary care based models varied across studies and countries. Support for greater primary care involvement was increased after involvement in trials in which primary care was adequately supported to take on this new role. Shared care requires clear guidance for patients and primary care professionals about treatment and follow-up plans, as well as management of treatment adverse effects and mechanisms for rapid referral and consultation to specialist advice if required. Early contact with the patient's primary care provider at the time of discharge is also important. Further research is needed to examine the role of electronic patient held records to improve communication as part of shared care models, as well as the role of risk stratification in cancer follow-up.

On the basis of the evidence we have reviewed, we make the following expert recommendations.

Recommendations

1. The Cancer Institute NSW works with Medicare Locals in NSW to develop a program to implement organisational change in partnership with local practices to increase cancer screening uptake and informed participation

    a. Organisational changes shown to increase cancer screening uptake in primary care include: GP endorsement letters, recall and reminder systems, feedback on screening uptake and cancer prevention clinics

    b. Involvement of non-medical staff including organising patient and clinician reminders, patient education, scheduling screening appointments and general administrative support are core elements of this organisational change

2. The Cancer Institute NSW considers commissioning a review of the evidence on decision aids in cancer screening to help inform strategies to increase informed participation, and develop a policy incorporating informed participation in cancer screening, which would align it with the emerging international perspective

3. The Cancer Institute NSW considers supporting research into the effect of risk assessment models such as QCancer and CAPER on cancer diagnosis and treatment outcomes in the Australian context

    a. The Cancer Institute NSW considers exploring with medical software providers and the Royal Australian College of General Practitioners approaches to implementing cancer risk assessment models into general practice clinical software as part of this research program

4. The Cancer Institute NSW works with Medicare Locals and Local Hospital Networks to define clear referral routes for patients with a high suspicion of cancer. Informed by the revised National Institute for Health and Clinical Excellence Guidelines or by the QCancer or CAPER risk models, they could consider a phased establishment of fast track referral routes within the public health system, commencing with colorectal and lung cancer

    a. Fast track referral routes require significant ongoing investment to be effectively implemented: GPs need to perceive these routes as offering a significant advantage and need to receive multiple, repeated information about these diagnostic routes. Again this would require close liaison with Medicare Locals to develop a program of information and education about these cancer diagnostic routes

5. Data collection processes are required to enable large scale audits of current and future referral pathways of patients with suspected cancer to allow calculation of conversion and detection rates and measure the impact of new diagnostic initiatives

6. The Cancer Institute NSW supports the development of new models of follow-up involving primary care in NSW, initially for breast and colorectal cancer while evidence from ongoing trials accumulates

    a. Cancer follow-up care should provide clear guidance for patients, primary care and cancer care professionals about treatment and follow-up plans as well as management of treatment adverse effects and mechanisms for rapid referral and consultation to specialist advice if required. Early contact with the patient's primary care provider at the time of discharge is important

    b. Current evidence about the role of patient held records is based on hard copy formats that do not appear to improve continuity of care, although some patients and providers do like them. Further consideration is recommended for the role of the

federally funded Patient-Controlled Electronic Health Record in cancer follow-up as this initiative is implemented

c. New models of follow-up should allow flexibility and consider patient and provider preferences in determining appropriate follow-up care for each patient

7. The Cancer Institute NSW fosters research into models of care with more structured shared cancer surveillance and psychosocial support, the role of risk stratification in planning cancer follow-up, models for longer-term cancer survivorship and economic evaluations of different cancer follow-up models.

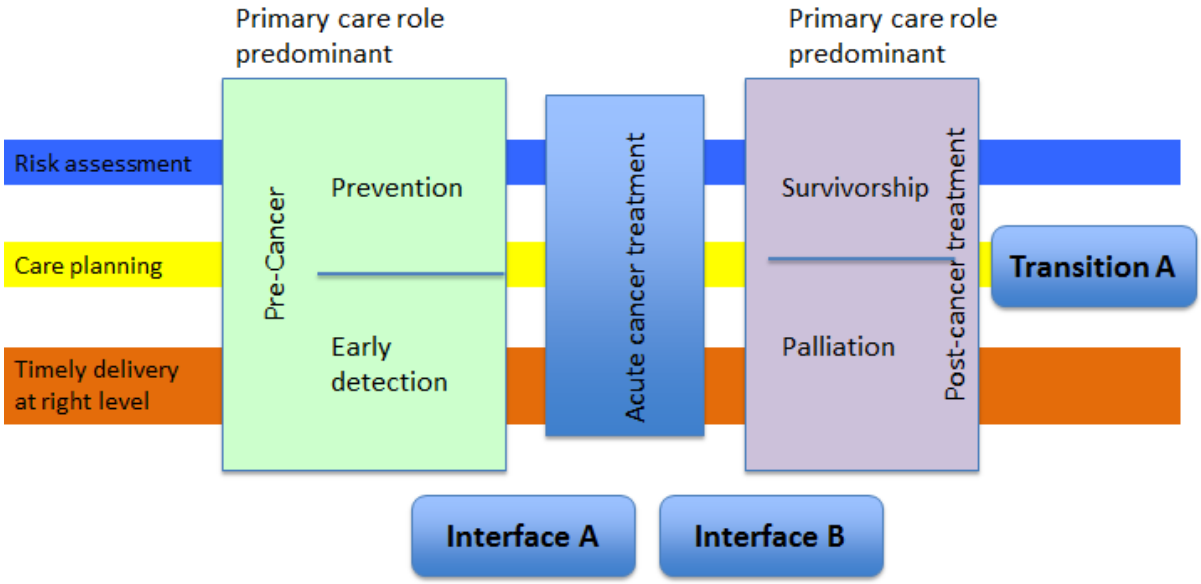
1 Background

Cancer is the leading cause of disease burden in Australia accounting for 19.4% of the total disease burden, more than cardiovascular disease (18.0%), diabetes (5.5%) and mental health disorders (13.3%).[1]

The role of primary care in cancer control is increasingly recognised as a vital component of cancer services in Australia. Cost-effective healthcare relies on the delivery of appropriate care by the right team at the right time. Healthcare systems with a strong primary care component have been demonstrated to be more cost-effective than those which are predominantly led by hospital specialists.[2] This is probably due to more efficient care when delivered and coordinated by a generalist, rather than multiple specialists, and through managing access to more expensive hospital-based care. The key elements in a conceptual model of general practice and generalism are accessibility, holistic patient-centred, team-based care, care coordination, continuity and management of complex multiple problems.[3]

Figure 1 presents an overview of processes of care along the cancer continuum, adapted from two key sources[4,5], both of which discuss the need for integrated approaches to disease prevention and management of cancer by applying chronic disease models.

Figure 1. Processes of care along the cancer continuum



Traditionally GPs are considered as 'gatekeepers' to hospital services, limiting the flow of patients from primary into secondary/tertiary care (Interface A in Figure 1) and therefore contributing to more cost-effective care. As cancer prevalence rises as a consequence of improvements in survival, managing patient flow across the 'gate' back into primary care is also a key consideration for future effective cancer care (Interface B). Along the cancer continuum, there is a third important transition that is less about the interface between primary and secondary care, but more to do with the transition from survivorship to palliative care (Transition A). This third transition is not the subject of this rapid review.

Ensuring effective care is delivered across these interfaces depends on the ability to correctly stratify patients according to the likelihood of a significant clinical outcome (e.g. cancer diagnosis, cancer recurrence, death):

1. Interface A depends on the ability to assess risk of an underlying cancer diagnosis to reduce diagnostic delay and minimise harms and costs associated with over-investigation of people at low risk of a cancer diagnosis
2. Interface B relies on the ability to identify cancer survivors who can safely and effectively be followed up in primary care. This might be determined by risk of recurrence, survivorship care needs, or both
3. Transition A depends on the ability to predict those who are most likely to die in a specific timeframe and require planned palliative care in the near future.

Thus primary care needs to be increasingly more explicit in considering risk assessment and risk stratification as important in determining who receives optimum care in a timely and safe manner. Unmet needs (medical and non-medical) have a crucial influence on quality of life of cancer patients. The GP's ongoing relationship with the patient and the patient's carers, together with the holistic nature of general practice as a discipline, and with a general practice serving as a 'medical home'[6] qualifies GPs to identify and address psychological, financial and other unmet needs.[7] In recognition of the potential of primary care to fulfil these needs, there is a call for an enhanced role of primary care in cancer management in Australia, complementing the growing demand for services role redesign.[8]

Challenges to enhanced primary care cancer management

Small numbers of cancers seen by individual GPs

An individual full-time GP may only see about seven to eight new cases of cancer per annum, excluding non-melanoma skin cancers.[9] Even for the commonest cancers an individual full-time GP with approximately 1,600 patients will likely see only one new case of lung, breast, prostate and colorectal cancer per annum, only one case of ovarian cancer every five years and one case of testicular cancer in 20 years. The challenge for general practice is therefore to distinguish between patients whose symptoms may be due to cancer and the much larger number of patients with similar symptoms due to other causes. This challenge is especially pertinent to patient groups such as teenagers. Results of a survey released in May 2012, by the United Kingdom (UK) Teenage Cancer Trust (TCT) show progress is still urgently needed. A third of all young cancer patients reported their GPs took no action despite presentation with common cancer symptoms, and a quarter of patients had to visit the GP four or more times before their symptoms were taken seriously.[10] In essence the challenge of earlier detection of cancer in children and young adults is even greater because the prevalence of cancer is very low in this population and therefore symptoms have even poorer predictive value.

Evidence of the challenge in identifying cases of cancer comes from recent English National Cancer Patient Experience Survey data on the management of people subsequently diagnosed with cancer in general practice.[11] There was wide variation between cancer types in the proportion of people who had at least three visits to their GP before being referred. Cancer sites where more than 20% of patients had three or more consultations included lung, lymphoma, myeloma, ovary, pancreas and stomach. In contrast only 7.4% of women with breast cancer had visited their GP more than three times before referral. There are no equivalent data from Australia or elsewhere.

Diagnostic delay

Another challenge lies in the issue of 'diagnostic delay' in cancer. Delays during the period between the first development of cancer symptoms and the eventual diagnosis have been broadly attributed to the patient, the GP and the healthcare system. In an English study of the time between presentation and treatment of six common cancers in general practice the median number of days between presentation of the first symptom or sign and initiation of referral was 0 days for breast, 20 days for prostate, 28 days for large bowel, 31 days for lung, 66 days for stomach and 84 days for oesophageal cancer.[12] There are no directly comparable Australian data. A recent study in rural Western Australia showed that the time from presentation in general practice to referral was significantly longer for colorectal and prostate cancer compared to breast or lung cancer (Emery in submission). A new model of diagnostic delay identified patient, healthcare system and tumour factors that interact to contribute to delays at the patient, GP and specialist levels.[13] This model could provide a framework to inform strategies aimed at reducing diagnostic delay of cancer.

Managing increasing numbers of survivors (follow-up)

Improvements in treatment and early detection have led to marked improvements in cancer survival in Australia. Five-year survival rose from 47% to 66% between the periods of 1982–87 and 2006–10, and several cancers now have survival rates of over 90%.[14] With an ageing population and a median age of diagnosis of new cancer of 67 years, there is a growing number of people requiring long term follow-up and management of the consequences of a cancer diagnosis and treatment. The escalating numbers of cancer survivors places an increasing burden on costly hospital oncology clinics, adding to the growing demand for more cancer services to be delivered in primary care.[8]

Cancer survivorship is increasingly recognised as an important focus for the ongoing care of patients following diagnosis and treatment.[15] Cancer survivors have unique health needs due to the consequences of their diagnosis and treatment. These include late-effects of chemotherapy and radiotherapy such as specific cardiac issues and increased risk of secondary cancers, as well as persistent fatigue, chronic pain, lymphoedema and infertility. Cancer survivors also experience ongoing anxiety, depression and fear of recurrence.[16] Specific cancer treatments may be associated with certain common physical and psychosocial consequences that require multidisciplinary input in their management. For example, prostate cancer survivors may require input from a broad clinical team to manage their incontinence, erectile dysfunction, bone health and cardiovascular risk all arising from the specific treatments for their cancer.

In addition, cancer survivors as part of the ageing population with increased longevity often have comorbidities. Many oncologists continue to monitor their patients for cancer recurrence long after the risk of recurrence has significantly diminished. This hospital-based model of follow-up focuses on detection of recurrence care, failing to attend to the management of other chronic comorbid conditions, many of which will ultimately cause death and morbidity in those who have survived cancer.[17] The multiple needs and comorbidities of these patients are more appropriately dealt with from a generalist perspective.

In recognition of this broader range of clinical needs and the limited capacity within the hospital system to provide long-term follow-up for cancer survivors, new models of care are being developed and evaluated.[18] A range of innovative models of follow-up or ongoing management exist including primary care follow-up, hospital nurse-led follow-up, telephone-based follow-up, patient initiated follow-up (or combinations of these) and various models of shared care.[19]

That primary care is well placed to undertake a significant role in survivorship care, is being recognised internationally: recently developed good practice guidelines have supported an

enhanced role of primary care in cancer management across the continuum of early diagnosis, treatment, follow-up, end-of-life care, and carer support.[20]

Identifying best practice in primary care cancer service delivery

Unlike other chronic conditions there is a relative paucity of research on cancer service delivery in primary care in Australia and abroad. There are significant knowledge gaps across the whole spectrum of primary care cancer service delivery, ranging from screening and timely case-finding, to survivorship through to palliative care. One of the few areas where considerable evidence of impact now exists is the establishment of fast track referral routes and 'Two-Week Wait' cancer diagnostic clinics by the English Department of Health. Allied to this significant policy innovation was the production of National Institute for Health and Clinical Excellence (NICE) Guidelines to help identify patients at higher risk of underlying cancer (based on their symptomatology) who were eligible to be referred to a Two-Week Wait clinic.[21] (Appendix 1) More recently the National Awareness and Early Diagnosis (NAEDI) Initiative in England has begun to develop additional strategies to promote earlier presentation by patients to general practice with symptoms suggestive of cancer and to improve GPs' diagnostic assessment of these patients.

With cancer burden in Australia growing, research priorities are attempting to target cancers and populations with the greatest disease burden. After non-melanoma skin cancers (NMSCs) the most common cancers in Australian men are prostate (19,403 cases in 2007), colorectal (7,804), melanoma (5,980) and lung (5,948). In women the most common cancers are breast (12,567 cases in 2007), colorectal (6,430), melanoma (4,362) and lung (3,755). Colorectal cancer is the most common cancer for men and women combined.[22] Current national priorities for cancer research, based on burden of disease and mortality across the community are in colon and rectum, lung, pancreas, stomach, cancer of unknown primary and lymphoma. Health service and health economic research and the translation of implementation of research are stated priorities for the national cancer research agenda.[23]

The current primary care context in Australia

Current Australian health care reform aims to 'shift the centre of gravity from hospitals to primary health care'[24], and better meet the needs of the community through improving coordination of care between hospitals and primary health care providers.[25] The reforms will increase the focus on prevention and early intervention and improve health literacy. They recognise the central role of general practice in coordinating care and organising additional primary care services identified through individual care planning. As a result of these reforms significant structural and cultural changes are sweeping across the Australian primary and community health care setting: the establishment of Medicare Locals, Lead Clinician Groups and Local Health Districts; the disestablishment of Divisions of General Practice and General Practice NSW, and changes in governmental responsibility for many community care programs.[26] Existing health structures do not fully support primary and community settings to deliver cancer care across the spectrum from prevention and diagnosis through to treatment and palliation.[26] These health care reforms and new service structures and governance create opportunities to develop new models of cancer care and create better synergies between the primary care and hospital systems.

The National Primary Health Care Strategy calls for strengthening the existing framework for prevention and early intervention in primary health care, to encourage more systematic approaches, with regular recall and follow-up, coordinated and integrated with other preventive activities, including a focus on improving health literacy, within local communities.[27] For those improvements to take place significant changes are required in existing health systems, i.e. closer collaboration with specialist care; enhanced GP involvement and understanding of the staging of cancer that will occur after diagnosis; increased support for the role of the GP in follow-up

including practical and psychological support to patient and carer; and an enhanced role of the GP to meet the complex needs of survivors and addressing carer needs.[28]

> *"A better understanding of the role of primary care in cancer management is vital if we are to improve outcomes and quality of life in our cancer patients. We need to know how primary care can contribute to new models of care. At present, there is little evidence on which to base service design and innovation. We need to develop new, genuinely integrated models of care that address important priorities for cancer patients, such as the availability of care close to home, timely management of symptoms, early detection of recurrences, and comprehensive psychosocial support.'*[29]

Unfortunately little has changed since this editorial was published in the Medical Journal of Australia in 2008. Identification of new models of care that address these issues and support their implementation is urgently needed and within the scope of this rapid review.

2 Review questions and scope

The role of primary and community-based healthcare professionals in early detection and follow-up in cancer care: a rapid review of best practice models.

Question 1: Models

What are the current **best practice models** for cancer care that include a role for health professionals in the primary and community setting?

- Early detection including symptomatic diagnosis and screening
- Follow-up care (after completion of treatment).

Question 2: Effectiveness

What is the **evidence** that the models identified in Question 1 are **effective** (i.e. improve cancer-related outcomes) for enhancing or supporting the role for primary and community health professionals in cancer care?

Question 3: Implementation

What are the **key drivers for implementation** of the models (identified in Question 1) with respect to the evidence of effectiveness (analysed in Question 2)? For models that have shown evidence of effectiveness, indicate whether the key drivers of success are different for early detection of cancer and follow-up care.

Question 4: Expert opinion

In consideration of the models identified, effectiveness outcomes, and key drivers for implementation, provide an expert opinion on the best practice application to the NSW setting.

Scope

- Models are as defined by the scope of this review – definitions and limitations of models are discussed within each section of the review
- High incidence cancers: breast, colorectal, prostate, and lung. Include models targeting childhood and adolescent cancer if found and relevant; include studies on remote/rural patients
- Year 2000 to present
- Hierarchy of evidence included:
  - Systematic reviews
  - Randomised controlled trials

  - Observational data if no other data available and where relevant to the type of research question

- Include symptoms as predictors and screening where relevant to primary care Follow-up: defined as post-completion of treatment but excluding palliative care; cancer screening does not include decision-aids
- Follow-up models include shared care models and potentially important components of care, such as patient- held records and survivorship care plans
- Cancer screening relates to the national screening programs for breast, cervical and colorectal cancer; prostate cancer screening is excluded as there is no national program.

3 Search methods

Rapid reviews streamline traditional systematic review methods and apply search limitations to conduct the review in a shortened timeframe.[30] Completeness of searching is determined by time constraints and synthesis of findings in typically narrative and tabular in order to achieve an assessment of what is already known about a topic.[31] We recognise the importance of declaring implications of methods used and potential bias in a rapid review, and address these here and under Review questions and scope. The subject of this rapid review is very broad and the time limitation was a key factor in determining the scope and search strategy. Regular meetings and teleconferences were held for that purpose and to review retrieved articles and reach consensus.

Search strategy

The following databases were searched between 17 and 20 September 2012:

- Medline
- PubMed
- AustHealth
- EMBASE
- Health and Medical Complete
- Scopus
-
- Science Direct.

The Cochrane Library was also searched for all cancer-related reviews.

Searches were limited to articles from 2000–2012. Search terms used were:

- Cancer [& related] and primary health care [& related] and diagnosis
- Cancer [& related] and primary care [& related] and follow-up or survivor.

For searches performed, search terms and MESH headings please see Appendix 2.

Findings were then limited to (1) Systematic reviews (2) Randomised control trials (RCTs) published since the most recent relevant systematic review. We also included relevant papers published after the specific systematic review, including large observational studies if this was the most relevant study design. Relevant policy documents were also reviewed as supplementary background material and to identify additional relevant research. Reference lists of relevant articles were manually checked for additional articles pertinent to the review questions. An additional strategy was the identification of references by the lead expert reviewers. Key papers, background papers and grey literature recommended for inclusion by the expert reviewer were hand searched for additional references. All references were entered into EndNote for reference management.

Inclusion and exclusion criteria/narrowing the scope

The scope of the review was limited to high incidence cancers: breast, colorectal, prostate, and lung. Models targeting childhood and adolescent cancer and studies on remote or rural patients were included where found, however no separate searching was conducted on these populations specifically. Findings on cancer screening and symptoms as predictors of cancer

were included where specific to primary care. Shared care models were included for follow-up. For the purposes of this review follow-up was defined as post-completion of treatment but excluded palliative care.

Study selection

All abstracts retrieved from database searching were first reviewed and vetted for relevance by one member of the review team. The resulting references were collated with references found via manual searching of article citations and additional references identified by the lead reviewers for each section of the review. The final papers were selected for inclusion after review and consensus by the expert team.

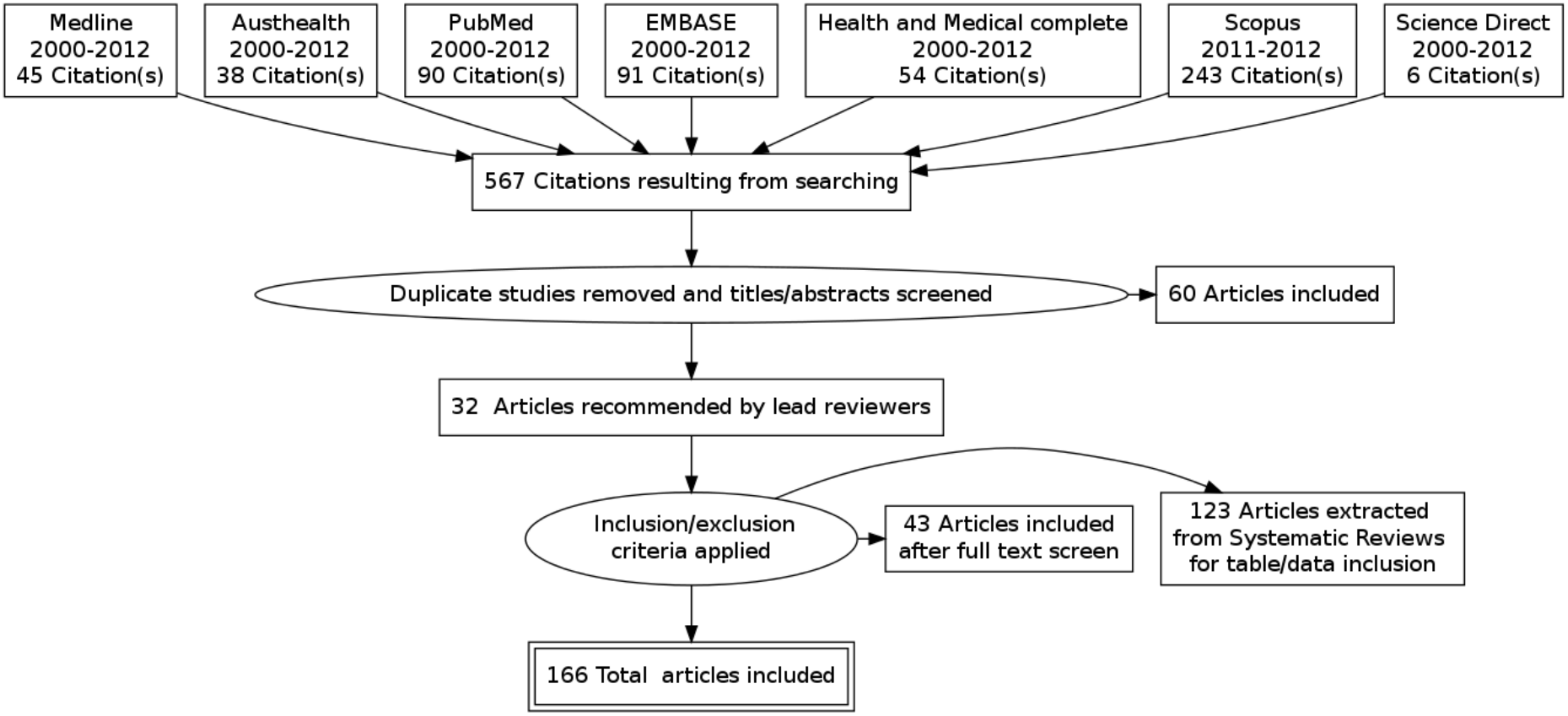
Data extraction and analysis

Systematic reviews were searched for relevant findings and studies within. Evidence pertaining to the review questions was extracted from systematic reviews. All such systematic-reviewed studies are directly referenced. Tables of systematic reviews were copied where that was the best summary of evidence. Studies cited by systematic reviews were referenced or tabulated as presented within the systematic review, and were not reviewed directly due to the time constraints of the rapid review. All tables were reviewed by an expert reviewer who performed evidence interpretation and wrote the expert commentary. The whole team reached consensus on the key recommendations for each section of this rapid review.

Results

A total of 567 articles were identified by searching the literature. Of these, a total of 60 were included after removing duplicate studies and screening titles and abstracts. Thirty-two additional articles were independently identified by the expert reviewers or in the reference lists of relevant articles. Forty-three references (18 systematic reviews and 25 subsequent studies) are included, with an additional 123 references extracted from the systematic reviews, totalling 166 papers for this rapid review. References fall under the following categories: screening, symptoms as predictors, diagnosis models, and follow-up models. Summaries of results from the search strategy are outlined in the PRISMA flowchart below.

Figure 2. PRISMA flowchart: Search strategy & results (generated by theta collaborative PRIMSA flow diagram generator[32])



Cancer screening

A total of five systematic reviews with 30 studies extracted from within, and eight subsequent RCTs were included in the review (see Appendix 3). Most studies examined the effect of interventions either on cancer screening participation rates or changes to primary care systems associated with uptake of screening tests. No studies reported on cancer incidence or stage at diagnosis as outcomes. Interventions targeting the delivery of screening for breast, cervical, and colorectal cancer were included.

Symptoms as predictors of underlying cancer

A total of four systematic reviews with 43 studies extracted from within, and five subsequent studies were included in this section of the review (see Appendix 4). Some of the systematic reviews included studies in which participants were recruited from hospital clinics (not primary care), which will tend to overestimate the positive predictive value of specific symptoms due to the higher prevalence of cancer in the referred populations.

Models of care to improve cancer diagnosis

A total of three systematic reviews with seven studies extracted from within, and two subsequent studies were included in the review (see Appendix 5). Two systematic reviews reported observational studies of fast- track referral routes, predominantly from the English Two-Week Wait referral system. We also included a large national audit of cancer referrals from England that was published after these systematic reviews. A separate systematic review reported studies of interventions delivered in primary care to reduce delay in cancer referral.

Follow-up

A total of six systematic reviews with 66 studies extracted from within, and five subsequent studies were included in the review (see Appendix 6). These systematic reviews covered various specific questions: (i) Alternative primary care based models of follow-up (ii) Patient and professional attitudes towards cancer follow-up (iii) Uptake of primary care services by long-term cancer survivors (iv) Patient held records in cancer follow-up, and (v) Interventions to improve continuity of care for cancer survivors. We also included a trial of survivorship care plans published since these systematic reviews and papers relating to an intervention to improve rural cancer care.

Limitation of rapid review methods

The limits enforced by the rapid review process mean we have limited our review to published systematic reviews and randomised controlled trials where they existed, in addition to other large observational studies published since the systematic reviews. The expert reviewers have significant content expertise and guided the review to capture key evidence in this area. However, this is a broad and large topic and the results may not include all available relevant evidence. We have not been able to review all the individual papers in detail and have relied on the evidence summaries published within the systematic reviews. Studies additional to Cochrane reviews in this rapid review have not been assessed in detail for quality.

4 Early detection of cancer

Screening

What are the current best practice models for cancer care that include a role for health professionals in the primary and community setting? What is the evidence that the models are effective?

This section will discuss the evidence relating to current models involving primary care in the delivery of screening for breast, cervical and colorectal cancer. We base our discussion predominantly on the findings of five systematic reviews (Ellis 2003[33], Bonfill 2001[34], Sabatino 2008[35], Everett 2011[36] and Arroyave 2011[37]) in addition to some subsequent relevant RCTs relating to colorectal cancer screening. Of note, the Ellis review included 41 systematic reviews relating to the broader subject of approaches to disseminate five cancer control interventions including breast and cervical cancer screening.[33] We extracted data relevant to the research questions of this rapid review. While there is significant literature in this area, most studies have examined the effect of interventions either on cancer screening participation rates or changes to primary care systems associated with uptake of cancer screening tests. No studies report on outcomes such as cancer incidence or stage at diagnosis.

Most reviews have examined several strategies aimed at altering either physician recommendation for ordering cancer screening tests, or of primary care level interventions that improve patient uptake of tests. These include: audit and feedback, office prompt systems, physician education and training, academic detailing, organisational change initiatives and financial incentives. The effect of GP involvement in the initial invitation to have a cancer screening test has also been examined in several trials. The effectiveness of these interventions are summarised across cancer screening for breast, cervical and colorectal cancer. While there are some differences between the results of studies within and between cancers there is sufficient commonality of findings across the three cancers to be able to summarise by type of intervention.

Audit and feedback

This approach summarises data on a clinician's or practice's performance in offering cancer screening and presents this information back to the clinician, sometimes with comparative data or against a given standard. The Sabatino systematic review identified ten studies examining this approach to increase screening for breast, cervical or colorectal cancer, of which eight were included.[35] All studies found a positive effect on screening participation rates with a median increase across tests of 13% (median increase respectively: breast 14%, cervical 9% and colorectal 13%).

Office system prompts

Office system prompts include various systems aimed at reminding the clinician to discuss or order a cancer screening test when the patient presents. Earlier studies examined paper-based reminders attached to medical records; more recent studies have examined computer- reminder systems. Many systematic reviews that examine the effectiveness of this approach have found generally positive outcomes in terms of increased screening participation, particularly in breast and cervical cancer where there is more evidence.[33] Snell and Buck examined the effect of office system prompts across all cancer screening tests (pap, mammography and faecal occult blood tests (FOBT)).[38] They found an average effect size of 0.17 across trials. Shea et al.'s systematic review of computer-based reminder systems showed a statistically significant increase in mammography participation but not for pap tests (Odds Ratio (OR) 1.88, 95% Confidence

Interval (CI) 1.44–2.45 for mammography; OR 1.15 95% CI 0.89–1.49 for cervical screening).[39] Positive effects of computer reminders were seen in separate systematic reviews by Balas (increase in screening participation: 11.5% mammography, 18.5% pap tests[40]) and Kupet et al. (increase in screening participation: 24% mammography, 23% pap tests[41]). It can be reasonably concluded that this is an effective strategy to increase uptake of cancer screening tests in primary care, although it should be noted that baseline rates of screening participation were relatively low in some of the systematic reviews.

Physician education and training and academic detailing

Several systematic reviews and individual studies have examined the effect of a range of educational approaches including workshops and academic detailing on physician ordering of cancer screening tests and patient participation. However, they have often been part of a strategy to disseminate other interventions that also increase participation including office prompt systems and patient reminders. It is therefore difficult to disentangle the effectiveness of each component of the intervention. Jepson conducted a systematic review of trials evaluating the effect of educational sessions, printed materials and educational outreach visits to primary care providers on mammography screening.[42] This review found a small increase in mammography uptake across the four trials. A systematic review by Shekelle found an overall positive effect of provider education on mammography screening (OR 2.26 95% CI 1.81–2.82) and cervical cancer screening (OR 1.59 95% CI 1.29–1.97).[43]

Kinsinger et al. conducted a cluster RCT in the USA of academic detailing visits that aimed to implement office systems to increase breast screening.[44] While this found significant changes in some process measures, there were no differences in reported mammography rates based on medical record audit; only seven of 32 practices reported having a complete office system for breast screening at the end of the trial.

Lemelin et al. conducted a similar cluster RCT of academic detailing visits to primary care practices in Canada.[45] Intervention practices implemented reminder systems, used patient educational materials and implemented a customised patient flow sheet. There was a significant difference at follow-up in a measure of preventive performance but no overall difference in mammography or pap screening participation.

Dietrich et al. performed a cluster RCT in the USA that compared, in a factorial design, the effect of an educational workshop or an educational facilitator in the practice.[46] All three intervention groups showed significantly higher rates of mammography uptake at 12 months (facilitator plus workshop vs. controls 0.78 vs. 0.57, $p<0.01$; facilitator only vs. controls 0.77 vs. 0.57, $p<0.01$; workshop only vs. controls 0.71 vs. 0.57, $p<0.01$), but not of pap tests (facilitator plus workshop vs. controls 0.65 vs. 0.61; facilitator only vs. controls: 0.71 vs. 0.61; workshop only vs. controls 0.63 vs. 0.61).

Other organisational change interventions

Arroyave reported a systematic review of organisational change strategies aimed at increasing breast, cervical and colorectal cancer screening in primary care.[37] They identified 11 relevant trials, some of which have already been discussed in the context of reminder systems, audit and feedback and change processes following academic detailing visits. There were other alternative organisational change processes worth describing in more detail that were included in this systematic review. Three RCTs examined the role of non-physician staff in supporting the delivery of cancer prevention within a primary care practice (Herman 1995[47], Mohler 1995[48], Binstock 1997[49]). These staff played a variety of important roles in improving cancer screening, including organising clinician and patient reminders, patient education, scheduling mammography appointments and general administrative support. All three trials showed reasonably large increases in screening participation (increased mammography 18–32%[47,48]; pap smears 18%). Two trials tested new service models aimed at increasing cancer screening. Williams

et al. introduced a planned preventive care consultation linked to a patient-initiated computer screening tool to identify cancer screening requirements.[50] They found significant increases in mammography screening but not in pap or FOBT screening. Belcher tested the establishment of a 'health prevention clinic' on subsequent cancer screening.[51] This showed an increase in FOBT uptake of 47% after five years, the largest effect on cancer screening uptake seen in any trial identified in the systematic reviews for this rapid review. Atlas et al. trialled a population-based informatics system that identified women who were due mammography and provided feedback to individual practitioners.[52] Doctors could then send an automated reminder letter to their patients with a mammography referral. This intervention led to a significant increase in mammography rates at one year (31.4% vs. 23.3% p<0.001).

Financial incentives

The effect of financial incentives on cancer screening in primary care is surprisingly under-researched. This is of note given that the Medicare Practice Incentives Program (PIP) uses financial incentives as a strategy to increase cervical screening rates in general practice. In their systematic review Sabatino identified only three studies that examined the effect of some form of financial incentive on cancer screening recommendations by healthcare providers.[35] This review found insufficient evidence to determine the effectiveness of financial incentives. A Scottish study examined the effect of introducing remuneration on the basis of reaching a defined target for pap screening and showed a significant 8% increase in screening at six months.[53] Hillman tested a similar target bonus scheme for mammography, pap and FOBT screening in several US primary care practices.[54] They found no effect of the incentive scheme after 18 months compared to practices not offered the incentives. The third study also conducted in the US compared an incentive plus feedback and reminder intervention with practices just receiving feedback and reminders, and found no difference in mammography ordering between groups.[55]

Primary care involvement in screening invitation process

There have been many studies examining approaches to improve the uptake of cancer screening based on the initial invitation process and potential involvement of primary care. Two Cochrane reviews have summarised the literature on strategies to increase participation in breast and cervical screening respectively.[34,36] Tables 3.5 and 3.6 in Appendix 3 present summaries of relevant trials from these Cochrane reviews that specifically relate to primary care involvement in the screening invitation process and studies of primary care involvement in colorectal screening.

Several studies have examined the effect of the letter of invitation, either the initial or just reminder letter coming from the GP. This has been compared with invitation from the screening organisation, a community health clinic or no specific invitation. While a few trials have had negative results (e.g. in mammography[48,56] and for pap smears[57] there is reasonably strong evidence across all three cancer screening tests that a letter of endorsement by the GP improves subsequent participation rates.[58-66]

A lot of this research, particularly for cervical and colorectal screening, has been conducted in Australia making it more directly applicable. Irwig et al. compared a follow-up letter of invitation for mammography from a GP with or without a specific appointment date, with no letter in 440 women in Sydney. Both GP-based interventions increased mammography attendance (OR 4.10 95% CI 2.57–6.54).[59] Sanson-Fisher et al. have conducted several trials relating to pap smear screening in NSW. Their initial trial compared two GP strategies within the consultation: one in which the GP reminded the woman that she was due a pap, the second in which the GP also explored barriers for non-participation.[61] A later trial of 7000 women compared GP reminder letter vs. women's health clinic letter found no significant difference in uptake (Relative Risk (RR) 1.69 95% CI 0.75–3.83).[57] A third trial compared the effects of a TV media campaign, a media plus invitation letter and TV media plus a GP intervention to increased pap participation in three regions of NSW.[67] The media campaign alone increased participation in one region by 13.3%; the media plus letter increased participation in two regions by 52.7% and 43.2% respectively; the

media plus GP intervention increased participation in all three regions by 50.2% in the rural locality, 80.8% in the country town and 15.7% in the rural centre.

Young et al. have conducted several trials in South Australia testing strategies to increase participation in colorectal cancer screening. They have compared standard invitation against: (i) An invitation letter indicating endorsement of the screening test by the general practice or (ii) An invitation letter on practice letterhead, signed by their GP.[64,66] Both these GP invitations led to significantly higher participation rates at initial invitation (32.0% vs. 38.0% and 40.7%). A subsequent longitudinal analysis demonstrated that these approaches were also associated with higher re-participation rates.[66]

Key drivers of implementation and expert opinion

It is clear that primary care can play an important role in improving the uptake of cancer screening tests for breast, cervical and colorectal cancer. We have deliberately avoided entering the debate about informed decision making/informed choice in cancer screening, which may result in lower participation rates[68] compared with the public health perspective that national cancer screening programs should aim to maximise uptake. The scope of this review was to recommend strategies that increase screening uptake and this should be taken into account when reading the following recommendations. The authors of this review note that international policy in screening, particularly in North America and Europe has moved to considering cancer screening in the context of informed participation rather than on screening uptake alone. We have not examined the literature about the role of decision aids in cancer screening and their use in primary care. This is an important but separate issue that is beyond the scope of this rapid review.

Cancer screening uptake can be improved by a range of practice level interventions including audit and feedback and office system prompts. These may be incorporated as part of a wider organisational change process within a practice to improve their cancer screening systems. Support for these changes is vital but can be provided through academic detailing visits.

GP endorsement of invitation letters or reminders for cancer screening tests is another important strategy to increase participation rates. The current national cancer screening programs in Australia operate with varying degrees of involvement of primary care. The National Cervical Screening Program operates recall and reminder systems through state registries but the program relies on general practice to actually perform the screening test. Many general practices also operate their own pap recall system, perhaps partly related to the current PIP incentive scheme. Two year participation rates in the National Cervical Screening Program in Australia are 61.2% in the target group in 2007–2008.[69] BreastScreen Australia functions almost independently of general practice, organising invitations, recalls and reminders and follow-up of abnormal tests. BreastScreen will write to the GP if a patient fails to respond to an invitation, but only if the woman has previously nominated a GP to receive the results of their screening test. Most recent data show a national participation rate in BreastScreen of 54.9% in the target group in 2007–2008. The National Bowel Cancer Screening Program is organised slightly differently again. The invitation process is organised by the state registries with no GP involvement or endorsement. Participants are invited to nominate a GP to receive the results of their bowel screening test and GPs are expected to follow-up positive results as part of routine clinical care. Participation rates in the National Bowel Cancer Screening Program are currently approximately 38%. It is worth comparing these figures with the bowel cancer screening program in Ontario, Canada where there is much greater involvement of primary care in the ordering of screening tests and initial risk assessment. Most recent figures show a participation rate of 53% of the eligible population.[70]

There are various barriers to implementing the evidence on how primary care can contribute to cancer screening programs. As described, the Australian national programs are currently

designed with varying degrees of engagement with primary care, but all miss the opportunity to translate the evidence about GP endorsement within the invitation letter. Incorporating reminders or pre-invitation letters from GPs would endorse the invitation that patients receive from the screening program, particularly for breast and colorectal screening. This of course assumes that there is shared information between the screening program and general practices about which practice a patient usually attends. Only approximately 50% of participants in the National Bowel Cancer Screening Program reply to the question asking them to nominate a GP to receive their result. While there is no current model of patient enrolment with a general practice in Australia, a majority of patients will tend to visit a particular practice regularly, thereby creating a quasi-patient register. This is the basis on which practices organise their pap recall and other chronic disease systems and could be used to support GP endorsement of cancer screening invitations.

General practices play an important role in opportunistic endorsement of cancer screening, aided in no small part by office system prompts. A patient attending for another reason may be flagged by the office system prompt that they are due a particular screening test. This can then be discussed as part of the consultation resulting in subsequent uptake of the test. A significant barrier to this process in Australia is the variable functionality of general practice clinical software, and also variable use by practices of software functionality. Some software systems enable office system prompts as well as automated recall systems, others do not. Similarly, not all practices would be aware of or use these functions. The Royal Australian College of General Practitioners has developed a tool, the *Primary Care Sidebar*, as an approach to implementing the Red Book of preventive activities including cancer screening. The tool is designed to identify which screening and preventive activities a particular patient is due and prompt the GP to discuss them. No data have been published yet about use of this tool or its effect on screening activities but this general approach is worthy of further consideration as a method of engaging GPs in discussing cancer screening tests. However, this should be considered as only one element of organisational change aimed at increasing practice involvement in cancer screening. Other key components include audit and feedback of screening uptake in the practice population and recall and reminder systems. While the evidence is limited, alternative strategies that involve non-medical staff and the establishment of cancer prevention clinics could also form part of an organisational change at a practice level. To achieve this degree of change probably requires ongoing input through academic detailing, potentially with financial incentives to justify such change. The workload implications of this degree of organisational change, and the underlying business models to make this attractive to general practice, must be taken into account. The potential role of Medicare Locals in working with practices, especially in areas of relatively poor cancer screening uptake, to provide this type of academic detailing and practice support should be considered further. We recommend that the Cancer Institute NSW work with Medicare Locals in NSW to develop a program implementing organisational change in partnership with local practices to increase cancer screening uptake and informed participation. The types of organisational change to increase cancer screening uptake in primary care include: GP endorsement letters, recall and reminder systems, feedback on screening uptake, involvement of non-medical staff and cancer prevention clinics. We also recommend that the Cancer Institute NSW consider developing a policy that focuses on informed participation in cancer screening in line with international policy in screening, and that a review of the evidence on decision aids in cancer screening would help inform strategies to increase informed participation.

Recommendations:

- The Cancer Institute NSW works with Medicare Locals in NSW to develop a program to implement organisational change in partnership with local practices to increase cancer screening uptake and informed participation
    - Organisational changes shown to increase cancer screening uptake in primary care include: GP endorsement letters, recall and reminder systems, feedback on screening uptake, and cancer prevention clinics
    - Involvement of non-medical staff including organising patient and clinician reminders, patient education, scheduling screening appointments and general administrative support are core elements of this organisational change
- The Cancer Institute NSW considers commissioning a review of the evidence on decision aids in cancer screening to help inform strategies to increase informed participation, and develop a policy incorporating informed participation in cancer screening, which would align it with the emerging international perspective.

Early detection of symptomatic cancer

What are the current best practice models for early cancer diagnosis which include a role for health professionals in the primary and community setting?

What is the evidence that the models are effective (i.e. improve cancer-related outcomes)?

In responding to these questions, this section on symptomatic diagnosis of cancer in primary care will cover the following areas:

1. The evidence on symptoms as predictors of cancer risk in primary care populations
2. The evidence of interventions aimed at primary care or at the primary/secondary care interface on cancer diagnosis.

How well do symptoms predict cancer in primary care?

Appendix 5 summarises the findings of four systematic reviews and a number of subsequent studies that have attempted to estimate how well symptom profiles predict the likelihood of an underlying cancer. Shapley aimed to identify symptoms in primary care that have a positive predictive value (PPV) of more than 5%, a figure arbitrarily determined as sufficient to warrant further investigation by a GP.[71] An important point to note is that some of the studies included in some of the systematic reviews about colorectal cancer were conducted on referred populations, rather than people presenting in primary care. This will tend to overestimate the PPV of a symptom and probably accounts for the differences in findings between reviews. The systematic reviews had slightly different inclusion criteria and therefore there was some overlap between included studies between these systematic reviews. Some were more specific in terms of only including studies that recruited primary care populations, and are therefore potentially more relevant to the focus of this rapid review.

Breast cancer

We identified one paper reporting a study from primary care on symptoms as predictors of breast cancer risk.[72] They present a clinical prediction rule with adjusted odds ratios (AOR), as opposed to predictive values that have more direct clinical utility. The AORs for the following symptoms were: discrete lump (AOR 15.20, 95% CI=4.88 to 47.34), breast thickening (AOR 7.64, 95% CI=2.23 to 26.11), lymphadenopathy (AOR 3.63, 95% CI=1.33 to 9.92), and lump ≥2 cm (AOR 5.41, 95% CI=2.36 to 12.38). Three papers included in the Shapley systematic review all found that breast lump was the only symptom with a PPV of more than 5%.[73-75]

Colorectal cancer

There have been three separate systematic reviews examining symptoms as predictors of colorectal cancer, which are summarised in Tables 4.3 through 4.10 in Appendix 4. These papers confirm that single symptoms, such as rectal bleeding, are not strongly predictive of colorectal cancer with a pooled estimated PPV of 8.1% in people over 50 years old.[76] A second systematic review examined the effect of additional symptoms in the presence of rectal bleeding.[77] The presence of anaemia increased the PPV to 21.6% and weight loss to 13%. Therefore, even classical 'red flag' symptoms in patients in primary care are by no means diagnostic of colorectal cancer.

Since these systematic reviews were published Hippisley-Cox has published a diagnostic algorithm for colorectal cancer risk that incorporates baseline characteristics (e.g. age, gender, BMI, family history) with current symptoms (the QCancer colorectal model).[78] The model was developed and validated using data from 566 UK general practices including 4798 incident cases of colorectal cancer. The model showed good discrimination: the area under the curve (AUC) was 0.89 and 0.91 for females and males respectively; 10% of patients with the highest predicted risks contained 71% of all cases. This model has been separately validated in a different British general practice dataset that confirmed the validity of the QCancer colorectal model.[79]

Lung cancer

There are fewer studies examining symptoms as predictors of lung cancer. Hamilton's CAPER studies used a different general practice database to Hippisley-Cox to examine the risk of cancer associated with single and pairs of symptoms and clinical signs. He showed that as a single symptom haemoptysis had the highest PPV, but this was only 2.4%.[80] Haemoptysis in combination with weight loss had a PPV of 9.2%. The Jones study stratified symptoms by age and this showed that haemoptysis in people aged over 55 years had a PPV greater than 8%.[81] Hippisley-Cox has published a QCancer lung model that incorporates symptoms with baseline risk factors (age, smoking history, chronic obstructive pulmonary disease, deprivation, BMI).[82] In the validation cohort the risk model had an AUC of 0.92; the 10% of patients in the highest risk stratum accounted for 77% of all lung cancers. A separate validation study of this model has not yet been published.

Prostate cancer

Shapley only identified two relevant papers in their systematic review relating to prostate cancer. Bruyninckx showed that macroscopic haematuria in men over 60 years had a PPV of 22.1% but this was for all urological cancers, including prostate cancer.[83] The CAPER prostate cancer study showed that haematuria had a PPV of 1% specifically for prostate cancer.[80] The strongest single predictor was a malignant rectal examination (PPV=12%); weight loss and nocturia in combination had a PPV of 12%. A QCancer model has not yet been published for prostate cancer.

Hippisley-Cox et al. have also developed separate QCancer risk models for men and women that estimate risks of different cancers according to baseline risk factors and patterns of symptoms. These have not yet been published, but we understand are in press, and so could not be included in this review. However, they have the obvious strength that they acknowledge that

patients present with symptoms and that common symptoms are associated with more than one cancer. These models potentially have good clinical utility.

Models of care to improve diagnosis of cancer in primary care

As discussed already, the most significant model of care applied at a national level was the introduction of fast track cancer referral pathways (The Two-Week Wait Referral system - 2WWR) in England. A patient with symptoms who met the criteria in these guidelines was deemed eligible for fast track referral and hospital services were established to ensure such patients were assessed within two weeks of receipt of the faxed referral. These referral pathways were linked to the NICE Referral guidelines for suspected cancer[21], (Appendix 1) although when the NICE guidelines were published the evidence base relating to symptoms as predictors of cancer risk in primary care was much weaker than now, and much of the guidance was based on expert opinion. These guidelines are currently being revised and are expected to be published in 2013.

Following the introduction of the 2WWR system there have been many audits of cancer diagnostic pathways to assess the impact of this new model of care. There are some important metrics of the quality of GP referrals for cancer diagnosis and the effect of the 2WWR system:

1. The conversion rate – the proportion of 2WW referrals that result in a cancer diagnosis (i.e. the PPV of a referral)
2. The detection rate – the proportion of cancers that are referred via the 2WW referral pathway (i.e. the sensitivity of a referral)
3. The referral ratio – the indirectly standardised number of 2WW referrals relative to the GP patient population size.

Lewis et al. published a systematic review of audits of cancer referrals and the effectiveness of the 2WW initiatives, summarised in Appendix 5 (Tables 5.1 and 5.2).[84] We present just those results available relating to breast, lung, lower GI and childhood cancers. Of note is the considerable variation in findings between individual audits. Cancer detection rates varied significantly with some as low as 0% (lung and lower GI) and 4% (breast cancer) to as high as 83% for breast cancer and 57% for lung cancer. Similarly, conversion rates varied between hospital audits and tumour site with some reporting very low rates for all cancers (0–5%) but others as high as 75% for lung and 34% for breast cancer. In most audits there was reasonably high conformity of GP referrals with the 2WW guidelines, suggesting that GPs did in fact follow them when determining who to refer along the fast track route (Table 5.2). Relatively few of these referrals along the 2WW route were deemed clinically inappropriate by the hospital clinician. With the exception of one audit for lower GI cancers, the symptoms recorded at the first hospital appointment were generally consistent with those stated by the GP, suggesting that GPs again used the route appropriately.

Thorne et al. subsequently published a systematic review of audits to 2WW referrals for colorectal cancer.[85] A meta-analysis of the audits estimated a summary conversion rate of 2WW referrals of 10.3% and a detection rate of 24% via the 2WW route. More than 50% of colorectal cases were referred through alternative outpatient services and 24% were referred as emergency admissions.

A national audit of 2WW referrals made in 2009 was reported recently, providing data on 865,494 referrals and 224,984 cancers.[86] This demonstrated an overall conversion rate of 11% and a detection rate of 43%. There was significant inter-practice variation and important correlations between the three metrics relating to referral efficiency. Practices with higher 2WW referral ratios tend to have lower conversion rates but higher detection rates, but practices with higher

conversion rates also have higher detection rates. Practices with high conversion and detection rates (14% and 50% respectively) represent good clinical practice in that they are using the 2WW route efficiently but also diagnosing cancers through that route rather than through slower diagnostic routes or via emergency admissions. Practices with low conversion and detection rates (4% and 17% respectively) are inefficient users of the 2WW route but also fail to identify patients with cancer who would benefit from rapid access to diagnostics.

We identified two other papers relating to fast track referral routes from other countries. Scotland produced its own referral guidelines for cancer[9] and urgent referral routes for patients meeting these criteria. Baughan et al. reported an audit of 18,775 urgent suspected cancer referrals made from 516 general practices in Scotland.[87] This also demonstrated significant variation between practices and tumours. The overall conversion rate was 18.3% but varied by cancer: breast (16.3%), prostate (52.6%), lung (39.7%) and colorectal (12.8%). GPs used the guidelines appropriately with more than 90% compliance. Importantly, there were a significant number of cancers referred that did not meet the criteria for urgent referral (lung 8.8%, colorectal 8.4% and breast 6.4%). Catalonia, Spain also introduced a fast track referral system to reduce diagnostic delay for breast, colorectal and lung cancer.[88] This led to an overall detection rate of approximately 50% and a mean time from general practice to treatment commencement of 32, 30 and 37 days for breast, colorectal and lung cancer respectively.

General practice level interventions to reduce diagnostic delay in primary care

Mansell et al. recently published a systematic review of studies of interventions delivered in primary care that aimed to reduce diagnostic delay of cancer.[89] The review specifically excluded cancer screening and 2WW referral systems. They identified 22 papers reporting studies from several countries including Australia, the UK, USA and the Netherlands. Interventions that were tested included audit and feedback, electronic or paper decision support, guidelines and educational visits. The individual studies relevant to cancers in this rapid review are summarised in Appendix 5 Table 5.5. None of the studies was designed specifically to measure the outcome defined by the review authors as most important: diagnostic delay in primary care. There was some evidence to suggest potentially positive effects on clinical management of audit and feedback linked to management guidelines (e.g. Cockburn et al.[90]). The few trials of decision support systems had mixed results. Jiwa et al. tested an electronic referral letter pro forma to improve the quality of referrals of people with suspected colorectal cancer.[91] They found no positive effect of this intervention, nor of an educational outreach visit on appropriateness of referrals. Logan et al. tested an intervention in which guidance on investigation of iron deficiency was sent as part of an abnormal pathology report; this had no effect on subsequent referrals.[92] A Dutch trial of a distance learning intervention that included guidelines and a decision tree relating to the assessment of lower urinary tract symptoms and prostate-specific antigen (PSA) testing found a reduction in urology referrals and increase in PSA testing.[93] One study explored the implementation of the CAPER risk score using a paper format for assessment of patients with symptoms suggestive of colorectal cancer.[94] They found limited uptake of the tool and only 55% of CAPER scores correctly calculated.

It is worth noting related work in progress in Australia and the UK. The Improving Rural Cancer Outcomes trial is currently in its recruitment phase and is due to report in 2015 (NMHRC Partnership grant 572765, PIs Holman and Emery). It is testing, in a factorial 2x2 design, a community level intervention aimed at raising awareness of cancer symptoms, and a GP level intervention. The practice intervention is an information resource relating to the four most common cancers, which includes: the CAPER scores for lung, colorectal and prostate cancer, the National Breast and Ovarian Cancer Centre breast cancer diagnostic algorithm, and information about referral routes. Its primary outcome is the total diagnostic interval. In England the CAPER lung and colorectal scores were distributed on computer mouse mats to all general practices as part of the NAEDI program; the same CAPER scores are currently being incorporated into a number of different general practice computing systems as an alternative implementation strategy. Similar approaches are in progress to incorporate the QCancer algorithms into general

practice computing systems in England. Following the Royal College of General Practitioners National Audit of Cancer Diagnosis, a pilot project is under way offering English general practices 'Significant Event Analysis' of recent cancer diagnoses as an approach to audit and feedback.

Key drivers of implementation and expert opinion

Diagnosing cancer in a low prevalence population such as primary care is not easy because the evidence is clear that even so-called 'red flag' symptoms are not strong predictors of cancer risk. However, the development of more sophisticated approaches to combining symptoms and underlying risk factors to provide reasonably valid estimates of risk of an underlying cancer shows significant promise. The Hamilton CAPER scores provide useful information on the PPVs of single and pairs of symptoms and signs and the associated risk assessment charts have potential clinical utility for general practice. However, it should be noted that the only paper reporting their use to date showed limited uptake[94] but further evidence on the use of CAPER scores is currently being acquired in England and Australia. The QCancer scores provide an alternative and perhaps even more sophisticated method to assess risk of cancer given that they account for baseline risk factors as well as current symptoms. They currently cover a narrower range of cancers but more are in development including gender-specific calculators for multiple cancers. The challenge for both these cancer risk assessment tools is not their validity but how to get them used in general practice, particularly in the context of a consultation with a patient present who may be worried about a diagnosis of cancer. Further evidence is required to examine the effect of electronic prompts to use these risk tools, for example by linking them to symptom codes within the GP clinical computing systems. As described this is currently in progress in England through the Informatica Systems platform to implement the CAPER and QCancer risk tools into several GP systems. In Australia further work is required to examine the potential to develop similar electronic prompt systems that integrate with Australian general practice computing software. An alternative approach with the QCancer system, which is suggested in the associated publications, is to use it as an audit tool to identify a population of patients who have consulted recently and who are at high risk of having an underlying cancer. Further research is required to examine the feasibility of this approach to improve the identification of patients with cancer in primary care who have not yet been investigated.

The NICE guidelines for urgent cancer referral are currently being revised in the light of the significant amount of new evidence on symptoms as predictors of cancer. These will undoubtedly be used to inform the current 2WW referral systems in England. Audits of referral to 2WW clinics found these guidelines were mostly adhered to but even so the conversion rates are only 20–30% from the best performing practices[86], although some individual audits found higher rates for some cancers.[84] The detection rates from the best performing practices was only 50%[86] although again some individual audits found higher rates for some cancers. There are some important conclusions to be drawn from this evidence:

1. Fast track referral routes will only ever detect a moderate proportion of cancers because symptoms are a poor predictor of cancer and some patients with cancer will present with subtle symptoms that do not meet criteria for urgent referral. However, they may still be a useful approach to reducing diagnostic delay for a large number of cases in systems that have long waiting times for outpatient diagnostic services. This may well be the case in the public hospital system in Australia
2. GPs complied with the 2WW guidelines surprisingly well, in contrast to much evidence about the use of clinical guidelines by GPs. There are probably several reasons for this: there was a significant and sustained communications and implementation strategy for the 2WW system that included enforced referral pro formas to access the clinics. Furthermore, the establishment of the 2WW system provided a significant advantage to GPs to ensure that patients about whom they had clinical suspicion were able to be seen

much sooner than in the current health system. Consequently, they were likely to use it and comply with the guidelines

3. There is significant variation between general practices in how they use fast track referral routes. The causes of such variation and how to reduce such variation have not been adequately studied.

Would such a system function in Australia? In Western Australia the Cancer and Palliative Care Network has developed models of care for many common cancers that include guidance about cancer symptoms, referral and suggested timeframes in which a patient should see a specialist.[95] We found no published data on the effectiveness of these models of care. However, it should be noted that these models of care have not been implemented in the same way as the English 2WW model. There has been no significant or sustained communications, nor an implementation strategy and the level of awareness and use of them remains low in general practice. Nor were hospital systems established to create clear fast track routes of referral for patients with suspected cancer.

The Australian health care system is significantly more complex than the English National Health Service (NHS). In the latter there is a small private healthcare sector and the vast majority of patients are managed entirely within the public hospital system. The 2WW clinics are part of the public hospital system and GPs access the fast track referral route relevant to their local public hospital. In Australia patients are not all referred to a public hospital; many are managed entirely in the private hospital system and some traverse both systems. For example, in 2010–11 only 31% of all hospital separations for prostate cancer occurred in public hospitals.[96] A large proportion of patients will be referred initially to a specialist working in private rooms, which will be partially funded through Medicare. In some cities in Australia there may be relatively good access for patients who can afford to see a specialist in their private rooms and so for these patients creating fast track referral routes may be of limited benefit. However, for patients managed entirely in the public hospital system in Australia, fast track referral routes could potentially be of some benefit. The development of such routes could be informed by the new guidance being developed by NICE on symptoms as predictors of cancer. However, this would require significant investment in implementation in both hospital systems and primary care. This might be supplemented by additional strategies in primary care to improve cancer diagnostic performance and conversion and detection rates, for example through implementing the QCancer tools.

This leads us to a series of key recommendations about service development and future research:

Recommendations:

- The Cancer Institute NSW considers supporting research into the effect of risk assessment models such as QCancer and CAPER on cancer diagnosis and treatment outcomes in the Australian context.
    - The Cancer Institute NSW to consider exploring with medical software providers and the Royal Australian College of General Practitioners approaches to implementing cancer risk assessment models into general practice clinical software as part of this research program.
- The Cancer Institute NSW works with Medicare Locals and Local Hospital Networks to define clear referral routes for patients with a high suspicion of cancer. Informed by the revised NICE Guidelines or by the QCancer or CAPER risk models, they could consider a phased establishment of fast track referral routes within the public health system, commencing with colorectal and lung cancer.
    - Fast track referral routes require significant ongoing investment to be effectively implemented: GPs need to perceive these routes as offering a significant advantage and need to receive multiple, repeated information about these diagnostic routes. Again, this would require close liaison with Medicare Locals to develop a program of information and education about these cancer diagnostic routes.
- Data collection processes are required to enable large scale audits of current and future referral pathways of patients with suspected cancer to allow calculation of conversion and detection rates and measure the impact of new diagnostic initiatives.

5 Follow-up

Questions 1 & 2: What are the current best practice models for cancer care which include a role for health professionals in the primary and community setting? And what is the evidence that the models are effective (i.e. improve cancer-related outcomes) for enhancing or supporting the role for primary and community health professionals in cancer care?

We identified six systematic reviews and two additional RCTs that provide evidence for models of follow-up care for cancer involving health professionals in the primary and community setting. The relevant individual studies from these systematic reviews were extracted (Appendix 6) and we report against the identified models of care: (1) Early survivorship – primary care-led and shared care (2) Longer-term survivorship. In addition to these models specific components of follow-up care that have been evaluated within a range of models include patient held records, survivorship care plans. One of the systematic reviews summarised patient and clinician attitudes to various models of follow-up care and these results are included in the response to Questions Three and Four as potential drivers for implementation.

a. Early survivorship period

Primary care-led vs. hospital-led care

Models of follow-up care reported under this section are those in which the patients' cancer follow-up is driven mainly by a primary care professional. Our work has identified five published RCTs and two ongoing RCT's of primary-led follow-up care compared against hospital-based follow-up.

A systematic review by Montgomery[97] aimed to investigate models of follow-up for breast cancer patients. Of the seven RCTs included in this systematic review, two of the studies evaluated models of follow-up for breast cancer that compared primary care-led versus hospital-led care.[98,99]

Grunfeld[98] conducted an 18-month randomised controlled trial of follow-up in general practice vs. hospital. Two hundred and ninety-six operable breast cancer patients, free of metastatic disease, attended routine follow-up either through their GP or through hospital specialist clinics. A 'discharge' letter was sent by the hospital consultant to the GP about each patient discharged to general practice care. It outlined the patient's breast cancer history, described the follow-up routine recommended and assured the GP that rapid re-referral was possible if any problems developed. The letter was accompanied by an educational handbook on breast cancer follow-up care. All clinical examinations and mammograms were initiated by the GP in the intervention group. Outcome measures included: quality of life (QoL) as measured by several validated questionnaires, number of recurrences, number of deaths and time to diagnose recurrence from onset of symptoms. It was found that twice as many metastatic recurrences were diagnosed in the hospital group (13 vs. 6 in general practice, difference 4.7%, 95% CI 0.8 to 10.3%). Of interest, while all the recurrences in the general practice group were detected by the GP, 44% of the

recurrences in the hospital follow-up group were also diagnosed by the general practitioner. There was a slight excess in mortality in hospital follow-up compared with general practice (two deaths in the general practice group and seven in the hospital group from 148 patients in each cohort). No differences in QoL were found between control and study groups.

Grunfeld[99] conducted another randomised control trial involving 968 women between nine and 15 months after diagnosis of early-stage breast cancer who had completed treatment and were disease free. For participants randomised to the intervention, their family physicians (FPs) were provided with a one-page guideline on follow-up that recommended the following: physical examination and medical history every 3 to 6 months for 3 years, every 6 months for 2 years, and then yearly indefinitely; mammograms yearly; diagnostic tests to investigate signs or symptoms suggestive of recurrent or new primary cancer (but not to be performed routinely). For women taking tamoxifen, the guideline recommended a history of vaginal bleeding be taken at each visit and a pelvic examination be performed annually. FPs were instructed to refer patients back to the cancer centre if a recurrence or new primary breast cancer developed. For patients in the FP group, if a surgeon had been involved in the patient's follow-up care, that follow-up was also transferred to the FP. Control participants received routine follow-up at the hospital following the same protocol. Enrolled patients were followed up for a period of between two to six years. Outcome measures included: QoL using validated questionnaires, significant clinical events (metastases related) and number of local recurrences, and deaths. Grunfeld[99] found no significant difference in the proportion of women presenting with local or distant recurrences between the two groups (11.2% in general practice group compared with 13.2% in the hospital group). Time to recurrence detection was not provided. No difference was found in the rate of serious clinical events (SCEs) between hospital and general practice follow-up (3.7% of patients vs. 3.5%, respectively). There were 29 deaths in the general practice group and 30 in the hospital group, and no difference was found in QoL between control and study groups.

A systematic review by Lewis[18] compared the effectiveness and cost-effectiveness of primary versus secondary follow-up in a range of cancer types. The review included six RCTs of follow-up models of care involving primary care health professionals (including the two Grunfeld trials described above). On closer inspection two of these models are actually a form of shared care and will be discussed in the next section.[100,101] Overall, Lewis concluded that 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 health 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. 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.

One of the RCTs assessing primary versus secondary-led follow-up examined the optimal setting for follow-up of patients after treatment for colon cancer.[102] Two hundred and three patients who had undergone potentially curative treatment for colon cancer were randomised to follow-up by GPs or surgeons, of whom 170 were available for follow-up at 12 months and 157 at 24 months. All participants had follow-up guidance provided based on current clinical practice, which was inserted into either the patient's GP or surgeon/hospital records. There was no compulsion for clinicians in either setting to adhere to the guidance. Participating clinicians received regular study information from contact with the study researcher and a newsletter. Patients allocated to 'GP-led' follow-up could be referred back to surgical clinics at any point in the study; similarly, patients in the 'surgeon-led' follow-up group could consult their GP at any time during the course of the study. At 12 and 24 months there were no differences in scores for QoL, anxiety, depression or patient satisfaction. GPs ordered more FOBTs than surgeons, whereas more colonoscopies and

ultrasounds were undertaken in the surgeon-led group. Results suggest similar recurrence, time to detection and death rates in each group. In conclusion, colon cancer patients with follow-up led by surgeons or GPs experience similar outcomes, although patterns of investigation vary.

The other RCT[103] included 91 cancer patients from one Norwegian municipality and investigated whether increased contact with the patient's GP soon after cancer treatment can increase patients' QoL and satisfaction with follow-up. The intervention group received a 30 minute consultation with the patient's GP and an invitation to further GP follow-up. Since there was no structured sharing of care as part of this model, we have included it here as a form of GP-enhanced hospital-led follow-up. QoL and patient satisfaction with diagnosis, treatment and overall care were measured with validated instruments. Holtedahl[103] found that relatives' satisfaction with care increased over six months in the intervention group but otherwise there was no difference between the intervention and control groups concerning QoL, satisfaction with care or number of consultations. Patient satisfaction with care showed a tendency to increase when treatment intent was curative. Some functional QoL measures and satisfaction tended to increase during the first six months after treatment. Free text comments suggested that some patients appreciated the contact with their GP.

The Lake Superior Rural Cancer Care Project LSRCCP[104] tested an innovative, multimodal, multidisciplinary intervention that involved rural healthcare providers and their healthcare system. An experimental design was used, with the rural community as the unit of randomisation. Intervention communities received a complex intervention package including clinician education, guidelines on cancer management, conference attendance, a telephone link to the regional cancer centre, and a quarterly newsletter on cancer care. The model included cancer management across the entire continuum (diagnosis, treatment and follow-up). Since the model included explicit linkage to the regional cancer centre, it has been included as a shared care approach. Outcomes were measured at three levels: rural providers' knowledge of cancer management, providers' practice performance, and patient outcomes. Patient outcomes included; patients' travel to obtain health care, satisfaction with care, perceptions of economic barriers to care, and health-related QoL. This five year study was conducted in rural areas of northern Minnesota, Wisconsin, and the western part of the Upper Peninsula of Michigan. In total, 881 patients were included. Elliott[104-107] found that knowledge scores for providers in the experimental group significantly increased from pre-test to post-test: 66 to 79 for physicians (and physician assistants) ($p= .02$); 58 to 71 for nurses ($p= .01$); and 54 to 64 for pharmacists ($p=01$). At post-test participating providers in the experimental group performed significantly better on the knowledge tests ($p< .01$) than those in the control groups. The intervention significantly improved five of the 37 cancer practice end-points. The overall result of the study did not support the majority of the study hypotheses. Because 16 practice end-points were found to be at acceptable performance levels, the possibility of a measurable intervention effect was limited. Travel for health care was significantly reduced in the community group exposed to the intervention during months 13 to 24 following cancer diagnosis. The mean miles travelled per patient were 1,326 (Standard Error (SE)=306) for the experimental group and 2,186 (SE=347) for the control group ($p=0.03$). No significant differences in satisfaction with care, economic barriers to care, or health-related QoL were found.

We identified two ongoing RCTs of GP-led follow-up for cancer care after treatment.[108,109] The Senn study is being conducted in France and the UK and aims to enrol approximately 1200 patients following treatment for breast, colorectal or prostate cancer. GP follow-up will comprise of a trained GP who is responsible for follow-up with possible referral to the specialist physician (and their team) when requested. The methods of surveillance are exactly the same as that used in the control group. The GP and the specialist are meant to share information within the 15 days following each consultation. The control group will receive usual follow-up by the specialist physician (and their team). The trial will measure outcomes for the patient (satisfaction, QoL, iatrogenic effects); the physician (GP and specialist) perceptions of the model, actual

surveillance performed, and satisfaction; process measures include conduct of surveillance compared with recommendations, and costs.

Augestad[109] plans to recruit approximately 170 colorectal cancer patients in Norway. Patients randomised to GP follow-up will be referred to their GP. This referral will contain information about the patient's surgery and any complications, Duke's staging, guidelines for follow-up and suggested actions in the case of a serious clinical event. The regular check-ups will be performed at three-month intervals for the first two years and then six monthly. All patients with elevated Carcinoembryonic Antigen (CEA) (measurement, used as a tumor marker) prior to surgery will have this repeated at each visit. Chest X-ray and ultrasound will also be arranged. Colonoscopy will be performed twice during the follow-up period. The follow-up guidelines are the same in both arms. Control participants will have their regular follow-up at the hospital's surgical outpatient clinic, which will be performed by consultants or surgical interns.

In summary, there is evidence from five RCTs that primary care-led follow-up is at least equivalent in health outcomes and is acceptable to patients. There is no difference in quality of life outcomes for primary care-led care. The evidence is strongest for breast and colorectal cancer, although this is still limited to only three trials.

Shared care

Models of follow-up care reported under this section are those in which the patients' cancer follow-up is shared between one or more primary care professionals and hospital-based care—usually following a predetermined protocol in which some visits are in primary care and some at the hospital. In some models the role of the primary care professional is in managing post-treatment symptoms but not necessarily being responsible for pre-specified visits within the follow-up schedule. Shared care may involve a specialist oncologist sharing follow-up care with the patient's usual GP. It has also been used to describe models of sharing care between an oncologist and a cancer nurse.[110] Recent Government guidelines for England and Wales recommend that follow-up care managed by nurse specialists should be offered to patients with lung cancer who have completed treatment.[21,111] For the purposes of this review we did not include models of care that were entirely hospital-based but shared between doctors and nurses, nor does the scope of this review include models of care for later-stage, advanced cancer.

Our work has identified seven published RCTs and one ongoing RCT of shared care models of cancer follow-up.

The systematic review of models of follow-up for cancer by Lewis[18] contained two relevant shared care trials.[112,100]

Nielsen[112] conducted a randomised controlled trial in Denmark to determine the effect of a shared care program on the attitudes of newly referred cancer patients towards the healthcare system and their health-related quality of life and performance status, and to assess patients' reports on contact with their GP. Two hundred and forty eight patients completed questionnaires at three time points. The shared care program included three components: (1) Knowledge transfer (discharge summary letters following predefined guidelines, specific information on the disease and its treatment, general information about chemotherapy, general information about radiotherapy, general information about pain treatment, information about treatment of induced nausea and sickness, information about some acute oncological conditions) (2) Communication channels (names and phone numbers of doctors and nurses responsible for the patient were attached to the discharge summary letter to the GPs) (3) Active patient involvement (in the intervention group the patients received oral as well as written information about the information package to their GP, and were encouraged to contact their GP when facing problems). From the paper it appears that the GP role was mainly as a first line of contact if patients had problems in the post-treatment period. It appears to be more of a troubleshooting

role than a formal role for scheduled follow-up visits. Main outcome measures included patients' attitudes towards the healthcare services, their health-related quality of life, performance status and reports on contacts with their GPs. Nielson[112] found 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 European Organization for Research and Treatment of Cancer quality of life questionnaire and performance status showed no significant differences between the two groups.

Johansson[100] evaluated the effect of an individual support intervention, including intensified primary healthcare, on the utilisation of specialist care among cancer patients in Sweden. The study also investigated whether such an effect was modified by the patient's age (<70 years/>70 years). Four hundred and sixteen newly diagnosed cancer patients were randomised between the intervention and a control condition, and data were collected on the utilisation of specialist care within three months from inclusion. Intensified primary healthcare comprised of extended information from the specialist clinics and education and supervision in cancer care for GPs and home-care nurses. The support given also included interventions designed to diminish problems of weight loss and psychological distress. Johansson found the intervention reduced the number of admissions and days in hospital (DH) after adjustment for weight loss and psychological distress, but only for older patients. Older patients randomised to the intervention (n=82) experienced 393 fewer DH than the older control patients (n=79). In addition, the proportion of older patients in the individual support group who utilised acute specialist care was smaller compared with older control patients group. Thus, this shared care model focused mainly on the primary care providers managing symptoms after treatment.

A Cochrane review by Aubin[113] on continuity of care in follow-up of cancer patients contains a further five RCTs of shared care models of cancer follow-up.

De Wit[114] enrolled 104 patients in the Netherlands who were experiencing pain related to cancer, cancer therapy or illness and had been admitted to a hospital and were expected to live for more than three months. The intervention included a patient education component and a shared care program with the district nurse. The shared care was mainly focused on managing pain. District nurses were informed about the Pain Education program that the patients had received prior to discharge and received individual patient information via telephone and as a written summary. Control patients received regular pain treatment and district nurse visits without the additional information and instruction. Results showed that continuity of care was poor as only 36% of the district nurses were informed about patients' pain by hospital nurses. Pain was rarely the reason for referring the patient to district nursing after discharge. Although pain control was not a main reason for district nurses to visit a patient, pain was a subject for discussion in 76% of visits. Besides discussing the problem of pain with patients, district nurses provided only a few pain-relieving interventions. District nurses randomised to the intervention group significantly better estimated patients' pain intensity, and were more satisfied about patients' pain treatment, but no differences were found in their assessment of patients' pain relief.

Jefford[115] conducted an RCT of 97 patients completing chemotherapy for cancer treatment in Melbourne. Intervention participants had chemotherapy information faxed to their GP. This was in addition to the usual correspondence and included a cover letter and a chemotherapy information sheet relevant to their patients' regimen. The general practice was contacted to confirm that the fax had been received and was asked to file it in the patient's medical record. The cover letter was generic but contained several patient-specific fields: name of the patient, name of treating doctor, type of cancer, treatment intent (to cure the disease, to increase the chance of long-term, disease-free survival and adjuvant treatment), or to palliate symptoms

(improve QoL, to extend survival), and type of cancer treatment. The sheet also included the telephone number of the Drug Information Service and listed a number of relevant, reputable internet sites. The chemotherapy sheets were developed for 23 cancer treatment regimens used to treat haematological and solid tumours. Each sheet named component drugs, explained the treatment cycle, listed common adverse effects, suggestions for management and advice about when to call the cancer centre, how to contact relevant staff, and had a further information section. They were developed by a medical oncologist and behavioural scientist in collaboration with pharmacy staff following a focus group of 10 GPs and following a review by medical, nursing and pharmacy staff. It did not include a schedule of follow-up and (although there are many overlapping components) it is not quite a survivorship care plan, but rather a strategy to share the management of chemotherapy-related symptoms with GPs. GPs in the intervention group demonstrated a significantly greater increase in confidence (mean difference, 0.28; 95% CI, 0.10 to 0.47) and satisfaction (mean difference, 0.57; 95% CI, 0.27 to 0.88) compared with usual care, reflecting a 7.1% and 10.5% difference in score, respectively. No differences were detected for knowledge. GPs receiving the chemotherapy sheet found correspondence significantly more useful ($p < .001$) and instructive ($p < .001$) than GPs who received standard correspondence alone. The intervention was designed to use a shared care approach to managing symptoms and adverse effects of chemotherapy.

Kousgaard[116] randomised 248 patients of 199 GPs in Denmark who had been diagnosed with cancer of any type. The intervention participants were instructed to see their GP to discuss questions and problems. The structured oncology information for GPs comprised a discharge summary letter written for the GP by the oncology department with speciality developed guidelines. The summary included specific information on the disease and its treatment, general information about chemotherapy, radiotherapy, pain treatment, information about treatment of induced nausea and sickness and information about some acute oncological conditions (knowledge transfer). It also stated names and phone numbers of doctors and nurses responsible for the patient in the discharge summary letter to the GPs (improved communication channels). It also aimed to improve patient involvement in their own care by providing patients with oral as well as written information about the information package to their GP, and by encouraging patients to contact their GP when facing problems they assumed could be solved in this setting. The control group received normal procedures that included no process for informing the GP about newly diagnosed patients. The participating practitioner received the traditional information from the department, i.e. the discharge letter of an extract from the hospital record. The structured information pack improved GP knowledge of oncology; GPs found themselves better equipped to support and counsel patients during the course of their illness; and practitioner satisfaction with the department rose. Thus, this model of shared care also featured the GP role as managing symptoms after acute cancer treatment.

Luker[117] randomised 76 UK breast cancer patients to services from a breast care nurse plus patient-mediated information for primary care providers (the GP and district nurse) compared with breast care nurse only. The eleven information cards were developed by breast specialist providers for members of the primary healthcare team. Women were asked to take the cards to their GP. They covered information on the rationale for a specific treatment, prognostic indicators, complications and side effects, suggestions for dealing with side effects and indicators for referral back to specialist services. Women were given cards corresponding to their treatment and the number of types of cards given was determined by the treatment received. Control participants received the same services of a breast care nurse who offered home visits prior to admission for surgery and written patient information leaflets (these were not personalised and had no GP involvement). The cards did not impact on the utilisation of the primary health care team and women in the intervention group were no more likely to utilise primary care sources of information than women in the non-intervention group. Factors such as the long-standing relationship women had with their GP, the perceived lack of specialist knowledge on the part of GPs and district nurses, and the women's perception that information seeking was not a tangible reason for primary care contact had an impact on information-seeking behaviour. This shared

care strategy aimed to increase primary care management of symptoms after treatment through patient-mediated information cards.

Rutherford[118] reports an Australian RCT that randomised 200 women after treatment for gynaecological cancer aiming to improve communication between GP and the hospital. GPs were invited to contact patients in the hospital by either a personal visit or phone call to assist with discharge planning and continuity of care. Payment was available for either visiting (AUD150) or telephoning (AUD75). The discharge summary (DS) was collated by the research nurse and comprised diagnosis and management plans with input from allied health, information on the specific gynaecological cancer for each patient, and educational materials on chemotherapy and radiotherapy. It was either given to the patient on her discharge or mailed to her one to two days after discharge. Combinations analysed within the intervention arm include: (1) GPs not invited + DS (2) GPs invited + DS (3) GPs invited + No DS. Control participants received routine hospital discharge summary without any invitation to contact the hospital and no cancer-specific discharge summary. Significant increases in contact rates by the GPs followed invitation. The discharge summary was not effectively distributed. No significant differences in patient satisfaction and confidence in future management by their GPs were found. GPs valued hospital contact most in meeting their patients' needs for information.

Emery et al. are conducting an Australian phase II trial of shared care after treatment for prostate cancer, recruiting approximately 100 men who will be randomised to a shared care or usual (hospital-based) follow-up (NHMRC Project grant 1003414). Shared care participants will receive a personalised care plan and will visit their GP instead of the hospital at several pre-specified follow-up visits within the protocol. At the GP visits, patients are also asked to complete a brief self-assessment of health across core domains of QoL using a modified Distress Thermometer. GPs and patients are also provided with information and resources about managing common symptoms arising from prostate cancer treatment, including locally available services. The primary outcome will be a prostate cancer specific QoL outcome measure. Cancer Australia has also recently completed a demonstration project of shared care for women with breast cancer in a number of sites across Australia. This included use of a patient held electronic record in some sites. A report of the evaluation of this project is expected in 2013.

In summary, there is evidence from seven RCTS that shared care models of cancer follow-up can improve some process outcomes (patient and provider satisfaction, provider confidence, knowledge and patient perceptions of care). Most shared care models have focused on increasing the primary care team's involvement in managing symptoms following treatment for cancer. These have often included structured and tailored discharge letters, educational packages for providers and contact details for referral. There is evidence in one study that men and younger patients felt that their care was better coordinated through greater GP involvement. The two Australian studies showed a significant impact on GP confidence, knowledge and contacts through more structured and proactive engagement from the hospitals (faxed treatment summaries, education and invitations to contact patient with payment for service). We await the results of the ProCare trial that more formally shares follow-up between GP and specialist care.

b. Longer-term survivorship care (more than three years post-diagnosis)

More people are living longer in a cancer-free period after initial cancer treatment and this has implications for models of follow-up care. We found one systematic review[119] that included 10 observational studies of patients who had survived more than three years after cancer treatment and compared their use of primary health services with non-cancer patients. Of the ten studies, eight fit within the scope of this review.

Uptake of primary care services such as GP consultation rates, participation in cancer screening, accessing preventive health services and chronic disease management by longer-term cancer survivors were summarised across ten studies. Most of these were surveys of cancer survivors and there was only very limited comparison with the general community. Several studies indicated a slightly greater participation in cancer screening programs by longer-term cancer survivors compared with the general population, and one study showed a slightly lower compliance with cardiovascular and diabetes management amongst longer-term cancer survivors. Most of the studies have been conducted in the US. There were no studies assessing models of care for longer-term cancer follow-up. There is a need for further research into monitoring treatment-specific sequelae, the role of primary care in long-term cancer surveillance, and the quality of care for comorbid disease.

In summary, models of care for cancer surveillance and management of chronic sequelae of treatment appear to be an important area for future research, particularly as more people survive longer cancer-free lives after treatment. There is limited evidence that longer-term cancer survivors are more likely to participate in cancer screening and mixed results about engagement in other primary health care activities.

c. Potential components of follow-up care

There are several components of cancer follow-up in primary care that have been well evaluated although they in themselves do not constitute a 'model' of care. Depending on their implementation, they could become part of primary care-led or shared care models. We have therefore chosen to report on RCTs that evaluated the efficacy of these individual components since they are potential activities involving primary healthcare professionals in cancer follow-up. Note that many of the studies described in previous sections may have included some of these as part of their model, although the effect of the whole model (or complex intervention) is what was assessed in the studies reported earlier.

Patient Held Records

Patient Held Records (PHRs) can take a number of forms and have been tried in many different settings. They aim to increase patient involvement in healthcare, improve communication between members of a healthcare team and increase health literacy. For example, they may be a log-book format, an electronic shared record or folders containing health summaries and results.

We found one systematic review of seven RCTs and six non-experimental studies summarising the effect of PHRs on continuity of cancer care.[120] Of these 13 studies, four involved primary health professionals and cancer follow-up post-treatment.

Drury[121] randomised 650 radiotherapy outpatients with any cancer type to receive a supplementary record or not. It consisted of an A4-size plastic wallet containing communication/diary sheets for use by the patient, their family, health professionals, and carers, as well as pages for appointments, medication, and addresses and telephone numbers. The study nurse explained the use of the record as a means of communication and as an *aide memoire*. Patients were encouraged to read and write in it and to show it to anyone concerned with their care. The record explicitly invited carers to use it as an aid to communication. After three months they found no effect on satisfaction with communication, participation in care, or QoL. Two-thirds of participants with PHRs showed it to their GP.

Williams[122] randomised 1148 cancer patients to receive a PHR or usual care. Those randomised to the intervention were given the booklet with a full explanation of its use, supported by the following instructions, which were printed inside the front cover: "*Please use this booklet to note: questions you want to ask; all your current medication; problems with changes of medication;*

anything else you feel is important as a memory aid. Please take this booklet with you when you go to any hospital or to your doctor's surgery and ask whoever you see to write in it. If a doctor or nurse visits your home please also use this booklet". The booklet was A6 size with four different coloured sections for (1) Free text entries by the patient (2) Free text entries by health professionals (3) Details of medication (4) Dates of appointments. This simple four sectioned format was considered easier to use than a blank booklet but retained the convenience of being pocket sized. Twenty-seven per cent of GPs reported seeing the PHR, similar to physicians (26%) and surgeons (21%) but not as high as oncologists (86%) or radiotherapists (100%). The PHR did not have an impact on communication but was significantly helpful to patients in preparing for appointments, reducing difficulties in monitoring their own progress, and helping them to feel more in control ($p<0.05$). Fifty-three per cent of patients would have preferred not to have a PHR. There was a low level of use of the record by healthcare professionals but most of those who remembered using it indicated that they would prefer patients to have it.

Lecouturier[123] randomised 271 patients with colorectal or lung cancer to receive a PHR or no PHR. The format of the PHR is not well described in this article. The only significant difference was 86% of control patients compared with 58% of intervention patients were very satisfied with information received at the end of treatment (OR 4.4, 95% CI 1.2–15.6, $p< 0.05$). Fifty-three per cent of intervention respondents found the PHR helpful (63% hospital vs. 38% community patients), and 69% felt that it would be useful to them in the future. Primary healthcare (PHC) professionals found the PHR of more benefit than those working in hospitals ($p< 0.05$). The PHR did not improve measures of patient satisfaction with information or communication. Despite its limited use by many health professionals, the PHR was well received by recently diagnosed patients and those who did not receive negative responses to it from staff involved in their care. It was also positively valued by staff in PHC.

Johnson[124] reported a qualitative evaluation of a PHR used by 67 patients with a range of cancers (breast, haematological, colorectal and lung). Patients valued the record for providing information for personal reflection and in sharing information with family and friends. Health professionals also were positive about its role in sharing information.

In summary, PHRs are well liked by some but not all patients and by most primary healthcare professionals. There is no clear evidence that they improve communication, QoL, patient satisfaction or health, partly due to low levels of use by healthcare professionals.

Survivorship Care Plans

Survivorship Care Plans (SCPs) have gained increasing attention over the past decade, with the USA's Institute of Medicine releasing a report in 2006 describing the healthcare needs of cancer survivors. It issued 10 recommendations; chief among them was that all patients completing primary treatment for cancer should have an SCP (a comprehensive care summary and follow-up plan to be written by the principal providers who coordinated the oncology treatment). The key elements of SCPs are a personalised treatment summary, information on possible late and long-term effects, information on signs of recurrence, guidelines for follow-up care, identification of providers, recommendations for healthy living and identification of supportive care resources.

We found one RCT measuring the effect of SCP in primary-care led follow-up for cancer treatment.[125]

Grunfeld[125] conducted a randomised clinical trial to determine if a SCP for breast cancer survivors improves patient reported outcomes. Women with early-stage breast cancer who completed primary treatment at least three months previously were eligible. Consenting patients were allocated within two strata: less than 24 months and more than 24 months since diagnosis. All patients were transferred to their own primary care physician (PCP) for follow-up. In addition to

a discharge visit, the intervention group received an SCP that was reviewed during a 30-minute educational session with a nurse, and their PCP received the SCP and guideline on follow-up. The primary outcome was cancer-related distress at 12 months, assessed by the Impact of Event Scale. Secondary outcomes included QoL, patient satisfaction, continuity/coordination of care, and health service measures. Overall 408 survivors were enrolled through nine tertiary cancer centres. There were no differences between groups on cancer-related distress or on any of the patient-reported secondary outcomes, and there were no differences when the two strata were analysed separately. More patients in the intervention than control group correctly identify their PCP as primarily responsible for follow-up (98.7% vs. 89.1%; difference, 9.6%; 95% CI, 3.9 to 15.9; p= .0005). It should be noted that a number of methodological issues have been raised about this trial including the timing of the intervention, the high proportion of women who were more than 24 months post-diagnosis, and the choice of outcome measures.[126]

It is probably too early therefore to determine the precise role of SCPs as a method of empowering patients and improving communication between hospital and primary care providers. The ProCare trial described earlier includes a tailored SCP that is faxed to the GP at commencement of the trial. However, it is a static document with no capacity to update or share information between healthcare providers.

Key drivers of implementation and expert opinion

This review has identified six key drivers for implementation from the evidence: (1) Health professionals' and patients' attitudes (2) Cancer type and stage (3) Special subgroups (4) Cost-effectiveness (5) Clear lines of communication and access to support for hospital, primary healthcare professionals and patient (6) Duration of survivorship.

Health professionals' and patients' attitudes

We found one systematic review of 19 studies, 18 of which fit within the scope of this study, plus an additional six studies published subsequently, examining health professional and patient attitudes to different types of cancer follow-up care.

A second systematic review by Lewis[19] included 19 studies (mostly qualitative or surveys) examining patients' and healthcare professionals' views about models of cancer follow-up care. Seven of the studies were linked to RCTs, eight studies examined the views of health professionals (four of which included GPs) and 16 examined the views of patients. The majority of studies (10 out of 19) focused on breast cancer patients and their healthcare providers. Two studies looked at lung cancer, and another two examined colorectal cancer. The remaining four studies did not focus on a specific cancer. Patients' and GPs' views about different models were quite varied. Patients found hospital care sometimes disjointed, not holistic and generally hurried but were reassured by the access to specialists. Nurse perceptions were understudied, and one study reported that oncologists expressed a need to see healthy patients and have better support from GPs. Twelve descriptive themes were identified, from which 12 perceived implications for practice were derived. The twelve themes were:

1. Fear of recurrence was the main reason for patients' anxiety and need for reassurance
2. Conventional follow-up, although intended to allay anxiety, exacerbated patients' need for reassurance
3. Specialist knowledge and quick access to tests were thought to be the most important ingredients of follow-up, and were key concepts of alternative models
4. Information regarding the effectiveness (or limited evidence for) of follow-up tests and examinations was not given to patients
5. Patients lacked clear information that could aid coping and enable involvement

6. Continuity of care and unhurried consultations were of major importance to patients
7. Psychological support was important because of the impact of cancer on patients' lives (for example, social, domestic, economic) but was under-provided
8. Patients were reluctant to use their GP for cancer-related support between hospital visits
9. There were significant communication problems, in both directions, between primary and secondary care, which hindered GPs' ability to provide support
10. Cancer specialist nurse-led follow-up could benefit patients but some healthcare professionals lacked confidence in it
11. GPs were perceived as not willing or having insufficient expertise to conduct primary care follow-up
12. Patient-initiated follow-up was convenient but less reassuring.

Lewis made twelve recommendations for policy and practice arising from their review:

1. Patients should be given full and clear information using plain language on the following:
    - effectiveness of different tests and examinations in detecting recurrence
    - risk of recurrence and what they can do to reduce this
    - potential side-effects of treatment and how to deal with them
    - signs and symptoms of potential recurrence and what to do if these are experienced
    - alternative models of follow-up that may be available
2. A follow-up care plan that has been negotiated with the patient/carer should be provided for each patient on completing treatment, including the patient's preferred model of follow-up. Generally, patients' main concern is fear of recurrence and many find regular follow-up reassuring
3. Healthcare professionals should provide sufficient time, and encourage patients during follow-up to raise questions and concerns
4. Psychological support should be an integral part of follow-up, especially during the initial stages
5. Tests and examinations should not be conducted purely for reassurance, but only where there is a reason or there is evidence to support their use; and this must be explained to the patient/carer
6. Patients should be given contact details of a key person whom they can contact when needed and who can provide them with support and continuity of care
7. Multidisciplinary teams should include representation from primary care, but this does not have to be the individual patient's GP or someone from the patient's practice
8. There needs to be a formal handover and exchange of information between primary and secondary care. This should include complete discharge information and exchange of contact details (hospital clinicians to GPs and vice versa)
9. As an adjunct to routine hospital follow-up, a member of the primary care team should make contact with the patient immediately after hospital discharge to discuss the type of support that primary care could offer
10. Patients should be given informed choice about whether to attend scheduled appointments or just when they have problems or symptoms (i.e. patient-initiated follow-up)

11. If alternative models of follow-up (for example, primary care, hospital nurse, or patient-initiated follow-up) are to be developed and tested in further research, then these models should:
    - include a system of rapid referral for investigations
    - include training/education for GPs, nurses, and other healthcare professionals
    - include support from the specialist team, established with the collaboration of the whole cancer team and primary care from the outset with clear protocol/guidelines agreed by all parties in advance
    - enable individual GPs to be able to opt out of primary care follow-up
    - alternative primary care-based follow-up should be provided if the patient wishes this
12. The role of cancer support groups needs to be explored further.

Aubin[127] conducted a prospective longitudinal study of patients with lung cancer to assess their family physician's (FPs) involvement in their follow-up at the different phases of cancer. In five hospitals in the province of Quebec, Canada, 395 patients with a recent diagnosis of lung cancer were surveyed every three to six months, whether they had metastasis or not, for a maximum of 18 months, to assess aspects of their family physician's involvement in cancer care. Aubin found that 92% had a regular FP 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 FP. At baseline only 16% of patients perceived a shared care pattern between their FP and oncologists but this proportion increased with cancer progression. Most patients would have liked their FP to be more involved in all aspects of cancer care.

Mao[128] aimed to describe the perceptions of postmenopausal breast cancer survivors' (BCSs) about survivorship care provided by their primary care provider (PCP). A cross-sectional survey was distributed to 300 BCSs seen in an outpatient breast oncology clinic at a large university hospital. The primary outcome measure was a seven-item self-reported measure on perceived survivorship care. Mao found that overall BCSs rated PCP-related survivorship care as 65 out of 100. 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=.001 for both).

Hudson[129] explored patient perspectives on PCPs roles in their cancer follow-up care and their care preferences. Qualitative, semi-structured, in-depth interviews were conducted with patients recruited from two National Cancer Institute–designated comprehensive cancer centres and six community hospitals in the US. Survivors were at least two years beyond completion of their active cancer treatment. Forty-two survivors participated in Hudson's (2012) study. Most participants expressed strong preferences to receive follow-up care from their cancer specialists (52%). They described the following barriers to the PCPs engagement in follow-up care: (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: (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.

A study by Burg[130] examined the issues surrounding SCPs in a sample of American minority BCSs. During four focus groups with minority BCSs, data were collected about the types of information survivors remember receiving from their oncologists about follow-up health care needs. Survivors were also asked their opinions on the value and content of a SCP. Burg found that minority BCSs received variable amounts of information about their cancer treatments. They were dissatisfied with the amount of information they received on cancer-related side effects, including race-specific information. The American Society of Clinical Oncology's breast cancer SCP was viewed as important, but too highly technical and limited in information on side effects and self-care approaches.

Brennan[131] explored survivors' experiences with follow-up care and attitudes, including a tailored SCP and involvement of GPs and breast care nurses. Twenty women across Australia participated in semi-structured telephone interviews. Brennan et al. (2011) found that participants had a strong reliance on their specialist but were open to an increased role for their GP in a shared model of care. Communication between multidisciplinary team members was perceived as an ongoing problem and there was enthusiasm for a patient-held written SCP to address this, and to meet information needs.

An Australian study by Baravelli[132] aimed to survey key stakeholders in the care of people with colorectal cancer (survivors, primary care providers and hospital-based healthcare professionals) regarding follow-up and SCP. In study 1, cancer survivors completed a questionnaire regarding their follow-up and experiences during survivorship. Participants' GPs 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. In Baravelli's study 20 survivors completed the questionnaire, 14 primary care providers GPs completed a phone interview and 12 survivors reviewed the sample SCP. Ninety-five healthcare professionals (30 medical professionals and 65 nurses) completed the questionnaire. 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.

In summary, patients and health professionals vary in their preferences for cancer follow-up models of care but this may partly reflect international differences in the role of primary care more broadly. Rapid access to specialist care is important and reassuring to patients and GPs. GPs varied in their preference for involvement in cancer follow-up. However, several RCTs have shown that confidence of GPs and patients in the ability of primary care to provide follow-up can be increased if provided with appropriate guidelines, clear communications and access to specialist care if required. Psychosocial support, better informed patients and improved communication between primary and secondary care in both directions are crucial. More recent studies show more positive attitudes to GP involvement. Implementation should allow for a flexible approach to care that allows for patient and provider preferences, similar to antenatal care choices.

Cancer type and stage

The best available evidence for primary care-led and shared care models is in breast and colorectal cancer. Three RCTs have shown that primary care-led follow-up is at least equivalent for breast and colorectal cancer survivors. These three studies comprised patients with early stage and treatable cancer with no evidence of metastases. The longest period of follow-up was six years. Shared care models have been more widely tested across a range of cancer types, mainly involving a greater GP or nurse role in managing symptoms of cancer treatment. Provided appropriate re-referral mechanisms, clear discharge communication and provider educational support is in place, these models seem to be at least equivalent to hospital-based care.

Special subgroups (e.g. elderly, rural/remote)

One study showed that intensive primary care support in patients more than 70 years old with any cancer type reduced hospital readmission. One study showed that a model of care for rural/remote communities reduced travel to healthcare and increased provider knowledge but had no effect on a range of other outcomes. There were no studies on models of care for important subgroups of the NSW community, known to have worse cancer outcomes (e.g. Aboriginal and Torres Strait Islander and culturally and linguistically diverse populations). In summary, appropriate models of care for important subgroups is very limited but is likely to require different approaches. This is an important area for future research.

Cost-effectiveness

Grunfeld conducted a concurrent economic analysis of her 1996 trial of primary care-led follow-up for breast cancer in the UK (1999).[133] The study showed no increase in the clinical outcomes of delay in diagnosing recurrence and reinitiating specialist care as a result of primary care follow-up. Process measures of the quality of the clinical care such as frequency and length of visits were superior in primary care. The costs of physician visits and patient costs were lower in primary care. However, there was no difference in the total costs of diagnostic tests, with particular tests (Full blood count (FBC), erythrocyte sedimentation rate (ESR), liver enzymes, chest x-ray) being performed more frequently in primary care than specialist care. Thus the lower physician visit costs in primary care may be partly off-set by the excess costs of tests and false positives.

Wattchow[102] did not perform an economic evaluation of primary care follow-up in colorectal cancer but did note that GPs were more likely to order FOBT and surgeons more likely to order colonoscopies.

Thus, although physician visit costs may be lower in primary care, there is a variable pattern of diagnostic testing between primary and secondary care (in both directions) that would need to be monitored if different models of cancer follow-up were implemented.

Clear lines of communication and access to support for hospital, primary care professionals and patients

Most studies showed that effective models of care included well structured discharge letters from the hospital to the community, either by letter or fax. These included the patients' history and a recommended follow-up plan, along with clear and rapid access for referral between primary and secondary care and vice versa. Some studies called for a greater role of the GP in multidisciplinary meetings and one study invited GPs to contact patients prior to discharge from hospital. GPs and nurses can play a more active role in managing side effects of cancer treatment if guidelines are provided for the patient. As discussed already there is no evidence that PHRs or SCPs improve outcomes of care in any clear way. Patients perceived poor communication between the care team as a major problem. Patients also require better information.

In summary, regardless of the specific model of care, improved communication between primary and secondary care needs to be a priority for all cancer survivorship care. Improved information sharing with patients is also crucial.

Duration of survivorship

As cancer treatment improves and people survive longer after a cancer diagnosis and treatment there is a need to explore the best models of care for longer-term sequelae of treatment and for cancer surveillance beyond five years. Watson[134] on behalf of the Survivorship Sub-group of the National Cancer Research Institute Primary Care Clinical Studies Group has proposed a risk stratification approach to longer-term survivorship. This model suggests an annual risk/needs assessment for treatment effects based on incidence, timing and known risk factors. For example, in breast cancer this could include shoulder pain, hot flushes, lymphoedema, arthralgia,

premature menopause, osteoporosis, cardiovascular disease, wound pain/numbness, poor cosmesis, depression, sleep disturbance and fatigue. These will vary with factors such as treatment modality, age and years since treatment.

In general though, models of care for longer-term survivors are lacking. This is true for survivors of adult cancers as well as adult survivors of paediatric cancers.

International models of care

We have summarised the evidence on key drivers of implementation. However, it is worth noting that we identified several international models of care relating to follow-up and primary care in the grey literature. While they do not report evidence at this stage on effectiveness, they are of relevance to the broader consideration of models of follow-up care. We have included a summary of these international models in Appendix 7.

Expert opinion regarding models of care for cancer follow-up

A number of RCTs have assessed primary care-led and shared care for cancer follow-up, finding them to be broadly equivalent to hospital-specialist care. The strongest evidence for this is among patients with earlier stage breast and colorectal cancer. The results of the ProCare trial may inform a potential role for primary care in prostate cancer follow-up as well as provide more evidence relating to the role of SCPs. Patient and provider preferences for primary care-based models varied across studies and countries. Support for greater primary care involvement was increased after involvement in trials in which primary care was adequately supported through guidelines, good communication and clear access to specialist care. We recommend that the Cancer Institute NSW consider developing new models of follow-up based on this evidence, particularly for breast and colorectal cancer. Cancer follow-up care should provide clear guidance for patients and primary care professionals about treatment and follow-up plans as well as management of treatment adverse effects and mechanisms for rapid referral and consultation to specialist advice if required. Early contact with the patient's primary care provider at the time of discharge is important. Current evidence about the role of patient held records is based on hard copy formats, which do not appear to improve continuity of care although some patients and providers do like them. Further consideration should be made about the role of the federally funded Patient-Controlled Electronic Health Record in cancer follow-up as evidence about the implementation of this initiative is gathered.

Internationally there is growing interest in stratifying the care of cancer survivors according to risk of recurrence and clinical need.[134,135] New models of follow-up should consider patient and provider preferences in determining appropriate follow-up care. There is a need for more research into models of care with more structured shared cancer surveillance and psychosocial support, the role of risk stratification, models for longer-term cancer survivorship and economic evaluations of different cancer follow-up models.

Recommendations:

- The Cancer Institute NSW supports the development of new models of follow-up involving primary care in NSW, initially for breast and colorectal cancer while evidence from ongoing trials accumulates
    - Cancer follow-up care should provide clear guidance for patients, primary care and cancer care professionals about treatment and follow-up plans as well as management of treatment adverse effects and mechanisms for rapid referral and consultation to specialist advice if required. Early contact with the patient's primary care provider at the time of discharge is important
    - Current evidence about the role of patient held records is based on hard copy formats that do not appear to improve continuity of care, although some patients and providers do like them. Further consideration is recommended for the role of the federally funded Patient-Controlled Electronic Health Record (PECHR) in cancer follow up as this initiative is implemented
    - New models of follow-up should allow flexibility and consider patient and provider preferences in determining appropriate follow-up care for each patient
- The Cancer Institute NSW fosters research into models of care with more structured shared cancer surveillance and psychosocial support, the role of risk stratification in planning cancer follow-up, models for longer-term cancer survivorship, and economic evaluations of different cancer follow-up models.

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6 Appendices

Appendix 1.NHS National Institute for Health and Clinical Excellence (NICE) referral guidelines for suspected cancer

Lung cancer

Refer a patient who presents with symptoms suggestive of lung cancer to a team specialising in the management of lung cancer, depending on local arrangements. D

Immediate referral

Consider immediate referral for patients with: D

- signs of superior vena caval obstruction (swelling of the face/neck with fixed elevation of jugular venous pressure)
- stridor.

Urgent referral

Refer urgently patients with:

- persistent haemoptysis (in smokers or ex-smokers aged 40 years and older) D
- a chest X-ray suggestive of lung cancer (including pleural effusion and slowly resolving consolidation) D
- a normal chest X-ray where there is a high suspicion of lung cancer D
- a history of asbestos exposure and recent onset of chest pain, shortness of breath or unexplained systemic symptoms where a chest X-ray indicates pleural effusion, pleural mass or any suspicious lung pathology. C

Urgent chest X-ray

Refer urgently for chest X-ray (the report should be returned within 5 days) for patients with any of the following: D

- haemoptysis
- unexplained or persistent (longer than 3 weeks):
  - chest and/or shoulder pain
  - dyspnoea
  - weight loss
  - chest signs
  - hoarseness
  - finger clubbing
  - cervical or supraclavicular lymphadenopathy
  - cough
  - features suggestive of metastasis from a lung cancer (for example, secondaries in the brain, bone, liver, skin)
- underlying chronic respiratory problems with unexplained changes in existing symptoms. D

Risk factors

The following patients have a high risk of developing lung cancer: C

- all current or ex-smokers
- patients with chronic obstructive pulmonary disease
- people who have been exposed to asbestos
- people with a previous history of cancer (especially head and neck).

An urgent referral for a chest X-ray or to a specialist can be considered sooner in these patients (for example, if signs and symptoms have lasted less than 3 weeks).

Lower gastrointestinal cancer

Refer a patient who presents with symptoms suggestive of colorectal or anal cancer to a team specialising in the management of lower gastrointestinal cancer, depending on local arrangements. D

In a patient with equivocal symptoms who is not unduly anxious, it is reasonable to 'treat, watch and wait'. D

Urgent referral

Refer urgently patients:

- aged 40 years and older, reporting rectal bleeding with a change of bowel habit towards looser stools and/or increased stool frequency persisting 6 weeks or more C
- aged 60 years and older, with rectal bleeding persisting for 6 weeks or more without a change in bowel habit and without anal symptoms C
- aged 60 years and older, with a change in bowel habit to looser stools and/or more frequent stools persisting for 6 weeks or more without rectal bleeding C
- of any age with a right lower abdominal mass consistent with involvement of the large bowel C
- of any age with a palpable rectal mass (intraluminal and not pelvic; a pelvic mass outside the bowel would warrant an urgent referral to a urologist or gynaecologist) C
- who are men of any age with unexplained iron deficiency anaemia and a haemoglobin of 11 g/100 ml or below[3] C
- who are non-menstruating women with unexplained iron deficiency anaemia and a haemoglobin of 10 g/100 ml or below[3]. C

Risk factors

Offer patients with ulcerative colitis or a history of ulcerative colitis a follow-up plan agreed with a specialist in an effort to detect colorectal cancer in this high-risk group. C

There is insufficient evidence to suggest that a positive family history of colorectal cancer can be used to assist in the decision about referral of a symptomatic patient. C

Investigations

- Always carry out a digital rectal examination in patients with unexplained symptoms related to the lower gastrointestinal tract. C
- Where symptoms are equivocal a full blood count may help in identifying the possibility of colorectal cancer by demonstrating iron deficiency anaemia, which should then determine if a referral should be made and its urgency. C(DS)
- When referring, a full blood count may assist specialist assessment in the outpatient clinic. D
- When referring, no examinations or investigations other than abdominal and rectal examination and full blood count are recommended as this may delay referral. D

[3] In this guideline, unexplained is defined as 'a symptom(s) and/or sign(s) that has not led to a diagnosis being made by the primary care professional after initial assessment of the history, examination and primary care investigations (if any)'. In the context of this recommendation, unexplained means a patient whose anaemia is considered on the basis of a history and examination in primary care not to be related to other sources of blood loss (for example, ingestion of NSAIDs) or blood dyscrasia.

Breast cancer

Refer a patient who presents with symptoms suggestive of breast cancer to a team specialising in the management of breast cancer. D
In general:

- convey optimism about the effectiveness of breast cancer treatments and survival of breast cancer patients C
- discuss the information and support needs of your patient and respond sensitively D
- encourage all patients, including women over 50 years old, to be breast aware[4]. D

Always take the patient's history into account. For example, it may be appropriate, in discussion with a specialist, to agree referral within a few days in a patient who reports a lump or other symptom that has been present for several months. A

Urgent referral

Refer urgently patients:

- of any age with a discrete, hard lump with fixation, with or without skin tethering C
- who are female, aged 30 years and older with a discrete lump that persists after their next period, or presents after menopause C
- who are female, aged younger than 30 years:
  - with a lump that enlarges C
  - with a lump that is fixed and hard C
  - in whom there are other reasons for concern such as family history[5] D
- of any age, with previous breast cancer, who present with a further lump or suspicious symptoms C
- with unilateral eczematous skin or nipple change that does not respond to topical treatment C
- with nipple distortion of recent onset C
- with spontaneous unilateral bloody nipple discharge C
- who are male, aged 50 years and older with a unilateral, firm subareolar mass with or without nipple distortion or associated skin changes. C

Non-urgent referral

Consider non-urgent referral in:

- women aged younger than 30 years with a lump C
- patients with breast pain and no palpable abnormality, when initial treatment fails and/or with unexplained persistent symptoms. (Use of mammography in these patients is not recommended.) B(DS)

Investigations

In patients presenting with symptoms and/or signs suggestive of breast cancer, investigation prior to referral is not recommended. D

[4] Breast awareness means the woman knows what her breasts look and feel like normally. Evidence suggests that there is no need to follow a specific or detailed routine such as breast self examination, but women should be aware of any changes in their breasts (see www.cancerscreening.nhs.uk/breastscreen/breastawareness for further information).
[5] National Institute for Clinical Excellence (2004) Familial breast cancer: the classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care. *NICE Clinical Guideline* No. 14. London: National Institute for Clinical Excellence. Available from: www.nice.org.uk/CG014

Urological cancer

Refer a patient who presents with symptoms or signs suggestive of a urological cancer to a team specialising in the management of urological cancer, depending on local arrangements. D

Urgent referral

Refer urgently patients: • with a hard, irregular prostate typical of a prostate carcinoma. Prostate-specific antigen (PSA) should be measured and the result should accompany the referral. (An urgent referral is not needed if the prostate is simply enlarged and the PSA is in the age-specific reference range[6].) C • with a normal prostate, but rising/raised age-specific PSA, with or without lower urinary tract symptoms. (In patients compromised by other comorbidities, a discussion with the patient or carers and/or a specialist may be more appropriate.) C • with symptoms and high PSA levels. C	Prostate
Refer urgently patients: • of any age with painless macroscopic haematuria C • aged 40 years and older who present with recurrent or persistent urinary tract infection associated with haematuria C • aged 50 years and older who are found to have unexplained microscopic haematuria C • with an abdominal mass identified clinically or on imaging that is thought to arise from the urinary tract. C	Bladder and renal
• Refer urgently patients with a swelling or mass in the body of the testis. C	Testicular
• Refer urgently patients with symptoms or signs of penile cancer. These include progressive ulceration or a mass in the glans or prepuce particularly, but can involve the skin of the penile shaft. (Lumps within the corpora cavernosa can indicate Peyronie's disease, which does not require urgent referral.) D	Penile

[6] The age-specific cut-off PSA measurements recommended by the Prostate Cancer Risk Management Programme are as follows: aged 50–59 ≥ 3.0 ng/ml; aged 60–69 ≥ 4.0 ng/ml; aged 70 and over ≥ 5.0 ng/ml. (Note that there are no age-specific reference ranges for men over 80 years. Nearly all men of this age have at least a focus of cancer in the prostate. Prostate cancer only needs to be diagnosed in this age group if it is likely to need palliative treatment.)

Appendix 2.Database searches

The following database searches were conducted for articles between 2000 and 2012 (unless otherwise stated) with results as below:

- Medline, Monday 17 Sept 2012:
    - Subject headings: neoplasms and primary health care and diagnosis including all subheadings: 8 results; 4 new citations included, saved to EndNote group Medline 2012–07
    - Keywords: cancer and primary health care and diagnosis (terms mapped to subject headings): 359 results (did not search these)
        - And systematic review (filtered 359 results by keyword 'systematic review'): 7 results – 3 new citations included; 4 citations had already been identified
        - And randomised controlled trial (filtered 359 results by publication type): 11 results – 3 new citations included
    - Keywords shared care and cancer and primary care: 19 results. 4 new relevant citations
    - A total of 45 citations resulted; 14 were kept after abstracts were reviewed

- PubMed, Monday 17 Sept
    - (CANCER DIAGNOSIS[Body - All Words]) AND PRIMARY HEALTH CARE[Body – All Words] Limits: Article Types: Research/Review Articles 90 results) – 4 potential citations

- AustHealth, Tuesday 18 Sept 2012
    - "CANCER" AND "PRIMARY" AND "DIAGNOSIS" OR "SURVIVOR" subject search: 38 results – 5 potential citations

- EMBASE, Thursday 20 Sept 2012
    - Search mapped to subject headings: (neoplasm and primary health care and (diagnosis or follow-up)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]: 91 results – 4 potential citations found

- Health and Medical complete, Thursday 20 Sept 2012
    - Using subject headings: su.Exact("primary health care" AND "cancer") AND (diagnosis OR follow-up) – 26 results – 2 potential citations
    - Using MeSH Headings: mesh.Exact("Early Detection of Cancer" AND "Primary Health Care") – 14 results – 4 potential citations
    - mesh.Exact("Neoplasms" AND "Primary Health Care") AND ab((diagnosis OR follow-up)) – 14 results – 2 potential citations (many already cited)
    - A total of 54 citations resulted; 8 articles kept

- Scopus, Thursday 20 Sept 2012
    - KEY(cancer) AND KEY(primary care) AND KEY(diagnosis) – 1398 results – searched 2012 & 2011 results (243) –identified 23 potential citations

- Science Direct
    - 'systematic review primary health care' [title] and 'cancer' [any field] –
    - TITLE(systematic review) and TITLE-ABSTR-KEY(cancer + primary health care) 6 articles resulted – 2 potential citations

The following search terms were identified by the reviewers to guide the above searches:

Primary care [& related]; cancer [& related]; diagnosis

1. & systematic reviews
2. then narrow to models

MESH terms identified:

Primary Care: Tree Number 1
Health Services Administration [+3]
    Patient Care Management [+13]
        Comprehensive Health Care [+6]
            Comprehensive Dental Care
            Nursing Process [+2]
            Patient Care Planning [+3]
            Patient-Centered Care
            Primary Health Care [+3]
                Continuity of Patient Care [+1]
                Patient-Centered Care
                Refusal to Treat
            Progressive Patient Care

Tree Number 1
Neoplasms [+16]
    Cysts [+26]
    Hamartoma [+3]
    Neoplasms by Histologic Type [+14]
    Neoplasms by Site [+17]
    Neoplasms, Experimental [+11]
    Neoplasms, Hormone-Dependent
    Neoplasms, Multiple Primary [+3]
    Neoplasms, Post-Traumatic
    Neoplasms, Radiation-Induced [+1]
    Neoplasms, Second Primary
    Neoplastic Processes [+8]
    Neoplastic Syndromes, Hereditary [+14]
    Paraneoplastic Syndromes [+3]
    Precancerous Conditions [+8]
    Pregnancy Complications, Neoplastic [+1]
    Tumor Virus Infections [+6]

Appendix 3.Screening tables

Summary of tables:

- **Five systematic reviews & extracted studies:**
    - Ellis 2003: 11 systematic reviews & five studies extracted
    - Sabatino 2008
    - Arroyave 2011: five studies extracted
    - Bonfill 2001: five extracted studies
    - Everett 2011: four extracted studies

- **Eight RCTs/trials:**
    - Colorectal screening studies (seven):
        - Brawarsky 2004
        - Cole 2007
        - Ling 2009
        - Zajac 2010
        - Senore 2010
        - Hewitson 2011
        - Jean-Jacques 2012
    - Breast:
        - Atlas 2011

Table 3.1 Systematic reviews of the effectiveness of cancer control interventions in mammography and cervical cancer screening (Ellis 2003[33] evidence tables 3 & 4)

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Austin 1994[136] **Review purpose:** The objective of this study was to assess the clinical value of the physician reminder, an information intervention, in increasing compliance for selected preventive health care measures	**Inclusion criteria**: RCT A comparison of information or utilisation management intervention in the study group with no similar assistance in the control group An evaluation of the change in process and/or outcome of patient care **Dates of articles reviewed:** Not clearly stated (<1994 assumed) **Total number of studies:** 6 **Total RCTs:** 6 **Studies focusing on cervical cancer screening:** 3 **RCTs focusing on cervical cancer screening:** 3 **Meta-analysis performed?** Yes	**Results:** Three RCTs were identified which addressed the effect of physician reminders on preventive care; more specifically cervical cancer screening The OR from the combination of evidence from the 3 cervical cancer screening trials was significant (OR 1.180, 95% CI 1.020–1.339) **Conclusions:** Based on results of this meta-analysis, further trials testing the effect of physician reminders on tetanus immunisation would be unnecessary and probably unethical

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Mandelblatt 1995[137] **Review purpose:** This study was designed to review research articles assessing the effectiveness of interventions to enhance physician breast cancer screening behavior **Quality assessment rating:** Moderate	**Inclusion criteria:** Studies in the US only Concurrent controls Start date chosen to coincide with publication of formal guidelines **Dates of articles reviewed:** January 1980–April 1993 **Total number of studies:** 20 **Total RCTs:** 11 **Studies focusing on screening mammography:** 20 **RCTs focusing on screening mammography:** 11 **Meta-analysis performed?** No	**Results:** The results were presented with clinical breast exam In university settings, physician reminders and audit with feedback each significantly increased use of mammography by approximately 5% to 20% In community based settings the effects of physician education also had a positive impact on mammography rates, which ranged from 6% to 14% Three studies were identified which addressed the use of audit and feedback interventions All three reported a significant increase in mammography screening The overall range of effect size was 15–24% **Conclusions:** Physician-based interventions can be effective in increasing screening use *Interventions should emphasise community practices and practices caring for underserved and older population
Shea 1996 [39] **Review purpose**: To conduct a meta-analysis of computer-based and manual reminder systems and to assess the overall effectiveness in ambulatory settings directed at preventive care	**Inclusion criteria:** Randomised, concurrent controls trials where the control group received no intervention Ambulatory settings **Dates of articles reviewed:** 1966–December 1995 **Total number of studies:** 16 **Total RCTs:** 16 **Studies focusing on screening mammography:** 11 **RCTs focusing on screening mammography:** 11 **Studies focusing on cervical cancer screening:** 9 **RCTs focusing on cervical cancer screening:** 9 **Meta-analysis performed?** Yes	**Results for mammography:** The following interventions improved preventive practices compared with the control condition for breast cancer screening – computer generated reminder (OR 1.88, 95% CI 1.44–2.45), manual reminder (OR 1.63, 95% CI 1.21–2.18) and computer plus manual reminder (OR 1.88, 95% CI 1.44–2.45) – unadjusted **Results for cervical cancer screening:** Very limited information provided for cervical cancer screening specifically Computer reminders improved preventive practices compared with the control condition for several other preventive care services, but not cervical cancer screening (OR 1.15, 95% CI 0.89–1.49) For all 6 classes of preventive practices combined, the adjusted OR was 1.77 (95% CI 1.38–2.27) **Computer plus manual reminders vs. manual reminders:** The adjusted OR for this comparison was 1.42 for all 6 preventive categories combined (95% CI 1.02–1.97; P=0.04), however, both methods had a lesser effect on cervical cancer screening than other preventive care practices (i.e. vaccinations, colorectal cancer screening) **Conclusions:** Computer generated reminders were effective for increasing, breast cancer screening Evidence from randomised controlled studies supports the effectiveness of data-driven computer-based reminder systems to improve prevention services in the ambulatory care setting

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Snell 1996[38] **Review purpose:** The focus of this meta-analysis was on studies that employed an intervention directed at either patients or physicians, or both, and measured its effects on screening rates for breast, cervical, and colorectal cancers. The objectives were to discern which intervention or combination of interventions was most successful and whether screening rates were enhanced more by targeting the patients, the physicians, or both patients and physicians	**Inclusion criteria:** Primary care setting directed at a patient, physician or both Addressed screening for breast, cervical or colorectal cancer **Dates of articles reviewed:** 1989–1994 **Total number of studies:** 38 **Total RCTs:** Unclear **Studies focusing on screening mammography:** Unclear **Studies focusing on cervical cancer screening:** Unclear **RCTs focusing on screening mammography or cervical cancer screening**: Unclear **Meta-analysis performed?** Yes	**Results:** Results are presented as a combination of breast, cervical and colorectal cancer and could not be separated. Interventions targeting either physician or patient were equally successful (d value (difference between 2 means)=+0.1894 and d=+0.1756, respectively) Studies targeting both physician and patient demonstrated a smaller effect size (d=+0.0514) Greater success was found for interventions targeting the physician both during and outside the patient visit (d=+0.1222 during visit, d=+0.1849 outside visit, d=+0.3375 both) Screening behaviour improved when the physicians were the targets of more than one, but not more than three, interventions (d=0.1360, d=+0.2495, d=+0.6829, d=-0.0058) Since a combination of during- and outside-visit interventions showed a larger effect size than either alone, a multifaceted approach to changing physician behaviour seems to be the best Effect size by screening activity for breast screening (n=41 cases) was d=+0.2236 (95% CI 0.1960–0.2512) Effect size by screening activity for cervical cancer screening (n=35 cases) was d+0.0083 (95% CI=-0.0174–0.0340) **Conclusions:** Cancer screening activities increase with interventions that target either the physician or the patient and, when physicians are targeted, multiple interventions to serve as behaviour cues and increase awareness appear optimal
Pirkis 1998[138] **Review purpose:** To determine the effectiveness of patient-reminder systems and GP-reminder systems in promoting uptake of Pap tests. The a priori hypothesis was that both would be more effective than 'normal care' in doing so	**Inclusion criteria:** RCT GP or family medicine setting, examining the effectiveness of GP and patient reminder in increasing the proportion of women screened for cervical cancer **Dates of articles reviewed:** 1966–December 1996 **Total number of studies:** 10 **Total RCTs:** 10 **Studies focusing on cervical cancer screening:** 10 **RCTs focusing on cervical cancer screening:** 10 **Meta-analysis performed?** Yes	**Results:** The women whose GPs had been prompted to remind them to have a Pap test were significantly more likely to do so than were control women (typical risk difference (TRD) -6.6%, 95% CI=5.2–8.0) The corresponding estimate of the number of women needed to be involved in a GP reminder scheme in order to generate one additional screen is 15.2(95% CI=12.6–19.3) The TRD for the patient reminder studies was 4.9% (95% CI=-2.6–7.2) In both cases, sensitivity analysis revealed that one study stood out as an exceptional result. The omission of this study induced homogeneity among remaining studies Once this study was removed, the TRD's for the GP reminder and patient reminder studies were 7.9% (95% CI=6.5–9.4) and 10.8% (95% CI=8.1–13.6), respectively **Conclusions:** The results strongly suggest that GPs should make use of GP and patient reminder systems

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Mandelblatt 1999[139] **Review purpose:** To determine the effectiveness of interventions targeted at providers to enhance the use of mammography **Quality assessment rating:** Moderate	**Inclusion criteria:** English language only Studies conducted in the US that used a RCT or concurrent non-RCT design, had defined outcomes, and presented data that could be abstracted for re-analysis Included studies that used either outcomes of ordering screening or completion rates of screening **Dates of articles reviewed:** 1980–1998 **Total number of studies**: 35 **Total RCTs:** 23 **Studies focusing on screening mammography:** 35 **RCTs focusing on screening mammography:** 23 **Meta-analysis performed?** Yes	**Results:** Behavioural interventions increased screening by 13.2% [95%CI=7.8–18.4] as compared with usual care and by 6.8% [95%C=4.8–8.7] as compared with active controls Cognitive intervention strategies improved mammography rates by 18.6% [95%CI=12.8–24.4] Sociological interventions also had a similar magnitude of effect on screening rates [13.1% increase, 95%CI=6.8–19.3] Interventions targeting both patients and providers were not significantly better at increasing screening than those targeting providers alone, and multiple approaches (e.g. behavioral and cognitive) were generally not more effective than a single approach All interventions targeted at physicians were effective in increasing screening rates **Conclusions**: Interventions were more effective in increasing mammography use when compared with usual care than with active controls Strategies that targeted both patients and providers were not significantly more effective than those targeting providers alone Decisions on the ultimate selection of an intervention to improve mammography receipt that targets providers should depend on feasibility, resources, expertise, and cost-effectiveness
Shekelle 1999[43] **Review purpose:** To determine the best strategies for early detection and prevention currently covered by Medicare and to assess interventions designed to improve influenza and pneumococcal immunisation rates, mammography rates, cervical smear cytology (pap test) and colon cancer screening	**Inclusion criteria:** Had to address one or more of the 5 services of interest and employ one of the following study designs: RCT, controlled clinical trial, controlled before-and-after study, or interrupted time series Primarily searched for data relevant to the Medicare population **Dates of articles reviewed:** 1980–1995 **Total number of studies:** 187 **Total RCTs:** 136 **Studies focusing on screening mammography:** 65 **RCTs focusing on screening mammography:** Not clear	**Mammography:** The effectiveness of interventions to improve the use of clinical preventive and screening services for mammography were: patient financial incentives OR 3.57 (95% CI 2.36–5.40); patient reminder OR 2.57 (95% CI 2.22–2.98); organisational change OR 2.26 (95% CI 1.81–2.82); provider education OR 2.26 (95% CI 1.81–2.82); provider reminder OR1.59 (95% CI 1.36–1.86); feedback OR 1.49 (95% CI 1.24–1.80) and patient education OR 1.31 (95% CI 1.12–1.52) **Cervical cancer screening:** Personalised reminders (signed by the patient's physician) were more effective than generic ones. And finally, feedback appeared to be a relatively ineffective intervention, as it was statistically beneficial only for increasing screening mammography **Conclusions:** Conclusions are presented across all screening topics Organisational change and financial incentives were most consistent at producing the largest improvements in use of all preventive and screening services

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Balas 2000[40] **Review purpose:** To assess the impact of clinician prompting on the provision of preventive care and to identify the effect of various covariates (reimbursement type, clinical characteristics, clinician specialty, and computerisation) **Quality assessment rating:** Strong	**Inclusion criteria:** RCT Physician prompt in the study group and no similar intervention in the control group Measurement of the effect on the number of preventive care activities **Dates of articles reviewed:** January 1, 1966–December 31, 1996 **Total number of studies:** 33 **Total RCTs:** 33 **Studies focusing on screening mammography:** 14 **RCTs focusing on screening mammography:** 14 **Studies focusing on cervical cancer screening:** 15 **RCTs focusing on cervical cancer screening:** 15 **Meta-analysis performed?** Yes	**Results In mammography:** The effect of prompting on mammography (n=14) 11.5% rate difference (95% CI 7.1–16.0) Results in cervical cancer screening: Very little data pertaining specifically to cervical cancer screening alone was reported The effect of prompting on Pap smear (n=15) showed a rate difference of 5.8% (95% CI 1.5–10.1) **Overall results:** Of the studies included, most addressed the clinical areas of cancer screening and prevention (20), immunisation (14), and diabetes management (4) Generally, prompting can significantly increase preventive care performance by 13.1% (95% CI 10.5–15.6 – including cancer screening – fecal occult blood, Pap smear, and mammography) Overall, prompting can significantly increase preventive care performance by 13.1% (95% CI 10.5–15.6) **Conclusions:** Prompting physicians can lead to a significant improvement in health maintenance Observed increase in performance of preventive care efforts could reap substantial reductions in total mortality The many prompting tools offer a wide selection of options that are equally effective and easily applicable in most healthcare organisations (e.g. checklists attached to the patient chart, tagged notes, computer-generated encounter forms, prompting stickers, patient carried prompting cards)

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Jepson 2000[42] **Review purpose:** To systematically review factors associated with the uptake of screening programs and to assess the effectiveness of methods to increase uptake **Quality assessment rating**: Moderate	**Inclusion criteria:** RCTs, quasi-RCTs, cohort and prospective case-control studies of any screening programs, where the outcome was screening uptake Must have used some form of multivariate analysis **Dates of articles reviewed:** 1996–1998 **Total number of studies:** 190 **Total RCTs:** 130 **Studies focusing on screening mammography:** 34 **RCTs focusing on screening mammography:** 16 **Studies focusing on cervical cancer screening:** 12 **RCTs focusing on cervical cancer screening:** 8 **Meta-analysis performed?** No	**Results:** 12 RCTs were identified which invited women by letter (vs. no letter) to attend mammograms. Three showed a significant effect of intervention and 5 showed no effect. Data could not be extracted from the remaining four studies 5 studies were identified by the review comparing reminder letters versus control or another intervention and showed evidence of some effectiveness of reminders for mammograms Four studies evaluated the impact of educational sessions, printed materials or educational outreach visits targeted towards health care providers. The studies suggest a small increase in the uptake of screening tests in the intervention group when compared with the control group. RRs were not calculated due to lack of data One RCT evaluating a day long education session for 8 screening procedures (Pap, mammography, breast self exam, cholesterol screening, etc) reported that physician education intervention ultimately increased the proportion of women having a mammogram ($p<0.01$) For printed educational materials 2 RCTs were identified for which RRs could be calculated and found no effect of printed materials. However, 7 other studies in which RRs could not be calculated, 1 found that printed materials were more effective than control; the other 6 did not Five RCTs evaluated the effectiveness of physician reminders in increasing uptake. RR's were calculated for three of the RCTs. All three reported an effect of the intervention, but one was only a small cluster RCT. One good quality RCT reported the mean mammography completion rate was 47.9 versus the control 34.6 which was statistically significant. (p value not reported) Five RCTs were identified for the combination of physician reminders and individual letters or reminders to increase mammography uptake. RRs were calculated for four RCTs and all reported a statistically significant effect of the intervention. One did not present enough details of uptake **Conclusions:** Interventions for which there is evidence of effectiveness are invitation appointments, letters (less effective for mammography), telephone calls, telephone counseling, reduction of financial barriers and chart reminders for physicians Most educational materials have limited effectiveness, but educational home visits may increase uptake To increase informed uptake, future interventions should include information on the likely harms and risks, as well as the benefits of screening These studies should include a measure of the knowledge and whether this knowledge was used in the decision to undergo screening Furthermore, more studies are needed that target ethnic-minority groups and other groups where uptake is low

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Bonfill 2001[34] **Review purpose:** To assess the effectiveness of different strategies for increasing the participation rate of women invited to community (population-based) breast cancer screening activities or mammography programs	**Inclusion criteria:** RCT Published and unpublished trials in which women were invited to a community breast screening activity or program **Dates of articles reviewed:** 1996–2000 **Total number of studies:** 14 **Total RCTs:** 14 **Studies focusing on screening mammography:** 14 **RCTs focusing on screening mammography:** 14 **Meta-analysis performed?** No	**Results:** The evidence favoured five active strategies for inviting women into community breast cancer screening services: letters of invitation (OR 1.66, 95% CI=1.43–1.92), mailed education material (OR 2.81, 95% CI 1.96–4.02), letter of invitation plus phone call (OR 2.53, 95% CI 2.02–3.18), phone call (OR 1.94, 95% CI 1.70–2.23), and training activities plus direct reminders for the women (OR 2.46, 95% CI 1.72–3.50) Home visits did not prove to be effective (OR 1.06, 95% CI 0.80–1.40) and letters of invitation to multiple examinations plus educational material favored the control group (OR 0.62, 95% CI 0.32–1.20) **Conclusions:** Most active recruitment strategies for breast cancer screening programs examined in this review are more effective than no intervention Combinations of effective interventions can have an important effect Some costly strategies, such as a home visit and a letter of invitation to multiple screening examinations plus educational material, are not effective Further reviews comparing the effective interventions and studies that include cost-effectiveness, women's satisfaction, and equity issues are needed

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country Review purpose/Aim	Inclusion criteria, Dates articles reviewed, Number of studies included, Meta-analysis performed?	Results Conclusions
Kupets 2001[41] **Review purpose:** To determine the most effective strategies for the implementation of breast and cervical cancer screening delivered to women	**Inclusion criteria:** Study conducted in North America RCT Primary care physician (including family physician, GP, gynaecologist and internist); Study included assessment of both breast and cervical screening **Dates of articles reviewed:** 1966–2000 **Total number of studies:** 14 **Total RCTs:** 14 **Studies focusing on screening mammography:** 14 **RCTs focusing on screening mammography:** 14 **Studies focusing on cervical cancer screening:** 14 **RCTs focusing on cervical cancer screening:** 14 **Meta-analysis performed?** No	**Results:** Physician-based strategies, especially manual and computer-generated reminders, appear to be the most effective approach in the implementation of breast cancer screening delivery to women. Computer-generated reminders improved the delivery of mammography to patients by an absolute rate of 6–30% 2 studies were identified and found that both studies indicate a significant improvement in the delivery of mammograms, with an absolute increase of 14–30% for performance rates and 15% for delivery rates. The NNI (Number needed to intervene: refers to the number of physicians or physician–patient pairs that must be exposed to the intervention before one screening test is performed) was 3–7 physicians There was a significant improvement of delivery of breast screening with an absolute increase of 35%, with an NNI of 2.5–3 physicians for the use of a manual reminder placed on the chart from studies identified (N=2) 4 studies addressed patient reminders. The results were conflicting. 2 studies did not show a significant improvement, while 2 studies did show an improvement (10%, results not reported) Interventions targeting the patient alone showed an absolute increase in breast cancer screening of 10%, those targeting physician and patients for breast screening was 5–23% and those targeting the physician alone for breast screening ranged from 6–35% **Cervical cancer screening**: Of the 6 studies reviewed for computer-generated reminders, 3 showed significant improvements in cervical cancer screening The delivery of cervical cancer screening improved by 9–30% with an NNI of 3–10 physicians For the 2 studies identified for audit and feedback, neither study showed improvement for cervical cancer screening when compared. The results for mailed patient reminders are mixed. Of the 4 studies assessed for the review, 2 studies showed improvement in cervical cancer screening (10%, the other study does not report numbers), and 2 show no significant improvement; in fact, there is a negative effect in the study arm with a decrease in screening of 10%ing intervention versus control arm Interventions targeting patients alone showed an absolute increase in cervical cancer screening of 10%. Interventions involving both the patient and physician resulted in an absolute increase of 10–30%, and those targeting physicians alone resulted in an increase of 9–40% **Conclusions:** Despite the availability of screening tests for the detection of breast and cervical cancer, the rates with which these are being offered are low Generally, patient interventions with the highest level of accrual to screening were mailed letter invitations. The interventions with the highest success rates included physician reminder systems, both computerised and manual

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country	Study design Target group Purpose	Dissemination Strategy Evaluated	Interventions	Findings
Dietrich 1992[46] United States	**Study design:** RCT **T** Office based GPs and general internists in New Hampshire and Vermont **Purpose:** To test the impact of physician education and facilitator assisted office system interventions on cancer early detection and preventive services	(1) Facilitator visited each practice 3 to 4 times over 3 months; each visit lasted approximately 120 minutes. Performed an initial audit of each practice to assess the status of preventive care and assisted practices in the design and implementation of office system interventions. Practices only implemented those interventions that meet their perceived needs (2) Facilitator + workshop same as (1) plus physician from each practice attended a 1 day workshop led by an expert who reviewed the US National Cancer Institute's prevention and screening recommendations and taught specific skills. Also provided a written syllabus. Note: The workshop only and the control groups did not receive information on the use of office systems interventions for cancer prevention or early detection	Multiple office system interventions including preventive care flow sheets, chart stickers, health education posters and brochures, and patient health diaries (None of the interventions were computer-based)	**Mammography:** The response rate for the cross-sectional survey pre-experiment was 91% (n=2,436 patients) and 93% (n=2,595) at 12 months follow-up: More patients in each of the 3 experimental groups reported having a mammogram than patients in the control group at 12 month follow-up (facilitator + workshop vs. controls proportion: 0.78 vs. 0.57, p<0.01; facilitator only vs. controls 0.77 vs. 0.57, p<0.01; and workshop only vs. controls 0.71 vs. 0.57, p<0.01; baseline proportions were used as covariates) There was no significant difference between the facilitator + workshop, facilitator only or workshop only groups in proportion of patients reporting having had a mammogram at 12 month follow-up Report's overall conclusion: Community practices assisted by a facilitator in the development and implementation of an office system can substantially improve provision of cancer early detection and preventive services **For cervical cancer screening:** The response rate for the cross-sectional survey pre-experiment was 91% (n=2436 patients) and 93% (n=2595) at 12 months follow-up. There was no significant increase in the number of eligible patients in the facilitator only group reporting having a Pap test compared with patients in the control group at 12 month follow-up (Proportion 0.71 vs. 0.61) There was no significant increase in the number of eligible patients in the facilitator + workshop group reporting having a Pap test compared to patients in the control group at 12 month follow-up (Proportion 0.65 vs. 0.61) Report's overall conclusion: Community practices assisted by a facilitator in the development and implementation of an office system can substantially improve provision of cancer early detection and preventive services

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country	Study design Target group Purpose	Dissemination Strategy Evaluated	Interventions	Findings
Williams 1998[50] United States	**Study design:** One group, pre-post test **Target Group:** GPs and their support staff.	Purpose: To test the feasibility of 'academic detailers' calling on GPs in their offices and to determine if they: (1) facilitate the office management of cancer prevention activities, and (2) increase doctors' knowledge and use of educational and patient service resources of the American Cancer Society (ACS). The study also sought to determine what barriers prevent performance of cancer prevention and screening activities in GPs' offices	Academic detailing (by either a study nurse or physician) Multiple interventions: Medical record prompts, recall systems and patient educational materials	Practices were assessed at baseline and at follow-up. The follow-up time frame was not reported • Baseline: Only one of the practices used the ASC patient information. Follow-up: All 10 practices used the ACS patient information and 9 displayed the information in the wall racks provided • Baseline: Two practices used some form of prompt on the medical record (both indicated the date of the last Pap test). In 2 other practices, nurses were responsible for determining what preventive procedures were due (but no chart summary or prompt existed). Follow-up: There were only minor changes to medical records. Practices that had not previously used chart summaries or prompts did not add them. However, practices that previously used chart summaries or prompts added items, typically Pap test and mammography notations • Baseline: One practice had a recall system for scheduling mammography and 5 had a recall system for Pap tests Follow-up: One practice with a Pap test recall system at baseline added mammography recalls, and one practice with no recall system at baseline added both mammography and Pap recalls • The total cost of the 17 office visits by the academic detailers was USD913 • Barriers to delivering preventive care: time, administrative process and lack of third party reimbursement

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country	Study design Target group Purpose	Dissemination Strategy Evaluated	Interventions	Findings
Kinsinger 1998[44] United States	**Study Design:** RCT **Experimental group:** Academic detailing on how to develop office systems for breast cancer screening **Purpose**: To evaluate an outreach intervention designed to improve performance rates of breast cancer screening through implementation of office systems in community primary care practices	**Purpose:** Academic detailing (Facilitators met with practice physicians and staff in the intervention group an average of 3 times with additional telephone calls or drop-in visits over a period of 12–18 months to assist in developing office systems tailored to increase breast cancer screening)	Office systems (Defined as an organised approach within a medical practice for routinely providing a given service, such as breast cancer screening, to patients for whom this service is indicated. These systems involve teamwork among a number of office staff, not just physicians. Tools such as flow sheets, chart prompts and patient educational materials can all be part of an office system, but most important is how these materials are integrated within the usual procedures of the practice)	**Mammography:** Significant increases in 3 of 5 indicators in intervention compared to control practices from baseline to follow-up: Indicator 1: Practices with ≥ 50% of records having an entry on a flow sheet increased from 10–29% in intervention practices compared to a decrease from 19–7% in control practices (p=0.02); Indicator 2: Practices in which ≥ 50% of physicians report having written preventive care policy increased from 16–57% in intervention practices compared to a decrease from 13–7% in control practices (p=0.01); and Indicator 3: Practices in which ≥ 50% of physicians report that nurses frequently or sometimes recommend mammograms to patients increased in intervention practices from 41–58% compared to a decrease from 48-33% in controls (p=0.04) No significant differences were found for the 2 other indicators in intervention compared to control practices from baseline to follow-up. Indicator 4: The percentage of practices in which ≥ 50% of physicians report that nurses identify patients due for mammograms (intervention 37–65%; control 39–44%). Indicator 5: The percentage of practices where ≥ 50% of physicians report frequent use flow sheets or computerised reminders to identify patients due for mammograms (intervention 35–65%; control 29–44%). Mean number of indicators increased significantly in intervention practices (1.3–2.8) compared with control practices (decrease 1.5–1.4) (p=0.0003). However, at follow-up, only 23% of intervention practices reported a complete office system for breast cancer screening The proportion of records with “mention” of mammogram in the last year increased significantly more in intervention practices than in controls (12.7% vs. 3.5%, p=0.014). However, there was no difference between intervention and control practices in the change in proportion of women's records with a mammogram report in the last year (4.7% vs. 3.4%)

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country	Study design Target group Purpose	Dissemination Strategy Evaluated	Interventions	Findings
Scott 1999[140] United States	**Study design:** Descriptive study **Target group:** Managed care organisations **Purpose:** To assess the dissemination of a mammography intervention manual in a managed care setting and to measure the effect of the manual on the managed care organisation's choice of intervention strategies	**Compared 2 strategies:** (1) One-day workshop and user guide to accompany the intervention manual (2) Passive dissemination (Delivery of the intervention manual to the managed care organisations)	**Intervention manual:** Summarised research findings, highlighted the most effective intervention strategies and provided practical material (such as template letters and telephone scripts)	• There was little difference in interventions implemented between plans that attended the workshop and those that did not (no statistical analysis reported) • Seven of the managed care organisations implemented more interventions in the year after receiving the manual than in the year prior to dissemination of the intervention manual and there was an improvement in the type of interventions implemented (i.e., evidence-based interventions). The 7 managed care organisations that used the manual all implemented an intervention directed to physicians. Some managed care organisations also implemented interventions directed towards patients (e.g. reminder letters) • Mammography rates in the year prior to dissemination of the manual were compared to the rates in the year after dissemination. In all 7 of the managed care organisations that used the intervention manual, mammography-screening rates increased (range: 0.22–4.0%). In the 1 managed care organisation that did not use the intervention manual, its mammography-screening rate decreased 2.67% • A key factor for intervention implementation appeared to be the length of employment of the point person. The 2 plans that implemented the least intensive interventions had point people who had only been in their positions for short periods of time • Factors facilitating use of the manual and implementation of interventions were: (1) motivation of the point person to improve mammography rates, (2) support of senior management, (3) adequate resources (time, personnel, and funds), and (4) organisation and content of the intervention manual • Barriers to use and implementation were (finances, time, and programing) and data limitations (identifying population to be targeted and getting correct contact information)

Table 3.2 Mammography and cervical cancer screening interventions that targeted healthcare providers through academic detailing (Ellis 2003[33])

Reference Country	Study design Target group Purpose	Dissemination Strategy Evaluated	Interventions	Findings
Lemelin 2001[45] Canada	**Study design:** RCT **Target Group:** Primary care practices that have a payment system based primarily on capitation in Ontario, Canada **Purpose:** To evaluate a multifaceted outreach intervention, delivered by nurses trained in prevention facilitation, to improve prevention in primary care	Educational facilitators Over an 18 month period each practice was visited an average of 33 times; each visit lasted approximately 1 hour. The facilitators performed an initial audit and feedback of each practices baseline preventive performance rates; facilitated the development of practice goals and policy for preventive care; and assisted practices in selecting and implementing interventions to improve preventive care)	Multiple interventions including reminder systems, flow charts and patient educational materials	Random chart audit of 100 records/practice was performed a baseline and again at follow-up: • At baseline, the preventive performance index was not significantly different between the facilitator and control groups (31.9% and 32.1%, respectively). At follow-up, the corresponding values were 43.2% and 31.9%, the absolute increase in the facilitator group was of 11.5% was statistically significant (p<0.001) **Mammography specific findings:** • On chart audit, at baseline, 53.6% of eligible patients had mammograms in the facilitator group and 53.4% in the control group. At follow-up, the corresponding values were 67.5% and 58.7%; there was no significant difference in change between the two groups Results pertaining to cervical cancer screening: Random chart audit of 100 records/practice was performed a baseline and again at follow-up: At baseline, the preventive performance index was not significantly different between the facilitator and control groups (31.9% and 32.1%, respectively). At follow-up, the corresponding values were 43.2% and 31.9%, the absolute increase in the facilitator group of 11.5% was statistically significant (p<0.001) **Cervical cancer screening specific findings:** On chart audit, at baseline, Pap testing was performed with 60.8% of eligible patients in the facilitator group and with 57.9% in the control group. At follow-up, the corresponding values were 66.2% and 59.1%, there was no significant difference in change between the two groups **Overall findings from the process evaluation:** • All facilitator group practices received preventive performance audit and feedback, achieved consensus on a plan for improvement, and implemented a reminder system. 90% implemented a customised flow sheet, 10% used a computerised reminder system, 95% wanted critically appraised evidence for prevention, and 100% received patient educational materials • Audit and feedback, consensus building, and development of reminder systems were identified as the key components by content and bivariate analysis • 95% of physicians were satisfied or very satisfied with the educational facilitator approach

Table 3.3 Change in the percentage of individuals completing cancer screening between intervention and control practices among unscreened individuals (Arroyave 2011[37])

Reference Country	Preventive services offered	Type(s) of cancer(s) addressed in the study	Screening test analysed	Change in proportions or percentages	Intervention
Herman 1995[47] United States	Cancer screening	Breast	Mammogram CBE	18.4* 13.7	Nurse/ancillary staff role was redefined to expedite administrative support for providing preventive services
Mohler 1995[48] United States	Cancer screening	Breast	Mammogram	32*	Medical assistant from the practice was used for telephone call interventions
Binstock 1997[49] United States	Cancer screening	Cervical	Pap Smear	18.8**	Clerk was responsible for calling patients, making appointments affixing chart reminders, sending letters and provider memos

Statistically significant * P <0.05; ** P < 0.001

Table 3.4 Change in the proportion of individuals receiving cancer screening services between intervention and control practices (Arroyave 2011 Table 3)

Type of organisational change Author/year/observation time	Country	Type of preventive service offered	Type(s) of cancer(s) addressed in the study	Screening test analysed	Change in proportions or percentages
Belcher 1990	United States	Cancer screening counselling services Immunisation services History & physical Lab services	Breast, cervical, colon	FOBT	47*
Williams 1998	United States	Cancer screening	Breast, cervical, colon	Mammogram CBE Pap Smear FOBT FS	8.8* 8.3 2.7 1.0 1.3

Statistically significant * $P<0.05$

Table 3.5 Bonfill systematic review and extracted trials

Bonfill 2001[34]	Randomised or controlled clinical trials assessing the effect of different strategies of recruitment into any community breast cancer screening activity or program, compared with no active intervention Opportunistic interventions, that is, those arising from recruitment when women seek help for a nonspecific problem in any health care setting, have not been included	We identified 151 articles. Thirty-four studies were excluded because they lacked a control group; 58 of the other 117 articles were considered as opportunistic and not community-based; 59 articles, which reported 70 community-based randomised controlled trials or clinical controlled trials, were accepted. In 24 of these, the control group had not been exposed to any active intervention, but 8 of the 24 had to be excluded because the denominator for estimating attendance was unknown. At the end, 16 studies constituted the material for this review, although two studies were further excluded because their groups were not comparable at baseline. Data from all but one study were based on or converted to an intention-to-treat analysis. Attendance in response to the mammogram invitation was the main outcome measure	The evidence favoured five active strategies for inviting women into community breast cancer screening services: letter of invitation (OR 1.66, 95% CI 1.43 to 1.92), mailed educational material (Odds Ratio (OR) 2.81, 95% Confidence Interval (CI) 1.96 to 4.02), letter of invitation plus phone call (OR 2.53, 95% CI 2.02 to 3.18), phone call (OR 1.94, 95% CI 1.70 to 2.23), and training activities plus direct reminders for the women (OR 2.46, 95% CI 1.72 to 3.50). Home visits did not prove to be effective (OR 1.06, 95% CI 0.80 to 1.40) and letters of invitation to multiple examinations plus educational material favoured the control group (OR 0.62, 95% CI 0.32 to 1.20). Most active recruitment strategies for breast cancer screening programs examined in this review were more effective than no intervention. Combinations of effective interventions can have an important effect. Some costly strategies, as a home visit and a letter of invitation to multiple screening examinations plus educational material, were not effective. Further reviews comparing the effective interventions and studies that include cost-effectiveness, women's satisfaction and equity issues are needed
Clementz 1990[56]	**Geographic region:** Illinois Kansas (USA) **Subjects**: Women registered in a Family Medicine Center **Eligibility criteria:** No personal history of breast cancer **Aged**: 50–69 years N=220	RCT by women. Random number computer-generated **Duration:** 4 months **Losses**: 14 of 116 in the intervention group (12%). 28 of 104 in the control group (26.9%). Reanalysis data by intention to treat	**Intervention:** Personalised letter signed in a blinded fashion by the patient's personal physician plus a second recall letter with patient educational material **Outcomes:** The percentages of patients having a screening cancer test Other intervention: fecal occult testing, Papanicolau smears. Intervention and control group were comparable **Chart audit evaluation:** The control group had a higher rate of attendance in response to the mammogram invitation than the group in which the intervention (letter of invitation to multiple examinations plus educational material) was implemented

Irwig 1990[59]	**Geographic region:** Sydney, Australia **Subjects:** General population	**Eligibility criteria:** Women registered in a breast screening centre who failed to attend **Aged:** 45–70 years. RCT by women. Stratification by the range of previous involvement with the Breast X-Ray Program No further details **Duration:** 2 years **Losses:** 22 of the 440 (5%). Analysis by intention to treat	**Intervention:** 1. Letter from the GP with appointment (162) 2. Letter from the GP without appointment (126) 3. Control (152) **Outcomes:** Attendance rates Attendance to mammogram: Intervention group: 91/288; Control group: 10/152. Test for overall effect: Z=5.93 (P<0.00001) Peto Odds ratio: Peto, Fixed, 95% CI: 4.10 [2.57, 6.54]
Lantz 1995[60]	**Geographic region:** Wisconsin, USA **Subjects:** Women enrolled in a low income managed care program	**Eligibility criteria:** Not breast screened in the previous 18 months **Aged:** 40–79 years METHODS. RCT by women. No further details **Duration:** 6 months **Losses:** 33 of 337 in the intervention group (9%). No description of losses in the control group. Analysis by intention to treat	1. Reminders letters from GP plus follow-up phone call from a health educator (337) 2. Control (322) **Outcomes:** Attendance rates **Other intervention:** Pap smear Intervention and control groups were comparable **Intervention group:** 88/337; Control group: 28/322. Peto Odds Ratio, Peto, Fixed, 95% CI: 2.53 [2.02, 3.18]
Mohler 1995[48]	**Geographic region:** Colorado, USA **Subjects:** Women registered in a private practice GP in a community hospital	RCT by women. Random number computer-generated **Duration:** 2 months **Losses**: 0 **Analysis by intention to treat eligibility criteria:** No mammogram in the preceding 2 years, seen in the office the preceding 5 years, no current address and phone number, no personal history of breast cancer, active patient of the practice **Aged:** 50–59 years N=151	**Interventions:** 1. Physician telephone call (38) 2. Medical assistant telephone call (37) 3. Physician letter (38) 4. Control (38) **Outcomes:** The proportion of mammograms obtained; Cost and cost-effectiveness. Notes: Women without health insurance had to pay up to 80$ for their mammography (15-20%) Intervention and control groups were comparable

Atri 1997[58]	**Geographic region:** London, UK **Subjects:** General multi-ethnic population **Eligibility criteria:** Women registered in a breast screening centre who failed to attend. **Aged:** 50–64 years N=2064	**Interventions:** 1. Training program for GP reception staff (contact all women by telephone or by sending a GP letters) 2. (995) 3. Control (1069) **Methods:** RCT by GP. Stratification and practices matched No further details **Duration:** 12 months **Losses:** 78 of 995 (8%) in the intervention group. No description of losses in the control group. Analysis by intention to treat	**Outcomes:** Overall attendance rate and by ethnic group. NOTES: Intervention and control groups were comparable The one study comparing a training program plus a reminder with no intervention (Atri 1997) had 995 women in the intervention group and 1069 in the control group. The odds ratio for the outcome, 'attendance in response to the mammogram invitation during the 12months after the invitation', was 2.46 (95%CI 1.72 to 3.50), which was statistically significant. However, the study (Atri 1997) was a cluster-randomised study

Table 3.6 Everett systematic review & extracted trials

Everett 2011[36]	Randomised controlled trials (RCTs) and cluster RCTs of universal, selective or opportunistic cervical cancer screening	Invitations, reminders, education, message framing, counselling, risk factor assessment, procedures, economic	GP invitation letter versus invitation letter from other authority sources: Bowman 1995 found little difference between GP invitation letters and health clinic invitation letters in the uptake of cervical screening (RR=1.69, 95% CI: 0.75 to 3.82). Segnan 1998 found that women who received GP letters to attend a cervical screening program had a significantly higher uptake of screening than those who received invitation letters from program coordinators (RR=1.13, 95% CI: 1.05 to 1.21). ANALYSIS 2.1 Three-way comparison of television media, television media combined with invitation letter and television media combined with GP based recruitment: A trial of each television media intervention was carried out in three postal regions in New South Wales – a rural locality, a country town and a major rural centre. Three control regions were selected to be demographically similar to the corresponding regions. Television media alone was associated with a significant increase in attendances for screening in the rural centre. The media/ letter based campaign was associated with a significant increase in attendances in the rural locality and rural centre. The media/GP based campaign was associated with significant increases in attendances in all three regions.
Ward 1991[61]	RCT **Country:** Australia Comparison of face-to-face counselling by a GP with no counselling	**Design:** RCT **Baseline comparability:** No significant differences between the study groups in terms of factors studied Follow-up – 1month Country – Australia Setting – General practice Initial screening status – due 204 female patients of 16 GPs in the inner metropolitan region of Sydney **Inclusion criteria:** Women: aged 20–65 years; provided consent Physicians: provided consent; complied with study procedures **Exclusion criteria:** Women: pregnant; had smear in past year; attending for smear that day; hysterectomy; never sexually active with male partner; insufficient command of English to complete questionnaire **Physicians:** Worked<20 hrs/week; were on leave/sick leave at time or recruitment; were expected to take leave during the study period; did not have the equipment to take smears	**1. Minimal intervention:** GP advised eligible women of need for smear and offered to perform it immediately. Those not consenting advised to make appointment for smear within a week n=99 **2. Maximal intervention:** GP advised woman of need for smear and offered to perform it immediately; GP attempted to persuade those not consenting during that consultation by exploring barriers and reasons for self-exclusions. If still did not consent, GP advised making an appointment for smear within a week n=103 **Outcome:** Pap smear uptake determined by administrative records **Results:** Total events: 60 (Counselling), 52 (Control) Heterogeneity: not applicable Test for overall effect: Z=1.75 (P=0.080) **Conclusion:** Women given counselling to encourage attendance of a cervical screening program had a significantly higher uptake of screening than those given no counselling or patient prompts alone (RR=1.23, 95%, CI: .98–1.55)

Bowman 1995[57]	RCT **Country:** Australia **Setting:** General practice **Initial screening status:** Overdue	Over 7000 potentially eligible women in an Australian community were identified by a random household survey (developed by the Australian Bureau of Statistics) **Inclusion criteria:** Aged 18–70 years **Exclusion criteria:** Not sexually active; could not speak English; infirm; not at home when contacted; hysterectomy **Method:** Design – RCT Baseline comparability – No significant differences between study groups Follow-up – 6 months	**GP reminder letter:** 1. GP reminder letter n=255 2. Women's health clinic invitation n=220 3. Pamphlet n=219 4. Control group (not stated) n=219 **Outcome:** Pap smear uptake determined by administrative records Bowman 1995 found little difference between GP invitation letters and health clinic invitation letters in the uptake of cervical screening (RR=1.69, 95% CI: 0.75 to 3.82)
Segnan 1998[141]	RCT **Country:** Italy **Setting:** GP practice in national screening program **Initial screening status**: Due 8385 women attending GPs in Turin who were part of the population based screening program ('Prevenzione Serena')	**Inclusion criteria:** Aged 25–64 years Resident of Turin **Exclusion criteria:** Previously diagnosed cervical cancer; suffering from terminal illness or severe psychiatric symptoms **Method:** Design - RCT Baseline comparability – no significant differences were found between the study groups in terms of the variables examined Follow-up – 1 year	**Interventions:** 1. Personal letter signed by GP with prefixed appointment (Control) n=2100 2. Personal letter, signed by GP prompting appointment, n=2093 3. Personal letter signed by program co-ordinator with prefixed appointment n=2094 4. Personal letter with extended text signed by GP with prefixed appointment n=2098 **Outcome:** Pap smear uptake determined by administrative records **Results:** Segnan 1998 found that women who received GP letters to attend a cervical screening program had a significantly higher uptake of screening than those who received invitation letters from program coordinators (RR=1.13, 95% CI: 1.05–1.21)

Byles 1996[67]	RCT **Country:** Australia **Setting:** Community **Initial screening status:** Due and overdue Nine geographically discrete, regions were selected within three adjacent TV broadcasting areas	The regions were randomly assigned to the study groups and data gathered on eligible women through administrative records pre-and post-intervention **Inclusion criteria:** Aged 18–70 years English-speaking **Exclusion criteria:** Physically/intellectually impaired **Methods:** Design - RCT (cluster) Baseline comparability - study regions matched on census data Follow-up - 3 months (TV media and letter), 6 months (GP intervention) 1. TV media campaign 2. TV media combined with invitation letter 3. TV media combined with GP based recruitment through workshops Control	The cluster RCT of Byles 1994 assessed the effectiveness of three community based strategies to promote screening for cervical cancer. A trial of each television media intervention was carried out in three postal regions in New South Wales – a rural locality, a country town and a major rural centre. Three control regions were selected to be demographically similar to the corresponding regions. Television media alone was associated with a significant increase in attendances for screening in the rural centre. The media/letter based campaign was associated with a significant increase in attendances in the rural locality and rural centre. The media/GP based campaign was associated with significant increases in attendances in all three regions. All three interventions were associated with significant increases in the number of women attending for screening above those observed in the control regions. Furthermore, these increases were not restricted to women at low risk. They were also found for older women (aged 50 to 69 years) and women who had not had a Pap smear within the past three years

Table 3.7 Colorectal studies

Brawarsky 2004[63]	**Country:** United States This study explored: (1) patient characteristics associated with physician recommendation for colorectal cancer (CRC) screening and patient adherence to recommendation, and (2) the combined effect of recommend-ation and adherence on CRC testing, broadly defined	Data were from the 1999 MA Behavioral Risk Factor Surveillance System (BRFSS) and a call-back survey of 869 BRFSS participants, age 50 and older. Logistic regression was used to identify correlates of recommendation, adherence, and testing	Patient–physician factors were positively associated with recommendation, adherence and testing. Inadequate health insurance was negatively associated with recommendation (OR=0.45, 95% CI=0.27–0.78) and testing (OR=0.64, 95% CI=0.38–1.1). Men were not more likely to be recommended (OR=1.1, 95% CI=0.78–1.5), but were more likely to adhere (OR=1.9, 95% CI=1.2–2.0) and to be tested (OR=1.4, 95% CI=1.0–1.9). There were gender differences in recommendation when considering health and risk factor measures. Research is needed to understand differences in recommendation and adherence. Greater encouragement and follow-through may be needed for groups less likely to adhere
Cole 2007[64]	**Country:** Australia **Objectives:** To investigate the influence of general practitioner (GP) endorsement on participation in screening for colorectal cancer based on a faecal occult blood test (FOBT)	**Setting:** South Australian residents (n=2400), in 1999, aged >50 years **Method:** Random selection of three groups (GP1, GP2, GP3) from two general practices and of one group (ER) from the federal electoral roll; n=600 per group. Without previous communication or publicity, subjects were posted an offer of screening by immunochemical FOBT. The GP1 and ER groups were invited without indication that their GP was involved; GP2 received an invitation indicating support from the practice; and GP3 received an invitation on practice letterhead and signed by a practice partner. A reminder was posted at 6 weeks. Participation was defined as return of correctly completed FOBT sample cards within 12 weeks	**Results:** Participation rates were: GP1 192/600 (32.0%), GP2 228/600 (38.0%), and GP3 244/600 (40.7%); c2=10.2, p=0.006. Both GP2 and GP3 differed significantly from GP1 (odds ratio (OR) 0.77, 95% confidence interval (95% CI) 0.60 to 0.98 and relative risk (RR)=0.69, 95% CI 0.54 to 0.87 respectively). ER (193/600 (32.2%)) and GP1 were not significantly different. Age but not sex was significantly associated with participation. Overall test positivity rate was 4.6%; five malignancies were found in the 918 who performed FOBT **Conclusions:** Association of a GP of recent contact with a screening offer in the form of a personalised letter of invitation achieves better participation than does the same letter from a centralised screening unit that does not mention the GP. Thus, GP enhanced participation is achievable without their actual involvement. Additional strategies are needed to further improve participation.

Ling 2009[65]	**Country:** United States **Background:** Colorectal cancer screening is underused. Our objective was to evaluate methods for promoting colorectal cancer screening in primary care practice	**Method**: A22 factorial randomised clinical trial measured the effects of a tailored vs non-tailored physician recommendation letter and an enhanced vs. Non-enhanced physician office and patient management intervention on colorectal cancer screening adherence. The enhanced and non-enhanced physician office and patient management interventions varied the amount of external support to help physician offices develop and implement colorectal cancer screening programs. The study included 10 primary care physician office practices and 599 screen-eligible patients aged 50 to 79 years. The primary end point was medical-record-verified flexible sigmoidoscopy or colonoscopy. Statistical end-point analysis (according to randomisation intent) used generalised estimating equations to account for correlated outcomes according to physician group	**Results:** During a 1-year period, endoscopy in the lower gastrointestinal tract (lower endoscopy) occurred in 289 of 599 patients (48.2%). This finding included the following rates of lower endoscopy: 81 of 152 patients (53.3%) in the group that received the tailored letter and enhanced management; 103 of 190 (54.2%) in the group that received the non-tailored letter and enhanced management; 58 of 133 (43.6%) in the group that received the tailored letter and non-enhanced management; and 47 of 124 (37.9%) in the group that received the non-tailored letter and non-enhanced management. Enhanced office and patient management increased the odds of completing a colonoscopy or flexible sigmoidoscopy by 1.63-fold (95% confidence interval, 1.11-2.41; P=.01). However, the tailored letter increased the odds of completion by only 1.08-fold (95% confidence interval, 0.72-1.62; P=.71) **Conclusions:** Approximately one-half of the screen eligible primary medical care patients aged 50 to 79 years obtained lower endoscopic colorectal cancer screening within 1 year of recommendation. An enhanced office and patient management system significantly improved colorectal cancer screening adherence
Zajac 2010[66]	**Country:** Australia **Objectives:** To investigate the effect of general practice (GP) and general practitioner (GPR) endorsement for faecal occult blood test (FOBT)-based screening on maintenance of participation in screening over four successive screening rounds	**Setting:** South Australian residents aged 50 years **Method:** Random selection of four groups (n ¼ 600 per group): one from the Commonwealth electoral roll (ER) and three from the combined patient lists of two collaborating GPs (GP1, GP2, GP3). Subjects were mailed offers to screen using a faecal immunochemical test over four successive rounds, spaced approximately 18 months apart. The GP1 and ER groups were invited to screen without any endorsement from a GPR or medical practice; GP2 invitees received an invitation indicating support for screening from their medical practice; and GP3 invitations were printed on practice letterhead and were signed by a GPR	**Results:** Multivariate analyses indicated that initial participation as well as re-participation over four successive rounds was significantly enhanced in the GP2 (39%, 42%, 45% and 44%) and GP3 groups (42%, 47%, 48% and 49%) relative to the ER group (33%, 37%, 40% and 36%). The analyses also indicated that 60–69 year olds were most likely to participate in all rounds (relative risk [RR] 1.49, 1.39, 1.43 and 1.25), and men were generally less likely to participate than women in all screening rounds (RR 0.86, 0.84, 0.80 and 0.83) **Conclusions:** Associating a GPR or medical practice of recent contact with an invitation to screen achieves better participation and re-participation than does an invitation from a centralised screening unit. Furthermore, enhanced participation can be achieved by practice endorsement alone without requiring actual GPR involvement

Senore 2010[142]	**Country:** Italy **Purpose:** The objective of this study was to study predictors of patients ' participation in colorectal cancer (CRC) screening	**Method**: Men and women, aged 55–64 years, were randomised to the following: (i) biennial faecal occult blood test (FOBT) delivered by mail (n=2,266); (ii) FOBT delivered by a general practitioner (GP) / screening facility (n=5,893); (iii) " once-only " sigmoidoscopy (FS) (n=3,650); (iv) FS followed by FOBT for screenees with negative FS (n=10,867); and (v) patient's choice between FS and FOBT (n=3,579). A stratified (by screening arm) random sample of attenders and non-attenders was contacted by trained interviewers 4 months after the initial invitation Subjects giving their consent were administered a questionnaire (available online) investigating perceptions of individual CRC risk, attitudes toward prevention, adoption of health protective behaviours, and reasons for attendance / nonattendance. Adjusted prevalence ORs were computed by multivariable logistic regression	**Results:** The response rate was 71.9% (701 of 975) among non-attenders and 88.9% (773 of 870) among attenders. Adjusting for screening arm, centre, gender, age, and education, participation was significantly higher among people who consulted their GP before undergoing screening (OR: 4.24; 95% CI: 3.11–5.78), who mentioned one first-degree relative with CRC (OR: 3.62; 95% CI: 2.0 –6.49), who reported regular physical activity (OR: 1.85; 95% CI: 1.33–2.55), and who read the mailed information (letter only: OR: 1.85; 95% CI: 1.23–2.78; letter + leaflet: OR: 3.18; 95% CI: 2.12–4.76). People who considered screening to be ineffective (OR: 0.12; 95% CI: 0.08–0.19), those who considered it to be effective but reported even moderate levels of anxiety (OR: 0.32; 95% CI: 0.23–0.45), and those who mentioned previous knowledge of CRC screening tests were less likely to accept the invitation (OR: 0.49; 95% CI: 0.34–0.70) **Conclusions:** Adoption of health protective behaviours is associated with a higher attendance rate, whereas anxiety represents a strong barrier, even among people who deemed screening to be effective. Increasing the proportion of people who consult their GP when making a decision regarding screening might enhance participation
Hewitson 2011[62]	**Country:** UK **Purpose:** The trial aimed to investigate whether a general practitioner's (GP) letter encouraging participation and a more explicit leaflet explaining how to complete faecal occult blood test (FOBT) included with the England Bowel Cancer Screening Program invitation materials would improve uptake	**Method:** A randomised controlled 2 × 2 factorial trial was conducted in the south of England. Overall, 1288 patients registered with 20 GPs invited for screening in October 2009 participated in the trial. Participants were randomised to either a GP's endorsement letter and/or an enhanced information leaflet with their FOBT kit. The primary outcome was verified with return of the test kit within 20 weeks	Both the GP's endorsement letter and the enhanced procedural leaflet, each increased participation by ~6% - the GP's letter by 5.8% (95% CI: 4.1–7.8%) and the leaflet by 6.0% (95% CI: 4.3–8.1%). On the basis of the intention-to-treat analysis, the random effects logistic regression model confirmed that there was no important interaction between the two interventions, and estimated an adjusted rate ratio of 1.11 (P=0.038) for the GP's letter and 1.12 (P=0.029) for the leaflet. In the absence of an interaction, an additive effect for receiving both the GP's letter and leaflet (11.8%, 95% CI: 8.5–16%) was confirmed. The per-protocol analysis indicated that the insertion of an electronic GP's signature on the endorsement letter was associated with increased participation (P=0.039) **Conclusion and implications:** Including both an endorsement letter from each patient's GP and a more explicit procedural leaflet could increase participation in the English Bowel Cancer Screening Program by 10%, a relative improvement of 20% on current performance. Adding a GP's letter and a more explicit instruction leaflet appears able to increase participation by at B10% (potentially providing a 20% relative improvement in the current participation rate). However, as less than half the GP practices recruited to this trial provided an electronic signature to the screening hub on request, this suggests there is a lack of GP engagement with the program. Including bowel cancer screening uptake as a QoF indicator may provide the necessary incentive to remedy this lack of engagement

Jean-Jacques 2012[143]	**Country:** United States **Purpose:** More effective strategies are needed to improve rates of colorectal cancer screening, particularly among the poor, racial and ethnic minorities, and individuals with limited English proficiency. We examined whether the direct mailing of faecal occult blood testing (FOBT) kits to patients overdue for such screening is an effective way to improve screening in this population	**Method:** All adults aged 50 to 80 years who did not have documentation of being up to date with colorectal cancer screening as of December 31, 2009, and who had had at least 2 visits to the community health centre in the prior 18 months were randomised to the outreach intervention or usual care. Patients in the outreach group were mailed a colorectal cancer fact sheet and FOBT kit Patients in the usual care group could be referred for screening during usual clinician visits. The primary outcome was completion of colorectal cancer screening (by FOBT, sigmoidoscopy, or colonoscopy) 4 months after initiation of the outreachprotocol. Outcome measures were compared using the Fisher exact test	**Results:** Analyses were based on 104 patients assigned to the outreach intervention and 98 patients assigned to usual care. In all, 30% of patients in the outreach group completed colorectal cancer screening during the study period, compared with 5% of patients in the usual care group (P <.001). Nearly all of the screenings were by FOBT. The groups did not differ significantly with respect to the percentage of patients making a clinician visit or the percentage for whom a clinician placed an order for a screening test **Conclusions:** The mailing of FOBT kits directly to patients was efficacious for promoting colorectal cancer screening among a population with high levels of poverty, limited English proficiency, and racial and ethnic diversity. Non–visit-based outreach to patients may be an important strategy to address suboptimal rates of colorectal cancer screening among populations most at risk for not being screened

Table 3.8 Additional RCT

Atlas 2011[52]	Women 42–69 years old with no record of a mammogram in the prior 2 years. To evaluate whether a primary care network-based informatics intervention can improve breast cancer screening rates	Cluster-randomised controlled trial of 12 primary care practices conducted from March 20, 2007 to March 19, 2008. In intervention practices, a population-based informatics system was implemented that: connected overdue patients to appropriate care providers, presented providers with a Web-based list of their overdue patients in a non-visit-based setting, and enabled 'one-click' mammography ordering or documented deferral reasons. Patients selected for mammography received automatically generated letters and follow-up phone calls. All practices had electronic health record reminders about breast cancer screening available during clinical encounters	The primary outcome was the proportion of overdue women undergoing mammography at 1-year follow-up Baseline mammography rates in intervention and control practices did not differ (79.5% vs. 79.3%, p=0.73). Among 3,054 women in intervention practices and 3,676 women in control practices overdue for mammograms, intervention patients were somewhat younger, more likely to be non-Hispanic white, and have health insurance. Most intervention providers used the system (65 of 70 providers, 92.9%). Action was taken for 2,652 (86.8%) intervention patients [2,274 (74.5%) contacted and 378 (12.4%) deferred]. After 1 year, mammography rates were significantly higher in the intervention arm (31.4% vs. 23.3% in control arm, p<0.001 after adjustment for baseline differences; 8.1% absolute difference, 95% CI 5.1–11.2%). All demographic subgroups benefited from the intervention. Intervention patients completed screening sooner than control patients (p<0.001) A novel population-based informatics system functioning as part of a non-visit-based care model increased mammography screening rates in intervention practices

Appendix 4.Symptoms as predictors – models

Summary of tables:

- All cancers:
  - Shapley

- Breast:
  - McCowan and three studies extracted from Shapley

- Colorectal
  - Astin 2011: 23 extracted studies
  - Olde 2010: eight extracted studies
  - Jellema 2010: 12 symptomatic reviews extracted (seven new/additional to Astin and Olde)
  - Shapley (nine extracted studies – two additional)
  - Hippisley-Cox & Collins independent validation
  - Hamilton CAPER

- Lung:
  - Shapley: two extracted studies
  - Hippisley-Cox
  - Hamilton CAPER

- Prostate:
  - Shapley: two extracted studies
  - Hamilton CAPER

Table 4.1 Symptoms, signs and non-diagnostic tests in unselected primary care populations with a PPV of ≥5% for cancer for which there is robust evidence (Shapley 2010[71])

Symptom	Cancer	Sex	Age, years	Evidence level for PPV of 5% or more in other cohorts
Rectal bleeding computer code or new onset rectal bleeding	Colorectal	M+F	≥75	None aged <60 years, aged 60-74 years equivocal
Iron deficiency anaemia Haemoglobin (Hb) <12 g/dl	Colorectal	M	≥60	Moderate evidence for gastrointestinal malignancy in men with Hb ≤12 g/dl aged >20 years and women with Hb ≤11 g/dl aged >50 years
Iron deficiency anaemia Hb <11 g/dl	Colorectal	F	≥70	
Iron deficiency anaemia Hb <9 g/dl	Colorectal	F	≥60	
Haematuria	Urological	M+F	≥60	None aged <49 years, aged 40-60 years equivocal
Rectal examination malignant	Prostate	M	≥40	No other evidence for PPV of 5% or more in other cohorts
Haemoptysis computer code	Lung	M	≥55	No other evidence for PPV of 5% or more in other cohorts
Haemoptysis computer code	Lung	F	≥65	
Dysphagia computer code	Oesophagus	M	≥55	No other evidence for PPV of 5% or more in other cohorts
Breast lump or mass	Breast	F	≥20	No other evidence for PPV of 5% or more in other cohorts
Postmenopausal bleeding computer code	Gynaecological	F	75–80	No other evidence for PPV of 5% or more in other cohorts

Table 4.2 Symptoms as predictors of breast cancer: McCowan 2011[72] study and 3 extracted from Shapley 2010[71]

Study	Country & Type	Symptom or characteristic	PPV, % (95%)
McCowan 2011[72]	UK Cohort study	Increasing age by year	Adjusted odds ratio (AOR) 1.10, 95% CI=1.07 to 1.13
		Presence of a discrete lump	AOR 15.20, 95% CI=4.88 to 47.34
		Breast thickening	AOR 7.64, 95% CI=2.23 to 26.11
		Lymphadenopathy	AOR 3.63, 95% CI=1.33 to 9.92
		Lump ≥2 cm	AOR 5.41, 95% CI=2.36 to 12.38
		Skin tethering	All 8 patients with skin tethering had breast cancer
Eberl 2008[73]	United States Retrospective cohort	Breast lump/mass symptom	8.1 (6.3 to 10.3)
Barton 1999[74]	United States Retrospective cohort	Breast lump/mass symptom	10.7 (4.6 to 16.9)
Bywaters 1977[75]	UK Retrospective cohort	Breast lump/mass sign	24.6 (15.2 to 37.1)

Table 4.3 Symptoms as predictors of colorectal cancer risk. Sensitivity, specificity, positive and negative likelihood ratios of unpaired symptoms (Astin 2011[76])

Symptom and study	Sensitivity, % (95% CI)	Specificity, % (95% CI)	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)
Rectal bleeding				
Panzuto 2003[144]	44 (28.5 to 60.3)	60 (53.3 to 66.1)	1.09 (0.75 to 1.60)	0.94 (0.70 to 1.25)
Hamilton 2005[145]	42 (37.2 to 47.8)	96 (94.8 to 96.7)	10.13 (7.85 to 13.08)	0.60 (0.55 to 0.66)
Hamilton 2009[146]	16 (14.6 to 16.6)	99 (98.7 to 98.9)	12.97 (11.62 to 14.48)	0.85 (0.84 to 0.86)
Summary estimates	17 (16.4 to 18.4) I^2=96.4%, P<0.001	98 (98.3 to 98.6) I^2=99.6%, P<0.001	5.31 (1.65 to 17.07) I^2=98.7%, P<0.001	0.77 (0.57 to 1.03) I^2=98.7%, P<0.001
Abdominal pain				
Hamilton et al. 2005	42 (37.2 to 47.8)	91 (89.2 to 92.0)	4.54 (3.75 to 5.49)	0.64 (0.58 to 0.70)
Hamilton et al. 2009	30 (28.5 to 31.0)	92 (91.6 to 92.1)	3.65 (3.46 to 3.85)	0.77 (0.75 to 0.78)
Panzuto et al. 2003	73 (57.1 to 85.8)	19 (14.4 to 24.8)	0.91 (0.75 to 1.10)	1.39 (0.79 to 2.46)
Summary estimates	31 (29.6 to 32.0)	91 (91.1 to 91.6)	2.47 (1.09 to 5.61)	0.75 (0.62 to 0.90)
Weight loss				
Hamilton et al. 2005	27 (22.3 to 31.9)	95 (93.6 to 95.7)	5.11 (3.92 to 6.65)	0.77 (0.72 to 0.82)
Hamilton et al. 2009	10 (9.5 to 11.1)	96 (95.8 to 96.2)	2.57 (2.34 to 2.81)	0.94 (0.93 to 0.94)
Panzuto et al. 2003	37 (22.1 to 53.1)	89 (84.0 to 92.4)	3.24 (1.89 to 5.54)	0.72 (0.56 to 0.91)
Summary estimates	11 (10.6 to 12.3) I^2=97.7%, P<0.001	96 (95.7 to 96.1) I^2=93.0%, P<0.001	3.48 (2.08 to 5.80) I^2=91.6%, P<0.001	0.82 (0.69 to 0.97) I^2=95.1%, P<0.001

Table 4.3 Symptoms as predictors of colorectal cancer risk. Sensitivity, specificity, positive and negative likelihood ratios of unpaired symptoms (Astin 2011[76])

Symptom and study	Sensitivity, % (95% CI)	Specificity, % (95% CI)	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)
Diarrhoea				
Hamilton et al. 2005	38 (32.7 to 43.1)	90 (88.7 to 91.6)	3.86 (3.17 to 4.69)	0.69 (0.63 to 0.75)
Hamilton et al. 2009	18 (17.0 to 19.1)	94 (94.1 to 94.6)	3.18 (2.97 to 3.41)	0.87 (0.86 to 0.88)
Panzuto et al. 2003	24 (12.4 to 40.3)	69 (62.3 to 74.4)	0.78 (0.44 to 1.37)	1.10 (0.91 to 1.34)
Summary estimates	19 (18.3 to 20.3) I^2=97.2%, P<0.001	94 (93.8 to 94.2) I^2=99.0%, P<0.001	2.44 (1.57 to 3.79) I^2=92.7%, P<0.001	0.86 (0.70 to 1.04) I^2=94.4%, P<0.001
Constipation				
Hamilton et al. 2005	26 (21.5 to 31.0)	85 (83.5 to 86.8)	1.76 (1.43 to 2.17)	0.87 (0.81 to 0.93)
Hamilton et al. 2009	27 (25.8 to 28.2)	89 (89.1 to 89.7)	2.55 (2.42 to 2.69)	0.82 (0.80 to 0.83)
Panzuto et al. 2003	51 (35.1 to 67.1)	53 (46.2 to 59.2)	1.08 (0.78 to 1.50)	0.93 (0.66 to 1.30)
Summary estimates	27 (25.9 to 28.2)	89 (88.7 to 89.3)	1.74 (1.11 to 2.72)	0.84 (0.79 to 0.88)
Anaemia				
Hamilton 2008[147] (UK)	37 (35.7 to 39.1)	92 (91.2 to 92.3)	4.62 (3.03 to 7.06)	0.68 (0.65 to 0.71)
Panzuto et al. 2003	68 (51.9 to 81.9)	83 (77.5 to 87.4)	3.98 (2.81 to 5.64)	0.38 (0.24 to 0.60)
Change in bowel habit				
Hamilton et al. 2008	11 (10.4 to 12.1)	99 (98.9 to 99.1)	11.47 (10.12 to 13.00)	0.90 (0.89 to 0.91)
Panzuto et al. 2003	20 (8.8 to 34.9)	80 (73.8 to 84.4)	0.95 (0.49 to 1.86)	1.01 (0.86 to 1.19)
Bloating				
Panzuto et al. 2003	54 (38.7 to 67.9)	39 (33.4 to 45.6)	0.88 (0.63 to 1.15)	1.18 (0.79 to 1.64)

Table 4.4 Sensitivity, specificity, positive and negative likelihood ratios of symptom pairs (Astin 2011[76])

Symptom pairs and study	Sensitivity % (95% CI)	Specificity % (95% CI)	Positive likelihood ratio (95% CI)	Positive predictive value % (95% CI)
Rectal bleeding with:				
Abdominal pain				
Fijten 1995[148] (Netherlands)	33 (7.5 to 70.1)	49 (43.0 to 55.5)	0.66 (0.26 to 1.67)	2.22 (0.46 to 6.36)
Mant 1989[149] (Australia)	25 (7.3 to 52.4)	70 (60.8 to 77.4)	0.82 (0.34 to 1.99)	9.30 (2.59 to 22.1)
Nørrelund and Nørrelund 1996[150] (Denmark)	31 (16.1 to 50.0)	78 (71.6 to 84.2)	1.45 (0.81 to 2.60)	20.8 (10.5 to 35.0)
Nørrelund and Nørrelund 1996 (Denmark)	50 (28.2 to 71.8)	77 (68.8 to 83.7)	2.16 (1.29 to 3.63)	26.2 (13.9 to 42.0)
Robertson 2006[151] (UK)	20 (5.7 to 43.7)	60 (55.8 to 64.0)	0.50 (0.21 to 1.21)	1.72 (0.47 to 4.36)
Summary estimates	33 (24.0 to 42.5) I^2=0.0%, P<0.42	63 (60.1 to 65.3) I^2=91.3%, P<0.000	1.03 (0.63 to 1.69) I^2=61.1%, P<0.025	7.58 (3.00 to 19.2) I^2=83.8%, P<0.001
Change in bowel habit				
Ellis and Thompson 2005[152] (UK)	100 (71.7 to 100.0)	58 (51.3 to 63.8)	2.26 (1.88 to 2.72)	9.24 (4.7 to 15.9)
Fijten et al. 1995	78 (40.0 to 97.2)	71 (66.8 to 78.3)	2.85 (1.91 to 4.26)	8.97 (3.7 to 17.6)
Mant et al. 1989	38 (15.2 to 64.6)	61 (51.6 to 69.2)	0.95 (0.49 to 1.86)	10.7 (4.04 to 21.9)
Metcalf et al. 1996[153] (UK)	50 (15.7 to 84.3)	62 (50.8 to 71.6)	1.30 (0.62 to 2.72)	10.3 (2.87 to 24.2)
Nørrelund and Nørrelund, 1996	59 (40.6 to 76.3)	77 (69.8 to 82.7)	2.55 (1.72 to 3.77)	31.7 (20.6 to 45.0)
Nørrelund and Nørrelund, 1996, 2	46 (24.4 to 67.8)	72 (63.2 to 79.1)	1.60 (0.94 to 2.73)	20.8 (10.5 to 35.0)
Robertson et al. 2006	59 (36.4 to 79.3)	55 (50.6 to 58.9)	1.31 (0.91 to 1.87)	4.83 (2.6 to 8.12)
Summary estimates	58 (49.0 to 67.3) I^2=66.5%, P=0.006	63 (60.4 to 65.1) I^2=88.0%, P<0.001	1.81 (1.33 to 2.46) I^2=74,6%, P=0.001	11.8 (6.78 to 20.4) I^2=77.1%, P<0.001
Anaemia				
Fijten et al. 1995	33 (7.5 to 70.1)	96 (92.6 to 97.9)	7.88 (2.65 to 23.4)	21.4 (4.70 to 50.8)

Table 4.4 Sensitivity, specificity, positive and negative likelihood ratios of symptom pairs (Astin 2011[76])

Symptom pairs and study	Sensitivity % (95% CI)	Specificity % (95% CI)	Positive likelihood ratio (95% CI)	Positive predictive value % (95% CI)
Rectal bleeding with:				
Decreased appetite				
Fijten et al. 1995	11 (0.30 to 48.2)	84 (79.2 to 88.4)	0.71 (0.11 to 4.57)	2.4 (0.06 to 12.6)
Diarrhoea				
Metcalf et al. 1996	25 (3.20 to 65.1)	73 (62.2 to 81.4)	0.91 (0.26 to 3.16)	7.4 (0.91 to 24.3)
Constipation				
Metcalf et al. 1996	13 (0.30 to 52.7)	58 (47.4 to 68.5)	0.30 (0.05 to 1.90)	2.6 (0.07 to 13.5)
Peri-anal symptoms				
Ellis and Thompson 2005	36 (10.9 to 69.2)	22 (17.0 to 27.5)	0.47 (0.21 to 1.02)	2.0 (0.54 to 4.80)
Tenesmus				
Mant et al. 1989	13 (1.6 to 38.3)	78 (70.2 to 85.1)	0.58 (0.15 to 2.19)	6.7 (0.82 to 22.1)

Figure 4.5 Positive predictive values of rectal bleeding in the diagnosis of colorectal cancer in primary care. Random effects pooled estimate (diamond) is based on subgroup [B] aged ≥ 50 years.

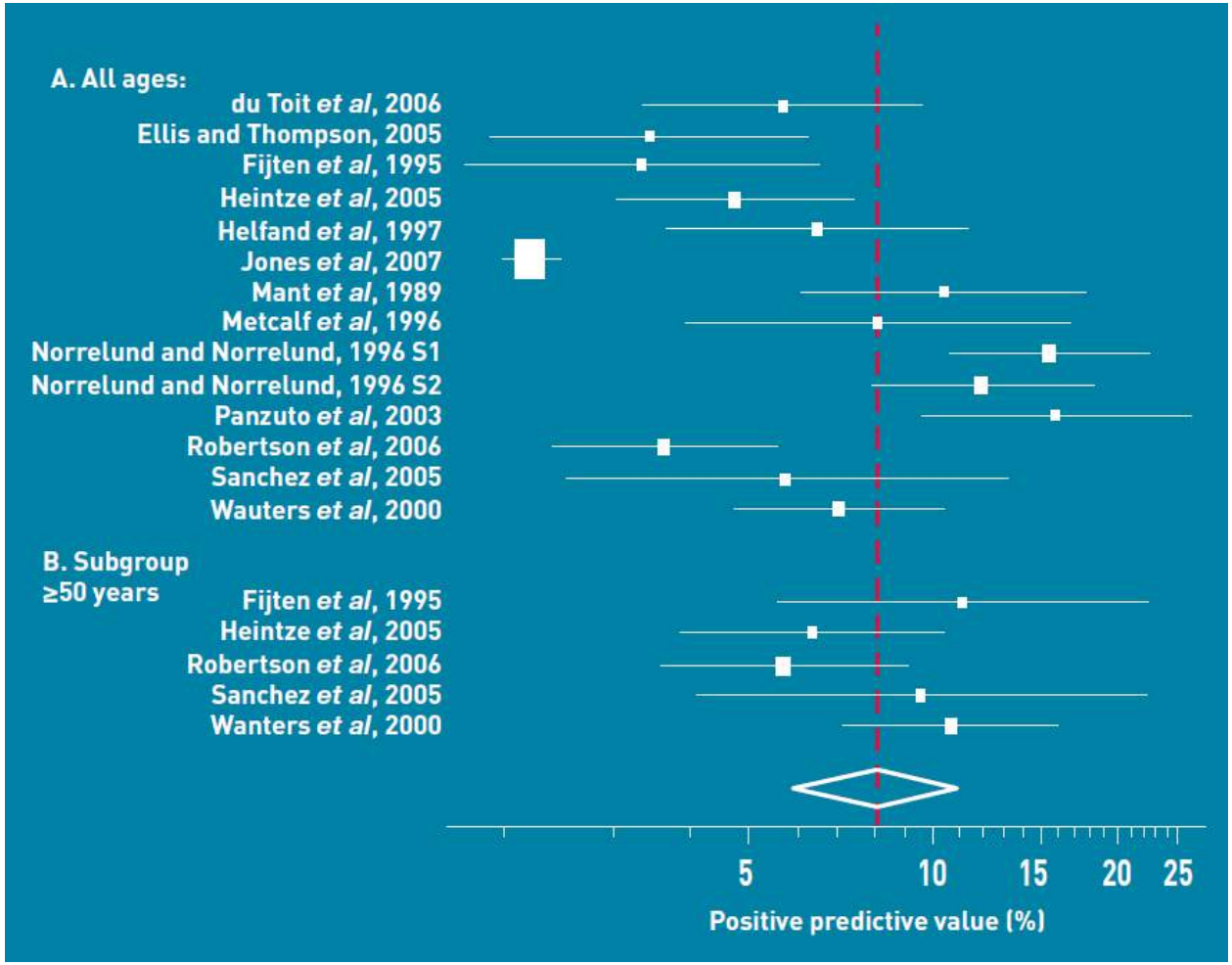

Table 4.6 Positive predictive values of unpaired symptoms (Astin 2011[76])

Symptom	Study	PPV, % (95% CI)
Rectal bleeding	*See above forest plot – refs:* All ages: du Toit et al. 2006[154] Ellis and Thompson, 2005[152] Fijten et al. 1995[148] Heintz et al. 2005[155] Helfand et al. 1997[156] Jones et al. 2007[81] Mant et al. 1989[149] Metcalf et al. 1996[153] Nørrelund and Nørrelund 1996 S1[150] Nørrelund and Nørrelund 1996 S2[150] Panzuto et al. 2003[144] Robertson et al. 2006[1151] Sanchez et al. 2005[157] Wauters et al. 2000[158] Subgroup ≥50 years Fijten et al. 1995[148] Heintze et al. 2005[155] Robertson et al. 2006[151] Sanchez et al. 2005[157] Wauters et al. 2000 (typo in forest plot)	
Subgroup ≥50 years		
Pooled estimate	*See above forest plot*	8.1 (6.0 to 10.8)*
Abdominal pain	Bellentani et al. 1990[159]	3.94 (1.90 to 7.12)
	Muris et al. 1993[160]	0.52 (0.11 to 1.51)
	Panzuto et al. 2003[144]	13.5 (9.26 to 18.7)

Symptom	Study	PPV, % (95% CI)
Summary estimate		3.29 (0.69 to 15.6, I^2=94.1%, P<0.001)
Anaemia	Farrus et al. 2000[161]	2.30 (0.28 to 8.06)
	Lucas et al. 1996[162]	6.92 (3.21 to 12.7)
	Panzuto et al. 2003[144]	40.6 (28.9 to 53.1)
	Yates et al. 2004[163]	8.59 (6.12 to 11.6)
Summary estimate		9.70 (3.52 to 26.8), I^2=91.7%, P<0.001)
Weight loss	Panzuto et al. 2003[144]	35.7 (9.3 to 18.6)
Change in bowel habit	Panzuto et al. 2003[144]	14.0 (6.26 to 25.8)
Diarrhoea	Panzuto et al. 2003[144]	11.8 (5.8 to 20.6)
Constipation	Panzuto et al. 2003[144]	15.7 (10.0 to 23.0)
Bloating	Panzuto et al. 2003[144]	13.2 (8.44 to 19.3)

* Positive predictive value of rectal bleeding (Astin): Sufficient data to calculate PPVs for rectal bleeding were available in 13 papers with 18 634 participants. This is displayed as a Forest plot (Astin Figure 1A). The PPV ranged from 2.2% to 15.8%. A subgroup analysis of five studies with data from 887 patients over 50 years of age (Figure 1B) provided a pooled estimate of 8.1% (95% confidence interval [CI]=6.0 to 10.8), with moderate inconsistency between studies (I2=31%, P=0.21). Data were pooled in three studies of rectal bleeding with 46 164 patients. However, a large degree of inconsistency (I2>96.0%, P<0.001) was present.

Table 4.6 Positive predictive values of unpaired symptoms (Astin 2011[76])

Table 4.7 Summary of included studies (Olde 2010[77])

Author Year	Number of patients (pt) Mean age (range) Sex	Patient population setting	Prior colorectal cancer	Reference standard and number or percentage of patients receiving it Follow- up	Prevalence of symptoms/signs/patient characteristics	Positive likelihood ratio
Du Toit et al. 2006[154]	265 pt ND years (45–ND years) M ND; F ND	Pt ≥45 years with new onset rectal bleeding, irrespective of other symptoms. Rural practice in England; four doctors; one registrar	5.7% (15 of 265)	Rigid sigmoidoscopy with barium enaema (most patients), flexible sigmoidoscopy, or colonoscopy	*Patient characteristics* Age 45–54 years, 19% Age 55–64 years, 28% Age 65–74 years, 24% Age ≥75 years, 29%	 0.7 0.2 1.8 1.4
					Symptoms/signs/patient characteristics Bleeding and CIBH (n=119), 37% Bleeding and CIBH, 26% (loose +/- frequent) (n=83) Bleeding and no perianal symptoms (n=63), 20% Bleeding CIBH and abdominal pain (n=63), 21% Dark blood (n=31), 10% Age ≥60 years (n=155), 49% Blood on paper only (n=2), 26% Large volume of blood (n=79), 25% First time rectal bleeding (n=106), 33% Blood mixed with stool (n=33), 10%	 2.4 1.3 2.9 1.0 2.1 1.5 0.6 0.3 1.2 0.7

Author Year	Number of patients (pt) Mean age (range) Sex	Patient population setting	Prior colorectal cancer	Reference standard and number or percentage of patients receiving it Follow- up	Prevalence of symptoms/signs/patient characteristics	Positive likelihood ratio
Fijten et al. 1995[148]	269 pt 42 years (18–75 years) M 118; F 151	Patients ≥18 years and ≤75 years with overt rectal bleeding as a reason for consult or history of recent (<3 month) blood loss visible. 83 GPs in the south of the Netherlands	3.3% (9 of 269)	A total of 31% had further investigations initiated by the GP by means of sigmoidoscopy (9%) colon roentenography (9%), proctoscopy (8%), sonography (6%) and colonoscopy (2%). Some patients underwent more than one investigation **Follow-up:** At least 1 year (mean 20 months) Medical records and information of the GP	*Symptoms/signs* Blood seen: Mixed with stool only, 5% On stool or mixed with stool only, 20% Others or combinations, 45% Abdominal pain, 50% Change in bowel habit (more frequently or diarrhoea or variously, but not constipation), 29% Pain at night, 19% Decreased appetite, 16% Nausea, 25% Weight loss, 16% Family history of abdominal disease, 31% Previous history of rectal bleeding, 36% Pale conjunctivae, 2% Perianal eczema, 6% Rectal palpation (n+208): Haemorrhoid Tumour Abnormal prostate *Patient characteristics* Age 18–29 years, 23% Age 30–39 years, 26% Age 40–49 years, 20% Age 50–59 years, 15% Age 60–75 years, 15% Male, 44% *Laboratory test results* Anaemia (Hb Females <7.5 mmol l^{-1} Male <8.5 mmol l^{-1}) ESR high (Female >28 mm h l^{-1} Male > 8.5 mm h l^{1}), 5%, 9% ESR high (>30 mm h l^{-1}), 4% High white blood cell count (>109 per litre) (n=219), 9% Haemoccult ≥1 positive out of 3, 15%	8.0 3.8 0.4 0.7 2.9 0.0 0.7 0.4 3.0 0.0 0.0 5.8 6.2 2.5 1.0 22.3 0.0 0.0 0.0 0.7 7.2 1.8 6.6 4.2 8.8 5.8 2.3

Author Year	Number of patients (pt) Mean age (range) Sex	Patient population setting	Prior colorectal cancer	Reference standard and number or percentage of patients receiving it Follow- up	Prevalence of symptoms/signs/patient characteristics	Positive likelihood ratio
Heintze et al. 2005[155]	422 pt ND years (ND–ND years) M 199; F 222	Patients >15 years 94 GPs in Germany	4.0% (17 of 422)	Diagnostic work-up: sonography (52 pt); sigmoidscopy (26 pt); colonoscopy (195 pt); treatment by GP (93 pt); **Follow-up:** Unclear	*Symptoms/signs/patient characteristics* Male, 53% Age <50 years, 38% Age ≥50 years, 62% Age 15–24 years, 2% Age 25–34 years, 11% Age 35–44 years, 14% Age 45–54 years, 16% Age 55–64 years, 28% Age 65–74 years, 18% Age 75–84 years, 8% Age 85–94 years, 2% Weight loss, 3% Changed bowel habit, 18% Abdominal pain, 24% Anaemia, 6% Dark red blood, 12% Blood mixed with stool, 19% Family history of colon carcinoma, 7%	 1.3 0.2 1.5 0.0 0.4 0.3 0.5 1.3 1.7 0.5 8.4 1.3 1.2 0.7 2.4 1.1 1.9 3.6

Author Year	Number of patients (pt) Mean age (range) Sex	Patient population setting	Prior colorectal cancer	Reference standard and number or percentage of patients receiving it Follow- up	Prevalence of symptoms/signs/patient characteristics	Positive likelihood ratio
Mant et al. 1989[149]	145 pt 58 years (40–95 years) M 77; F 68	Pt ≥40 years who consulted the GP for rectal bleeding; 40 GPs in Australia	11% (16 of 145)	- Total colonoscopy (104 pt) - Endoscopy to at least 30 cm and an air-contrast barium enaema (32 pt) - Investigations not complete, but an obvious source was found, e.g. rectal cancer in proctoscopy (9 pt) **Follow-up**: Unclear	*Symptoms/signs/patient characteristics* Male, 53% First-degree relative with CRC (n=143), 14% Abdominal pain (n=144), 30% Change in bowel habit (n=143), 39% Feeling of incomplete evacuation of rectum, 29% Weight loss, (n=143), 10% Anal itch, 25% Pain on defecation, 21% Anal protrusion noticed by patient, 21% Dark red blood (n=144), 16% Blood mixed with faeces (n=140), 36% Haemorrhoids identified by GP, 51%	 0.8 0.9 0.8 1.0 1.1 1.3 0.2 0.6 0.3 1.7 2.2 0.5
Metcalf et al. 1996[153]	99 pt 58 years (40–86 years) M 42; F 57	Patients ≥40 years 17 GPs in Newcastle upon Tyne, England	8.1% (8 of 99)	Questionnaire (99 pt); colonoscopy (98 pt); barium enaema in any patient whom a satisfactory colonoscopy was not completed (1 pt) **Follow-up:** Unclear (Practices participated between 1–9 months)	*Symptoms/signs/patient characteristics* Dark red blood loss, 31% Blood mixed with stool, 46% Diarrhoea, 32% Associated slime, 28% Constipation, 39% Change in bowel habit, 39% Abdominal pain, 42% Weight loss, 15%	 1.2 1.4 0.9 1.4 0.3 1.3 0.9 1.8
Nørrelund and Nørrelund 1996 (I)[150]	208 pt 42 years (18–75 years) M 97; F 111	Patients ≥40 years presenting with a first episode of rectal bleeding 96 GPs from Denmark	15.4% (32 of 208)	GPs were asked to arrange either a barium enaema or a colonoscopy at the first consultation **Follow-up:** 32 months Colorectal cancer microscopically verified or yearly letter to GP	*Symptoms/signs/ patient characteristics* Male, 47% Age 40–69 years, 68% Age 70–79 years, 25% Age 80+ years, 7% Weight loss, 11% Abdominal pain, 23% Change in bowel habits, 29% Discomfort, 27%	PLD 1.3 0.3 3.3 2.2 1.6 1.5 2.6 1.3

Author Year	Number of patients (pt) Mean age (range) Sex	Patient population setting	Prior colorectal cancer	Reference standard and number or percentage of patients receiving it Follow- up	Prevalence of symptoms/signs/patient characteristics	Positive likelihood ratio
Nørrelund and Nørrelund 1996 (2)[150]	156 pt 42 years (18–75 years) M 71; F 85	Patients ≥40 years first bleeding episode or change in usual bleeding pattern 112 GPs from Denmark	14.1% (22 of 156)	GPs were asked to arrange either a barium enaema or a colonoscopy at the first consultation **Follow-up:** 22 months CRC microscopically verified or yearly letter to GP	*Symptoms/signs/patient characteristics* Male, 46% Age 40–69 years, 72% Age 70–79 years, 21% Age 80+ years, 7% Weight loss, 14% Abdominal pain, 27% Change in bowel habits, 31% Discomfort, 26% New rectal bleeding, 69%	PLR 1.0 0.7 2.4 0.6 1.8 2.2 1.6 0.9 0.8
Wauters et al. 2000[158]	386 pt ND years (ND–ND years) M ND; F ND	Network of sentinel practices in Belgium	7.0% (27 of 386)	Investigations such as endoscopy were not systematically performed. 'To obtain the number of all new cases of cancer, we sent recall letters to the practices every six months and at the end of the follow-up period.' (p 998) **Follow-up (clinical):** 18–30 months	*Symptoms/signs/patient characteristics* Age <50 years, 37% Age 50 – 59 years, 15% Age 60 – 69 years, 18% Age 70 – 79 years, 17% Age ≥80 years, 13% Pain, 9% Spasms, 29% Weight loss, 6% Palpable tumour, 5%	PLR 0.1 0.2 1.7 3.6 0.8 0.0 0.8 2.5 6.1

Table 4.7 Summary of included studies (Olde 2010[77])

Table 4.8 Symptoms with PPV>5% for colorectal cancer (Shapley 2010[71])

Study	Type	Data	Follow-up	Age, years	Sex	Number with symptom	Symptom	PPV/ Comments
Studies giving a PPV of <5% of rectal bleeding for colorectal cancer								
Hamilton et al. 2009[80]	Case-control	Routinely recorded computer codes	NA	≥30	M+F	853 cases 460 controls	Rectal bleeding computer codes	PPV stratified by age and sex but numbers of cases and controls by age and sex not given
Hamilton et al. 2005[145]	Case-control	Routinely recorded data including free text	NA	≥40	M+F	148 cases 73 controls	Rectal bleeding	PPV 2.4% (95% CI=1.9 to 3.2)
Thompson et al. 2000[164]	Prospective cohort	Self-reported questionnaire	4–5 years	>16	M+F	197	Rectal bleeding and consulted GP	No cases of rectal cancer; two cases of caecal cancer felt not to cause bleeding but not stated if in consultation cohort
Nørrelund and Nørrelund 1996[150]	Prospective cohort	Specifically registered	22–57 months	≥40	M+F	45	Current bleeding episode similar to previous	PPV 4.4% (95% CI=1.2 to 14.8)
Studies giving a PPV of ≥5% change in bowel habit for colorectal cancer or a predictive value of <5% in an equivalent stratum								
Lawrenson et al. 2006[165]	Retrospective cohort	Routinely recorded computer codes	1 year	40–89	M+F	Not given	Change in bowel habit computer codes	PPV, % (95% CI): 60–69 years 6.9; 70–79 years 8.5; 80–89 years 7.7
Hamilton et al. 2009[80]	Case-control	Routinely recorded computer codes	NA	≥30	M+F	Not given	Change in bowel habit computer codes	PPV, % (95% CI): 60–69 years 3.0 (2.1 to 4.2); 70–79 years 4.2 (3.2 to 5.4); 80–89 years 3.9 (2.8 to 5.5)

Table 4.9 Studies giving a PPV of ≥5% in one or more strata of rectal bleeding with another symptom for colorectal cancer (Shapley 2010[71])

Study	Symptom	Additional symptom, sign or test result	Sex	Age (years)	Number with symptom	PPV, % (95% CI)
Ellis and Thompson 2005[152]	Primary complaint rectal bleeding	Change in bowel habit	M+F	>34	119	9.2 (5.2 to 15.8)
		Change in bowel habit (loose and/or frequent)			83	12.1 (6.7 to 20.8)
		Change in bowel habit with no abdominal pain			52	9.6 (4.2 to 20.6)
		No peri-anal symptoms			63	11.1 (5.5 to 21.2)
		Dark blood			31	9.7 (3.3 to 24.9)
		Small volume of blood			187	5.3 (2.9 to 9.6)
Fijten et al. 1995[148]	Overt rectal bleeding reason for encounter or history of rectal blood loss visible to the patient in the previous 3 months	Change in bowel habit more frequent or diarrhoea or variously but not constipation	M+F	18–71	78	9.0 (4.4 to 17.4)
		Blood seen on stool or mixed with only			54	7.4 (2.9 to 17.6)
		Weight loss			42	9.5 (3.8 to 22.1)
		Perianal eczema			17	17.6 (6.2 to 41.0)
		Rectal palpitation haemorrhoid			20	10.0 (2.8 to 30.1)
		High ESR			23	8.7 (2.4 to 26.8)
		High WBC			25	12.0 (4.2 to 30.0)
		Haemoccult positive			41	4.9 (1.3 to 16.1)
Leicester et al. 1984[166]	Any abdominal or bowel complaint	Haemoccult positive	M+F	≥40	25	16.0 (6.4 to 34.7)

Table 4.10 Studies giving a PPV of ≥5% in one or more strata of iron deficiency anaemia for colorectal cancer or a predictive value of <5% in an equivalent stratum (Shapley 2010[71])

Study	Type	Data source	Follow-up	Age, years	Sex	Symptom	Stratification with PPV			
							Sex	Age, years	Number with symptom	PPV % (95% CI)
Stellon et al. 1997[167]	Prospective cohort	Specifically registered	Not given	>50	M+F	Hb<12.0 and/or MCV <80 with ferritin ≤16	M+F	>50	26	7.7 (2.1 to 24.1)
Yates et al. 2004[163]	Retrospective cohort	Routinely recorded data	1 year	>20	M	Hb ≤12 MCV <hospital normal range, RBC <5.5	M	>20	154	17.5 (12.3 to 24.3)
				>50	F	Hb ≤11 MCV <hospital normal range, RBC <5.5	F	>50	277	3.2 (1.7 to 6.1)
Hamilton et al. 2008[147]	Case-control	Routinely recorded	NA	≥30	M+F	Hb 11.0-11.9 with indicators of iron deficiency	M	60–69	Not given	6.5 (2.0 to 19)
						Hb <11.0 with indicators of iron deficiency	M	≥60	Not given	All age bands and Hb levels PPV >5 (range 5.5 to ≥31)
							F	70–79	Not given	All Hb levels PPV >5 (range 5.7 to 10%)
						Hb <10.0 with indicators of iron deficiency	F	≥80	Not given	All Hb levels PPV >5 (range 5.7 to 10%)
						Hb <9.0 with indicators of iron deficiency	F	60–69	Not given	>5 (likelihood ratio)

Table 4.11 Diagnostic performance of symptom combinations and referral guidelines in diagnosis of colorectal cancer (Jellema 2010[168])

Index test and setting; Symptom combinations	TP	FP	FN	TN	Sensitivity (95% CI)	Specificity (95% CI)	Risk with positive test result (95% CI)	Risk with negative test result (95%)
All bleeding, CIBH, abdominal pain, primary care								
Ellis 2005[152]	6	61	5	194	0.55 (0.23 to 0.83)	0.76 *(0.70 to 0.81)	0.09 (0.03 to 0.19)	0.03 (0.01 to 0.06)
All bleeding, prediction model including age, CIBH, blood mixed with or on stool, primary care								
Fijten 1995[148]	9	26	0	234	1.00 (0.66 to 1.00)	0.90 (0.86 to 0.93)	0.26 (0.13 to 0.43)	0.00 (0.00 to 0.03)
All bleeding, CIBH, age >69, primary care								
Norrelund 1996[150]	19	27	31	271	0.38 (0.25 to 0.53)	0.91 (0.87 to 0.94)	0.41 (0.27 to 0.57)	0.10 (0.07 to 0.14)
All bleeding, dark and mixed with stool, primary care								
Robertson 2006[151]	9	79	31	271	0.38 (0.25 to 0.53)	0.91 (0.87 to 0.94)	0.41 (0.27 to 0.57)	0.10 (0.07 to 0.14)
Bleeding, CIBH*								
Chohan 2005[169]	29	123	35	275	0.45 (0.33 to 0.58)	0.69 (0.64 to 0.74)	0.19 (0.13 to 0.26)	0.11 (0.08 to 0.15)
Bleeding, CIBH, >6 weeks to looser/more frequent*								
Flashman 2004, GP findings[170]	28	174	37	456	0.43 (0.31 to 0.56)	0.72 (0.69 to 0.76)	0.14 (0.09 to 0.19)	0.08 (0.05 to 0.10)
Flashman 2004, clinic findings	26	144	39	486	0.40 (0.28 to 0.53)	0.77 (0.74 to 0.80)	0.15 (0.10 to 0.22)	0.07 (0.05 to 0.10)
Bleeding, CIBH >6 weeks, age >45*								
Barwick 2004[171]	3	45	11	85	0.21 (0.05 to 0.51)	0.65 (0.57 to 0.74)	0.06 (0.01 to 0.17)	0.12 (0.06 to 0.20)
Bleeding, no peri-anal symptoms, age >60*								
Flashman 2004, GP findings	17	143	48	487	0.26 (0.16 to 0.39)	0.96 (0.92 to 0.99)	0.13 (0.08 to 0.18)	0.09 (0.07 to 0.12)
Flashman 2004, clinic findings	4	27	61	603	0.06 (0.02 to 0.15)	0.96 (0.94 to 0.97)	0.13 (0.04 to 0.30)	0.09 (0.07 to 0.12)
Bleeding, no peri-anal symptoms, age >55*								
Chohan 2005	37	164	27	234	0.58 (0.45 to 0.70)	0.59 (0.54 to 0.64)	0.18 (0.13 to 0.25)	0.10 (0.07 to 0.15)
Bleeding, no peri-anal symptoms, age >65*								
Barwick 2004	3	25	11	105	0.21(0.05 to 0.51)	0.81 (0.73 to 0.87)	0.11 (0.02 to 0.28)	0.10 (0.05 to 0.16)

Table 4.11 Diagnostic performance of symptom combinations and referral guidelines in diagnosis of colorectal cancer (Jellema 2010[168])

Index test and setting; Symptom combinations	TP	FP	FN	TN	Sensitivity (95% CI)	Specificity (95% CI)	Risk with positive test result (95% CI)	Risk with negative test result (95%)
CIBH >6 weeks to looser/more frequent*								
Chohan 2005	27	171	37	227	0.42 (0.30 to 0.55)	0.57 (0.52 to 0.62)	0.14 (0.09 to 0.19)	0.14 (0.10 to 0.19)
CIBH >6 weeks to looser, more frequent, age >45*								
Barwick 2004	5	65	9	65	0.36 (0.13 to 0.65)	0.50 (0.41 to 0.59)	0.07 (0.02 to 0.16)	0.12 (0.06 to 0.22)
CIBH >6 weeks, no bleeding, age >60*								
Flashman 2004 – GP findings	17	261	48	369	0.26 (0.16 to 0.39)	0.59 (0.55 to 0.62)	0.06 (0.04 to 0.10)	0.12 (0.09 to 0.15)
Flashman 2004 – clinic findings	11	161	54	469	0.17 (0.09 to 0.28)	0.74 (0.71 to 0.78)	0.06 (0.03 to 0.11)	0.10 (0.08 to 0.13)
All bleeding, at least 1 of: dark red, large volume, mixed with stool, streaked on stool, family history, personal history , CIBH, mucus, anaemia, or FOBT, secondary care								
Marderstein 2008[172]	19	503	7	696	0.73 (0.88 to 0.52)	0.58 (0.61 to 0.55)	0.04 (0.02 to 0.06)	00.01 (0.00 to 0.02)
Bleeding, CIBH, secondary care								
Thompson 2007[173]	249	1802	218	6260	0.53 (0.49 to 0.58)	0.78 (0.77 to 0.79)	0.12 (0.11 to 0.14)	0.03 (0.03 to 0.004)
Thompson 2008[174]	466	4096	480	11391	0.49 (0.46 to 0.53)	0.74 (0.73 to 0.74)	0.10 (0.09 to 0.11)	0.04 (0.04 to 0.04)
Bleeding, CBH, peri-anal symptoms, secondary care								
Thompson 2007	101	1200	366	6862	0.22 (0.18 to 0.26)	0.85 (0.84 to 0.86)	0.08 (0.06 to 0.09)	0.05 (0.05 to 0.06)
Bleeding, CIBH, no peri-anal symptoms, secondary care								
Thompson 2007	148	602	319	7460	0.32 (0.28 to 0.36)	0.93 (0.92 to 0.93)	0.20 (0.17 to 0.23)	0.04 (0.04 to 0.05)
Bleeding, CIBH, abdominal pain, secondary care								
Thompson 2007	101	1068	366	6994	0.22 (0.18 to 0.26)	0.87 (0.86 to 0.88)	0.09 (0.07 to 0.10)	0.05 (0.05 to 0.06)
Bleeding, CIBH, abdominal pain, secondary care								
Thompson 2008	181	2696	765	12791	0.19 (0.17 to 0.22)	0.83 (0.82 to 0.83)	0.06 (0.05 to 0.07)	0.06 (0.05 to 0.006)
Bleeding, CIBH, no abdominal pain, secondary care								
Thompson 2007	148	734	319	7328	0.32 (0.28 to 0.36)	0.91 (0.90 to 0.92)	0.17 (0.14 to 0.19)	0.04 (0.04 to 0.05)
Bleeding, no CIBH, secondary care								

Index test and setting; Symptom combinations	TP	FP	FN	TN	Sensitivity (95% CI)	Specificity (95% CI)	Risk with positive test result (95% CI)	Risk with negative test result (95%)
Thompson 2007	84	3277	383	4785	0.18 (0.15 to 0.22)	0.59 (0.58 to 0.60)	0.03 (0.02 to 0.03)	0.07 (0.07 to 0.08)
Bleeding, no CIBH, peri-anal symptoms, secondary care								
Thompson 2007	37	2515	430	5547	0.08 (0.06 to 0.11)	0.69 (0.68 to 0.70)	0.01 (0.01 to 0.02)	0.07 (0.07 to 0.08)
Bleeding, no CIBH, no peri-anal symptoms, secondary care								
Thompson 2007	47	762	420	7300	0.10 (0.08 to 0.13)	0.91 (0.09 to 0.91)	0.06 (0.04 to 0.08)	0.05 (0.05 to 0.06)
Bleeding, abdominal pain, secondary care								
Thompson 2008	227	4140	719	11347	0.24 (0.21 to 0.27)	0.73 (0.73 to 0.74)	0.05 (0.05 to 0.06)	0.06 (0.06 to 0.06)
Bleeding, peri-anal symptoms, secondary care								
Thompson 2007	138	3715	329	4347	0.30 (0.25 to 0.34)	0.54 (0.53 to 0.55)	0.04 (0.03 to 0.04)	0.07 (0.06 to 0.08)
Bleeding, no peri-anal symptoms, secondary care								
Thompson 2007	195	1364	272	6698	0.42 (0.37 to 0.46)	0.83 (0.82 to 0.84)	0.13 (0.11 to 0.14)	0.04 (0.04 to 0.04)
CIBH, no bleeding, secondary care								
Thompson 2007	110	1725	357	6337	0.24 (0.20 to 0.28)	0.79 (0.78 to 0.80)	0.06 (0.05 to 0.07)	0.05 (0.05 to 0.06)
CIBH, no bleeding, abdominal pain, secondary care								
Thompson 2007	40	726	427	7336	0.09 (0.06 to 0.12)	0.91 (0.90 to 0.92)	0.05 (0.04 to 0.07)	0.06 (0.05 to 0.06)
Abdominal pain, CIBH, secondary care								
Thompson 2008	246	4525	700	10962	0.26 (0.23 to 0.29)	0.71 (0.70 to 0.72)	0.05 (0.05 to 0.06)	0.06 (0.06 to 0.06)
Abdominal pain, no CIBH, no bleeding, secondary care								
Thompson 2007	16	634	451	7428	0.03 (0.02 to 0.06)	0.92 (0.92 to 0.93)	0.03 (0.01 to 0.04)	0.06 (0.05 to 0.06)
Selva score, secondary care, Selvachandrum 2002 †								
≥40 v <40	151	1733	5	1413	0.97 (0.93 to 0.99)	0.45 (0.43 to 0.47)	0.08 (0.07 to 0.09)	0.00 (0.00 to 0.01)
≥50 v <50	134	1167	22	1979	0.86 (0.79 to 0.91)	0.63 (0.61 to 0.65)	0.10 (0.09 to 0.12)	0.01 (0.01 to 0.02)
≥60 v <60	72	495	23	1678	0.76 (0.66 to 0.84)	0.77 (0.75 to 0.79)	0.13 (0.10 to 0.16)	0.01 (0.01 to 0.02)
≥70 v <70	66	266	29	1907	0.70 (0.59 to 0.79)	0.88 (0.86 to 0.89)	0.20 (0.16 to 0.25)	0.02 (0.01 to 0.02)

Table 4.11 Diagnostic performance of symptom combinations and referral guidelines in diagnosis of colorectal cancer (Jellema 2010[168])

Table 4.11 Diagnostic performance of symptom combinations and referral guidelines in diagnosis of colorectal cancer (Jellema 2010[168])

Index test and setting; Symptom combinations	TP	FP	FN	TN	Sensitivity (95% CI)	Specificity (95% CI)	Risk with positive test result (95% CI)	Risk with negative test result (95%)
Bellentani >0, primary care								
Bellentani 1990[159]	10	111	0	133	1.00 (0.69 to 1.00)	0.55 (0.48 to 0.61)	0.08 (0.04 to 0.15)	0.00 (0.00 to 0.03)
Kruis <44, primary care								
Bellentani 1990	9	84	1	160	0.90 (0.56 to 1.00)	0.66 (0.59 to 0.72)	0.10 (0.05 to 0.18)	0.01 (0.00 to 0.03)
TP=true positives; FP=false positives; FN=false negatives; TN=true negatives; CIBH=change in bowel habit; FOBT=faecal occult blood test *Two week referral criterion †For this study we extracted data for some index tests from a more recent paper of Hodder et al.72								

Table 4.12 Comparison of strategies to identify patients at risk of having a diagnosis of colorectal cancer (Hippisley Cox Table 5[78])

Criteria	Risk threshold %	True negative[a]	False negative[b]	False positive[c]	True positive[d]	Sensitivity, %	Specificity, %	Positive predictive value (%)	Negative predictive value (%)
Rectal bleeding alone	n/a	1 204 833	1762	28 111	841	32.3	97.7	2.9	99.9
Abdominal pain alone	n/a	1 108 552	1758	124 392	845	32.5	89.9	0.7	99.8
Appetite loss alone	n/a	1 227 674	2557	5270	46	1.8	99.6	0.9	99.8
Weight loss alone	n/a	1 219 043	2497	13 901	106	4.1	98.9	0.8	99.8
Change in bowel habit alone[a]	n/a	617 486	1402	742	21	1.5	99.9	2.8	99.8
Anaemia alone	n/a	1 216 368	2356	16 576	247	9.5	98.7	1.5	99.8
Top 10% risk score	0.5	1 111 261	765	121 683	1 838	70.6	90.1	1.5	99.9
Top 5% risk score	1.2	1 172 641	1134	60 303	1 469	56.4	95.1	2.4	99.9
Top 1% risk score	5.2	1 221 229	1963	11 715	640	24.6	99.0	5.2	99.8

n/a=not applicable

[a] Criterion not met does not have disease

[b] Criterion not met does have disease

[c] Criterion met does not have disease

[d] Criterion met does have disease

Table 4.13 Collins 2012[79] table: Comparison of strategies to identify patients of having a diagnosis of colorectal cancer in the next 2 years

Criterion	Risk threshold %	True negative	False negative	False positive	True positive	Sensitivity, %	Specificity, %	Positive predictive value (%)	Negative predictive value (%)
Women									
Rectal bleeding	NA	1 046 859	1105	27 240	571	34.1	97.5	2.1	99.9
Abdominal pain	NA	930 900	1078	143 199	598	35.7	86.7	0.4	99.9
Appetite loss	NA	1 070 824	1656	3 275	20	1.2	99.7	0.6	99.8
Weight loss	NA	1 058 792	1585	15 307	91	5.4	98.6	0.6	99.8
Anaemia	NA	1 060 613	1503	13 486	173	10.3	98.7	1.3	99.9
Top 10% risk score	0.4	970 241	491	103 858	1 185	70.7	90.3	1.1	99.9
Top 5% risk score	0.8	1 021 128	739	52 971	937	55.9	95.1	1.7	99.9
Men									
Rectal bleeding	NA	1 030 097	1245	27 632	791	39.9	97.4	2.8	99.9
Abdominal pain	NA	956 159	1414	101 570	622	30.6	90.4	0.6	99.9
Appetite loss	NA	1 055 272	2012	2 457	24	1.2	99.8	1.0	99.8
Weight loss	NA	1 044 962	1912	12 767	124	6.1	98.8	1.0	99.8
Change in bowel habit behaviour	NA	2 056 108	1987	1 621	49	2.4	99.8	2.9	99.8
Anaemia	NA	1 053 398	1901	4 331	135	6.6	99.6	3.0	99.8
Top 10% risk score	0.5	953 979	528	103 751	1 509	74.1	90.2	1.4	99.9
Top 5% risk score	0.9	1 006 421	787	51 307	1 249	61.3	95.1	2.4	99.9

Table 4.14 Collins 2012[79] table: Performance data in the original development cohort and the external validation (THIN) cohort

	QRESEARCH (Hippisley-Cox and Coupland, 2012) (internal validation)		THIN (external validation)		
			Multiple imputation (m=10)	Complete-case	
	Women (n=616 361)	Men (n=620 240)	Men (n=1 059 765)	Women (n=1 075 775)	Men (n=417 560)
R^2 (95% CI)[a]	64.8 (63.2–66.3)	66.7 (65.3–68.0)	68.32 (67.32–69.32)	65.81 (64.62–67.01)	65.30 (63.71–66.89)
D-statistic (95% CI)[b]	2.78 (2.68–2.87)	2.90 (2.81–2.98)	3.00 (2.93–3.07)	2.84 (2.76–2.92)	2.81 (2.71–2.91)
c-Statistic (95% CI)[c]	0.89 (0.88–0.90)	0.91 (0.90–0.91)	0.918 (0.913–0.923)	0.909 (0.903–0.915)	0.901 (0.892–0.910)

[a] R^2 statistic and [b] D-statistic are measures of discrimination and explained variation, respectively, and are tailored for censored survival data

[c] Discrimination, or the ability of the risk score to differentiate between patients who experience an event during the study period and those who do not. This measure is quantified by calculating the area under the receiver operating characteristic curve *c*-statistic; a value of 0.5 represents chance and 1 represents perfect discrimination

Table 4.15 CAPER Hamilton table[80]:

Positive predictive values (%) for colorectal cancer for individual features, repeat presentations and for pairs of features (in the context of a background risk of 0.25%). *Notes:* (1) The top row (bold) gives the PPV for an individual features. The cells along the diagonal relate to the PPV when the same feature has been reported twice. Thus, the constipation/constipation intersect is the PPV for colorectal cancer when a patient has attended twice (or more often) with constipation. Other cells show the PPV when a patient has two features. (2) The top figure in each cell is the PPV. It has only been calculated when a minimum of 10 cases had the feature or combination of features. The two other figures are the 95% confidence intervals (CIs) for the PPV. These have not been calculated when any cell in the 2 x 2 table was below 10. For haemoglobin <10g dl $^{-1}$ with abdominal tenderness, no controls has this pair. It was scored as a PPV of > 10%. (3) The yellow shading is when the PPV is above 1%. The amber shading is when the PPV is above 2%, which approximates to a risk of colorectal cancer of eight times normal. The red shading is for PPVs above 5.0% approximating to a risk 20 times normal.

Constipation	Diarrhoea	Rectal bleeding	Loss of weight	Abdominal pain	Abdominal tenderness	Abnormal rectal exam	Haemoglobin 10-13g dl $^{-1}$	Haemoglobin <10g dl $^{-1}$	
0.42 0.3 0.5	**0.94** 0.7 1.1	**2.4** 1.9 3.2	**1.2** 0.9 1.6	**1.1** 0.9 1.3	**1.1** 0.8 1.5	**1.5** 1.0 2.2	**0.97** 0.8 1.3	**2.3** 1.6 3.1	**PPV as a single symptom**
0.81 0.5 1.3	**1.1** 0.6 1.8	**2.4** 1.4 4.4	**3.0** 1.7 5.4	**1.5** 1.0 2.2	**1.7** 0.9 3.4	**2.6**	**1.2** 0.6 2.7	**2.6**	**Constipation**
	1.5 1.0 2.2	**3.4** 2.1 6.0	**3.1** 1.8 5.5	**1.9** 1.4 2.7	**2.4** 1.3 4.8	**11**	**2.2** 1.2 4.3	**2.9**	**Diarrhoea**
		6.8	**4.7**	**3.1** 1.9 5.3	**4.5**	**8.5**	**3.6**	**3.2**	**Rectal bleeding**
			1.4 0.8 2.6	**3.4** 2.1 6.0	**6.4**	**7.4**	**1.3** 0.7 2.6	**4.7**	**Loss of weight**
				3.0 1.8 5.2	**1.4** 0.3 2.2	**3.3**	**2.2** 1.1 4.5	**6.9**	**Abdominal pain**
					1.7 0.8 3.7	**5.8**	**2.7**	**>10**	**Abdominal tenderness**

Table 4.16 Symptoms as predictors of lung cancer risk

Shapley[71]: Studies giving a PPV of ≥5% in one or more strata of symptoms for lung cancer or a predictive value of <5% in an equivalent stratum										
Jones et al. 2007[81]	Retrospective cohort	Routinely recorded computer codes	3 years	≥15	All	Haemoptysis computer codes	M	55–64	514	8.4 (6.1 to 11.1)
								65–74	552	14.9 (12.0 to 18.1)
								75–84	393	17.1 (13.5 to 21.1
								≥85	93	20.4 (12.8 to 30.1)
							F	65–74	358	8.4 (5.7 to 11.8)
								75–84	258	10.5 (7.0 to 14.9
Hamilton et al. 2005[145]	Case-control	Routinely recorded data including free text	Not applicable	≥40	All	Haemoptysis as a single symptom	M+F	≥40	Cases 50, controls 19	2.4 (1.4 to 4.1)

Table 4.17 (Hippisley-Cox 2011[82]): Adjusted hazard ratios (95% CI) for the final model for lung cancer for males and females in the derivation cohort

	Adjusted hazard ratios for females (95% CI)	Adjusted hazard ratios for males (95% CI)
Symptoms presented to GP		
Current haemoptysis[a]	23.9 (20.6 to 27.6)	21.5 (19.3 to 23.9)
Current appetite loss[a]	4.14 (3.15 to 5.45)	4.71 (3.69 to 6.00)
Current weight loss[a]	5.52 (3.80 to 5.38)	6.09 (5.33 to 6.95)
New onset cough in last 12 months[a]	1.90 (1.56 to 2.32)	1.47 (1.23 to 1.75)
Recorded haemoglobin<11 g/dl in last 12 months[a]	1.75 (1.38 to 2.22)	1.47 (1.23 to 1.75)
Smoking status		
Non smoker	1	1
Ex-smoker	3.37 (2.83 to 4.01)	2.13 (1.87 to 2.43)
Light smoker (<10/day)	6.57 (5.37 to 8.03)	3.70 (3.20 to 4.27)
Moderate smoker (10-19/day)	8.32 (7.05 to 9.82)	4.95 (4.26 to 5.76)
Heavy smoker (≥20/day)	10.6 (8.49 to 13.2)	6.35 (5.43 to 7.43)
Prior diagnosis other cancer except lung cancer[a]	1.33 (1.09 to 1.63)	NS
Chronic obstructive airways disease[a]	1.82 (1.57 to 2.11)	1.51 (1.31 to 1.69)
Townsend deprivation score (5 unit increase)	1.17 (1.08 to 1.27)	1.17 (1.10 to 1.24)

[a]Compared with person without this characteristic. NS=not significant. Hazard ratios were adjusted for all other terms in the table and models accounted for age as underlying time function and also included fractional polynomial terms for body mass index (BMI). For females, the terms were BMI^{-2}, ln(BMI). For males the terms were BMI^{-1}, BMI^{-1}ln(BMI).

Table 4.18 (Hippisley-Cox 2011[82]): Validation statistics for the risk-prediction algorithm in the validation cohort

	Mean (95% CI)
Females	
R^2 statistic, [a] %	71.70 (70.30 to 73.10)
D statistic[b]	3.25 (3.15 to 3.37)
ROC statistic[c]	0.92 (0.91 to 0.93)
Males	
R^2 statistic, [a] %	72.11 (71.04 to 73.18)
D statistic[b]	3.29 (3.20 to 3.38)
ROC statistic[c]	0.92 (0.91 to 0.93)

[a] R^2 statistic shows explained variation in time to diagnosis of lung cancer – higher values indicate more variation is explained.
[b] D statistic is a measure of discrimination – higher values indicate better discrimination.
[c] ROC statistic is a measure of discrimination – higher values indicate better discrimination.

Table 4.19 (Hippisley-Cox 2011[82]): Comparison of strategies to identify patients at risk of having a diagnosis of lung cancer in the next 2 years based on the validation cohort

	Risk threshold at 2 years, %	Number with criterion	Number of patients with criterion AND lung cancer	Total number of new diagnoses of lung cancer	Sensitivity, % (95% CI)	Positive predictive value, % (95% CI)
Haemoptysis	n/a	7861	504	2196	23.0 (21 to 24.8)	6.4 (5.9 to 7.0)
≥40 years AND haemoptysis AND current or ex-smoker	n/a	4144	404	2196	18.4 (16.8 to 20.1)	9.7 (8.9 to 10.7)
Top 10% risk score	0.37	126 672	1697	2196	77.3 (75.5 to 79.0)	1.34 (1.28 to 1.40)
Top 5% risk score	0.68	63 336	1377	2196	62.7 (60.6 to 64.7)	2.2 (2.1 to 2.3)
Top1% risk score	2.21	12 667	796	2196	36.2 (34.2 to 38.2)	6.3 (5.9 to 6.7)
Top 0.5% risk score	4.47	6333	602	2196	27.4 (25.6 to 29.3)	9.5 (8.8 to 10.3)

Table 4.20 (Hamilton CAPER 2009[80]): Symptoms of cancer recorded in primary care, their prevalence in cases (%) and their likelihood ratios (LR)

Symptom	% of patients with symptom	Positive likelihood ratio
Haemoptysis	20	13
Loss of weight	27	6
Loss of appetite	19	5
Dyspnoea	56	4
Chest or rib pain	42	3
Fatigue	35	2
Cough	65	2

Figure 4.21 (Hamilton CAPER 2009[80])

Figure Hamilton CAPER: Positive predictive values (%) for lung cancer for individual risk markers, and for pairs of risk markers in combination (against a background risk of 0.18%).
Notes: (I) The top row gives the PPV for an individual feature. The cells along the diagonal relate to the PPV when the same feature has been reported twice. Other cells show the PPV when a patient has two different features. (2) The top figure in each cell (in bold) is the PPV. It has only been calculated when a minimum of 10 cases had a feature or combination of features. The two other features are the 95% CIs for the PPV. These have not been calculated when any cell in the 2 × 2 tables was below 10. (3) The yellow shading is when the PPV is above 1%. The amber shading is when the PPV is above 2%. The red shading is for PPVs above 5.0%.

Cough	Fatigue	Dyspnoea	Chest pain	Loss of weight	Loss of appetite	Thrombo-cytosis	Abnormal spirometry	Haemoptysis	
0.40 0.3, 0.5	**0.43** 0.3, 0.6	**0.66** 0.5, 0.8	**0.82** 0.6, 1.1	**1.1** 0.8, 1.6	**0.87** 0.6, 1.3	**1.6** 0.8, 3.1	**1.6** 0.9, 2.9	**2.4** 1.4, 4.1	**PPV as a single symptom**
0.58 0.4 0.8	**0.63** 0.5 0.9	**0.79** 0.6 1.0	**0.76** 0.6 1.0	**1.8** 1.1 2.9	**1.6** 0.9 2.7	**2.0** 1.1 3.5	**1.2** 0.6 2.6	**2.0** 1.1 3.5	**Cough**
	0.57 0.4 0.9	**0.89** 0.6 0.3	**0.84** 0.5 1.3	**1.0** 0.6 1.7	**1.2** 0.7 2.1	**1.8**	**4.0**	**3.3**	**Fatigue**
		0.88	**1.2** 0.9 1.8	**2.0** 1.2 3.8	**2.0** 1.2 3.8	**2.0**	**2.3**	**4.9**	**Dyspnoea**
			0.95 0.7 1.4	**1.8** 1.0, 3.4	**1.8** 0.9 3.9	**2.0**	**1.4**	**5.0**	**Chest pain**
				1.2 0.7 2.3	**2.3** 1.2 4.4	**6.1**	**1.5**	**9.2**	**Loss of weight**
					1.7	**0.9**	**2.7**	**>10**	**Loss of appetite**
							3.6	**>10**	**Thrombocytosis**
								>10	**Abnormal spirometry**
								17	**Haemoptysis**

Table 4.22 Symptoms as predictors of prostate cancer risk (Shapley 2010[71])

Studies giving a PPV of ≥5% in one or more strata of symptoms for urological cancer (Shapley)											
Study	Cancers	Type	Data source	Follow-up	Age, years	Sex	Symptom or sign	Stratification with PPV			
								Sex	Age, years	Number with symptom	PPV, % (95% CI)
Bruyninckx et al. 2003	Any of the urological tract	Prospective cohort	Routinely registered	18–30 months	Not given	M+F	Cases macroscopic haematuria	M	≥60	Not given	22.1 (15.8 to 30.1)
								F	40–59	Not given	6.4 (1.7 to 18.6)
									≥60	Not given	8.3 (3.4 to 17.9)
Hamilton et al. 2006	Prostate	Case-control	Routinely recorded data including free text	NA	≥40	M	Rectal examination malignant	M	≥40	Cases 5 Controls 41	12.0 (5.0 to 37.0)

Table 4.23 (CAPER Hamilton 2009[80])

Positive predictive values (%) for prostate cancer for individual features, repeat presentations and for pairs of features (against background risk of 0.35%).
Notes: (1) The top row (bold) gives the PPV for an individual feature. The cells along the diagonal relate to the PPV when the same feature has been reported twice. (2) The top figure in each cell is the PPV. It has only been calculates when a minimum of 10 cases had the feature or combination of features. The two other figures are the 95% CIs for the PPV. These have not been calculated when any cell in the 2x2 table was below 10. (3) The yellow shading is when the PPV is above 1%. The amber shading is when the PPV is above 2%. The red shading is for PPVs above 5.0%.

Haematuria	Loss of weight	Nocturia	Hesitancy	Rectal exam – benign	Rectal exam – malignant	Frequency/urgency	
1.0 0.57 1.8	**0.75** 0.38 1.4	**2.2** 1.2 3.6	**3.0** 1.5 5.5	**2.8** 1.6 4.6	**12** 5.0 3.7	**2.2** 1.1 3.5	**PPV as a single symptom**
1.6		**1.9**		**3.3**	**3.9**	**1.8** 0.9 3.9	**Haematuria**
	2.1	**12**		**9.4**		**1.8**	**Loss of weight**
		3.3	**2.8**	**3.9** 2.1 7.8	**15**	**3.2** 1.9, 6.0	**Nocturia**
			2.0	**3.3**	**10**	**4.7**	**Hesitancy**
						3.1 1.9 5.5	**Frequency/urgency**
						4.0 2.3 7.4	**Rectal examination – deemed benign enlargement**
						13	**Rectal examination – deemed malignant enlargement**

Appendix 5.Diagnosis models of care

Summary of tables:

- 2WW systematic reviews
  - Lewis 2005
  - Thorne 2006: eight relevant studies extracted

- Papers on models from other countries:
  - Baughan 2011
  - Prades 2011

- Systematic review on models:
  - Mansell & Shapley 2011: six relevant studies extracted

Table 5.1 Summary of systematic review of audits of 2-week-wait referrals (Lewis 2005[84])

CANCER SITE (no of audits included in analysis/no included in review)	Detection rate (Proportion of patients diagnosed with cancer referred via 2WW)	Conversion rates among 2WW referrals and among referrals considered 'urgent' by hospital	Conversion rates among non-2WW referrals (not all of which were GP referrals)	Conversion rates for 2WW referrals that were in line with the guidelines	Conversion rates for 2WW referrals that were not in line with the guidelines
Breast (59/72)	4–83% (9 audits)	2WWR: 0–34% (37 audits) Hospital: 16–50% (3 audits)	Urgent non-2WW: 4–20% (5 audits) Non-urgent: 0–10% (18 audits)	16% (1 audit)	0% (1 audit)
Children (9/9)		2WWR: 0% (3 audits)			
Lower GI (47/71)	0–46% (7 audits)	2WWR: 2–22% (30 audits)	All non-2WW: 14% (1 audit) Urgent non-2WW: 14% (1 audit) With 2WW symptoms: 6%; without 2WW symptoms; 1% (1 audit)	12-21% (2 audits)	0-3% (3 audits)
Lung (33/43)	0–57% (5 audits)	2WWR: 5–75% (15 audits)	Non-2WW: 62% (1 audit) Routine: 2% (1 audit)	51% (1 audit)	0-43% (2 audits)

Table 5.2 Summary of systematic review of audits of 2-week-wait referrals (Lewis 2005[84])

CANCER SITE (no of audits included in analysis/no included in review)	GP conformity		Appropriateness of referral		Ability of the guidelines to identify correct referral	
	Conformity of 2WW referrals to guidelines (2WWR: audits that included 2WW referrals) (Cancer: audits that included patients diagnosed with cancer)	Non-2WW referrals with symptoms in line with guidelines (Referrals: audits that included all referrals) (Cancer: audits that included patients diagnosed with cancer)	2WW referrals that warranted urgent referral according to the hospital clinician	Clinical symptoms (at 1st appointment) matching 2WW GP referral	2WW referrals that were not in line with guidelines, but were deemed clinically appropriate	2WW referrals that were in line with the guidelines, but were deemed clinically inappropriate
Breast (59/72)	2WWR: 65–99% (20 audits)	Cancer: 0% (1 audit)	18–96% (9 audits)	78% (1 audit)	14–45% (2 audits)	5–17% (2 audits)
Children (9/9)	2WWR: 91–100% (4 audits)		60–100% (4 audits)			
Lower GI (47/71)	2WWR: 53–100% (26 audits)	Cancer: 29% (1 audit)	52–74% (6 audits)	33–87% (3 audits)	9–19% (2 audits)	0% (1 audit)
Lung (33/43)	2WWR: 78–100% (15 audits)		87–97% (5 audits)	95% (1 audit)	0–5% (2 audits)	6% (1 audit)

Table 5.3 From a Systematic review of two-week rules on NHS colorectal cancer diagnostic services (Thorne & Hutchings 2006[85])

First author & reference	N° TWR referrals	% of CRCs identified from TWR referrals (n)	Total number of CRC cases diagnosed ✝	Total % of CRC cases referred as		
				TWR	Emergency	Other
Chohan 2005[169]	462	13.8% (64)	195	32%	20%	47.2%
Maruthachalam 2005[175]	639	8% (51)	234	21.8%	10.6%	67.6%
Eccersley 2003[176]	180	14.4% (26)	145	18%	17%	66%
Walsh 2002[177]	78	10.3% (8)	23	47.8%	52.2%	
Debnath 2002[178]	237	8.9% (21)	96	21.9%	78.1%	
Flashman 2004[170]	695	9.4% (65)	249	26.1%	35.3%	38.6%
Barwick 2004[171]	149	10% (14)	84	16.7%	41.7%	41.7%
Trickett 2004[179]	NA	NA	147	20%	29%	51%
Weighted averages of all values combined		**10.3%**		**24%**	**24.1%**	**52.4%**

Key: NA=Data not available in article; ✝=Total number of CRC cases diagnosed during the time of the study in the same locality.

Table 5.5 Other international studies of fast track referral routes

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Baughan 2011 [87] **Scotland**	Late diagnosis con-tributes to the UK having poorer cancer survival than many countries in Europe. Cancer refer-ral guidelines help GPs decide which patients to refer urgently for further investigation.	**Aim:** To examine primary care referral patterns, compliance with referral guidance, and eventual outcome for patients. Design and setting: Prospective audit within general practice in Scotland. Method: GPs in Scotland reviewed all urgent suspected cancer referrals over a 6-month period. They noted the final diagnosis and assessed whether the referral was in accordance with agreed referral guidelines.	**Results:** A total of 18 775 urgent suspected cancer referrals were analysed from 516 GP practices Suspected breast cancer (n=3436, 18.3%) and colorectal cancer (n=3370, 17.9%) were the two most likely reasons, by far, for a GP to refer a patient, accounting for 36.3% of all referrals There was no apparent association between the proportion of urgent referrals and cancer incidence for the five most common cancers: Breast had 18.3% of cancer referrals and 14.8% of cancer incidence. Colorectal had 17.9% of cancer referrals and 13% of incidence. Lung had 5.6% of cancer referrals and 16.8% incidence. Prostate had 3.1% of cancer referrals and 9.3% incidence The proportion of all urgent cancer referrals with an eventual diagnosis of cancer (either the cancer suspected or a different cancer) was 18.3% (n=3432). This varied according to tumour group The proportion of patients subsequently diagnosed with cancer was: prostate (52.6%), lung cancer referrals (39.7%), breast (16.3%), colorectal (12.8%). Compliance with referral guidelines was 90.9%. A large proportion of referrals considered to be outside the guidelines still had a cancer diagnosed (lung 8.8%, colorectal 8.4%, and breast 6.4). Conclusion: There is wide variation in GP referral rates for suspected cancer with a greater than expected proportion of referrals for younger people. Many referrals considered to be outside the national guidelines were diagnosed with cancer, suggesting factors other than those in referral guidelines alert GPs to the possibility of cancer			

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Prades 2011[88] Spain	The Cancer Fast-track Program's aim was to reduce the time that elapsed between well-founded suspicion of breast, colorectal and lung cancer and the start of initial treatment in Catalonia (Spain). We sought to analyse its implementation and overall effectiveness		Major findings: About half of all new patients with breast, lung or colorectal cancer were diagnosed via the fast track, though the cancer detection rate declined across the period. Mean time from detection of suspected cancer in primary care to start of initial treatment was 32 days for breast, 30 for colorectal and 37 for lung cancer (2009). Professionals associated with the implementation of the program showed that general practitioners faced with suspicion of cancer had changed their conduct with the aim of preventing lags. Furthermore, hospitals were found to have pursued three specific implementation strategies (top-down, consensus-based and participatory), which made for the cohesion and sustainability of the circuits. Conclusions: The program has contributed to speeding up diagnostic assessment and treatment of patients with suspicion of cancer, and to clarifying the patient pathway between primary and specialised care			

Table 5.5 Other international studies of fast track referral routes

Table 5.6 Mansell systematic review & extracted studies

GP level interventions to reduce diagnostic delay

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Mansell 2011[89] UK	Interventions that reduce primary care delay in the referral of patients with cancer to secondary care	Eight electronic databases were searched using terms for primary care, cancer, and delay. Exclusion criteria included screening and the 2-week-wait referral system	Searches identified 1798 references, of which 22 papers were found to meet the criteria. Interventions concerning education, audit and feedback, decision support software and guideline use, diagnostic tools, and other specific skills training were identified. Most studies reported a positive effect on their specified outcomes, although no study measured a direct effect on reducing delay. Conclusion: There was no evidence that any intervention directly reduced primary care delay in the diagnosis of cancer. Limited evidence suggests that complex interventions, including audit and feedback and specific skills training, have the potential to do so			Of 22 tabulated interventions, 14 were skin cancer interventions, 1 bowel cancer; 2 breast studies excluded b/c of country setting, Egypt/Tunisia and Pakistan. Most studies educational targeted at GPs
Cockburn 2001[90] Australia HCP: GPs; Breast cancer; type of study: before and after study	Evaluate the impact of guidelines, audit, education, and feedback on investigations of new breast symptoms	**Intervention components:** Participating doctors completed an audit of the management of all women attending with a new (incident) breast symptom over a 12-week period before and after the intervention. The intervention consisted of feedback from the first audit from their own practice and grouped data from other practices, and a seminar on the guideline recommendations and evidence. Number of participants recruited: 227. Number of participants completing study: 104. Intervention delivered by: breast specialists and study authors. Length of intervention: 5–7 months. Length of follow up: approx. 6 months (unclear). How intervention was assessed: via feedback from the audits	Guideline adherence improved following the intervention, but already appeared to be quite high at the first audit; statistically significant improvement in five criteria	Before and after study	Mansell, Shapley 2011 systematic review	**Problems with study:** Selection bias; no control group; no details about who presented the audit findings or what format this took; authors acknow-ledge that participating GPs had more of an interest in breast health and only 18% completed both audits [high dropout rate]; not consistent with UK guidelines

GP level interventions to reduce diagnostic delay

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Logan 2002[92] England; General practices; RCT; Bowel	To assess the adequacy of investigation of iron deficiency anaemia and to establish whether a simple computer-generated prompt would increase the completeness of treatment and investigation of patients presenting in general practice	**Intervention components:** Practices were randomised after being stratified by district and practice size. Patients were identified from their blood indices – laboratory computers were programmed to print an appropriate prompt. Number of participants recruited: 603. Number of participants completing study: 431 patients included in analysis. Intervention delivered by: Hospital pathologists. Length of interv-ention: 12 months. Length of follow-up: 12 months. How intervention was assessed: patient records were analysed for adequate management of anaemia instigated within 3 months of symptom presentation, as defined by four criteria	47% of patients were managed adequately, but the prompt was not found to affect the level of investigation or adequacy of follow-up. There was an increase in iron therapy	RCT		No 'no prompt' control group; cross-contamination (GPs in control and intervention groups may influence each other); outcome measure based on secondary care management guidelines

GP level interventions to reduce diagnostic delay

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Wolters 2004[93] The Netherlands; GPs; RCT; prostate	To examine the effects of a distance-learning programme on patient outcomes	Intervention components: the intervention group received a multifaceted distance learning programme: (1) a package for individual learning (PIL), (2) consultation support materials including a voiding diary, the International Prostate Symptom Score and Brother Score, (3) the Dutch lower urinary tract symptoms (LUTS) guideline summarised into a decision tree (4) 2 PILs (one on PSA testing and one on LUTS treatments). The PIL consisted of a knowledge test – answers were sent to a central institute and a set of standard correct answers were returned as feedback.	How intervention was assessed: via the questionnaire. Outcome of study: PSA testing requests were higher in the intervention group (not a desired study outcome); patients' fear of cancer was more of a motivating factor for GPs. Intervention did decrease the number of urology referrals. This was not expected, as the decision-support tree was felt to suggest a low rate of testing.		Mansell & Shapley 2011 systematic review	Problems with the study: high dropout rate; small sample size

GP level interventions to reduce diagnostic delay

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Jiwa 2006[91] UK; HCP General practices (not clear if GPs only or other healthcare professionals were included); RCT; Colorectal cancer	To examine whether the introduction of an electronic interactive referral pro forma or educational outreach visits by a colorectal surgeon to general practice can alter the case mix of patients referred to lower-bowel specialists	**Intervention components:** practices were randomised to receive either an educational outreach visit, an interactive electronic pro forma for processing referrals, both, or neither: The outreach visit involved a surgeon delivering short educational sessions tailored to the needs of the target audience, which summarised the features of significant colorectal disease and encouraged questions. The electronic forms requested information from drop-down menus for 15 signs and symptoms previously identified by GPs and surgeons as predicting colorectal disease. Once clinical data were entered, a referral letter was automatically produced, seeking an appropriate appointment at a hospital clinic. Number of participants recruited: 44 practices (180 GPs). Number of participants completing study: not stated (assumed all recruited). Intervention delivered by: colorectal surgeons. Length of intervention: 6 months. Length of follow-up: 6 months	**How intervention was assessed:** An 'assessment score was given for the quality of referral letters and the proportion of patients referred. Interviews were carried out with participants who were assigned the electronic referral, but no information is given for the other groups. No evidence that either intervention was successful and did not increase the proportion of patients with pathology who were referred; pro forma documented better assessment of patients	RCT	Mansell, Shapely 2011 systematic review	**Problems with study**: Little information on assessment of participants; only 18% of GPs actually used the software; no assessment of knowledge before and after the education visit to assess impact

GP level interventions to reduce diagnostic delay

Ref	Background	Methods/Intervention/Model	Results incl. outcome measures	Quality of findings	Source	Notes
Nekhyludov 2008[180] US; primary care clinicians (physicians, nurse practitioners, certified nurse midwives, and physician assistants); Before and after study; Breast	Pilot test and evaluation of an office-based intervention aimed at improving outcomes	**Intervention components:** Sites were split into intervention and controls (no information about how this was done). At the intervention sites, at every visit of a female patient with breast symptoms, clinicians were sent a packet of materials containing two guidelines and a patient information sheet. Control sites were informed of the materials but were not given any directly **Number of participants recruited:** 123. Number of participants completing intervention: 101. Intervention delivered by: not stated. Length of intervention: 8 months. Length of follow-up: not stated	**How intervention was assessed:** Surveys to measure knowledge of breast symptoms based on information provided by the guidelines were administered before and after the intervention. The intervention was found to increase guideline use, but had no statistically significant effect on knowledge and attitudes	Before and after study	Mansell & Shapley 2011 systematic review	Short follow-up; not randomised-participants were mainly female which makes generalising the results more difficult; small sample size; no objective evidence that the guidelines were actually used
Khan 2009[94] UK; GPs; feasibility study; colorectal cancer	To test the feasibility of a paper-based assessment tool incorporating the CAPER score (a clinical prediction rule for patients presenting to primary care with lower-gastrointestinal symptoms)	**Intervention components:** A paper-based assessment tool was developed using the CAPER score and NICE guidelines for colorectal cancer. The GP had to record the patients' symptom history, clinical and rectal examinations, full blood count (FBC), and faecal occult blood (GOB) (if no overt bleeding), and then follow the referral advice. Number of participants recruited: 122. Number of participants completing study: 122. Intervention delivered by: GPs. Length of intervention: maximum of 3 months. Time to follow up: 3 months	**How intervention was assessed:** Three audits were conducted during and after the intervention to obtain consultation data and to check if the assessment tool was being correctly filled in. The final audit collected the clinical outcomes and final diagnosis of patients. Recruitment rates were poor, with only 24% of the recruitment target being achieved. As directed by the assessment tool, 93% of patients had a clinical examination but only 64% had a rectal examination. 48% had a FBC and 38% FOB tests. In only 55% were the CAPER scores correctly calculated	Feasibility study	Mansell, Shapely 2011 systematic review	**Problems with the study:** Inadequate amount of follow-up; poor recruitment; selection bias; not powered to detect clinical effect

Appendix 6.Follow-up

Summary of tables:

- **Five systematic reviews:**
  - Montgomery 2007: two extracted studies
  - Lewis 2009: four extracted studies
  - Aubin 2012: seven extracted studies
  - Khan 2008: eight extracted studies
  - Gysels 2006: four extracted studies
  - Lewis 2009: 18 extracted studies

- **Nine Additional RCTS/trials:**
  - Elliott 2004
  - Grunfeld 2011
  - Grunfeld 1999
  - Baravelli 2009
  - Burg 2009
  - Mao 2009
  - Aubin 2010
  - Brennan 2011
  - Hudson 2012

Table 6.1 Montgomery systematic review & extracted studies

Reference, Country	Methods	Results
Montgomery 2007[97] Investigates what alternative follow-up methods (including reduced frequency of visits) have been subjected to controlled trial and to establish what evidence exists from controlled trials to advise the guidelines.	Reviewed all randomised controlled trials comparing different follow-up frequencies or comparing an alternative method with clinical follow up after breast cancer	Two trials compared frequency of traditional follow up. Five trials assessed alternative methods. All were of inadequate power or duration to establish ideal frequency of clinic visits or safety of alternative follow-up methods. Alternative follow up had no detrimental effect on satisfaction or outcome. Few trials have been conducted, all of which are underpowered to establish safety of reducing or replacing clinic visits. Alternative methods of follow up are acceptable to patients and may be associated with other benefits
Grunfeld 1996[98] England	296 primary operable patients attending routine follow up at all stages of follow up and free of metastatic disease 18 month randomised controlled trial of follow up in general practice vs. hospital **Outcome measures:** Quality of life as measured by several validated questionnaires Number of recurrences Number of deaths Time to diagnose recurrence from onset of symptoms	**Detection of recurrence:** Twice as many metastatic recurrences diagnosed in the hospital group (13 vs. 6 in general practice, difference 4.7%, 95% CI - 0.8 to 10.3%). Of interest, while all the recurrences in the general practice group were detected by the general practitioner, 44% of the recurrences in the hospital follow up group were also diagnosed by the general practitioner initially **Survival:** Slight excess in mortality in hospital follow up compared with general practice (two deaths in the general practice group and seven in the hospital group from 148 patients in each cohort) **Quality of life:** no differences in quality of life between control and study groups
Grunfeld 2006[99] Canada	968 women between 9 and 15 months after diagnosis of early-stage breast cancers, who had completed treatment and were disease free. Median follow up: 4.5 years from diagnosis (3.5 from randomisation) **Outcome measures:** Quality of life using validated questionnaires Significant clinical events (metastases related) Number of local recurrences and deaths	**Detection of recurrence:** No significant difference in the proportion of women presenting with local or distant recurrences between the two groups (11.2% in general practice group compared with 13.2% in the hospital group, difference of 2.02%, 95% CI - 2.13 to 6.16%). Time to recurrence detection is not provided **Adverse clinical events:** No difference in rate of SCEs (serious clinical events) between hospital and general practice follow up (3.7% of patients vs. 3.5%, respectively, difference 0.19%, 95% CI - 2.26 to 2.65%) **Survival:** 29 deaths in the general practice group and 30 in the hospital group **Quality of life:** no differences in quality of life between control and study groups

Table 6.2 Lewis 2009 systematic review & extracted studies

Reference Country Aim	Methods	Results
Lewis 2009[18] Wales Compares the effectiveness and cost-effectiveness of primary versus secondary care follow-up of cancer patients, determines the effectiveness of the integration of primary care in routine hospital follow-up, and evaluates the impact of patient-initiated follow-up on primary care	A search was carried out of 19 electronic databases, online trial registries, conference proceedings, and bibliographies of included studies. The review included comparative studies or economic evaluations of primary versus secondary care follow-up, hospital follow-up with formal primary care involvement versus conventional hospital follow-up, and hospital follow-up versus patient-initiated or minimal follow-up if the study reported the impact on primary care	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 health 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
Johansson 2001[100] Sweden Evaluates the effect of an individual support (IS) intervention including intensified primary healthcare on the utilisation of specialist care among cancer patients, and to investigate if such an effect was modified by the patient's age (<70 years/>70 years)	416 newly diagnosed cancer patients were randomised between the intervention and a control condition, and data were collected on the utilisation of specialist care within 3 months from inclusion. Intensified primary healthcare comprised extended information from the specialist clinics, and education and supervision in cancer care for GPs and home-care nurses. The support given also included interventions designed to diminish problems of weight loss and psychological distress	The intervention reduced the number of admissions (NoA) and the days of hospitalisation (DoH) after adjustment for weight loss and psychological distress, but only for older patients. Older patients randomised to the intervention (n=82) experienced 393 fewer DoH than the older control patients (n=79). In addition, the proportion of older patients in the IS group who utilised acute specialist care was smaller compared with older control patients group
Nielsen 2003[101] Denmark Determines the effect of a shared care program on the attitudes of newly referred cancer patients towards the healthcare system and their health related quality of life and performance status, and to assess patients' reports on contacts with their GP	RCT in which 248 patients completed questionnaires at three time points. The shared care program included transfer of knowledge from the oncologist to the GP, improved communication between the parties, and active patient involvement Main outcome measure included patients' attitudes towards the healthcare services, their health related quality of life, performance status, and reports on contacts with their GPs	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

Reference Country Aim	Methods	Results
Holtedahl 2005[103] Norway Investigates whether increased contact with the patient's general practitioner (GP) soon after cancer treatment can increase patient quality of life (QoL) and satisfaction with follow-up	RCT with 91 patients from one Norwegian municipality. The intervention group got a 30 minute invited consultation with the patient's GP and an invitation to further GP follow-up. Quality of life and patient satisfaction with diagnosis, treatment and overall care were measured with validated instruments	Relatives' satisfaction with care increased over 6 months in the intervention group (P=0.018), but otherwise, there was no difference between the intervention and control groups concerning QoL, satisfaction with care or number of consultations. Patient satisfaction with care showed a tendency to increase when treatment intent was curative. Some functional QoL measures and satisfaction tended to increase during the first 6 months after treatment. Free text comments suggested that some patients appreciated the contact with their GP
Wattchow 2006[102] Australia Examines the optimal setting for follow-up of patients after treatment for colon cancer by either general practitioners or surgeons	203 patients who had undergone potentially curative treatment for colon cancer were randomised to follow-up by general practitioners or surgeons Primary outcome measures were (1) quality of life, (2) anxiety and depression and (3) patient satisfaction Secondary outcomes were: Investigations, number and timing of recurrences and deaths	170 patients were available for follow-up at 12 months and 157 at 24 months. At 12 and 24 months there were no differences in scores for quality of life (physical component score, P=0.88 at 12 months; P=0.28 at 24 months: mental component score, P=0.51, P=0.47; adjusted), anxiety (P=0.72; P=0.11) depression P=0.28; P=0.80) or patient satisfaction (P=0.06, 24 months) General practitioners ordered more FOBTs than surgeons (rate ratio 2.4, 95% CI - 1.4–4.4), whereas more colonoscopies (rate ratio 0.7, 95% CI - 0.5–1.0), and ultrasounds (rate ratio 0.5, 95% CI 0.3–1.0) were undertaken in the surgeon-led group. Results suggest similar recurrence, time to detection and death rates in each group. Colon cancer patients with follow-up led by surgeons or general practitioners experience similar outcomes, although patterns of investigation vary
The following articles were not included in the systematic review		
Elliott 2004[104] USA Tests the effects of a strategy targeting rural providers and their practice environment on patient travel for care, satisfaction, economic barriers, and health-related quality of life	A group-randomised trial was conducted with 18 rural communities in the north-central United States. Twelve of these communities were included and defined as the unit of analysis for the patient outcome portion of the study. The intervention targeted rural providers and their practice environment. The subjects were patients with breast, colorectal, lung and prostate cancers from the rural communities. The main outcomes were patients' travel to obtain health care. Satisfaction with care, perceptions of economic barriers to care, and health related quality of life. In total 881 were included	Group randomisation was balanced. Travel for health care was significantly reduced in the community group exposed to the intervention during months 13 to 24 following cancer diagnosis. The mean miles travelled per patient were 1326 (SE=306) for the experimental group and 2186 (SE= 347) for the control group (P=0.03). No significant differences in satisfaction with care, economic barriers to care, or health-related quality of life were found

Table 6.3 Aubin systematic review & extracted studies

Reference Country	Methods	Results
Aubin 2012[113] Classifies, describes and evaluates the effectiveness of interventions aiming to improve continuity of cancer care on patient, healthcare provider and process outcomes	Randomised controlled trials (including cluster trials), controlled clinical trials, controlled before and after studies and interrupted time series evaluating interventions to improve continuity of cancer care were considered for inclusion. Included studies involved a majority (> 50%) of adults with cancer or healthcare providers of adults with cancer. Primary outcomes considered for inclusion were the processes of healthcare services, objectively measured healthcare professional, informal carer and patient outcomes, and self- reported measures performed with scales deemed valid and reliable. Healthcare professional satisfaction was included as a secondary outcome	Fifty-one studies were included. They used three different models, namely case management, shared care, and interdisciplinary teams. Six additional interventional strategies were used besides these models: (1) patient-held record, (2) telephone follow-up, (3) communication and case discussion between distant healthcare professionals, (4) change in medical record system, (5) care protocols, directives and guidelines, and (6) coordination of assessments and treatment. Based on the median effect size estimates, no significant difference in patient health-related outcomes was found between patients assigned to interventions and those assigned to usual care. A limited number of studies reported psychological health, satisfaction of providers, or process of care measures. However, they could not be regrouped to calculate median effect size estimates because of a high heterogeneity among studies
Luker 2000[117] **Setting:** Hospital-based specialist service/UK	Shared care CCT Women newly diagnosed with breast cancer **Unit of allocation:** Patient; Stratified by: Week in which women attended the breast specialist unit **Type of cancer:** Breast **Phase of care:** Pre-treatment, treatment, discharge, surveillance **Sample size at randomisation:** 76 Services from a breast care nurse (same as control) + information cards: Eleven information cards were developed by breast specialist secondary care professionals for members of the primary healthcare team. Women with breast cancer were asked to take the information cards to their own general practitioner (GP) practice. They covered information on the rationale for a specific treatment, prognostic indicators, complications and side effects, suggestions for dealing with side-effects and indicators for referral back to specialist services. Women were given cards corresponding to their treatment and the number and type of cards given to each woman was determined by the treatment received **Control:** Services of a breast care nurse who offered home visits prior to admission for surgery and written patient information leaflets on a variety of treatment regimes	**Process:** Number of contacts with GP and district nurse

Reference Country	Methods	Results
de Wit 2001[114] **Setting:** A 180-bed cancer centre (Antoni van Leeuwenhoek Hospital) Netherlands	Shared care RCT Patients experiencing pain related to cancer, cancer therapy, or illness, admitted to a hospital, and expected to live for at least 3 months **Unit of allocation:** Patient; Stratified by: With/without district nursing, and by gender, age, metastatic sites **Pain Education Program (PEP):** The Pain Education Program included the use of multiple teaching methods, which were provided both in the hospital and post-discharge by telephone. The PEP was started in the hospital and consisted of pain information and instruction that was tailored to the needs and abilities of the individual patient. The purposes of the pain education program for patients were: (1) to improve knowledge of their pain and pain treatment; (2) to enhance motivation to adhere to the drug regimen; (3) to monitor pain daily by means of a pain diary; and (4) to stimulate help-seeking behaviour (how to communicate about pain and how to contact healthcare providers). Topics discussed included: the definition of pain, pharmacological pain management, side-effects, myths and misconceptions related to pain management, non-adherence, use of non-pharmacological pain treatment and pain assessment. The verbal instruction, which was provided in the hospital, was audio-taped on a cassette so that it could be listened to at home. Patients were called at home at three and seven days post discharge by the same nurse to determine whether the pain information and instruction provided in the hospital was fully understood, and to offer the opportunity to ask questions **Shared care:** The second part of the intervention consisted of informing district nurses about the PEP that patients received. District nurses of intervention group patients received additional information about patients' pain complaints by telephone and by means of a written summary. By informing district nurses about patients' pain treatment, the purpose of the PEP was to improve their knowledge and understanding regarding patients' pain experience, to enhance their involvement in the pain treatment, and to ensure optimal continuity of care **Control:** Regular pain treatment provided to patients; district nurses of control group patients received no additional information and instruction.	**Patient:** QoL, pain, pain knowledge, pain cognition, pain experience, nurses estimation of patient's pain intensity, nurses assessment of patient's pain relief **Professional:** Pain management, nurse satisfaction with the pain treatment **Process:** Number of visits at home to the patients by the district nurses (after discharge), number of district nurses who contacted another healthcare provider, frequency of contacts with the general practitioner, extent of information provided by hospital nurse

Reference Country	Methods	Results
Rutherford 2001[118] **Setting:** Royal Women's Hospital oncology unit / Australia	Shared care RCT Patients admitted to the hospital for major surgery and having a GP or agreeing to be referred to a GP in living area **Unit of allocation:** Patient-GP dyad **Type of cancer:** Endometrial, cervical /ovarian **Phase of care:** Discharge, surveillance **Sample size at randomisation:** 200 Increased general practitioners (GPs) contacts with hospital: GPs were invited to contact patients in the hospital by either personal visit or telephone call, to assist with discharge planning and continuity of care. Payment was available for visiting (150 AUSD) or telephoning (75 AUSD) Discharge summary (DS) for the patient: The discharge summary was collated by theresearch nurse and comprised diagnosis and management plans with input from allied health, information on the specific gynaecological cancer for each patient, educational materials on chemotherapy and radiotherapy. It was either given to the patient on her discharge or mailed to her 1-2 days after discharge Combination studied included: (1) GPs not invited + DS (2) GPs invited + DS (3) GPs invited + No DS **Control:** Routine hospital discharge summary without any invitation to contact the hospital and no reception of cancer specific discharge summary	**Process:** Number of GP contacts during admission to hospital and after discharge

Reference Country	Methods	Results
Kousgaard 2003[116] **Setting:** Department of Oncology of Aarhus University Hospital / Denmark	Shared care Cluster-RCT Cancer patients newly referred to the department of oncology and scheduled for treatment or attendance for control **Unit of allocation:** General practitioner **Type of cancer:** Any type **Phase of care:** Pre-treatment, treatment, discharge, surveillance, recurrence, Second primary- cancer **Sample size at randomisation:** 199 GPs (248 patients) **Shared care program:** The patient was instructed to see his/her own GP about questions and problems. A discharge summary letter was written for the GP by the department of oncology in accordance with specially developed guidelines. The discharge summary included specific information on the disease and its treatment, general information about chemotherapy, radiotherapy, pain treatment, information about treatment of induced nausea and sickness and information about some acute oncological conditions (knowledge transfer). It also stated names and phone numbers of doctors and nurses responsible for the patient in the discharge summary letter to the GPs (improved communication channels). It also aimed to improve patient involvement in their own care by providing patients with oral as well as written information about the information package to their GP, and by encouraging patients to contact their GP when facing problems they assumed could be solved in this setting. **Control:** Normal procedure which included no procedure for informing the GP about newly diagnosed patients. The participating practitioner received the traditional information from the department, i.e. the discharge letter of an extract from the hospital record	**Patient:** Performance status, QoL, attitudes of patients towards contacts with the GP **Process:** Patient perception of cooperation within the healthcare system, number of contacts with GP (patient interview), number of contacts with patient (GP interview)

Reference Country	Methods	Results
Senn 2007[108] **Setting:** Health Network / France and United Kingdom	RCT Cancer patients who went through initial treatment **Unit of allocation:** Patient GP follow-up: a trained GP will be responsible for follow-up with possible referral to the specialist physician (and its team) when requested. The procedure of surveillance is exactly the same used in the control group. The GP and the specialist give relevant information to each other within the 15 days following each consultation **Control:** Usual follow-up by the specialist physician (and their team)	**Patient:** Satisfaction, QoL, iatrogenic effects **Professional:** Physician's (GP and specialist) perception or the surveillance performed in the study, satisfaction **Process:** Adequacy between the reference protocol and the carried-out surveillance (performed exams, date of exam versus forecast schedule), presence of relevant information according to the surveillance, costs
Augestad 2008[109] **Setting:** Three hospital trusts and one university hospital / Norway	Multi-centre RCT study Patients undergoing surgery for colon cancer **Unit of allocation:** Patient; Stratified by: Dukes's staging and whether there is a stoma **Type of cancer:** Colorectal **Phase of care:** Surveillance, treatment, discharge **Planned sample size at randomisation:** 170 Patients randomised to GP follow-up (intervention group) will be referred to their GP. This referral will contain information about the surgery and any complications, Dukes's staging, guidelines for follow-up and behavioural strategy in the case of a Serious Clinical Events (SCE). The regular check-ups will be performed at three-month intervals for the first two years and then every six months. All patients with elevated CEA prior to surgery will be requested to undergo this test at every postoperative clinical examination. Chest x-ray and ultrasound will be performed on a regular basis. Colonoscopy will be performed twice during the follow up period. The follow-up guideline will be similar in both arms **Control:** Regular follow-up will take place at the hospital's surgical outpatient clinic. This follow-up will be performed by consultants or internship doctors in digestive surgery	**Patient:** QoL, SCE, costs of follow-up: travelling/transportation, production losses, co-payments and other patient/family expenses **Process:** Costs of follow-up: outpatient visits, GP visits, laboratory tests, radiographs/ultrasound, examinations due to suspected relapse, treatment of relapse

Reference Country	Methods	Results
Jefford 2008[115] **Setting:** Peter MacCallum Cancer Centre / Australia	Shared care Cluster-RCT **Unit of allocation:** General practitioner **Type of cancer:** Not mentioned **Phase of care:** Treatment, discharge, surveillance **Sample size at randomisation:** 97 Tailored chemotherapy information faxed to general practitioners (GPs): In addition to usual correspondence, a cover letter and a chemotherapy information sheet relevant to their patients' regimen were faxed to the patients' GP. The GP practice was then contacted to confirm receipt of information and asked to file it in the patient's record. The cover letter was generic but contained several patient-specific fields: name of the patient, name of treating doctor, type of cancer, treatment intent (to cure the disease, to increase the chance of long-term, disease-free survival [adjuvant treatment], or to palliate symptoms/improve quality-of-life/extend survival), and type of CT. The sheet also included the telephone number of the drug information service and listed a number of relevant, reputable Internet sites. The chemotherapy sheets were developed for 23 CT regimens, used to treat haematological and solid tumours. Each sheet named component drugs, explained the treatment cycle, listed common adverse effects, suggestions for management and advice about when to call the cancer centre, how to contact relevant staff, and had a further information section. They were developed by a medical oncologist and behavioural scientist in collaboration with pharmacy staff following a focus group of 10 GPs and following a review by medical, nursing and pharmacy staff **Control:** Usual correspondence to GPs from their patient's oncologist	**Professional:** Satisfaction with communication received from the treatment centre, perceived confidence in managing chemotherapy adverse effects **Process:** Perceptions on the utility of correspondence

Table 6.4 Khan systematic review & extracted studies

Reference Country	Methods	Results
Khan 2008[119] Systematically reviews the literature on the use of primary and community care services by long-term survivors of adult cancers	A systematic search of eight databases was conducted. Considered papers looked at primary care aspects of surviving cancer at least 3 years past diagnosis	Ten eligible papers 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 with long term breast cancer survivors and controls
Andersen 1998[181] USA	**Study design:** Cross sectional interview **Type of cancer:** Breast **Length of survival:** All more than 3 years, 87% more than 5 years post-diagnosis **Number of participants:** 351 women interviews, 248 interviews analysed	83% participated, 59% analysed **Mammogram:** 70% of women were adhering to guidelines *Predictors of screening:* Physician recommendation or if the original breast cancer was picked up by mammogram
Chait 1998[182] UK	**Study design:** Questionnaire survey **Type of cancer:** Mixed **Length of survival:** All over 5 years post-diagnosis **Number of participants:** 41	88% and 95% response rates to the 4 and 12 month Q

Reference Country	Methods	Results
Earle 2003[183] USA	**Study design:** Retrospective case-control using SEER/Medicare data **Type of cancer:** Breast **Length of survival:** All at least 5 years post-diagnosis **Number of participants:** 5968 survivors, 6062 controls	93.7% response rate/follow-up **Mammogram:** Survivors were more likely than non-survivors to receive screening (74% of survivors compared to 41% of controls p<0.001) *Predictors of screening:* Breast cancer survivors not seeing an oncologist were significantly less likely to be undergoing surveillance mammography **Colorectal screening:** Survivors were more likely than non survivors to receive colon exam (17% of survivors versus 14% of non survivors, p=0.0001) **Pap smear/cervical screen:** Survivors were more likely than non-survivors to receive cervical screening (31% of survivors versus 27% of non-survivors p<0.0001) **Flu vaccine:** 65% of survivors versus 58% of non-survivors received vaccine over 1 year (p<0.0001) **Lipid testing:** 48% of survivors versus 43% of non-survivors received test over 1 year (p<0.0001) **Bone density:** 8.3% of survivors versus 6.8% of non-survivors over 1 year (p=0.001) *Predictors of screening:* Patients with higher SES, not African-American, decreasing age, living in an urban area or receiving care in a teaching hospital were more likely to receive preventative services. Those seeing a PCP were more likely to receive all other preventative services (except bone densitometry). Patients who saw both oncologists and PCPs received the highest rates of preventative services

Reference Country	Methods	Results
Earle 2004[184] USA	**Study design:** Retrospective case-control using SEER/Medicare data **Type of cancer:** Colorectal **Length of survival:** All at least 5 years post-diagnosis **Number of participants:** 14884 survivors 16659 controls	79.6% response rate **Pap smear/cervical screen:** Survivors were less likely than non survivors to receive cervical screen (17.8% of survivors versus 21.9% of non-survivors, p<0.001) **Flu vaccine:** 53.2% of survivors versus 55.4% of non-survivors (p<0.001) **Lipid testing:** 36.5% of survivors versus 39.4% of non-survivors (p<0.001) **Bone density:** 4.2% of female survivors versus 5.7% of non survivors (p<0.001) **Eye exam:** 47.4% of survivors versus 50.6% of non-survivors (p<0.001) *Predictors of screening:* Patients seen only by a PCP were more likely to receive flu vaccine and bone densitometry
Bellizzi 2005[185] USA	**Study design:** Retrospective case-control using NHIS survey data **Type of cancer:** Mixed **Length of survival:** 60.9% more than 5 years post-diagnosis **Number of participants:** 7384 survivors and 121 347 controls from 1998,1999,2000 and 2001 NHIS surveys	Response rates 74%, 69.2%, 72.1% and 73.8% for each year respectively **Mammogram:** Survivors were 34% more likely than non-survivors to adhere to guidelines (95% CI 1.18–1.51) **PSA:** Survivors were 32% more likely than non-survivors to adhere to guidelines (95% CI 1.21–1.52) **Pap smear/cervical screen:** Survivors were 36% more likely than non-survivors to adhere to guidelines (95% CI 1.10–1.57)

Reference Country	Methods	Results
Trask 2005[186] USA	**Study design:** Retrospective case-control using National Health Interview Survey data **Type of cancer:** Mixed **Length of survival:** All at least 5 years post-diagnosis **Number of participants:** 2151 survivors, 30195 controls from NHIS 2000	88.9% response to NHIS 2000 **Mammography:** Survivors were more likely to follow guidelines than non-survivors (OR=1.8 95% CI 1.5–2.1, OR=1.5 95% CI 1.3–1.9 if breast cancer survivors excluded) **PSA:** Survivors were more likely than non survivors to have a PSA (OR=2.48, 95% CI 2.04–3.0, OR=1.59, 95% CI 1.23– 2.0 if prostate survivors excluded) **Colorectal screening:** Survivors were more likely than non survivors to have a colon screening exam (OR=2.16, 95% CI 1.9–2.5 OR=1.9, 95% CI 1.6–2.4 if CRC survivors excluded) **Pap smear/cervical screen:** Survivors were more likely than controls to have a pap smear (OR=1.28, 95% CI 1.08–1.5, not significant when cervical survivors excluded)
Doubeni 2006[187] USA	**Study design:** Retrospective cohort in HMO (Health Maintenance Organisations) Administrative Data project **Type of cancer:** Breast **Length of survival:** 83.8% followed up for 3 years **Number of participants:** 797 women at start of cohort	262 women followed up for 5 years, 33% follow-up **Mammogram:** 80% of women had a mammogram in year 1, dropped to 63% in year 5 *Predictors of screening:* Visit to a gynaecologist (odds ratio (OR)=3.5, 95% CI 2.55–4.79) or a primary care physician (OR=2.2, 95% CI1.73–2.82)

Reference Country	Methods	Results
Mayer 2007[188] USA	**Study design:** Retrospective case-control using the National Cancer Institute's 2003 Health Information National Trends Survey (HINTS) data **Type of cancer:** Mixed **Length of survival:** Average 11.9 years post-diagnosis **Number of participants:** 619 survivors,2141 controls	Overall response of 32.6% **Mammography:** Excluding breast cancer survivors, female cancer survivors were not significantly more likely than non survivors to ever have had a mammogram (OR 1.83, 95% CI 0.82–4.05) **PSA:** Excluding prostate cancer survivors, male cancer survivors were not significantly more likely than non survivors to ever have had a PSA test (OR 1.13, 95% CI 0.39–3.3) **Colorectal screening:** Excluding CRC survivors, cancer survivors were significantly more likely than non-survivors to ever have had CRC screening (OR 2.03, 95% CI 1.29–3.2) **Pap smear/cervical screen:** Excluding cervical cancer survivors, female cancer survivors over 21 were not significantly more likely than non-survivors to ever have had a pap smear (OR 1.85, 95% CI 0.48–7.16)a

Table 6.5 Gysels systematic review & extracted studies

Reference Country	Methods	Results
Gysels 2006[120] Assesses the effectiveness of the patient-held record (PHR) in cancer care	Relevant literature was identified through five electronic databases (Medline, Embase, Cinahl, CCTR and CDSR) and hand searches. Inclusion criteria Patient-held records in cancer care with the purpose of improving communication and information exchange between and within different levels of care and to promote continuity of care and patients involvement in their own care	Seven randomised control trials and six non-experimental studies were identified. Evaluations of the PHR have reached equivocal findings. Randomised trials found an absence of effect; non-experimental evaluations shed light on the conditions for its successful use. Most patients welcomed introduction of a PHR. Main problems related to its suitability for different patient groups and the lack of agreement between patients and health professionals regarding its function
Drury 2000[121] UK	450 patients with any form of cancer **Setting:** Radiotherapy outpatient clinic **Duration:** 6 months **Intervention:** *Function:* clinical plus informal (means of communication and aide-memoire) *Content:* communication/diary sheets for use by patient, family, professionals, cares Pages for appointments, medication, addresses and telephone numbers *Format:* A4-size plastic wallet **Evaluation:** RCT **Outcome measures:** *Outcomes of intervention:* Global health status Emotional functioning Cognitive functioning By European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) Satisfaction with communication and participation by 19 item questionnaire *Use of PHR:* Patients: Questionnaire about the use of the record; Professional: questionnaire about attitudes to patients holding their own records	**No significant differences:** Between groups in any of the outcome measures: Patients in both groups expressed a high level of satisfaction with communication and participation in their care GP's views on patients having access to their medical records **Use:** *Patients:* 82.2% showed PHR to doctors, 61.7% wrote in it; *GP's:* 27.3% had seen PHR

Reference Country	Methods	Results
Williams 2001[122] UK	229 GPs; carers; 344 patients with difference types of cancers; 166 professionals **Setting:** Hospital **Duration:** 16 months **Intervention:** *Function:* clinical plus informal (means of communication and aide-memoire) *Content:* free text entries by patient, by professionals, details of medication, dates of appointment *Format:* pocket-sized A6, four coloured sections (diary function and aide-memoire) **Evaluation design:** RCT **Outcome measures:** *Outcomes of intervention:* Health related QoL by EORTC QLQ-C30 NHS resource and booklet use by telephone interviews *Design PHR:* Health-care professionals' views on content; patients' views by a questionnaire *Use of PHR:* Health-care professionals' views on use; patients' views by a questionnaire	**Significant difference in:** Preparing for appointments, monitoring patients' own progress, feeling in control *No difference:* QoL, NHS resource use, communication **Use:** 53% preferred not to have it but those who had it found it of value. Low use by professionals but those using it preferred patients to have it

Reference Country	Methods	Results
Lecouturier 2002[123] UK	137 patients newly diagnosed with lung or colorectal cancer (hospital, patients with cancer at any stage(community); 8 newly diagnosed patients outside RCT; 66 professionals **Setting:** Hospital and community **Duration:** 7 months **Intervention:** *Function:* clinical plus informal *Content:* seven differently coloured sections personal details, diary, communication, information *Format:* A5 size with a flexible loose leaf ring binder and a pocket to inert additional leaflets and appointments **Evaluation:** RCT **Outcome measures:** *Outcomes of intervention:* patient satisfaction with information and communication; patients' views of PHR by face to face interviews *Design PHR:* Outside RCT: 8 patients newly diagnose were interviewed by telephone about their opinion of the introduction of the PHR at the time of diagnosis *Use of PHR:* Health care professionals' views of PHR by postal questionnaire	**Only significant difference:** Control group were very satisfied with information (86%) intervention group (58%) 53% found it useful, and 69% found that it would be useful for them in the future Primary care professionals found it more useful than professionals in the hospital Well received by recently diagnosed patients **Use:** 87% patients used PHR; 83% responded to questionnaire; 4% reported not used

Reference Country	Methods	Results
Johnson 2002[124] UK	67 Breast, haematological, colorectal, lung near to diagnosis; 31 carers; 145 health professionals **Setting:** District hospital **Duration:** 1 year **Intervention:** *Function:* clinical plus informal *Content:* information, communication *Format:* not specified **Evaluation design:** Qualitative evaluation **Outcome measures:** *Design PHR:* How the PHR was used by patients, carers, health professionals by questionnaires How the PHR could be improved When the PHR is best introduced Communication between patients and health professionals Patients who had returned the questionnaires were invited to take part in focus group discussions	Patients like the record and placed importance on access to information early in the treatment process. They valued the health diary as a means of therapy and personal reflection and shared information with family and friends Health professionals found it a good tool to exchange information between different parties The majority of patients commented on the PHR's content was not personal enough
The following studies were not included in the systematic review		
Grunfeld 2011[125] Determines if a Survivorship care plan (SCP) for breast cancer survivors improves patient-reported outcomes	Women with early-stage breast cancer who completed primary treatment at least 3 months previously were eligible. Consenting patients were allocated within two strata: less than 24 months and ≥ 24 months since diagnosis. All patients were transferred to their own primary care physician (PCP) for follow-up. In addition to a discharge visit, the intervention group received an SCP, which was reviewed during a 30 minute educational session with a nurse, and their PCP received the SCP and guideline on follow-up. The primary outcome was cancer-related distress at 12 months, assessed by the Impact of Event Scale (IES). Secondary outcomes included quality of life, patient satisfaction, continuity/coordination of care, and health service measures	Overall 408 survivors were enrolled through nine tertiary cancer centres. There were no differences between groups on cancer-related distress or on any of the patient-reported secondary outcomes, and there were no difference when the two strata were analysed separately. More patients in the intervention that control group correctly identify their PCP as primarily responsible for follow up (98.7% v 89.1%; difference, 9.6%; 95% CI, 3.9 to 15.9; P=.0005)

Table 6.6 Lewis 2009 systematic review & extracted studies

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Lewis 2009[19] Systematic review of qualitative studies examining patients' and healthcare professionals' views about cancer follow-up	Comprehensive literature searches included: 19 electronic databases, online trial registries, conference proceedings, and bibliographies of included studies. Eligible studies included qualitative studies examining patients' and healthcare professionals' views of cancer follow-up. Studies of patients with any type of cancer, considered free of active disease, or no longer receiving active treatment were included. Findings were synthesised using thematic analysis	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
Bradburn 1995[189] UK Describes the use of patient focus groups as a method of gaining information for the development of a randomised trial looking at community versus hospital care in breast cancer follow up	Focus groups were used to obtain patients from a local cancer support group network	Initial responses from the focus group participants appeared to be unfavourable to the protocol. In all, more than five issues were raised which might lead to reluctance to cooperate in the trial. Participants identified key issues related to their follow up
Wood 1996[190] Canada Explores oncologists' perspectives on the process of cancer patient follow up and to identify what oncologists need from family physicians during the remission stage of cancer disease	Qualitative study with in-depth interviews A purposive sample of 10 oncologists. The nine who participated represented both radiation and medical oncology. Oncologists who had practised at the cancer centre for less than 2 years were excluded from the study Main outcome measures included existing barriers to communication and collaboration between oncologists and family physicians in cancer patient follow up	Oncologists described roles for themselves in reassuring patients, detecting recurrence, monitoring toxicity of treatment, and gathering data for clinical trials. Collaboration with family physicians in the remission phase was identified as desirable but inhibited by variable and unpredictable interest, poor communication with family physicians, and patients' own preferences for follow up. Oncologists perceived the cancer system structure as a "black box" within which multidisciplinary teams worked well but seldom included family physicians. Oncologists expressed a need to see healthy patients and to have more understanding and support from family physicians, preferably through sharing follow up care. Developing dialogue and a more collaborative approach were suggested
Adewuyi-Dalton 1998[191] UK Investigates the experience of specialist hospital follow-up among 109 women with breast cancer in remission	Qualitative interviews explored views of follow-up at an outpatient clinic	Continuity of care and an unrushed consultation were considered to be both desirable and efficient. There were concerns that discontinuity led to a lack of personal and case familiarity and communication difficulties. Access to cancer expertise, the availability of diagnostic tests and specialist facilities were valued features of hospital follow-up, and further analysis indicated that this was particularly important in the early stages of follow-up

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Johansson 2000[192] Norway Describes the role of the General Practitioner (GP in the care of one specified cancer patient per GP, and to explore the GP's knowledge about that patient's disease and treatments, and what information she/he wanted versus received from the specialist clinic. Also evaluates the effects of an Extended Information Routine (EIR), including increased information from the specialist clinic to the GP	Semi-structured interviews with GPs about a patient randomised between an extended information routine and standard information from the specialist clinics.20 GPs, 10 who received extended information about the specified patient and 10 who did not Main outcome measured included the extent of GPs' contact with the patient, GPs' potential or actual possibilities to support the patient, desired and received information from the specialist clinic	GPs are commonly involved in the care of cancer patients, particularly in the diagnostics of the disease but also during the periods of treatment and follow-up. The information from the specialist clinic to the GP is insufficient in standard care. The extended information routine increased the GPs' knowledge of the disease and treatments, and facilitated their possibilities to determine patients' need for support
Pennery 2000[193] UK Ascertains patients 'perceptions of routine follow- up care after completion of treatment for breast cancer	A cross-sectional survey of a stratified systematic sample of patients was utilised. Data were collected using semi- structured, taped interviews. The tapes were inductively analysed and coded to ascertain predominant themes. Twenty-four patients were recruited	Analysis indicated that follow-up examinations were hurried (18 patients), investigations were not reassuring (11) and that the lack of continuity was unacceptably poor (22). Many patients (19) felt uncomfortable expressing emotional concerns or asking questions. The majority (18) stated that they would prefer to receive all or part of their follow-up from a breast care nurse
Sahay 2000[194] Canada Uses qualitative methods to contribute to a complete patient perspective on the psycho-social impact of colorectal cancer	Qualitative descriptive study conducted in 20 patients attending a gastrointestinal follow-up clinic at the Toronto-Sunnybrook Regional Cancer Centre. The data documented included patient satisfaction and perceptions regarding to quality of care, information received, involvement in decision making, and long-term management of the illness	Overall, patients were satisfied with their treatment, including the quality and timeliness of the information they received, the quality of their health care, and the level of involvement in decision making. However, some patients were dissatisfied with information concerning long-term management of their illness. Patient care, including information and social support, was provided by cancer specialists, family physicians, family, and friends. Patient's looked to cancer specialists as their primary source of information, but relied on family physicians to fill in gaps in understanding, to provide support, to manage overall care, and to act as a sounding board for ideas and treatment options. Social support was also provided by family and friends. All patients had a relatively positive outlook on their illness experience, although those with colostomies had some added difficulty. Despite the focus on positive change, many patients acknowledged difficulty coping with the side effects of treatment

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Koinberg 2001[195] Sweden Describes the needs of the patient with breast cancer and satisfaction with routine follow-up visits to the physician	A strategic sample of 20 women with breast cancer, routinely followed-up at an oncology outpatient clinic, was interviewed. A qualitative descriptive design inspired by the phenomenographic method was used	The results identified the need for routines, accessibility, security, continuity, confidence and information. The women's views demonstrated that there are strong reasons for reviewing and changing the design of the traditional follow-up system to obtain the most effective and well-functioning system possible to better meet these women's needs
Allen 2002[196] UK Insight into the experience of attending for follow-up after primary breast cancer	Qualitative approach using the method of phenomenological enquiry in order to gain understanding from the perspective of the women who attend follow-up clinic. Six women were interviewed. Interviews were taped and transcribed verbatim	Analysis of the transcripts indicated a cycle of emotions associated with attendance at follow-up clinic. Required attendance produced anxiety in women who were otherwise living free from anxiety about breast cancer recurrence. This anxiety appeared to create a need to attend in order to gain reassurance of continued well-being. Despite gaining reassurance all of the women in this study reported feelings of dissatisfaction with the follow-up clinic experience. In the current climate of over-extended and under-staffed clinics it may be timely to examine current practice for effectiveness in terms of physical and psychological impact on the patient and efficient use of healthcare resources
Brown 2002[197] UK	RCT assessing two types of outpatient follow up for women previously treated for stage 1 breast cancer now in remission. These were standard clinic follow up and patient initiated follow up The latter method involved giving the women written information on the signs and symptoms of recurrence and instructing them to telephone the Breast Care Nurse if they encountered any problems. The groups were compared in terms of cancer and breast cancer specific quality of life, and psychological morbidity at recruitment, 6 months and 1 year	There were no major differences in quality of life and psychological morbidity between the groups although more women in the standard clinic group reported reassurance and being checked as advantages whereas more women in the patient initiated follow up group reported convenience as an advantage. Patient initiated follow up is a potential alternative to standard clinic follow up for this group of women and appears to have no adverse effects
Koinberg 2002[195] Sweden Describes breast cancer patients' satisfaction with a spontaneous system of check-up visits to a specialist nurse.	A strategic sample of 19 breast cancer patients, who were not involved in a routine follow-up system but who had the possibility of contacting a specialist nurse when necessary, were interviewed. A qualitative descriptive design inspired by the method of phenomenographic analysis was used	Five description categories and 606 statements showing similarities and differences in conceptions were obtained. The patient's satisfaction with the knowledgeable and professional skills of the nurses was high. Confirmation and trust were important and necessary in order for the women with breast cancer to feel secure. Patients had a need for information and self-care education. Accessibility and early assessment by professional personnel or an oncology nurses were essential in a system without routine follow ups

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Wong 2002[198] China (Hong Kong) Reports the results of a qualitative study that examined the experiences of cancer patients with the intention of incorporating consumer perspectives into the development of quality cancer care in Hong Kong	Eight focus group interviews were conducted with of 41 cancer patients	The results indicate that patients lack clear guidance and support regarding the management of sequelae and surveillance against recurrence. Patients also raised concerns about the lack of access to information, and the lack of health care provider accountability. Any understanding of the scope and goals of follow-up cancer care is obscured when the healthcare environment is not conducive to good doctor–patient communication. Patients are calling for more explicit goals and clinical practice guidelines to serve as frames of reference for both patients and doctors
McIlveney 2004[199] UK	Semi-structured interview with patients (n=6) and HCPs (n= 5, from multidisciplinary team) **Type of follow up:** Nurse (clinic) (3 patients had attended nurse-led follow-up, 3 not yet attended)	
Rozmovits 2004[200] UK Identifies the range of patient pathways following surgery for colorectal cancer and explore patients' needs and preferences for follow-up	A survey of hospitals within the UK Colorectal Cancer Services Collaborative and qualitative thematic analysis of 39 in-depth narrative interviews with colorectal cancer patients. Participants volunteered or were contacted through hospital consultants, support groups and general practitioners (GPs). Most of the interviews were collected in respondents' homes, throughout the 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
Beaver 2005[201] UK Investigates the nature and content of hospital follow-up visits following treatment for breast cancer using a mixed methods approach	Direct observation and audio recording of 104 consultations, semi-structured interviews with 14 health care professionals (HCP) involved in follow-up service provision and a patient survey	Consultations were focused on detection of recurrent disease by clinical examination, despite this being a rare event. HCPs' style of interaction could foster the illusion that follow up visits were intended to detect recurrence. Consultations were generally of brief duration (mean 6 min) and were overwhelmingly optimistic, although patients gained reassurance from minimal interaction. Few opportunities were available to meet information and psychosocial needs

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Anvik 2006[202] UK Describes and analyses the role of the GP during initial follow-up of patients with recently treated cancer, from the perspective of patients, their relatives and their GPs	One focus group interview with six GPs from the city of Bodø and individual interviews with 17 GPs from the city of Tromsø in North Norway. Text analysis of the transcribed interviews and of free text comments in two questionnaires from 91 patients with cancer diagnosed between October 1999 and September 2000 and their relatives from Tromsø	
Cox 2006[203] UK Assesses the acceptability of nurse-led follow-up in a large general lung cancer clinic seeing approximately 250 new patients annually	Over a 34-week period, there were 487 follow-up attendances and 94 (19.3%) of these were made by 72 patients deemed eligible for nurse-led follow-up. Sixty patients were approached and 54 (90%) agreed to participate in the study. A questionnaire containing vignette scenarios of nurse-led, telephone, GP-led, and standard (hospital, medical) follow-up was completed by 34/54 (63%) of eligible patients, 10/20 (50%) carers, 20/31 (65%) staff, and 11/38 (29%) GPs. Patients also completed the EORTC QLQ C30 and lung module questionnaire. Subsequent interviews were carried out with samples of these respondent groups	Fatigue, dyspnea, cough, and pain were the most common general symptoms. Both standard and nurse-led follow-up scenarios were highly rated by patients and other respondents and both were highly significantly favoured over GP follow-up, which was the least favoured in all areas of the questionnaire. Telephone follow-up tended to elicit more polarised reactions, both positive and negative. In interviews, in relation to nurse-led follow-up, the importance of clear protocols, training, and easy access to medical review were highlighted
Jiwa 2006[204] UK Identifies the elements of a follow-up protocol for treated breast cancer patients in primary care with reference to key stakeholders in one region of the UK	Stage 1: a survey of 100 consecutive hospital records relating to patients treated for primary breast cancer. The most common problems managed at follow-up and the type and frequency of resources used were identified Stage 2: focus groups with stakeholders identifying potential barriers to follow-up of breast cancer patients in primary care after successful therapy Stage 3: a nominal group outlined the elements of a follow-up protocol in primary care	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. Health care 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
Moore 2006[111] UK Describes the preparation and development of a model of nurse led follow-up care, identify key nursing interventions provided within nurse led follow-up care and provides insight into the experiences of nurse specialists providing follow-up care	Data were collected from nurse specialists' patient case records and from meetings held with the study team. Semi-structured interviews were conducted with the nurse specialists providing follow-up care and the study coordinators	

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
The following studies were not included in the systematic review		
Grunfeld 1999[133] England Randomised controlled trial (RCT) comparing specialist follow-up with follow-up by the patient's own general practitioner showed no increase in delay in diagnosing recurrence and reinitiating specialist care as a result of primary care follow-up (Grunfeld 1996) Reports the results of an economic evaluation to assess the relative costs of the two alternative schemes of follow up that was conducted concurrent with the RCT	Cost minimisation analysis was conducted whereby the two schemes are examined for the least costly alternative	Costs to patients and to the health service were lower in primary care. There was no difference in total costs of diagnostic tests, with particular tests being performed more frequently in primary care than in specialist care. Data are provided on the average frequency and length of visits, and frequency of diagnostic testing for breast cancer patients during the follow-up period
Baravelli 2009[132] Australia Surveys key stakeholders in the care of people with colorectal cancer (survivors, primary care providers and hospital-based healthcare professionals) regarding follow-up and SCP	In study 1, cancer survivors completed a questionnaire regarding their follow-up and experiences during survivorship. Participants' primary care physicians 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	Twenty survivors completed the questionnaire, 14 primary care providers completed a phone interview and 12 survivors reviewed the sample SCP. Ninety-five healthcare professionals (30 medical professionals and 65 nurses) completed the questionnaire. 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

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
The following studies were not included in the systematic review		
Burg 2009[130] USA Explores minority breast cancer survivors' recall of information from their oncologists about their cancer and follow-up care and their views on the potential use of survivorship care plan	During four focus groups with minority breast cancer survivors, data were collected about the types of information survivors remember receiving from their oncologists about follow-up health care needs. Survivors were also asked their opinions on the value and content of a survivorship care plan	Minority breast cancer survivors received variable amounts of information about their cancer treatments. They were dissatisfied with the amount of information they received on cancer-related side-effects, including race-specific information. The American Society of Clinical Oncology's breast cancer survivorship care plan was viewed as important, but too highly technical and limited in information on side-effects and self-care approaches
Mao 2009[128] USA Describes postmenopausal breast cancer survivors' (BCS) perceptions of PCP-related survivorship care	Cross-sectional survey of 300 BCSs seen in an outpatient breast oncology clinic at a large university hospital. The primary outcome measure was a seven-item self-reported measure on perceived survivorship care (Cronbach's α=.89). Multivariate regression analyses were used to identify factors associated with perceived care delivery	Overall, BCSs rated PCP-related survivorship care as 65 out of 100 (standard deviation_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*=.001 for both)
Aubin 2010[127] Canada Longitudinal study of patients with lung cancer to assess their family physician's involvement in their follow-up at the different phases of cancer	In 5 hospitals in the province of Quebec, Canada, patients with a recent diagnosis of lung cancer were surveyed every 3 to 6 months, whether they had a metastasis or not, for a maximum of 18 months, to assess aspects of their family physician's involvement in cancer care	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
Brennan 2011[131] Australia Explores survivors' experiences with follow-up care and attitudes to alternative models including a tailored survivorship care plan and involvement of primary care physicians and breast care nurses	Twenty women across Australia participated in semi-structured telephone interviews. All continued to attend follow-up visits with a specialist oncologist and reported a high level of satisfaction with care	Participants described a strong reliance on their specialist but were open to an increased role for their primary care physician in a shared model of care. Communication between multidisciplinary team members was perceived as an ongoing problem and there was enthusiasm for a patient-held written survivorship care plan to address this, and to meet information needs

Reference Country Review Purpose/Aim	Inclusion criteria, dates, Articles reviewed, number of studies included, meta-analysis performed?	Results, Conclusions
Hudson 2012[129] USA Examines patient perspectives on these physicians' roles in their cancer follow-up care or their care preferences	Explored survivor preferences through qualitative, semi structured, in-depth interviews drawing on patients recruited from 2 National Cancer Institute – designated comprehensive cancer centres and 6 community hospitals. We recruited a purposive sample of early-stage breast and prostate cancer survivors aged 47 to 80 years, stratified by age, race, and length of time from and location of cancer treatment. Survivors were at least 2 years beyond completion of their active cancer treatment	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 the primary care physician's engagement in follow-up care: (1) lack of cancer expertise (2) limited or no involvement with original cancer care, and (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: (1) performing routine cancer-screening tests (2) supplementing cancer and cancer-related specialist care, and (3) providing follow-up medical care when "enough time has passed" or the survivors felt that they could reintegrate into the non-cancer population

Appendix 7.International models of follow up

Reference		
Adams 2009[205]: Extracted refs below Investigates rural cancer service delivery models in Australia and in countries with comparable demographic and geographic features to NSW and identifies common elements of best practice.		
Location	**Current model**	**Innovative models**
British Columbia, Canada	The management of cancer services is centralised through the British Columbia Cancer Agency (BCCA). There are four regional comprehensive cancer centres located throughout the province funded directly by BCCA and providing the following range of services: - patient assessment, diagnostic and therapy planning - radiation therapy - chemotherapy services - nursing care - patient and family counselling - nutrition counselling - pharmacy services - pain and symptom control service - teaching and applied research activities - cancer information library The Agency delivers care and sets standards of care across all provinces via a Community Oncology Network of community cancer centres, services, consultative clinics, and other community hospitals; the Community Physician Oncology Network and the Surgical Oncology Network. The BCCA generates and transfers knowledge through the continuous maintenance of the Cancer Management Guidelines, Cancer Drug Manual, Chemotherapy Protocols, Evidence Based Guidelines for all disciplines, education for the community health care professionals, and outcome evaluation and research. This is facilitated by the BCCA's interactive website The Communities Oncology Network (CON) is a collaborative voluntary partnership with community services including community-based Community Cancer Centres, six community-based Community Cancer Services and 12 Consultative Clinics across the province, in conjunction with the Regional Cancer Centres and the Systemic and Radiation Programs. The Network also supports appropriate delivery of cancer patient care and support in 33 other community hospitals Components include patients and their families, community health care providers and volunteers, hospitals, community groups, Health Regions, the BC Cancer Agency Regional Centres and all processes facilitated by the Agency. The components are interdependent and held together by trust, mutual respect, communication and education	- A community physician oncology network including a preceptor program has been established. This includes a two-month training course in oncology in a module format, which can be taken as an entire program or by individual modules. The aim is to have at least one family physician with oncology expertise in every BC community with 15,000 people. The program is offered in each of the four cancer centres (Kelowna, Surrey, Victoria and Vancouver). There are several funding sources to support these positions - The CON has clearly defined levels of service and expectations at each level - BCCA has implemented a Surgical Oncology Network, which includes all providers of surgical oncology services from surgeons in remote areas to sub-specialists. Its purpose is to provide strong linkages with surgeons and hospitals across the province, including the BC Cancer Agency's four cancer centres and 17 clinics. The Network's goal is to establish a structure and a system to enable the integration of quality surgical oncology services into the formal cancer care system. Functions include developing communication tools to enhance surgical decision making provincially; participating in the identification and/or development of peer-reviewed, evidence-based guidelines based on 'best practice' principles; developing a high quality continuing education program; and conducting regionally-based research and outcome analyses - Generation and transfer of knowledge throughout the province is achieved through the continuous maintenance of the Cancer Management Guidelines, Cancer Drug Manual, Chemotherapy Protocols, Evidence Based Guidelines for all disciplines, education for community health care professionals, and outcome evaluation and research. This is facilitated by the BCCA's interactive website, which is a dynamic, interactive resource for physicians, pharmacists and nurses who provide

Reference		
Adams 2009[205]: Extracted refs below Investigates rural cancer service delivery models in Australia and in countries with comparable demographic and geographic features to NSW and identifies common elements of best practice.		
Location	**Current model**	**Innovative models**
	BCCA Medical Oncologists who transfer care to the community to receive chemotherapy have the responsibility to ensure that the accepting physician has the necessary knowledge, skill and ability to manage this care and that the community facility meets the BCCA standards as defined by the Communities Oncology Network (CON) model. The standards outlining infrastructure and processes necessary for a comprehensive community cancer care program are found at the BCCA website The CON facilities must have at a minimum, appropriately trained and competent staff (nurses, physicians and pharmacists) to administer and manage the cytotoxic and hazardous products used to treat cancer. As well, they must have access to clinical diagnostic services, such as haematology, with the capability to provide all of the information required to monitor cancer therapy. Additionally, these communities are required to have the capabilities to respond to complications of therapy 24 hours per day Each of the community health care professionals are supported to develop and maintain their competency. BCCA medical oncologists do not refer patients to communities that have not met the standards.	systemic therapy throughout the region. BC is currently implementing a Northern Health Strategy to improve care to people living in rural and remote areas. This includes additional training and support for northern physicians on cancer control, including access to BCCA resources through outreach and telehealth services. There will be greater focus on cancer screening and early diagnosis and introduction of patient-centred care with navigational supports. The strategy intends to strengthen the network of care that extends from smaller communities to the largest centres through the family practice and community oncology networks
Ontario, Canada	Cancer Care Ontario (CCO) is not responsible for service provision, but rather oversees and performance manages all cancer services. The performance management system allows for the monitoring and management of 11 integrated cancer programs (ICPs) across the province. The system comprises four elements: reporting frequency; reporting requirements; review meetings; and accountability and continuous improvement activities. Some of the lessons learned from this performance management approach: - data must be valid and reliable - performance management requires commitments from both parties in the performance review exercises - streamlining performance reporting is beneficial - technology infrastructure that allows for cohesive management of data is vital for a sustainable performance management system - performance indicators need to stand up to scrutiny by both parties providing comparative data across the province is valuable Ontario health services are organised into 14 Local Health Integrated Networks (LHIN), covering	A video-conferencing program for the North East LHIN which has 7 small hospitals and no academic centre. The regional surgical oncology leader has organised multidisciplinary care conferences that include all surgeons performing cancer surgery within the region for biweekly meetings. The video-conferencing allows high resolution diagnostic and lab pathology slide imaging so all participants can review charts at the same time. A medical oncologist from a larger centre participates in the conferences - Another LHIN in the Champlain region has developed a strong community of practice across the region with multidisciplinary cancer team and patients. The program oversees the administration of the chemotherapy home infusion pump program for patients living in Eastern Ontario to avoid travel for overnight stays in larger centres Depending on local priorities, service arrangements and focus of innovations vary. For instance, some of the LHINs use telehealth significantly, while others do not. There have been experiments with the development of local community services in remote areas in Ontario. In

Reference		
Adams 2009[205]: Extracted refs below Investigates rural cancer service delivery models in Australia and in countries with comparable demographic and geographic features to NSW and identifies common elements of best practice.		
Location	**Current model**	**Innovative models**
	the full range of community, acute and rehabilitation health services. CCO has appointed a regional vice president (VP) of cancer control for each of the LHINs. The regional VPs meet on a regular basis and provide cancer representation at the executive level. The VPs appoint surgical leaders and other staff to support quality care within each LHIN. Depending on the needs of their regional population they also implement other initiatives to improve access and quality of care. The CCO focuses on quality issues and has developed a set of quality and performance measures on which the regional VPs report each quarter. Surgeons and hospitals, for example, participating in the regional surgical oncology program have to enter standards agreements to meet criteria of volume and quality to participate. LHINs are described in detail on the Cancer Care Ontario website Guided by the Ontario Cancer Plan, Regional Cancer Programs link health care professionals, organisations, patients and decision makers across the spectrum of cancer services from prevention to treatment. Their goal is to ensure that every patient, regardless of address, has access to high-quality care as close to home as possible. While individual organisations provide cancer services, Regional Cancer Programs (RCPs) are responsible for creating an annual cancer service plan and forging networks of cancer services in their LHINs, by building on existing relationships and using agreements and other accountability mechanisms Regional Cancer Programs access Cancer Care Ontario's (CCO) planning expertise, policy leadership, cancer information and the provincial standards and programs that are needed to deliver a consistently high quality of care. RCPs have the critical local relationships and structures needed to make improvements appropriate to the local context The CCO Provincial Leadership Council and Clinical Council are forums where Regional Vice Presidents and clinical leaders from across the cancer system come together to work on common issues and provide advice to Cancer Care Ontario on cancer priorities for the province. These councils provide a forum to work through issues that cut across LHIN boundaries, such as determining the best way to organise and locate highly specialised treatment services	1992 outreach services were provided in thirteen small remote communities in north-western Ontario to provide chemotherapy and supportive care to clients. Once each community entered into an agreement to maintain an oncology service in its hospital, local physicians, nurses and pharmacists were designated as oncology providers and were given the opportunity to attend clinical training sessions at the regional cancer centre. Continuing education opportunities were made available using teleconferencing technology In 1997 the Centre for Rural and Northern Health Research evaluated the program and reported in 2001 that, 'the evidence suggests that the community cancer care program is maturing into a reliable system of care serving a small, but widely dispersed population'

Reference		
Adams 2009[205]: Extracted refs below Investigates rural cancer service delivery models in Australia and in countries with comparable demographic and geographic features to NSW and identifies common elements of best practice.		
Location	**Current model**	**Innovative models**
Scotland	Scotland's cancer strategy, Cancer in Scotland: Action for Change proposes managed clinical networks (MCN) as the model of cancer service delivery to support cancer patients, regardless of location. The concept of MCNs evolved following a review of acute services. It was defined in a management executive letter in 1999 as 'linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland'. The Scottish Office suggests that MCNs differ from hub and spoke models in that the interests of the network theoretically dominate those of individual hospitals. Details regarding the establishment and rollout of MCNs are included in an NHS circular. The cancer strategy proposed comprehensive coverage of tumour-specific MCNs across Scotland. To achieve this, three regional cancer networks covering all of Scotland were created: West of Scotland Cancer Network (WoSCAN), South East Scotland Cancer Network as (SCAN) and North of Scotland Cancer Network (NoSCAN). The establishment of networks in the Scottish context has had the following outcomes: - they are clinician led - they have added local focus to healthcare planning frameworks. Regional Cancer Advisory Groups have been established in each network and work with the local NHS Boards to plan cancer services for each area considering local needs - a major clinical redesign initiative within the program has focused on establishing regional tumour-specific networks. However, treatment of rare and/or specialised cancers is through a national network	

The following references were not included in the literature review		
Model Country Aim	**Methods**	**Results**
Primary Care Cancer Lead Clinician (PCCL) England Developed from an undertaking, set out in the NHS cancer plan, that each primary care trust (PCT) should have the funds to recruit a PCCL for at least one session (3–4 hours) per week. The initiative aimed to improve communication and understanding of cancer across primary and secondary care and provide a link between Cancer Networks and primary care	Leese et al. (2006[206]) sent a postal questionnaire to all PCT chief executives in all PCTs in England and some were passed on to other PCT managers for completion. The response rate was 61 per cent. PCT directors of public health were the largest group of respondents (29 per cent). Most (74 per cent) PCCLs were GPs and 22 per cent were nurses	PCCLs were most likely to focus on palliative care and preventive services. Key achievements were identified as raising awareness of cancer, developing relationships and promoting primary care. The personal skills of the PCCLs were important as was support of colleagues at all levels. Lack of time was a major barrier to achievement, as was a lack of understanding of the role from others. Links with the Cancer Networks were being developed. About 85 per cent of managers wanted the role to continue