

The expanding role of primary care in cancer control



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The nature of cancer control is changing, with an increasing emphasis, fuelled by public and political demand, on prevention, early diagnosis, and patient experience during and after treatment. At the same time, primary care is increasingly promoted, by governments and health funders worldwide, as the preferred setting for most health care for reasons of increasing need, to stabilise health-care costs, and to accommodate patient preference for care close to home. It is timely, then, to consider how this expanding role for primary care can work for cancer control, which has long been dominated by highly technical interventions centred on treatment, and in which the contribution of primary care has been largely perceived as marginal. In this Commission, expert opinion from primary care and public health professionals with academic and clinical cancer expertise—from epidemiologists, psychologists, policy makers, and cancer specialists—has contributed to a detailed consideration of the evidence for cancer control provided in primary care and community care settings. Ranging from primary prevention to end-of-life care, the scope for new models of care is explored, and the actions needed to effect change are outlined. The strengths of primary care—its continuous, coordinated, and comprehensive care for individuals and families—are particularly evident in prevention and diagnosis, in shared follow-up and survivorship care, and in end-of-life care. A strong theme of integration of care runs throughout, and its elements (clinical, vertical, and functional) and the tools needed for integrated working are described in detail. All of this change, as it evolves, will need to be underpinned by new research and by continuing and shared multiprofessional development.

Part 1: Introduction

Cancer control in high-income countries has long been dominated by highly technical, disease-centred interventions intended to save or prolong life. This is changing as health policies drive an increased emphasis on public awareness, screening, and early diagnosis of symptomatic disease as a means to further improve outcomes. At the same time, more people are surviving cancer and will live with the long-term effects of their disease and its treatment. This is not a unique problem for the wealthiest nations. Middle-income countries are starting to face the same challenges, as non-communicable diseases, especially cancer, become a prominent health-care issue.

For a long time, the role of primary care in cancer was largely seen as peripheral, but as prevention, diagnosis, survivorship, and end-of-life care assume greater importance in cancer policy, the defining characteristics of primary care become more important. Care that is more patient-centred brings with it not only considerations of patient choice and convenience, but also the whole-person approach that patients seek. Health services striving for affordable cancer care seek optimal models of care delivery, and some deeply held sociomedical cultural practices might need to be re-engineered.¹

The purpose of this Commission is to distil the evidence for the effectiveness of interventions for cancer control based in primary care at each stage of the cancer journey (figure 1) and to consider how cancer care might be delivered differently in the future. It discusses how and whether health policy for cancer control will help or hinder such change. Finally, it examines the implications for the future education and training of doctors, and

identifies emerging examples of good practice worldwide. The Commission brings together leading members of the international primary care cancer community, together with cancer specialists and policy researchers. We have elected to restrict our Commission to high-income countries and mainly to countries with universal health-care systems, since these have a more clearly defined and discrete element of primary care to their services.

The current and future cancer burden

The lifetime risk of developing cancer in the UK is now 50%.² The incidence of many cancers is increasing as a result of lifestyle and environmental factors and an increasingly aged population, especially as the so-called baby boom generation reaches its seventh and eighth decades. The number of cancer survivors is rising too, as 10-year cancer-specific survival has increased from one in four in the 1970s to one in two nowadays. For example, the Dutch Cancer Society has predicted a 61% increase in cancer survivors between 2010 and 2020 in the Netherlands.³

A cancer diagnosis is a relatively common event in primary care: a primary care physician (PCP) with 2000 patients typically sees 6–8 new cases per year, which is similar to the number of new cases of diabetes, and twice as frequent as new cases of stroke. The difference, of course, is that cancer is a heterogeneous entity, and the diagnosis of any single cancer type a rare event, with each characterised by different presenting signs and symptoms. A PCP can expect only one case of each of the common cancers (colorectal, prostate, breast, and lung) in any year and might see only one or two of some rarer cancers during his or her entire professional career. As survival

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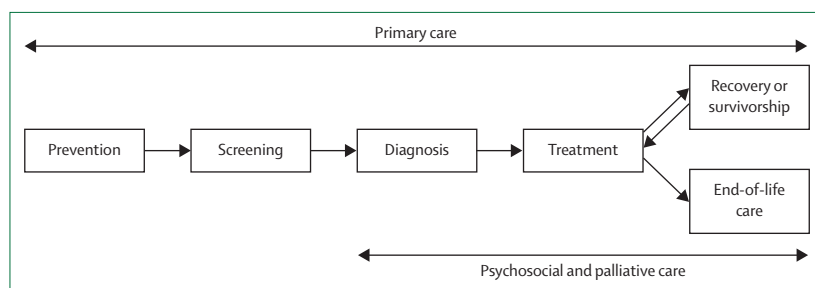


Figure 1: The cancer journey
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improves, prevalence of cancer in the practice population increases. At present, a PCP with 2000 patients has around 70 patients with or surviving cancer, and this number is predicted to double by 2040.⁴ In comparison, the PCP typically looks after 120 patients with diabetes mellitus.

The diagnostic process for cancer has now been well described and broken down into its component elements (figure 2), together with much needed clarity about how these elements are best defined.⁶ This model underpins much of the more recent thinking about the process of cancer diagnosis and, taken together with the theoretically derived model of pathways to treatment (figure 3),⁷ informs our detailed consideration of the diagnostic process (discussed in Parts 3 and 4) and the patient help-seeking dimension (addressed in Part 2).

A minority of cancers are detected through screening programmes, which in most high-income countries run for colorectal, breast, and cervical cancers. In the UK and Australia, three in ten breast cancers and one in 20 colorectal cancers are detected through screening.⁸ In Part 2 of this Commission, we consider in more detail the role of primary care in screening programmes.

Around 85% of cancers are diagnosed after symptomatic presentation to a PCP.⁹ More than 90% of patients with a cancer that typically has characteristic symptoms or signs (eg, breast cancer and melanoma) are referred to a specialist after one or two PCP consultations. For those with a cancer with less distinctive symptoms (eg, lung cancer, myeloma, and pancreatic cancer), a third or more will have three or more PCP consultations before being referred.¹⁰ One consequence is that, for such cancers, presentation to specialist care is more likely to be as an emergency rather than a planned referral,⁸ with associated poor clinical outcome and patient experience.

The diverse nature of cancer symptoms is the key challenge for PCPs in diagnosis—namely, the accurate and timely assessment of symptoms and signs that are much more frequently caused by mild illnesses. In several countries, such as the UK, Denmark, Spain, and Australia, urgent referral pathways have been developed to help with assessment of the symptomatic patient. Because up to half of patients with some cancers do not have alarm symptoms,¹¹ there is a growing interest to develop pathways that assess those patients with non-specific or

non-alarm symptoms (see Part 8). Although the priority is to achieve a prompt diagnosis, the pathway shown in figure 2 conceals many complexities—eg, short diagnostic intervals are associated with advanced disease and poor survival (known as the waiting time paradox; see Part 3).

A substantial minority of all cancers (24% in England)⁸ are diagnosed after attending emergency departments of acute hospitals or after emergency admission to hospital. The extent to which these patients have interacted with primary care is not well understood, although they are most likely to come from a deprived background and frequently use the emergency department as a source of primary health care.^{12–14}

Finally, an unknown proportion of cancers are diagnosed incidentally, either because the symptoms were not caused by the cancer or during the course of investigation for an unrelated problem. These cancers might be important because they might be of earlier stages and amenable to treatment.¹⁵ However, the cancer might not become a health problem in the patient's lifetime (the PCP's role in judicious use of diagnostic tests is discussed in Part 4). Interest in this dimension of the overdiagnosis debate is growing as patients undergo testing for cancer at increasingly lower levels of risk. Nevertheless, the scale and seriousness of overdiagnosis in symptomatic patients remain poorly understood.

In the next 10 years, the primary care workload associated with cancer will increase across the entire cancer pathway (figure 1). Health-care systems are increasingly introducing guidance on urgent referral for investigation of suspected cancer. The UK National Institute for Health and Care Excellence (NICE) guidelines,¹⁶ revised in 2015, have set an explicit threshold of risk in adults of 3%, which could double the number of patients who are tested or referred with the more subtle patterns of symptoms and signs of cancer. Earlier guidance from NICE advising CA125 as the initial test for suspected ovarian cancer resulted in test requests from primary care to increase by three times, although only half of all patients with ovarian cancer were referred by the urgent pathway for suspected cancer.¹⁷ Diagnostic testing might also be inconclusive, giving rise to the need for repeat tests after intervals that remain to be defined and assessed.

The resolution of these dilemmas will need close collaboration between PCPs and specialists for cancer diagnosis, as envisaged by the Royal College of General Practitioners (RCGP) in the UK.¹⁸ This collaboration will also affect the way in which workload is managed within the practice. In Part 7, we review in detail the ways in which integration between primary and specialist care can work for cancer control.

For patients undergoing treatment, whether for primary cancer or relapse, the effect on workload in primary care is unlikely to change substantially. Patients with acute complications of cancer treatment—such as the effects of myelosuppression, neutropenic sepsis, nausea and vomiting, and diarrhoea—will continue to be managed by

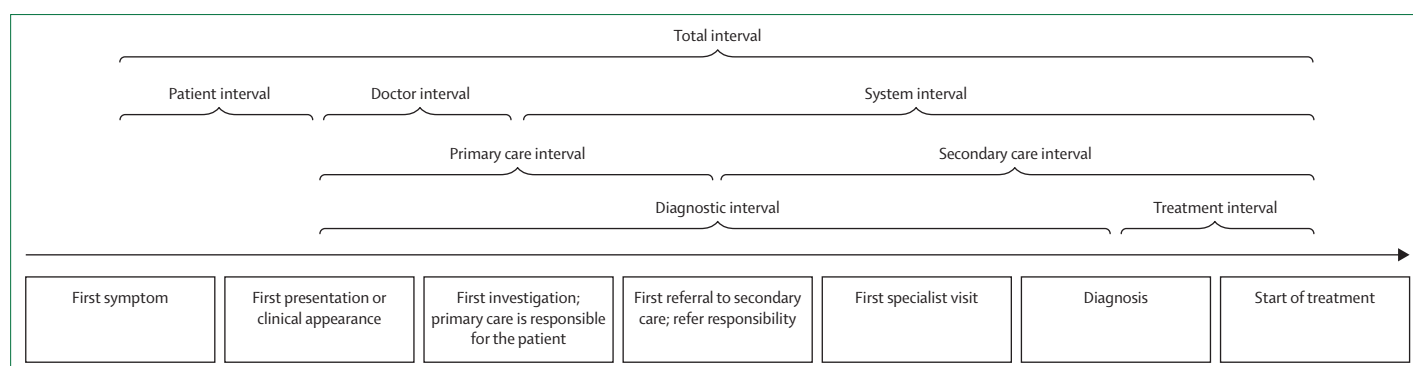


Figure 2: Overall milestones and time intervals from first symptom to start of treatment
Reproduced with permission from Olesen and colleagues.⁵

acute oncology services.¹⁹ Some patients might, in spite of advice to use the emergency arrangements of their oncology service provider, first contact their PCP about treatment-related effects, such as neutropenic sepsis, especially if their treatment is being delivered in a community setting. PCPs will need the necessary skills and organisational capacity to assess the patient accurately and arrange prompt access to treatment.²⁰

The future configuration of long-term follow-up after cancer treatment, and the role of primary care in this, remains unclear, although moves to reduce the role of the specialist in follow-up of patients with breast and other cancers are likely to result in an increasing role for PCPs. Taking the example of breast cancer, the consensus is that routine follow-up aimed at detection of metastatic disease before the patient is aware of symptoms is not effective in improving survival. NICE guidance for other aspects of breast cancer follow-up merely invites a discussion between patients and their doctors (either specialists or PCPs, depending on patients' preference) to decide what to do in the event of recurrence, but emphasises the value of psychological support, which can be achieved by continual contact with the breast cancer team.²¹ For example, the European Society of Medical Oncology guidelines on follow-up of patients after initial treatment of primary breast cancer acknowledge the absence of evidence from clinical trials to support any particular follow-up policy, but suggest a schedule that includes annual follow-up beyond the fifth year.²²

Much of the research on which shared care or transfer of follow-up care is based was undertaken 10 or more years ago. In the meantime, the treatment options for metastatic breast cancer have increased considerably, while long-term bone and cardiac sequelae are increasingly recognised. In the future, the quality of follow-up care for cancer will be measured by its ability to ensure appropriate monitoring and timely receipt of these new treatments.

A further development in which the PCP might become more important is as a navigator for access to specialist services. The gatekeeping function and the role of navigators in integrated care are discussed in Parts 7 and 8.

Two other factors are likely to require greater PCP involvement if they are to be effectively addressed. The first is the recognition that elderly patients are less likely to receive timely diagnosis and treatment for cancers even when the absence of comorbidity would otherwise allow it.²³ The second is the effect of continued efforts to redress socioeconomic inequalities in access to cancer care. Socioeconomic inequalities impair timely access to lung cancer treatment, but do not affect the nature of the treatment.²⁴

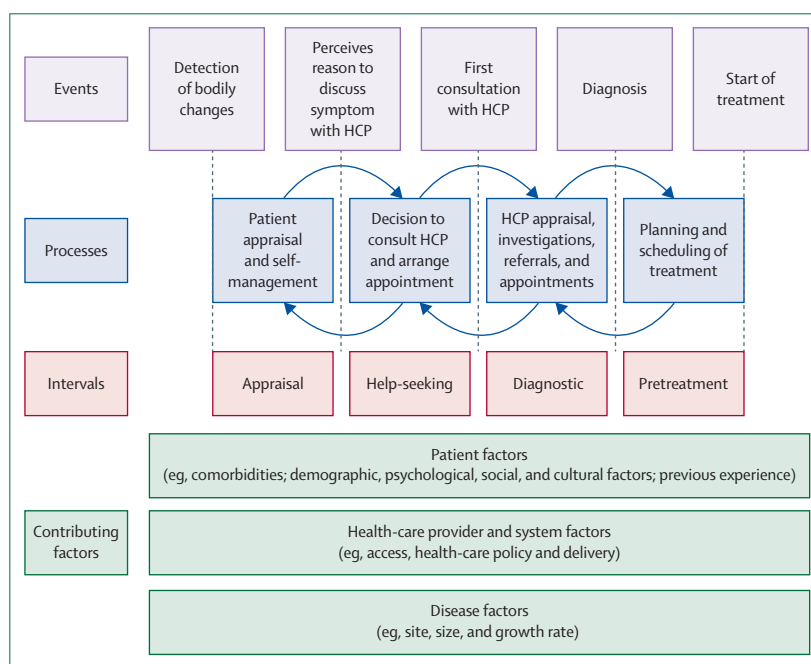


Figure 3: Model of pathways to treatment

Walter and colleagues' model⁷ defines key events and intervals, including the appraisal, help-seeking, diagnostic, and pretreatment intervals. Additionally, contributing factors to time to diagnosis are categorised into patient, health-care provider and system, and disease factors. Although this model is focused on adult malignancies, it is transferable to cancers in children, teenagers, and young adults (but specific contributing factors might differ). The diagnostic interval—ie, the time between the first contact with the health-care system for cancer-related symptoms and the diagnosis—is likely to be of greatest interest to primary care physicians. HCP=health-care professional. Reproduced with permission from Walter and colleagues.⁷

What is primary health care and how is it evolving?

Most developed countries have health-care systems with an identifiable component of primary care. Primary care is defined by WHO as “first-contact, accessible, continued, comprehensive and coordinated care. First-contact care is accessible at the time of need; ongoing care focuses on the long-term health of a person rather than the short duration of the disease; comprehensive care is a range of services appropriate to the common problems in the respective population and coordination is the role by which primary care acts to coordinate other specialists that the patient may need.”²⁵ Primary care is typically, although to varying extents, provided by clinicians who are generalists, as distinct from those with specialist expertise restricted to a specific area of clinical practice (eg, cardiology and palliative care).

Although the organisation and functions of primary health care differ from one country to another because of historical developments and different economic, social, and cultural circumstances, the PCP has been, and often still is, an essential element and frequently the most important player in delivery of primary care. However, primary care is now mainly delivered through multidisciplinary teams (centred around general or family practices) that consist of up to 30 individual professionals, each making complementary contributions to patient care. PCPs, nurses, pharmacists, physical therapists, and many others could contribute to the care of any individual. Whether they operate as a team or as team of teams is an important question that is not fully understood.²⁶

The enduring and universal strength of primary care is a core commitment to generalism. This is supported by a continuous longitudinal relationship with patients, and the PCP’s clinical expertise with the often undifferentiated and ill-defined nature of the problems presented. Analyses of data from the USA, UK, and Europe²⁷ have shown that having more PCPs per person is associated not only with better health outcomes, but also with less expensive services and better patient experience.

Worldwide, primary care practice has had to adapt continually to the changing political and social context in which it operates. In England, these adaptations were exemplified by the creation of a professional body and mandatory postgraduate training programmes in the 1970s, incentives to commission health services from the 1990s, and an increased emphasis on performance-related pay, quality, regulatory, and governance mechanisms in the 2000s. Although societal changes affecting primary care practice might have subtle variations between countries, they fall into four main groups: demographic pressure, new technology, patient expectations and expertise, and financial pressure.²⁸

Internationally, ageing populations have led to a raised demand for complex medical care because an increased number of people are living with multiple long-term conditions. Low-income and middle-income countries face the added burden of burgeoning incidence of

non-communicable diseases.²⁹ With the widespread use of mobile phones and the internet, technological advances offer new platforms for people to access health information and communicate with PCPs, and for PCPs to monitor symptoms and treatments, and support and motivate health-behaviour change. Despite the availability of such technologies, primary care systems have often been slow to adopt these changes and redesign services.³⁰ At the same time, patient expectations about access to care continuously rise, and growing evidence shows that so-called expert patients expect a partnership model of decision making and more responsibility to manage their own health and health care.²⁹ Finally, although the needs of patients and populations continue to grow in complexity and volume, publicly funded health-care systems are under increasing financial pressure with constrained spending as a result of the global economic recession.

In response, primary care practice has evolved to be at the core of a multiprofessional primary care team in many countries. Nurses and allied health professionals now undertake many routine and non-clinical tasks and an expanded range of activities (eg, chronic-disease management, triage, and management of acute minor illnesses), allowing PCPs to increasingly focus on complex cases. In the UK, the RCGP has pledged by 2022 to develop the role of general practitioners (GPs) as “expert generalists” by developing new generalist-led integrated services to deliver personalised, cost-effective care; expanding and enhancing the capacity and skills of the primary care workforce to provide complex care; and supporting flexible models of care with the organisational development of community-based practices, teams, and networks.¹⁸ New Zealand, the Netherlands, Canada, and the USA already have examples of multipractice organisations delivering high-quality primary care on a greatly increased scale.³¹

Inequalities and primary health care

Inequalities in the availability of health care have long been recognised. Tudor Hart first proposed the inverse care law in 1971, stating that “the provision of good medical care tends to vary inversely with the need for it in the population served”.³² This law, formulated in relation to socioeconomic deprivation, seems to operate through an interaction of patient, physician, and service factors. Primary care patients from socioeconomically deprived areas have more long-term health problems, psychological problems, and multimorbidity than do those from least deprived areas; they wait longer for scheduled access to a PCP, have shorter clinical encounters, consult doctors who are more stressed, and are less satisfied with the experience.³²

Socioeconomic inequalities in cancer care and outcomes are increasingly recognised, but their causes are less well understood. Evidence shows that differences in access to or uptake of treatment contribute to such inequalities, but speed of diagnosis, patient factors (eg, willingness to access health care or undergo investigations), and

differences in tumour biology in the presence of environmental factors such as smoking might all play a part.³³ In lung cancer, these differences are most pronounced in patients whose symptoms are ill-defined,³⁴ suggesting differences at the level of the patient–clinician interaction.

Some insights into how primary care might contribute to these socioeconomic inequalities, and how they might be redressed, can be drawn from the wider research literature. An analysis of physician utilisation by income in 21 Organisation for Economic Co-operation and Development (OECD) countries, drawing on data from national surveys or the European Community Household Panel,³⁵ reported no inequity in PCP visits but, in all countries for which data were available, an inequity in specialist consultations that favoured those with high incomes. This inequity persisted even after controlling for differences in need.³⁵ When educational attainment is used as a measure of socioeconomic status, similar findings were obtained. After adjustment for health status, as determined by the Johns Hopkins Adjusted Clinical Groups Case-Mix System, equality was reported in contacts with primary care, but a pro-higher education inequity in specialist visits.³⁶ In countries with gatekeeping systems, the referral process itself might be generating inequalities, being more challenging for deprived patients to navigate,³⁷ although the readiness of some PCPs to refer might be greater for patients from more affluent socioeconomic backgrounds.³⁸ However, while acknowledging a socioeconomic gradient in access to specialist care, some have argued that part of the association is explained by geographical clustering of affluent patients and specialist services. For cancer, inequalities are apparent in longer intervals from first presentation to diagnosis for women and the elderly than for men and young people, respectively.³⁹

The geographical distribution of PCPs is a policy concern for many countries. Inequalities in per-person availability of PCPs between countries with universal health-care systems are small,⁴⁰ and within countries seem not to be strongly socioeconomically patterned. However, for some countries (eg, Canada and Australia), rurality is associated with great inequality in health-care availability.⁴⁰ Yet, policies that strive for per-person equity of PCP availability fail to address the substantially raised illness burden in deprived populations. This problem has been conceptualised as the so-called deep end of primary care.⁴¹ Even with per-person equity of PCP provision, the capacity to effectively manage the complex health-care needs of a practice population is proportionately smaller in practices serving deprived populations than in those serving more affluent populations. One consequence is that women from deprived areas with breast cancer are twice as likely as those from affluent areas to be admitted to hospital for unrelated conditions in the 2 years after treatment completion.⁴² Cervical screening uptake is also low in practices located in socioeconomically deprived areas.

Panel 1: Introduction to primary care

- Primary care is now characterised by multiprofessional teams led by expert generalists providing increasingly complex medical care to people who often have several long-term illnesses
- Primary care practices increasingly collaborate in networks and federations to provide more cost-effective care at scale
- Primary care is an increasingly important component in the early identification of patients with possible cancer and in provision of long-term care to cancer survivors
- Primary care should reduce socioeconomic inequalities in access, particularly to specialist health care

Studies of quality of primary health care in deprived populations report conflicting findings, with low uptake of cervical cancer screening and low scores for interpersonal care and patient satisfaction, but no difference in quality of chronic-disease management.⁴³ Nevertheless, the areas that have the greatest problems with PCP recruitment and retention in those countries with universal health-care systems tend to be deprived urban areas in the UK, and rural areas in Canada and Australia.

These inequities assume greater importance in countries with universal health-care systems where gatekeeping is often a prominent feature. For cancer, access to urgent assessment is increasingly restricted by specific referral criteria, but at a population level an association exists between gatekeeping and cancer-specific mortality. Although these so-called ecological associations are prone to several biases, this relation needs to be better understood (see Part 8).⁴⁴

Conclusion

Primary care is first-contact and continuing care provided in community settings by multiprofessional teams led by expert generalist physicians. These teams will increasingly join together in federations or networks to provide care on a large scale. Cancer and its consequences will be an increasingly prominent part of the primary care workload in the future, while the breadth of involvement of PCPs in cancer care will also increase. PCPs will be at the forefront to address the persistent socioeconomic and age inequalities in cancer care (panel 1).

Part 2: Prevention, screening, and promotion of help-seeking

PCPs are at the front line of health-care services and have important roles in primary prevention and screening for cancer. In this section, we review the evidence for the effectiveness of their involvement, although these efforts should be ideally coordinated with broader public health efforts.

Primary prevention

There is considerable evidence showing that PCP-based prevention strategies are effective, although substantial variation exists in the level of change achieved, with

Panel 2: The “3As” approach to prevention—smoking cessation

The Ask, Advise, and Act framework

- 1 Ask and record smoking status: is the patient a smoker, ex-smoker, or non-smoker?
- 2 Advise on the best way of quitting, which is with a combination of drugs and specialist support.
- 3 Act on patient response—build confidence, give information, refer, and prescribe. Patients are up to four times more likely to quit successfully with support from the National Health Service.

How to refer to a stop smoking service

- “Call this number and they will put you in touch with someone who can arrange treatment and support you to stop.”⁴⁸
- “I can refer you to the stop-smoking service, and they will phone you to go through the options for treatment and support.”⁴⁸
- “When you are ready to stop, make an appointment at reception with our stop-smoking advisor (in practices where an in-house service is available).”⁴⁸

effect sizes usually described as small or moderate.⁴⁵ Multifaceted interventions are probably the most effective because a large number of barriers to change can be addressed. However, interventions delivered to patients at low risk might be of marginal benefit only.⁴⁶ Further, few such studies base their intervention strategies on theories of behaviour change.⁴⁷ PCP-based interventions can be usefully divided into those that are directly delivered by the PCP (eg, brief advice with or without drug treatment), and more-intensive interventions that the PCP can recommend to the patient and, in some cases, make a referral. The Ask, Advise, and Act framework⁴⁸ (panel 2) in the UK has been widely used in smoking cessation, but could also be applied to other areas of behaviour change.

Brief interventions based in primary care are now generally recognised to have potential to reduce rates of smoking. Brief advice and print-based, self-help interventions have been shown to have a modest, but significant effect.^{49,50} Combinations of brief advice, counselling, and nicotine replacements seem to be particularly effective.⁵¹ Little is known about how efforts of primary care will work alongside recent initiatives such as the introduction of electronic cigarettes.⁵² Primary care in the UK led the early development of smoking cessation clinics, for which good evidence now exists for their effectiveness in reducing smoking rates.

Primary-care-based brief interventions can reduce alcohol consumption. Evidence for this has accumulated over several decades, and the studies have wide applicability in primary care settings.⁵³ Interest has focused particularly on motivational interviewing, a structured counselling approach that initiates the patient's own motivation for change by exploring and resolving ambivalence, which seems to outperform straightforward advice from a PCP, although more evidence is needed before it can be incorporated into routine practice.⁵⁴ The best interventions in key subgroups (eg, women, older and younger drinkers, ethnic minority groups, and dependent or comorbid

drinkers), and the ideal intervention length and frequency to maintain long-term effectiveness, also need to be studied further.⁵⁵

By contrast with smoking and alcohol use, fewer studies of primary care intervention in diet and obesity have been done, although one study found that a health professional's recommendation was associated with an increased likelihood of weight loss attempts.⁵⁶ Nevertheless, evidence exists for the effectiveness of primary-care-based programmes, particularly when combined with interventions from other agencies (eg, such as lifestyle coaches, dietitians, or remote counselling),⁵⁷ although referral to commercial programmes might be more cost effective than primary-care-led programmes.⁵⁸ Weight reduction interventions are poorly documented in primary care, and access to appropriate programmes might be a key issue.

In the UK, NICE guidance (2013) recommends brief advice on physical activity in primary care using an approach based on the Ask, Advise, and Act framework.⁴⁸ Advice and counselling in general practice can lead to increases in physical activity (at 12 months),⁵⁹ although little is known about the amount of physical activity advice provided in UK general practice. Many studies have examined the concept of exercise on prescription, in which PCPs prescribe exercise provided by a third party. Although this approach is generally acceptable to PCPs and patients, its effectiveness (eg, its effect in hard-to-reach groups, such as those from ethnic minorities or with low socioeconomic status) is still unclear. A systematic review⁶⁰ concluded that physical activity promotion to sedentary adults (recruited in primary care) significantly increases the amount of physical activity at 12 months, although evidence to draw distinctions between exercise referral schemes and counselling interventions was insufficient.

Patient appraisal and help-seeking in primary care

Since most cancer diagnoses come from patients presenting symptomatically in primary care, a better understanding of the processes affecting the length of time between the patient noticing a symptom and seeking medical advice (ie, the patient interval) is an important step in the development of strategies to minimise diagnostic delay.

Qualitative studies interviewing patients after diagnosis have identified three elements in prolonged patient intervals: not recognising the seriousness of the symptom, fear of receiving a cancer diagnosis, and reluctance to interact with the primary care system.⁶¹ Community-based studies using standardised measures of awareness in population-based samples reached similar conclusions:⁶² people had poor recall of potential cancer symptoms other than lumps, a significant minority said they would avoid a cancer diagnosis, and many reported a range of barriers to help-seeking. All three domains have been shown to be modestly associated with so-called anticipated delay (ie, the time people say they would wait before seeking help if

they have a particular symptom).⁶³ New studies have combined large-scale surveys designed to quantify symptom prevalence and attribution with qualitative studies designed to explore patients' views in more detail.^{64,65} These studies report that people with cancer alarm symptoms rarely recognise them as cancer; among those who do, some are too fearful of cancer to seek help, and among those who consider seeking help, barriers such as worry about seeming hypochondriacal can put them off. These delay processes can be broadly classified as cognitive, emotional, and behavioural.

Understanding extended patient intervals

The cognitive domain (ie, not recognising the symptom as serious) is especially important. More than half of people older than 50 years report experiencing at least one alarm symptom in the past 3 months,⁶³ and very few attribute such symptoms to cancer or even perceive them as serious. People tend to normalise most symptoms and attribute them to other factors (eg, other illnesses, ageing, and stress). Previous reassurance from the PCP about the same type of symptom can also reduce the likelihood that the patient will interpret the symptom as serious.⁶⁶ The emotional domain (ie, fear of a cancer diagnosis) is less often cited than the cognitive domain as a reason to avoid help-seeking, but where it is, it can cause lengthy delays. In community surveys, around 10% of people said they would not want to know if they had cancer, and almost half thought that cancer treatment was worse than cancer. An analysis⁶⁷ found that fatalistic views of cancer were associated with a substantially increased risk of advanced-stage diagnosis in lung and colorectal cancers. The behavioural domain refers to the barriers (perceived or actual) to help-seeking behaviour. In many community surveys, worry about "wasting the doctor's time" emerges as a barrier; this is particularly common in the UK, although the underlying motivation is not clear. Having had a previous negative investigation for the same symptom can also be a deterrent to help-seeking, often because patients feel fully reassured, but sometimes because previous consultations about the same symptom have been frustrating,⁶⁵ or because patients worry that the PCP would be dismissive of further questions about the same symptom.^{63,64} Other barriers that are less commonly cited in studies asking the public why they might avoid help-seeking include embarrassment about the symptom, worry about an examination, and practical difficulty in making a PCP appointment.

Implications for interventions in primary care

PCPs should have an understanding of the cognitive, emotional, and behavioural processes that tend to increase risk of delay in symptomatic presentation in their patients. PCPs have an obvious role to educate patients about symptoms to look out for, and teachable moments might exist for such educational interventions, such as after a negative symptomatic investigation or after a discussion

of screening. Reduction of excessive cancer fear is more challenging; however, if PCPs are able to help patients to discuss their worries about cancer, this could help them to face a diagnosis. PCPs should be well placed to address barriers to attendance in doctor–patient interactions. In general terms, primary care systems that welcome rather than deter are needed. Some have argued that a conflict exists between the dominant medical approach of identifying the so-called chief reason for consulting and patients' experience of minor and indistinct complaints that do not reach the threshold to seek medical care.⁶⁸ This conflict might explain the finding that one of the predictors of help-seeking for potentially malignant oral symptoms was having another reason to consult a health professional—ie, the oral symptom did not deserve its own consultation.⁶⁹ Asking patients, particularly those of low socioeconomic status, if there are any other issues they would like to ask about (a core PCP consulting skill) could help to promote discussion of minor or indistinct complaints that might nonetheless suggest a need for investigation. More time might also need to be allocated to discussion with patients about what to do if symptoms come back after a negative investigation; the use of safety-netting procedures should, in theory, be helpful, and such recommendations for primary care have been developed.⁷⁰

Public awareness campaigns and how they relate to primary care

Improvement of symptom awareness in the UK has been tackled mainly with public education campaigns about specific symptoms, often linked with subtle messaging that the PCP would welcome a consultation. Raised awareness⁷¹ and increased visits to PCPs with the target symptoms in response to these campaigns have been reported, although the effects might be short lived. Faced with symptomatic patients, the challenge for PCPs is to identify those with the highest likelihood of having cancer when most patients they see will not have the disease; indeed, the symptoms involved are both common and not cancer specific.

Nowhere do these issues apply more than in the case of lung cancer. Campaigns to promote early referral of patients suspected of having lung cancer have been the most successful reported so far in terms of achieving significant increases in referrals for chest x-ray and specialist assessment, increased diagnoses, a stage shift to earlier disease, and a rise in potentially curative treatment.⁷¹ The public awareness campaign in England, based on the strapline "Been coughing for three weeks or more? Tell your doctor" (figure 4), led to a 67% overall increase in patients across all age groups visiting their PCPs with a cough; despite this increase, most PCPs surveyed were supportive of the campaign.

Cancer screening and primary care

Primary care has equally important roles in cancer screening, even in the context of centrally organised national programmes. Well established principles exist for



Figure 4: Be Clear on Cancer campaign poster
Reproduced with permission from Public Health England, UK Department of Health, and NHS England.

the implementation of national screening programmes, which emphasise adequate information, and good acceptability and uptake—all within the remit of primary care. In Europe, the number of countries that are introducing national screening programmes is growing. European programmes typically have centrally organised recruitment and follow-up, and the three most widely available programmes are for breast, cervical, and colorectal cancer screening. The USA tends to do opportunistic screening, but a recent review for the Centers for Disease Control and Prevention emphasised the value of learning from organised cancer screening programmes in other countries.⁴⁷ One issue has been the controversy over breast cancer screening,⁷² which has highlighted the need for balanced information. The role of primary care in meeting information needs such as these, and in providing other key elements of screening, varies between countries and is shared to varying degrees with screening programme organisers.

In the past few years, focus has been placed on personalised medicine, which emphasises the need to tailor preventive and treatment strategies to individual patients, taking into account information from genomics, family history, lifestyle, and other areas. For example, a growing interest lies in the concept of risk stratification in

cancer screening—ie, designing screening strategies on the basis of individual risk, rather than assuming that everyone in the target population has the same risk. PCPs have potentially important roles in the collection of genetic and family history. Information on family history can help PCPs to personalise health messages, and patients typically attach high importance to such information.⁷³ However, family history information seems to be collected inconsistently in primary care settings; although tools have been developed that could add substantial family health information, few are specific for primary care.⁷⁴

Although little primary-care-based testing for specific genes might emerge in the next few years, such information will need to be combined with family history and a range of sociodemographic, behavioural, and environmental risk factors to be useful in risk stratification.⁷⁵ Further, the complex ethical issues associated with this kind of information will need to be addressed. At present, there is little evidence on how such an approach might work in practice, but primary care should actively engage in emerging strategies.

Case study: colorectal cancer screening

Colorectal cancer is a leading cause of cancer-related mortality in high-income countries, and screening programmes can lead to significant reductions in mortality or, in the case of endoscopic screening, reductions of incidence too. Such screening programmes are typically designed for asymptomatic individuals who are at average risk and aged 50 years or older. Most colorectal cancer screening in Europe is based on the faecal occult blood test or the faecal immunochemical test, with colonoscopy for individuals who test positive, although the UK is implementing a national flexible sigmoidoscopy programme alongside the faecal occult blood test programme.

Development of such screening varies in Europe. Screening on a national level has been implemented in 20 European Union countries, and the involvement of PCPs varies depending on the chosen strategy and local health-care policy. For example, in Germany, the Czech Republic, and Slovakia, PCPs perform faecal occult blood tests in their offices; in Poland, they recruit patients for colonoscopic screening; in Italy, their involvement varies across the country; and in the UK, the Netherlands, Spain, and Finland, PCPs are not directly involved in the provision of the programme.⁷⁶ PCPs also have varying roles in follow-up for individuals tested positive; in some countries, they are responsible for referral to colonoscopy, whereas in others the referral is organised by the programme itself.

For cancer screening programmes to bring about reductions in mortality, a substantial proportion of the population must participate. Organised, but opportunistic programmes, such as those established in Germany in 1976 or the Czech Republic in 2000, have low participation

rates.⁷⁷ Clear evidence exists for the importance of PCPs in the implementation of such screening programmes,^{78–80} with evidence from randomised controlled trials that their endorsement of programme-generated screening invitations increases screening uptake.⁸¹ Further, inadequate PCP involvement seems to reduce recruitment to screening programmes in groups of low socioeconomic status.⁸² Educational interventions targeting PCPs also seem to be effective in improving screening rates,⁸³ although evidence from individual studies for educational interventions increasing screening rates is less consistent.⁸⁴ Further research is needed to assess new approaches to promotion of uptake, such as information technology-based programmes, and to identify strategies that are balanced, self-sustaining, and affordable.

Informed choice and screening uptake

Although coverage is a key outcome in screening, a growing emphasis has been placed on information provision and informed choice (or informed uptake).⁸⁵ Screening has the potential to cause harm, and an ethical imperative exists to provide balanced information on cancer screening. An informed choice has been defined as one that is “informed, consistent with the decision maker’s values, and behaviourally implemented”.⁸⁶ Patients sometimes receive insufficient or inadequate information about screening (particularly in areas such as overdiagnosis and overtreatment), compromising the informed-choice process.⁸⁷ To ensure equal access to screening, information is needed to suit adults from a broad range of literacy levels. Health promotion activities in the community could benefit from targeting low-literacy populations.⁵⁰ Screening recruitment can be customised for low-uptake groups, such as ethnic minorities: screening invitations typically require adaptation; ideally, they should address specific language, attitude, and cultural barriers to participation.⁵⁰ Again, the PCP is ideally placed to undertake these tasks, but few such models are available.

Conclusion

PCPs have important roles in primary prevention, screening, and patient help-seeking. Although evidence supporting these roles is emerging, substantial unrealised potential remains. Specifically, PCPs need more effective models to incorporate primary prevention into their routine practice. Although much progress has been made in facilitating early cancer diagnosis in primary care,⁵⁰ an improved understanding of how primary care might best tackle the many factors that contribute to patient-related delay is needed. Educational issues exist, but the interplay between barriers to consultation and the messages patients take away from PCP consultations needs to be better understood. Finally, great consistency and sharing of best practice in PCPs’ involvement in cancer screening are necessary (panel 3).

Panel 3: Prevention, screening, and promotion of help-seeking

Key messages

- Primary care physicians (PCPs) have established roles in reducing smoking and harmful alcohol use, and these have proved effective
- With the obesity epidemic, PCPs and primary care teams should develop more-effective strategies targeting weight loss and physical activity
- Complex cognitive, emotional, and behavioural determinants of symptomatic presentation for cancer exist; PCPs should have an understanding of these psychological processes so as to give effective advice to promote early presentation
- Public awareness campaigns can increase the frequency with which patients present to primary care with potentially serious symptoms; campaign organisers should work closely with primary care to develop the most effective and integrated programmes
- PCPs have several roles in cancer screening, including promotion of uptake and informed choice, information provision, and involvement with follow-up of individuals tested positive; engagement with primary care is an important priority for cancer screening programmes

Action points

- Primary care needs to move beyond its focus on smoking and alcohol use in primary prevention, and engage effectively in initiatives to promote physical activity and reduce obesity
- Primary care should prepare itself for growth in genomic information and how this information can be incorporated with lifestyle and other factors to develop individualised preventive strategies
- Population-level early diagnosis and screening strategies need to fully engage primary care to maximise their potential

Part 3: Early diagnosis in children, teenagers, and young adults

Cancer is the leading cause of disease-related death in children in high-income countries. The prompt and early diagnosis of cancer in children, teenagers, and young adults (younger than age 25 years) has long been of concern to caregivers, physicians, and policy makers. In this section, we review the effect of prolonged times to diagnosis, common presentations of cancers arising in this age period, the role of PCPs in the diagnosis of such malignancies, the challenges they face, and possible strategies to meet these challenges.

Diagnostic intervals

In view of the complexity of the pathways leading to cancer diagnosis, an appropriate conceptual framework is necessary. Through a systematic review, Walter and colleagues⁷ adapted the Andersen model of total patient delay to the cancer diagnostic pathway (figure 3). Although this model was implicitly focused on adult malignancy, it is directly transferable to teenagers and young adults, and indirectly so to children.

The effect of diagnostic interval lengths on survival among children, teenagers, and young adults with cancer is still controversial. Several studies have linked prolonged intervals to advanced stage at diagnosis and consequently worse cancer outcomes, particularly in cancers such as retinoblastoma and Hodgkin’s

Panel 4: Early diagnosis in children, teenagers, and young adults

Disease-related barriers

- Rarity of cancers in this age group
- Heterogeneity of cancers
- Overlap of many symptoms with those of common, benign conditions

Patient-related or caregiver-related barriers

- Inability of young children to articulate symptoms
- Low health-seeking behaviour in many teenagers and adolescents
- Little awareness of cancers in this age group among patients and caregivers

Action points

- Prompt diagnosis will need new and innovative assessment pathways and tools
- Alternative models for patients to access diagnostics and assessment should be piloted
- Rapid and robust referral mechanisms from primary care to specialist facilities should be developed, particularly for teenagers and young adults

	Boys	Girls
All ICCC sites	196.7	182.3
Leukaemia	52.0	43.1
Acute lymphocytic leukaemia	38.4	30.2
Acute myeloid leukaemia	7.9	8.0
Lymphomas and reticuloendothelial neoplasms	29.8	20.7
Hodgkin's lymphoma	12.9	11.8
Non-Hodgkin lymphoma	15.1	7.7
Brain and CNS cancers	45.5	45.9
Ependymoma	3.2	2.4
Astrocytoma	16.5	15.5
Medulloblastoma	5.1	3.3
Neuroblastoma and ganglioneuroblastoma	8.5	7.6
Retinoblastoma	2.9	3.3
Wilms tumour	5.3	6.3
Hepatic tumours	2.8	1.8
Bone tumours	9.8	7.7
Osteosarcoma	5.5	4.5
Ewing sarcoma	3.3	2.4
Rhabdomyosarcoma	5.4	4.2
Testicular germ-cell tumours	9.9	..
Ovarian germ-cell tumours	..	4.4
Thyroid carcinoma	3.0	12.6
Melanoma	3.7	5.8

Rates are per 1 000 000 and age-adjusted to the 2000 standard population in the USA. Rates include benign and borderline brain tumours. ICCC=International Classification for Childhood Cancer. Reproduced with permission from Ward and colleagues.⁹⁸

Table 1: Paediatric cancer incidence rates, all races

lymphoma.^{88,89} Two studies^{90,91} have suggested that long times to diagnosis in childhood leukaemia lead to poor outcomes, although they have predominantly focused on the time interval between diagnosis and treatment initiation, and might therefore be confounded by the clinical condition of the child at presentation.

By contrast, other studies^{92,93} have associated prolonged diagnostic intervals with improved survival, a counter-intuitive finding known as the waiting time paradox, for which two explanations have been proposed. First, aggressive disease might be easier to appraise than mild disease, leading to shorter diagnostic intervals, but is associated with inherent increased mortality. Second, being more ill at presentation might result in greater prioritisation and faster referrals by PCPs (ie, shorter diagnostic intervals), but nonetheless result in inferior survival (so-called sick-quick). These two mechanisms are of course not exclusive. Two systematic reviews of diagnostic delays in children, and one of delays in children and young adults, found evidence of the waiting time paradox.⁹⁴⁻⁹⁶ However, many of the included studies have serious methodological restrictions. For example, most studies did not have sufficient statistical power to explore U-shaped associations between diagnostic interval length and survival, as shown in some adult malignancies.⁹⁷ Finally, most of these studies have relied either on primary data from patients or providers, or on chart abstraction of medical records, and therefore had issues related to recall bias or data availability.

The effect of prolonged diagnostic intervals on psychosocial outcomes in children and young adults with cancer is not as controversial. Prolonged diagnostic intervals are a source of substantial distress and guilt to patients, caregivers, and indeed PCPs themselves,⁹⁶ and might also result in a loss of caregiver confidence in the health-care system. Thus, targeting earlier diagnosis in children, teenagers, and young adults will lead to improved non-survival-based outcomes and might additionally improve survival in some malignancies or populations.

Challenges to diagnosis

Prompt diagnosis of cancer in children and young adults is a substantial challenge and is made more difficult by disease, patient, and caregiver factors (panel 4).

Disease

Despite being the leading cause of disease-related death in this age group in high-income countries, childhood cancer accounts for less than 1% of all cancers across all age groups. Childhood cancer also represents a heterogeneous group of diverse malignancies that are very different from those seen in older age groups, which present to PCPs more often. For the average PCP in the UK, diagnosis of cancer in a child or teenager is a twice-in-a-career event and is hence understandably low on their list of differential diagnoses (table 1).

Presenting symptoms and signs

Presenting symptoms of childhood cancer can generally be grouped into three categories. The first group includes symptoms that are commonly encountered in primary care, and rarely signify serious illness or warrant referral, such as fever, abdominal pain, or headache. However, these symptoms are also frequently seen in children

presenting with cancer. The second group includes symptoms that are less common in paediatric patients, but are still likely to have a benign underlying cause (eg, first afebrile seizure, new-onset Bell's palsy, and lymphadenopathy). These symptoms are likely to prompt referral to secondary care for further investigation and management, although such referral might not always be necessary. Finally, the third group of symptoms and signs, although rare, are almost always pathological, likely to represent malignancy, and need rapid work-up and referral (eg, an abdominal mass, proptosis, and leukocoria). Teenagers and young adults have a changing type and incidence of cancers, resulting in variation in presenting symptoms compared with children, so that lumps or lymphadenopathy, skin changes, fatigue, testicular swelling, and more specific symptoms associated with early-onset carcinomas become more prominent.

A UK population-based case-control study investigating the predictive value of symptoms in children presenting to primary care⁹⁹ reported that cancer alert symptoms, as described in the NICE guidance for urgent referral for suspected cancer, were uncommon in children subsequently diagnosed with cancer. In the 3 months before diagnosis, just over a quarter of children with cancer had any alert symptom recorded by their GPs. This proportion only increased to a third when the preceding year was taken into account. Alert symptoms were also recorded in those without cancer. This finding, together with the rarity of childhood cancer, meant that most individual alert symptoms had a positive predictive value for cancer of 0·05% or less.⁹⁹ A further study from this group,¹⁰⁰ also using electronic UK primary care records, identified 12 symptoms that increased the risk of cancer by at least ten times, but with a low absolute risk. The positive predictive value for each symptom increased by two to three times in patients with three or more attendances for the same problem (figure 5). Thus, repeat visits might represent a cause for heightened suspicion in PCPs.

The role of alert symptoms is also likely to vary by cancer type and the symptom in question. In a Danish study of 253 children with cancer using retrospective questionnaires,¹⁰¹ alert symptoms were recorded in only 5% of patients with bone sarcomas, compared with 44% of those with lymphoma. A second study of 550 children¹⁰² analysed the association between symptoms and the diagnostic interval. Children with leukaemia were more likely to have a long diagnostic interval when pain was reported than when other presenting symptoms existed, and the shortest intervals in children with brain tumours were observed when vomiting was present.

Patient and caregiver

Young children are unable to articulate their symptoms or access health care independently. They are thus reliant

	PPV* as a single variable (95% CI)	PPV combined with three or more consultations (95% CI)
Pallor	0·41% (0·12–1·34)	0·76% (0·10–5·70)
Lump mass swelling head and neck	0·30% (0·10–0·84)	0·76% (0·10–5·70)
Lump mass swelling	0·11% (0·06–0·20)	0·30% (0·09–0·99)
Lymphadenopathy	0·09% (0·06–0·13)	0·20% (0·10–0·39)
Abnormal movement	0·08% (0·04–0·14)	0·15% (0·07–0·32)
Bruising	0·08% (0·05–0·13)	0·38% (0·09–1·64)
Fatigue	0·07% (0·04–0·12)	0·12% (0·06–0·23)
Bleeding	0·06% (0·03–0·10)	0·11% (0·04–0·31)
Headache	0·06% (0·04–0·08)	0·13% (0·08–0·22)
Visual symptoms	0·06% (0·03–0·10)	0·23% (0·07–0·77)
Pain	0·04% (0·03–0·06)	0·14% (0·07–0·31)
Musculoskeletal symptoms	0·04% (0·03–0·07)	0·13% (0·08–0·19)
Three or more consultations	0·02%	..

Figure 5: PPVs for childhood cancer of individual symptoms and in combination with three or more consultations for any reason in a 3-month period, against a background risk of 0·035%

Symptoms are ordered by PPV as a single variable. Red=PPV 0·1–0·2%; blue=PPV 0·2–0·5%; purple=PPV >0·5%. PPV=positive predictive value. *Values are point estimates of the PPV. Reproduced with permission from Dommett and colleagues.¹⁰⁰

on the caregiver's interpretation of their signs and symptoms, and on the caregiver's own health-care-seeking behaviour. Parental thresholds for consultation vary substantially; many are willing to self-manage non-specific symptoms such as tiredness and viral-type infections initially, whereas others attend primary care practice frequently.¹⁰³ Low educational attainment of the caregiver has been shown to be associated with prolonged diagnostic intervals in children.¹⁰⁴ The caregiver's level of concern can affect both the decision to attend primary care practice and the outcome of the consultation. Persuading doctors of the reality and seriousness of their child's symptoms, without themselves recognising the possibility of cancer, is commonly reported by parents.¹⁰⁵

Conversely, parents of teenagers and young adults are reliant on their child to report a problem. Several studies report an association between older patient age and increased patient and diagnostic intervals, which might show young people's reluctance to discuss health concerns with caregivers or doctors, with teenagers and young adults making infrequent use of primary care compared with older age groups.^{106,107} The most common barriers to help-seeking in a study of British children aged 11–17 years were "worry about what the doctor might find" (72%), embarrassment (56%), fear (54%), and "not feeling confident to talk about symptoms" (53%). Low awareness of the features of cancer was also reported among the teenagers, highlighting them as a risk group for delayed diagnosis.¹⁰⁸

The role of the PCP

In some health-care systems, paediatric primary care is a specific entity, with clinicians restricting their practice to children. In others, including those of the UK and Denmark, the first consultation for an ill child is with a PCP, who offers primary care to all ages. Such a

clinician will rarely encounter a child with cancer and thus accumulates less practical experience of children's health than paediatric specialists. To expect education about particular cancers to be of use is unrealistic: diagnosis of possible cancer in children, teenagers, and young adults will be a recognition of the unusual, perhaps supplemented by observation over a short period. A small proportion of presentations will be obvious, such as palpable abdominal masses, an absent red reflex with retinoblastoma, or clear cerebellar signs with a posterior fossa tumour, although most presentations are subtle. Moderate-quality evidence suggests that primary care summation of the total risk of serious disease in febrile children is more than just the simple addition of specific risk markers.¹⁰⁹ This extra component, sometimes known as intuition, has not been shown in paediatric cancer but probably exists—eg, in adults, PCPs have a moderate ability to discriminate malignant enlargement from benign enlargement in both cervical lymphadenopathy¹¹⁰ and prostate masses.¹¹¹ Such skills are likely to translate to paediatric practice. An overall malignant probability of 0.5% for lymphadenopathy in someone aged 16–24 years is almost certainly much higher if the person has particular features suggesting a cancer diagnosis (eg, hard consistency and large size of masses, accompanying symptoms of fever, weight loss, or night sweats).¹¹² Similarly, fatigue, pallor, and bruising have very low absolute risks but, when supplemented by repeated consultations or parental anxiety, probably carry sufficiently high risks to warrant blood tests.

One potential advance is electronic clinical decision support. Diagnostic software can be integrated into primary care clinical computers to automatically search the records for relevant entries and compute an absolute risk of current cancer. This is already in use for adult cancer in the UK (see Part 4), although a definitive trial has yet to be done. In children, teenagers, and young adults, repeated attendance is a clear marker of risk and could be incorporated into the algorithm. However, selection of the specific risk threshold for prompting the clinician to the possibility of cancer will be difficult because absolute risks will be small, and so-called prompt fatigue is a real possibility (diminishing attention to the message when prompts are very frequent). Thus, the usefulness of electronic clinical decision support algorithms in helping early cancer diagnosis in this age group remains to be elucidated.

Finally, the PCP could have a role in the initial work-up of a child with a suspected malignancy. On occasion, a PCP can institute testing—eg, plain x-ray for bone sarcoma, or ultrasound for soft-tissue masses. Leukaemia is usually obvious on a full blood count. Easy and timely PCP access to these simple diagnostic tests is therefore important. However, these cancer types are the exceptions, and most children with possible cancer will need access

to specialist investigations. Organisation of such services needs to accommodate two opposing principles: first, most children will ultimately not have cancer; second, the few who do have cancer will benefit from rapid diagnosis. Arguably, the second of these principles is the more important one, particularly when some of the referred children will have alternative, albeit benign, diagnoses, which might also benefit from swift identification. Most of the specialised investigations require imaging, supplemented by biopsy if necessary, which argues for either moderately large specialist paediatric practices or strong referral systems. Treatment of cancer in children, teenagers, and young adults is highly specialised and generally concentrated in tertiary referral centres; this level of specialisation is rarely needed for diagnosis. Some countries have established guidance for selection of patients for investigation of possible cancer. These guidelines have mostly been based on secondary-care studies, which have little applicability to primary care. In the UK, NICE criteria for urgent referral for suspected cancer in this age period have been shown to have very low absolute risks (figure 5). Even so, adult patients value investigation of cancer, even when the likelihood is very low,¹¹³ and the same is likely to be true for children, teenagers, and young adults.

Effects of health-care-system factors

Health-care-system factors might affect the likelihood of prompt diagnosis in several ways. First, in view of the diagnostic significance of multiple consultations and of detecting persistent or worsening symptoms in the child with an underlying cancer, continuity of care is important to minimise diagnostic intervals. Both relational and informational continuity are under threat as the demand for primary health care increases.

Second, even when PCPs suspect a possible malignant cause, they are usually unable to initiate definitive diagnostic procedures. Health-care systems with defined and rapid referral mechanisms between PCPs and specialty paediatric facilities are therefore likely to enable prompt diagnoses. Such referral mechanisms might be of particular importance for teenagers and young adults, whose care in many jurisdictions is dispersed across paediatric and adult care settings.

An early diagnosis of cancer in children, teenagers, and young adults will generally decrease parental guilt and increase caregiver confidence in the health-care system, and might decrease stage at presentation in some malignancies and improve long-term outcomes. Substantial challenges exist in recognition and diagnosis of childhood, teenage, and young-adult cancer in the primary care setting and in design of the optimum referral service. Despite these challenges, the crucial role of PCPs in ensuring prompt diagnosis can be supported through clinical strategies, which could potentially include electronic decision support, accessible primary care, and strong referral systems (panel 4).

Part 4: Early diagnosis in adults

Even for cancers for which screening programmes exist, the great majority of cases present symptomatically in primary care. Most patients with symptoms that could signal cancer have a benign cause. PCPs should assess the probability of cancer in these patients, their need for referral for further investigations, and the urgency with which referral and investigation should be done. The conceptual framework (pathways to treatment; figure 3) within which diagnosis of cancer should be considered was described in Part 3, while the stages that make up the total time from first presentation to diagnosis and treatment were shown in figure 2.

For several cancers, growing evidence shows that early diagnosis of symptomatic disease is associated with improved clinical outcomes.¹¹⁴ Further, delay in referral to a specialist is associated with worse patient experience of subsequent cancer care, particularly the aspects delivered in primary care such as practice staff support and care integration.¹¹⁵ Prevention of avoidable delays in primary care by accurate assessment of the likelihood of cancer, and acceleration of the diagnostic process, could therefore contribute to improvements in cancer survival.

The diagnostic process

PCPs are confronted with a wide range of complaints and symptoms in their daily consultations; the most prevalent being respiratory, musculoskeletal, and gastrointestinal. In most patients, the prognosis of these symptoms is favourable, and the complaints are self-limiting. In view of this good prognosis, a single consultation is sufficient for most patients, and additional diagnostic testing is needed in only 5–15% of primary care patients.¹¹⁶

Clinical decision making in primary care is mainly directed by prognosis rather than diagnosis, and is based on risk estimation. The overall aim is to identify, in a timely way, patients with a high risk of serious disease because they need early additional diagnostic tests and therapeutic interventions.¹¹⁷ To prioritise among the many potential differential diagnoses, PCPs use hypothetico-deductive methods or pattern recognition strategies, matching the presenting symptoms to their knowledge and clinical experience.¹¹⁸ Diagnostic reasoning in primary care generally follows a Bayesian approach, one of the cornerstones of evidence-based medicine. The baseline risk of the patient is determined by preset individual characteristics, such as age, gender, and family history, and is added to the baseline population risk (ie, prior risk or incidence in the primary care population). In a stepwise diagnostic process, this risk profile is further detailed. The presence or absence of each individual symptom and physical sign makes the target disease more or less likely. This results in an integrated diagnostic model that estimates the individual risk of disease (ie, posterior risk) and that forms the basis of further management.

If the risk of serious disease is low, then no further action is needed, and a watchful waiting policy can be

applied. If the risk is high, further action, usually specialist referral, is necessary. In case of intermediate risk,¹¹⁹ additional diagnostic testing can upgrade or downgrade the risk to a level that helps with further management by the PCP. In the case of potentially life-threatening diagnoses, such as cancer, the need for an adequate diagnostic process is high, and the level of risk triggering investigation or referral is low. This implies that, in the case of cancer suspicion, the threshold for additional testing and referral is usually lower than for less dangerous diseases. Although PCPs do not explicitly think about their diagnostic reasoning in this way,¹²⁰ and particularly not in relation to specific numerical risk thresholds, this balancing of probability and potential for harm is the basis for most diagnostic reasoning in primary care.

Several factors modulate this diagnostic process. PCPs are aware of the delicate balance between the potential benefit and harm of additional diagnostic testing, especially in systems where they have a strong gatekeeping role. Patients with serious disease need an adequate and timely diagnosis, but irrational use of diagnostic testing in low-risk patients might result in incidental diagnoses, stress for the patient, and increased health-care costs. Continuity of care is important for good primary care. The longstanding relationship with patients provides the PCP with valuable additional information about their medical and psychosocial history, which might change the prior risk of disease. Furthermore, acquaintance with the patients and their preferences about health care might modify the thresholds in the decision-making process, making the PCP accept different risk thresholds between patients before further diagnostic testing. However, continuity of care can have negative effects on timely cancer diagnosis by altering patients' help-seeking behaviours and potentially making doctors complacent about their symptoms, especially if they are frequent attenders to primary care practices.¹²¹ However, the effect of doctor-patient continuity on time to diagnosis seems to be small (a maximum of 7 days for colorectal cancer) and not clinically important.¹²² Finally, presumed life expectancy also affects different steps in the diagnostic process, because PCPs take the benefit of an early diagnosis into account in their decision for additional testing and referral for people who might be close to death.

PCPs face several challenges in accurately diagnosing cancer. First, symptoms are common, but cancer is rare. A PCP in the Netherlands typically sees 20–30 patients every day, but in an average year will only diagnose one patient with colorectal cancer, one with prostate cancer, and one with lung cancer. Many will only see one or two patients with rare cancers, such as myeloma or glioma, in their entire career. The low prevalence means that the prior risk of cancer in primary care is usually low, which restricts the predictive value of signs and symptoms, and of diagnostic tests. Second, the presentation of cancer in primary care is often non-specific, especially in the early

stage, and isolated symptoms are usually poor predictors. Common symptoms such as cough, abdominal pain, and fatigue are present in most patients with lung or gastrointestinal cancer, but the large majority of patients presenting with these symptoms do not have cancer. In some patients, adequate diagnosis requires time for symptoms to evolve.¹²³ Finally, the presentation of cancer might be obscured by factors that hamper timely diagnosis, such as comorbidity. Existing respiratory disease can prolong the diagnosis of lung cancer,¹¹ and a high burden of psychiatric or psychosocial comorbidity is associated with delayed diagnosis of colorectal cancer.¹²⁴

Epidemiology of cancer symptoms

Accurate diagnostic reasoning in primary care requires an understanding of how well symptoms predict risk of a cancer diagnosis. In the past 10 years, the amount of evidence on epidemiology of symptoms and signs and diagnostic tests associated with cancer in primary care has improved, with various studies addressing the issue of early detection and diagnosis. Each epidemiological study has strengths and weaknesses, and provides different, but complementary information that can help to improve the diagnostic accuracy of cancer in primary care.¹²⁵

Case-control studies, exemplified by the Cancer Prediction in Exeter (CAPER) series of studies of colorectal, lung, prostate, brain, and ovarian cancers have made major contributions to this evidence base.¹²⁶ This methodological approach using large primary care databases has been extended to cover 16 cancers. The strength is that this approach can establish the positive predictive values of individual symptoms, signs, and diagnostic tests associated with these cancers. However, the nature of the case-control study design has shortcomings such as recall bias in terms of recorded symptoms and spectrum bias because of inability to include the totality of the control population who did not develop cancer.

Prospective studies that use large primary care databases, alongside case-control studies, have been used to develop and validate algorithms that estimate absolute risks of different types of cancers in men and women, incorporating multiple symptoms and risk factors.^{127,128} This approach allows the independent effects of several clinically important factors to be estimated: high-risk symptoms such as weight loss, abdominal pain, indigestion, dysphagia, abnormal bleeding, and lumps; general non-specific symptoms such as tiredness and constipation; and risk factors such as age, family history, smoking status, alcohol intake, deprivation, body-mass index (BMI), and current medical conditions. Regression analysis enables the development of a risk equation for an overall risk of cancer based on the combined elements of different cancers. The QCancer web tool applies these models to estimate the risk of patients having current, but as-yet-undiagnosed, cancer, taking into account their risk factors and symptoms.¹²⁹ The strengths of this approach

include the large, representative sample, duration of follow-up, and lack of selection, recall, and responder bias. Shortcomings include the absence of formally adjudicated outcomes such as cancer diagnosis, potential information bias (ie, more information collected for patients with a diagnosis of cancer than for those without), and missing data in relation to symptoms, signs, and diagnostic tests, particularly in patients without a cancer diagnosis. Other large databases have taken a different, but complementary approach, examining the association of alarm symptoms (eg, first occurrence of haematuria, haemoptysis, dysphagia, and rectal bleeding) with cancer. This approach enables a more accurate quantification of cancer risk with classical presentation,¹³⁰ but many patients with cancer in primary care do not necessarily present initially with these classical features.

Several smaller prospective observational studies have investigated individual risk of cancers, particularly colorectal, breast, and lung cancers and melanoma. They also used a multivariable approach to estimate the probability of a target cancer on the basis of a combination of independent predictors of symptoms, signs, and available diagnostic tests. The strength of this approach is that all relevant predictors are included, irrespective of cancer outcome, and thus ascertainment of both symptoms and outcomes is high. Here, we present a brief overview of the current evidence base of commonly presenting symptoms of some common cancers.

Systematic reviews of prospective observational studies of colorectal cancer have established the diagnostic value of well recognised symptoms and signs, including rectal bleeding, abdominal pain, appetite loss, alteration in bowel habit, and weight loss. These independent effects have greater diagnostic yield when presenting in combination than individually. The prior probability of colorectal cancer in patients presenting to their PCPs in primary care ranged from 3.3% to 15.4% in eight community-based studies,¹³¹ so even when a patient presents with a full complement of symptoms and signs, the probability of colorectal cancer remains modest at around 20–25%. This means that further diagnostic testing is always needed.¹³¹ Further research from the QCancer (colorectal) study showed that assessment of anaemia in a patient presenting with rectal bleeding is important for additional diagnostic yield.¹³²

Breast symptoms are a common reason for encounter in primary care. Prospective studies have shown that the probability of breast cancer is low (around 3%) in women presenting with breast symptoms. Symptoms and signs associated with an increased probability of breast cancer include increasing age, presence of a discrete lump, a lump of 2 cm or bigger in diameter, thickening of the breast, lymphadenopathy, and tethering to the skin or chest wall. This clinical prediction rule has performed well in the context of patients referred to a breast-care clinic, but validation in a primary care population is needed.¹³³

The QCancer (lung) study¹³⁴ showed that independent predictors include haemoptysis, appetite loss, weight loss, presence of cough, smoking, history of chronic obstructive pulmonary disease (COPD), increased BMI, and high deprivation. The challenges of diagnosing lung cancer and its associated symptoms are discussed in the next section.

The weighted seven-point checklist for melanoma¹⁶ includes change in size of lesion, irregular pigmentation, irregular border, inflammation, itch or altered sensation, size of lesion greater than 7 mm, and oozing or crusting of the lesion. A recent validation study in English primary care¹³⁵ suggests that a cutoff score of four performs best at identification of clinically suspicious pigmented skin lesions.

Difficult diagnoses and rare cancers

Cancer is a heterogeneous collection of different diseases. These cancer types all manifest in different ways, and such heterogeneity accounts for why some are harder, and some easier, to diagnose in primary care. There is an emerging literature on this heterogeneity, and several metrics can be used to compare the differences between cancer sites in relative difficulty of diagnosis. These metrics include the number of prereferral consultations,¹³⁶ various measures of time interval—eg, the primary care interval and the diagnostic interval⁶—and route to diagnosis (routine, urgent, or emergency referral).⁸

Lyratzopoulos and colleagues¹⁰ have classified cancers into one of three groups on the basis of ease of diagnosis. Those categorised as easier to suspect, because of more obvious symptoms, include melanoma and breast, endometrial, and bladder cancers. Those categorised as intermediate cancers include colon cancer, renal cancer, and lymphoma. Those categorised as harder to suspect include myeloma and pancreatic, stomach, and lung cancers. These harder-to-suspect cancers are typified by non-specific presenting symptoms. Additionally, but not exclusively, they might be some of the rare cancers. The median diagnostic intervals (ie, the time from first presentation in primary care to diagnosis) in a large English study were 112 days for lung cancer, 156 days for myeloma, 89 days for stomach cancer, and 56 days for pancreatic cancer.¹³⁷ Here, we consider each of these in turn, examining specific reasons why they are difficult to diagnose and giving practical recommendations to improve their diagnosis.

Although lung cancer is one of the most common cancers, it remains one of the hardest to diagnose and can be easily missed. The diagnostic difficulty stems from the absence of a clear so-called symptom signature,¹³⁸ the presence of pre-existing lung disease causing similar symptoms, non-respiratory presenting symptoms, atypical symptoms, and patient factors.¹³⁹ False-negative tests are an important factor in delayed cancer diagnosis in general, but are common in lung cancer. In two case series, initial chest x-rays were normal in 20–25% of

people who were subsequently diagnosed with lung cancer.¹⁴⁰ Improving direct access to CT scans could reduce the risks from false-negative investigations in people with suspected lung cancer. The positive predictive values of lung cancer symptoms in primary care are generally low, but are increased with current smoking, multiple and persistent symptoms, and age. The symptom with the highest positive predictive value is haemoptysis, although this presents infrequently.¹¹

Compared with lung cancer, the evidence base for the other three difficult-to-diagnose cancers is much smaller. Myeloma is one of the rarer cancers, and an average GP in the UK will see only one new case every 8–10 years. The presenting symptoms all have low positive predictive values,¹⁴¹ meaning that many cases are not diagnosed until irreversible organ damage has occurred. Symptom onset could be gradual and attributable to ageing. For stomach cancer, the positive predictive values of symptoms are all relatively low, especially in young people.¹²⁷ Intra-abdominal solid tumours tend to cause varied symptoms, which are usually associated with benign causes. More predictive symptoms (eg, bleeding) only tend to be present when the disease becomes advanced. For pancreatic cancer, the positive predictive values of symptoms are all low, at least before advanced disease is present. This cancer is often indicated by jaundice, by which time the diagnosis is easier.

What can be done to help with the diagnosis of these harder-to-diagnose cancers? The principles of good medical practice are paramount. They include a thorough history and examination, adherence to referral guidelines, safety netting,^{71,139} and the use of diagnostic tests. Greater use of existing investigations in primary care settings has been advocated by others,¹⁰ but this should not be to the detriment of urgent specialist referral when such referral is mandated, because use of PCP-initiated investigations is associated with a longer time to referral for a range of common cancers.¹⁴²

Risk assessment tools and decision support

One approach advocated, particularly for cancers that are difficult to diagnose, is the use of decision support interventions in primary care practice.¹⁰ This is based on evidence from systematic reviews^{143,144} that decision support systems can improve clinician performance and diagnostic test ordering. The development of risk models that predict likelihood of an undiagnosed cancer has led to the creation of risk assessment tools to implement these risk models into primary care. The largest implementation projects have been in the UK, of tools that use either the CAPER or QCancer risk models. In one study, paper versions of the CAPER charts for lung and colorectal cancers were provided to 165 general practices in England, and cancer referral data were compared for 6 months before and after introduction of the risk tool.¹⁴⁵ Use of the CAPER charts was associated with an increase in referrals to urgent clinics for

Constipation	Diarrhoea	Rectal bleeding	Weight loss	Abdominal pain	Abdominal tenderness	Abnormal rectal exam	Haemoglobin 10–13 g dL ⁻¹	Haemoglobin <10 g 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	Weight loss
				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	>10.0	Abdominal tenderness

Figure 6: PPVs (95% CI) for colorectal cancer of individual features and repeat presentations, and of pairs of features, against a background risk of 0.25%

The top row shows the PPV for an individual feature. 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 different features. CIs were not calculated when any cell in the 2×2 table had n<10. For haemoglobin <10 g dL⁻¹ with abdominal tenderness, no controls had this pair; therefore, it was scored as a PPV of >10%. Yellow=PPV 1–2%; orange=PPV 2–5%; red=PPV >5%. PPV=positive predictive value. Reproduced with permission from Hamilton and colleagues.¹²⁶

suspected cancer, and an increase in lung and colorectal cancer diagnoses (figure 6).

Electronic risk assessment tools that implement the CAPER and QCancer risk models and integrate them into the electronic medical records of general practices have been developed and are being piloted in England.¹⁴⁶ PCPs can enter a patient's symptoms into the tool and calculate cancer risk, and they are prompted to consider a cancer diagnosis if the prior risk of cancer is greater than 2% when a patient presents. The risk tool can also audit the whole practice population to identify those at high risk of undiagnosed cancer who might benefit from further assessment. Substantial challenges in implementation of these types of tool in general practices exist. PCPs express concerns about use of these tools within the consultation, while those with long experience are more likely to trust their intuition than the estimated risk score.¹⁴⁷

Several randomised controlled trials (eg, ISRCTN 12595588) of risk assessment tools are in progress, which should provide more robust evidence about their effects on clinical decision making and diagnostic delay. However, their clinical usefulness and cost-effectiveness

are unknown at present. Further work is also needed to understand how best to implement these types of tool into routine practice.

Conclusion

There is increasing interest in the early diagnosis of cancer and the critical contribution of primary care in reducing diagnostic delay. However, uncertainties remain, including the most appropriate risk threshold for referral to secondary care. This is a key question as guidelines for urgent referral for suspected cancer are increasingly adopted and electronic tools are implemented, which provide estimates of the risk of undiagnosed cancer. Current thresholds range from 2% risk upwards,¹²⁵ but low thresholds are likely to increase the burden of low-risk patients being referred to specialist diagnostic services, with attendant costs in terms of psychological damage to patients and opportunity costs to the health service. Additionally, PCPs might become more risk averse and lower their thresholds in response to the public and political discourse around diagnostic delay.

An improved understanding of the symptomatology and development of risk models and tools might be of use for some cancers, but whether they will be useful for the cancers that are most difficult to diagnose remains to be seen. Early diagnosis of these cancers could depend on the identification of accurate biomarkers that could be used in populations at high baseline cancer risk. Until then, heightened awareness of key symptoms, and signs and application of best epidemiological evidence on how they predict cancer risk remain at the heart of early diagnosis of cancer in primary care (panel 5).

Part 5: Cancer survivorship care

The number of cancer survivors is rising rapidly, mainly as a result of improvements in cancer outcomes because of advances in screening, early diagnosis, and treatments for cancer, coupled with an increased number of cases resulting from an ageing population. In the UK, for example, roughly 2 million people (around 3% of the population) are cancer survivors, and this number is predicted to rise to 4 million by 2030.⁴ Traditional models of follow-up in which patients continue to attend hospital outpatient clinics, typically for 3–5 years, or sometimes much longer, are no longer sustainable. Comprehensive approaches to follow-up are needed to meet the range of needs of cancer survivors. The effects of cancer and its treatment put cancer survivors at increased risk for morbidity and mortality, and reduced quality of life. The role of PCPs in the survivorship phase is not well defined; yet, with their knowledge of the patients' medical history, comorbidities, and family situation, and their holistic approach to care, PCPs have much to offer. Here, we consider the role of primary care in optimising the provision of cancer survivorship care

Long-term and late effects of treatment

Cancer and its treatment can have a wide range of adverse effects, including physical, psychological, social, and financial, on both the patients and their families. Effective management of these effects is central to good survivorship care. In terms of physical effects, some damage to normal tissues during treatment is inevitable, and the effect on quality of life varies with the type of treatment. Although some treatment effects can be short term, for a substantial minority of patients, problems following treatment can persist and become long-term effects.¹⁴⁸ Examples include urinary, gastrointestinal, and sexual functioning problems after treatment for pelvic cancers, and lymphoedema and menopausal symptoms after breast cancer treatment. In addition, some problems, referred to as late effects, do not arise until months or even years after the end of treatment. Examples include the development of osteoporosis after endocrine therapies,¹⁴⁹ heart disease after certain types of chemotherapy or radiotherapy,¹⁵⁰ and the development of second cancers.¹⁵¹ Studies of childhood and young-adult cancer survivors have helped to quantify the risk of long-term and late effects, and have shown, among other findings, that patients treated at a young age (younger than 40 years) with radiotherapy or chemotherapy for Hodgkin's lymphoma, non-Hodgkin lymphoma, or testicular cancer have a roughly fourfold increased risk of developing a new malignancy and over a fivefold increased risk of developing congestive heart failure, both of which typically take place more than 10 years after treatment.^{152–154} Little is known about the magnitude of the risks after treatment for cancer as an adult, and most research so far has been done in selected populations of patients recruited in secondary care. Study of long-term and late effects in adults is an important area of future research, and genetic profiling might be useful for predicting those at greatest risk of late effects.¹⁵⁵

The PCP and other members of the primary care team have a potentially important role in management of these effects. Indeed, increased contact between patients and the PCP has been reported after a cancer diagnosis for help with both treatment-related side-effects and psychological problems;^{156,157} as patients have often been discharged from secondary care when they develop late effects, most will first report symptoms to the PCP. Additionally, many patients with cancer are elderly with comorbidities, and the PCP is best placed to provide them with holistic care. Guidelines have been produced for the management of long-term and late effects of cancer therapy in survivors of childhood cancer (eg, by the Children's Oncology Group in the USA¹⁵⁸) and are beginning to be developed for survivors of adult cancer.¹⁵⁹ Although some guidelines make specific reference to primary care,¹⁶⁰ in many cases no formal role is described for the PCP during the treatment or survivorship phases. At present, many PCPs have little awareness of the range

Panel 5: Early diagnosis in adults

- Most cancers present symptomatically in primary care, but the symptoms that could signal cancer usually have a benign cause
- Advances in the epidemiology of cancer symptoms in primary care allow more accurate risk assessment and selection of patients who need urgent investigation
- Internationally, evidence for the epidemiology of symptoms should be systematically applied to inform diagnostic pathways aimed at reducing time to cancer diagnosis
- Risk assessment tools could potentially improve early diagnosis of many cancers in primary care, but trials are needed to study their effectiveness
- If research confirms the usefulness of risk assessment tools and electronic clinical decision support, such tools should be rapidly incorporated into the clinical software used by primary care physicians
- Certain cancers might be inherently more difficult to diagnose than others in primary care, and the development of accurate biomarkers is needed to support early diagnosis
- Effective biomarkers for early diagnosis, both in symptomatic patients and in those with a high baseline risk, are a research priority

and scale of potential treatment effects that cancer survivors might have.¹⁶¹ Education is required to ensure that they have the necessary information and skills to assess patients; offer support and advice; refer back to secondary care or signpost to other services as appropriate (eg, counselling and financial and social support); and be aware of the possibility of a second cancer or cardiovascular problems at a younger age than generally expected.¹⁶²

Psychosocial effects

Studies from the psychosocial oncology literature have consistently found that around 25–30% of patients with cancer develop some form of psychological disorder across the trajectory of cancer, including the survivorship phase.¹⁶³ Adjustment and post-traumatic stress disorders, depression, and anxiety are the most common disorders, with higher incidence in patients with cancer than in the general population. Fear of recurrence, body image consciousness,¹⁶⁴ concerns about sexuality and fertility, stigmatisation and discrimination, altered social relationships, problems in returning to work and reassimilating with social groups, and negative feelings (eg, mistrust towards body, anger, and guilt) have been reported as common concerns in cancer survivors in different clinical contexts,¹⁶⁵ including primary care services.¹⁶⁶

For these reasons, screening for and monitoring of psychosocial effects are an important part of clinical practice for both oncologists and PCPs.¹⁶⁷ Risk factors for psychological disorders—such as a history of psychiatric illness, poor social support, personality factors (eg, negative affectivity and social introversion), and stressful life events—should also be regularly assessed in the clinical encounter by oncologists and PCPs.

Consideration of the effects of cancer on the patient's family is also important, since cancer causes psychosocial harm not only to the patient with cancer, but also to spouses and other family members. Research exploring

Panel 6: Routine surveillance tests in patients with no symptoms or signs that have a rationale or evidence-base for outcome improvement

- Anal cancer: anoscopy
- Bladder cancer: urine cytology, cystoscopy, or urinary tract imaging, or a combination of these
- Breast cancer: mammography
- Cervical cancer: cervical or vaginal cytology
- Colorectal cancer: endoscopy, tumour marker (carcinoembryonic antigen), and chest and abdomen imaging (pelvis imaging for rectal cancer)
- Head and neck cancer: endoscopy or imaging (if necessary) of the primary site
- Hodgkin's lymphoma: chest, abdomen, and pelvis imaging
- Kidney cancer: chest and abdominal imaging
- Leukaemias: complete blood count and bone marrow assessment in some types (eg, acute lymphoblastic leukaemia and chronic myeloid leukaemia)
- Prostate cancer: tumour marker (prostate-specific antigen)
- Sarcomas: imaging of the primary site if necessary and chest imaging
- Testicular cancer: tumour markers (alpha-fetoprotein and beta human chorionic gonadotropin) and chest, abdomen, and pelvis imaging

families' needs across the trajectory of cancer and cancer survivorship, and identification of adaptive, functional, and non-adaptive family coping mechanisms, family structure, and level of functioning (ie, cohesive *vs* conflicting or disruptive family dynamics) is needed. Empirical studies showed that, irrespective of sex, age, ethnicity, and stage of the disease, 25–35% of caregivers develop symptoms of emotional distress and 15% have depression, with repercussions on quality of life and physical health.¹⁶⁸ Therefore, psychopharmacological¹⁶⁹ and psychological interventions, in their many possible formats (eg, individual, couple, family, or group therapy) and models (eg, cognitive-behavioural, relational, or psychodynamic),¹⁷⁰ represent a specific part of an interdisciplinary approach to cancer survivorship, including primary care, to properly respond to psychosocial needs, reduce the levels of emotional stress, and increase coping efficiency among cancer survivors.

Detection of recurrence

Detection of recurrence is central to survivorship care. Recurrences can be detected either by proactive surveillance testing or after presentation with clinical signs and symptoms. The goals of surveillance are to improve outcomes, salvage the disease and cure it, or, at the very least, institute palliative therapy to improve survival or quality of life, or both. These benefits should be weighed against potential harms, such as the anxiety and stress caused by false-positive testing, complications of subsequent invasive procedures (eg, biopsies and radiation from imaging), and costs.¹⁷¹

The essential components of surveillance are generally considered to be: history and physical examination to detect symptoms and signs that could portend recurrence; examination of the primary site (eg, mammography for breast cancer and endoscopy for colorectal cancer); testing

of tumour markers (eg, carcinoembryonic antigen for colorectal cancer and prostate-specific antigen for prostate cancer); and imaging for distant recurrence.¹⁷² Assessment of the primary site can also identify second cancers, because genetic predisposition or environmental exposures responsible for the original diagnosis, or treatments such as radiotherapy, often leave patients at increased risk for another cancer.¹⁷³

Regarding history and physical examination, although any persistent new symptom usually merits investigation, clinical assessment should be particularly focused on recognition of the symptoms and signs in the few clinical situations in which early detection of recurrences can improve outcomes.^{174,175} Often, such symptoms consist of pain or some other abnormality at the primary site for a local recurrence. For cancers in which few metastases (so-called oligometastases) could potentially be resected for cure, right upper quadrant abdominal pain might suggest liver metastases, whereas a persistent dry cough could signify lung metastases. Constitutional symptoms such as fatigue, anorexia, and weight loss might suggest metastatic disease, but are non-specific.¹⁷⁶ Patients also need to be well informed about the potential signs and symptoms of recurrence.

Unfortunately, most metastatic cancers cannot be cured and, in most cases, early treatment of asymptomatic incurable disease has not been shown to improve outcomes. This finding is why routine testing for metastases from breast cancer, for example, has been shown to provide no benefit in randomised trials and is not recommended.¹⁷⁷ Even potentially curable haematological malignancies are not clearly benefited from aggressive surveillance. For example, by the time recurrent lymphoma is detectable by imaging studies, a combination of symptoms, signs, and lactate dehydrogenase measurement would also have picked up almost all lymphoma relapses.¹⁷⁸ In fact, few situations exist in which specific surveillance testing has been shown to be beneficial (panel 6). Consequently, most guidelines (eg, those of the US National Comprehensive Cancer Network¹⁷⁹) recommend clinical assessment with further testing only as clinically indicated. Notable exceptions include colorectal cancer,¹⁸⁰ some sarcomas,¹⁸¹ and kidney cancers,¹⁸² in which a minority of patients with oligometastases to the liver or lungs can be cured surgically, and testicular cancer and Hodgkin's lymphoma,¹⁸³ which can be salvaged with aggressive chemotherapy. In these situations, testing with tumour markers and imaging to detect recurrences earlier, as opposed to simple symptomatic follow-up, makes sense, and in cases such as colorectal cancer evidence from a systematic review and meta-analysis¹⁸⁴ has shown improvements.

Prevention

Research into the effects of nutrition and physical activity in cancer survivors is still in its early stages. Some evidence suggests that addressing exercise and diet can lead to improvements in the quality of life of cancer

survivors. A growing body of evidence also exists in relation to the potential to reduce the risk of recurrence and mortality in some cancer types. The evidence is strongest for the relationship between exercise and breast cancer: a systematic review of cohort studies¹⁸⁵ reported that increased amounts of physical activity post-diagnosis were associated with up to a 34% (95% CI 16–38%) decreased risk of breast cancer mortality. In colorectal and prostate cancers, some evidence suggests that physical activity might decrease mortality,^{186,187} although it is inconclusive. Physical activity also improves heart health and can reduce the risk of osteoporosis, and might be helpful in limiting the cardiotoxic and other long-term effects of some cancer treatments. Levels of physical activity in cancer survivors are not high,¹⁸⁸ and primary care services can play an important part by advising on the potential benefits of exercise and actively encouraging participation—eg, through exercise prescription.

Evidence on the effectiveness of specific dietary interventions in cancer survivors in reducing the risk of recurrence is still emerging. Growing evidence shows the importance of maintenance of a healthy BMI, but further evidence is needed before specific guidance in this area is warranted. For now, the World Cancer Research Fund recommends cancer survivors to follow the same guidance as they would do for reducing the risk of primary cancers.¹⁸⁹

Models to deliver survivorship care

With increasing numbers of cancer survivors and consequent demands on secondary care, the potential for primary care to have an extended role in survivorship care is attracting growing interest. Studies have shown willingness from PCPs and support from secondary care for increased primary care involvement in follow-up, provided that adequate guidelines, educational support (knowledge and skills), clear lines of communication with easy access back to secondary (hospital) care, robust monitoring systems in primary care, and adequate resourcing are available.^{190,191} Patients recognise the potential benefits in terms of convenience, familiarity, and knowledge of comorbidities and family situation offered by primary care, but they express concerns about PCPs having the level of knowledge needed.¹⁹¹ Nevertheless, some patients gain considerable reassurance from follow-up care delivered in hospital settings. It has been acknowledged that patients are not well informed about the evidence of limited benefit for conventional follow-up schedules and that their preferences might change if the evidence was more widely understood.¹⁹²

To promote communication between all providers of cancer care (both secondary and primary care) and the patient, survivorship care plans were recommended by the US Institute of Medicine in its 2005 report *From cancer patient to cancer survivor: lost in transition*.¹⁹³ These plans were intended to make it explicit what the diagnosis was, treatment received, and specific recommendations for

future care. These recommendations include surveillance for recurrence, reminders to not ignore any non-cancer comorbidities, other screening and preventive health maintenance, and guidance around common survivorship issues such as long-term and late effects, psychosocial concerns, employment, and insurance challenges. The plan also identifies which specific provider was responsible for which aspect of survivorship care. Although a general agreement exists that survivorship care plans would be desirable, their uptake in the USA and elsewhere has been slow.¹⁹⁴ Such slow uptake is mostly because oncology providers have had difficulty incorporating the formal formulation of these plans into routine workflow, mainly because of the time needed. Moreover, randomised trials of survivorship care plans were unable to detect an improvement in outcomes.^{195–197} Recognising these challenges, efforts have focused on identification of the essential elements that are necessary for communication and care.¹⁹⁸ The actual form of the plan is a secondary consideration. Informal communication is preferable to no communication. Survivorship care planning needs to be tailored to accommodate the specific needs and capabilities of all involved.¹⁹⁸

PCPs now have an important role in management of the continual care of patients with complex health conditions such as diabetes, coronary artery disease, and COPD, and some advocate that follow-up care could similarly be shifted to primary care for certain cancers and for so-called low-risk individuals. Others favour an integrated or a shared-care approach with some hospital contact maintained at least for the first period of survivorship. Two trials comparing primary care and secondary care follow-up for breast cancer^{199,200} and one for colorectal cancer²⁰¹ suggest no differences in quality of life, patient satisfaction, or clinical outcomes (recurrence and all-cause mortality). Similarly, studies of integrated models of cancer follow-up point to improved patient satisfaction and cost efficiency with no detriment to clinical and quality-of-life outcomes.²⁰² More work is needed to ascertain the most appropriate role for primary care. Secondary-care-based, nurse-led clinics using remote follow-up (eg, telephone, internet, or post) or outreach clinics based in the community provide alternative models with reduced input from primary care.

Conclusion

Our understanding of the key elements of good survivorship care is growing. As the numbers of cancer survivors continue to increase, and with at least some cancers becoming more akin to other chronic illnesses, primary care has a potentially important and increasing role in addressing these needs (panel 7).

Part 6: Palliative care in advanced cancer

A third of patients diagnosed with cancer will die from their disease.²⁰³ The conceptual approach to the transition from curative to palliative treatment has changed from

Panel 7: Key issues in cancer survivorship care and action points

- Numbers of cancer survivors with a range of physical and psychosocial needs are increasing
- As knowledge of the potential long-term and late effects of cancer diagnosis and treatment increases, methods for optimising survivorship care are needed
- New models of cancer follow-up care should draw on the principles that apply for other long-term conditions
- After further development to arrive at the optimum model, plans for survivorship care should become a feature of follow-up care
- Primary care, with its holistic approach, has a potentially important role in cancer survivorship care, but its role in such care needs to be clearly defined
- Evidence suggests that primary-care-based and shared-care models of follow-up can be just as effective as secondary-care-led follow-up for breast and colon cancers; good communication between all care providers and clear guidance for primary care professionals are key

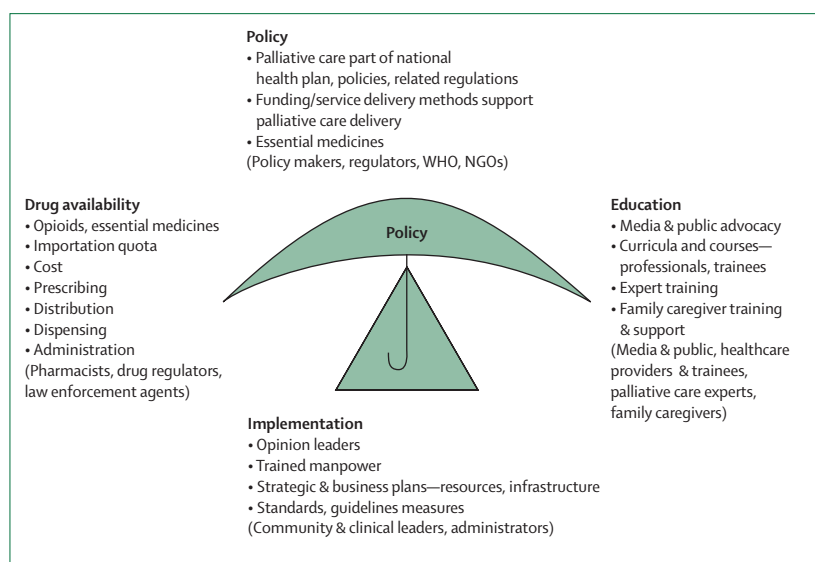


Figure 7: The WHO policy for successful integrated palliative care
 NGO=non-governmental organisation. Reprinted from Stjernsward J, Foley KM, Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage* 2007; **33**: 486–93.

occurring at a discrete point in time to being a gradual introduction of hoping for the best, but preparing for the worst. As the chance of cure diminishes, oncology treatments have less of a role and palliative care becomes more important. Patients frequently want to spend most of their time at home, and most express a preference to die there.²⁰⁴ Despite the substantial input needed from primary care to accommodate such wishes, this transition could be made from one specialist team to another, with little thought of engaging the PCP in a meaningful way.²⁰⁵ Although ideally all PCPs would be involved in palliative care, their involvement in high-income countries ranges from around 85%^{206,207} in the UK and Australia to less than 50% in Japan.²⁰⁸ Differences might also exist in PCP involvement between urban and rural settings.²⁰⁵

Palliative and primary care both take the perspective of treating the whole person, their immediate family, the application of best practice, and consideration of issues beyond the physical to encompass psychosocial, practical, and spiritual ones. Thus, the nature of the care is the same, although palliative care is more intense and has a shorter timeframe than primary care. In this section, we examine the evidence for and against primary care involvement, discuss the barriers and facilitators that exist, and describe the level of involvement to which health systems should aspire.

The value of primary care in end-of-life care

Primary care is in a unique position to provide palliative care. It has the ability to start early in the course of life-threatening disease; meet all dimensions of need (physical, social, psychological, and spiritual); provide care in clinics, care homes, and at home (thus preventing unnecessary hospital admissions); support family carers; and provide bereavement care.²⁰⁹ Having a regular PCP, particularly one who does home visits, increases the chance of patients dying at home²¹⁰ and reduces emergency department visits.²¹¹ Done well, primary palliative care is valued by patients and carers.²¹² Accessibility is an important element of their satisfaction,²¹² as is symptom control.²¹³ However, much room for improvement exists,^{213,214} especially with regard to PCPs having lack of confidence in providing and unwillingness to assume responsibility for palliative care.²⁰⁷

Primary care and national health models

The provision of palliative care by PCPs is highly dependent on the policy environment in which they operate. Factors include the place of the PCP in the health-care system, access to essential medicines, the existence or otherwise of community nurses attached to primary care, and health insurance arrangements.²¹⁵ The WHO Public Health Strategy for palliative care describes four domains of public policy to facilitate community-based palliative care (figure 7),²¹⁶ and primary care involvement in palliative care should be embedded in all of these domains.

In future, governmental health policies will be judged by WHO partly on the basis of their delivery of palliative care.²¹⁷ Because most deaths will not involve specialist palliative-care practitioners, helping PCPs to deliver timely and competent end-of-life care has to be a core part of national palliative-care strategies. The European Association of Palliative Care (EAPC) has adapted the WHO policy framework to identify the place of primary care in end-of-life care at a national level.²¹⁵

National policies that enable palliative care in primary care settings are not always in place. Of 20 European countries reported in an EAPC-sponsored review,²¹⁵ only two keep palliative-care registers in primary care, eight are encouraged to use tools to identify patients at risk of dying in the foreseeable future, and ten have community nurses that work with primary care. Home visits are available in all but three countries. Payment structures for PCPs can

make end-of-life care more or less attractive, whereas specialist support ranges from extensive to limited.

Availability of appropriate medicines

To deliver palliative care in the community, PCPs must have access to appropriate medicines and education in their use. Both WHO and the International Association for Hospice and Palliative Care have published recommended medicine lists for palliative care.^{218,219} Symptom management guidelines have also been developed in specific countries, and they represent the national and local availability of particular medicines.

Barriers to primary palliative care

The barriers that prevent the involvement of PCPs in palliative care can be grouped broadly into logistical or practical barriers, barriers related to coordination of care, those related to perceived competence in palliative care, and personal barriers of PCPs. However, these barriers overlap and are not mutually exclusive.

Logistical issues related to time and travelling to provide home visits are cited by PCPs as prominent barriers,²⁰⁶ particularly outside regular office hours. Provision of palliative care is time intensive because of the complexity of symptom management, the psychosocial issues that arise or are intensified at the end of life, the necessity of communicating sensitively with both patients and their families, and the fact that care is often delivered in the home setting.^{207,220} Willingness to provide care after hours varies widely by country and partly depends on remuneration and availability of large-scale out-of-hours cooperatives.²²¹ Out-of-hours availability is greater when PCPs have more perceived duties of care and lesser with PCPs being in a salaried job, working in a city-based practice, and living far from the practice.²²²

Issues related to organisation of care are prominent, if potentially modifiable, barriers to palliative-care provision by PCPs. Patients might lose contact with their PCPs after they are diagnosed with cancer,²²³ which makes re-involvement of PCPs difficult at the end-of-life care of a patient with whom they have had little recent contact. This issue might be compounded by poor communication between specialists and PCPs.²²⁴

Both oncologists and PCPs might have difficulties in identifying patients who are in need of palliative care, resulting in delayed referrals and poor planning.²²⁵ Prognostic estimates are notoriously optimistic,²²⁶ which might delay the commencement of a palliative approach and increased support, particularly in countries such as the USA where hospice services are linked to a prognosis of less than 6 months.²²⁷

Once PCPs are involved in palliative care, barriers at an organisational level might surface. Dutch PCPs reported that arrangement of home care services or procedures such as oxygen therapy, intravenous medications, or paracentesis is time-consuming and that extra care (eg,

assistants to aid with care, such as nurses) is difficult to obtain.²²⁰ PCPs in rural areas might have less access to education programmes and advice from specialists.²²⁸ Finally, they might feel that palliative care is not sufficiently valued or remunerated:²⁰⁹ extra fees are available for palliative care home visits in the Netherlands, Norway, and Denmark, but not in the UK; in Luxembourg, patients have to pay directly for home visits.²¹⁵

Lack of expertise in provision of palliative care is another prominent barrier.²²⁹ One systematic review²³⁰ reported that PCPs often did not feel fully competent to deliver palliative care, particularly in relation to control of symptoms other than pain, emotional distress of patients and relatives, and bereavement care. Subsequent surveys have confirmed that these inadequacies persist, although PCPs have a strong interest in education in palliative care. Finally, PCPs might not involve themselves in palliative care because they have little or no interest in doing so, or because of personal or family commitments.²⁰⁷

Enabling PCP provision of palliative care

The success of some countries in addressing these barriers can be attributed largely to structured programmes, services, and educational opportunities to support PCPs in the provision of palliative care. In a survey of GPs in the UK, agreement that palliative care was a central part of their role increased with the number of physicians in the group, from 47% for solo physicians to 85% for groups with more than eight physicians.²⁰⁶ In countries such as the Netherlands, Denmark, and the UK, the establishment of out-of-hours cooperatives has changed the manner in which care is provided.

One challenge for these services is the transfer of information regarding terminally ill patients from the PCP to the out-of-hours service. When such transfer does occur, it is associated with positive outcomes, including fewer hospital admissions.²³¹ In Scotland and in many parts of England, an electronic Palliative Care Summary is available to provide out-of-hours staff with an up-to-date briefing of patients' medical history, understanding of their end-of-life care preferences, and wishes.²³² Access by the covering physician to such electronic records promotes continuity of care and provides medical information for patients whose decline was not anticipated.

Collaborative care is important not only among PCPs, but also between PCPs and other health-care providers, including oncologists, community nurses, and palliative-care specialist teams. Patients value continual care by their PCPs but are at times unsure of their PCP's role following a cancer diagnosis.²³³ Oncologists can promote continued involvement of PCPs throughout the cancer trajectory by regular communication about their mutual patients and by encouraging patients to maintain contact with their PCPs.²³³ Interdisciplinary teamwork can facilitate the organisation of care; for example, the job of coordinating

palliative care could be delegated to community nurses, with the PCP acting as a point of contact for problems.²³⁴

Specialist palliative-care teams improve quality of life, mood, satisfaction with care, and possibly even survival when involved early in the care of patients with advanced cancer;²³⁵ they enable patients to die in the setting of their choice²³⁶ and have an important role in supporting PCPs. PCPs could work with these services in different ways, using them as a resource, working together as an extended team, or handing over responsibility completely. Regardless of the model adopted, clear allocation of responsibilities is important.²³⁷

In addition to support from palliative-care teams, education of PCPs is essential to increase their confidence in provision of palliative care. Improved palliative-care education can be achieved through medical training, workshops, online courses, training programmes, and access to resources such as care pathways and websites. In countries such as Japan, courses have been developed to provide education on palliative care in primary care settings.²³⁸ Electronic resources such as Caresearch in Australia provide access to comprehensive educational and research material.²³⁹

In the UK, initiatives such as the Liverpool Care Pathway and Gold Standards Framework have been developed to improve end-of-life care in generalist settings.^{240,241} The importance of applying the principles of end-of-life care planning properly, using them as a guide to high-quality care and not just a task to be signed off, has been shown by the criticism that application of the Liverpool Care Pathway has received, and its subsequent withdrawal, and by the recommendation to refer to end-of-life planning rather than a clinical pathway.²⁴²

Specific tools and interventions have also been designed to promote early identification of patients with palliative-care needs. Simple prognostic tools have been developed on the basis of performance status and other clinical indicators. Routine use of the surprise question—would you be surprised if this patient died within a year?—was effective in predicting 1-year survival of patients with advanced cancer.²⁴³ In Ontario, Canada, symptom screening and symptom management guidelines have been incorporated into all cancer centres,²⁴⁴ and they are now being incorporated into primary care practices. A range of tools to identify patients in primary care who are at risk of dying from cancer and other causes have been developed or are in various stages of testing.²⁴⁵ They all use a combination of subjective clinical judgment, non-specific indicators of deterioration, and disease-specific markers of deterioration to highlight people at risk of dying.

There is also increasing acknowledgment that palliative care is emotionally taxing for those providing it and that self-care of PCPs is essential to mitigate compassion fatigue and burnout.²⁴⁶ Specific interventions that increase self-awareness and informal self-awareness practices could enable physicians to continue providing palliative care with empathy and effectiveness.

Facilitating multidisciplinary palliative care

Appropriate end-of-life cancer care should be based on needs, with the level of services matching the complexity of need. For most of the cancer journey, the problems the patient will face are fairly straightforward and well within the competency of the PCP. Specialist involvement could range from a telephone consultation and a single visit to full care. The system should be designed to facilitate seamless transitions to the most appropriate level of care. Taking this approach and assessing patient needs regularly with a needs assessment tool optimise the use of scarce resources and reduce the intensity of needs of patients and their carers.²⁴⁷

Much of palliative care is complex. It requires coordination of health professionals and appropriate resources. The elements of good integrated planning include adequate resourcing of all professionals, appropriate knowledge and skills, good communication between professionals, active engagement with patients and their carers, clarity on the contribution of each part of the health system, and effective management systems and decision-making capacity.²⁴⁸

The fragmented nature of some health-care systems can make the engagement of primary care in the management of patients with advanced cancer an operational challenge. However, the outcomes could be worth the effort. For example, two randomised controlled trials have shown that just one case-conference involving a PCP and a specialist palliative-care team confers benefits, including improved patient performance capacity, reduced hospital admissions and referrals to the emergency department,²⁴⁹ and improved quality of life in the patient's last month of life.²⁵⁰

PCPs also have a role in caring for the carers of people with advanced cancer. The use of a self-administered questionnaire to facilitate a carer-focused consultation reduced intensity of needs in carers who were anxious or depressed: those caring for very ill people articulated more needs, the expression of which potentially allowed these needs to be addressed.²⁵¹

Advance care planning

Advance care planning is a process that allows people to express their choices about their future care in a legally binding document should they become incapable of expressing them because of advancing illness. Most high-income countries have enacted legislation to enable this. Advance care plans are effective in ensuring that the patients' wishes are known and followed, reducing futile and unwanted treatments in hospitals, and leading to more satisfied, bereaved carers, who experience less anxiety and depression.²⁵² The process could also give rise to a more timely and smooth transition to end-of-life care.

Advance care planning should also address clinical care that anticipates and prepares for potential clinical problems. Generating a case management plan that takes into account the patient's goals of care and treatment wishes can ensure that they are enacted

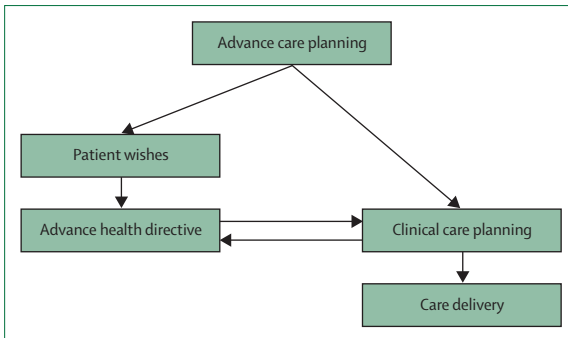


Figure 8: Conceptual map of advance care planning

Reproduced with permission from Mitchell GK. End-of-life care for patients with cancer. *Aust Fam Physician* 2014; **43**: 514–19. Available at www.racgp.org.au/afp/2014/august/end-of-life-care-for-patients-with-cancer.

(figure 8). The absence of this sort of approach could lead to a more reactive, crisis-driven form of care.

Ideal primary palliative care for advanced cancer

A person with advanced cancer who approaches the end of life would ideally have this recognised early by the oncology team. Supportive and palliative care would be presented as a means of hoping for the best, but preparing for the worst. Because the PCP has been part of the team and has had a role in the assessment and management of the carer's needs as the disease progressed, his or her involvement would be a matter of course. The PCP would work with the specialist palliative-care team to develop a care plan that respected the patient's wishes and ensured that each team member's responsibility was clearly set out. A copy of the patient's advance health directive would be in the clinical notes and readily available to all relevant health professionals.

In the community, the PCP would commit to regular review of the patients, paying home visits if necessary. He or she would have had effective training at undergraduate and vocational levels and would have been treating palliative patients from the beginning of his or her professional career, receiving subsequent case-based training through shared care of several patients over time. The PCP would have ready access to and regularly use evidence-based treatment guidelines. The care provided would extend to the bereavement phase of the carer. Finally, the health system would recognise the complex nature of this care and provide appropriate remuneration for the extra effort involved (panel 8).

Part 7: Integration of primary and specialist care

Integration of services between primary and specialist care is vital to optimise the quality and outcomes of care,²⁵³ but is known to be problematic.²⁵⁴ Patients often need to consult many health professionals across several health-care settings, which can lead to fragmented and uncoordinated care,^{193,254} jeopardising care quality and patient safety.²⁵⁵ Accordingly, introduction of models and

Panel 8: Palliative care

- Primary care should be an integral part of palliative care services, which should be based on the WHO Public Health Strategy for palliative care
- Primary care physicians should participate in provision of palliative care; they should be supported, provided with high-quality training, and adequately resourced to do so
- All patients receiving palliative care should have an advance care plan, which should include a plan for their clinical care

Panel 9: Integrated care

Elements of integrated care

- Clinical: establish processes to coordinate patient care and clearly define clinical roles, including those of interdisciplinary health professionals
- Vertical: establish structures and processes to support coordination in the delivery of cancer services between formal cancer care system and community-based primary care
- Functional: establish structures and processes to enhance coordination between providers, including between health and non-health settings

Action points

- Care pathways are key to integrated care, but effective lines of communication need to be established to ensure their success
- Cross-sector education is central to integrated care and should extend beyond clinical content to include care pathways, systems, and quality improvement
- Patient navigators show promise as a means to enhance integrated care, and their contribution should be further assessed
- Health-care providers and policy makers should adapt evidence-based models and tools to improve integration between primary and specialist care for each phase of cancer control
- These models and tools should be introduced with strategies for implementation, adoption, and sustainability with proven effectiveness

tools to improve integration is essential to optimise the role of primary care along the breadth of the cancer care continuum. In this section, we review approaches to models of care, how these can be applied to the structuring of health-care services, and tools that have the potential to facilitate integration of primary and specialist care.

Models of integrated care

The concept of care integration is pervasive in the medical literature relating to patients with cancer who have complex medical and psychological needs, and whose care is delivered by a range of providers with distinct roles and skills. Integration between providers is defined as the creation and maintenance of a common health-care structure and connection between different providers to coordinate patient care, while retaining each provider's unique role.²⁵⁶ Integration can be seen to have three core elements²⁵⁷ that need to be considered in the design of care models (panel 9).

The first element is clinical integration—ie, the extent to which patient care services are coordinated across the various functions, activities, and operation units of the cancer care system. Such integration needs to establish structures and processes that define and clarify clinical roles, and can include education and training of interdisciplinary health professionals, such as patient navigators or clinical nurse specialists. The second is vertical integration, whereby structures and processes are set up to support regional collaboration, coordination, and leadership with respect to the delivery of cancer services both in the formal cancer care system and in community settings that involve cancer and non-cancer providers. Examples include care pathways and guidelines for care. The last element is functional integration, whereby structures and processes are established to support key coordination activities across providers—eg, building platforms to enhance communications using electronic tools. These structures and processes can also enhance connections between providers in health and non-health (eg, social care) settings, fostering horizontal integration especially at the local community level. These elements are brought together operationally in the way in which health services are structured through the design of models of care,²⁵⁸ which represent a systematic approach to achieving high-quality, holistic care that addresses all the needs of patients with cancer.

The components of a model of care include the settings (cancer centre, hospital, or community) and providers (oncologists, nurses, and PCPs) involved with operational specifics (care pathways, care plans, and information systems) informed by the elements of integration. Fairly well-established evidence supports the transition of cancer survivors who are well from secondary to primary care.²⁵⁹ Such a transition has been shown to have equivalent cancer outcomes, better overall care through management of non-cancer health issues, better supportive care, and lower cost compared with follow-up care provided by specialists.²⁶⁰ For many patients with complex needs during and after cancer treatment, a shared-care approach is proposed,²⁶¹ but the operational specifics are more complicated, and there is little evidence on how to achieve this even in settings where primary care is well established. In the following sections, we review how health-care services can be structured to enable integration at various stages of the cancer care continuum, and propose tools that can be used to facilitate integration.

Structuring of health-care services

The possibilities for integration depend on the actual organisation of the health-care system and are very different between high-income and low-income countries, and for the different stages of the cancer journey. Although there is much evidence of efforts to transfer, substitute, or relocate from specialised treatment to primary care, very few examples of real integration exist.

In most countries, primary care is responsible for primary prevention, and major effects of primary prevention of cancer are based on public health policy initiatives by legislation (eg, smoking and taxes), together with environmental and occupational initiatives. In low-income and middle-income countries, where prevention might be the most effective approach to cancer control, WHO has proposed a model for integration of primary prevention with screening (ie, secondary prevention of asymptomatic disease)²⁶² so that primary care forms a clinically integrated system linking the two.

In many countries, although screening programmes are centralised and managed by health authorities, they are usually integrated between primary and secondary health care (but substantial difference exists among systems). The main efforts of such programmes relate to maximising uptake, improving access, and providing efficient screening. In health-care systems of high-income countries, integration between primary and secondary care seems to increase these measures of screening effectiveness.²⁶³

Cancer diagnosis relies on access to a health-care system and relevant investigations; thus, well established integration between primary and specialist care is crucial. Health-care systems in which primary care acts as a gatekeeper to specialist care are associated at a population level with poorer cancer outcomes than those in which no gatekeeper function exists.⁴⁴ These so-called ecological associations are prone to several types of bias; in this case, the association is probably due not to the gatekeeper function itself but rather to the absence of integration with respect to PCP access to cancer investigations (eg, imaging and endoscopies). This concurs with studies showing that cancer control is better when there is better access to both primary and specialist care.^{264,265} Research has shown that integration of cancer investigations is possible and might have positive effects.^{266,267} In several health-care systems, urgent referral pathways for suspected cancer have been implemented as a means to integrate primary and specialist care.^{16,268}

Little research into integration during cancer treatment has been done,²⁶⁹ and most studies have focused on information and communication skills. However, important reasons for improved integration of primary and specialist care during active cancer treatment include symptom control²⁶⁹ and management of toxicities to avoid emergency department visits and hospital admissions,²⁷⁰ management of patients with concurrent mental health problems,²⁷¹ and management of geriatric patients with multimorbidity.²⁷²

Follow-up, after-care, and survivorship care after cancer diagnosis have traditionally been based on specialist care. However, acknowledgment of increasing cancer incidence and concerns about efficiency have fostered calls for studies on integration of follow-up care after cancer.²⁷³ Randomised trials of primary-care-led follow-up of cancer survivors in the UK,¹⁹⁹ Canada,²⁰⁰ and Australia^{201,274} show

that integration of follow-up care improves patient satisfaction and cost-effectiveness, with no negative consequences on cancer outcomes.^{199,200} Palliation is an area in which much effort has been made to integrate primary and specialist services, largely predicated on models of shared and collaborative care.

Tools for better integration

Care pathways

Care pathways for patients with suspected cancer have evolved as a result of marked variation in treatment and outcomes for patients in an attempt to equate outcomes both within and between countries. Such patients can present via screening programmes (as for breast, prostate, and colorectal cancers), via primary care with or without alarm symptoms, or as an emergency with, for example, bleeding or perforation. Regardless of the route of presentation, care pathways need to be coordinated so that there is no delay in investigation and diagnosis, while recognising that most patients will not have cancer.

In high-income countries, the management of cancer is now multimodal—usually involving a combination of surgery, radiotherapy, chemotherapy, and hormonal manipulation—and thus requires multidisciplinary management. Such teams are usually led by a surgeon or an oncologist who is assisted by a pathway manager, a role usually filled by a nurse specialist or an administrator who provides a direct point of contact for the patient and carers, and who ensures full distribution of decisions of the multidisciplinary team.²⁷⁵

As care becomes more complex, communication between patients, carers, PCPs, and the clinical team is vital, and this is best managed through frequent multidisciplinary meetings²⁷⁶ and joint specialist clinics with same-day communication with primary care. The care pathway should be flexible for the individual and not driven mainly by prescribed targets. Such pathways have led to centralisation of services, which for certain cancers (eg, oesophagogastric) has improved surgical outcomes.²⁷⁷ However, as much of the pathway (diagnosis, staging) should be delivered as close to home as possible, restricting travel to what is necessary for essential oncology services and surgery.

Overall, care pathways for cancer are complex and multifaceted, but there is good evidence that suggests such pathways have reduced variation in outcomes for high-risk cancer within and between countries.^{25,47} Pathways should be adapted to take account of advances in treatment, but quality of life should remain at the centre of all decisions.

Education and audit

Education is arguably the most important aspect of integration of cancer care across sectors. Education has to flow between primary and specialist care in both directions, be tailored to the full range of primary care and specialist health professionals, and inform the changes

needed to achieve the highest-quality care. Provision of such education will be an enormous, costly, and time-consuming agenda, particularly because little evidence exists to inform the best modes of education to improve integration of primary care and oncology services.

Integrated oncology education is less well-developed than programmes for other disease areas, such as heart disease or diabetes. Lessons from those areas are abundant, but whether education is best delivered in a multidisciplinary format is still unclear.²⁷⁸ In view of the breadth of the cancer control continuum,⁹ relevant education for health professionals will vary along the continuum by tumour type, patient age, and multimorbidity. Such education should be complemented by education about communication systems, referral and re-referral processes, team coordination, and processes of care, and will ideally lead to a patient experience of so-called seamless care, informed by both patients' needs and high-quality, equitable provision. Cross-sector education about key differences in the prevalence and presentation of disease in each health-care setting will help health practitioners appreciate each other's roles and grasp diagnostic and investigation problems. Frameworks that underpin measurement of cancer-related processes, for example, the Aarhus Statement,⁹ or ongoing management of cancer care,²⁷⁹ and statements promoting shared-care models,²⁸⁰ should inform international curriculum development.

Little has been done to study the most effective type of educational interventions to enhance integration of cancer care. Outcomes of such education should include improved integrated cancer-care systems, communication, knowledge, and diagnostic expertise, and an increase in relevant competencies across sectors. Agreed curricula across and between primary and specialist care are needed. A systematic review from the USA of skin cancer education for PCPs showed promising effects from a range of isolated educational interventions but noted the need for improved methodological rigour.²⁸¹

Cross-national audit is a powerful tool to illuminate variations in care that could be addressed with specific interventions at the primary care–specialist interface. The International Cancer Benchmarking Partnership (ICBP; see Part 8)²⁸² has illustrated large variations between countries in national guidelines and patterns of cancer care and highlighted what countries can learn from each other. Effective audit and education need to extend beyond clinical content to the nature of care pathways, quality and governance mechanisms, and quality-enhancing practices such as access to clinical trials. A key driver for improvement in cross-sector integration is unified electronic information systems across health-care sectors; good education and training in the use of such systems across sectors will harmonise care, enable regular clinical audit, and provide a platform for feedback systems to record and analyse errors and near-misses. A systematic review of audit and feedback

interventions for health professionals in other cross-sector clinical areas²⁸³ suggests that such interventions tend to make small, but important, improvements in clinical practice.

Finally, it is important to harness educational capacity from health-care providers, the higher-education sector, and the voluntary sector. Some clinicians who are already working at the interface between primary care and specialists, such as nurse specialists, might have key roles as both educators and change agents.

Patient navigation

Patient navigation is one model of interdisciplinary care with the expressed goal of improving integration. Patient navigation started in 1990 with an initial demonstration project in Harlem, New York City, USA, to address disparities in access to cancer services for vulnerable populations.²⁸⁴ The principle of navigation is to provide active coordination of care that removes barriers to access. Navigation programmes seek to provide patients and their families with a map and a guide (the navigator) to overcome system fragmentation. This is of particular interest when several providers are needed to manage both cancer and non-cancer health issues. Most studies of navigation in cancer have involved nurses in this role. A randomised trial investigated the use of a navigator early in the care trajectory of patients with newly diagnosed breast, colorectal, and lung cancers,²⁸⁵ and showed clear improvements in the patient experience and greater adherence to therapy compared with usual care, although no differences were seen in quality of life. The role of a navigator might be particularly valuable during active therapy. A navigation programme that coordinates care between primary care providers and oncologists in vulnerable populations—such as the elderly, patients with pre-existing serious co-morbidities, and those undergoing complex therapies with substantial toxicity (eg, patients with head and neck cancer)—could overcome gaps in the management of comorbid conditions that result in suboptimal outcomes. In view of the positive results on patient-reported outcomes, further studies using navigators with a specific focus on provider integration in at-risk populations are warranted.

Electronic communication tools

With the rapid growth of eHealth technology (ie, health-care practice supported by electronic processes and communication) and the computerisation of clinical practice, electronic tools are widely implemented in the care of patients across the cancer care continuum: computer-based risk assessment tools are being used for screening, decision-support systems are applied at points of diagnosis and treatment, and secure patient portals facilitate remote management or self-management of symptoms and side-effects.^{286,287} Electronic communication between patients and physicians could bring about individualised care and make information readily

accessible across different health-care settings.²⁸⁸ In primary care, patients and health-care providers alike have expressed comfort with the notion of using electronic communication, such as email, as a means to facilitate care processes,²⁸⁹ and evidence suggests that electronic patient–physician communication can lead to improved clinical and patient-reported outcomes.²⁹⁰ Little research has been done on electronic communication tools in cancer care, but there is ample scope for the use of such tools to connect PCPs and cancer specialists to improve continuity of care.²⁹⁰

Conclusion

Enhanced integration between primary and specialist care throughout the cancer care continuum is vital to improve the quality of care. Strategies that can potentially lead to better integration include structuring health-care services and establishing care pathways, education, audit, care navigation, and electronic communication tools. However, few of these strategies have so far been assessed and implemented. Rigorous assessment through pragmatic randomised trials and of how different contextual factors might impede or enhance effectiveness is warranted (panel 9).

Part 8: Health policy on primary care and cancer control

While the incidence of cancer is increasing, partly as a result of a rapidly growing ageing population, the number of cancer survivors is also increasing because of improvements in diagnosis and treatment. However, these gains are not experienced in every health system or social group, with some countries performing much better than others and some population groups having better care and outcomes than others. The reasons for this variation are complex and, for the most part, remain poorly understood.

This mixed picture has substantial implications for primary care in terms of both early diagnosis and after-care. PCPs will treat more cancer survivors in future years because cancer survivors visit their PCPs more often than do controls without cancer.¹⁶⁶ A report from the US Institute of Medicine¹⁹³ concludes that the needs of cancer survivors are not being adequately addressed. These needs centre on psychosocial support; management of the long-term complications of cancer treatment; addressing ongoing symptoms, recurrences, and new cancers; and accessing information about the disease. They are all tasks that PCPs are well placed to perform.

Starfield and colleagues²⁷ have shown that investment in primary health care is the foundation of any high-performing health system. Countries with stronger primary care generally have healthier populations and a more equitable distribution of health in populations.²⁷ Such a development is also supported by other policies aimed at universal health coverage promoted by WHO

and the World Bank. In many countries, a growing emphasis is placed on models of integrated care that bring together primary, secondary, and social care. These moves are partly driven by cost-control imperatives to ease demand and pressure on expensive secondary-care services, despite the lack of evidence for such a conclusion, and partly by the perception that integrated care improve patient outcomes. We structure this section around three key areas affecting the performance of primary care in cancer control: lessons for policy making from international comparisons; the gatekeeping role of primary care in cancer care; and financial incentives to improve the quality of cancer care.

International comparisons

International studies comparing cancer outcomes have focused policy makers' attention on cancer diagnosis, treatment, and survival outcomes. The EURO CARE (European cancer registry) collaboration has produced comparative evidence about the survival of patients with cancer in different European countries since 1995.^{291,292} Despite initial scepticism about data comparability by some authors, EURO CARE has transformed public policy on cancer control in many European countries. In the UK, publication of data from the EURO CARE-2 study in 1999 underpinned the launch of the first National Health Service Cancer Plan in 2000.²⁹³ UK policy responses initially focused on improving the effectiveness of treatment services; however, attention has now shifted to timeliness of presentation and diagnosis.²⁹⁴ A similar policy direction has been pursued in Denmark, where poor cancer survival led to the production of three national cancer plans accompanied by substantial additional funding. Comparisons with the other Nordic countries through the NORDCAN collaboration led to increased political awareness. Although policy initiatives have focused on cancer treatment outside primary care, awareness of the important role of primary care in outcome improvement has been growing in recent years.

Two important findings can be drawn from the present landscape of international comparative studies of cancer outcomes. First, with few notable exceptions, including the two CONCORD studies,^{295,296} most of the research is concentrated in a small number of countries with a fairly high index of human development. Second, again with few notable exceptions, most available evidence relates to a single (albeit important) outcome measure—namely, cancer-specific survival. There is a distinct paucity of comparative evidence about the population and health-care-system determinants of survival, including public understanding of cancer symptoms; timeliness of diagnosis; availability, quality, and uptake of screening programmes; and quality of cancer treatments (which include those of patients with advanced disease).

Knowledge of the reasons for variations in cancer outcomes is difficult to acquire, but evidence of variation in determinants of survival is needed to support cancer

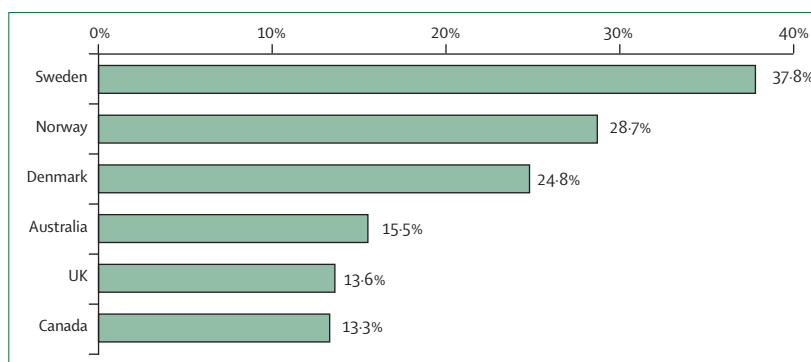


Figure 9: Differences between countries in awareness that cancer risk increases with age²⁹⁸

The graph shows proportion of respondents who said that people aged 70 years are most likely to be diagnosed with cancer (rather than people aged 30 years or 50 years, or people of any age). Reproduced with permission from Forbes and colleagues.⁶²

control policies. Increased attention to the diagnostic pathway and role of primary care has led to the formation of the ICBP project, which involved 12 jurisdictions in six countries (Australia, Canada, Denmark, Norway, Sweden, and the UK).²⁸² ICBP is a comparative multimodular study that aims to deepen epidemiological evidence and complement it with studies of variation in psychosocial or health-care factors. ICBP evidence so far has supported variation in survival between jurisdictions.²⁹⁷ Furthermore, ICBP studies suggest that psychosocial factors, such as awareness of symptoms and attitudes and beliefs about cancer among the public, vary between jurisdictions, but are not associated with survival in a straightforward way (figure 9). Still, such differences might be important because variation has also been reported in how health-care systems are organised around the cancer diagnosis. Nevertheless, evidence about the role of organisational factors—eg, the way primary care is organised and the way new treatments, including pharmaceutical and interventional ones, are introduced in clinical practice after assessment using health technologies—and the role of private medical practice or insurance coverage in survival is inconclusive.⁴⁰

The gatekeeping role of primary care in cancer care

A key feature of strong primary care systems is the gatekeeping role, which acts as the first line of the health-care system.²⁹⁹ Gatekeeping can be combined with a patient list for which the PCP is responsible and, in varying degrees, people are required to access services via contact with primary care in the first instance.

Gatekeeper systems can be in the interest of policy makers for reasons of resource management. Although people should have access to the health care they need, it has to be affordable at the same time. Encouraging patients to seek support from primary care in the first instance conserves hospital resources and is therefore seen as desirable and more cost effective. In some health-care systems (eg, in France and Sweden), reimbursement of specialist consultation costs is contingent on a PCP

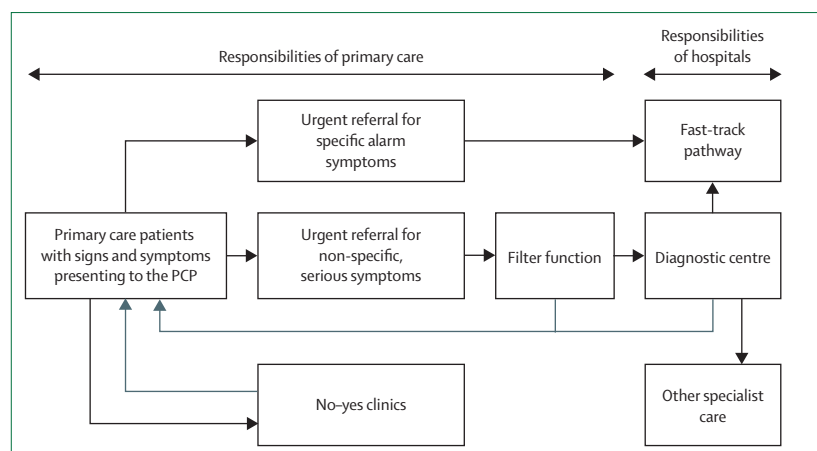


Figure 10: Structure of the Danish three-legged diagnostic strategy

This strategy consists of urgent referral for patients with alarm symptoms, diagnostic centres for those with non-specific but serious symptoms, and so-called no-yes clinics for other patients in whom the PCP needs rapid access to simple investigations in order to rule cancer out (no) or in (yes) while retaining clinical responsibility for the patient. Arrows represent movement of patients. A “yes” from the no-yes clinic directs the patient back to the PCP. PCP=primary care physician. Reproduced with permission from Vedsted and Olesen.³⁰⁵

referral. In many gatekeeper systems, 90–95% of all patient contacts are managed solely in primary care.³⁰⁰ Arguments against gatekeeper systems centre on the patient’s lack of freedom of choice to obtain a second opinion and on the detrimental effect on patient–doctor trust that might arise from the doctor’s prerogative to decide on any referral to secondary care.³⁰¹

A gatekeeper system has an important effect on the role of primary care in preventive work and health promotion, diagnostic work, the treatment of minor illnesses, visits to specialised treatment, rehabilitation, and follow-up. Despite its importance as a mainstay of effective primary care, remarkably little research has been done on the possible effects of gatekeeping on the quality of care.

Primary care has been successful in delivering evidence-based screening tests—eg, cervical cytology and human papilloma virus immunisation. Health-care systems with a gatekeeper function are associated with higher utilisation of recommended cancer screening procedures than those without such a function.³⁰²

Although politicians and the media have had a tendency to blame PCPs for poor and slow diagnosis, causes of delays are much more complex and multifactorial, and inadequate clinical competence is an unlikely cause.¹⁰ Access to diagnostics and specialist assessment for suspected cancer is a key consideration in health-care systems with gatekeeping and has been blamed for diagnostic delay.

Cancer presents in the early phases with a range of symptoms.⁹ Good access to primary care could be a factor in providing improved diagnosis of cancer, although evidence that reform of access to specialist assessment could reduce time to diagnosis is stronger.³⁰³ By contrast with this view, evidence showed an association between low cancer survival and the strength of the gatekeeper

system, although other country-level factors (such as service organisation) might also be involved.⁴⁴ Such an association suggests that, in some health-care systems, the gatekeeper is rationing the use of investigations by setting a high threshold for referral. Further, the pivotal interaction between patients and PCPs can be adversely affected if the PCP is reluctant to refer for specialist assessment, with patients coming to believe that symptoms have to be serious before visiting their PCPs.

Progress in improving cancer outcomes can be made by policies that aim to accelerate and integrate the diagnostic process. Political awareness of this initial step in the diagnosis of cancer has led to the National Awareness and Early Diagnosis Initiative, and the Accelerate, Coordinate, Evaluate Initiative in the UK, and the Danish three-legged strategy for cancer diagnosis (figure 10).^{304–306} In Denmark, the diagnostic interval has shortened significantly, and direct access to investigations has been appropriately used.^{303,307} Progress can also be made by technological innovation in point-of-care testing and detailed clinical audit studies. However, any system making referrals that are contingent on the presence of symptoms with high positive predictive values risks delays in the diagnosis of those with less specific symptoms. PCPs also have a gatekeeper role in follow-up, survivorship, and end-of-life care (discussed in Parts 5 and 6).

Performance measurement, public reporting, and financial incentivisation to improve the quality of cancer care

Routine measurement of cancer burden and related diagnostic activity in primary care can help to underpin public reporting and financial incentivisation of care quality. In England, indicators relating to the burden of cancer and to the diagnostic and screening activity for each general practice have been collated since 2010.³⁰⁸ Summary statistics by practice are made available to primary care teams to motivate reflective learning, and they have been reported publicly since 2013. However, assessments of the effectiveness of these quality improvement initiatives are lacking.

As is the case for any quality improvement policy, indicators need to represent processes of care that are clearly amenable to improvement. In England, public reporting of the frequency of three or more prereferral consultations among patients subsequently diagnosed with cancer has been proposed. However, such events often result from factors other than the quality of clinical reasoning of individual doctors—eg, the need for primary care investigations before referral.³⁰⁹

The UK was the first country to experiment with financial incentives for cancer care with the introduction of incentives to reach cervical cytology targets in the early 1990s. At that time, few general practices had computerised medical records; the introduction of the incentive was associated with the rapid development of recall systems and with an increase in the percentage of

practices meeting the target of 80% of eligible women screened from 61% in 1991 to 88% in 1999. Furthermore, a reduction in inequalities in the delivery of care over that period was reported.³¹⁰

In the USA, incentives to PCPs to promote cancer screening are now common, but not universal. Screening for breast, cervical, and colon cancers is a measure of the Healthcare Effectiveness Data and Information Set (HEDIS) established by the National Committee for Quality Assurance to assess health plans.³¹¹ To achieve high HEDIS scores, plans often provide incentives to PCPs to promote screening, although monetary amounts vary substantially. Cancer screening as a measure of high-quality care is also included in most emerging accountable care organisation payment models. Although the distribution of surplus money is determined by each individual accountable care organisation, provision of financial incentives to PCPs based on achievement of specific quality measures is a common approach. Data regarding the effects of quality incentives are inconsistent, although the size of the incentive is a likely predictor of such effects.³¹² The effect of removing incentives has only been reported in one study from Kaiser Permanente in the USA.³¹³ When incentives were introduced for cervical cancer screening in 1999 and 2000, screening rates increased slightly from 77.4% to 78.0%. They then fell back to 74.3% in 2001–05 when incentives were removed, and increased again in 2006–07 when incentives were reintroduced. In the USA, incentives linked to the quality of treatment for patients diagnosed with cancer are uncommon. Where incentives are used, they are directed to members of the treatment team and usually exclude primary care.

The UK primary care pay-for-performance scheme³¹⁴ contains two incentivised indicators of the quality of cancer care—namely, that “practices should have a register of patients with cancer” and “the percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review recorded as occurring within 6 months of the date of diagnosis”. The effectiveness of these measures, which were designed to strengthen the coordinating role of the GP, is not known.

An alternative approach to incentivisation is to provide patients with financial incentives, mainly to attend screening programmes. A systematic review³¹⁵ reported that financial incentives to patients increased uptake of mammography (33 studies; odds ratio [OR] 2.7), cervical cytology (27 studies; OR 2.8), and faecal occult blood testing (19 studies; OR 1.8).

Conclusion

Although improvements in outcomes for and care of patients with cancer have been seen, more needs to be done to build on past successes. The variations in outcomes and access to services described in Part 1 persist, and these are generally poor for older patients and those from deprived socioeconomic groups. Countries without universal health coverage are more

Panel 10: Key policy areas affecting the performance of primary care in cancer control

Key messages

- International comparisons have shown variation in public awareness, attitudes, and beliefs about cancer; differences also exist between health-care systems, but the role of organisational factors is inconclusive
- Financial incentives to doctors or patients could improve the uptake of screening tests, but no evidence suggests that they would improve other aspects of cancer care
- Little research has been done on the effect of gatekeeping on quality of care, but gatekeeping might lead to rationing of primary care physicians' use of investigations
- Improvements to the gatekeeping role and cancer diagnostic pathway might achieve greater gains than incentivisation

Action points

- Health-care systems need to develop strategies that support primary care as the cornerstone in prevention, early detection, survivorship care, and palliative care
- An important priority for health policy is to focus on integration of primary and secondary cancer care
- More research is needed to identify the effects of gatekeeping on the quality of care

likely to experience worse outcomes and poorer access to services than those with universal health care. Nevertheless, some countries with universal health care, such as the UK, have striking health inequalities: cancer-specific survival rates in England are 10% lower than the European average, and outcomes are especially poor for older patients.

The causes of these deficiencies, as in other health-care systems, seem to be attributable to a complex mix of factors, including patient attitudes and behaviours, and poor access to and possibly poor quality of diagnosis and treatment services. The evidence concerning the importance of incentives is either mixed or lacking, and such incentives might be of little use in tackling these factors. Introducing and sustaining improvements to primary care's gatekeeping role and attending to other aspects of the cancer care pathway might achieve greater gains and might be a better investment of resources than incentivisation. Finally, future research needs to address important gaps in the international evidence base, especially with regard to community and primary care policy initiatives and their effects (panel 10).

Part 9: Equipping primary care for its growing role in cancer care and control

Barton and colleagues³¹⁶ discussed cancer as a growing public health problem and emphasised the crucial role of PCPs in providing patient-centred care for people affected by cancer. PCPs are involved across the cancer care continuum from screening to end-of-life care. A 2009 survey of PCPs in the USA showed that more than 90% provided general medical care for people with cancer, more than half assisted patients with decisions about treatment options and use of surgery, and 19% reported heavy involvement in cancer treatment.³¹⁷

Although the historical engagement of PCPs in cancer care provides some insights, it is insufficient to guide the future. Primary care will have to play a growing part in certain aspects of cancer care in which it has been less involved previously, such as survivorship, palliative, and end-of-life care. In the USA, a 40% growth in demand for cancer services is expected over the next 20 years, with an increasing number of cancer survivors because of an ageing population and improvements in cancer survival.³¹⁸ However, PCPs will face challenges when they assume a wider responsibility for the care of patients in whom cancer is diagnosed or suspected. None of these challenges is greater than the relative inattention to cancer education for PCPs, which begins in medical school, persists in specialty training, and continues in the domain of continuing professional development (CPD). Although the reasons for such inattention are undoubtedly complex, it is hard to ignore that cancer arguably has the most comprehensive, well resourced, and self-sufficient system of patient care, research, and training of all common diseases. The very strength of this system and its willingness to stand somewhat apart might have had the inadvertent effect of weakening the ability and confidence of other parts of the system, including primary care, to care for patients with cancer. In Part 7, we detailed the evidence for the quality of cancer care and patient experience that could be delivered in primary care settings, and evidence that the cancer care system is turning increasingly to primary care to have a larger role. The challenge is therefore to equip primary care for this work and identify the evidence-based educational strategies that will enable PCPs at all points in their training and practice to assume this responsibility.

Oncology training in medical education

Cancer education for PCPs begins formally in medical school. Surveys in several countries regarding curricula have reported problems in undergraduate oncology teaching.³¹⁹ In a Canadian survey, 58% of curriculum leaders and 67% of medical students thought that undergraduate oncology education was inadequate, and both agreed that oncology is the worst-taught of the medical subspecialties.³²⁰ Recommended oncology curricula for medical students have been developed and promoted in the USA, Australia, and the UK. Innovative programmes such as oncology summer schools,³²¹ compulsory cancer medicine rotations,³²² and pairing of students with tutors in multidisciplinary team cancer conferences³²³ have been developed both within and outside these curricula to address perceived deficiencies. A stronger base of cancer education in undergraduate years will be necessary to support the role of all physicians, especially PCPs, in cancer care. However, our focus here is on the status of cancer-related education in registrar or residency training programmes and in the realm of CPD for PCPs in practice. It is instructive to review briefly the status of such education in key national jurisdictions.

In the UK, the postgraduate GP curriculum is overseen by the RCGP. PCPs in training need to provide evidence of learning against a series of “curriculum statements”, which are summaries of what the RCGP considers is needed to practise as an independent practitioner. Cancer is no longer presented as a curriculum statement because the curriculum addresses the principles of the discipline without covering all possible contexts. Oncology is rarely included in GP trainee rotations, but all trainees will have gained exposure to the care of patients with cancer during their GP placements. However, the RCGP has identified cancer as an “enduring priority” and is developing educational resources for trainees and practitioners, such as the Cancer Education Hub.³²⁴ Other organisations, including cancer charities (eg, Cancer Research UK, Macmillan Cancer Support, and Target Ovarian Cancer), have also focused on primary care cancer education to support the CPD required of British GPs as part of their revalidation. This CPD is provided in various formats: lectures, seminars, e-learning, and written material. Although revalidation is mandatory, cancer topics are not required to be included in the practitioner’s portfolio. A recent review of educational interventions for GPs around early cancer diagnosis reported several types of educational interventions: didactic education, educational outreach, audit and feedback, interactive education, reminder systems, and local opinion leaders.³²⁵ It found little evidence for long-term effectiveness of any of these interventions.

In Canada, a 2014 survey of PCP residents and residency programme directors showed that, of ten medical subspecialty areas, both groups rated oncology as the poorest taught in their specialty training and as the area in which residents were the least adequately prepared for their role in patient care.³²⁰ No Canadian training programmes for family medicine had a mandatory oncology rotation, or recommended text or reference resource, and only two had a set of oncology objectives for their learners. Nationally, the College of Family Physicians of Canada (CFPC) has enunciated 99 priority topics as examination objectives for family medicine residents. Cancer is one of these areas, for which seven “key features” have been identified. Several provincial cancer agencies have developed primary care education and liaison programmes for CPD.³²⁶ These programmes offer cancer education for practitioners, with one publishing a comprehensive assessment of PCPs’ learning needs.³²⁷ Nationally, the CFPC has formed a Cancer Care Program Committee, which sponsors cancer-related CPD sessions at its national meeting.

The Royal Australian College of General Practitioners (RACGP) has recognised the importance of oncology in its Curriculum for Australian General Practice. It details training outcomes in oncology across a PCP’s professional life from medical student, prevocational doctor, vocational registrar, to independent practitioner. The curriculum includes the continuum of cancer care

in general practice as one of its 34 chapters. Vocational training for PCPs in Australia is run by local training providers (such as the Victorian Melbourne Alliance) who decide its detailed content, with national oversight by Australian General Practice Training and the Remote Vocational Training Scheme. Thus, although oncology is a subject tested in the RACGP Fellowship examination, substantial variation exists among training providers in terms of time spent addressing learning in oncology. From the perspective of CPD, some state-based cancer councils deliver PCP education programmes that are mainly seminar based. Other more innovative programmes have been introduced. In Western Australia, brief oncology placements for PCPs have been established, focusing on learning about common side-effects of chemotherapy and their management. To better meet the needs of PCPs in rural areas, Cancer Australia, a federal cancer agency, has developed online training called Education Program in Cancer Care.³²⁸

In summary, several jurisdictions have formalised oncology-related learning outcomes for registrar training. These outcomes necessarily have to compete for attention with many other priorities in crowded primary care training programmes and, in some jurisdictions, are seen as being more poorly taught than other topic areas. Cancer authorities and charities are often the taking the lead to offer cancer-related CPD to primary care. In view of this reality, it is pertinent to ask two fundamental questions. First, what are the present trends and best practices in both registrar training and CPD that will need to be capitalised on to equip primary care to have a larger role in cancer care? Second, who should take the lead in ensuring that this education takes place?

Competency-based education typically has an emphasis on the demonstration of outcome abilities and is organised around competencies derived from an analysis of societal and patient needs. It de-emphasises time-based training and promises greater accountability, flexibility, and learner-centredness.³²⁹ Although the main focus of this approach has been on postgraduate training,³³⁰ these training periods are short, and advanced competencies need to be defined by and for physicians in practice to provide guidance for CPD.³³¹ Examples of emerging competencies for practising PCPs include areas outlined in Parts 2–5: the application of Qcancer and other risk assessment tools to estimate risks of possible cancer symptoms, incorporation of genetic risk assessment tools into practice, screening for distress and psychosocial difficulty in patients, and surveillance and management of both long-term and late effects of cancer treatment. These advanced competencies for practitioners should build on those described for undergraduate and postgraduate learning, in the manner of the RACGP curriculum. They need to reflect broadly defined physician roles such as those enunciated in the Canadian CanMEDS Physician Competency Framework,³³² particularly the communicator and collaborator roles that are central to cancer care.

Team-based approaches to health care are driven by the intuitive conclusion that clinical practice is too complicated to be managed by any single practitioner. Cancer care is one of the better examples of an area that requires both technical expertise and multifaceted knowledge of an individual and their family. Teams that can divide functions and expertise but serve a common point of care for the patient are therefore a solution that could better address the needs of patients and practitioners themselves. However, the key is to create a team that shares a common goal and manages the interdependent tasks of caring for an individual over time. Such tasks could include the management of cancer rehabilitation and comorbid conditions, alleviation of symptoms, and the anticipation of end-of-life care. As interest and promotion of team-based care have grown, team-based education, or so-called team training, has emerged correspondingly. In the USA, TeamSTEPPS was created by the Agency for Healthcare Research and Quality to promote increased safety in medical practice.³³³ This workplace-based programme encourages teams to assess themselves and their environment, and provides education regarding the skills fundamental to successful teamwork, including situational awareness, closed-loop communication, mutual support, and team structure. A large body of published work showed the success of such training in achieving improved skills and reduced errors in such varied settings as neonatal units, long-term care facilities, and general hospitals, and with student health-care professionals.^{334–336} The application of team-based education for the care of patients with cancer in primary care is a promising approach that builds on the increasingly interprofessional make-up of primary care services in many countries.

Practice audits and performance feedback in primary care

The movement towards quality improvement in the UK has a particular concern with enhancing patient safety and includes several continuous improvement techniques that have been adapted for issues in cancer care. These methods include clinical audit and significant event analysis, both of which are required of PCPs as part of their revalidation process. The RCGP has been instrumental in leading a national cancer audit³³⁷ and developing significant event analyses triggered by new diagnoses of cancer in general practice (panel 11).¹³⁹ These tools prompt GPs to review their own practice of cancer diagnosis and to identify opportunities for improvement.

Other types of feedback systems use data about primary care practices derived from electronic health records or patient surveys. Such feedback systems allow PCPs to compare their practice with that of peers or to an outside standard. A strength of these feedback systems is their reliance on frequent, personalised feedback that, in adult education terms, is associated

Panel 11: Significant event analysis

These analyses are an opportunity for the primary care team to discuss each stage of an event, such as a cancer diagnosis, in detail, pinpoint any learning needs, identify actions to be taken and changes to be made, and agree on how these will be progressed.

This team-based quality improvement technique asks the following questions:

- What happened and why?
- How could things have been different?
- What can we learn from what happened?
- What needs to change?
- What was the effect on those involved (patient, carer, family, primary care physician, and the practice)?

Panel 12: Cancer education for primary care

- Cancer receives little attention in undergraduate and registrar training, and is seen as poorly taught
- Undergraduate and primary care physician (PCP) specialty training curricula need to be reviewed to ensure that they adequately prepare PCPs for their future role in cancer care and control
- Competencies need to be defined and taught at all stages of training and practice to equip PCPs for an extended role in cancer control
- Team-based approaches to training align well with the multiprofessional make-up of primary care services
- Continuous quality improvement methods, such as audit, significant event analysis and performance feedback, are associated with optimum learning and should become a core function of primary care teams
- Educational interventions for PCPs should be embedded into new models of shared care
- Primary care itself—in university departments, professional associations, and vocational training systems—should take the responsibility to define the cancer education needed for trainees and practitioners

with best possible learning. In many jurisdictions, these kinds of CPD activities also garner a higher level of credit than traditional group learning activities. These feedback and audit techniques form part of a larger movement towards so-called practice-based continuing medical education, which features learning at the point of care, woven into the rhythms of the workplace rather than in a distant lecture theatre. This broader category also includes clinical decision support systems, which have been shown to have a powerful effect on physician performance (discussed in Parts 3 and 4).

Education embedded in new models of shared care

New models of shared care in primary care and oncology services are being developed to meet the growing demand for cancer services and the relatively slow growth in number of oncologists to keep pace with such demand.³³⁸ Such models involve renewed attention to information transfer that can also function as high-quality continuing education for PCPs. Reminder systems provide patient-specific communication from an expert source to an

individual physician or a team at the point and time of care, and recommend the need for a specific test, exam, or procedure. The provision of tailored chemotherapy information to PCPs after the initial oncology consultation has been shown in a randomised trial²⁶⁸ to improve the confidence of PCPs in managing adverse effects and their satisfaction with shared care, but not improvement in PCP knowledge. Similarly, a 2009 survey in the USA showed that PCPs who always or almost always received a “survivorship care plan” from the oncology team reported greatest confidence in patient management and care coordination across a range of responsibilities.³³⁹ As new shared-care models develop at different points in the cancer care continuum, opportunities should be taken to develop patient-specific educational interventions for PCPs that can be certified as CPD activities and that function in primary care electronic health records.

Taking the lead in cancer education for primary care

Primary care trainees and practitioners should be equipped to have a growing role in cancer care and control, and developments in the practice and educational environments should be harnessed to support this goal. But who should take the lead in providing these kind of cancer education? In many jurisdictions, the impetus for this work has come from cancer charities and authorities, with the enthusiastic support of PCPs invited into their work. With the large number of competing health priorities that individual PCPs and their associations need to respond to on a weekly basis, it is not surprising that the push to address this educational gap has come from bodies for whom cancer is a primary concern. The danger is that their perspective does not reflect the context, realities, and concerns of primary care.

Cancer has become the leading public health challenge in developed countries. In Canada, for example, cancer is the leading cause of death and also of premature death, and has the greatest burden of disease and years of life lost.³⁴⁰ To address this enormous challenge, primary care itself needs to take the lead in university departments of general practice or family medicine, professional associations, and vocational training systems. For example, the RCGP has benefited from a social consensus on the importance of improving cancer outcomes and from the influence and enthusiasm of key academic PCPs on making cancer care an organisational priority. Rather than sitting back, primary care needs to take the lead in equipping itself in both registrar training and CPD programmes for its central role in improving cancer outcomes and the quality of care (panel 12).

Part 10: Conclusions and recommendations

Primary care is continuous, coordinated, and comprehensive care for individuals and families, from the first contact for health care through to the end of life. It is an integral part of the care of all disease and at different stages of an illness. Crucially, the PCP works at

the key interface between the patient and specialist care, facilitating timely and appropriate access and sometimes protecting the patient from unnecessary or inappropriate interventions. At the same time, the PCP is the health professional whose role is to provide whole-person, rather than disease-centred, care and to place his or her contribution to the care of a person's illness in the context of their other physical, emotional, and social needs. Highly technical interventions for diagnosis and treatment of cancer have long been the focus of innovation in care. But patients also want care that is coordinated, with a clear and seamless journey between care settings.³⁴¹ They want care that is close to home where possible and that is accessible when they need it, regardless of the stage of their cancer journey. They want continuity of care in the informational, organisational, and relational senses of the term.³⁴²

This Commission has identified aspects of care at all stages of the cancer pathway where good evidence is available for the positive benefits of input from primary care. The possibilities and benefits are potentially wide ranging (table 2). In the USA, long-term cancer survivors who see both oncologists and primary care providers are most likely to get the full array of care they need: prevention, care of comorbid illnesses, and appropriate surveillance for treatment effects and recurrence.³⁴³ This fact alone should motivate models of shared care, but the demand for oncology services is anticipated to grow by 40% in the next 20 years, whereas the number of oncologists is expected to grow by only 25%.^{318,338} It is too simplistic to assume that substitution is the solution, when demand for primary health care is also rising, but the models of shared care for follow-up, survivorship care, and particularly end-of-life care offer better ways to meet this need (table 2). Indeed, the dominant theme of this Commission is integration of care. Such models have existed in mental health for a generation.³⁴⁴ They are widely applied in management of chronic disease in Europe, but have not been implemented in cancer. In Part 7, we described the principles of integrated care, how it can be implemented, and why it is vital for improving quality of care and outcomes for cancer.

Fundamental to shared care is addressing transitions in care. These transitions occur when information and responsibility need to be transferred between groups or settings, when an abnormality is seen in cancer screening (eg, mammography), when someone is discharged from the hospital, and when a symptom we see in primary care needs to be assessed in oncology.^{338,345} Such transitions takes place across the cancer continuum, and they are recognised as weak points where failures and errors can occur.²⁵² Despite their widespread recognition, there is little evidence regarding how to measure such failures or their effects. For example, failures in follow-up to abnormal screening tests for breast, colon, and cervical cancers are widespread in the USA.³⁴⁶ Metrics of failures at critical

Possible solutions from primary care	
Incidence of cancer is rising, and the number of patients surviving cancer has increased substantially	Integrate primary care with specialist care, particularly for follow-up, underpinned by guidelines for best practice
Primary prevention is not well implemented despite having substantial potential to reduce incidence	Develop effective models to incorporate primary prevention into routine practice
Patient-related delays are an important component of overall time to diagnosis	Configure access to primary care to minimise barriers to consultation
Variations and inequalities exist in uptake of cancer screening	Share and implement best practice, especially in the contribution of the PCP in promotion of population-based screening programmes
Symptoms that could be cancer are common in primary care, but cancer is rare; those symptoms with low positive predictive values for cancer present a particular challenge	Develop and systematically apply electronic clinical decision support to select patients for urgent assessment, together with tools to overcome cognitive error; develop a range of models for access to diagnostics to accommodate different levels of risk
Follow-up care requires expertise not only in cancer, but also in its wider physical and psychological sequelae	Develop integrated models of follow-up care with embedded CPD for PCPs; PCPs to work in wider networks or federations to enable sharing of expertise
People will continue to die as a result of cancer and wish to die in comfort and at home	Integrate primary care with palliative care, underpinned by CPD and the breakdown of logistical barriers in primary care
PCP=primary care physician. CPD=continuing professional development.	
Table 2: Cancer care challenges and possible solutions from primary care	

transitions in cancer care are needed to address the challenges they represent.

One of the key roles of PCPs is in the initial assessment of patients who might have cancer. Around 90% of patients present first with symptoms in primary care. The likelihood of cancer, even with the presence of alarm symptoms, is small in adults and smaller still in children, teenagers, and young adults. In Parts 3 and 4, we identified the approaches being used to support clinicians in achieving earlier and more accurate diagnosis. There has been much innovation, but more remains to be done, particularly for cancers with a weak symptom signature, where a step change in diagnostic technology might offer the greatest prospect of significant improvement. At present, the development of increasingly sophisticated clinical decision support tools, together with referral pathways that offer flexibility in assessment options, has the best prospects of quality improvement. However, for some cancers, new diagnostic biomarkers or screening modalities remain to be discovered and developed.

Finally, there are two key considerations if care integration for cancer is to become a reality. First, health policy needs to actively involve community-based provision of services and ensure that high-quality primary care is available, affordable, trusted, and valued by the public. This could include ensuring good access to primary care, the organisation of gatekeeping systems to enable rather than restrict access to secondary care, and different approaches to incentivisation. Second, the curricula relevant to cancer care in undergraduate, postgraduate,

	Timescale	Stakeholders
Define and share widely the educational competencies for cancer care required for PCPs and primary care trainees	1–3 years	National PCP colleges; patient groups; health-care commissioners and providers; cancer charities and authorities; residency and registrar training programmes
Adapt evidence-based models and tools to improve integration between primary and specialist care for each phase of cancer control	1–5 years	Health-care commissioners and providers; policy makers
Cross-sector education programmes to support integrated care should be developed; they should extend beyond clinical content to include care pathways, systems, and quality improvement	1–5 years	Health education providers; PCPs and specialist clinicians; professional bodies
Patient navigators show promise as a means to enhance integrated care, and their role should be further assessed	1–2 years	Health-service researchers and providers; research funders
Primary care needs to engage more effectively in initiatives to promote physical activity and reduce obesity	1–8 years	Health-care commissioners and funders; public health agencies; researchers; health education providers
Primary care should prepare itself for the growth in genomic information and how such information can be incorporated with lifestyle and other factors to develop individualised preventive strategies	2–8 years	Researchers in primary and specialist care, epidemiology, and informatics; public health agencies
Alternative models of access for children, teenagers, and young adults to diagnostics and assessment should be piloted	1–3 years	Health-care providers, funders, and commissioners
Rapid and robust referral mechanisms from primary care to specialist facilities should be developed, particularly for teenagers and young adults	1–3 years	Health-care providers, funders, and commissioners; PCPs
If research confirms the usefulness of electronic clinical decision support, such tools should be rapidly incorporated into the clinical software used by PCPs	1–5 years	Researchers; companies providing clinical software
Biomarkers for early diagnosis, effective in primary care populations for symptomatic patients and for those with a high baseline risk, are a research priority	2–10 years	Research groups of primary care and of basic and applied science
New models of cancer follow-up care should be developed, drawing on the principles that apply for other long-term illnesses	1–5 years	PCPs and specialist clinicians; professional bodies; health-service providers, commissioners and funders; patients
Survivorship care plans should be further developed to arrive at the optimum model and be fully implemented as a feature of follow-up care	1–3 years	Health-service researchers; health-care providers
Palliative-care services should be integrated between primary and secondary care on the basis of the WHO Public Health Strategy for palliative care	1–5 years	Providers of primary and palliative care; health-care funders and commissioners
PCPs should participate in provision of palliative care; they should be supported, provided with high-quality training, and adequately resourced to do so	1–5 years	PCPs; health-care funders; providers of health education and training
All patients who may need to receive palliative care should have an advance care plan, which should include a plan for their clinical care	1–2 years	Palliative-care specialists; PCPs; patients
A focus on integration of primary and secondary cancer care is an important priority for health policy	1–8 years	Health departments; health-care providers, funders, and commissioners; professional bodies
Gatekeeper systems have an important effect on the role of primary care in many aspects of cancer control; more research is needed to study their effect on quality of care	1–5 years	Health-service researchers; research funders
Audit and performance feedback should become a core function of primary care teams providing cancer care	1–3 years	Professional bodies; health-care funders; PCPs
PCP=primary care physician.		
Table 3: Summary of action points		

and CPD programmes are variable in depth and breadth. A consistent approach between countries could help to reduce inequalities in outcomes. In some countries, the performance of PCPs over their existing roles, especially in cancer diagnosis, is called into question and forms the basis of objections to an extended role. The evidence now largely refutes this: the suboptimal performance of a small minority is a feature of all medical specialties and is no grounds for restricting the scope of their practice. Performance review through clinical audit and feedback is well accepted as a tool for quality improvement in primary care but has been little used in cancer care.

Much remains to be understood. Evidence is needed for the clinical effectiveness and cost-effectiveness of risk

thresholds of urgent investigation, and for the effectiveness of risk assessment tools in supporting that selection process. Specifically, we need to understand the means by which the research so far can be translated into standard practice and their clinical and cost-effectiveness in pragmatic settings. Initiatives to support multidisciplinary research capacity will be essential to delivery of that research. For example, the Primary Care Collaborative Cancer Clinical Trials Group (PC4) in Australia supports research capacity building and the development of trials of interventions across the cancer continuum in primary care.

On the basis of the evidence and expert opinion contained in this Commission, we propose a set of actions

that should be considered and implemented by all stakeholders involved in cancer control (table 3). We believe that work should start now in order to ensure that in future patients get the optimum care to prevent, receive a diagnosis of, and survive cancer, and the best possible care should they die from the disease. Many of our recommendations relate to greater integration of care, and we call upon clinicians in both primary and specialist care to join together and take a lead in realising the benefits that this can bring to patient care.

Contributors

Part 1: lead author was GR; coauthors were FW, SH, SMC, and ST. Part 2: lead author was DW; coauthors were JWa, BS, and MP. Part 3: lead author was SG; coauthors were JWhe, WH, RD, and JWhi. Part 4: lead author was JE; coauthors were RDN, NdW, and TF. Part 5: lead author was EW; coauthors were AB, LG, and CE. Part 6: lead author was GM; coauthor was CZ. Part 7: lead author was EG; coauthors were RM, JSu, PV, CW, and TV. Part 8: lead author was DH; coauthors were MR, GL, RW, and PV. Part 9: lead author was JSi; coauthors were ST, UM, and JE. Part 10 was written by GR. GR edited the entire Commission; all authors reviewed the entire Commission.

Declaration of interests

GR reports personal fees from Medx and Eli Lilly outside the submitted work. SMC reports travel sponsored by Boehringer Ingelheim and Celgene. GL reports an honorarium from PACE (sponsored by Eli Lilly). MP reports payments for lectures and being a member of an advisory board from Eli Lilly. ST is a US Government employee; all opinions are strictly his own and nothing he says should be construed to represent the position of the US Government or the National Cancer Institute. All other authors declare no competing interests.

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