

# **The expanding role of primary care in cancer control.**

Professor Greg Rubin, FRCGP (corresponding author)

School of Medicine, Pharmacy and Health, Durham University, Queen's Campus, University Boulevard, Stockton on Tees, UK, TS17 6BH. [g.p.rubin@durham.ac.uk](mailto:g.p.rubin@durham.ac.uk)

Annette Berendsen, PhD

Department of General Practice, University of Groningen, Netherlands.  
[a.j.berendsen@umcg.nl](mailto:a.j.berendsen@umcg.nl)

S Michael Crawford, MD

Airedale NHS Foundation Trust, Keighley, UK. [Michael.Crawford@anhst.nhs.uk](mailto:Michael.Crawford@anhst.nhs.uk)

Rachel Dommett, PhD

School of Clinical Sciences, University of Bristol, UK. [r.dommett@bristol.ac.uk](mailto:r.dommett@bristol.ac.uk)

Professor Craig Earle, MD

Ontario Institute for Cancer Research, Toronto, Canada. [craig.earle@ices.on.ca](mailto:craig.earle@ices.on.ca)

Professor Jon Emery, D Phil

Department of General Practice, University of Melbourne, Australia  
[jon.emery@unimelb.edu.au](mailto:jon.emery@unimelb.edu.au)

Professor Tom Fahey, MD

Royal College of Surgeons in Ireland, Dublin, Ireland [tomfahey@rcsi.ie](mailto:tomfahey@rcsi.ie)

Professor Luigi Grassi, MD

Department of Biomedical and Specialty Surgical Sciences, University of Ferrara, Ferrara, Italy. [luigi.grassi@unife.it](mailto:luigi.grassi@unife.it)

Professor Eva Grunfeld, PhD

Ontario Institute for Cancer Research, University of Toronto, Toronto, Canada  
[eva.grunfeld@utoronto.ca](mailto:eva.grunfeld@utoronto.ca)

Sumit Gupta, MD

Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto  
[sumit.gupta@sickkids.ca](mailto:sumit.gupta@sickkids.ca)

Professor Willie Hamilton, MD

Medical School, University of Exeter, Exeter, UK [w.hamilton@exeter.ac.uk](mailto:w.hamilton@exeter.ac.uk)

Sara Hiom, PhD

Cancer Research UK, London, UK. [sara.hiom@cancer.org.uk](mailto:sara.hiom@cancer.org.uk)

Professor David Hunter,

School of Medicine, Pharmacy and Health, Durham University, Stockton on Tees, UK.  
[d.j.hunter@durham.ac.uk](mailto:d.j.hunter@durham.ac.uk)

Georgios Lyratzopoulos, MD  
Department of Epidemiology and Public Health, University College London, London, UK  
[gl290@medschl.cam.ac.uk](mailto:gl290@medschl.cam.ac.uk)

Professor Una Macleod, PhD  
Hull-York Medical School, University of Hull, Hull, UK [Una.Macleod@hyms.ac.uk](mailto:Una.Macleod@hyms.ac.uk)

Professor Robert Mason, MD  
Faculty of Life Sciences and Medicine, Kings College London, London UK  
[robert.mason@gstt.nhs.uk](mailto:robert.mason@gstt.nhs.uk)

Professor Geoffrey Mitchell, FRACGP  
Faculty of Medicine and Biomedical Sciences, University of Queensland, Brisbane, Australia  
[g.mitchell@uq.edu.au](mailto:g.mitchell@uq.edu.au)

Professor Richard D Neal, PhD  
North Wales Centre for Primary Care Research, Bangor university, Bangor, Wales  
[r.neal@bangor.ac.uk](mailto:r.neal@bangor.ac.uk)

Michael Peake, FRCP  
Glenfield Hospital, Leicester, UK. [mick.peake@uhl-tr.nhs.uk](mailto:mick.peake@uhl-tr.nhs.uk)

Professor Martin Roland, DM  
Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK  
[mr108@cam.ac.uk](mailto:mr108@cam.ac.uk)

Bohumil Seifert, PhD  
Department of General Practice, Charles University, Prague, Czech Republic  
[bohumil.seifert@lf1.cuni.cz](mailto:bohumil.seifert@lf1.cuni.cz)

Professor Jeff Sisler, MD  
Department of Family Medicine, University of Manitoba, Winnipeg, Canada.  
[Jeff.sisler@umanitoba.ca](mailto:Jeff.sisler@umanitoba.ca)

Jonathan Sussman, MD  
Juravinski Cancer Centre, Hamilton, Ontario, Canada [jonathan.sussman@jcc.hhsc.ca](mailto:jonathan.sussman@jcc.hhsc.ca)

Stephen Taplin, MD  
Division of Cancer Control and population Sciences, National Cancer Institute, Bethesda, USA  
[taplins@mail.nih.gov](mailto:taplins@mail.nih.gov)

Professor Peter Vedsted, PhD

Department of Public Health, Aarhus University, Denmark [p.vedsted@alm.au.dk](mailto:p.vedsted@alm.au.dk)

Teja Voruganti,  
Faculty of Medicine, University of Toronto, Toronto, Canada  
[teja.voruganti@mail.utoronto.ca](mailto:teja.voruganti@mail.utoronto.ca)

Fiona Walter, MD  
Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK.  
[fmw22@medschl.cam.ac.uk](mailto:fmw22@medschl.cam.ac.uk)

Professor Jane Wardle, PhD  
Department of Epidemiology and Public Health, University College London, London UK.  
[j.wardle@ucl.ac.uk](mailto:j.wardle@ucl.ac.uk)

Professor Eila Watson, PhD  
Department of Clinical Health Care, Oxford Brookes University, Oxford, UK  
[ewatson@brookes.ac.uk](mailto:ewatson@brookes.ac.uk)

Professor David Weller, PhD  
Centre for Population Health Sciences, University of Edinburgh, Scotland  
[david.weller@ed.ac.uk](mailto:david.weller@ed.ac.uk)

Richard Wender, MD  
American Cancer Society, Atlanta, USA

Professor Jeremy Whelan, PhD  
Research Department of Oncology, University College London, London, UK  
[j.whelan@ucl.ac.uk](mailto:j.whelan@ucl.ac.uk)

Professor James Whitlock, MD  
Department of Paediatrics, University of Toronto, Toronto, Canada. [jim.whitlock@sickkids.ca](mailto:jim.whitlock@sickkids.ca)

Professor Clare Wilkinson, MD  
North Wales Centre for Primary Care Research, Bangor University, Bangor, Wales  
[c.wilkinson@bangor.ac.uk](mailto:c.wilkinson@bangor.ac.uk)

Professor Niek de Wit, PhD  
Department of General Practice, UMC Utrecht, Netherlands [N.J.deWit@umcutrecht.nl](mailto:N.J.deWit@umcutrecht.nl)

Camilla Zimmermann PhD  
Division of Medical Oncology and Haematology, Department of Medicine, University of Toronto, Toronto, Canada; [camilla.zimmermann@uhn.ca](mailto:camilla.zimmermann@uhn.ca)

## **Abstract**

The nature of cancer control is changing, with an increasing emphasis, fuelled by public and political demand, on prevention and early diagnosis, and on the 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, stabilising healthcare costs and patient preference for care close to home. It is timely, then, to consider how this can work for cancer control, which has long been dominated by highly technical interventions centred on treatment, and where 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 from cancer specialists, has contributed to a detailed consideration of the evidence for cancer control provided in primary and community care settings. Ranging from primary prevention to end of life care, the scope for new models of care is explored. The strengths of primary care, its continuous, co-ordinated 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, as well as 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 as well as continuing and shared multi-professional 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. That paradigm is changing as health policies drive greater 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. Nor is this 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 more prominent health care issue for their populations.

For a long time the role of primary care in cancer was largely perceived as peripheral, but as prevention, diagnosis, survivorship and end of life care assume greater significance, so the defining characteristics of primary care become more important. Care that is more patient-centred brings with it 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, which may require the re-engineering of some deeply held socio-medical cultural practices.<sup>1</sup>

### The cancer journey

*Better cancer services every step of the way*

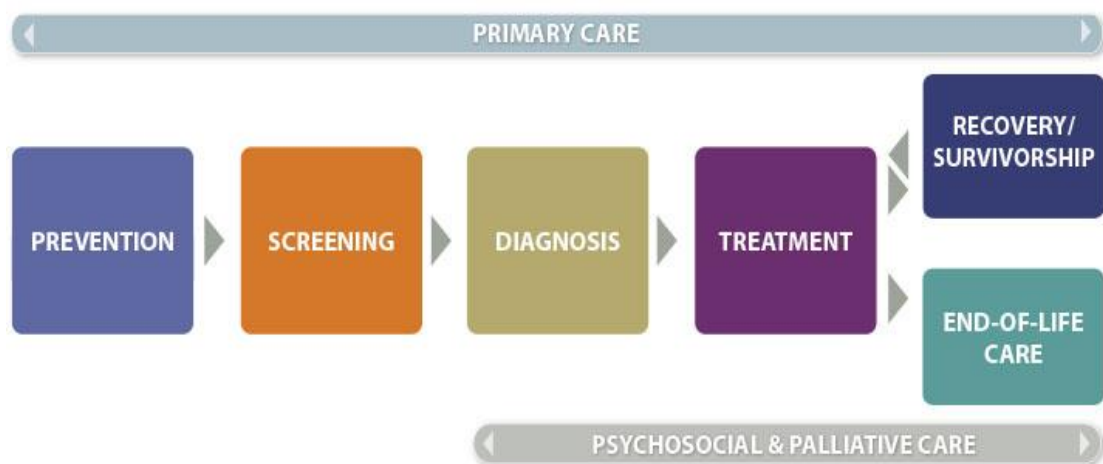


Figure 1.1 The Cancer Journey (courtesy of Cancer Care Ontario)

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 (Fig 1.1), and to consider how cancer care might be delivered differently in the future. It

considers how and whether health policy for cancer control will help or hinder such change. Lastly it considers the implications for the future education and training of doctors and identifies emerging examples of good practice world-wide. 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 review to high income countries, and largely to countries with universal health care systems, since these have a more clearly defined and discrete primary care element to their services.

**The current and future cancer burden from the primary care perspective**

The lifetime risk of cancer in the UK is now 50%.<sup>2</sup> The incidence of many cancers is increasing, as a result of lifestyle and environmental factors as well as an increasingly aged population, especially as the ‘baby boom’ generation reaches its 7<sup>th</sup> and 8<sup>th</sup> decades (Figs 1.2, 1.3).

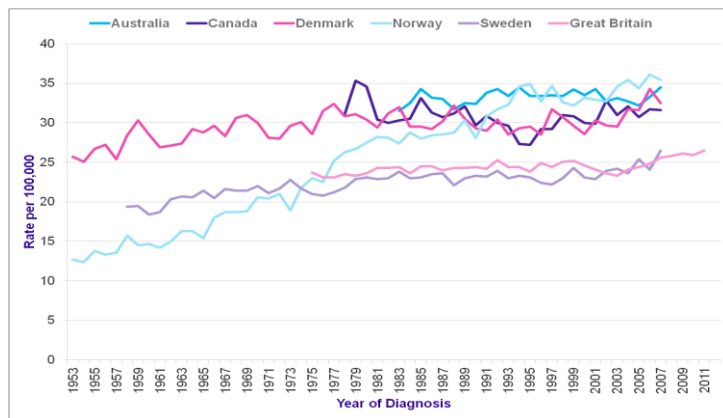


Figure 1.2 Colorectal cancer - world Age-Standardised Incidence Rates per 100,000 Population, Females, By Country (Cancer Research UK)

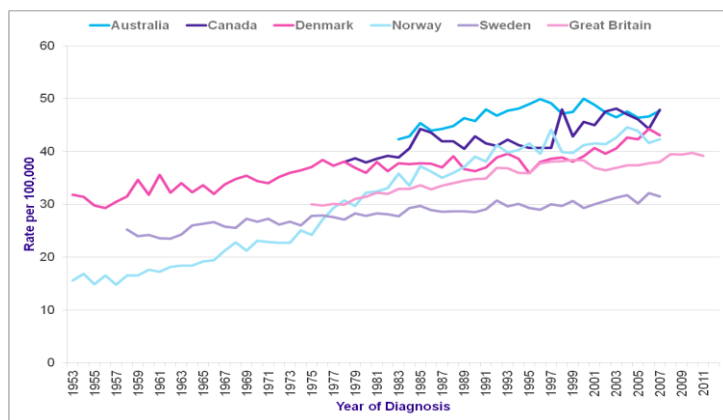


Figure 1.3 Colorectal cancer - World Age-Standardised Incidence Rates per 100,000 Population, Males, By Country (Cancer Research UK)

Prevalence is rising too, as 10-year cancer-specific survival has increased from one in four in the 70s, to one in two today. The Dutch Cancer Society has predicted a 61% increase in cancer survivors between 2010 and 2020.<sup>3</sup>

A cancer diagnosis is a relatively common event in primary care: a PCP with 2000 patients currently sees 6-8 new cases per year in total, comparable to the number of new cases of diabetes mellitus for example, and twice as frequent as new cases of stroke. The difference, of course, is that cancer is a heterogenous entity and any single cancer type a relatively rare event, each characterised by different presenting signs and symptoms. The same PCP can expect only one case of each of the common cancers (colorectal, prostate, breast, lung) in any year and may only see one or two of some rarer cancers during their entire professional career. As survival improves, so prevalence of cancer in the practice population increases. At present the PCP with 2000 patients will have around 70 patients with or surviving cancer, and this is predicted to double by 2040.<sup>4</sup> In comparison he or she will currently look after 120 patients with diabetes mellitus.

The diagnostic process for cancer has now been well described and broken down into its component elements (Fig 1.4) together with much needed clarity about how those elements are best defined.<sup>5</sup> 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,<sup>6</sup> informs our detailed consideration of the diagnostic process contained in parts 3 and 4, as well as the patient help-seeking dimension addressed in part 2.

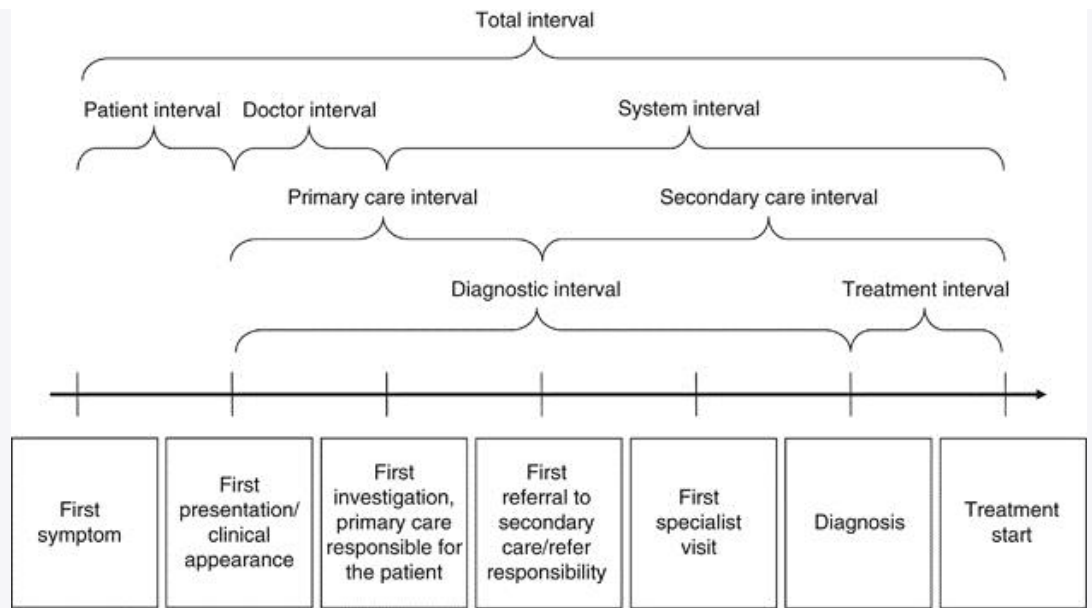


Figure 1.4 An illustration of the overall milestones and time intervals in the route from first symptom until start of treatment <sup>7</sup>

A minority of cancers are detected through screening programmes, which in most high-income countries operate for colorectal, breast and cervical cancer. In the UK and Australia 3 in 10 breast cancers are diagnosed this way; only 1 in 20 colorectal cancers are detected through screening.<sup>8</sup> In the second part of this Commission we consider in more detail the role played by primary care in screening programmes.

Around 85% of cancers are diagnosed following symptomatic presentation to a PCP <sup>9</sup>Over 90% of patients with a cancer that typically has characteristic symptoms or signs (e.g. breast, melanoma) are referred to a specialist after one or two PCP consultations. For those with a cancer that lacks a distinctive symptom signature (e.g. lung, myeloma, pancreas) a third or more will have three or more PCP consultations before being referred.<sup>10</sup> One consequence is that for such cancers, presentation to specialist care is more likely to be as an emergency, rather than a planned referral,<sup>8</sup> with associated poorer clinical outcome and patient experience.

The diverse nature of cancer symptoms is the key challenge for PCPs in making a cancer diagnosis, namely the accurate and timely assessment of symptoms and signs that are much more frequently caused by less serious illnesses. In several countries, urgent referral pathways have been developed to facilitate assessment of the symptomatic patient. Because up to half of patients with some cancers do not have alarm symptoms,<sup>11</sup> there is increasing interest in pathways for the assessment of those with non-specific or non-alarm



symptoms. These assessment pathways are considered in more detail in part 8. Whilst achieving a prompt diagnosis of cancer is a priority, the diagnostic pathway shown in Figure 1.4 conceals many complexities, For example, short diagnostic intervals are associated with more advanced disease and poorer survival – the waiting time paradox described in detail in part 3.

A significant minority of all cancers (24% in England)<sup>8</sup> are diagnosed following attendance at emergency departments (ED) of acute hospitals or emergency admission to hospital. The extent to which these patients have interacted with primary care is not well understood, though they are more likely to come from a deprived background and more frequently use the ED as a source of primary health care.<sup>12, 13 14</sup>

Lastly, an unknown proportion of cancers is diagnosed incidentally, either because the symptoms were not caused by the cancer, or during the course of investigation for an unrelated problem. These cancers may be important, however, as they may be earlier stage and more amenable to treatment.<sup>15</sup> On the other hand, the cancer may not become a health problem in the patient's lifetime. We consider more fully the PCP's role in judicious use of diagnostic tests 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 significance of overdiagnosis in symptomatic patients remains poorly understood.

Over the next ten years, the primary care workload associated with cancer will increase across the entire cancer pathway. Health care systems are increasingly introducing guidance on urgent referral for investigation for suspected cancer. The recently revised English National Institute for Health and Care Excellence (NICE) guidelines<sup>16</sup>, have set an explicit threshold of risk in adults of 3%, which may 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 a threefold increase in test requests from primary care, though only half of all patients with ovarian cancer were referred by the urgent pathway for suspected cancer.<sup>17</sup> Diagnostic testing may also be inconclusive, giving rise to the need for repeat tests after intervals that remain to be defined and evaluated.

The resolution of these dilemmas will require much closer working between PCPs and specialists for cancer diagnosis, as envisaged by the RCGP for the UK.<sup>18</sup> This will also have an impact on the way in which workload is managed within the practice. In Part 7 of this Commission we review in detail the ways in which integration between primary and specialist care can work for cancer control.

For patients undergoing treatment whether primary or for relapse, the impact on workload in primary care is unlikely to change significantly. Patients with acute complications of cancer treatment such as the consequences of myelosuppression, neutropenic sepsis, nausea and vomiting and diarrhoea will continue to be managed by acute oncology services.<sup>19</sup> Some patients may, in spite of advice to use the emergency arrangements for 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 require the necessary skills and organisational capacity to assess the patient accurately and arrange prompt access to treatment.<sup>20</sup>

The future configuration of long-term follow up after cancer treatment, and the role of primary care in this, remains unclear, though 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 GPs. Taking the example of breast cancer, the consensus is that routine follow-up aimed at detecting 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 simply invites a discussion between the patient and her doctors to decide what to do in the event of recurrence, but emphasises the value of psychological support, which can be achieved by continued contact with the breast cancer team.<sup>21</sup> For example, The European Society of Medical Oncology guidelines on follow-up of patients after initial treatment of primary breast cancer acknowledge a lack of clinical trials evidence to support any particular follow-up policy but suggest a schedule which includes annual follow-up beyond the fifth year.<sup>22</sup>

The research evidence on which shared care or transfer of care for follow-up is based is no longer recent. In the meantime the treatment options for metastatic breast cancer have widened 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 newer treatments.

A further development where the role of the PCP may increase in importance is as navigator for access to specialist services. The gatekeeping function and the role of navigator in integrated care are considered in parts 7 and 8 of this Commission.

Two other factors are likely to increase the cancer workload in primary care. One is the recognition that elderly patients are less likely to receive timely diagnosis and treatment for cancers even when a lack of comorbidity would otherwise permit it.<sup>23</sup> The second is the impact of continued efforts to redress socio-economic inequalities in access to cancer care. Socio-economic inequalities impair timely access to lung cancer treatment but do not affect the nature of the treatment.<sup>24</sup>

### **What is primary health care and how is it evolving?**

Most countries in the developed world have health care systems with an identifiable component that is primary care. Primary care is defined by the 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'*.<sup>25</sup> Primary care is commonly, though to a varying extent, provided by clinicians who are generalists, as distinct from those with specialist expertise restricted to a specific area of clinical practice (e.g. cardiology, palliative care).

While the organisation and functions of primary health care differ from one country to another due to historical developments and different economic, social and cultural circumstances the general practitioner (GP) or primary care physician (PCP) has been, and often still is, an essential element and often most significant single player in its delivery. However, primary care is now largely delivered through multidisciplinary teams (centred around general or family practices) that comprise up to 30 individual professionals, each making complementary contributions to patient care. PCPs, nurses, pharmacists, physical therapists and many others may contribute to the care of any individual. Whether they operate as a team or team of teams is an important question that is not fully understood.<sup>26</sup>

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 United States, United Kingdom and Europe have shown that having more PCPs per capita is associated not only with better health outcomes, but also with less expensive services and better patient experience.<sup>27</sup>

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 demonstrated by the creation of a professional body and mandatory post-graduate 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 over the last decade. While societal changes impacting on primary care practice may have subtle variations between countries, they fall into four main groups: demographic pressure, new technology, patient expectations and expertise, and financial pressure.<sup>28</sup>

Internationally, ageing populations have led to increasing demand for complex medical care for more people living with multiple long-term conditions. Low- and middle-income countries face the added burden of burgeoning incidence rates of non-communicable diseases.<sup>29</sup> With the widespread use of mobile phones and the internet, technological advances offer new platforms for people to access health information and communicate with primary care, as well as for monitoring symptoms and treatments, and to support and motivate health-behaviour change. Despite this, primary care systems have often been slow to adopt technological changes and redesign services.<sup>30</sup> At the same time, patient expectations about access to care continuously rise, and there is growing evidence of the 'expert patient' who expects a partnership model of decision-making, and more responsibility for managing their own health and healthcare.<sup>29</sup> Finally, while the needs of patients and populations continue to grow in complexity and volume, publically-funded health care systems are under increasing financial pressure with constrained spending due to the global economic recession.

In response, primary care practice has evolved to be at the core of a multi-professional primary care team in many countries. Nurses and allied health professionals now undertake many routine and non-clinical tasks and a broader range of activities, allowing PCPs to increasingly focus on complex cases. In the United Kingdom, the Royal College of General Practitioners (RCGP) has pledged by 2022 to develop the GP (PCP) role as an 'expert

generalist' 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.<sup>18</sup> New Zealand, the Netherlands, Canada and the United States already have examples of multi-practice organisations delivering quality primary care on a greatly increased scale.<sup>31</sup>

Panel 1

- Primary care is now characterised by multi-professional teams led by expert generalists providing increasingly complex medical care to people who often have multiple long-term conditions
- Primary care practices increasingly collaborate in networks and federations to provide more cost-effective care at scale
- Two aspects of cancer care where primary care involvement is growing rapidly are in early identification of patients with possible cancer and in providing long-term care to cancer survivors.
- Primary care should play an important role in reducing current socio-economic inequalities in access, particularly to specialist health care.

### **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'. This law, formulated in relation to socio-economic deprivation, appears to operate through an interaction of patient, physician and service factors. Primary care patients who are socio-economically deprived have more long term health problems, psychological problems and multi-morbidity than those from least deprived areas, but 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.<sup>32</sup>

Socio-economic inequalities in cancer care and outcomes are increasingly recognised, but their causes are less well understood. There is evidence for differences in treatment but speed of diagnosis, patient factors and biological differences may all play a part.<sup>33</sup> In lung

cancer, these differences are more pronounced in patients whose symptoms are ill-defined<sup>34</sup> suggesting differences at the level of the patient / clinician interaction.

Some insights into how primary care might contribute to these observed socio-economic inequalities, and how they might be redressed, can be drawn from the wider research literature. An analysis of physician utilisation by income in 21 OECD countries, drawing on data from national surveys or the European Community Household Panel, found no inequity, or a pro-poor distribution, for PCP visits. In all countries for which data were available, however, there was pro-rich inequity for specialist consultations, after controlling for differences in need.<sup>35</sup> When educational attainment is used as a measure of socio-economic status, comparable findings result. After adjustment for health status, there is equity in contacts with primary care but a pro-higher education inequity in specialist visits.<sup>36</sup> For countries with gatekeeping systems, the referral process may itself may be generating inequalities<sup>37</sup>, being more challenging for deprived patients to navigate, though the readiness of some PCPs to refer may also be socio-economically patterned.<sup>38</sup> Others, however, while confirming a socioeconomic gradient in access to specialist care, have argued that part of the association is explained by geographical clustering of more affluent patients and specialist services. For cancer, inequalities are apparent in longer intervals from first presentation to diagnosis for women and the elderly.<sup>39</sup>

The geographical distribution of PCPs is a policy concern for many countries. Inequalities in per capita availability of primary care physicians between countries with Universal Health Care Systems (UHCS) are small<sup>40</sup>, and within countries appears not to be strongly socio-economically patterned. For some countries, such as Canada and Australia, however, rurality creates great inequalities in health care availability.<sup>40</sup> However, policies that strive for per capita equity of PCP availability fail to address the considerably greater illness burden among deprived populations. This problem has been conceptualised as the 'Deep End' of primary care.<sup>41</sup> Even with per capita equity of PCP provision, the capacity to effectively manage the complex health care needs of a practice population care is proportionately less in practices serving deprived populations. One consequence for cancer is that women from deprived areas with breast cancer are twice as likely to be admitted to hospital for unrelated conditions in the two years after completing treatment.<sup>42</sup> Cervical screening uptake is also lower in practices located in SE deprived areas.

Studies of quality of primary health care in deprived populations report conflicting findings, with lower uptake of cervical cancer screening and lower scores for interpersonal care and patient satisfaction, but no difference in quality of chronic disease management.<sup>43</sup> Nevertheless, the areas that experience the greatest problems with PCP recruitment and retention 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 there is an ecological association between gatekeeping and cancer-specific mortality, which needs to be better understood and is addressed in detail in Part 8.<sup>44</sup>

### **Conclusions**

Primary care is first contact and continuing care provided in community settings by multi-professional teams led by expert generalist physicians working in practices. These will increasingly join together in federations or networks to provide care on a greater 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 in addressing the persistent socio-economic and age inequalities in cancer care.

## **Part 2: The role of the PCP in prevention, screening and promoting help-seeking**

PCPs sit at the frontline of healthcare 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 co-ordinated with broader public health efforts.

- GPs have established roles and efficacy in reducing smoking and harmful alcohol use
- With the advent of the obesity epidemic it is important that GPs and primary care teams develop more effective strategies targeting weight loss and physical activity.
- There are complex cognitive, emotional and behavioural determinants of symptomatic presentation for cancer – it is important that GPs have an understanding of these psychological processes in their patients if they are to deliver effective advice to promote early presentation
- Public awareness campaigns are able to increase the frequency with which patients present to primary care with potentially significant symptoms – it is vital that campaign organisers work closely with primary care in developing the most effective and integrated programmes
- GPs have multiple roles in cancer screening, including promotion of uptake and informed choice, information provision and involvement with follow-up of test-positive individuals. Engagement with primary care is an important priority for cancer screening programmes

Panel 2

### **Primary prevention**

Considerable evidence has accumulated in the efficacy or otherwise of PCP-based prevention strategies - although there is significant variation in the level of change achieved, with effect sizes usually described as 'small or moderate'.<sup>45</sup> Multifaceted interventions are probably the most effective, as more barriers to change can be addressed. Interventions delivered to patients at low risk may, however, only be of marginal benefit.<sup>46</sup> Further, few such studies base their intervention strategies on theories of behaviour change.<sup>47</sup> PCP-based interventions can be usefully divided into those that are directly delivered by the PCP (for example 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 framework<sup>48</sup> has been widely used in the smoking cessation field but could also be applied to other areas of behaviour change (Table 2.1).

<b>ASK</b> and record smoking status—is the patient a smoker, ex-smoker, or non-smoker?
<b>ADVISE</b> on the best way of quitting—the best way of stopping smoking is with a combination of medication and specialist support
<b>ACT</b> on patient response—build confidence, give information, refer, and prescribe. Patients are up to four times more likely to quit successfully with NHS support
<b>How to refer to a stop smoking service</b>
<ul style="list-style-type: none"><li>• ‘Call this number and they will put you in touch with someone who can arrange treatment and support you to stop’ or</li><li>• ‘I can refer you to the stop smoking service and they will phone you to go through the options for treatment and support’ or</li><li>• ‘When you are ready to stop, make an appointment at reception with our stop smoking advisor.’*</li></ul>
<small>* (In practices, where there is an in-house service).</small>

Table 2.1 The ‘3As’ approach to prevention

### *Smoking*

It is now generally recognised that brief interventions based in primary care have the potential to reduce rates of smoking. Brief advice, as well as print-based, self-help interventions, have been shown to have a modest but significant effect<sup>49, 50</sup> Combinations of brief advice, counselling and prescribing nicotine replacements appear to be particularly effective.<sup>51</sup> We know less about how primary care efforts will work alongside recent initiatives, such as the introduction of e-cigarettes.<sup>52</sup> Primary care in the UK has been innovative in contributing to the establishment of smoking cessation clinics - for which there is a solid evidence base.

### *Alcohol*

Brief interventions in primary care can reduce alcohol consumption - evidence for this has accumulated over several decades, and the studies have wide applicability in primary care settings.<sup>53</sup> Recent interest has focused particularly on motivational interviewing, which appears to out-perform simple advice from a PCP, although more evidence is needed before it is incorporated into routine practice.<sup>54</sup> We also need to know more about the best interventions in key sub-groups (women, older and younger drinkers, minority ethnic groups, dependent/co-morbid drinkers), and the ideal intervention length and frequency to maintain longer-term effectiveness.<sup>55</sup>

### *Diet and obesity*

In contrast to smoking and alcohol, there have been fewer studies of primary care intervention in diet and obesity, although a recent study found that a health professional recommendation was associated with higher likelihood of weight loss attempts.<sup>56</sup>

Nevertheless, evidence exists for the efficacy of primary care based programmes, particularly when combined with interventions from other agencies,<sup>57</sup> although referral to commercial programmes may be more cost-effective.<sup>58</sup> Weight reduction interventions are poorly documented in UK primary care, and access to appropriate programmes may be a key issue.

### *Physical activity*

In the UK, NICE guidance (2013) recommends brief physical activity advice in primary care, using an approach based on the Ask, Advise, Act framework.<sup>48</sup> Advice and counselling in general practice can lead to increases in physical activity (at 12 months),<sup>59</sup> 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 from a third party provider; while this approach is generally acceptable to PCPs and patients, we lack a comprehensive picture of its effectiveness (for example, its impact in hard-to-reach groups). A recent systematic review concluded that physical activity promotion to sedentary adults (recruited in primary care) significantly increases physical activity levels at 12 months, although there was insufficient evidence to draw distinctions between exercise referral schemes and counselling interventions.<sup>60</sup>

### **Patient appraisal and help-seeking in primary care**

Given that most cancer diagnoses come from patients presenting symptomatically in primary care, a better understanding of the processes influencing the length of time between the patient noticing a symptom and seeking medical advice (the patient interval) is an important step in developing 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.<sup>61</sup> Community-based studies using standardised measures of awareness in population-based samples reach similar conclusions:<sup>62</sup> people have poor recall of potential cancer symptoms other than 'lump', a significant minority say they would avoid a cancer diagnosis, and many report a range of barriers to help-seeking. All three domains have been shown to be modestly associated with 'anticipated delay' (the time people say they would wait before seeking help if they experienced a particular symptom).<sup>63</sup> Newer studies have combined

large-scale surveys designed to quantify symptom prevalence and attribution, with qualitative studies designed to explore patients' views in more detail.<sup>64, 65</sup> These confirm that people who are experiencing cancer 'alarm' symptoms rarely recognise them as cancer; among those who do, some are too fearful of cancer to seek help, and that 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 (not recognising the symptom as serious) is especially important; more than half of people aged over 50 report experiencing at least one alarm symptom in the past three months,<sup>63</sup> and very few attribute such symptoms to cancer or even perceive them as serious. A 'normalisation' process means that most symptoms are attributed to other factors (eg other illnesses, ageing, 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.<sup>66</sup> The emotional domain (fear of a cancer diagnosis) is less often cited as a reason for avoiding 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. A recent analysis found that fatalistic views of cancer were associated with a substantially greater risk of advanced stage diagnosis in lung and colorectal cancer.<sup>67</sup> 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, and this is particularly common in the UK although the exact 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,<sup>65</sup> or patients worry that the doctor would be dismissive of further questions about the same symptom.<sup>63, 64</sup> Other barriers cited in studies asking the public why they might avoid help-seeking include embarrassment about the symptom or worry about an examination, as well as practical difficulty making a PCP appointment; although these are rarely mentioned in symptom surveys or in patient interviews.

### *Implications for interventions in primary care*

It is important that PCPs 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 in educating patients about symptoms to look out for, and there may be 'teachable moments' for such educational interventions, such as after a negative symptomatic investigation or after discussion of screening. Reducing excessive cancer fear is more challenging; but if PCPs are able to help patients discuss their worries about cancer, this could help them to face a diagnosis. PCPs should be well-placed to address barriers to attendance in the doctor-patient interactions. In general terms, primary care systems that welcome rather than deter are needed. It has also been argued that there is a conflict between the dominant medical approach of identifying the 'chief reason' for consulting, and patients' experience of minor and indistinct complaints that don't reach the threshold for seeking medical care.<sup>68</sup> This may 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'; i.e. the oral symptom did not deserve its own consultation.<sup>69</sup> Asking patients, particularly those from lower SES backgrounds, if there are any other issues they would like to ask about (a core PCP consulting skill), could help promote discussion of more minor or indistinct complaints that might nonetheless indicate a need for investigation. More time may 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 recommendations for primary care have been developed.<sup>70</sup>

### *Public awareness campaigns and how they relate to primary care*

Improving symptom awareness in the UK has been tackled largely with public education campaigns about specific symptoms; often linked with subtle messaging that the PCP would welcome a consultation. There is clear evidence of increased awareness in response to these campaigns,<sup>71</sup> and evidence of more visits to the PCP with the target symptoms, although the effects may be short-lived. Faced with symptomatic patients, the challenge for primary care doctors 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 earlier referral of patients suspected of having lung cancer has been the most successful

reported to date in terms of achieving significant increases in referrals for chest X-ray and specialist assessment, more diagnoses, a stage shift to earlier disease and an increase in potentially curative treatment.<sup>71</sup>

The public awareness campaign in England, based on the strapline: *“Been coughing for three weeks or more? Tell your doctor”* (Fig 2.1) led to a 67% overall increase in patients across all age groups visiting their PCP with a cough, though the majority of PCPs surveyed were supportive of the campaign.



Fig 2.1 Be Clear on Cancer campaign poster

### **Cancer screening and primary care**

Moving to screening for cancer, primary care has equally important roles - even in the context of centrally organised national programmes. There are well-established principles for 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 United States tends to do opportunistic screening, but a recent review for the CDC emphasised the value of learning from organised cancer screening

programmes in other countries.<sup>47</sup> One recent issue has been the controversy over breast cancer screening<sup>72</sup> 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 recent years there has been a focus on ‘personalised medicine’ which emphasises the need to tailor preventive and treatment strategies to individual patients – taking account of information from genomics, family history, lifestyle and other areas. There is, for example, growing interest in the concept of risk stratification in cancer screening – that is, designing screening strategies based on individual risk, rather than assuming everyone in the target population has the same risk. PCPs have potentially important roles in the collection of genetic and family history information. Information on family history can help GPs personalise health messages – patients typically attach high significance to such information.<sup>73</sup> It appears, however, that family history information is collected inconsistently in primary care settings; while tools have been developed which could add significant family health information, few are specific for primary care.<sup>74</sup>

While limited primary care-based testing for specific genes may 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 if it is to be useful in risk stratification;<sup>75</sup> 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 it is vital that primary care actively engages in emerging strategies.

#### *How involved are PCPs in screening?*

Our ‘case study’ is colorectal cancer (CRC) screening. CRC is a leading cause of cancer-related mortality in western countries and screening programmes can lead to significant mortality reductions or in the case of endoscopic screening, to reductions of incidence as well. CRC screening programmes are typically designed for asymptomatic individuals at average risk, 50 years of age or higher. Most CRC screening in Europe is based on the faecal occult blood test (FOBT) or the faecal immunochemical test (FIT), with colonoscopy for test-positive individuals, although the UK is implementing a national flexible sigmoidoscopy programme alongside the FOBT programme.

The level of CRC screening development varies in Europe. Screening on a national level has been implemented in 20 EU countries and the involvement of PCPs varies according to the chosen strategy and local health care policy. For example, in Germany, the Czech Republic and Slovakia, PCPs perform FOB testing in their offices; in Poland they recruit patients for colonoscopic screening; in Italy the involvement varies across the country; and in the UK, Netherlands, Spain and Finland, PCPs are not directly involved in the provision of the programme.<sup>76</sup> PCPs also have varying roles in follow-up for test-positive individuals; in some countries they are responsible for referral to colonoscopy while in others this is organised by the programme itself.

#### *The role of PCPs in CRC screening uptake*

For cancer screening programmes to bring about reductions in mortality, a substantial proportion of the population must participate. Organized but opportunistic programmes, such as those established in Germany in 1976, or the Czech Republic in 2000, suffer from low participation rates.<sup>77</sup> There is a clear evidence for the importance of PCPs in the implementation of such CRC screening programmes;<sup>78-80</sup> with RCT evidence that their endorsement of programme-generated screening invitations increases screening uptake.<sup>81</sup> Further, inadequate PCP involvement appears to reduce recruitment in lower SES groups.<sup>82</sup> Educational interventions targeting primary care physicians also appear to be effective in improving CRC screening rates,<sup>83</sup> although this evidence is less consistent.<sup>84</sup> Further research is needed to assess newer approaches to promoting uptake, such as IT-based programs, and to identify strategies that are balanced, self-sustaining, and affordable.

#### *Informed choice and CRC uptake*

While coverage is a key outcome in screening, there is a growing emphasis on information provisions and informed choice, or 'informed uptake';<sup>85</sup> screening has the potential to cause harm, and there is an ethical imperative 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'. Patients sometimes receive insufficient or inadequate information about screening, (in areas such as over-diagnosis and overtreatment), compromising the informed choice process.<sup>86</sup> 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 may benefit from targeting lower-literacy

populations.<sup>50</sup> Screening recruitment can be customized for low-uptake groups, such as ethnic minorities - screening invitations typically require adaptation; ideally, they should address specific language, attitudes, and cultural barriers to participation.<sup>50</sup> Again, the PCP is ideally placed to undertake these tasks, but there are few such models available in the literature.

## **Conclusion**

PCPs have important roles in primary prevention, screening and patient help-seeking. While a body of evidence supporting these roles is emerging, there remains significant unrealised potential. Specifically, PCPs need more effective models to incorporate primary prevention into their routine practice. While significant progress has been made in facilitating early cancer diagnosis in primary care<sup>50</sup> we need a better understanding of how primary care might best tackle the many factors which contribute to patient-related delay. There are educational issues, but the interplay between barriers to consultation and the messages patients take away from PCP consultations needs to be better understood. Finally, we need great consistency and sharing of 'best practice' in the way PCPs are involved in cancer screening.

Primary care needs to move beyond its focus on smoking and alcohol in primary prevention, and engage more effectively in initiatives to promote physical activity and reduce obesity

- Primary care should prepare itself for the growth in genomic information, and how this information can be incorporated with lifestyle and other factors in developing individualised preventive strategies
- Population-level early diagnosis and screening strategies need to fully engage primary care if they are to maximise their potential

Action points 2



### Part 3: Early Diagnosis in Children, Teenagers, and Young Adults

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

#### Diagnostic intervals

Given the complexity of the pathways leading to cancer diagnosis, an appropriate conceptual framework is necessary. Through a systematic review, Walter et al. adapted the Andersen Model of Total Patient Delay to the cancer diagnostic pathway (Figure 3.1).<sup>6</sup>

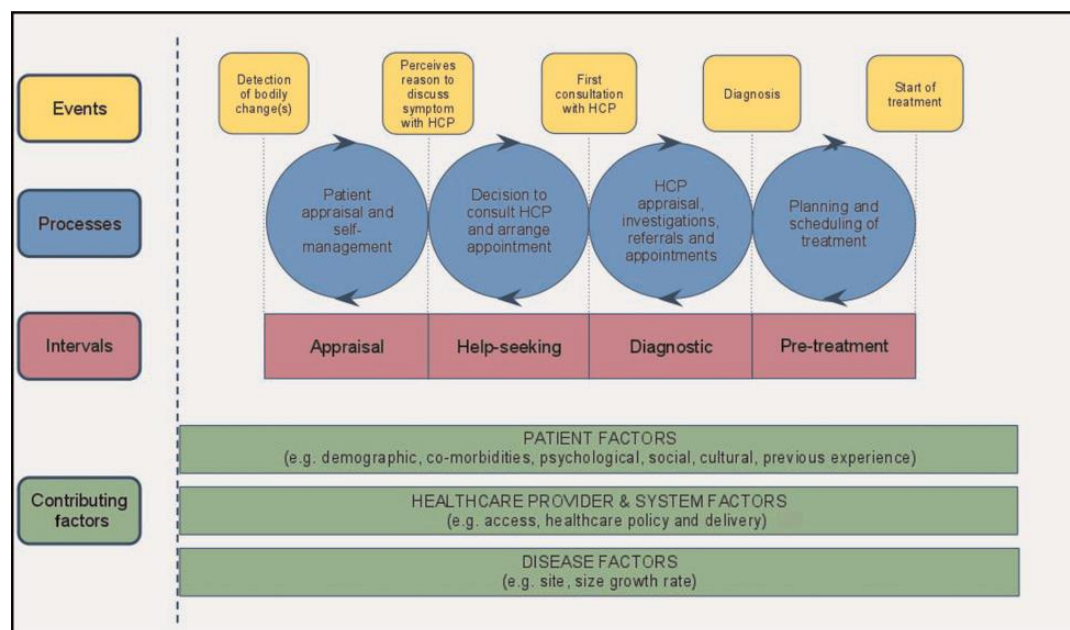


Figure 3.1: Model of Pathways to Treatment

The Model defines key events and intervals, including the appraisal, help-seeking, diagnostic and pre-treatment intervals. In addition, contributing factors to time to diagnosis are categorized into disease, patient, and health care provider/system factors. While Walter et al. focused on adult malignancies, their model is transferrable to CTYA cancers, though specific contributing factors may differ. The diagnostic interval, i.e. the time between the first contact with the healthcare system for cancer-related symptoms and the diagnosis, is likely to be of greatest interest to PCPs and will be the focus of much of this chapter.

### **Impact of prolonged diagnostic intervals**

The impact of diagnostic interval lengths upon survival among CTYA with cancer is still controversial. Several studies have linked prolonged intervals to advanced stage at diagnosis and consequently inferior cancer outcomes, particularly in cancers such as retinoblastoma and Hodgkin lymphoma.<sup>87, 88</sup> Two studies have suggested an adverse effect of longer times to diagnosis in childhood leukaemia, though these have predominantly focused on the time interval between diagnosis and treatment initiation, and may therefore be confounded by the clinical condition of the child at presentation.<sup>89, 90</sup>

By contrast, other studies have associated prolonged diagnostic intervals with superior survival, a counterintuitive finding known as the “waiting time paradox”.<sup>91, 92</sup> Two explanations for the waiting time paradox have been proposed. Firstly, aggressive disease may be easier to appraise, leading to shorter diagnostic intervals but associated with inherent increased mortality. Secondly, being more ill at presentation may result in quicker prioritization and referrals by primary care physicians (i.e. shorter diagnostic intervals) but nonetheless result in inferior survival (“sick-quick”). These two mechanisms are of course not exclusive. Three systematic reviews all found evidence of the waiting time paradox in children, as did recent studies in medulloblastoma, Ewing sarcoma and acute leukemia.<sup>93-95</sup> It should be noted however that many of the above studies suffer from significant methodological limitations. For example, most studies lacked sufficient power to explore U-shaped associations between diagnostic interval length and survival, as demonstrated in some adult malignancies.<sup>96</sup> Finally, the vast majority of studies have relied either on primary data from patients or providers, or on chart abstraction of medical records, with consequent issues of recall bias or availability.

Much less controversial is the impact of prolonged diagnostic intervals on psychosocial outcomes among children with cancer. Long diagnostic intervals are a source of significant distress and guilt to patients, caregivers, and indeed PCPs themselves.<sup>95</sup> Prolonged diagnostic intervals may also result in a loss of confidence in the healthcare system. Thus targeting earlier diagnosis among CTYA cancer patients will lead to improved non-survival based outcomes, and may additionally improve survival in select malignancies or populations.

## Challenges to diagnosis

Prompt diagnosis of cancer in CTYA is a significant challenge, made more difficult by both disease, patient, caregiver factors.

### *Disease*

Despite being the leading cause of disease-related death among CTYA in high-income countries, cancer is rare, accounting for less than 1% of all cancers. Childhood cancer also represents a heterogeneous group of diverse malignancies very different to those seen in older age groups more commonly presenting to PCPs. For the average PCP in the UK, diagnosing cancer in a child or teenager is a twice-in-a career event and hence understandably low on their list of differential diagnoses.

Table 3.1 Paediatric Cancer Incidence Rates

	ALL RACES	
	BOYS	GIRLS
All ICCC sites	196.7	182.3
Leukemia	52.0	43.1
Acute lymphocytic leukemia	38.4	30.2
Acute myeloid leukemia	7.9	8.0
Lymphomas and reticuloendothelial neoplasms	29.8	20.7
Hodgkin lymphoma	12.9	11.8
Non-Hodgkin lymphoma	15.1	7.7
Brain and CNS	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 tumor	5.3	6.3
Hepatic tumors	2.8	1.8
Bone tumors	9.8	7.7
Osteosarcoma	5.5	4.5
Ewing sarcoma	3.3	2.4
Rhabdomyosarcoma	5.4	4.2
Testicular germ cell tumors	9.9	-
Ovarian germ cell tumors	-	4.4
Thyroid carcinoma	3.0	12.6
Melanoma	3.7	5.8

CNS – Central nervous system; ICCC – International Classification of Childhood Cancers  
Rates are per 1,000,000 and age-adjusted to the 2000 US standard population. Rates include benign and borderline brain tumors.<sup>97</sup>

### *Presenting symptoms and signs*

Presenting symptoms of childhood cancer may generally be grouped into three categories. The first group includes symptoms that are commonly encountered in primary care and which rarely signify serious illness or warrant referral, such as fever, abdominal pain, or headache. These symptoms are however also commonly seen in children presenting with cancer. The second group of symptoms are those which are less common in paediatric patients, but are still much more likely to have a benign underlying cause (e.g. first afebrile seizure, new onset Bells palsy, lymphadenopathy). These symptoms are more likely to prompt referral to secondary care for further investigation and management, though this may not always be necessary. Finally, there remains a group of symptoms and signs which although rare are virtually always pathological, likely to represent malignancy and require rapid work up and referral. Examples would include an abdominal mass, proptosis, and leukocoria.

In TYA, the changing spectrum of cancers results 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 care reported that cancer 'alert' symptoms, as described in England's NICE guidance for urgent referral for suspected cancer, were relatively uncommon in children subsequently diagnosed with cancer.<sup>98</sup> In the three months prior to diagnosis just over a quarter had any alert symptom recorded by their GP. This proportion only rose to a third when the preceding year was considered. Alert symptoms were also recorded in those without cancer. This, coupled with the rarity of childhood cancer, meant that most individual alert symptom had a positive predictive value (PPV) for cancer of 0.05% or less.<sup>98</sup> A further study from this group, also using electronic UK primary care records, identified twelve symptoms that increased the risk of cancer at least tenfold, though with a low absolute risk. The PPV for each symptom increased 2-3 fold in patients with three or more attendances for the same problem.<sup>99</sup> (Table 3.2) Thus repeat visits may represent a cause for heightened suspicion among PCPs.

Table 3.2. Positive predictive values 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%.<sup>98</sup>

**Table 4. Positive predictive values for 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%)**

Symptom <sup>a</sup>	PPV <sup>b</sup> as a single variable (95% CI)	PPV combined with three or more consultations (95% CI)
Pallor	0.41 [0.12 to 1.34]	0.76 [0.10 to 5.70]
Lump mass swelling head and neck	0.30 [0.10 to 0.84]	0.76 [0.10 to 5.70]
Lump mass swelling	0.11 [0.06 to 0.20]	0.30 [0.09 to 0.99]
Lymphadenopathy	0.09 [0.06 to 0.13]	0.20 [0.10 to 0.39]
Abnormal movement	0.08 [0.04 to 0.14]	0.15 [0.07 to 0.32]
Bruising	0.08 [0.05 to 0.13]	0.38 [0.09 to 1.64]
Fatigue	0.07 [0.04 to 0.12]	0.12 [0.06 to 0.23]
Bleeding	0.06 [0.03 to 0.10]	0.11 [0.04 to 0.31]
Headache	0.06 [0.04 to 0.08]	0.13 [0.08 to 0.22]
Visual symptoms	0.06 [0.03 to 0.10]	0.23 [0.07 to 0.77]
Pain	0.04 [0.03 to 0.06]	0.14 [0.07 to 0.31]
Musculoskeletal symptoms	0.04 [0.03 to 0.07]	0.13 [0.08 to 0.19]
Three or more consultations	0.02	

<sup>a</sup>Symptoms are ordered by PPV as a single variable. <sup>b</sup>Values are point estimates of the PPV. The red shading is for symptoms with a PPV over 0.1%, the blue shading is when the PPV is above 0.2%, and the purple shading is for PPVs above 0.5%. PPV = positive predictive value.

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, alert symptoms were recorded in only 5% of patients with bone sarcomas compared to 44% of those with lymphoma.<sup>100</sup> A second study of 550 children analysed the association between symptoms and the diagnostic interval. Children with leukaemia were more likely to experience a long diagnostic interval when pain was reported and the shortest intervals among children with brain tumours were observed when vomiting was present.<sup>101</sup>

#### *Patient and Caregiver*

Young children are unable to articulate their symptoms or access healthcare independently. They are thus reliant on the caregiver's interpretation of their signs and symptoms, and on the caregiver's own healthcare seeking behaviour. Parental thresholds for consultation vary

considerably; many are willing to self manage non-specific symptoms such as tiredness and viral-type infections initially, while others attend more frequently.<sup>102</sup> Low parental education level has been shown to be associated with prolonged diagnostic intervals in children.<sup>103</sup> The caregiver's level of concern can influence both the decision to attend and the outcome of the consultation. Persuading doctors of the reality and seriousness of their child's symptoms, without themselves recognizing the possibility of cancer, is commonly reported by parents.<sup>104</sup>

Conversely, parents of teenagers and young adults are reliant on their child to report a problem. A number of studies report an association between older patient age and increased patient and diagnostic intervals that may reflect a young person's reluctance to discuss health concerns with caregivers or doctors, though the use of primary care by teenagers and young adults is relatively frequent.<sup>105, 106</sup> The most common barriers to help seeking in a study of 11-17 year old British children were 'worry about what the doctor might find' (72%), embarrassment (56%), fear (54%) and 'not feeling confident to talk about symptoms' (53%). Low levels of awareness of the features of cancer were also reported amongst the teenagers, highlighting them as a risk group for delayed diagnosis.<sup>107</sup>

### **Part 3 panel**

Barriers to the prompt diagnosis of childhood, teenager and young adult (CTYA) cancers:

#### Disease-related

- Rarity of CTYA cancer
- Heterogeneity of cancers
- Overlap of many symptoms with those of common, benign conditions

#### Patient/Caregiver-related

- Inability of young children to articulate symptoms
- Low health seeking behaviour in many teens and adolescents
- Limited awareness of CTYA cancer among patients and caregivers

### **The role of the primary care physician**

In some health care systems, paediatric primary care is a specific entity, with clinicians restricting their practice to children. In others, including the UK and Denmark, the first consultation for an ill child is with a PCP, who offers primary care to all ages. As noted earlier, such a clinician will encounter a child with cancer rarely – perhaps twice in their career, and thus accumulates less practical experience of children's health. It is unrealistic to expect specific education about particular cancers to be of use: diagnosis of possible CTYA

cancer will be 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, though most are much more subtle. There is moderate evidence to suggest 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.<sup>108</sup> This extra component, sometimes labeled 'intuition,' has not been shown in paediatric cancer, but probably exists. In adults, PCPs have moderate ability to discriminate malignant enlargement from benign enlargement in both cervical lymphadenopathy<sup>109</sup> and prostate masses.<sup>110</sup> It is likely such skills translate to paediatric practice. An overall malignant probability of 0.5% for lymphadenopathy in someone aged 16-24 is almost certainly much higher if it has particular features suggesting a cancer diagnosis (e.g hard consistency, large size, accompanying symptoms of fever, weight loss or night sweats).<sup>111</sup> 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 venepuncture.

One potential advance involves electronic clinical decision support. It is possible to integrate diagnostic software into primary care clinical computers that automatically searches the records for relevant entries and computes an absolute risk of current cancer. This is a reality in adult cancer in the UK, and is discussed in detail in the Part 4, though a definitive trial has yet to be performed. In CTYA, repeated attendances are a clear marker of risk, and could be incorporated into the algorithm. Selection of the specific risk threshold for prompting the clinician to the possibility of cancer will, however, be difficult as absolute risks will be small, and 'prompt fatigue' a real possibility. The 'real world' utility of electronic clinical decision support algorithms in facilitating early cancer diagnosis in CTYA remains to be elucidated.

Finally, the PCP may play a role in the initial work-up of a child with a suspected malignancy. On occasion, a PCP can institute testing – such as 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 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 and second, the few who do have cancer will benefit from rapid diagnosis. Arguably, the second of these principles is the

more important, particularly when some of the referred children will have alternative, albeit benign, diagnoses, which may also benefit from swift identification. Most of the specialized investigations require imaging, supplemented by biopsy if necessary. This argues for either moderately large specialist paediatric practices or strong referral systems. Treatment of CTYA cancer is highly specialized and generally concentrated in tertiary referral centres – diagnosis rarely requires this level of specialization. Some countries have established guidance for selection of patients for investigation of possible cancer. These have mostly been based on secondary care studies, which have limited applicability to primary care. In the UK, NICE criteria for urgent referral for suspected CTYA cancer has been shown to have very low absolute risks. Even so, patients value investigation of cancer, even when the likelihood is very low<sup>112</sup> and the same is likely to be true of CTYA.

### **Impact of healthcare system factors**

Healthcare system-level factors may impact upon the likelihood of prompt diagnosis in several ways. Given 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 in minimising diagnostic intervals. Both relational and informational continuity are being threatened as the demand for primary health care increases.

Second, even when suspicious of a possible malignant aetiology, PCPs are highly unlikely to be able to initiate definitive diagnostic procedures, as noted above. Healthcare systems with defined and rapid referral mechanisms between PCPs and specialty paediatric facilities are therefore more likely to facilitate prompt diagnoses. This may be of particular importance in the TYA population, whose care in many jurisdictions is dispersed across paediatric and adult care settings.

### **Conclusions**

An early diagnosis of cancer in CTYA will generally decrease parental guilt, increase caregiver confidence in the healthcare system, may decrease stage at presentation in some malignancies, and even improve long-term outcomes. Significant challenges exist in recognising and diagnosing childhood and TYA cancer in the primary care setting and in designing the optimal referral service. Despite these challenges, the crucial role PCPs play in ensuring prompt diagnosis can be supported through clinical strategies, potentially including electronic decision support, accessible primary care and strong referral systems.



Prompt diagnosis of cancer in CTYA will need new and innovative assessment pathways and tools  
Alternative models of access for patients to diagnostics and assessment should be piloted.  
Rapid and robust referral mechanisms from primary care to specialist facilities should be developed, particularly for the TYA population.

Action points 3

## **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 much more commonly have a benign cause. PCPs must 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 conducted. The conceptual framework (Pathways to Treatment) within which diagnosis of cancer should be considered was described in the preceding section, while the stages that go to make up the total time from first presentation to diagnosis and treatment appear in the introduction to this Commission.

There is growing evidence for several cancers that earlier diagnosis of symptomatic cancer is associated with improved clinical outcomes.<sup>113</sup> Further, prompt diagnosis is associated with better patient experience of subsequent cancer care, particularly those aspects delivered in primary care.<sup>114</sup> Preventing avoidable delays in primary care by accurate assessment of the likelihood of cancer, and expediting the diagnosis, could therefore contribute to improvements in cancer survival.

### **The diagnostic process in primary care**

PCPs are confronted with a wide spectrum of complaints and symptoms in their daily consultations; the most prevalent being respiratory, musculoskeletal and gastro-intestinal. In the majority of patients the prognosis of these symptoms is favourable, and the complaints are self-limiting. Given this good prognosis a single consultation is sufficient for most patients, and in only 5-15% is additional diagnostic testing required.<sup>115</sup>

Clinical decision making in primary care is primarily directed by prognosis rather than diagnosis, and is based on risk estimation. The overall aim is to identify in a timely way those patients with a high risk of serious disease, as they need early additional diagnostic tests and therapeutic interventions.<sup>116</sup> To prioritize among the many potential differential diagnoses GPs use hypothetico-deductive methods or pattern recognition strategies, matching the presenting symptoms to their knowledge and clinical experience.<sup>117</sup> 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 pre-set individual characteristics, such as age, gender and family history, which is added to the baseline

population risk (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 (posterior risk), and forms the basis of further management.

If the risk of serious disease is low, no further action is required and a watchful waiting policy can be applied. If the risk is high, further action is required, usually specialist referral. In case of intermediate risk<sup>118</sup> additional diagnostic testing can up- or downgrade the risk to a level that facilitates further management by the PCP. In the case of high stake diagnoses such as cancer the need for an adequate diagnostic process is high, and the level of risk triggering investigation or referral is lower. This implies that in the case of cancer suspicion the threshold for additional testing and referral is usually lower. Although PCPs do not explicitly think about their diagnostic reasoning in this way,<sup>119</sup> and particularly not in relation to specific numerical risk thresholds, this 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 play a strong gatekeeping role. Patients with serious disease need an adequate and timely diagnosis, but irrational use of diagnostic testing in low risk patients may result in incidental diagnoses, stress for the patient and societal costs. Continuity of care is a cornerstone of good general practice. The longstanding relationship with a patient provides the PCP with valuable additional information about the medical and psychosocial history which may alter the prior risk of disease. Furthermore, acquaintance with the patient and their preferences about healthcare may modify the thresholds in the decision making process, making the PCP accept different risk thresholds between patients before further diagnostic testing. Continuity of care can have negative impacts on timely cancer diagnosis by altering patients' help-seeking behaviours and potentially making doctors complacent about their symptoms, especially if they are frequent attenders.<sup>120</sup> However, the impact of doctor – patient continuity on time to diagnosis appears to be small (a maximum of 7 days for colorectal cancer) and not clinically important.<sup>121</sup> Finally, presumed life expectancy also affects different steps in the diagnostic process, as PCPs take the benefit of

an early diagnosis into account in their decision for additional testing and referral for people who may be close to death.

PCPs face several challenges in accurately diagnosing cancer. First of all, symptoms are common, but cancer is rare. PCPs in the Netherlands may see 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. Given the low prevalence the prior risk of cancer in primary care is usually low, which limits the predictive value of signs and symptoms and of diagnostic tests. Secondly, 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 like cough, abdominal pain and fatigue are present in most patients with lung or gastro-intestinal 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.<sup>122</sup> Finally the presentation of cancer may be obscured by factors that hamper timely diagnosis such as co-morbidity. Existing respiratory disease can prolong the diagnosis of lung cancer<sup>11</sup>, and a high burden of psychiatric or psychosocial comorbidity is associated with delayed diagnosis of colorectal cancer.<sup>123</sup>

#### **Panel Part 4**

- Most cancers present symptomatically in primary care but the symptoms that could signal cancer more commonly have a benign cause.
- Advances in the epidemiology of cancer symptoms in primary care allow more accurate risk assessment and selection of patients who require urgent investigation. Risk assessment tools could potentially improve early diagnosis of many cancers in primary care but trials are needed to confirm this. If these trials demonstrate efficacy, implementation of risk assessment tools through primary care clinical software systems would be justified.
- Certain cancers may be inherently more difficult to diagnose in primary care and will require the development of accurate biomarkers to support early diagnosis

#### **Epidemiology of cancer symptoms in primary care**

Accurate diagnostic reasoning in primary care requires an understanding of how well symptoms predict risk of a cancer diagnosis. In the last ten years the evidence-base around

the epidemiology of symptoms, signs and diagnostic tests associated with cancer in primary care has improved, with a variety of 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 improve the diagnostic accuracy of cancer in primary care.<sup>124</sup>

Case-control studies, exemplified by the Cancer Prediction in Exeter (CAPER) series of studies, into colorectal, lung, prostate, brain and ovarian cancer have made major contributions to this evidence base.<sup>125</sup> This methodological approach using large primary care databases has been extended to cover 16 cancers. The strength of this approach is that the positive predictive value of individual symptoms, signs and diagnostic tests associated with these cancers are determined. The shortcomings include the nature of the case-control study design, including 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 also using 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.<sup>126, 127</sup> This approach allows the independent effects of several clinically important factors to be estimated: higher risk symptoms that include weight loss, abdominal pain, indigestion, dysphagia, abnormal bleeding, lumps; general “non-specific” symptoms such as tiredness, constipation; and risk factors such as age, family history, smoking status, alcohol intake, deprivation, body mass index, 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 account of their risk factors and current symptoms.<sup>128</sup> The strengths of this approach include the large, representative sample, duration of follow-up, and lack of selection, recall and responder bias. Shortcomings include a lack of formally adjudicated outcomes such as cancer diagnosis, potential information bias (greater information collected for patients with a diagnosis of cancer), and missing data in relation to symptoms, signs and diagnostic tests, particularly in those patients without a cancer diagnosis. Other large databases have taken a different, but complementary approach, examining the association of alarm symptoms (first occurrence of

haematuria, haemoptysis, dysphagia and rectal bleeding) with cancer. This approach enables a more accurate quantification of cancer risk with classical presentation<sup>129</sup> but many patients with cancer in primary care do not necessarily present initially with classical features.

Several smaller, prospective observational studies of individual risk of cancers, particularly colorectal, breast, lung and melanoma have been published. They also adopt a multivariable approach, estimating the probability of a target cancer based on 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, thus ascertainment of both symptoms and outcomes is high. A brief overview of the current evidence-base for common cancers includes the following studies:

#### *Colorectal cancer*

Systematic reviews of prospective observational studies have confirmed 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 present in combination. The prior probability of colorectal cancer in patients presenting to their GP in primary care ranged between 3.3-15.4% in eight community based studies<sup>130</sup>, so even when a patient presents with a full complement of symptoms and signs, the probability of colorectal cancer remains modest, approximately 20-25%. This means that further diagnostic testing is always needed.<sup>130</sup> Further research from the QCancer (Colorectal) study shows the importance of determining anaemia in a patient presenting with rectal bleeding in terms of additional diagnostic yield.<sup>131</sup>

#### *Breast cancer*

Breast symptoms are a relatively common reason for encounter in primary care. Prospective studies have shown that the probability of breast cancer is relatively low amongst women presenting with breast symptoms, in the region of 3%. Symptoms and signs associated with increased probability of breast cancer include increasing age, presence of a discrete lump, a lump  $\geq 2\text{cm}$ , thickening of the breast, lymphadenopathy and tethering to the skin or chest wall. This clinical prediction rule has been found to perform well in the context of patients referred to a breast care clinic but validation in a primary care population is needed.<sup>132</sup>

#### *Lung cancer*

The Q Cancer (Lung) study shows that independent predictors include haemoptysis, appetite loss, weight loss, presence of cough, smoking and history of chronic obstructive airways disease as well as increased body mass index and higher deprivation.<sup>133</sup> The challenges of diagnosing lung cancer and its associated symptoms are discussed further below.

### *Melanoma*

The weighted seven point checklist includes the following features: change in size of lesion, irregular pigmentation, irregular border, inflammation, itch or altered sensation, size >7mm and oozing or crusting of the lesion. A recent validation study in English primary care suggests a cut-off score of four performs best at identifying clinically suspicious pigmented skin lesions.<sup>134</sup>

### **Difficult diagnoses and rarer cancers**

Cancer is, of course, not a single disease, rather a heterogeneous collection of different diseases. These all manifest in different ways, and this accounts for why some are harder, and some easier, to diagnose in primary care. There is an emerging literature on this, and a number of metrics that can be compared between cancers to determine the harder to diagnose cancers. These include the number of pre-referral consultations,<sup>135</sup> various measures of time interval, for example the primary care interval and the diagnostic interval<sup>5</sup>, and route to diagnosis (routine, urgent or emergency referral).<sup>8</sup>

Lyratzopoulos and colleagues have classified cancers into one of three groups based upon ease of diagnosis.<sup>10</sup> Those categorised as easier to suspect, because of more obvious symptoms, include breast, melanoma, endometrial and bladder. Those categorised as intermediate cancers include colon, renal and lymphoma. Those categorised as harder to suspect cancers include myeloma, pancreas, stomach and lung. These harder to suspect cancers are typified by non-specific presenting symptoms. Additionally, but not exclusively, they may be some of the rarer cancers. The median diagnostic intervals (time from first presentation in primary care to diagnosis for these cancers) in a large English study were: lung 112 days; myeloma 156 days; stomach 89 days; and pancreas 56 days.<sup>136</sup> We consider each of these in turn, examining specific reasons why they are difficult to diagnose, leading to practical recommendations to improve their diagnosis.

Whilst one of the commoner cancers, lung cancer remains one of the harder to diagnose, and can be easily missed. The diagnostic difficulty stems from the lack of a clear 'symptom signature',<sup>137</sup> the presence of pre-existing lung disease causing similar symptoms, non-respiratory presenting symptoms, atypical symptoms and patient-mediated factors.<sup>138</sup> False negative tests are an important factor in delayed cancer diagnosis generally, but they are common in lung cancer. In two case series initial chest x-rays were normal in 20-25% of people subsequently diagnosed with lung cancer.<sup>139</sup> Improving direct access to CT scans could reduce the risks from false negative investigations in people with suspected lung cancer. The positive predictive values (PPVs) of lung cancer symptoms in primary care are generally low but higher with current smoking, multiple and persistent symptoms and age. The symptom with the highest PPV is haemoptysis, although this is an infrequently experienced symptom.<sup>11</sup>

There is a much smaller evidence base regarding the other three 'difficult to diagnose' cancers. Myeloma is one of the rarer cancers and an average PCP in the UK will only see only one new case every 8-10 years. The presenting symptoms all have low PPVs,<sup>140</sup> meaning that many cases are not diagnosed until irreversible organ damage has occurred. Symptom onset may be gradual, and may be attributed to ageing. For stomach cancer, the PPVs of symptoms are all relatively low, especially in younger people.<sup>126</sup> Intra-abdominal solid tumours tend to cause varied symptoms which are more usually associated with benign causes. More predictive symptoms, for example bleeding, only tend to be present when the disease is more advanced. For pancreatic cancer, the PPVs of symptoms are all low, at least until advanced disease is present, often indicated by jaundice, by which time the suspicion of a pancreatic cancer diagnosis is easier.

What can be done to facilitate the diagnosis of 'harder to diagnose' cancers, such as those described above? The principles of good medical practice are paramount. They include; a thorough history and examination; adherence to referral guidelines; safety-netting;<sup>71, 138</sup> and the use of diagnostic tests. The greater use of currently available investigations has also been advocated by others,<sup>10</sup> but this must not be to the detriment of urgent specialist referral where this is mandated, as use of PCP-initiated investigations is associated with longer time to referral for a range of common cancers.<sup>141</sup>



## Risk assessment tools and decision support

One approach advocated, particularly for cancers which are more difficult to diagnose, is the use of decision support interventions in primary care practice.<sup>10</sup> This is based on systematic review evidence that decision support systems can improve clinician performance and diagnostic test ordering.<sup>142, 143</sup> The development of risk models which predict likelihood of an undiagnosed cancer has led to the creation of risk assessment tools to implement these risk models into general practice. The largest implementation projects have been in the UK of tools implementing either the CAPER or QCancer risk models. In one evaluation, paper versions of the CAPER charts for lung and colorectal cancer 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.<sup>143</sup> They were associated with an increase in referrals for investigation and urgent cancer clinics, and an increase in lung and colorectal cancer diagnoses.

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

Figure 4.1. Positive predictive values (%) for colorectal cancer for individual features, repeat presentations and for pairs of features (in the context of a background risk of 0.25%).<sup>125</sup>

Electronic risk assessment tools which implement the CAPER and QCancer risk models and integrate them into the primary care practice electronic medical record have now been developed and are being piloted in England.<sup>145</sup> PCPs can enter a patient's symptoms into the tool and calculate cancer risk, and are prompted to consider a cancer diagnosis if there is

prior risk of cancer >2% when a patient presents. The risk tool can also audit the whole practice population to identify those at higher risk of undiagnosed cancer who might benefit from further assessment. There are significant challenges to implementing these types of tool into general practice. PCPs express concerns about using these tools within the consultation while those with long experience are more likely to trust their intuition than the estimated risk score.<sup>146</sup>

Several randomised controlled trials of risk assessment tools are in progress which should provide more robust evidence about their impact on clinical decision-making and diagnostic delay. At present, however, their clinical and cost-effectiveness is unknown. Further work is also required to understand how best to implement these types of tool into routine practice.

### **Conclusions**

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 risk of undiagnosed cancer. Current thresholds range from 2% risk upwards,<sup>124</sup> 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. PCPs may become more risk averse and lower their thresholds anyway, in response to the public and political discourse around diagnostic delay.

Improved understanding of the symptomatology and development of risk models and tools may be of use for some cancers but whether they will help with the most difficult cancers to diagnose remains to be seen. Earlier diagnosis of these could depend on the identification of accurate biomarkers that could be used in specific populations at higher 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.

#### Action Points 4

- Internationally, evidence for the epidemiology of symptoms should be systematically applied to inform diagnostic pathways aimed at reducing time to cancer diagnosis.
- If research currently under way confirms the utility of electronic clinical decision support, such tools should be rapidly incorporated into the clinical software used by PCPs
- Effective biomarkers for early diagnosis, both in symptomatic patients and in those with a higher baseline risk, are a research priority

## **Part 5: Cancer Survivorship Care**

The number of cancer survivors is increasing rapidly, largely as a result of improvements in cancer outcomes due to improvements in screening, early diagnosis and treatments for cancer, coupled with more cases as a result of an ageing population. In the UK, for example, it is estimated there are approximately two million cancer survivors currently, around 3% of the population, predicted to rise to four million by 2030<sup>4</sup>. Traditional models of follow-up where patients continue to attend hospital out-patient clinics typically for three to five years, or sometimes much longer, are no longer sustainable. More comprehensive approaches to follow-up are required that meet the range of needs that cancer survivors can have. The consequences 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, and yet with their knowledge of the patient's prior medical history, co-morbidities and family situation, and their holistic approach to care, PCPs have much to offer. The purpose of this section is to consider the role of primary care in optimising the provision of cancer survivorship care.

### **Long term and late effects of treatment**

The consequences of cancer and its treatment can have a wide range of adverse effects, including physical, psychological, social and financial, on both patients and their families. Effective management of these consequences is central to good survivorship care. In terms of physical effects, some damage to normal tissues during treatment is inevitable, with the impact on quality of life varying with the type of treatment. Whilst some treatment effects can be relatively short term, for a significant minority of patients problems following treatment can persist and become 'long-term effects'.<sup>147</sup> Examples include urinary, gastro-intestinal, sexual functioning problems following treatment for pelvic cancers; lymphoedema and menopausal symptoms following breast cancer treatment. In addition, some problems do not arise until months or even years after the end of treatment - referred to as 'late effects'. Examples include the development of osteoporosis following endocrine therapies,<sup>148</sup> heart disease following certain types of chemotherapy or radiotherapy,<sup>149</sup> and the development of second cancers.<sup>150</sup> Studies of childhood and young adult cancer survivors have helped quantify the risk of long-term and late effects and have shown, for example, that patients who were treated when young with radiotherapy or chemotherapy for Hodgkin lymphoma, Non-Hodgkin lymphoma, or testicular cancer have an approximately four fold-increased risk of developing a

new malignancy, and over a five-fold increased risk of developing congestive heart failure, typically occurring more than 10 years after treatment.<sup>151-153</sup> Less is known about the magnitude of the risks following treatment for cancer as an adult, and most research to date has been performed in selected populations of patients recruited in secondary care. This is an important area of future research, and it is hoped that genetic profiling may be useful for predicting those at greatest risk of late effects.<sup>154</sup> The PCP and other members of the primary care team have a potentially important role to play. Indeed, increased contact rates with the PCP have been observed following a cancer diagnosis for help with both treatment-related side effects and psychological problems<sup>155, 156</sup> and, as patients have often been discharged from secondary care when they develop late effects, the majority will first report symptoms to the PCP. In addition, many patients with cancer are elderly with co-morbidities and are 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 (e.g. [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) or [www.nccn.org](http://www.nccn.org)) and are beginning to be developed for adults with cancer.<sup>157</sup> Although some guidelines make specific reference to primary care<sup>158</sup>, however, in many instances no formal role is described for the PCP during either the treatment or survivorship phases. At present, many PCPs will lack awareness of the range and scale of potential treatment effects that cancer survivors may experience.<sup>159</sup> Education is required to ensure 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 e.g. counselling, financial and social support; and to be aware of the possibility of a second cancer or cardiovascular problems at a younger age than one would generally expect.<sup>160</sup>

### **Psychosocial Impact**

Studies from the psychosocial oncology literature have consistently found that around 25-30% of cancer patients develop some form of psychological disorder across the trajectory of cancer, including the survivorship phase.<sup>161</sup> Adjustment and post-traumatic stress disorders, depression and anxiety are the most common clinical conditions observed, with higher rates than seen in the general population. Fear of recurrence, body image consciousness<sup>162</sup> concerns about sexuality and fertility, stigmatization and discrimination, altered social relationships and problems in return to work and in re-assimilating with social groups, and negative feelings (mistrust toward body, anger, and guilt) have been reported as common concerns in cancer survivors seen in different clinical contexts,<sup>163</sup> including primary care services.<sup>164</sup>

For these reasons, screening for and monitoring s, are an important part of clinical practice for both oncologists and PCPs.<sup>165</sup> Risk factors for psychological disorders such as a history of psychiatric illness, poor social support, personality factors (e.g. negative affectivity and social introversion), stressful life events, and should also be regularly assessed in the clinical encounter by oncologists and PCPs.

Consideration of the impact of cancer on the family is also important, since cancer reverberates in the family system with potential negative consequences on spouses and other family members. Exploring the family needs across the trajectory of cancer and cancer survivorship and identifying adaptive, functional and non-adaptive family coping mechanisms, as well as family structure and level of functioning (cohesive versus conflicting or disruptive families) is all extremely important. Empirical studies demonstrate that, irrespective of gender, age, ethnicity, and stage of the disease, 25-35% of caregivers develop symptoms of emotional distress, and to a lesser extent (15%) depression, with repercussions on quality of life and physical health.<sup>166</sup> Psychopharmacological<sup>167</sup> and psychological interventions, in their many possible formats (e.g. individual, couple, family, or group therapy) and models (e.g. cognitive-behavioural, relational, psychodynamic)<sup>168</sup> therefore represent a specific part of an interdisciplinary approach to cancer survivorship, including primary care, in order to properly respond to psychosocial needs, and reduce the levels of emotional stress and increase coping efficacy among cancer survivors.

### **Detecting recurrence**

Detection of recurrence is also central to survivorship care. Recurrences can either be detected by proactive surveillance testing, or following 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 earlier to either improve survival and/or quality of life. These benefits must be weighed against potential harms, such as the anxiety and stress caused by false positive testing, complications of subsequent invasive procedures (biopsies, radiation from imaging), and costs.<sup>169</sup>

The essential components of surveillance are generally considered to be 1) history and physical examination to detect symptoms and signs that could portend recurrence, 2) examination of the primary site (e.g., mammography for breast cancer, endoscopy for colorectal cancer), 3) tumour markers (CEA for colorectal cancer, PSA for prostate cancer), and 4) imaging for distant

recurrence.<sup>170</sup> Evaluation of the primary site also serves to identify second cancers, as genetic predisposition or environmental exposures responsible for the original diagnosis, or treatments like radiotherapy, often leave patients at increased risk for another.<sup>171</sup> Regarding the history and physical examination, while any persistent new symptom usually merits investigation, clinical evaluation should be particularly focused on recognizing the symptoms and signs in the relatively few clinical situations where early detection of recurrences can improve outcomes.<sup>172, 173</sup> Often this consists of pain or some other abnormality at the primary site for a local recurrence. For cancers where a limited number of metastases ('oligometastases') could potentially be resected for cure, right upper quadrant abdominal pain may suggest liver metastases, while a persistent dry cough could signify lung metastases. Constitutional symptoms such as fatigue, anorexia, and weight loss may suggest metastatic disease, but are non-specific.<sup>174</sup> It is also important that patients are 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 is why routine testing for metastases from breast cancer, for example, has been shown to provide no benefit in randomized trials and is not recommended.<sup>175</sup> Even potentially curable hematologic malignancies are not clearly benefitted by 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.<sup>176</sup> In fact, there are actually relatively few situations where specific surveillance testing has been shown to be beneficial (Table 5.1). Consequently, most guidelines (e.g., [www.nccn.org](http://www.nccn.org)) recommend clinical evaluation with further testing only as clinically indicated. Notable exceptions include colorectal cancer,<sup>177</sup> some sarcomas,<sup>178</sup> and kidney cancers,<sup>179</sup> where a minority of patients with oligometastases to the liver or lungs can be cured surgically, and testicular cancer and Hodgkin's disease,<sup>180</sup> 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 some cases such as colorectal cancer, high level evidence has shown improvements.<sup>181</sup>

Table 5.1: Routine surveillance tests in patients with no symptoms or signs that have a rationale and/or evidence base for improving outcomes

<b>Cancer</b>	<b>Tests</b>
<b>Anal</b>	<ul style="list-style-type: none"> <li>• Anoscopy</li> </ul>
<b>Bladder cancer</b>	<ul style="list-style-type: none"> <li>• Urine cytology, cystoscopy and/or urinary tract imaging</li> </ul>
<b>Breast</b>	<ul style="list-style-type: none"> <li>• Mammography</li> </ul>
<b>Cervical</b>	<ul style="list-style-type: none"> <li>• Cervical/vaginal cytology</li> </ul>
<b>Colorectal</b>	<ul style="list-style-type: none"> <li>• Endoscopy</li> <li>• Tumor marker: CEA</li> <li>• Chest, abdomen (&amp; pelvis for rectal) imaging</li> </ul>
<b>Head and neck</b>	<ul style="list-style-type: none"> <li>• Endoscopy or imaging if necessary to examine the primary site</li> </ul>
<b>Hodgkin's Disease</b>	<ul style="list-style-type: none"> <li>• Chest, abdomen, pelvis imaging</li> </ul>
<b>Kidney</b>	<ul style="list-style-type: none"> <li>• Chest and abdominal imaging</li> </ul>
<b>Leukemias</b>	<ul style="list-style-type: none"> <li>• Complete Blood Count</li> <li>• Bone marrow assessment in some (e.g., ALL, CML)</li> </ul>
<b>Prostate cancer</b>	<ul style="list-style-type: none"> <li>• Tumor marker: PSA</li> </ul>
<b>Sarcomas</b>	<ul style="list-style-type: none"> <li>• Imaging of the primary site if necessary</li> <li>• Chest imaging</li> </ul>
<b>Testicular</b>	<ul style="list-style-type: none"> <li>• Tumor markers: AFP, BHCG</li> <li>• Chest, abdomen, pelvis imaging</li> </ul>

### **Prevention**

Research into the effects of nutrition and physical activity in cancer survivors is still in its early stages. There is some evidence that addressing exercise and diet can lead to improvements in the quality of life in cancer survivors. There is also a growing body of evidence in relation to the potential to reduce the risk of recurrence and mortality in some cancer types. The evidence is strongest in relation to exercise and breast cancer, where a recent systematic review of cohort studies found that increasing levels of physical activity post-diagnosis was associated with up to a 34% (95%CI=16–38%) decreased risk of breast cancer mortality.<sup>182</sup> In colorectal cancer and prostate cancer there is also some evidence to suggest physical activity may decrease mortality,<sup>183,184</sup> although more evidence is needed. However, physical activity also improves heart health and can reduce the risk of osteoporosis, and may be helpful in



limiting the cardio-toxic and other long term effects of some cancer treatments. Levels of physical activity in cancer survivors are not high<sup>185</sup> and primary care services can play an important role in advising on the potential benefits of exercise and actively encouraging participation, for example through exercise prescription.

Evidence on the effectiveness of specific dietary interventions in cancer survivors in reducing the risk of recurrence is still developing. There is growing evidence of the importance of maintaining a healthy BMI, but further evidence is required before specific guidance in this area is warranted. For now, the World Cancer Research Fund recommends cancer survivors follows guidance for reducing the risk of primary cancers.<sup>186</sup>

## **Part 5 Panel**

### Key cancer survivorship issues

- There are increasing numbers of cancer survivors with a range of physical and psychosocial needs
- As knowledge increases regarding the potential long term and late effects of cancer diagnosis and treatment, methods for optimising survivorship care are needed
- Primary care, with its holistic approach, has a potentially important role in cancer survivorship care. At present, this is poorly defined.
- Evidence suggests 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 cancer. Good communication between all care providers and clear guidance for primary care professionals is key.

### **Models for delivering survivorship care**

With the increasing numbers of cancer survivors and consequent demands on secondary care, there is growing interest in the potential for primary care to play a greater role in survivorship care. Studies have shown willingness from PCPs and support from secondary care for greater primary care involvement in follow up, provided there is the provision of adequate guidelines, educational support (knowledge and skills), clear lines of communication with easy access back into secondary (hospital) care, robust monitoring systems in place in primary care and adequate resourcing.<sup>187, 188</sup> Patients recognise the potential benefits in terms of convenience, familiarity, knowledge of co-morbidities and family situation offered by primary care, but have

also expressed concerns about PCPs having the required level of knowledge.<sup>188</sup> Some gain considerable reassurance from on-going hospital follow-up, although it has been acknowledged that patients are not well-informed about the evidence for the benefits of conventional follow-up appointments this may alter if the evidence for the benefits of follow-up was better understood.<sup>189</sup>

To promote communication between all providers of cancer care (secondary and primary care) and the patient, survivorship care plans were recommended by the Institute of Medicine (IOM) in its 2005 report *From cancer patient to cancer survivor: Lost in transition*.<sup>190</sup> These plans were intended to make it explicit what the diagnosis was, treatment received, and specific recommendations for care going forward. The latter includes surveillance for recurrence, reminders to not ignore any non-cancer comorbidities and other screenings and preventive health maintenance, and guidance around common survivorship issues like long-term and late effects, psychosocial concerns, employment, and insurance challenges. The plan would also identify which specific provider was responsible for which aspect of survivorship care.

Although there is general agreement that survivorship care plans would be desirable, their uptake in the US and elsewhere has been slow.<sup>191</sup> This is largely because oncology providers have had difficulty incorporating their creation into routine workflow, mainly because of the time required. Moreover, randomized trials of survivorship care plans have been unable to detect an improvement in outcomes.<sup>192-194</sup> Recognizing these challenges, efforts have recently focused on identifying the essential elements necessary for communication and care.<sup>195</sup> The actual form the plan takes is a secondary consideration. Informal communication is preferable to no communication. Survivorship care planning must be tailored to accommodate the specific needs and capabilities of all involved.

PCPs now play a large role in managing the on-going care of patients with complex health conditions such as diabetes, coronary artery disease and COPD – and some advocate that cancer follow-up care could similarly be shifted to primary care for certain cancers and for ‘low risk’ individuals. Others favour an integrated or shared care approach with a level of hospital contact maintained at least for the first period of survivorship. Two trials comparing primary and secondary care follow up for breast cancer<sup>196, 197</sup> and one for colorectal cancer<sup>198</sup> suggest no differences in quality of life, patient satisfaction or clinical outcomes (recurrence and survival). 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.<sup>199</sup>

Further work is required to ascertain the most appropriate role for primary care. Secondary care based, nurse-led clinics using remote follow-up (e.g. telephone, internet, postal) or outreach clinics based in the community provide alternative models requiring less 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 at least some cancers become more akin to other chronic conditions, primary care has a potentially important and increasing role to play.

### **Action points 5**

New models of cancer follow-up care are required that draw on the principles that apply for other long term conditions

Following further development to arrive at the optimal model, survivorship care plans should become a feature of follow-up care

The role of PCPs in survivorship care needs to be more clearly defined.

## **Part 6: Palliative care in Advanced Cancer**

A third of patients diagnosed with cancer will die from their disease.<sup>200</sup> The conceptual approach to the transition from curative to palliative treatment intent has changed from being a point in time to being a gradual introduction of the idea of hoping for the best but preparing for the worst. As the chance of cure diminishes, there is less of a role for oncology treatments and more involvement of palliative care. Patients frequently want to spend most of their time at home and most express a preference to die there.<sup>201</sup> While this requires a significant role for primary care, this transition may be from specialist team to specialist team, with little thought of engaging the primary care doctor in a meaningful way.<sup>202</sup>

Although ideally all PCPs would be involved in palliative care, the rate of their involvement in palliative care in developed countries ranges from around 85%<sup>203, 204</sup> to less than 50%.<sup>205</sup> There may also be differences in PCP involvement between urban and rural settings.<sup>202</sup>

Palliative care and primary care practice 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 issues. The difference is that palliative care is more intense and shorter timeframe, compared with broader primary care. The *nature* of the care is the same.

We examine the evidence for and against primary care involvement, the barriers and facilitators that exist, and describe the level of primary care involvement that health systems should aspire to.

### **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 the life-threatening disease, meet all dimensions of need (physical, social, psychological, spiritual), provide care in clinics, care homes and at home thus preventing unnecessary hospital admissions, and support family carers and provide bereavement care.<sup>206</sup> Having a regular PCP, particularly one who does home visits, increases the chance of dying at home<sup>207</sup> and reduces emergency department visits.<sup>208</sup>

Done well, primary palliative care is valued by patients and carers.<sup>209</sup> Accessibility is an important element of their satisfaction<sup>209</sup>, as is symptom control.<sup>210</sup> However, there is considerable room for

improvement,<sup>210, 211</sup> with lack of confidence and unwillingness to assume responsibility for palliative care being major factors.<sup>204</sup>

*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 healthcare system, access to essential medicines, the existence or otherwise of community nurses attached to primary care, and health insurance arrangements.<sup>212</sup>

The WHO Public Health Strategy for palliative care describes four domains of public policy to facilitate community based palliative care.<sup>213</sup> (Figure 6.1) Primary care involvement in palliative care should be embedded in all of these domains.

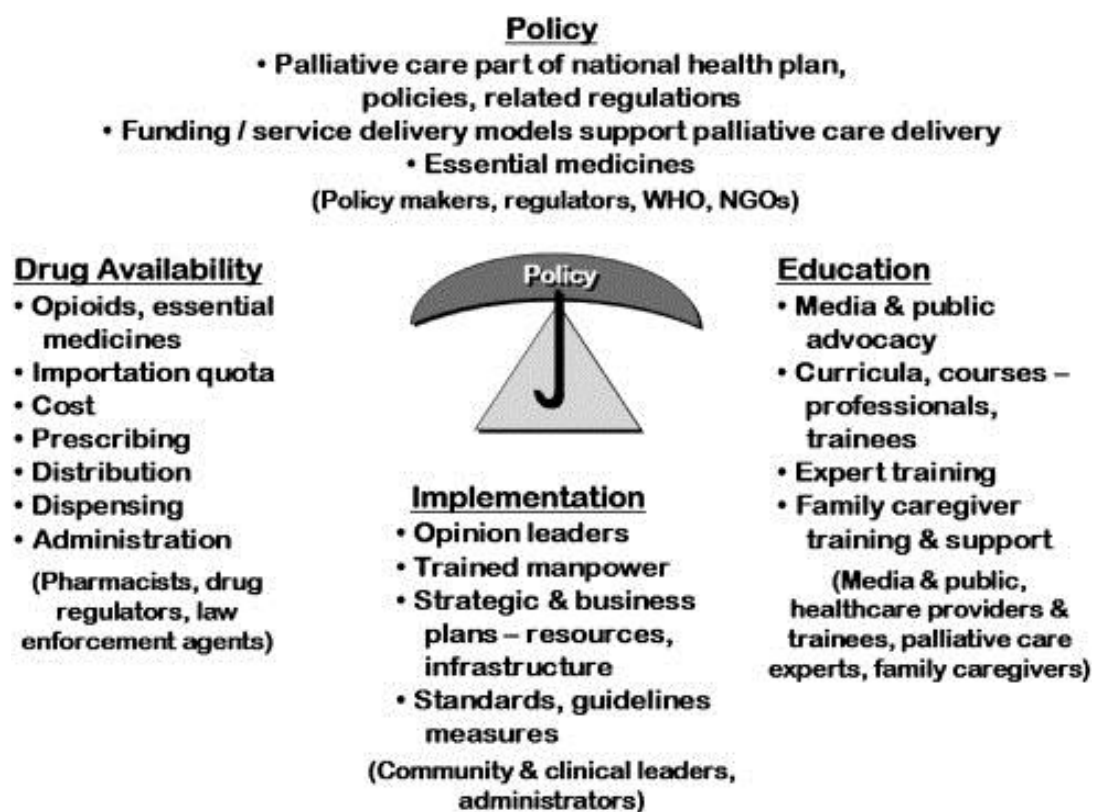


Figure 6.1: The WHO policy for successful integrated palliative care

Governmental health policies will in future be judged by the WHO in part on the basis of their delivery of palliative care.<sup>214</sup> Because most deaths will not involve specialist palliative care practitioners, facilitating primary care practitioners to deliver timely, 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.<sup>212</sup>

National policy settings that facilitate this in primary care are not always in place. Of 20 European countries reported in an EAPC sponsored review<sup>212</sup>, 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 half 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, while specialist support ranges from extensive to limited.

#### *Availability of appropriate medicines*

In order to deliver palliative care in the community, PCPs must have access to appropriate medicines and education in their use. Both the World Health Organization (WHO) and IAHPHC have published lists of recommended medicine lists for palliative care.<sup>215, 216</sup> Symptom management guidelines have also been developed within specific countries, and reflect the national and local availability of particular medicines.

#### *Barriers to primary palliative care*

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

*Logistical issues* related to time and traveling to provide home visits are cited by PCPs as prominent barriers<sup>203</sup>, particularly outside of regular office hours. Providing 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.<sup>204, 217</sup>

Willingness to provide care after hours varies widely by country. In part it depends on remuneration and availability of large-scale out-of-hours cooperatives.<sup>218</sup> Out-of-hours availability correlates positively with PCPs' perceived duties of care, and negatively with being in a salaried job, working in a city-based practice, and living far from the practice.<sup>219</sup>

Issues related to organization of care are prominent if potentially modifiable barriers to palliative care provision by PCPs. Patients may lose contact with their PCP after they are diagnosed with cancer.<sup>220</sup> It then becomes difficult for the PCP to become re-involved at the end of life in the care of a patient with whom they have had little contact. This issue may be compounded by poor communication between specialists and PCPs.<sup>221</sup>

Both oncologists and PCPs may have difficulties recognizing patients who are in need of palliative care, resulting in delayed referrals and poor planning.<sup>222</sup> Prognostic estimates are notoriously optimistic<sup>223</sup> and this may delay the commencement of a palliative approach and increased support, particularly in countries such as the United States where hospice services are linked to a prognosis of less than 6 months.<sup>224</sup>

Once PCPs are involved in palliative care, there may be other barriers on an organizational level. Dutch PCPs reported that it was time-consuming to arrange home care services or procedures such as oxygen, intravenous medications, or paracentesis, and difficult to obtain extra care.<sup>217</sup> Those in rural areas may have less access to education programs and advice from specialists.<sup>225</sup> Lastly, they may feel that palliative care is not sufficiently valued or remunerated.<sup>206</sup> extra fees are available for palliative care home visits in the Netherlands, Norway and Denmark but not in the UK; in Luxembourg patients must pay directly for home visits.<sup>212</sup>

Lack of expertise in providing palliative care is another prominent barrier.<sup>226</sup> One systematic review 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.<sup>227</sup> Subsequent surveys have confirmed that these inadequacies persist although interest in education in palliative care is strong. Lastly, they may not involve themselves in palliative care because they have little or no interest in doing so, or because of personal or family commitments.<sup>204</sup>

#### *Enablers for PCP provision of palliative care*

The success of some countries in addressing the barriers described above can be attributed largely to structured programs, services and educational opportunities to support PCPs in the provision of palliative care.

In a survey of PCPs 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 >8 physicians.<sup>203</sup> In some countries such as 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 primary PCP to the out-of-hours service. When such transfer does occur, it is associated with positive outcomes including fewer hospital admissions.<sup>228</sup> 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 and wishes.<sup>229</sup> Access by the covering physician to patients' electronic records promotes continuity of care, and provides medical information for patients whose decline was not anticipated.

Collaborative care is important not only among GPs, but also between GPs and other health care providers, including oncologists, community nurses, and palliative care specialist teams. Patients value ongoing care by their GP but are at times unsure of their GP's role following a cancer diagnosis.<sup>230</sup> Oncologists can promote continued involvement of GPs throughout the cancer trajectory by regular communication about their mutual patients and by encouraging patients to continue to maintain contact with their GP.<sup>230</sup> Interdisciplinary teamwork can facilitate the organisation of care; for example the job of coordinating palliative care, may be delegated to community nurses, with the GP acting as a point of contact for problems.<sup>231</sup>

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,<sup>232</sup> enable patients to die in the setting of their choice<sup>233</sup> and play an important role in supporting PCPs. PCPs may work with these services in different ways, using them as a resource, working together as an extended team, or handing over responsibility completely. Clear allocation of responsibilities is important, whichever model is adopted.<sup>234</sup>

In addition to support from palliative care teams, education of PCPs is essential to increase their confidence in providing palliative care. This includes improved palliative care education during medical training, continuing education through workshops, online courses and training programs, and access to resources such as care pathways and websites. In countries such as Japan, courses have been developed to provide primary palliative care education in primary care.<sup>235</sup> Electronic



resources such as Caresearch in Australia provide access to comprehensive educational and research material.<sup>236</sup>

In the UK, initiatives like the Liverpool Care Pathway (LCP) and Gold Standards Framework have been developed to improve end-of-life care in generalist settings.<sup>237, 238</sup> The importance of applying the principles of end of life care planning properly, using them as a guide to high quality care and not simply a task to be signed off, has been demonstrated by the criticism that application of the LCP has received, and the recommendation to refer to end of life planning rather than a clinical pathway.<sup>239</sup>

Specific tools and interventions have also been designed to promote early identification of patients with palliative care needs. Simple prognostic tools have been developed based on 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 one-year survival of patients with advanced cancer.<sup>240</sup> In Ontario, Canada, symptom screening together with symptom management guidelines has been incorporated into all cancer centres<sup>241</sup> and is now being incorporated into the practices of PCPs. A range of tools to identify patients in primary care at risk of dying from cancer and other causes have been developed or are in various stages of testing.<sup>242</sup> They all use a combination of subjective clinical judgement, non-specific indicators of deterioration, and disease specific markers of deterioration to highlight people at risk of dying.

There is also increasing acknowledgement that palliative care is emotionally taxing for those providing it and that self-care of PCPs is essential to mitigate compassion fatigue and burnout.<sup>243</sup> Specific interventions that increase self-awareness, as well as informal self-awareness practices, may enable physicians to continue providing palliative care with empathy and effectiveness.

### **Facilitating primary care into multidisciplinary care**

Appropriate end of life cancer care should be needs-based with the level of services matching the complexity of need. For most of the cancer journey, the problems the patient will face are relatively straightforward and well within the competency of the PCP. Specialist involvement could range from a telephone consultation to 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 evaluating patient needs regularly, using a needs assessment tool, optimizes the use of scarce resources, and reduces the intensity of patient and carer needs.<sup>244</sup>

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 and active engagement with the patient and carer, the health system clarity, and effective management systems and decision making capacity.<sup>245</sup>

The fragmented nature of some health care systems can make the engagement of primary care in the management of advanced cancer patients an operational challenge. However, the outcomes may be worth the effort. For example, two RCTs have shown a single case conference involving a PCP and specialist palliative care team confers benefits, including improved patient performance capacity, less hospital and ED referrals<sup>246</sup>, and improved quality of the patient's life in the last month of life.<sup>247</sup>

PCPs also have a role in caring for the carers of persons with advanced cancer. The use of a self-completed 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, which potentially allowed them to be addressed.<sup>248</sup>

### **Advance care planning**

Advance care planning is a process that allows people to express their choices about their future care in a document that is legally binding should they become incapable of expressing them due to advancing illness. Most developed countries have enacted legislation to facilitate 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.<sup>249</sup> The process may also facilitate a more timely, 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 in to account the patient's goals of care and treatment wishes can ensure that they are enacted. The absence of this sort of approach may lead to a more reactive, crisis driven form of care. (Figure 6.2)

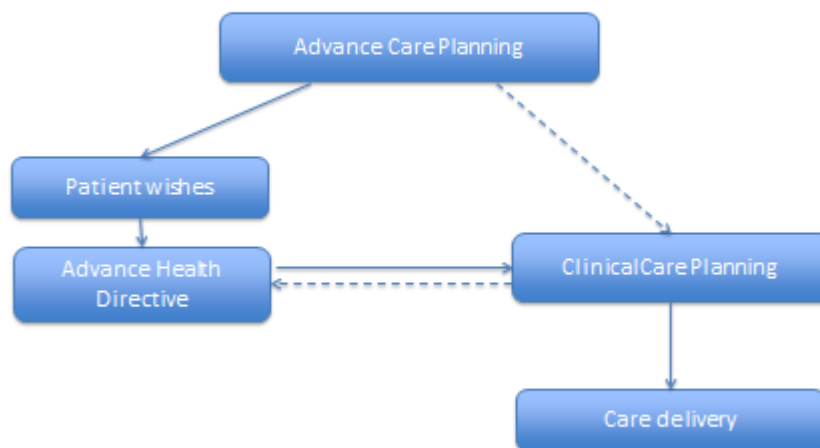


Figure 6.2 Conceptual map of advance care planning

### **Ideal primary palliative care for advanced cancer**

A person with advanced cancer who approaches the end of life would ideally have this recognized 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 assessing and managing 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 patients' wishes, and ensured that each team members' responsibility were 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 person, performing home visits where necessary. He or she would have had effective training at undergraduate and vocational training levels and would have been treating palliative patients from the beginning of their professional career, receiving subsequent case based training through shared care of multiple patients over time. The PCP would have ready access to, and use regularly, evidence based treatment guidelines. The care provided would extend to the bereavement phase of the carer. Lastly, the health system would recognize the complex nature of this care, and provide appropriate remuneration for the extra effort involved.

## Action points 6

- Palliative care services should be integrated and be based on the WHO Public Health Strategy for palliative care
- PCPs should participate in provision of palliative care. They should be supported, provided with high quality training and adequately resourced to do this.
- All patients receiving palliative care should have an advance care plan, which should include a plan for their clinical care

## **Part 7: Integration between Primary Care and Cancer Specialist Care**

Integration of services between primary care and cancer specialist care is vital to optimize the quality and outcomes of care,<sup>250</sup> and yet is known to be problematic.<sup>251</sup> Patients often need to consult many health professionals across multiple healthcare settings. This can lead to fragmented and uncoordinated care<sup>190, 251</sup> which, in turn, can jeopardize quality and patient safety.<sup>252</sup> Accordingly, introduction of models and tools to improve integration is essential to optimize the role of primary care along the breadth of the cancer care continuum. We review here approaches to models of care, how these can be applied to the structuring of healthcare services, and tools that have the potential to facilitate integration between primary care and cancer specialist care.

### **Part 7 Panel: Integrated Care: Elements and Tools**

Elements of Integrated Care:

Clinical Integration:

- Establishing processes to coordinate patient care
- Clear definition of clinical roles, including interdisciplinary health professionals

Vertical Integration:

- Establishing structures and processes to support coordination between the formal cancer system and community-based primary care

Functional Integration:

- Establishing structures and processes to enhance coordination between providers in health and non-health settings

Tools to Facilitate Integrated Care:

- Care paths
- Education and audit
- Patient Navigation
- Electronic Communication Tools

### **Models of Integrated Care**

The concept of care integration is pervasive in the medical literature, especially when considering the care of cancer patients with complex medical and psychosocial needs that is delivered by a variety of providers with distinct roles and skills. Integration between

providers is defined as the process of creating and maintaining a common structure and connection between different providers for the purpose of coordinating patient care, while retaining each provider’s unique role.<sup>253</sup> Integration can be seen to have 3 core elements<sup>254</sup> that need to be considered in the design of models of care (Table 7.1).

<p><b>Clinical integration:</b> the extent to which patient care services are coordinated across the various functions, activities and operations units/levels of the cancer system. These would involve structures and processes to define and clarify clinical roles and can include education and training of interdisciplinary health professionals such as patient navigators or clinical nurse specialists.</p>
<p><b>Vertical integration:</b> structures and processes to support regional collaboration, coordination and leadership with respect to the delivery of cancer services both in the formal cancer “system” as well as in community settings that involve cancer and non-cancer providers. Examples would include care pathways and guidelines for care.</p>
<p><b>Functional integration:</b> structures and processes to support key coordination activities across providers such as platforms to enhance communications such as electronic tools. These structures and processes can also enhance connections between providers in health and non-health (e.g., social care) settings, fostering horizontal integration especially at the level of the community.</p>

Table 7.1 Elements of integrated care

These elements of integration are brought together operationally in the way in which health services are structured through the design of models of care,<sup>255</sup> which represent a systematic approach to achieving high quality, holistic care that address all the needs of patients living with cancer.

The components of a model of care include the settings (cancer centre, hospital or community) and providers (oncologists, nurses, family physicians) involved with operational specifics (care pathways, care plans, information systems) informed by the elements of integration. There is fairly well established evidence to support the transition of well patients with certain cancers during survivorship to primary care settings.<sup>256</sup> This body of research demonstrates equivalent cancer outcomes, better overall care (through management of non-cancer health issues) better supportive care and lower cost.<sup>257</sup> For many cancer patients with ongoing complex needs during and after cancer treatment, a

shared care approach is proposed,<sup>258</sup> but the operational specifics are more involved and published evidence on how to achieve this even in settings where primary care is well established, are limited. In the subsequent sections we review how healthcare 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 Healthcare Services**

The possibilities for integration depend on the actual organisation of the healthcare system and are very different for high-income and low-income countries, as well as for the different stages of the cancer continuum. While much of the available research reflects efforts to transfer, substitute or relocate from specialised treatment to primary care, there are very few examples of real integration.

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 (e.g. smoking and taxes) together with environmental and occupational initiatives. In low and middle income countries, where prevention might be the most effective approach to cancer control WHO has proposed a model for integrating primary prevention with screening (secondary prevention of asymptomatic disease)<sup>259</sup> so that primary care forms a clinically integrated system linking the two.

In many countries although screening programmes are centralized and managed by health authorities, they are usually integrated between primary and secondary healthcare (although there are substantial difference among systems). The main efforts of such programmes relate to maximising uptake, improving access, and providing efficient screening. In high-income healthcare systems it seems that integration between primary and secondary care increases these measures of screening effectiveness.<sup>260</sup>

Cancer diagnosis relies on an accessible healthcare system and access to relevant investigations; thus well-established integration between primary and specialist care is critical. There is an ecological association between health care systems where primary care functions as a gatekeeper and poorer cancer outcomes.<sup>44</sup> It has been suggested that this is not due to the gatekeeper function *per se*, but rather to the lack of integration with respect to PCP access to cancer investigations (e.g. imaging and endoscopies). This concurs with

studies showing better cancer control where there is better access to both primary care and specialised care.<sup>261, 262</sup> Research has shown that integrating cancer investigations is possible and might have positive effects.<sup>263, 264</sup> In a number of healthcare systems urgent referrals pathways for suspected cancer have been implemented as a means to integrate primary care and specialist care.<sup>16, 265</sup>

Very little research has been done on integration during cancer treatment<sup>257</sup> and has mainly been focused on information and communication skills. There are, however, important reasons for better integration of primary care and specialist care during active cancer treatment: symptom control<sup>266</sup> and management of toxicities to avoid emergency department visits and hospitalizations;<sup>267</sup> management of patients with concurrent mental health problems;<sup>268</sup> and management of geriatric patients with multimorbidity.<sup>269</sup>

Follow-up, after-care and survivorship after cancer diagnosis has traditionally been based on specialist care. However, acknowledgement of increasing cancer incidence and concerns about efficiency have fostered calls for studies on integrating follow-up care after cancer.<sup>270</sup> Randomised trials evaluating primary care led follow-up of cancer survivors in the UK<sup>196</sup>, Canada<sup>197</sup> and Australia<sup>198, 271</sup> show that integrating follow-up produces improves patient satisfaction with no negative consequences on cancer outcomes and better cost-efficiency.<sup>196, 197</sup>

Palliation is an area with a long tradition for integration of primary and specialised palliative services, largely predicated on models of shared care and collaborative care and is addressed more fully in section 6.

## **Tools for Better Integration**

### *Care paths*

Care pathways for patients with 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 cancer or via primary care, whether presenting with or without “alarm symptoms”, or as an emergency with for example bleeding or perforation. It is crucial that regardless of route of presentation, care pathways are coordinated so that there is no delay in investigation and diagnosis, accepting that the vast majority will not have cancer.



In the developed world the management of cancer is now multimodal usually involving a combination of surgery, radiotherapy, chemotherapy and hormonal manipulation. This requires management by a multidisciplinary team. Such teams are usually led by a surgeon or oncologist assisted by a pathway manager, a role usually filled by a nurse specialist or administrator who provides a direct point of contact for the patient and carers, and ensures full distribution of decisions of the multidisciplinary team.<sup>272</sup>

As care becomes more complex, communication between patient, carers, primary care physicians and the clinical team is vital and this is best managed through frequent multidisciplinary meetings<sup>273</sup> and joint specialist clinics with same day communication with primary care. The care pathway must be flexible for the individual and not driven primarily by prescribed targets. Such pathways have led to centralization of services which for certain cancers (e.g., oesophagogastric) has improved the surgical outcome.<sup>274</sup> It is important however to ensure that as much of the pathway (diagnosis, staging) as possible is delivered close to home, restricting travel to what is necessary for essential oncology and surgery.

In conclusion, care pathways for cancer are complex and multifaceted. There is good evidence that they have standardized outcomes for high-risk cancer within and between countries<sup>25, 47</sup> They start with presentation and involve all specialties with the patient and carers at the centre. Quality of life is central to all decisions and the pathway should be adapted to take account of advances in treatment and patients encouraged to be enrolled in trials wherever possible.

#### *Education and Audit*

Education is arguably the cornerstone of integration of cancer care across sectors. Education must flow both ways, be tailored to full range of primary care and specialist health professionals involved with cancer care, and inform the changes needed to achieve highest quality care. This will be an enormous, costly and time consuming agenda, particularly because evidence is lacking as to the optimal modes of education to improve integration of primary care and oncology.

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 it is still uncertain whether education is best delivered in a multidisciplinary format.<sup>275</sup> Given the breadth of the cancer control continuum,<sup>9</sup> relevant education for health care professionals will vary along the continuum, by tumour type, age of the patients, and multimorbidity. This must be complemented by education about communication systems, referral and re-referral processes, team coordination, and processes of care. Integration will ideally lead to a patient experience of 'seamless' care, informed by both their needs and high quality, equitable provision. Cross sector education about key differences in the prevalence and presentation of disease in each 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,<sup>5</sup> or ongoing management of cancer care<sup>276</sup> and statements promoting shared care models<sup>277</sup> should inform international curriculum development.

There is little research regarding the most effective type of educational interventions for enhancing integration of cancer care. Outcomes should include improvement of systems, better communication, improved knowledge and diagnostic expertise, and increase in relevant competencies across sectors. Agreed curricula across and between primary and specialist care are needed. One relevant systematic review from the US, regarding skin cancer education for primary care physicians showed promising effects from a range of isolated educational interventions but noted the need for improved methodological rigour.<sup>278</sup>

Cross national audit is a powerful tool for illuminating variations in care that could be addressed with specific interventions at the primary care / specialist interface. The International Cancer Benchmarking Partnership, considered in more detail in Part 8, has illustrated large national variations between national guidelines and patterns of cancer care, and highlights what countries can learn from each other.<sup>279</sup>

Effective audit and education needs 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 improving integration across sectors will be unified electronic information systems across sectors; good education and training in the use of

such systems across sectors will allow for harmonization of 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 areas suggests they tend to make small but important improvements in clinical practice.<sup>280</sup>

Finally it will be important to harness educational capacity from health care providers, the higher education sector, and third sector sources. Some clinicians already working at the primary / specialist interface, such as nurse specialists, may 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 has its origins in 1990 with an initial demonstration project in Harlem, NYC to address disparities in access to cancer services for vulnerable populations.<sup>281</sup> The principle of navigation is to provide active coordination of care that removes barriers to access. Navigation programs 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 a number of providers are needed to manage both cancer and non-cancer health issues. Most studies of navigation in cancer have involved nursing in this role. A recent randomized trial of use of a navigator early in the care trajectory of newly diagnosed breast, colorectal and lung cancer<sup>282</sup> demonstrated clear improvements in the patient experience over usual care, and greater adherence to therapy, although no differences were seen in quality of life. The role of a navigator may be of particular interest during active therapy. A navigation program that coordinates care between primary care providers and oncologists in vulnerable populations such as the elderly, patients with pre-existing significant co morbidities and those undergoing complex therapies with significant toxicity (for example head and neck cancer patients) could overcome gaps in the management of comorbid conditions that result in suboptimal outcomes. Given 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 and the computerization of clinical practice, electronic tools are being widely implemented in the care of patients across the cancer care continuum; computer-based risk assessment tools are being employed for screening, decision-support systems are being used at points of diagnosis and treatment, and secure patient portals facilitate remote or self-management of symptoms and side-effects.<sup>283, 284</sup> Electronic communication between patients and physicians could bring about care that is individualized and make information readily accessible across settings.<sup>285</sup> 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 of facilitating care processes<sup>286</sup> and there is evidence to suggest that electronic patient-physician communication can lead to improved clinical and patient-reported outcomes.<sup>287</sup> There is relatively little research available on electronic communication tools in the cancer context but there is ample scope for such tools to be used to connect primary care physicians and cancer specialists to improve continuity of care.<sup>287</sup>

### **Conclusion**

Better integration between primary care and cancer specialist care throughout the cancer care continuum is vital to improve the quality of care. We have summarized a range of strategies that have the potential to facilitate better integration: the way in which healthcare services are structured, care paths, education and audit, care navigation, and electronic communication tools. However, to date, the extent to which any of these strategies have been evaluated and implemented is limited. Rigorous evaluation through pragmatic randomized trials and assessment of how differing contextual factors might impede or enhance effectiveness is warranted.

## Action points 7

- Care pathways are key to integrated care but effective lines of communication are vital for their success
- Cross-sectoral 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 of enhancing integrated care and should be further evaluated
- Healthcare providers and policy makers must adapt evidence-based models and tools to improve integration between primary care and cancer specialist care for each phase of cancer control .
- These must be introduced with strategies for implementation, adoption, and sustainability that are of proven effectiveness.

## **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 aging population, the number of cancer survivors is also increasing due to improvements in diagnosis and treatment. However, these gains are not experienced in every health system or in every social group with some countries performing much better than others and some population groups experiencing better care and outcomes. The reasons for this variation are complex and for the most part remain poorly understood.

This somewhat mixed picture has significant implications for primary care both in terms of early diagnosis and after-care. Family physicians will treat more cancer survivors in future years since we know that cancer survivors visit their PCP more often than non-cancer controls.<sup>164</sup> A recent report from the Institute of Medicine concludes that the needs of cancer survivors are not being adequately addressed.<sup>190</sup> These needs centre on psychosocial support, treating the long-term complications of cancer treatment, addressing on-going symptoms, recurrences and new cancers, and accessing information about the disease. They are all tasks that PCPs are well-placed to perform.

Starfield has shown that investing in primary healthcare is the foundation of any high performing health system.<sup>27</sup> Countries with stronger primary care generally have healthier populations and a more equitable distribution of health in populations, a finding that holds in studies across and within countries. Such a development is also supported by other policies aimed at universal health coverage promoted by the WHO and World Bank. In many countries, there is growing emphasis on models of integrated care which bring together primary, secondary and social care. Integrated care lies at the heart of moves towards universal health coverage. 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, but also because they are seen to improve patient outcomes. This section is structured around three key areas affecting the performance of primary care in cancer control: lessons for policy-making from international comparisons; primary care, cancer and gatekeeping; and financial incentives to improve the quality of cancer care.

Panel

**Key policy areas affecting the performance of primary care in cancer control**

- **Lessons from international comparisons:** there is variation in public awareness, attitudes and beliefs about cancer. There are also differences in health care systems but the role of organisational factors is inconclusive
- **Financial incentives:** Financial incentives to doctors or to patients may improve the uptake of screening tests for cancer but there is no evidence that they would improve other aspects of cancer care.
- **Gatekeeping:** there is little research on its impact on quality of care, but it may lead to rationing of PCPs' use of investigations.
- Improvements to the gatekeeping role and cancer diagnostic pathway may achieve greater gains than incentivisation

**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 cancer patients in different European countries since 1995.<sup>288, 289</sup> 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, the publication of data from the EURO CARE-2 study in 1999 underpinned the launch of the first NHS Cancer Plan in 2000.<sup>290</sup> UK policy responses initially focused on improving the effectiveness of treatment services; however, attention has more recently shifted to timeliness of presentation and diagnosis.<sup>291</sup> A similar policy direction has been pursued in Denmark where poor cancer survival rates led to the production of three national cancer plans accompanied by significant additional funding. Comparisons with the other Nordic countries through the NORDCAN collaboration led to increased political awareness. While policy initiatives have focused on cancer treatment outside primary care, in recent years there has been a growing awareness of the important role of primary care in improving outcomes.

Two important observations can be drawn from the current landscape of international comparative studies of cancer outcomes. First, with few notable exceptions including the two CONCORD studies,<sup>292, 293</sup> most of the research is concentrated in a small number of countries with a relatively high index of human development. Secondly, again with few notable exceptions, the vast majority of available evidence relates to a single (albeit important) outcome measure, namely cancer survival. There is a distinct paucity of comparative evidence about the population and healthcare 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 – including that of patients with advanced disease.

Knowledge concerning the reasons for variations in cancer outcomes is difficult to acquire but evidence about variation in determinants of survival is required to support cancer control policies. Increased attention to the diagnostic pathway and role of primary care has led to the formation of the International Cancer Benchmarking Partnership (ICBP) project, involving 12 jurisdictions in 6 countries (Australia, Canada, Denmark, Norway, Sweden and the UK).<sup>279</sup> ICBP is a comparative multi-modular study that aims to both deepen and complement epidemiological evidence with studies of variation in psychosocial or healthcare factors. ICBP evidence thus far has confirmed variation in survival between jurisdictions.<sup>294</sup> Furthermore, ICBP studies indicate 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. Fig 8.1) Still, such differences might be important as there is also variation in how healthcare systems are organised around the cancer diagnosis. Nevertheless, evidence about the role of organisational factors (including, for example, the way primary care is organised, the way new treatments, including pharmaceutical and interventional treatments are introduced in clinical practice after health technology assessment, and the role of private medical practice or insurance coverage) is inconclusive.<sup>40</sup>



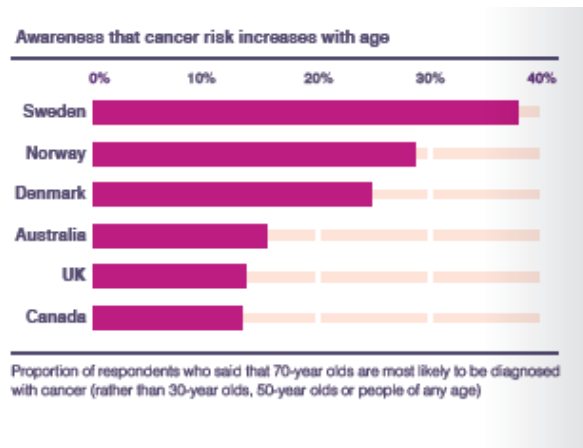


Fig 8.1 Inter-country differences in awareness of cancer risk <sup>295</sup>

### Primary care, cancer and gatekeeping

A key feature of strong primary care systems is the gatekeeping role, acting as the first line of the health care system.<sup>296</sup> Gatekeeping can be combined with a patient list for which the GP 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 policymakers for reasons of resource management. While people should have access to the health care they need, at the same time health care has to be affordable. Encouraging patients to seek support from general practice in the first instance conserves hospital resources and is therefore seen as desirable and more cost-effective. Consequently, some health care systems provide health care enrolment at reduced cost if people choose to have a gatekeeper and register on a list.<sup>297</sup> In many gatekeeper systems, 90-95% of all patient contacts are managed solely in primary care.<sup>298</sup> 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.<sup>299</sup> A gatekeeper system has an important impact on the role of primary care in preventive work and health promotion, in diagnostic work, in the treatment of minor illnesses, in visits to specialised treatment, rehabilitation and follow-up. Despite its significance as a mainstay of effective primary care, remarkably little research has been conducted on the possible impact of gatekeeping on the quality of care.

### *Prevention, screening and health promotion*

Primary care has been successful in delivering evidence-based screening tests, e.g. cervical cytology, and HPV immunisation. Health care systems with a gatekeeper function are associated with higher utilization of recommended cancer screening procedures compared to those without.<sup>300</sup>

### *Diagnostic work up*

Although there has been a tendency to blame GPs for poor and slow diagnosis, causes of delays are much more complex and multifactorial, and inadequate clinical competence is an unlikely cause.<sup>10</sup> 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 spectrum of symptoms.<sup>9</sup> Good access to primary care may be a factor in providing better diagnosis of cancer, though the evidence for reform of access to specialist assessment reducing time to diagnosis is stronger.<sup>301</sup> In contrast to this view is evidence of a correlation between lower cancer survival and the strength of the gatekeeper system – although other country-level factors (such as service organisation) may also be involved.<sup>44</sup> This suggests that in some health care systems the gatekeeper is rationing the use of investigations by setting a higher threshold for referral. Further, the pivotal interaction between patient and GP can be adversely affected if the GP is reluctant to refer, with patients coming to believe that symptoms have to be serious before visiting their GP.

Progress can be made by policies that aim to accelerate and integrate the diagnostic process. Recently, political awareness of this initial step in the diagnosis of cancer has led to the National Awareness and Early Diagnosis Initiative in the UK, the Danish 'three-legged strategy' for cancer diagnosis (Fig 8.2) (urgent referral for those with alarm symptoms, diagnostic centres for those with non-specific but serious symptoms, 'No-Yes clinics for other patients in whom the PCP needs rapid access to simple investigations in order rule cancer out (No) or in (Yes)) and most recently the ACE (Accelerate, Co-ordinate, Evaluate) initiative in the UK.<sup>302-303</sup> In Denmark, the diagnostic interval has shortened significantly and direct access to investigations has been appropriately utilised.<sup>301, 305</sup> Progress can also be made by technological innovation in point of care testing and detailed clinical audit studies. It is, however, important to realise that any system that makes referral contingent on the

presence of symptoms with a high positive predictive value risks delays in the diagnosis of those with less specific symptoms.

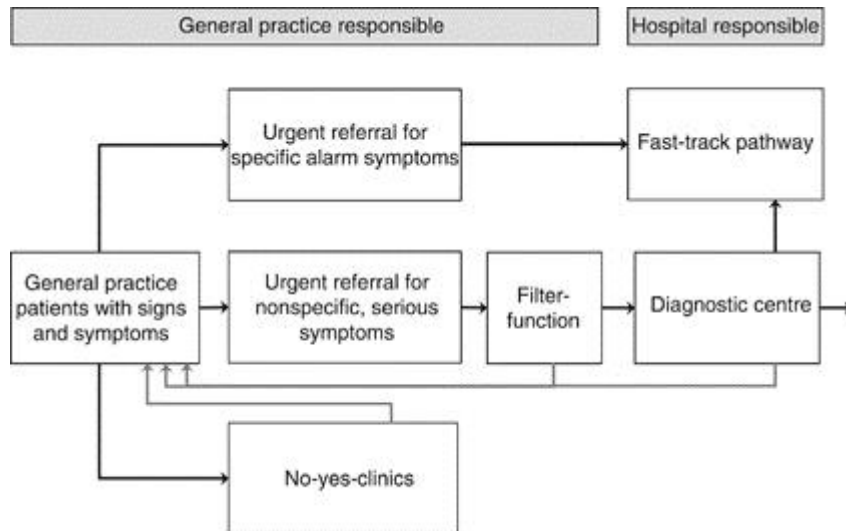


Figure 8.2 The structure of the Danish three-legged diagnostic strategy<sup>303</sup>

#### *Follow-up and survivorship*

The gatekeeper role in follow-up, survivorship and end of life care is addressed in an earlier section of this Commission.

#### **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, diagnostic and screening activity for each individual general practice has been collated since 2010 and reported publicly since 2013.<sup>306</sup> Summary statistics by practice are made available to practitioners and managers, to motivate reflective learning, and in recent years they are reported publicly. However, evaluations of the effectiveness of these quality improvement initiatives are lacking.

As is the case for any quality improvement policy, indicators need to reflect processes of care that are clearly amenable to improvement. In England, public reporting of the frequency of 3 or more pre-referral 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, for example the need for primary care investigations prior to referral.<sup>307</sup>

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 primary care practices had computerised medical records and the introduction of the incentive was associated with the rapid development of recall systems, and 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 there was a reduction in inequalities in the delivery of care over that period.<sup>308</sup>

In the United States, incentives to primary care clinicians to promote cancer screening are now common though not universal. Screening for breast, cervical, and colon cancer are HEDIS measures established by the National Committee for Quality Assurance to evaluate health plans<sup>309</sup> and to achieve high HEDIS scores, plans often provide incentives to primary care clinicians to promote screening, although monetary amounts vary considerably. Cancer screening as a measure of high quality care is also included in most emerging Accountable Care Organization (ACO) payment models. Although the distribution of surplus dollars is determined by each individual ACO, providing financial incentives to primary care clinicians based on achievement of specific quality measures is a common approach. Data regarding the impact of quality incentives are inconsistent though the size of the incentive is a likely predictor of impact.<sup>310</sup> The impact of removing incentives has only been reported in one study from Kaiser Permanente in the United States.<sup>311</sup> 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% between 2001 and 2005 when incentives were removed, to increase again in 2006-2007 when incentives were reintroduced. In the United States, 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 scheme<sup>312</sup> 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 – designed to strengthen the coordinating role of the primary care physician – is not known.

An alternative approach to incentivisation is to provide patients with financial incentives, mainly to attend screening programmes. A systematic review has suggested that for mammography, cervical cytology and faecal occult blood screening, financial incentives to patients could increase uptake rates.<sup>313</sup>

## **Conclusion**

While improvements in outcomes for and care of cancer patients have occurred there is more to be done building on past successes. Variations in outcomes and access to services persist and these are generally poorer for older patients and those from deprived socio-economic groups. Therefore countries with growing health inequalities and lacking universal health coverage are more likely to experience worse outcomes and poorer access to services. However, countries like the UK with universal health coverage has some of the highest health inequalities anywhere in the world with survival rates in England 10% lower than the European average with outcomes especially poor for older patients.

The causes of these deficiencies, as in other healthcare systems, seem to be due to a complex mix of factors, including patient attitudes and behaviours and poorer access to, and possibly quality of, diagnosis and treatment services,. The evidence concerning the importance of incentives is either mixed or lacking and they may be of limited utility in tackling the factors noted above. Introducing and sustaining improvements to primary care's gatekeeping role and attending to other aspects of the cancer care pathway may achieve greater gains and may be a better investment of resources. Finally, there is a need for further research to address important gaps in the international evidence base especially in regard to community and primary care policy initiatives and their impact.

#### Action points 8

- Health care systems must develop strategies that support primary care as the cornerstone in prevention, early detection, survivorship and palliative care
- A focus on integrating primary and secondary cancer care is an important priority for health policy
- Gatekeeper systems have an important impact on the role of primary care in many aspects of cancer control. More research is needed on their impact on the quality of care

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

In a 2006 Lancet Oncology editorial, Barton et al discuss cancer as a growing public health problem and emphasize the critical role of PCPs in providing patient-centred care for people affected by cancer.<sup>314</sup> PCPs are involved across the cancer care continuum from screening to end of life. A 2009 survey of PCPs in the USA showed that over 90% provided general medical care for people with cancer, over 50% assisted patients with decisions about treatment options and use of surgery, and 19% reported heavy involvement in cancer treatment.<sup>315</sup>

While the historic engagement of PCPs in cancer care provides some insights, it is insufficient to guide the future. Primary care will have to take a growing role in certain aspects of cancer care where previously it has been less involved, such as survivorship, palliation, 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 due to an aging population and improvements in cancer survival.<sup>316</sup> However, PCPs will face challenges in assuming a wider responsibility for the care of patients in whom cancer is diagnosed or suspected. None of these may be greater than the relative inattention to cancer education for generalist physicians, which begins in medical school, persists in specialty training, and continues in the domain of continuing professional development (CPD). While the reasons for this 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 the common diseases. The very strength of this system and its willingness to stand somewhat apart may have had the inadvertent effect of weakening the ability and confidence of other parts of the system, including primary care, to care for cancer patients. Earlier in this Commission, we have detailed the evidence for the quality of cancer care and patient experience that could be delivered in primary care settings and the cancer care system is turning increasingly to primary care to play a larger role. The challenge becomes one of equipping primary care for this work, and identifying the evidence-based educational strategies that will enable PCPs at all points in their training and practice to assume this responsibility.

## Part 9 Panel

- Cancer receives limited attention in undergraduate and registrar training and is seen as poorly taught.
- 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 to the multi-professional makeup of primary care services.
- Continuous quality improvement methods, such as audit and significant event analysis, can be integrated into the 'work' of primary care and are associated with optimal learning.
- Educational interventions for PCPs should be embedded into new models of shared care.
- Primary care itself – university departments, professional associations, vocational training systems – should take the responsibility for defining the cancer education needed for primary care trainees and practitioners

### *Cancer in undergraduate education*

Cancer education for PCPs begins formally in medical school. Surveys in several countries regarding curricula demonstrate problems in undergraduate oncology teaching.<sup>317</sup> In a recent Canadian survey, undergraduate oncology education was thought to be inadequate by 58% of curriculum leaders and 67% of medical students, and both agreed that oncology is the worst-taught of the medical subspecialties.<sup>318</sup> Recommended oncology curricula for medical students have been developed and promoted within the USA, Australia and the UK. Innovative programs such as oncology summer schools,<sup>319</sup> compulsory cancer medicine rotations,<sup>320</sup> and pairing of students with tutors in multidisciplinary team cancer conferences<sup>321</sup> 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 generalist physicians, in cancer care. Our focus here, however, will be on the status of cancer-related education in registrar/residency training programs 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.



### *Cancer in registrar training and CPD*

In the UK, the postgraduate GP curriculum is overseen by the Royal College of General Practitioners (RCGP). General practitioners (PCPs) in training need to provide evidence of learning against a series of "curriculum statements", summaries of what the RCGP considers is required to practise as an independent practitioner. Cancer is no longer presented as a curriculum statement, as 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 cancer patients during their GP placements. The RCGP has however identified cancer as an 'enduring priority' and is developing educational resources for trainees and practitioners, such as the Cancer Education Hub.<sup>322</sup> Other organizations, including the cancer charities, have also focused on primary care cancer education to support the CPD which is required by British PCPs as part of their revalidation. This CPD is provided in a variety of formats: lectures, seminars, e-learning and written material. Although revalidation is mandatory, there is no requirement for cancer topics to be included in the practitioner's portfolio. A recent review of educational interventions for PCPs 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.<sup>323</sup> The review found limited evidence for long-term effectiveness of any of these interventions.

In Canada, a 2014 survey of family medicine (FM) residents and residency program directors demonstrated 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.<sup>324</sup> No Canadian FM training programs 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 that serve as examination objectives for FM residents. Cancer is one of these areas, with seven "key features" identified.. Where CPD is concerned, several provincial cancer agencies have developed primary care education and liaison programs<sup>325</sup> These programs offer cancer education programs aimed at practitioners, with one publishing a comprehensive FP learning needs assessment.<sup>326</sup> 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 recognized 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 determine its detailed content, with national oversight by Australian General Practice Training and the Remote Vocational Training Scheme. Thus, although oncology is an examinable subject in the RACGP Fellowship examination, there will be significant variation across training providers in terms of time spent addressing learning in oncology. From the perspective of CPD, some State-based Cancer Councils deliver PCP education programs which are mainly seminar-based. Other more innovative programs have been introduced. In Western Australia, brief oncology placements for PCPs have been established focused on learning about common side-effects of chemotherapy and their management. To better meet the needs of rural PCPs, Cancer Australia, a federal cancer agency, has developed an online 'Education Program in Cancer Care'.<sup>327</sup>

In summary, several jurisdictions have formalized oncology-related learning outcomes for registrar training. These necessarily must compete for attention with many other priorities in crowded general practice training programs, 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 in offering cancer-related CPD to primary care. Given this present reality, it is pertinent to ask two fundamental questions. First, what are the present trends and best practices in both registrar training and in CPD that will need to be capitalized on to equip primary care to play a larger role in cancer care? Second, who should take the lead in ensuring that this education happens?

#### *Trends in medical education*

Competency-based education is marked by an emphasis on the demonstration of outcome abilities and is organized around competencies derived from an analysis of societal and patient needs. It de-emphasizes time-based training and promises greater accountability, flexibility, and learner centredness.<sup>328</sup> While the main focus of this approach has been on postgraduate training,<sup>329</sup> these training periods are short, and advanced competencies need to be defined by and for physicians in practice to provide guidance for CPD.<sup>330</sup> Examples of

emerging competencies for practising PCPs include areas outlined earlier in this Commission: the application of tools such as QCancer and RATs to perform risk assessments of possible cancer symptoms, incorporation of genetic risk assessment tools into practice, screening for distress and psychosocial difficulty in cancer patients, and surveillance and management of both long term and delayed, "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 described earlier. They need to reflect broadly defined physician roles such as those enunciated in the Canadian CanMEDS Competency Framework,<sup>331</sup> particularly the 'communicator' and 'collaborator' roles that are central to cancer care.

#### *Trends in practice organization and education*

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 locus for care for the patient are therefore a solution that may better address the needs of patients and practitioners themselves. The key however is creating a team that shares a common goal and manages the interdependent tasks of caring for a single individual over time. Such tasks could include the management of cancer rehabilitation, co-morbid conditions, alleviation of symptoms, and the anticipation of end of life care. As interest and promotion of team based care has grown, there has also been a corresponding emergence of team-based education, or "team training." In the USA, TeamSteps was created by the Agency for Healthcare Research and Quality to promote increased safety in medical practice.<sup>332</sup> This workplace-based program encourages teams to assess themselves and their environment, and provides education regarding the skills fundamental to successful teamwork. These include situational awareness, closed loop communication, mutual support, and team structure. A large body of literature demonstrates the success of such training in achieving improved skills and reduced errors in a variety of settings.<sup>333-335</sup> The application of team-based education for the care of cancer patients in primary care is a promising approach that builds on the increasingly interprofessional makeup 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 a number of continuous improvement techniques which have been adapted for issues in cancer care. These methods include clinical audit and significant event analysis, both of which are required to be undertaken by PCPs as part of the revalidation process. The RCGP has been instrumental in leading a national cancer audit<sup>336</sup> and developing "significant event audits" for general practice triggered by new diagnoses of cancer in the practice (Box 9.1).<sup>138</sup> These tools ask PCPs to review their own practice of cancer diagnosis, to reflect on it and to identify opportunities for improvement. Other types of feedback systems utilize data about practice that is derived from electronic health records or patient surveys. This allows a physician to compare their practice with that of peers and/or to an outside standard. A strength of these feedback systems is their reliance on frequent, personalized feedback, that in adult education terms is associated with optimal learning. In many jurisdictions, these kinds of CPD activities also garner a higher level of CPD credit than traditional group learning activities. These feedback and audit techniques form part of a larger movement towards "practice-based CME" 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 and are discussed in more detail in the section on Early Diagnosis.

#### **Significant Event Analysis for cancer**

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 impact on those involved (patient, carer, family, GP, practice)?

SEA team discussions are an opportunity for the primary care team to:

- discuss each stage of the diagnosis in detail
- identify any learning needs
- identify actions to be taken and changes to be made and agree how these will be progressed.

### *Education embedded in new models of shared care*

New models of shared care among primary care and oncology are being developed to meet the growing demand for cancer services and the relative shortfall in oncologists.<sup>337</sup> 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 provide a recommendation regarding 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 randomized trial to improve the confidence of PCPs in managing adverse effects and their satisfaction with shared care, although improved knowledge was not demonstrated.<sup>265</sup> Similarly, a 2009 survey in the USA demonstrated that PCPs who always or almost always receive a "survivorship care plan" from the oncology team reported greater confidence in patient management and care co-ordination across a range of responsibilities.<sup>338</sup> 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 must be equipped to play 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 the kind of cancer education for primary care trainees and physicians that has been described? In many jurisdictions, the impetus for this work has come from cancer charities and authorities, with the energetic 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 the cancer system. The danger, though, is that this focus can be viewed as special pleading by an interest group, and not the authentic voice and concern of primary care itself. Cancer has become the leading public health challenge in developed countries. In Canada, for example, cancer is the leading cause of death and also the leading cause of premature death, with the greatest burden of disease and years of life lost of any illness.<sup>339</sup> This enormous challenge requires primary care itself to take the lead, in our university departments of general practice/family medicine, our professional associations, and in our vocational training

systems. The example of the Royal College of General Practitioners in the UK is exemplary, which has benefited from a social consensus on the importance of improving cancer outcomes and from the influence and energy of key academic PCPs on making cancer care an organizational priority. Rather than sitting back, primary care needs to take the lead in equipping itself both in its registrar training and CPD programs for its central role in improving cancer outcomes and the quality of cancer care.

**Action points 9**

- Undergraduate and training curricula need to be reviewed to ensure that they adequately prepare PCPs for their future role in cancer control
- Audit and performance feedback should become a core function of primary care teams providing cancer care

## **Part 10: Conclusions and recommendations**

Primary care is continuous, co-ordinated 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, to a greater or lesser extent and at different stages of the illness. Crucially, the PCP is the key interface between the patient and specialist care, facilitating timely and appropriate access and sometimes protecting that patient from unnecessary or inappropriate interventions. At the same time, the PCP is the one healthcare professional whose role is to provide whole-person, rather than disease-centred care, and to place his contribution to the care of a person's cancer in the context of their other physical, emotional and social needs. The highly technical interventions that surround diagnosis and treatment of cancer have long been the focus of innovation in care. But patients also want care that is co-ordinated, with a clear and seamless journey between care settings.<sup>340</sup> They want care that is close to home where possible, and is accessible when they need it, whatever the stage of their cancer journey. They want continuity of care, in the informational and organisational as well as the relational senses of the term.<sup>341</sup>

This Commission has identified aspects of care at all stages of the cancer pathway where there is good evidence for the positive benefits of input from primary care. The possibilities and benefits are potentially wide-ranging (Table 1). There is evidence in the United States that long term cancer survivors who see both oncologists and primary care providers are more likely to get the full array of care they need: prevention, care of comorbid conditions, appropriate surveillance for treatment effects and recurrence.<sup>342</sup> This fact alone should motivate models of shared care, but the demand for oncologic care is also anticipated to grow by 40% in the next 20 years while the population of oncologists will only grow by 25%.<sup>316, 337</sup> 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 described, for follow up, survivorship, and end of life care in particular, offer better ways of meeting this need.

<b>Challenges</b>	<b>Possible solutions from primary care</b>
Rising incidence of cancer and considerable increase in the number of patients surviving cancer	Integrated care, particularly for follow-up, underpinned by guidelines for best practice
Primary prevention offers considerable potential for reducing incidence but is not well implemented	Effective models developed for incorporating primary prevention into routine practice
Patient –related delays are an important component of overall time to diagnosis	Access to primary care configured to minimise barriers to consultation
Variations and inequalities in uptake of cancer screening	Wider sharing and implementation of best practice, especially in the contribution of the PCP to promoting population-based screening programmes
Symptoms that could be cancer are common in primary care, but cancer is rare. Those symptoms with a low PPV for cancer present a particular challenge	Development and systematic application of electronic clinical decision support to select patients for urgent assessment, together with tools to overcome cognitive error. A range of models for access to diagnostics is developed to accommodate differing levels of risk.
Follow-up care requires expertise in cancer but also in its wider physical and psychological sequelae	Integrated models of follow up care with embedded CPD for PCP. PCPs 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	Integrated working with palliative care, underpinned by CPD and the breaking down of logistical barriers in primary care

Table 10.1 Cancer care challenges and possible primary care solutions

Indeed, the dominant theme of this review is of integration of care. Such models have existed in mental health for a generation.<sup>343</sup> They are widely applied in chronic disease management in Europe, but they have not been implemented in cancer. In part 7 we describe in detail the



principles of integrated care, how it can be implemented and why it is vital if quality of care and outcomes for cancer are to improve.

Fundamental to sharing care is addressing transitions in care. These transitions occur when information and responsibility needs to be transferred between groups or settings; when a cancer screening abnormality is found on mammography, when someone is discharged from the hospital, when a symptom we see in primary care needs to be evaluated in oncology.<sup>337, 344</sup> Such transitions occur across the cancer continuum and they are recognized as a source of failures in care by any clinician in practice.<sup>249</sup> Despite their widespread recognition, there is little evidence regarding how to measure them or their effects. For example, failures in follow-up to abnormal screening tests for breast, colon, and cervical cancer are widespread in the US.<sup>345</sup> We need metrics of failures at critical transitions in cancer care to help us address the challenges they represent.

One of the key roles for the PCP is in the initial assessment of the patient who might have cancer. Around 90% of patients present first with symptoms in primary care. The likelihood of cancer, even with so-called '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 taken to support clinicians in achieving earlier and more accurate diagnosis. There has been much innovation but there remains more to be done, particularly for those cancers with a weak symptom signature, where a step change in diagnostic technology may 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 the options for assessment, offer the best prospects of quality improvement. For some cancers, however, new diagnostic biomarkers or screening modalities are awaited.

Two last considerations are key if care integration for cancer is to become a reality. Firstly, 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. The means by which this is achieved include ensuring good access to primary care, the organisation of gatekeeping systems so to enable rather than restrict access to secondary care, and different approaches to incentivisation. Secondly, the curriculum relevant to cancer care within undergraduate, post-graduate and CPD programmes is variable in its depth and breadth. A more consistent approach between countries could contribute to

reducing inequalities in outcomes. . In some countries the performance of PCPs is called into question over the roles they currently play, especially in cancer diagnosis, and forms the basis of objections to a more extended role. The evidence now largely refutes this, while the sub-optimal performance of a small minority is a feature of all medical specialties and no grounds for limiting the scope of their practice. Performance review through clinical audit and feedback are well accepted tools for quality improvement in primary care but have been little used in the field of cancer care.

Much remains to be better understood. We need evidence for the clinical 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 to date can be translated into standard practice and its clinical and cost-effectiveness in pragmatic settings. Initiatives to support multi-disciplinary research capacity will be essential to delivering that research. In Australia, for example, the Primary Care Collaborative Cancer Clinical Trials Group (PC4, <http://www.pc4tg.com.au/>) supports research capacity building and the development of trials of interventions across the cancer continuum in primary care.

#### **Author contributions**

Part 1: lead author GR; contributing authors FW, SH SMC ST. Part 2: lead author DW; contributing authors JW, BS, MP. Part 3: lead author SG; contributing authors JW, WH, RD, JW. Part 4: lead author JE; contributing authors RDN, NdeW, TF. Part 5: lead author EW; contributing authors AB, LG, CE. Part 6: lead author GM; contributing author CZ. Part 7: lead author EG; contributing authors RM, JS, PV, CW, TV. Part 8: lead author DH; contributing authors MR, GL, RW, PV. Part 9: lead author JS; contributing authors ST, UM. Part 10: GR. GR edited the complete manuscript; all authors reviewed the complete manuscript.

#### **Conflicts of interest**

(to be completed when all author declarations received)

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