The expanding role of primary care in cancer control

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

Lancet Oncol 2015; 16: 1231–72

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Part 1: Introduction

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

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

The purpose of this Commission is to distil the evidence for the effectiveness of interventions for cancer control based in primary care at each stage of the cancer journey (figure 1) and to consider how cancer care might be delivered differently in the future. It discusses how and whether health policy for cancer control will help or hinder such change. Finally, it examines the implications for the future education and training of doctors, and identifies emerging examples of good practice worldwide. The Commission brings together leading members of the international primary care cancer community, together with cancer specialists and policy researchers. We have elected to restrict our Commission to high-income countries and mainly to countries with universal health-care systems, since these have a more clearly defined and discrete element of primary care to their services.

The current and future cancer burden

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

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

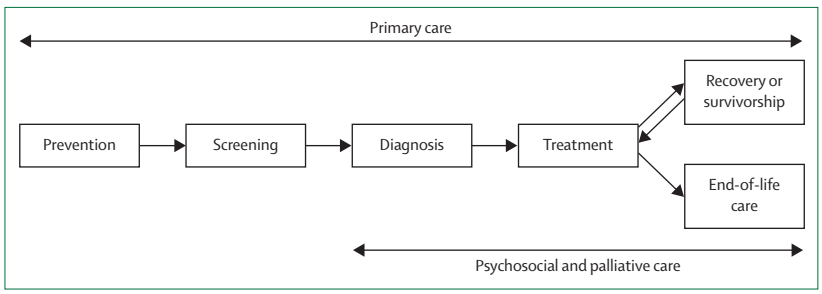

Figure 1: **The cancer journey**
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improves, prevalence of cancer in the practice population increases. At present, a PCP with 2000 patients has around 70 patients with or surviving cancer, and this number is predicted to double by 2040.[4] In comparison, the PCP typically looks after 120 patients with diabetes mellitus.

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

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

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

The diverse nature of cancer symptoms is the key challenge for PCPs in diagnosis—namely, the accurate and timely assessment of symptoms and signs that are much more frequently caused by mild illnesses. In several countries, such as the UK, Denmark, Spain, and Australia, urgent referral pathways have been developed to help with assessment of the symptomatic patient. Because up to half of patients with some cancers do not have alarm symptoms,[11] there is a growing interest to develop pathways that assess those patients with non-specific or non-alarm symptoms (see Part 8). Although the priority is to achieve a prompt diagnosis, the pathway shown in figure 2 conceals many complexities—eg, short diagnostic intervals are associated with advanced disease and poor survival (known as the waiting time paradox; see Part 3).

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

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

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

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

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