What is the value of routine follow-up after diagnosis and treatment of cancer?

The outcome for cancer treatment is improving: over 50% of people diagnosed with cancer survive for 5 years and there are at least 2 million people in the UK living with or beyond cancer. In many cases, the management of cancer and its sequelae are long term, and cancer is increasingly managed as a chronic disease. This view has been given increased impetus by the publication of the Cancer Reform Strategy in 2007 with its chapter dedicated to survivorship issues.

Two linked systematic reviews in this issue examine the literature comparing follow-up in primary versus secondary care and patients’ and healthcare professionals’ views on follow-up. Overall, the evidence base informing follow-up regimes for cancers is scanty; this is not surprising as cancer follow-up is a complex intervention and cancer is not a single entity but a range of diseases, affecting individuals of different ages and with a range of treatments and outcomes.

There is a number of reasons why patients might be seen routinely following primary treatment of cancer. These include clinical reasons such as early detection of recurrence, monitoring ongoing treatment and managing any side-effects, and identifying late effects of treatment (for example, second cancers and other health problems resulting from treatment). Follow-up is also important for providing ongoing supportive care to patients and their families, providing, for example, information and reassurance, advising on whether the cancer has a heritable component, and identifying any psychosocial or practical problems. Referral or signposting to services that can provide further help with some of these issues (for example, counselling services for psychosocial or psychosexual problems or advice on financial and employment concerns) may be warranted. A recent survey by NHS Improvement which is yet to be published, asked patient and professional groups to rate the different aims of follow-up on a Likert scale: 97% of patients agreed or strongly agreed that the aim of follow-up was to detect early recurrence compared with 90% of GPs and 83% of specialist doctors. However, only 71% of patients and 78% of doctors agreed or strongly agreed that follow-up should inform and enhance wellbeing compared with 95% of specialist nurses.

The outcome of recurrent cancer may be improved with early detection but the principles of monitoring chronic diseases apply: is monitoring beneficial and, if so, is there a suitable test, at what interval should the test be applied and when should monitoring cease? Knowledge of the natural history of each cancer is essential in this respect and there must be an effective intervention for detected disease.

A Cochrane review of breast cancer follow-up concluded that there was no advantage in a more intensive follow-up regime, either comparing radiological and laboratory tests with clinical examination and mammography or secondary care compared with primary care follow-up. There is a biomarker for prostate cancer (prostate specific antigen) but no strong evidence that early detection of recurrence improves mortality. The exception is colorectal cancer where intensive follow-up has shown benefit. Both a biomarker (carcino-embryonic antigen) and regular scanning are used to detect asymptomatic recurrence in the liver and lung. Surgical resection of localised metastases has an acceptable outcome, and new chemotherapeutic agents improve outcome in those not suitable for surgery. Two meta-analyses of trials comparing more with less intensive follow-up in colorectal cancer demonstrated that more intensive follow-up improved survival and is cost-effective. However, the authors of both papers note that it was not possible to identify exactly which regime(s) conferred the benefit.

The first paper by Lewis et al in this issue reviews qualitative studies of follow-up from the perspectives of patients and health professionals. The paper highlights that fear of recurrence is a major source of anxiety for patients and that they derive reassurance from follow-up appointments with hospital specialists. However, many shortcomings of follow-up were identified including poor communication, information needs not being addressed, lack of continuity in care, and lack of time to address psychosocial issues. Patients clearly value both the clinical and supportive aspects of follow-up. Both patients and oncologists believed that GPs currently lack the expertise needed to provide cancer follow-up care, although GPs did not see this as a barrier and felt they could access expert help when required. GP follow-up was the least favoured option by patients. As discussed by Lewis et al, perhaps patients should be better informed about the purpose and (lack of) proven clinical benefits of intensive follow-up in many cancers and offered a greater choice in the type of follow-up they receive. Patients with more realistic expectations from the outset may be more likely to accept alternative models.

Traditional consultant-led follow-up after cancer treatment requires significant resources and hospitals are now beginning to develop other modalities of follow-up. In addition to shared care and earlier transfer of care to GPs, these include follow-up by nurse specialists, use of telephone and postal questionnaire, and even e-mail. These methods may be more convenient for patients, especially those at
low risk of recurrence, and there is some recent evidence that telephone follow-up is at least equivalent to a face-to-face meeting in dealing with both the physical and psychological outcomes of breast cancer.11

In the second linked article, Lewis et al present a systematic review of studies comparing primary with secondary care follow-up.2 The review does not identify any differences between primary and secondary care for recurrence rate, survival, patient wellbeing, and satisfaction. However, there were few papers to review and only three papers used survival as an outcome, two for breast and one for colon cancer.

The role of primary care in the follow-up of cancers has increased in the last decade. The introduction of a formal cancer care review within 6 months of diagnosis (as part of the Quality and Outcomes Framework) has given GPs a specific role in this area but there has been no evaluation of the content or benefit of these reviews. Many patients, particularly those with breast and prostate cancer, continue treatment with chemotherapeutic agents for several years after primary treatment. As the trend continues for earlier discharge from hospital follow-up, GPs will have an increasing responsibility to monitor the impact of these treatments, particularly for side effects and late effects. However, the care of long-term survivors is currently largely informal and patient-initiated. Primary care doctors and nurses may be better placed than secondary care to give advice on areas related to psychosocial need, employment, and family matters. Primary care will need further education to identify and manage the long-term and late effects of treatment, a method of identifying those at risk and a recall system to ensure that a primary care-based service is of the highest quality. Macmillan Cancer Support has recently extended its remit to include cancer follow-up and now provides valuable educational resources in this area for patients, their families, and health professionals.12

In summary, the evidence base to inform the optimal follow-up regime for cancers is currently weak. There is some evidence for breast and colorectal cancer but very little for other cancers. In the absence of good clinical evidence, the views of patients, their family members and healthcare professionals should be used to inform policy developments in this area. Undoubtedly, there will be increasing involvement of primary care with patients who are living with or beyond cancer. The introduction of a cancer survivors care plan as part of the Cancer Reform Strategy should enhance communication between secondary and primary care. Ideally, primary care would also become involved in multidisciplinary team meetings. It is unlikely that the evidence base to inform follow-up regimes will increase rapidly but there are areas that primary care can address now in education, communication (both with secondary care and patients), and in the introduction of management systems to ensure the quality of any future primary care service.

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REFERENCES

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