

# Towards a personalised approach to aftercare: a review of cancer follow-up in the UK

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## Abstract

**Introduction** Due to growth in cancer survivorship and subsequent resource limitations, the current UK position of follow-up services is unsustainable. With people living longer after a cancer diagnosis, supported self-management for ongoing treatment-related chronic conditions is a fundamental component of aftercare services. Alternative models to traditional hospital aftercare require consideration in terms of clinical effectiveness and cost-effectiveness.

**Methods** 'Evidence to Inform the Cancer Reform Strategy: The Clinical Effectiveness of Follow-Up Services after Treatment for Cancer' (Centre for Reviews and Dissemination 2007) has been updated using a number of quality-controlled databases. Correspondence with experts was also sought to identify current initiatives.

**Result** The review highlights a shift towards patient empowerment via individualised and group education programmes aimed at increasing survivor's ability to better manage their condition and the effects of treatment, allowing for self-referral or rapid access to health services when needed. The role of specialist nurses as key facilitators of supportive aftercare is emphasised, as is a move towards technology-based aftercare in the form of telephone or web-based services.

**Conclusions** The challenge will be replacing traditional clinic follow-up with alternative methods in a cost-effective

way that is either as equally effective, or more so. To establish this, more rigorous trials are needed, with larger sample sizes and longer follow-up assessments.

**Implications for cancer survivors** Increasing patient confidence to initiate follow-up specific to their needs is likely to increase the workload of primary care providers, who will need training for this.

**Keywords** Aftercare · Cancer · Neoplasm · Review · Survivors

## Introduction

Cancer survivorship

In the UK, growth in cancer survivorship has led to a substantial increase in the number of people requiring cancer follow-up care. Subsequently, current follow-up services are not meeting the needs of survivors and traditional routine medical follow-up frequently fails to meet their supportive care needs, often resulting in feelings of abandonment during transition from patient to survivor [1].

As part of the UK National Cancer Survivorship Initiative (NCSI), Macmillan Cancer Support and NHS Improvement are working together to pilot new models of aftercare to provide better post-treatment support for survivors [2]. This is funded by the Department of Health, as part of the Cancer Reform Strategy [3], which is a national plan designed to improve cancer outcomes in England. Within this strategy, the difficulties confronted by cancer survivors have been recognised and thus the NCSI evolved to consider a range of approaches to improve the services and support available for cancer survivors.

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The work of the NCSI is based on the definition of a survivor being “*someone who is living with or beyond cancer,*” which encapsulates those who have completed initial cancer management and have no apparent evidence of active disease, those living with progressive disease who may be receiving cancer treatment, but is not in the terminal phases of illness, and those who have had cancer in the past.

The drivers for change presented in the NCSIs future vision of follow-up care are largely based on the Cancer Reform Strategy [3] and the international trend towards self-management for chronic conditions [4]. A further consideration has been the need to develop a model of follow-up feasible within the current economic climate. The current position of follow-up services is unsustainable when the growth in demand reflected by increasing referral for new cancers, growing numbers of cancer survivors, and resource limitations is taken into consideration.

There is a clear need to identify evidence that will guide health care planning and provide a framework for the follow-up of cancer survivors. This review enhances current knowledge of follow-up services by updating ‘*Evidence to Inform the Cancer Reform Strategy: The Clinical Effectiveness of Follow-Up Services after Treatment for Cancer,*’ as conducted by the Centre for Reviews and Dissemination [5]. This review also presents current initiatives that are underway to address problems highlighted within the literature, the aim being to identify alternative models of follow-up that do not compromise the quality of the services available, either in terms of patient outcomes or cost-effectiveness.

## Method

The Cochrane Database of Systematic Reviews (CDSR), DARE and NHS EED were searched for reviews and economic evaluations from June 2007 to September 2009. MEDLINE and EMBASE were searched from 2008 to 2009 to detect recent systematic reviews not yet added to CDSR. Searches were restricted to using the terms “follow-up” and “surveillance” in the title field of MEDLINE and EMBASE and in the title or abstract field of the CDSR, DARE and NHSEED. International Cancer Research Portfolio, ClinicalTrials.gov and mRCT (Current Controlled Trials) were searched for ongoing trials.

Studies assessing follow-up services in survivors of breast, colorectal, lung, or prostate cancer were included. Any studies examining multiple sites, or generic follow-up (i.e. not site-specific) were considered. For clinical effectiveness, systematic reviews were included, and where none were identified, RCTs were included. For cost-effectiveness, systematic reviews and full economic evaluations were included.

## Results

Approximately 1,174 hits were obtained via the pre-defined search strategy, 62 of which were potentially relevant and thus full copies were obtained; 20 records were included in this review and are presented as ‘Evidence in the Literature’ and ‘How this Evidence is being Utilised.’ All studies are summarised in Table 1.

### Evidence in the literature

The review Centre for Reviews and Dissemination review identified three systematic reviews investigating breast cancer follow-up, five colorectal cancer follow-up, one economic evaluation for lung cancer, no reviews or economic evaluations for prostate cancer, and one review including a range of cancer types:

- There was insufficient evidence for or against surveillance mammography or to draw conclusions regarding best practice, patient involvement, reduction in morbidity, or cost-effectiveness [6]. Routine follow-up, based on regular physical examinations and yearly mammography alone, was found to be as effective as more intensive approaches (‘intensive’ is defined by NICE as “*designed to detect metastatic disease before symptoms develop*”; [7], p.58) [14]. In Australia, monthly follow-up consultations were found to be the most effective programme but at an excessive cost [8].
- All but one review [9] concluded that providing intensive (i.e. long-term) follow-up for colorectal cancer improves survival, with three concluding that it was slightly more effective than minimal follow-up [10–12]. All studies found intensive follow-up to be more costly than minimal follow-up; the incremental cost-effectiveness ratio varied from US \$4,926 per life year saved to US \$25, 926, respectively.
- The cost-effectiveness of a follow-up programme guided by lung cancer patients’ symptoms compared with regular follow-up including physical examination, chest radiograph, CT scan and liver function test showed that regular follow-up resulted in an extra 1.3-month of median survival at an extra cost of US \$1,502 per patient over two-years [13].
- Across cancers, forty-two studies of various designs demonstrated that there was no important difference between primary and secondary care follow-up for breast or colorectal cancer.

One systematic review was identified in the current review, describing seven breast cancer trials [14], two

**Table 1** Summary of follow-up evidence

Author	Population	Intervention	Results/Conclusions
Beaver [28]	Breast cancer ( $n=374$ )	Traditional hospital follow-up versus telephone follow-up by specialist nurses.	Telephone follow-up was well received by participants, with no physical or psychological disadvantage. It is suitable for women at low to moderate risk of recurrence and those with long travelling distances or mobility problems. However, the intensity of this intervention (frequency of contact and length of consultations) and its provision by specialist nurses, make it unlikely to prove more cost-effective than the current provision by junior doctors in outpatient clinics.
Fletcher et al. [33]	A heterogeneous sample of urological patients ( $n=287$ )	Drop-in group medical appointments versus individualised appointments.	Drop-in group medical appointments can be implemented successfully in a urological practice with high patient satisfaction despite the sensitive nature of topics discussed. Ideal patients are those with chronic or complex conditions and those requiring repetitive discussions, such as elderly individuals.
Koinberg et al. [30]	Stage I and II breast cancer patients ( $n=254$ )	Routine follow-up with a physician versus 'on-demand' (i.e. patient-initiated) follow-up with a nurse.	The difference in cost per year and patient by study arm is modest, but offers a substantial opportunity for reallocating resources.
Mandelblatt et al. [31]	Breast cancer ( $n=389$ )	Three strategies for improving survivorship transitions were compared: a booklet control condition; an educational video plus the control booklet; counselling plus the video plus the booklet.	The educational video was the most cost-effective way to improve transition to survivorship. It will be important to confirm whether there is an increased use of services after such interventions and if this represents appropriate use of rehabilitative and supportive care or over-use.
Sheppard et al. [29]	Breast cancer ( $n=237$ )	Point of need (patient-initiated) access compared to routine 6-monthly clinical reviews.	Findings suggest that after 2-years following diagnosis there is no evidence to support the view that regular clinical review improves psychological morbidity or QoL. Patients do not appear to be compromised in terms of early detection of recurrence. Point of need access can be provided by suitably trained specialist nurses and provides a fast, responsive management system at a time when patients need it.
Snyder et al. [24]	Stage 1–3 colorectal cancer ( $n=20,086$ ), diagnosed between 1997 and 2001	To explore (1) physician types (PCPs versus oncology specialists) survivors visit during survivorship year 1, (2) preventive care received, (3) how preventive care receipt relates to physician types visited, and (4) trends in physician types visited and preventive care received over time.	Oncology specialist follow-up in survivorship year 1 is intensifying over time. Survivors not being followed-up by both PCPs and oncology specialists were less likely to receive preventive care. Clarifying the roles of PCPs and oncology specialists during follow-up can improve the quality of care for survivors.
Melloni (unpublished)	Lung cancer ( $n=120$ )	Follow-up by conventional methods versus PET.	Intensive follow-up after curative-intent surgery for NSCL cancer is an accurate technique for detecting recurrent disease, but PET imaging compared to CT imaging follow-up did not change overall survival in this population.
Montgomery et al. [26]	Breast cancer ( $n=110$ )	Remote, automated telephone follow-up.	Seventy-one of the 75 patients found the system easy to use. Forty-nine of the 75 (65.33%) liked the system and were happy to use it as their sole method of follow-up. A further 12% were happy to use it as

**Table 1** (continued)

Author	Population	Intervention	Results/Conclusions
			part of their follow-up, whilst 16% were not. Automated telephone follow-up allows the generation of more data on quality of life and side-effects of treatment than would usually be available in clinical settings, outside of clinical trials. This model of follow-up is a potentially effective and efficient way of risk-stratifying patients according to patient-reported outcomes.
Moore et al. [27]	Lung cancer ( $n=203$ )	Nurse-led follow-up and conventional medical follow-up.	Nurse led follow-up was acceptable to lung cancer patients and GPs, leading to positive outcomes.
Pinto, Goldstein, and Papandonatos [47]	Breast cancer ( $n=192$ )	<i>Moving Forward with Life</i> , a theoretically-based physical activity RCT.	Feedback from healthcare providers suggested that study involvement did not present problems at the practice level. Eighty-five percent of patients reported receiving advice about the benefits of physical activity and 84% reported satisfaction with the advice. At 3-months, patients receiving extended advice were significantly more likely to achieve 150 mins/week of PA (7 Day PAR) vs. brief advice. These promising results suggest that effective health promotion can be integrated into follow-up care for cancer survivors.

comparing hospital follow-up with GP follow-up [15, 16], two comparing traditional with patient-initiated follow-up [17, 18], one comparing routine follow-up by doctors with routine follow-up by breast cancer nurses (BCNs) [19], and two comparing different frequencies of follow-up within a traditional model [20, 21]. Alternative models of follow-up were found to be acceptable to patients as well as being associated with other benefits, such as improved QoL and cost-effectiveness. However, higher quality trials are required to establish whether these alternative models are as safe as clinical examination.

In one randomised prospective study, comparisons were made between the cost-effectiveness of standard clinical (i.e. history and physical examination) versus intensive (i.e. in addition to the anamnesis and physical examination, biochemistry, hematogram, and the markers carcinoembryonic antigen (CEA) and CA15.3 assessed at every outpatient visit together with annual hepatic echography, chest x-ray, and bone scan) follow-up in stage I, II and III breast cancer patients ( $n=121$ ) post-treatment [22]. All patients, irrespective of group assignment, had annual mammography. Outpatient appointments were scheduled for every 4-months over the first year, every 6-months for the next 5 years, and annually thereafter. After a median of 3-years, there were 11 relapses in standard compared with 13 in intensive follow-up; 69% of relapses in the intensive

group were diagnosed between scheduled visits, when patients initiated clinic visits. The overall cost of follow-up was US \$35,376 in the standard group and US \$107,102 in the intensive group.

One trial comparing standard follow-up after colorectal surgery [23], used Office of National Statistics (ONS) data to calculate the number of colorectal cancers diagnosed for 2003 and projected for 2016, based on the population of England and Wales. The resource requirements and costs of follow-up over a 5-year period were then calculated for the two time periods. For the 2003 cohort, an intensive program would detect 853 additional resectable recurrences over 5-years with 795 fewer people requiring palliative care. An additional 26,302 outpatient appointments, 181,352 CEA tests and 79,695 CT scans over 5-years would be required to achieve this. The cost of investigating patients who would never develop detectable recurrences was US \$25 million. The cost per additional resectable recurrence was US \$28,944. An identical intensive follow-up policy with biennial faecal occult blood test (FOBT) screening in 2016 saw the cost per additional resectable recurrence rise to US \$58,051.

The effectiveness of follow-up intensity has also been examined in terms of accessibility to healthcare professionals. The Surveillance, Epidemiology and End Results (SEER) Medicare database in a retrospective cross-

sectional study of five cohorts of stage 1–3 colorectal cancer survivors in the first year of survivorship [24], found that in one study there was a trend over time of increased visits to all physician types; this was statistically significant for oncology specialists and other physicians but not GPs. The percentage of survivors receiving preventive services remained relatively stable across the five cohorts, but survivors who visited both a GP and oncology specialist were most likely to receive preventive care services.

Melloni (in press) conducted a randomised, open-label, uncontrolled trial in France, comparing traditional follow-up (i.e. thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy performed every 6-months after surgery for two-years) versus PET scanning only [25]. Patients were randomly assigned to two arms: 1) thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy were performed every 6-months after surgery for two-years; 2) PET scanning. For brain metastasis detection, CT was performed in the two arms. Recurrences were detected during scheduled or unscheduled procedure in asymptomatic patients. Intensive follow-up after curative-intent surgery for lung cancer was found to be an accurate technique for detecting recurrence, but PET imaging compared to CT imaging follow-up did not change overall survival in this population.

Rather than examine the intensity of follow-up, alternative methods have also been examined in the literature. In a prospective cohort study testing the acceptability and feasibility of remote, automated telephone follow-up annually, after breast cancer, as well as usual mammograms, patients who had completed adjuvant chemo-radiotherapy received a follow-up questionnaire administered on paper at baseline and then, in place of a clinic visit the following year, they completed the same questionnaire using an automated telephone system [26]. An electronic case record (Excelicare™) with linked telephone system (Excelicare Direct) was used, where questionnaire scripts were programmed onto the system, so that patients could complete the questionnaire using an ordinary touch tone telephone. The system can be programmed to calculate scores according to the answers given, an acceptable score resulting in a reassuring letter being generated by the system and a request for routine mammogram being sent to radiology, and poor scores resulting in an email being sent to a designated person to ensure that the low score is followed up. Ninety-five percent of patients found the system easy to use, and 65% liked the system and were happy to use it as their sole method of follow-up. A further 12% were happy to use the system as part of their follow-up. Sixteen percent of patients stated that they would not be happy to use this type of follow-up at all: two had medical problems; four had technical problems;

and, the rest stated that they would prefer to attend the clinic for an examination.

An RCT comparing the acceptability and feasibility of nurse-led follow-up with traditional medical follow-up in patients with lung cancer who had completed their initial treatment and were expected to survive for at least 3-months ( $n=203$ ), which did not meet the inclusion criteria for the CRD [5] review, has been included in this review [27]. The study has been included in this review due to its rigour and the knowledge gained from the outcomes. Nurse-led follow-up patients were assessed monthly by protocol using the telephone or in a nurse-led clinic. Patients also had access to the nurses via the telephone or in the clinic without an appointment. The mean number of contacts with patients was three per month: 14% of those were initiated by patients. The mean length of contact was 23-minutes (2–120 min). It was found that patient acceptability of nurse-led follow-up was high and patients who received the intervention had less severe dyspnoea at 3-months and had better scores for emotional functioning and less peripheral neuropathy at 12-months. They also scored significantly better in most satisfaction subscales of the EORTC QLQ-C30 at 3, 6, and 12-months. No significant differences in GPs overall satisfaction were observed between the two groups and no differences were observed in survival or rates.

Beaver [28] report on a two-centre UK randomised equivalence trial with low and moderate risk breast cancer patients [28], where participants were randomised to traditional hospital follow-up (consultation, clinical examination, and mammography as per hospital policy) or telephone follow-up by specialist nurses (consultation with structured intervention and mammography according to hospital policy), as provided 3-months for 2 years, 6-monthly for 2 years, and then annually for a further year, or annually for 10-years for both groups. Uptake of the intervention was 60% and there were no significant difference in psychological morbidity between groups. Although there were no significant differences initially regarding satisfaction with information received, the telephone group showed significantly more satisfaction at the middle and end of the trial. When asked if they felt the appointment had been helpful, at the middle and end of the trial responses were significantly more positive in the telephone group, with a higher percentage reporting “very helpful” (88%) in the telephone group compared to the hospital group (44%). Only 17 participants (5%) had a confirmed recurrence of cancer during the trial: six in the hospital group and 11 in the telephone group. The difference between randomised groups was not significant. The median time to confirmation was 60.5 days (range 37–131 days) in the hospital group and 39 days (10–152 days) in the telephone group.

Sheppard et al. [29] conducted an RCT ( $n=237$ ) comparing 'point of need access' (patient-initiated) versus routine 6-monthly clinical review [31]. Both groups continued to have annual access to routine mammography. Patients randomised to patient-initiated access were given information for how to contact the BCN if concerned. Nurses providing this service underwent training in clinical examination, physical assessment, and subsequent management of symptoms. The study was completed by 90% of the participants and two thirds found the approach acceptable. Regular review did not identify a larger number of recurrences, and the presentation of recurrence showed that the majority were admitted through an emergency route with a short symptom history and therefore were unlikely to be detected at routine review. Analysis of patient-initiated contacts made to the nurses during the study period showed that in addition to their routine review, a total of 68 contacts were made in the control group (an incidence of 0.42 contacts per person per year), compared to 61 contacts in the patient-initiated group (an incidence of 0.32 contacts per person per year).

The cost-effectiveness of the patient-initiated model of follow-up has been tested in a five-year prospective RCT conducted in Sweden, comprising stage I and II breast cancer patients ( $n=254$ ) who were randomised to traditional follow-up with a physician (PG;  $n=131$ ) or 'on-demand' (i.e. patient-initiated) follow-up with a nurse (NG;  $n=133$ ) [30]. Traditional follow-up involved a specialist in oncology or surgery examining the patient four times per year during the first two-years after surgery, followed by bi-annual examinations for up to 5 years, and yearly after five-years. At the follow-up visits, the patient was interviewed regarding symptoms that could signal a loco-regional relapse or distant metastases, and a clinical examination was carried out. Mammography was carried out at one-year intervals. Patient-initiated follow-up was introduced during a visit to the physician that took place following radiotherapy post-randomisation. Patients were given an appointment to meet with an experienced nurse approximately three-months post-surgery, where they received information about how to recognise a recurrence. The nurse arranged mammography at one-year intervals and informed the patient of the result by telephone or letter. After 3 years, patients were referred back to the routine mammography screening programme. The nurse gave advice on aspects of self-care, such as medication and breast self-examination, and spoke to the patient about her psychosocial situation. The patient was instructed to contact the nurse at any time with any questions or symptoms perceived to be related to breast cancer. The cost per person year of follow-up differed between groups, being US \$900 in the PG group compared to US \$707 in the NG group; the specialist nurse intervention with patient-initiated check-ups was 20% less expensive than traditional follow-up.

An economic evaluation alongside an RCT comparing three psycho-educational strategies was conducted with women who had received surgery for invasive breast cancer ( $n=389$ ) [31]. The three psycho-educational strategies were: a booklet control condition; an educational video plus the control booklet; and counselling plus the booklet and video. Women randomly assigned to the control arm were mailed a copy of the 1994 National Cancer Institute publication 'Facing Forward'. Women assigned to the educational videotape arm also received the booklet and a videotape entitled, 'Moving beyond Cancer' (designed to address physical health, emotional well-being, interpersonal relations, and life perspectives). The costs of the control, video, and video plus counselling arms were \$11.30, \$25.85, and \$134.47 per person, respectively. The video costs were \$2.22 per unit increase in energy compared with control. The video cost \$7,275 per unit change in distress versus control. The counselling arm was more expensive and less effective than the video for most outcomes. Overall, the educational video was the most cost-effective way to improve transition to survivorship.

In *Moving Forward with Life*, a theoretically-based physical activity RCT designed for breast cancer survivors ( $n=192$ ) who had completed treatment in the past 2-years, Pinto et al. [32] examined the effectiveness of integrating health promotion into follow-up care [32]. Oncologists and surgeons ( $n=14$ ) were trained to provide brief physical activity advice to breast cancer patients attending follow-up visits. Patients received brief advice from their healthcare providers (in person  $n=100$  or by letter  $n=92$ ) and were then randomised to a 12-week telephone counselling intervention promoting physical activity (extended advice) or contact control (brief advice). Feedback from healthcare providers suggested that study involvement did not present problems at the practice level. Eighty-five percent of patients reported receiving advice about the benefits of physical activity and 84% reported satisfaction with the advice. At 3-months, patients receiving extended advice were significantly more likely to achieve 150 mins/week of PA (7 Day PAR) versus brief advice.

Another study not included in the CRD [5], but which has been included in this review due to current economic interest in group models of follow-up is that of Fletcher et al. [33]. This study examined the acceptability of group ( $n=117$ ) visits based on gender rather than diagnosis in comparison to individual ( $n=110$ ) follow-up, in a heterogeneous sample of urological patients [33]. Most diagnoses were prostate cancer, erectile dysfunction, benign prostatic hyperplasia, incontinence, neurogenic bladder and chronic discomfort syndromes. In the group appointment compared to in individual follow-up, a 60-minute group teaching session was followed by a private 2 to 5-minute physical examination. Patient satisfaction with the group model was

as high as that of individual follow-up, with 87% of group patients rating their experience as excellent or very good versus 88% by individualised follow-up patients.

#### How this evidence is being utilised

The evidence identified within this review suggests a trend towards nurse-led and patient-initiated follow-up, both of which might also encapsulate the use of technology such as telephone or web-based contact. The patient-initiated follow-up evidence has been particularly influential in the UK, with there being a number of projects underway that are testing this alternative model. For example, the current protocol for breast cancer follow-up at Mount Vernon and Hillingdon Hospitals is: After primary treatment the Consultant Clinical Oncologist discusses patient preference for follow-up management (i.e. traditional follow-up or a self-management approach with early mammography for five-years and direct access to the clinic via the BCN). Patients also receive clear tailored information regarding future risk of recurrence, and understandable information on symptoms and effects to look out for. A self-management programme (*'New Perspectives'*) is available for patients to access at a nearby centre and surveillance through mammography continues as routine for all patients. Thus far, this model of follow-up has been found to be acceptable to patients, the hospital, and primary care staff, and access through a BCN appears feasible and safe without undue increased workload. As a result, follow-up appointments have dropped by 30% and evaluation of the new process shows that 89% of GPs were happy with the new model, 83% of patients were happy with the contact they received post-treatment, and 92% of patients felt secure with the new system [34].

Similarly, at Cambridge Breast Unit (CBU), each low risk patient undergoes an 'exit interview,' where symptoms and signs of recurrence are discussed, and contact details for specialist nurses are provided to allow rapid self-referral if concerns arise [35]. Regular clinical examinations, either by the GP or breast unit clinicians, do not form part of routine follow-up. All patients receive regular mammographic surveillance, either annually following breast conserving surgery or biannually following mastectomy, for a five-year period. Each patient's appointments are recorded on a mammography 'season ticket' which is posted to them. Following each mammogram a report is sent to the patient and their GP and, if abnormal, the patient is recalled for further assessment. The results of an audit demonstrate that 100% ( $n=106$ ) of patients were either very satisfied or satisfied with the patient-initiated process. However, based on concerns raised by patients regarding access to additional psychological support and advice about treatment side-effects, two additional meas-

ures have since been introduced to the programme: patients are now reassured during the exit interview that they can return to a nurse-led clinic to discuss psychological issues at any time; and, all patients are now contacted by telephone three-months following their exit interview in attempts to identify those with ongoing psychological morbidity.

Given the self-management skills required in patient-initiated follow-up, group educational support has played a prominent role in current patient-initiated follow-up initiatives. Evidence pertaining to group follow-up is limited, but has nevertheless influenced current initiatives due to cost-effectiveness. At Brighton and Sussex University Hospital NHS Trust, a 'support conference' is being tested with low risk patients prior to allocation to patient-initiated follow-up [36]. Patients continue to have rapid access to the BCN and continue with regular mammograms. On completion of treatment, patients are informed of the piloting of this new follow-up model and provided with the option of taking part or taking 'early' discharge with mammographic follow-up only. The conference includes a discussion of self-examination, endocrine therapies, financial issues, diet (by Consultant Dietician), sexual health, and psychological well-being. Feedback from attendees has been positive; over 50% found it 'very helpful' or 'helpful' and endorsed the benefit of providing holistic information, reassurance, and the opportunity for discussion with peers. The initiative reduced pressure on clinic time; 30 patients were removed from traditional clinical follow-up, equating to 30 scheduled appointments and up to a further 240 appointments collectively. Plans are being made to roll the program out to moderate risk women, as well as to change follow-up expectations at the beginning of the cancer journey (i.e. at diagnosis).

Patient-initiated models are being implemented with cancers other than breast cancer, but with less promising outlook. Primrose et al. (ongoing study) is conducting an ongoing RCT to determine the effect on survival of augmenting symptomatic follow-up (i.e. patient-initiated) in primary care with two intensive methods of follow-up (monitoring of tumour marker in primary care and intensive imaging in hospital) on the number of recurrences in Stage I, II and III colorectal cancer patients treated surgically with curative intent [37]. Recruitment has been completed, but no results can be obtained until the 5-year follow-up period, however, the low relapse rate in the entire study sample, irrespective of intervention, suggests the need to consider less intensive follow-up on the basis of clinical and cost-effectiveness. Correspondence with the primary investigator reveals the expert preference of single CT at 12–18 months plus CEA in primary care, 3-monthly for 2 years and 6-monthly for another three-years rather than a patient-initiated model.

The success of patient-initiated follow-up depends largely on patients being equipped to self-manage, self-monitor and recognise symptoms of recurrence, hence the various educational programmes included in some of the current described initiatives. An alternative is to progress towards patient-initiated follow-up by adopting a symptom tracking process that can be used to provide control to patients with the continued safety of professional supervision in this monitoring. At the Memorial Sloan-Kettering Cancer Center in New York, USA, a Symptom Tracking and Reporting for Patients (STAR) program has been introduced to facilitate follow-up consultations [38]. The National Cancer Institute Common Terminology Criteria for Adverse Events schema for seven common symptoms has been adapted into a web-based patient-reporting system, accessible from desktop computers in outpatient clinics and from home computers. On completion of the symptom checklist, patients receiving a grade 3 or 4 (indicative of severe toxicities) are automatically alerted to contact their clinician for follow-up care, and a designated nurse is also alerted. Otherwise, the symptom checklist is used to facilitate upcoming consultations or to confirm that a consultation is not required. The system has proved successful with gynaecological and breast cancers and is currently being tested with prostate cancer [40]. Improvements in attrition are anticipated with the integration of prompts to complete the online questionnaires. Furthermore, the next generation of these patient adverse symptom items, which are to be called PROTECT items, are currently being developed for monitoring symptoms during survivorship. Similar work is being conducted in the UK, where a randomised cross-over study has been designed to test the accessibility, feasibility, acceptability, security, and usefulness of a psychosocial educational two-way web-based information platform for use in a large, geographically diverse cancer network [39].

More frequently, empowering patients to manage their condition is being approached via the nurse-led telephone model. Launched in May 2008, ‘*Surviving Cancer, Living Life*’ is a pilot nurse-led telephone model of follow-up for breast and prostate cancer patients who have completed their active treatment [40]. Run by Guy’s and St Thomas’ NHS Foundation Trust and Pfizer Health Solutions, the service has three full-time, experienced and specially trained cancer nurses (i.e. care managers/key workers). Each person who signs up for the service is allocated a nurse, who contacts them by telephone at pre-arranged times and provides advice, support and encouragement on specific aspects of care as well helping people understand how to use other local NHS, social and voluntary services more effectively. The nurses also act to facilitate self-management by helping individuals to: understand their condition better; know when and how to get help; take

positive actions to improve their health; follow treatment regimes correctly; adjust to their ‘new normal’ life; and feel confident in doing everyday activities such as returning to work. This service is provided in addition to other health-care services and the nurses’ support and build on the care already provided by GPs and other healthcare professionals. Feedback from telephone interviews with a random sample of breast ( $n=10$ ) and prostate ( $n=12$ ) cancer patients in receipt of the programme are reported to be “unequivocally positive” in that the programme filled a need for support at a time period when patients felt in particular need for such support. An extended focus group with the three Care Managers demonstrated them to believe firmly in the positive benefits of the programme for patients, although some concern was raised in terms of their own role feeling somewhat imprecise, potentially leaving them vulnerable to abuse or burnout. Feedback from stakeholders was mixed, some feeling the programme to be a new and original innovation that was meeting a high level of unmet need and promoted patient empowerment, others raising concerns that the service might encourage patient dependency.

## Discussion

This has been an update of the evidence for the clinical and cost-effectiveness of cancer follow-up as reported by the Centre for Reviews and Dissemination, ‘*The Clinical Effectiveness of Follow-Up Services after Treatment for Cancer*’ [5]. In addition to establishing published literature, information has also been included as to how this literature has informed current UK initiatives and work in progress. Overall, there is a paucity of good quality evidence for most cancer sites, although there are a number of ongoing trials which may address some of the evidence gaps [37, 41, 42].

In breast cancer, recent trials have compared traditional follow-up with alternatives, including their acceptability and satisfaction to patients, their impact on quality of life, and any lack of disadvantage in detection of recurrence [28, 29]. Giving patients the option to initiate their own contact with specialist nurses based on self-assessed need is a growing trend [29, 30, 34, 39, 44]. In the main, there is high satisfaction with patient-led follow-up by low to moderate risk breast cancer survivors, as long as they are confident to assess their own symptoms, have a clear indication of their future risk profile, receive annual mammographic surveillance, and are provided with a safe, reliable, and quick route back to specialist care if needed.

With the growing trend in patient-led follow-up, there are studies which are investigating whether there is a need for some form of self-management support to be available in order that patients can develop confidence in their skills



to self-manage, as well as become knowledgeable about the consequences of their treatment [39, 41]. Interventions of interest include a tailored self-management course integrated and ‘prescribed’ as part of post-treatment preparation and self-initiated follow-up, a self-management course offered as a choice after treatment [34], self-management advice and support provided by specialist nurses as part of post-treatment consultations [30], and psycho-educational strategies [31].

In colorectal cancer, current trials and initiatives have, in the main, attempted to identify safe alternatives to costly intensive follow-up. An emphasis has been placed, in particular, on the range, combination, and frequency of the role of biochemical/technological testing and examinations, on the earlier detection of resectable recurrences, leading to improved survival rates. If the most reliable and cost-effective combination of blood tests for tumour markers and other examinations can be determined, risk stratification has been offered as a possible method of ascertaining which patients might benefit from a more costly intensive programme of aftercare [23, 37]. If risk-stratification were integrated into colorectal cancer follow-up, those patients at low risk could be empowered to manage their disease and educated about symptoms to look out for, as appears to be the direction with breast cancer follow-up. There is some evidence for augmenting symptomatic patient-initiated surveillance in primary care with a combination of imaging in secondary care and biomarker testing in primary care [37].

In the main, lung cancer trials have compared intensive follow-up with alternatives such as PET imaging or nurse-led follow-up. As with other cancer sites, the acceptability and feasibility of nurse-led clinic and telephone follow-up in patients with lung cancer has been shown to make aftercare more responsive to individual needs, increase patient satisfaction, and reduce the burden of hospital visits and clinical investigations [25].

Evidence of best practice for prostate cancer follow-up remains scarce, although the testing of patient-initiated follow-up supported by a symptom-monitoring system attached to the hospital is showing promise [46].

Overall, this review highlights a shift towards patient empowerment via individualised and group education programmes aimed at increasing survivor’s ability to better manage their condition and the effects of treatment, allowing for self-referral or rapid access to health services when needed. The focus is more on meeting individual care needs as opposed to the notion of ‘one size fits all.’ The challenge will be achieving this in a cost-effective way that is either as equally effective, or more so, than traditional clinical models of aftercare. To establish this, more rigorous trials are needed, with larger sample sizes and longer follow-up assessments. If the emphasis on cancer aftercare

is towards empowering and supporting patients to engage in self-management and to be able to make informed choices about the type of support they need, then alternative models of aftercare such as self-initiated or telephone-based could provide a means for achieving this.

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