

**National Cancer Survivorship Initiative
Supported Self-Management Workstream**

**CANCER FOLLOW-UP: TOWARDS A
PERSONALISED APPROACH TO AFTERCARE
SERVICES**

**A REVIEW OF CURRENT PRACTICE AND
SELECTED INITIATIVES**

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EXECUTIVE SUMMARY

Purpose

A growth in cancer survivorship has led to a substantial increase in the number of people requiring cancer follow-up care. Subsequently, it has become evident that current follow-up services are not meeting the needs of patients. In particular, traditional routine medical follow-up frequently fails to meet the supportive care needs of survivors, often resulting in feelings of abandonment during the transition from cancer patient to cancer survivor (Cardy, 2006; Macmillan Cancer Support, 2008). As part of the National Cancer Survivorship Initiative (NCSI), established in September 2008, Macmillan Cancer Support and NHS Improvement are working together to test new models of aftercare support services to provide better post-treatment support for survivors (Macmillan Cancer Support, 2008).

The purpose of this review was to update *'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 (CRD, 2007), as well as to identify studies and initiatives highlighting current alternative approaches to follow-up. The CRD review restricted the study to follow-up treatment after breast, colorectal, prostate and lung cancers, and generic non-site specific follow-up strategies. This review followed that pattern. There is clear interest in and emphasis on follow-up strategies, not least because of lack of clarity regarding efficacy of approach, growth in demand for follow-up services reflected by increasing referral for new cancers, and growing numbers of cancer survivors, as well as the quality of services which leave patients largely unsupported to manage a range of clinical and psychosocial sequelae.

Methods

The Cochrane Database of Systematic Reviews (CDSR), DARE and NHS EED were searched for systematic reviews and economic evaluations from June 2007 to September 2009. In addition, MEDLINE and EMBASE were searched from 2008 to 2009. Several other sources of literature were searched from July 2007 to September 2009. A full account of the search strategy can be found in the report. The search strategy identified 1,117 records and after removal of duplicates and records not relevant, 62 records were retrieved, and a total of 31 records and initiatives were included in this review. Descriptive synthesis of data was undertaken and summarised in Tables and Data Extraction records in Appendices of this report.

Conclusions

The aim of this review was to update the CRD evidence as well as to identify studies and initiatives highlighting current alternative approaches to follow-up. In achieving this aim, six types of follow-up were identified for breast cancer (i.e. intensive; GP-led; nurse-led (subsets: routine; automated; telephone; patient-initiated); patient-initiated (terminology: patient-triggered; point of need access; symptom-led); radiographer-led mammographic; and educational), four for colorectal cancer (i.e. intensive; primary care; routine imaging; and patient-initiated with routine imaging), two for lung cancer (i.e. PET; and nurse-led), four for prostate cancer (i.e. long-term; internet adjunct; nurse-led; and group), and three for all cancers (i.e. patient-initiated with internet support; telephone; and group).

When combining the CRD review findings with the studies and ongoing initiatives covered in this review, a number of key findings have emerged within breast cancer follow-up. There appears to be little clinical benefit for patients treated with curative intent to attend regular/routine appointments in specialist care as long as routine standard surveillance tests as recommended by NICE are carried out. Notwithstanding this, there remains a prevailing need on the part of clinicians and patients for definitive evidence that routine clinical specialist contact is unnecessary, and alternative approaches can be safe and effective. Growing pressure on resources for breast cancer follow-up appears to be driving considerable interest and service improvement initiatives to explore the acceptability and efficacy of alternative approaches. The trends are as follows:

- **Shifts away from secondary care based follow-up**
 - As these shifts have been slow (clinician and patient acceptability; risk aversion), the need for a multi-centre RCT to answer the questions around long-term survival and alternative approaches is to be undertaken.
 -
- **A range of aftercare models have been developed which continue to rely on health professionals (nurses/AHPs) taking the active/lead role:**
 - Through routine planned face-to-face contact in secondary care
 - Through routine planned telephone contact
- **'Patient-initiated' contact is growing – in place of routine contact, and taking a range of approaches:**
 - Following consultation with a health professional after treatment, providing a personalised shared contract with tailored risk assessment, and rapid access to specialist consultation should the need arise.
 - Following the exit consultation and including a self management education programme
 - Including some form of regularly collected patient reported symptoms, outcomes through specifically designed questionnaires, or current forms of symptom checklist, or outcome measures.
- **With the growing shift to some form of patient-triggered contact, the need for planned supported self-management, so that patients are confident, informed, and aware.**

For colorectal cancer, current trials and initiatives have, in the main, attempted to identify safe alternatives to 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, and on the earlier detection of resectable recurrences leading to improved survival rates. The general consensus is that intensive follow-up after curative resection does improve overall survival and resection rates for recurrent colorectal cancer, but that there was no significant improvement in cancer-related mortality, and the survival benefit is not related to earlier detection and treatment of recurrent disease (CRD, 2007).

If the most reliable and cost-effective combination of blood tests for tumour markers and other examinations for surveillance can be determined, then risk stratification has been offered as a possible method of ascertaining which patients might benefit from a more costly intensive programme of aftercare (Macafee, Whyne, and Scholefield, 2007; Primrose et al., ongoing). The COLOFOL study might be able to answer some of the questions surrounding the most reliable and cost-effective combination of blood tests for tumour markers and other examinations (Wille-Jørgensen, 2009).

Activity for colorectal cancer appears to be very much focused on surveillance, with limited attention on aftercare. There is a need to place more emphasis on other aspects of patient need as a survivor of colorectal cancer, particularly quality of life, lifestyle advice, coping and self-management.

The CRD review found no systematic reviews, ongoing studies or full economic evaluations for follow-up after prostate cancer. This review also found a paucity of evidence on which to base the development of alternative approaches to the aftercare of men who are living with and beyond prostate cancer. Initiatives are in development, which are attempting to blend a systematic collection of patient-reported symptoms using internet reporting methods, telephone reporting, or other less technologically driven methods, alongside risk stratification using various types of algorithms, self-referral, and nurse-led follow-up. These approaches have the potential to reduce outpatient attendance as well as improve the quality of aftercare for patients.

The absence of good quality evidence on which to base lung cancer follow-up still prevails. A number of studies are in progress which aim to address evidence gaps for FDG-PET scanning, symptom led follow-up, care planning, and involvement in decision-making. The efficacy of nurse-led aftercare for these patients has been established.

Evidence obtained that is not site-specific (all cancers) does not offer more than has been gained from the site-specific evidence covered in this review. There is a tendency, however, towards a shift to patient empowerment via individualised and group education programmes, and telephone based motivational support, aimed at increasing survivors' capability and motivation to better manage their condition and the effects of treatments. The focus is more on meeting individual assessed needs, rather than a 'one-size fits all' approach. The challenge will be to achieve this cost-effectively, and more effective than traditional models of follow-up. In this context, a useful distinction can be made between 'surveillance' and 'aftercare.'

INTRODUCTION

Cancer Survivorship

In the UK, there are an estimated two million people living with or beyond cancer, and this is expected to rise annually by more than 3% (KCL, 2008). A cancer survivor is someone living with or beyond cancer. This refers to someone who: has completed initial cancer management and has no apparent evidence of active disease, or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six-months of life), or someone who has had cancer in the past.

The growth in cancer survivorship has led to a substantial increase in the number of people requiring cancer follow-up care. Subsequently, it has become evident that current follow-up services are not meeting the needs of patients. In particular, traditional routine medical follow-up frequently fails to meet the supportive care needs of survivors, often resulting in feelings of abandonment during the transition from cancer patient to cancer survivor (Cardy, 2006).

As part of the National Cancer Survivorship Initiative (NCSI), established in September 2008, Macmillan Cancer Support and NHS Improvement are working together to pilot new models of survivorship services to provide better post-treatment support for survivors. Table 1 illustrates current follow-up care as well as the vision for future models of care, as highlighted in the Cancer Survivorship Agenda (Macmillan Cancer Support, 2008).

The drivers for change presented in the NCSIs future vision of follow-up care are largely based on policy developments, such as the *Cancer Reform Strategy* (Allberry, 2008) and the 'Your Health, Your Care, Your Say' consultation (DH, 2006) pertaining to self-management in long-term chronic conditions. A further consideration has been the need to develop a model of follow-up feasible within the current economic climate, which promotes quality and safety for patients, and which allows for choice based on individual need. In order to identify areas of significance in terms of these drivers for change, a key mapping project commissioned by the NCSI Research work stream highlights a number of issues pertaining to the follow-up experiences of people living with and beyond the four most common cancers: breast; colorectal; lung; and prostate (NCSI, 2009). Each of these four reports was conducted by independent organisations and the main findings are summarised in Table 2.

Table 1: The Cancer Survivorship Agenda: Follow-Up Now and in the Future (Macmillan Cancer Support, 2008)

	Follow-Up Care Now	Follow-Up Care in the Future
What is the aim?	<ul style="list-style-type: none"> • to provide medical support • to help detect recurrence of cancer • to help cancer survivors manage their symptoms better with the support of their clinician. 	<ul style="list-style-type: none"> • to provide medical support • to help detect recurrence of cancer • to help cancer survivors manage their symptoms better with the support of their clinician • to tell people living with or beyond cancer and their carers about, and refer them to, specialist services that can help with their medical, practical and emotional needs • to spot late effects more quickly and provide appropriate support and treatment • to provide data on outcomes of care.
What happens?	<p>What works well now:</p> <ul style="list-style-type: none"> • diagnostic tests (e.g. mammograms and blood tests) • clinical assessment by a clinician • conversation with a clinician. <p>Areas for improvement:</p> <ul style="list-style-type: none"> • long waits in hospital for outpatients • GPs are not always informed about treatment and follow-up care • people have to travel to and from hospital, costing them time and money. 	<ul style="list-style-type: none"> • assessments of people's full range of needs • cancer survivors and professionals will work in partnership to develop a post-treatment care plan • letters sent to GP and patient • tools to help people self-manage • information about local support groups • referral to support services that are tailored to people's individual needs.
How is it provided?	Health services determine how it is provided, usually in a hospital or a GP surgery.	<p>People should be able to choose whether they receive post-treatment support:</p> <ul style="list-style-type: none"> • from a clinician, either in hospital or at a GP practice • as part of a group of patients • over the telephone.
How often?	Every few months until clinicians determine it is not necessary.	<ul style="list-style-type: none"> • regularly - to update the care plan • people living with or beyond cancer can also self-refer whenever they need help.

Table 2: NCSI Key Mapping Project (NCSI, 2009)

Report	Summary of Findings
<p><i>'Mapping the needs for breast cancer survivors: information from qualitative stakeholder research and grey literature'</i> by Breakthrough Breast Cancer.</p>	<p>There is consensus among breast cancer survivors that follow-up care should be tailored to the individual and that survivors should be fully involved in decision-making (Breakthrough Breast Cancer, 2007; Sheldon et al., 2008). Members of one focus group (Breakthrough Breast Cancer, 2007) felt that group-based follow-up could not cover as many care issues as individual follow-up, and concerns were expressed that telephone-based follow-up would miss important clinical indications that could only be identified in a face-to-face, clinical appointment.</p>
<p>The <i>'Bowel Cancer Survivorship Report'</i> by Bowel Cancer UK.</p>	<p>There is a high variability in availability and quality of follow-up services and support for colorectal cancer survivors. The patient experience of treatment was generally positive, but follow-up experiences were highly variable. Half of the patients received no support whatsoever; some were provided with home visits by stoma nurses or colorectal nurse specialists; a minority saw dietitians; and some were provided with a mobile phone number to reach a nurse any time or day of the week.</p>
<p><i>'Lung Cancer Research Work stream Final Report'</i> by The Royal Castle Lung Foundation.</p>	<p>Initial analysis of the survivorship model indicates several prevalent issues which arise across all stages of the survivorship pathway, including follow-up: Anxiety, depression, fatigue, breathlessness; Common side effects of radiotherapy and chemotherapy; Psychosocial issues (e.g. anger, guilt and the stigma attached to having lung cancer); Access to services (e.g. cancer nurse specialists (CNS), lung oncologists, breathlessness clinics, new treatments, clinical trials, post-treatment rehabilitation and fitness planning, diet, and smoking cessation support); and lack of awareness in both the public and GPs as to the signs and symptoms of recurrent cancer.</p>
<p><i>'Identification of research needed into the experience of men living with and beyond prostate cancer'</i> by The Prostate Cancer Charity.</p>	<p>Follow-up care for men on hormone therapy often occurs unplanned and informally. Also, as with the other cancers within the mapping project, variations in the delivery of follow-up care are evident. Concerns are raised as to the impact of this variability on the patient experience.</p>

Not only did the NCSI Mapping Project (2009) highlight the need to review current models of follow-up care in light of increasing survivorship, but it also demonstrated the sheer lack of consensus on what follow-up is and how it is delivered. A report carried out by the Picker Institute elaborates on this lack of consensus, demonstrating that the definition of 'follow-up' care varies across and within cancer groups (Sheldon, Davis, and Parsons, 2008). This lack of consensus was evident among professionals as well as patients.

The review by the Picker Institute did, however, identify trends in follow-up care across different groups of people with cancer and their carers. Namely, most patients had their follow-up appointments with a specialist at the hospital, most also had more informal access to a CNS, and the main purpose of follow-up appointments was most often perceived as being to provide reassurance, particularly around recovery and absence of symptoms of a recurrence. Survivors living with the side-effects of treatment appeared to have had particularly poor experiences of follow-up support, the most common problems involving access to care (Sheldon, Davis, and Parsons, 2008).

Despite the recognised lack of clarity regarding the efficacy and consistency of follow-up care, there is no doubt that 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 also taken into consideration. However, some improvement initiatives thus far have merely contributed to a continued lack of continuity in the services provided to patients throughout the treatment trajectory (Dumont 2005; Gysels 2007; Haggerty 2003). To address this problem, the Institute of Medicine (US) (Hewitt, Greenfield, and Stovall, 2006) recommends that patients completing primary cancer treatment be given a comprehensive care summary and follow-up care plan to optimise both the continuity and the coordination of their care. This is also highlighted in the cancer survivorship initiative (Macmillan Cancer Support, 2008). In order to achieve this, the essential elements of survivorship care plans need to be identified, as do the optimal levels of involvement of various specialists and primary care providers in the creation and application of care plans. Work is underway as part of the NCSI to explore and evaluate systematic assessment and care planning for cancer survivors in a range of NHS secondary care settings (Hindle, 2009)

The current evidence provides little guidance on whether one model of follow-up care is superior to another, although consensus does exist that routine follow-up for breast cancer is not the most effective method of detecting recurrence (NICE, 2002). An audit conducted in Cornwall found that in breast cancer patients diagnosed with local recurrence between 1999 and 2004, 15% were detected at routine follow-up, 48% were first noticed by patients themselves, and 37% were detected at routine mammography (Morris, Wheatley, and Ingram, 2008). This gives some indication for the need to consider alternative approaches of supportive aftercare to be implemented so that healthcare professionals have more time for newly diagnosed patients, those on active treatment and those with relapsed disease, and so that cancer survivors receive support which is appropriate for their specific needs.

There is a clear need to identify evidence that will guide health care planning and provide a framework for the follow-up of patients living with or beyond cancer. This review updates

current knowledge of the clinical effectiveness of follow-up services after treatment for cancer, as well as provides insight into selective follow-up initiatives currently being tested within practice. 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 (CRD, 2007), followed by an evaluation of the literature and selected current oncology practice, it is anticipated that this review will shed light on the trends in follow-up care and provide some guidance to developing approaches tailored to need.

AIMS AND OBJECTIVES

This review was conducted with the primary aim of identifying evidence to guide health care planning in order to be able to consider a range of alternative approaches to the provision of aftercare services for patients living with or beyond cancer. This was achieved by:

- Updating the CRD report by reviewing follow-up literature from 2007 to present (2009) for the four largest cancer groups (i.e. breast; colorectal; lung; prostate).
- Networking with experts within the field of oncology follow-up, as well as those currently conducting new follow-up initiatives.
- Identifying trends within the acquired data.
- Incorporating current NCSI drivers for change into the acquired data.
- Producing recommendations for future approaches to support services for people living with or after cancer.

METHOD

Search Strategy

The Cochrane Database of Systematic Reviews (CDSR), DARE and NHS EED were searched for systematic reviews and economic evaluations from June 2007 to September 2009. In addition, MEDLINE and EMBASE were searched from 2008 to 2009 in order to detect any recent systematic reviews that had not yet been added to CDSR. In being consistent with the CRD (2007) review being updated, searches were restricted to using the terms "follow-up" and "surveillance" in the title field of the MEDLINE and EMBASE records and in the title or abstract field of the CDSR, DARE and NHSEED records. International Cancer Research Portfolio, ClinicalTrials.gov and mRCT (Current Controlled Trials) were searched for ongoing trials. For cancer sites where no systematic reviews of clinical effectiveness were identified, site-specific searches were conducted in PubMed from July 2007 to September 2009 to identify relevant randomised controlled trials (RCTs). For

frequently employed aftercare strategies as well as initiatives of particular interest, where pre-defined search criteria might not have been sufficient for the capture of relevant records, subsequent searches were conducted on PubMed. For example, “group follow-up” can also be located via the search terms “shared medical appointments,” “cluster visits,” and “drop-in group medical appointments.”

Reference lists from background and identified studies were handsearched. Further details of the search can be found in appendix 1.

Inclusion Criteria

Studies assessing follow-up services in patients who had undergone primary treatment for cancer and were in remission were included. The following cancer sites were of relevance: breast; colorectal; lung; prostate. In addition, any studies looking at multiple sites, or generic follow-up (i.e. not site specific) were considered. For clinical effectiveness, systematic reviews were included, and where no systematic reviews were identified, RCTs were included. For cost-effectiveness, systematic reviews and full economic evaluations were included. A full economic evaluation was defined as an evaluation of the cost-effectiveness of two or more follow-up interventions. Included reviews and economic evaluations were not restricted by outcome, but clinical outcomes considered to be of interest included survival, recurrence, morbidity, quality of life (QoL), and cost-effectiveness.

All titles and abstracts of studies identified by the searches were scanned for relevance in terms of topic and participant group. For any titles or abstracts that were potentially relevant, full paper manuscripts were obtained and the relevance of each study assessed according to the pre-specified inclusion criteria.

Grey literature was also utilised where this would provide information relevant to the topic of follow-up, and this included literature based on the work surrounding a range of long-term conditions.

Ongoing Studies

Ongoing studies referenced in the CRD (2007) review were located for progress updates. Where no information was available, lead researchers were contacted via email for further discussion. Additional ongoing studies were identified via referral from health professionals or as an outcome of the search strategy.

Quality Assessment

All systematic reviews were quality assessed in terms of their inclusion criteria (i.e. RCTs) and only those reaching a minimum standard were included. All randomised control studies (RCT) were included if they assessed the pre-defined outcomes of interest. Prospective cohort studies were included due to their relevance in examining the etiology of cancer outcomes. Pilot and feasibility studies, or those of a non-randomised design, were only included if they pertained to testing a new initiative consistent with current NCSI and government goals and priorities. They were also considered of relevance if they provided evidence of best practice pertaining to the often neglected cancers such as lung or colorectal.

Data Extraction

Data from all published RCTs, cohort, and feasibility studies were extracted using a standardised data extraction template (appendix 2), extracting the following details: author; title; aims; participants; outcomes; methods; randomisation; response rates; results; conclusions; and, strengths and limitations. A similar template was designed to extract information for ongoing studies (appendix 3), with the addition of details on length of study.

Data Synthesis

Data were combined in a narrative synthesis, categorised by cancer site and then type of aftercare. Summary sheets were created for all published studies (appendix 2) and all relevant ongoing studies (appendix 3).

RESULTS

Searches for systematic reviews, economic evaluations, RCTs and ongoing trials yielded approximately 1,174 hits in total (appendix 1). After removal of duplications and records not relevant to the review, abstracts were scanned and the full manuscripts of 62 potentially relevant papers and ongoing trial records were scanned. A total of 31 records and initiatives were included in this review.

The National Institute of Clinical Excellence (NICE) guidelines and recommendations have been presented for each cancer group, along with the key drivers for change. The overall findings of the Centre for Reviews and Dissemination report (2007) for each cancer group have been summarised, followed by a categorised narrative synthesis of newly identified data (i.e. categorised according to the type of follow-up). Details of all relevant ongoing studies have been summarised, including those referenced in the CRD review. Common trends within and between cancer groups and type of aftercare were identified and evaluated accordingly.

BREAST CANCER

The NICE *Improving Outcomes in Breast Cancer* guidance (NICE, 2002) recommend that “the primary aims of clinical follow-up should be to identify and treat local recurrence and adverse effects of therapy, not to detect metastatic disease in asymptomatic women” (p.10). The drivers for change in breast cancer follow-up include:

- Rising numbers of survivors
- High cost of follow-up
- Hospital capacity (i.e. waiting times)
- Limited resources (i.e. clinic and consultant time)
- Consistency of care (i.e. ‘key workers’; care plans across multidisciplinary teams/MDTs)
- Low efficacy of long-term follow-up (NICE, 2002)
- Increased need for personalisation and choice
- Symptom detection (i.e. most commonly by patient, NICE 2002)
- Unmet needs (e.g. adaptation, information, psychosocial, late effects, lifestyle change etc.).

The CRD review identified three systematic reviews investigating the clinical effectiveness of follow-up services for people with breast cancer. Two reviews found insufficient evidence to argue either for or against the practice of surveillance mammography or to draw conclusions regarding the best practice for breast cancer follow-up care in terms of patient involvement in care, reduction in morbidity, or cost-effectiveness of service provision (Collins, 2004). The remaining review concluded that routine follow-up, based on regular physical examinations and yearly mammography alone, is as effective as more intensive approaches (‘intensive’ defined by NICE as “*designed to detect metastatic disease before symptoms develop*”; NICE, 2002, p.58) (Rojas, 2000). In terms of economic evidence, one study conducted in Australia concluded that monthly follow-up consultations were by far the most effective programme but that the cost per patient (Aus\$3,870) was excessive (Grogan et al., 2002). Another study concluded that minimal follow-up was equally effective but more cost-effective than intensive follow-up (Mapelli, Dirindin, and Grilli, 1995). The findings indicated that intensive follow-up for breast cancer may be unnecessary based on current evidence, and that what might be more important is the provision of fast and straightforward access to appropriate healthcare resources should symptoms be discovered. At this time, the evidence did not allow for specific recommendations regarding follow-up strategies for breast cancer.

This current review identified sixteen records and initiatives in progress, which were categorised into six types of follow-up:

- a) Intensive
- b) Nurse-led
 - i. Automated
 - ii. Telephone
 - iii. Nurs- led support group
- c) Patient-initiated (patient-triggered/patient-initiated/point of need access)

- i. Patient initiated plus self management educational programme
 - ii. Patient initiated plus post treatment conference/group
- d) Radiographer-led
 - i. Radiographer-Led/Nurse Telephone/GP-Led with Self-Referral and Annual Monitoring.
- e) GP-led plus education and care plan
- f) Education as adjunct
 - i. Psycho-educational
 - ii. Physical education

One systematic review was identified.

Montgomery, Krupta, and Cooke (2007) conducted a systematic review with the aim of investigating alternative follow-up methods that have undergone a controlled trial, in order to establish evidence to inform and clarify guidelines for breast cancer follow-up. Using MEDLINE, Embase, CancerLit, Web of Sciences and EBM reviews as data sources, they reviewed all RCTs meeting the following inclusion criteria were: patients included had been treated for primary operable breast cancer and were free of distant metastases outside the breast or axilla at the time of initial treatment; and, the study was a randomised controlled trial comparing routine clinical and mammographic follow-up with an alternative, or comparing different frequencies or durations of clinical follow-up.

All outcome measures addressed in the trials were analysed. A total of seven records were obtained: two trials compared follow-up in hospital clinics with that provided by a GP (Grunfeld et al, 1996, 2006); two compared traditional follow-up with 'on-demand' (i.e. patient-initiated) follow-up by contacting a BCN (Brown et al, 2002; Koinberg et al, 2004); one compared routine follow-up by doctors with routine follow-up by BCNs (Baildam et al, 2004). Two trials compared different frequencies of follow-up within a traditional model of follow-up (Gulliford et al, 1997; Kokko et al, 2005).

The authors found that all trials were of inadequate power or duration to establish ideal frequency of clinic visits or safety of alternative follow-up methods. 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, larger and higher quality trials are required to establish whether these alternative models are as safe as clinical examination.

a) Intensive Follow-Up

A randomised prospective study to compare the cost-benefit of standard clinical versus intensive follow-up in stage I, II and III breast cancer patients (n = 121) who had completed treatment with curative intent was identified (Oltra et al., 2007). The outcomes of interest were the number of scheduled outpatient appointments kept, the number of relapses, and the overall cost of each model of follow-up.

Patients were randomised to standard clinical follow-up (n = 63) or to an intensive follow-up (n = 58). In the standard clinical follow-up arm, the patients had a careful history and physical examination; no complementary tests were undertaken if the clinical symptoms at the time did not require them. In the intensive follow-up arm, in addition to the anamnesis and physical examination, biochemistry, hematogram, and the markers carcinoembryonic antigen (CEA) and CA15.3 were assessed at every outpatient visit together with an annual hepatic echography, chest x-ray, and bone scan. All patients, irrespective of their group assignment, had annual mammography. Outpatient appointments were scheduled for every 4-months over the first year, every 6-months for the next five years, and annually thereafter. Surveillance followed the guidelines of the American Society of Clinical Oncology (ASCO) in operation at the time of the study.

The number of scheduled outpatient appointments kept was 359 in the standard clinical follow-up compared with 355 in the intensive follow-up group. After a median of 3-years of follow-up, there were 11 relapses in standard clinical follow-up compared with 13 in the intensive follow-up group; 69% of the relapses in the intensive follow-up group were diagnosed in the interval between scheduled visits, when patients initiated clinic visits because of the appearance of symptoms. The overall cost of follow-up was 24,567 euros in the standard clinical follow-up group and 74,171 euros in the intensive follow-up group. The authors concluded that performing additional investigations during breast cancer follow-up is associated with higher costs without difference in early detection of relapses. They also propose rapid patient access to medical support when needed (i.e. patient-initiated) as being the most efficient model of follow-up.

b) Nurse-Led Follow-Up

i. Automated Regular Telephone Follow-Up (Nurse-Led)

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, the main objectives were to improve the detection of psychosocial concerns and of treatment-related side-effects among patients who had completed their adjuvant chemo-radiotherapy (time in follow-up was between 1-20 years) (Montgomery et al., 2008). An initial seven questions were designed to encourage self-examination and allow the reporting of symptoms that may be associated with relapse, either locoregional or metastatic. The FACT-B questionnaire with endocrine and arm subscales was used to assess QoL. Outcomes were patient acceptability, which was assessed via a semi-structured interview, and clinic attendance.

The follow-up questionnaire was administered on paper at baseline and then, in place of a clinic visit the following year, the women completed the same questionnaire using an automated telephone system. 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 telephone in and complete the questionnaire using an ordinary touch tone telephone. The answers generated were recorded within an individual patient record. The system can be programmed to calculate scores according to the answers given in the questionnaire and undertake specific actions in the event of certain answers

being given or scores being achieved. An acceptable score can result in a reassuring letter being generated by the system and a request for a routine mammogram being sent to radiology. Poor scores or deterioration from the last-recorded score can result 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 with the system or were nervous about the new technology; and the rest of this group stated that they would prefer to come to clinic for an examination. Around 11% of concerns raised led to clinic attendance.

In conclusion, automated telephone follow-up also allows the generation of not only outcome data, but also far 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. Barriers to implementation might be patient anxiety regarding technology, as well as loss of regular face-to-face check-ups.

ii. Nurse-Led Routine (Planned) Telephone Follow-Up

Beaver et al (2009) report on a two centre UK randomised equivalence trial with low and moderate risk (primarily determined via the Nottingham Prognostic Index; NPI) breast cancer patients. 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-monthly for two years, 6-monthly for two years, and then annually for a further year, or annually for 10 years for both groups. The primary outcomes were psychological morbidity (state-trait anxiety inventory, general health questionnaire (GHQ-12), participants' needs for information, participants' satisfaction, clinical investigations ordered, and time to detection of recurrent disease.

Over the course of the study, 500 telephone and 500 hospital appointments were made with participants. Uptake of the intervention was 60%; those who refused to take part differed from participants in study site, social class, and follow-up status. Patients at the specialist breast unit (71%) were more likely to want to participate than those at the district general hospital (61%), participants from higher social classes (professional occupations) were more likely to want to participate than those from lower social classes, and participants with three to 12 months between visits (67.7%, 70.6%) were more likely to participate than those on six monthly follow-up (58.1%). Time from diagnosis did not differ significantly for those who did or did not take part. Differences between groups in state-trait score were not significant at the start, middle, or end of the trial under intention to treat or adjusted treatment received analyses, although means were consistently lower for the telephone group. Mean score did not significantly improve during the trial, the mean reduction from the start to the end of the trial being 0.33. Differences in GHQ-12 scores at the start, middle, or end of the trial were not significant, nor were differences

between time points. Although the percentage of cases (scores ≥ 4) was consistently higher in the hospital group at the start, middle, and end of the trial, differences between the groups at each time point were not significant. Initially, 22% were GHQ-12 cases compared with 17% at the end of the trial.

Participants clearly indicated their specific information needs, with, initially, the highest need relating to information about genetic risk and the lowest for information on sexual attractiveness. Within both randomised groups, information needs reduced over time for all items. There was little difference between the groups in information needs, apart from information on sexual attractiveness in the middle of the trial, where 15% of the hospital group compared to 7% of the telephone group required information on this. The need for information on genetic risk remained the highest at the end of the trial, with 31% of respondents still requiring information. There were no significant differences between randomised groups initially regarding satisfaction with information received. The telephone group showed significantly more satisfaction at the middle and end of the trial. Participants were asked if they had thought that the appointment had been helpful in dealing with their concerns. There was no difference between groups initially, but 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 44% in the hospital group) and few with negative responses. Contacts between appointments for both groups were relatively few, but were primarily with breast care nurses, GPs, and lymphoedema nurses. There were no significant differences between groups in terms of contact at any time point. There were no differences between groups in whether clinical investigations were ordered for participants as a result of appointments at the start (hospital 29% v telephone 24%), middle (36% v 34%), or end of the trial (40% v 43%). 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.

The telephone intervention was specifically designed to provide information. The percentage of participants requiring information on specific needs at the end of the trial, ranged from 10% to 32%. Considering that participants were a median of 20-months from diagnosis at the point of recruitment, and remained in the study for a mean of 24-months, many patients retained a need for information long after completion of treatment. The nurses who provided this service received a four half-day training programme with ongoing feedback. Telephone follow-up may reduce the burden on clinics, but at the intensity of this intervention (frequency of contact and length of consultations) and its provision by specialist nurses, it is unlikely to prove more cost-effective than the current provision by junior doctors in outpatient clinics.

iii. Nurse-Led Support Group

'Moving On,' which meets at the Force Cancer Support Centre in the grounds of the Royal Devon and Exeter Hospital, is a nurse-led support group for breast cancer survivors and their partners. The aim is to ease the transition from cancer 'patient' to cancer 'survivor' during the first 12-months of completion of treatment. The model includes both physical and psychological support. The group attend eight two-hourly sessions dealing with practical

issues such as the fear of recurrence, and the personal strengths and resources they can utilise in managing their condition. There is current consideration to whether this approach can be adapted to become part of the annual follow-up review (*Peter Donnelly, Consultant Breast Surgeon, Director Research and Development*).

c) Patient-Initiated Follow-Up

Hillingdon Breast Unit has been delivering a service which gives patients choice as to their mode of follow-up. Ongoing testing of the acceptability of 'patient-triggered' (i.e. initiated by the patient) follow-up has been in place since it was initiated in June 2000. The current protocol at Mount Vernon and Hillingdon Hospitals for patient-initiated follow-up is: After primary treatment the Consultant Clinical Oncologist discusses patient preference for follow-up management (i.e. regular follow-up or a self-management approach with early mammography for five-years and direct access to the clinic via the Breast Care Nurse; BCN). Patients also receive clear tailored information regarding future risk of recurrence, and understandable information on symptoms and effects to look out for. Any patient not suitable for the self-management approach, such as those who are anxious, single, have multiple co-morbidities, or presented late, is identified by the CNS; this is usually about 25% of patients. A self-management programme ('*New Perspectives*') is available for patients to access at a nearby centre. 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 89% of GPs were happy with the new model, 83% of patients were happy with the contact they received after completion of treatment, and 92% of patients felt secure with the new system (*Dr Jane Maher, Hillingdon Breast Unit Mount Vernon Cancer Centre*).

An audit to assess patient satisfaction and GP workload following the introduction of patient-led breast cancer follow-up for low-risk breast cancer survivors was conducted at the Cambridge Breast Unit (CBU), for the purpose of service improvement (Chapman et al., 2009). The outcomes assessed included patient satisfaction, GP workload, and number of self-referrals.

At CBU, each low risk patient (as determined according to post-menopausal patients who are node negative, or have a NPI score of < 4.4, or patients with ductal carcinoma in situ only) 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 to the breast clinic if concerns arise. 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 the audit demonstrated that 100% (n = 106) of patients were either very satisfied or satisfied with the process used to contact the breast unit. However, based on concerns raised by participants regarding access to additional psychological support and advice about treatment side-effects, two additional measures 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 an attempt to identify any patients with ongoing psychological morbidity requiring additional input.

Of the respondents, only 4% required re-referral to hospital, indicating how patient-initiated follow-up can result in more efficient use of resources. GP responses indicated that only 4% had re-referred a patient back to the breast unit during the study period. A further 71 GPs reported no consultations and 27 reported 1–2 patient consultations for their patients in the follow-up programme. The remaining 13 GPs had seen patients 3–5 times or more than 5 times.

In conclusion, the use of risk stratification allows low risk patients to undergo five-year mammographic surveillance without regular breast examination but with access to clinical input if necessary. It also allows time to be spent with new referrals and those patients at higher risk of recurrence. A potential problem is that such a model of follow-up will lead to an initial increase in workload for GPs as patients seek additional clinical follow-up in primary care. The authors highlight the need to prepare GPs prior to introducing such an initiative, in order to ensure its success.

Sheppard et al. (2009) conducted an RCT (n = 237) comparing '*point of need access*' (patient-initiated) versus routine 6-monthly clinical review. The aim of the study was to develop a model of care based on the concept of point of need access to specialist care via the breast care nurse, compared to routine hospital based 6-monthly clinical review at year two post-diagnosis. Both groups continued to have annual access to routine mammography. Patients randomised to point of need access were given information for how to contact the breast care nurse if concerned. Nurses providing this service underwent training in clinical examination, and physical assessment and subsequent management of symptoms. Primary outcomes were psychological morbidity and QoL measured at 9 and 18 months post-randomisation. Secondary outcomes included assessment of fear, isolation and the recording of clinical events.

The study was completed by 90% of the participants, demonstrating high acceptability. Findings suggest that two years post-diagnosis there is no evidence to support the view that regular clinical review improves psychological morbidity or QoL. Two thirds of patients found this 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 point of need

access group (an incidence of 0.32 contacts per person per year). Specialist nurses can be used to deliver a patient-initiated support pathway with many patients being effectively managed through telephone consultation. This provides a personalised approach to care after cancer treatment. Consideration should then be given to the patients need for tailored information and self-management support in order that they are well informed and confident when taking on this responsibility.

In a five-year prospective RCT conducted in Sweden, designed to evaluate the cost-effectiveness of two different models of follow-up, stage I and II breast cancer patients (n = 254) were randomised to a routine follow-up with a physician (PG; n = 131) or 'on-demand' (i.e. patient-initiated) follow-up with a nurse (NG; n = 133 (Koinberg et al., 2009). The primary outcome was cost-effectiveness.

Routine follow-up with a physician involved a specialist in oncology or surgery examining the patients four times per year during the first two years after surgery, followed by bi-annual examinations for up to five 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 of the breasts, chest wall and regional lymph nodes was carried out. Mammography was carried out at one-year intervals. Blood tests, chest x-ray or other imaging techniques were only performed on clinical indication. Patient-initiated follow-up with a nurse was introduced during a visit to the physician that took place following radiotherapy and after randomisation. Patients were given an appointment to meet with an experienced nurse approximately three months after surgery. In the course of this meeting, the patient received information about how to recognise a recurrence in breast, skin, axilla and scar. The nurse arranged mammography at one-year intervals and informed the patient of the result of the mammography by telephone or letter. After three years, the 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 took time to talk to the patient about her psychosocial situation. The patient was instructed to contact the nurse at any time if she had any questions or symptoms that she perceived could be related to breast cancer. The nurse co-ordinated the healthcare resources and consulted a physician or a physiotherapist when needed.

The cost per person year of follow-up differed between the groups, with 630 euro per person year in the PG compared to 495 euro per person year in the NG. Thus, specialist nurse intervention with check-ups on demand was 20% less expensive than routine follow-up visits to the physician. The main difference in cost between the groups was explained by the numbers of visits to the physician in the respective study arms. There were 21% more primary contacts in the PG than the NG. The authors concluded that the difference in cost per year and patient by study arm is modest, but transforms to nearly 900 euro per patient over a 5-year period, offering a substantial opportunity for reallocating resources.

i. Patient Education Programme plus Patient-Initiated Self-Referral to Nurse

An ongoing single-centre open, pilot RCT at Calderdale and Huddersfield NHS Foundation Trust aims to test the feasibility and acceptability of a model of follow-up based on supportive care with newly diagnosed breast cancer patients, who have been treated with

curative intent and are at low risk of recurrence. The primary outcome is the assessment of feasibility, process and acceptability of introducing the new model, as assessed, in the main, by descriptive analysis (i.e. satisfaction with the model, attendance at the course, an evaluation of the financial costs). At 12 and 24 months a member of staff will undertake a telephone patient satisfaction interview. Secondary outcomes will be QoL, psychosocial and lifestyle issues, as measured with the EORTC QLQ-C30 plus breast module, HADS and Concerns Checklist. Outcomes will be measured at 0, 6, 12, 18 and 24 months. They will also be asked to keep patient diaries for the duration of the trial, entering any comments about their experiences and contacts that they make over the following two years. If successful, the proposed model of follow-up would replace routine hospital appointments with a package of self-help, telephone support and rapid access to specialised clinics as required.

Eligible patients will attend a specifically designed Breast Cancer Care (BCC) course on *Living with Breast Cancer* comprising four half-day sessions running over four consecutive weeks. All patients who consent will attend the course and upon completion of the course, patients will be debriefed by the BCN before being randomised to either the trial arm (n = 40) where there is no routine follow-up or the standard arm (n = 40) where they will undergo routine follow-up in out-patients. Random permuted variable blocks will be used to ensure treatment groups are well-balanced. Block sizes will not be revealed to investigators or other study staff. All patients in the trial arm are given contact details and helpline telephone numbers to allow open access back into the service if required.

Patients in the trial group will be provided with written information concerning the issues covered in the course and details of how to get back into contact with breast surgical services (a telephone Helpline run by the BCN's) should they have any concerns about their breast cancer. If required, they will have direct access back into the breast surgical service without the need for a lengthy re-referral process, but they will not be followed up routinely in outpatient clinics.

At the end of the study, patients will be offered the option of continuing with the study model or to transfer to follow-up in outpatients.

The project has been running for a year and the last course of the pilot is October 2009; interim results are expected soon. Ongoing evaluations of the course content have been excellent; the patients have enjoyed the programme and the process of self-referral, despite initial reservations (*Dr Jo Dent and Veronica Allinson of Calderdale and Huddersfield NHS Foundation Trust Hospital Trust*).

ii. Post-Treatment 'Support Conference' followed by Patient-Initiated Follow-Up

At Brighton and Sussex University Hospital NHS Trust, a 'support conference' is being tested with "patients defined as low risk by the treating team" prior to allocation to patient-initiated follow-up (Chatfield and Simcock, 2008). Patients continue to have rapid access to

the BCN and continue with regular mammograms. On completion of treatment, patients were 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. Ninety-two patients were invited to the conference, 43% replying that they would attend and 31% actually attending. 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 (75% response rate) was 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 routine clinical follow-up, equating to 30 scheduled appointments and up to a further 240 appointments collectively.

As a result, 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. The time required to organise a successful conference (i.e. venue and programme planning; speaker and delegate administration) was cited as a potential barrier, highlighting the need to explore alternative resources for the conferences if they are to be expanded (*Caroline Huff, Macmillan Cancer Support, Nurse Director; and Dr Richard Simcock, Consultant Clinical Oncologist, Brighton and Sussex University Hospitals NHS Trust*).

d) Radiographer-Led Regular (Planned) Mammographic Follow-Up

The Velindre model is a radiographer-led mammographic follow-up service for breast cancer patients in Wales, which has been running since May 2003 (Vaile, Donovan and Barrett-Lee, 2006). Radiographers are trained in implementing this new system. At the patients' annual mammography visit the radiographer completes an Online health questionnaire on the patient database, the main aim of questions being to determine if patients have: experienced any new breast problems; developed any signs of lymphoedema; developed shoulder stiffness on the treated side; discovered any significant new, unexplained health problems; or whether they have been taking Tamoxifen /Arimidex™/ Femara™ for treatment of breast cancer and for how long.

As well as an abnormal finding at mammography triggering referral to a specialist BCN, certain problems identified via the electronic questionnaire also trigger such a referral: new breast problems including mild pain, swelling, skin rash; recent onset of shoulder stiffness on treated side; or recent onset of lymphoedema. Referral takes the form of a paper referral to the BCN, who then contacts the patient by telephone or letter. Similarly, answers to the hormone treatment questions inform radiologists of whether referral to a specialist oncology nurse is necessary. For those patients who have completed more than five-years hormone treatment, this is reviewed regarding discontinuation or change from Tamoxifen™ to an aromatase inhibitor licensed for extended adjuvant use (i.e. Femara™). *Adjuvant Online*, an online risk stratification tool for professionals, is used to determine the benefit of extended use of an aromatase Inhibitor and the GP is informed of any hormone therapy decisions via an electronically-generated result letter. Referral to a Consultant Oncologist takes place if

the patient reports: nipple discharge or bleeding, new breast lump, severe persistent breast pain, new breast distortion; chronic, severe bone pain; severe headaches; persistent nausea or unexplained weight loss; or persistent chest pain or shortness of breath.

The Velindre model has demonstrated a reduction in clinic visits (i.e. typically, patients need only one hospital visit each year) and improvement in the consistency of established relationships with radiographers and specialist nurses. Other benefits include that electronic sign-off of Radiology reports alerts the Consultant Oncologist to any abnormal mammogram reports. In the year from 1 August 2007 to 31 July 2008, 1,210 patients attended mammographic follow-up, 80% requiring no further input from the breast team; 9% requiring further input from a CNS; 2% requiring a referral to the outpatient clinic; 5% discharged from care; and 4% of questionnaires had no outcome recorded. Following presentations at two national conferences there has been interest from several other NHS Trusts who wish to operate a similar follow-up model.

i. Radiographer-Led/Nurse Telephone/GP-Led with Self-Referral and Annual Monitoring.

As demonstrated thus far, there is a growing body of evidence that alternative methods of follow-up can be as or more satisfactory to breast cancer survivors (Beaver et al., 2009; Sheppard et al., 2009). However, as noted in a critique by Montgomery (2009), there remains a lack of definitive evidence that routine clinical breast examination is unnecessary. Only a large RCT can provide such evidence on whether widespread implementation of alternative approaches will benefit patients.

A proposed large-scale multicentre phase III prospective RCT of hospital-based specialist versus risk-adjusted breast cancer follow-up that might be able to provide insight into this is that of '*ibreast*.' iBreast is open to breast cancer patients with either invasive or non-invasive disease treated with curative intent that are dischargeable from consultant led follow up. The trial is risk-adjusted to include patients up to 3 years post-diagnosis, depending on their risk. The trial has been designed to determine whether innovative alternative follow-up methods without clinical examination (n = 4,000) are equivalent to traditional specialist hospital-based follow-up with clinical examination (n = 4,000) in terms of survivorship and patient perception of living with cancer. Primary outcomes include disease-free survival, recurrence (time to recurrence and severity of recurrence), psychological assessments and QoL (EORTC QLC-C30 plus breast module, EUROQOL, HADS and GHQ-12), and health economics. Secondary outcomes include compliance with guidelines (e.g. bone health, adjuvant hormone blocking therapy and breast imaging), number of referrals back into the hospital system, satisfaction with follow-up strategies, acquisition of outcome data, molecular pathology of breast cancer and molecular biomarkers (ER, PgR, HER2, CK5/6, EGFr to select luminal A vs B, HER2 & Basal cancers), and long-term survival.

The alternative methods to be tested include: radiographer-led follow-up; nurse-led telephone follow-up; and GP/patient-initiated follow-up. Newly diagnosed patients have been registered for the trial, as well as patients 'flagged' at follow-up clinics. Patients were risk stratified into groups at diagnosis: Low risk (NPI<3.4) - randomise 1-year post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by

specialist hospital based consultant with clinical examination up to 5-years post-diagnosis; Moderate risk (NPI ≥ 3.4 and ≤ 5.4) - randomise 2-years post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by specialist hospital based consultant with clinical examination up to 5-years post-diagnosis; High risk (NPI > 5.4) - randomise 3-years post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by specialist hospital based consultant with clinical examination up to 5-years post-diagnosis followed by an agreed care plan and follow-up contract. Patients completing their randomised follow-up phase within the hospital setting will be then offered discharge to the alternative follow-up protocol. All patients will be followed up by annual questionnaire and annual mammography up to 10 years post diagnosis. Patients will be flagged for long-term survival (i.e. up to 20 years) with the Office of National Statistics.

The project has been through an intensive design phase, with engagement of breast and primary care research communities and evaluation of alternative methods of follow-up. Training packages for radiographer-led and patient-led follow-up are available as well as training for provision of a nurse-led telephone service. These can be rolled out to participating centres within the first 6 months. The study will start in December 2009 and the first 6 months will also involve setting up the trial at each centre (n = 200 centres). The recruitment phase will be 3 years with an additional 5 year follow-up (*Prof. Janet Dunn; Peter Donnelly, South Devon Healthcare NHS Foundation Trust; Dunn et al., 2009*).

e) Nurse-Led Educational Programme/Personalised Care Plan/GP-Led

In Canada, Grunfeld et al. (ongoing) are conducting a pragmatic multi-centre RCT of a patient-centered strategy to facilitate transition of breast cancer survivors' routine follow-up from specialist to primary care. The primary objective of the study is to evaluate a survivorship care plan intervention with the breast cancer survivorship population throughout nine specialist cancer care centres in Canada. Breast cancer patients (n = 400) identified by their oncologist as medically ready for transition from specialist care to primary care for routine follow-up will be included in the trial. The primary outcome will be the specific health-related QoL domain of adjustment to breast cancer at 12-months, as measured by the Impact of Events Scale, Profile of Mood States, and SF-36. Secondary outcomes will be adjustment at 24-months, patient satisfaction (Medical Outcomes Study-Patient Satisfaction Questionnaire), and health service outcomes (e.g. adherence, visits with multiple practitioners, coordination of care, and awareness of which physician is responsible for various aspects of care). An economic evaluation will be conducted alongside the clinical trial, using the SF-6D and assessing the costs of travel, follow-up visits and tests.

Patients (n = 400) will be randomised to receive usual care or to receive the care plan intervention. They will also be stratified into 2 groups: 1) diagnosed < 24 months previously and 2) diagnosed ≥ 24 months previously. Patients will be followed for 24-months, with outcome measures being completed at baseline, 3, 6, 12, 18, and 24 months.

The care plan comprises a binder of documents important to a patient's follow-up care, and is delivered through an educational session with a study nurse before the patient is discharged to their family physician. The documents within the care plan binder include: a personalised record of care (diagnosis, tumour characteristics, treatment received, plan for

initiating aromatase inhibitor, oncologist's recommendations, etc.); a survivorship care plan (summary of "what to expect," i.e. frequency and type of visits as well as important contact information for patient); a patient version of the Canadian Medical Association Journal (CMAJ) guidelines for the care and treatment of women with breast cancer ("Questions and answers on follow-up after breast cancer"); and a follow-up care reminder table. The study nurse will add additional documents that are locally available based on the meeting with the patient and an assessment of their particular needs (i.e. information about menopause, physical activity, nutrition, etc.). Family physicians of the patients in the intervention arm also receive a copy of the patient's care plan, a user-friendly version of the CMAJ guidelines, the full CMAJ guidelines, and a reminder table to keep track of their patient's visits and tests.

This large-scale study incorporates a variety of follow-up methods, including care plans, nurse-led education, and physician-led follow-up, in an attempt to provide breast cancer survivors with tools that will ease transition to primary care. The study has reached its target accrual goal and final analysis is expected to begin in 2011. It is anticipated that preliminary analysis might be completed during the Spring of 2010.

f) Educational Follow-Up

i. Psycho-Educational

An economic evaluation alongside an RCT comparing three psycho-educational strategies was conducted with women who had received surgery for invasive breast cancer ($n = 389$), the aim being to evaluate the most cost-effective way of improving transition to survivorship (Mandelblatt et al., 2008). Transition to survivorship was conceptualised as effectively coping with the impact of cancer, as measured via levels of distress and energy 6 months post-intervention (Revised Impact of Events Scale (IES-R) and the SF-36 vitality scale). Costs stratified by baseline level of preparedness for transition were also calculated. Preparedness was defined by responses to two items ("Overall, I feel very well prepared about what to expect during recovery; Overall, I feel the medical team has done a great deal to prepared me for what to expect during my recovery."). Overall 12-month health care costs were assessed by study arm. Women completed a baseline survey 4 to 6 weeks after primary treatment; the survey was repeated at 6 and 12 months after the intervention. The research staff used weekly logs to record the time and resources used to deliver the interventions. Participants were mailed calendars every 3 months to document all health services used; those not returning calendars were provided mail and telephone reminders.

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*.' This 23-minute film was designed to address 're-entry' challenges in physical health, emotional well-being, interpersonal relations, and life perspectives. The video includes peer modelling of active coping approaches to fatigue and other survivorship concerns.

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; among women who were the least prepared for transition to survivorship, the video was more effective, resulting in even lower costs. The video cost \$7,275 per unit change in distress versus control, but costs were lower in the subgroup least prepared for transition (\$355). The counselling arm was more expensive and less effective than the video for most outcomes. However, in one group of women more prepared for transition, counselling cost \$1,066 per unit decrease in distress compared with the video. Health care costs tended to increase as intervention intensity increased. In this trial, the educational video was the most cost-effective way to improve transition to survivorship

ii. Physical Education

In *Moving Forward with Life*, a theoretically-based physical activity RCT designed for breast cancer survivors who have completed treatment in the past 2-years, Pinto et al. (unpublished) examined the effectiveness integrating health promotion into follow-up care. The primary outcomes were physical functioning (SF-36), mood (SF-36), and fatigue (FACIT), as well as satisfaction with the intervention. Oncologists and surgeons (n=14, mean years in practice = 15.6 years) were trained to provide brief physical activity (PA) advice for 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 PA (extended advice) or contact control (brief advice). Assessments of patients' PA, physical functioning, mood and fatigue were completed at baseline, 3, 6, and 12 months. Healthcare providers completed questionnaires on PA counselling at baseline and provided feedback at study end.

The study has yet to be submitted for publication, but results have been presented at the Society of Behavioral Medicine Annual Meeting (Pinto, Goldstein, and Papandonatos, 2009). One hundred and ninety-two patients were randomised (13% Cancer Stage 0, 38% Stage 1, 41% Stage 2, 8% Stage 3-4; mean years since diagnosis = 2.9 years) after receiving 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 PA 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. Moderate intervention effects were also obtained for physical functioning and small effects for fatigue. These promising results suggest that effective health promotion can be integrated into follow-up care for cancer survivors.

Summary of Findings

When combining the CRD findings with the studies and ongoing initiatives identified in this review, a number of key findings have emerged within breast cancer follow-up: intensive, as defined mostly in speciality acute settings by intensity of frequency of contact/biomedical tests/duration, has generally been associated with higher costs without any benefits above those of minimal follow-up (Oltra et al., 2007); There appears to be little clinical benefit for

patients with breast cancer treated with curative intent to attend regular/routine appointments in specialist care, as long as routine standard tests (surveillance) as recommended by NICE (2002) are carried out. However, the iBreast study is designed to answer such questions definitively. Telephone follow-up by nurses through patient-initiated contact, or through planned regular nurse contact, has been associated with patient acceptability (by approximately two thirds of patients), improved patient satisfaction and convenience, as well as potential long-term reduced burden on hospital resources (Montgomery et al., 2008; Beaver, 2009); patient-initiated follow-up has been found to be acceptable to patients and healthcare providers, no increase in the risk of timely detection of recurrence, and leading to a reduction in appointments (Chapman et al., 2009; Sheppard et al 2009; Dent et al., unpublished; Maher; unpublished); and, radiographer-led mammographic follow-up has demonstrated a reduction in clinic visits and improvements in patient/provider relationships (Vaile, Donovan, and Barrett-Lee, 2006).

There is increasing testing of various educational interventions (Dent et al., ongoing; Wright et al., ongoing) alongside either patient-initiated follow-up, or nurse-led telephone follow-up, aimed at supporting patients to self-manage for symptom management, self-examination/monitoring, healthy lifestyle change, and smoothing transition to a new 'normal' life.

Another key trend in service development is the consideration of 'group' meetings (e.g. conferences and post-treatment clinics). There is as yet no clarity as to the purpose, role, and perceived outcomes of such interventions in relation to the follow-up and aftercare practices for breast cancer patients.

The trends as reflected in the studies completed and in progress, and the initiatives reviewed are summarised as follows:

- Shifts away from routine secondary care based follow-up (drivers for this change identified at the start of this section).
- As these shifts have been slow (clinician and patient acceptability; understandable risk aversion), the need for a large RCT to answer the questions around long-term survival and alternative approaches has been recognised and addressed.
- Alternative approaches being piloted as service initiatives need to demonstrate risk appropriate principles are built into them.
- A range of follow-up models have been developed which continue to rely on health professionals (nurses/AHPS) taking the traditional active/lead role:
 - Through routine planned face to face contact
 - Through routine planned telephone contact
- Patient-initiated contact in place of routine contact or visit is a growing development currently taking a range of approaches:
 - Following a consultation with health professional after treatment, providing a personalised shared contract with tailored risk assessment, and rapid access to specialist consultation as required
 - Following the exit consultation and including a self-management education programme

- Including some form of regularly collected patient-reported symptoms, outcomes, through specifically designed questionnaires, or current forms of symptom checklists, or outcomes measures.
- With the growing shift to patient-initiated contact, the need for some form of self-management/education preparation to be considered so that patients are confident, informed and aware.
- The effectiveness of nurse-led telephone support may rely on structured consultations and tailored telephone training, as well as development of skills to promote a self-management approach.

Given the current drivers for change, on the one hand, a clear need exists to reduce the utilisation of hospital resources whenever possible due to the increasing cost of follow-up as well as the limited resources available; and on the other hand, there appears to be little benefit to patients attending routine appointments, as currently prevails. However, there remains a need from clinicians and patients for strong evidence which provides definitive proof that routine clinical examination is unnecessary. In answer to this, a large randomised controlled trial is commencing which it is anticipated will answer these questions (Dunn et al., ongoing) and identify whether widespread introduction of alternative approaches to cancer surveillance and aftercare will benefit patients and avoid any harms.

In the meantime, this review offers evidence from trials and real life service change, for alternative approaches to aftercare and support for people who have reached the transition from treatment to living with and after breast cancer (at low/moderate risk of recurrence), which might include: tailored risk assessment; some form of educational programme followed by self-triggered, or planned nurse-led telephone support based on individual assessment and aftercare plan. Patients would self refer through a safe and reliable method, if they think referral is necessary. Patient-centred follow-up via risk stratification, as demonstrated in the planned ibreast trial looks promising in light of recognising the individualised needs between patients and across cancers, as well as the need for a more cost-effective follow-up service.

COLORECTAL CANCER

The NICE *Improving Outcomes in Colorectal Cancer* guidance (NICE, 2004) recommend that “short-term follow-up in the weeks after surgery for colorectal cancer should focus on post-operative problems, future planning (including the possible use of adjuvant therapy), and stoma management” (p.95). Nursing and dietetic support should be provided for all patients and CNS’ should specifically ask patients how they are coping with everyday life and provide appropriate advice and support, as well as arranging for patients to receive additional help they may need. It is recommended that patients who do not undergo complete colonoscopy before surgery are offered colonoscopy within six-months of discharge, and those patients who do not have a computed tomography (CT) scan of the liver before surgery have such a scan within six-months. MDTs in each Network should agree more ‘intensive’ (i.e. long-term) follow-up guidelines for patients who have undergone curative surgery for colorectal cancer, and these should be adopted throughout the Network and revised annually in light of new research evidence (NICE, 2004).

The guidance further recommends that colonoscopy may be offered at five-yearly intervals to check for new ‘polyps’ or tumours. Furthermore, CNS’ should check that patients and their carers have their contact details, and that they are aware they can make contact after discharge from hospital if they are concerned about the disease or its consequences. Patients with stomas require support for the rest of their lives. Patients and their GPs should be given full information on symptoms which might signify cancer recurrence and should have rapid access to the colorectal cancer team if they become aware of such symptoms (NICE, 2004).

The drivers for change in colorectal cancer follow-up include:

- Surveillance of patients at high risk
- Post-operative problems and management
- Patient-centred care
- Advice and support
- Uncertainty about the effectiveness of different aspects and forms of follow-up
- Consistency of care (i.e. key workers; care plans)
- Access to services (i.e. inequality of care)
- Rapid referral

The Centre for Reviews and Dissemination report (2007) identified five systematic reviews investigating the clinical effectiveness of follow-up services in patients with colorectal cancer (Jeffery, Hickey, and Hider, 2007; Renehan et al., 2005; Richard and McLeod, 1997; Rosen et al., 1998; Figueredo et al., 2003). All but one review (Richard and McLeod, 1997) concluded that providing intensive (i.e. long-term) follow-up services for colorectal cancer survivors can improve survival. Three of the studies concluded that intensive follow-up was slightly more effective in terms of survival than minimal follow-up (Jeffery, Hickey, and Hider, 2007; Renehan et al., 2005; Rosen et al., 1998). All studies found intensive follow-up to be more costly than minimal follow-up; for intensive follow-up compared to standard follow-up, the incremental cost-effectiveness ratio varied from £3,077 per life year saved to £16,192 per life year saved. The review concluded that intensive follow-up after curative resection

improved overall survival and resection rates for recurrent disease, but that there was no significant improvement in cancer-related mortality, and the survival benefit was not related to earlier detection and treatment of recurrent disease.

This current review identified five records and initiatives in progress, which were categorised into four types of follow-up:

- a) Intensive (i.e. long-term/frequency of contact/testing)
- b) Primary care
- c) Patient-initiated with routine biochemical/imaging testing
- d) Routine imaging testing (PET)

a) Intensive Follow-Up

One trial compared standard follow-up using the principles of the British Society of Gastroenterology (BSG) guidelines with intensive follow-up after colorectal surgery (FACS). Using Office of National Statistics (ONS) data, the number of colorectal cancers diagnosed in a given year was calculated 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. Risk stratifying entry to follow-up and the introduction of population screening were then considered. For the 2003 cohort, an intensive follow-up 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 (i.e. blood tests that detect recurrence) 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 £15.6 million. The cost per additional resectable recurrence was £18,077, a figure also found for a non-screened population in 2016. 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 £36,255. It was concluded that intensive follow-up will detect considerably more resectable recurrences but at considerable cost. It is unclear if such follow-up will be achievable in an already over-stretched NHS. The authors offer that if population-based screening increases the number of Dukes A cancers (low grade cancers), this may offer the possibility of risk stratifying future intensive follow-up to those at highest risk of recurrence (Macafee, Whynes, and Scholefield, 2007).

The COLOFOL study, launched in 2005 (ongoing) in order to evaluate two different time schedules for a follow-up programme in patients operated for colorectal cancer with curative intent, is an ongoing international multicentre RCT being conducted within eighteen surgical departments in Denmark, Sweden, Poland, Uruguay, and Ireland (Wille-Jørgensen, 2009). The primary outcomes are overall survival and disease-free survival, and secondary outcomes are QoL and cost-effectiveness. Data will be collected electronically via the internet to an already constructed database.

According to an interim analysis of recruitment, 576 patients have been randomised to one of two models of follow-up: 1) CT-scan of liver and lungs (or CT of liver + plain X-ray of lungs) + CEA after 6, 12, 18, 24, and 36 months, or 2) CT-scan of liver and lungs (or CT of

liver + plain X-ray of lungs) + CEA after 12 and 36 months. If recurrence is detected, the patient will be offered the best available treatment either as repeated surgery with curative intent or palliative treatment.

Eight of the participating departments have been able to report on recruitment. In total 1309 patients were operated on for colorectal cancer in the eight departments in the period since the beginning of the study up to 1 September 2007. Of these 241 patients were randomised, which is only 18.4% of the total population. Reasons for not being randomised included not meet the inclusion criteria, having previous or other malignancies, being involved in other trials, or refusing randomisation. Only 32 patients who comprise 6.4% of eligible patients directly refused randomisation. It is planned that recruitment will be at least 2,500 patients over two years (Wille-Jørgensen, 2009).

b) Primary Care Follow-Up

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 has been used to evaluate frequency of visits to different health professionals. 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, except for an increase in bone densitometry. Survivors who visited both a GP and oncology specialist were most likely to receive each preventive care service. The study indicates that oncology specialist follow-up in the first year of survivorship is intensifying over time and survivors not being followed-up by both GPs and oncology specialists tend to be less likely to receive preventive care. The authors concluded that clarifying the roles of GPs and oncology specialists during follow-up might improve the quality of care for survivors (Snyder et al., 2008).

c) Patient-Initiated Follow-Up/Routine Biomarker Testing/Routine Imaging

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. The primary outcome is number of recurrences treated surgically with curative intent by intention-to-treat analysis. The secondary outcomes are overall survival, QoL, cost of NHS services utilised, and NHS cost per life-year saved. All patients who have undergone curative treatment for primary colorectal cancer (R0 resections, Dukes A-C are being randomised to one of four arms: 1) symptomatic follow-up in primary care; 2) a single CT at 12-18 months plus CEA in primary care, 3-monthly for two years and 6-monthly for another three years; 3) hospital based imaging with CT 6-monthly for two years and annually for another three years; and 4) a combination of 2 and 3. All groups are given a patient handbook detailing symptoms suggestive of recurrence, as well as a colonoscopy at trial end (5-years) and ongoing contact with the CNS. Groups 3 and 4 receive an additional colonoscopy at year two.

A pilot study was completed between 2002 and 2004, with the main trial being planned as 4.5 years recruitment and a median of 5-years follow-up. Recruitment has been completed, but no results can be obtained until the 5-year follow-up period. Final data collection is anticipated to be December 2013. Baseline data is to be published soon, which will show that if a patient is well staged at the outset then the relapse rate is actually quite low. The low relapse rate in the entire study sample, irrespective of which arm they are in, leads to the need to consider less intensive follow up on the basis of clinical and cost effectiveness. Correspondence with the primary investigator reveals the expert impression that single CT at 12-18 months plus CEA in primary care, 3-monthly for two years and 6-monthly for another three years (arm 2) is a sufficient model of follow-up for colorectal cancer survivors.

d) Biochemistry/Imaging based Follow-Up

In France, there is an ongoing 3-year Phase III open-labelled, multicenter, multidisciplinary, randomised study, comparing two arms (n = 188 per arm) of stage II and III colorectal cancer patients. The primary objective is to evaluate PET performance in the earlier detection of colorectal cancer relapse in comparison with conventional control (including CEA levels and other radiological exams). The primary outcome is time to colorectal cancer relapse and the secondary outcome measures include evaluation of overall survival in the two groups, evaluation of the rate of curative surgery, and comparison of the medical cost in the two detection strategies. Little detail is available on this study, but correspondence with the primary investigator reveals that the anticipated end date of recruitment will be March 2010 (Tubiana-Mathieu, ongoing).

Summary of Findings

When combining the CRD findings with the studies and ongoing initiatives identified in this review, a number of key findings have emerged within colorectal cancer follow-up: intensive follow-up has generally been considered to offer benefits in terms of detection of resectable recurrences, but at considerable cost; more evidence is emerging that less intensive surveillance may offer acceptable safety; visits to GPs and oncology specialists were recommended above visits to only one, the reason being that preventive care services were more accessible if both professionals were consulted; and, the use of PET in the earlier detection of recurrence is currently being tested.

The trends as reflected in the studies completed and in progress, and the initiatives reviewed are summarised as follows:

- 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; as yet not clearly defined periods.
- Emphasis on the range/combination/frequency of the role of biochemical/technological testing and examinations, on the earlier detection of resectable recurrences, leading to improved survival rates.
- The focus is on surveillance through technology and biomarker testing, with little emphasis on other aspects of patient need as a cancer survivor.

In summary, the NCSI Mapping Project (NCSI, 2009) reported that there is high variability of follow-up services and support for colorectal cancer survivors. Significant numbers of patients report receiving no support at all; others were provided aftercare services from stoma/colorectal nurse therapists, and a small number saw dieticians for advice on how to manage their diet.

If the most reliable and cost-effective combination of blood tests for tumour markers and other examinations can be determined, then given the current drivers for change, risk stratification has been offered as a possible method of ascertaining which patients might benefit from a more costly intensive (i.e. long-term) model of follow-up care (Macafee, Whynes, and Scholefield, 2007; Primrose et al., ongoing). For those patients at low risk, self-referral, GP-led, or nurse-led follow-up offer potential alternatives.

LUNG CANCER

The Diagnosis and Treatment of Lung Cancer: Methods, Evidence and Guidance, as commissioned by NICE (National Collaborating Centre for Acute Care, NCCAC, 2005) recommends that for patients who have had attempted curative surgery for non-small cell lung carcinoma (NSCLC), any routine follow-up should not extend beyond five years. It is recommended that when patients finish their treatment a personal follow-up plan is discussed and agreed with them after discussion with the professionals involved in the patient's care. After completion of their treatment, patients with a life-expectancy of more than 3-months should have access to protocol-controlled, nurse-led follow-up. Patients who have received attempted curative surgery for NSCLC or radical radiotherapy should be followed up routinely by a member of the MDT for up to 9-months, to check for post-treatment complications (including thoracic imaging). Patients who have had palliative radiotherapy or chemotherapy should be followed routinely one month after completion of treatment (including a chest X-ray if clinically indicated). For patients who have received attempted curative treatment and completed their initial follow-up, trials should examine the duration of follow-up and whether regular routine follow-up is better than symptom-led follow-up in terms of survival, symptom control and QoL. As such, duration of follow-up and decision on biopsy will vary, although the presence of a negative PET scan enables a 'watch and wait' policy to be implemented (NCCAC, 2005).

The drivers for change in lung cancer follow-up include:

- Accuracy and efficacy of FDG-PET scanning
- Increased personalisation (i.e. care plan, involvement in decision-making)
- Consistency of care (i.e. multidisciplinary team work)
- Duration of follow-up
- Type of follow-up (symptom-led versus regular routine)
- Symptom monitoring/control and QoL (i.e. psychosocial issues)
- Survival
- Access to services (i.e. CNS, rehabilitation, smoking cessation support)

The CRD identified no systematic reviews for follow-up after lung cancer. One full economic evaluation of follow-up for lung cancer was identified (Younes, 1999). This study evaluated the cost-effectiveness of a follow-up programme guided by patients' symptoms compared with regular follow-up that included physical examination, chest radiograph, CT scan and liver function test. The study 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. The authors theorised that regular follow-up with physical examination and chest radiograph only would be more cost-effective than the full follow-up programme. The review concluded that the lack of good quality evidence indicates the need for further research.

This current review identified two records and initiatives in progress, which were categorised into three types of follow-up:

- a) PET
- b) Nurse-led

a) PET Follow-Up

Melloni et al. (in press) conducted randomised, open-label, uncontrolled trial in France, comparing follow-up by conventional methods (i.e. thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy are performed every 6-months after surgery for two-years) versus PET scanning only. The aim was to determine which of these models was more effective at detecting recurrence early. The primary outcomes were disease-free survival from the date of operation to the date of recurrence or censored at the date of last follow-up visit or date of the death. Secondary outcomes were overall survival from the date of the operation to the death, specificity, sensibility and accuracy of PET to detect recurrence, and direct cost of follow-up.

Patients were randomly assigned to two arms. In the first arm, thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy were performed every 6-months after surgery for two years. In the second arm, only PET scanning is received. For brain metastasis detection, CT was performed in the two arms. Recurrences were detected during scheduled or unscheduled procedure in asymptomatic patients. PET and CT were interpreted separately by two nuclear physicians and two radiologists.

The study demonstrated that intensive follow-up after curative-intent surgery for NSCL cancer is an accurate technique for detecting recurrent disease, but that PET imaging compared to CT imaging follow-up did not change overall survival in this population.

b) Nurse-Led Follow-Up

An RCT comparing the acceptability and feasibility of nurse-led follow-up with conventional 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 (2007) review, has been included in this review (Moore et al., 2002). The study has been included in this review due to its rigour and the knowledge gained from the outcomes, these outcomes being QoL, patients' satisfaction, general practitioners' satisfaction, survival, symptom-free survival, progression-free survival, use of resources, and comparison of costs.

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 minutes). 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. Intervention patients were more likely to die at home than in a hospital or hospice, attended fewer consultations with a hospital doctor during the first 3-months, had fewer radiographs during the first 6-months, and had more radiotherapy within the first 3-months. No other differences were seen between the two groups in terms of resource utilisation.

The results of this study indicate that a nurse-led model of follow-up can be used to make aftercare more responsive to individual needs, increase patient satisfaction, and reduce the burden of hospital visits and clinical investigations.

Summary of Findings

When combining the CRD findings with the studies and ongoing initiatives identified in this review, a number of key findings have emerged within lung cancer follow-up: ongoing studies are currently examining conventional follow-up with PET (Melloni et al., in press); and nurse-led follow-up has been demonstrated to be highly acceptable to patients and the healthcare service (Moore et al., 2002), resulting in less severe symptoms at 3, 6, and 12-months, as well as reduced hospital visits (Moore et al., 2002).

Given the current drivers for change, more research is required into the most efficacious and feasible follow-up model for lung cancer. Nurse-led follow-up offers the most promising evidence thus far for holistic aftercare and support, as well as addressing a number of the key drivers for change (i.e. increased personalisation, consistency of care, and symptom monitoring). This model is also favoured by patients. However, a number of drivers for change remain unaddressed in terms of follow-up, highlighting gaps in knowledge (i.e. accuracy of FDG-PET scanning, duration of follow-up).

PROSTATE CANCER

Prostate Cancer: Diagnosis and Treatment - Full Guidelines, as developed for NICE by the National Collaborating Centre for Cancer (NCCC, 2008), recommends that routine follow-up after treatment of localised disease is used to: identify local recurrent disease at a stage when further radical treatment might be effective; identify and treat the complications of therapy; give information and address concerns; and audit the outcomes of treatment (NCCC, 2008). It is advised within the guidelines that although follow-up needs to be long-term, this does not necessarily require traditional hospital-based follow-up; alternative models include telephone follow-up, nurse-led clinics, and follow-up in primary care.

The guidelines state that *“Healthcare professionals should discuss the purpose, duration, frequency and location of follow-up with each man with localised prostate cancer (and in some cases, locally advanced prostate cancer), and if he wishes, his partner or carers. Men with prostate cancer should be clearly advised about potential longer term adverse effects and when and how to report them”* (NCCC, 2008; p.14). Men with prostate cancer who have chosen a watchful waiting regimen with no curative intent should normally be followed up in primary care in accordance with protocols agreed by the local urological cancer MDT and the relevant primary care organisation(s). Their PSA should be measured at least once a year. PSA levels for all men with prostate cancer who are having radical treatment should be checked at the earliest 6-weeks following treatment, at least every 6-months for the first two-years and then at least once a year thereafter. Routine digital rectal examinations (DRE) are not recommended in men with prostate cancer while the PSA remains at baseline levels. After at least two-years with a stable PSA and no significant treatment complications, it is recommended that follow-up is offered outside of the hospital such as by telephone or secure electronic communications. Direct access to the urological cancer MDT should be offered and explained (NCCC, 2008).

The drivers for change in prostate cancer follow-up include:

- Optimising the detection of prostate cancer and disease recurrence
- Reducing unnecessary repeat investigations or prolonged follow-up
- Consistency of care (i.e. key workers; care plans)
- Involvement of family and carers, where desired
- Long-term effects
- Improving the patient experience
- Planned, formal follow-up after hormone therapy

The Centre for Reviews and Dissemination report (2007) identified no systematic reviews or economic evaluations for prostate cancer follow-up.

This current review identified five records and initiatives in progress, which were categorised into three types of follow-up:

- a) Long-term clinic follow-up
- b) Internet adjunct
- c) Nurse-led routine (planned)

d) Group

a) Long-Term Clinic Follow-Up

City of Hope, an NCS-designated Comprehensive Cancer Center in California, US, have developed a programme of research to test a specialised model of long-term follow-up for patients who have completed surgical treatment for localised prostate cancer at least one year from diagnosis, and who present with no current evidence of prostate cancer and no history of recurrence, progression, or metastasis: the Prostate Cancer Survivorship Programme (Landier, ongoing). The goal of the programme, which is carried out in collaboration with each patient's primary treatment team, is to help each survivor stay as healthy as possible, and to prevent problems from happening or catch them early, when they are most easily treated.

Patients who participate in this program are seen every 6 to 12 months in a clinic specially designed to meet the follow-up needs of prostate cancer survivors. Care is provided by a healthcare provider with expertise in prostate cancer care and survivorship issues. Patients in this program receive careful monitoring for possible recurrence of their cancer and have the opportunity to discuss their cancer treatment, its impact on their health, and ways to stay as healthy as possible. Each patient receives a Survivorship Care Plan, which is a personalised record of the details of their cancer treatment, with guidelines for continued monitoring, including recommendations for preventive care and information regarding available resources and services.

Patients enrolled on the programme will be seen in a long-term follow-up clinic every 6-months for the first five years after diagnosis, and then yearly thereafter. The clinic is provided by a healthcare professional with expertise in prostate cancer care and survivorship issues, who works in collaboration with the patients' primary treatment team. During each visit, medical history and any symptoms will be reviewed and a physical examination provided, including a PSA blood test. Digital rectal examinations will be done yearly. Additional testing or referrals may be recommended, if needed, based on the results of health history and physical examination. Patients will then be given the opportunity to discuss their diagnosis, treatment history, and ways to stay as healthy as possible, before being given their "Survivorship Care Plan," which includes a written record of the patients' treatment and follow-up recommendations based on treatment history and specific circumstances. If needed, patients will also receive additional information about any treatment-related health problems they might be experiencing, along with recommendations for management of these problems. A summary of each long-term follow-up visit will be sent to the patients' primary healthcare provider and primary treatment team. In addition, referrals are available to a social worker, dietician, psychologist, or physical therapist if appropriate.

b) Internet Adjunct Follow-Up

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. 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, which is 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 follow-up 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 (Basch et al., 2005; Basch et al., 2007). Improvements in attrition are anticipated with the integration of prompts to complete the online questionnaires.

Correspondence with the primary investigator informed that Basch and colleagues are currently developing the next generation of these patient adverse symptom items for the U.S. National Cancer Institute, which are currently called PRO-CTCAE items but will ultimately be called PROTECT items. These items cover 77 different symptoms with about 122 different items. They were developed in the context of measuring acute toxicities of cancer treatments, but with an eye towards monitoring symptoms during survivorship. The items are still undergoing validation and are being tested by a taskforce who are creating a web-based open-source technology platform for administration of these items.

c) Nurse–Led Routine (Planned) Follow-Up

At the Urology Department of the Royal United Hospital Bath, rather than seeing a Consultant for every follow-up visit, routine follow-up is overseen by a CNS, as assisted by a new piece of software. Patients receive a postal questionnaire asking them about their general state of health, whilst bloods for PSA testing are taken in primary care. The PSA levels and treatment history are captured on the computer software, 'PSA Tracker,' which automatically triggers routine postal follow-up or recall to an outpatient clinic based on clinically established algorithms for PSA.

The new care pathway is suitable for the majority of patients with slow-growing tumours who are willing and able to complete the health questionnaire. As a result, there has been 100 Consultant slots saved per annum (estimated around 80% of eligible patients will take up the questionnaire service) and the cost of follow-up has reduced from £88,200pa to £30.063pa (*Mr Jonathan McFarlane Consultant Urologist Royal United Hospital Bath*).

A pilot study is currently being planned at Worcestershire Royal Hospital to integrate the PSA Tracker, demonstrated to be successful in Bath, into the follow-up of prostate cancer patients who have had curative treatment (Hopcroft et al., ongoing). The proposal is for the pathway to be run by a urology nurse specialist who will measure PSA levels; a trigger will be activated if recurrence is found and the patient would then be recalled. An annual conference would be held once a year with suggested topics for speakers: diet, complementary therapies, psychosexual problems, benefits, new treatments. A patient information prescription is also proposed to be included in this model of follow-up, the aim being to reduce CNS workload via electronically prescribing information

d) Group Follow-Up

A study not included in the CRD (2007), but which has been included in this review due to current interest in group models of follow-up care is that of Fletcher et al. (2006). This study examined the acceptability of group visits in comparison to individual follow-up, in a heterogeneous sample of urological patients. The primary outcome of interest was patient satisfaction.

Patients (n = 287) were invited to participate in a 'drop-in group medical appointment,' where appointments were made based on gender rather than diagnosis. Most diagnoses were prostate cancer, erectile dysfunction, benign prostatic hyperplasia, incontinence, neurogenic bladder and chronic discomfort syndromes. In the group appointment (n = 117 compared to n = 110 in individual follow-up), a 60-minute group teaching session was followed by a private 2 to 5-minute physical examination or further testing, as indicated.

Patient satisfaction with the drop-in group medical appointment model was as high as that of individual follow-up, with 87% of group patients rating their experience as excellent or very good vs. 88% by individualised follow-up patients. The authors concluded that drop-in group medical appointments can be implemented successfully in a urological practice, despite the sensitive nature of topics discussed.

Summary of Findings

In prostate cancer, there is still a paucity of evidence on which to base the development of alternative approaches to the aftercare of men who are living with and after prostate cancer.

The NCSI Key Mapping Project (NCSI, 2009) identified that follow-up care for men on hormone therapy often occurs unplanned and informally, and as with other cancers there was many variations in the delivery of follow-up, which raised concerns as to the impact of this variability on the patient experience.

In privately funded health care systems, prolonged and frequent follow-up is common, whereas in publicly funded systems the approach is influenced by economic concerns. Use of the internet in various formats as part of aftercare support (symptom monitoring) is becoming more influential. Group follow-up has also demonstrated positive outcomes in terms of patient satisfaction, but more research is required in terms of detection of recurrence, increased survival, and patient acceptability. Given the current drivers for change, internet adjunct follow-up offers some promising evidence thus far, ultimately resulting in risk stratifying patients as well as acting as a self-monitoring technique. The internet adjunct model facilitates the reduction of unnecessary investigations, whilst also increasing patient involvement and optimising the use of health care resources.

ALL CANCERS

The current drivers for change across all cancers, as highlighted in the introduction, are largely based on government policy such as the *Cancer Reform Strategy* (Allberry, 2008), as well as the increase in survivorship and the need to develop a follow-up pathway feasible within the current economic climate.

The CRD identified one review comparing the effectiveness and cost-effectiveness of primary care versus secondary care follow-up, as well as the effects of alternative types of follow-up across a range of cancer types (e.g. patient-initiated) (Lewis et al., 2009). Forty-two studies of various designs were included in the review. The authors concluded that there was no important difference between primary and secondary care follow-up for breast or colorectal cancer. Nurse-led interventions included telephone and patient-initiated follow-up. There were no important differences between hospital nurse-led follow-up and GP-led follow-up for breast or lung cancer for patient health-related outcomes. Patient satisfaction with lung cancer follow-up was greater for patients receiving nurse-led telephone follow-up than those receiving conventional hospital follow-up. Neither nurse-led follow-up or patient-initiated follow-up had a significant effect on the workload or satisfaction of GPs relative to conventional follow-up.

A recent published version of the review (Lewis et al., 2009) identified some limitations of the evidence reviewed. The evidence relating to nurse-led follow-up was small and covered only breast, lung and prostate cancer. No full economic evaluations were identified, and only two cost analyses. The sample sizes were small and length of follow-up was generally short (12 months to 5 years). Although no statistically significant findings were found between the intervention groups for most outcome measures, this does not mean that the interventions were equivalent. Sample size and length of follow-up were insufficient to detect any difference in survival or recurrence rates.

This review identified four records and initiatives in progress, which were categorised into four types of follow-up:

- a) Patient-initiated with internet support
- b) Nurse-led telephone care management
- c) Group
- d) Alternative models (nurse-led telephone; patient-initiated; group)

a) Internet Adjunct with Educational Programme: Patient-Initiated

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 (Wright et al., ongoing). A purposive sample of participants of various genders, ages, with a range of cancers, and who are about to complete or have completed treatment with curative intent within 36-months prior to consent, will be recruited from patients attending the oncology outpatient clinics in the Leeds Cancer Centre and stratified into age-group and gender-specific subgroups. The outcomes to be assessed are the accessibility, feasibility,

acceptability, security, and usefulness of a web-based version of the SF-36 compared to a paper-based version.

Focus groups with patients and professionals have been held to facilitate the design of the web tool, and the web development stage has been completed. Patients attending outpatient oncology clinics at the Leeds Cancer Centre will be informed about the study and given a written information sheet and consent form. Following consent, patients will be asked if they have access to the internet before being split into two groups: 1) those with no internet access; 2) those with internet access. Patients in the first group will be asked to complete a questionnaire on their experience of computers, whilst patients from the second group will complete the same questionnaire before being recruited to the cross-over two arm RCT where they will be shown how to access the website being tested. Randomisation will determine which mode of presentation of questionnaires each participant will be presented with first: a) patients (n = 53) will complete the web questionnaire first, within four days of randomisation, and then the paper-based questionnaire within two weeks of completing the first questionnaire; 2) patients (n = 53) will complete the paper-based questionnaire first, within four days of randomisation, and then the web version within two weeks of completing the first questionnaire. On completion of both questionnaires, participants will be asked to take part in an audio-recorded structured interview designed to assess the accessibility, acceptability, perceived advantages and disadvantages, quality of information provision and support, and opinions on the use of a 'training and web-based model' for follow-up.

Good progress is being made, with around 60 participants consenting to the full cross-over part of the study. Over 50 consultants are supporting the study and they are recruiting from a range of clinics including breast, gynaecological, gastrointestinal, genitourinary, haematology, germ cell, and sarcoma. If successful, patients will be able to remain connected to the oncology service by way of a specially designed website that would not only provide information on support for patients, but would also offer a way for staff to collect comprehensive standardised clinical and psychological information from patients for the purpose of monitoring (*Dr Penny Wright, Psychosocial Oncology and Clinical Practice Research Group, St James's Institute of Oncology*).

b) Nurse-Led Telephone Care Management.

Launched in May 2008, '*Surviving Cancer, Living Life*' is a pilot nurse-led telephone model of follow-up run by Guy's and St Thomas' NHS Foundation Trust and Pfizer Health Solutions (Richardson et al., 2009). The pilot has been made available to breast and prostate cancer patients who have completed their active treatment. The primary outcome will be benefits to cancer survivors, their families and carers, and the wider healthcare system over a one-year period.

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 healthcare services and the nurses' support and build on the care already provided by GPs and other healthcare professionals.

The qualitative element of the evaluation process has been completed, which involved interviewing those involved in the programme in order to achieve an in-depth understanding of the feelings, perceptions and attitudes of the patients, the three Care Managers who provide the support which the programme entails, and stakeholders (Richardson et al., 2009).

Telephone interviews of up to an hour were conducted with a random sample of breast (n = 10) and prostate (n = 12) cancer patients in receipt of the programme, the key areas for exploration being: general patient reactions to the experience of the programme; patient views of telephonic care as experienced in terms of perceived advantages and disadvantages; the nature and quality of the relationship developed between patients and Care Managers; patient views of the literature supplied to them; the impact of the programme upon patients. Patient attitudes to 'Surviving Cancer, Living Life' 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. Comments were mainly expressed in terms of attitudes to the relationship experienced with Care Managers, as well towards the holistic approach adopted by Care Managers. Levels of overall satisfaction with the service varied to some degree, but in general were very high. Many felt the success of the service showed up some important fundamental inadequacies in the conventional approach to cancer follow-up. Telephone contact was generally viewed as being advantageous over face-to-face contact, particularly in terms of convenience, confidentiality and continuity. Patients felt they benefited from the programme in various ways. It helped them to understand their illness and treatment better, to improve their morale and face life with renewed confidence, to adopt necessary changes in lifestyle and in some cases to develop better relationships with their families and an increase in personal confidence when dealing with other professionals.

An extended focus group of 2-hours plus, with the three Care Managers currently responsible for the programme, explored all of the key areas covered in the patient interviews, plus their commentary on issues such as: the impact on themselves of the demands of the programme; the feasibility of the current structure of the programme, including the software; any requirement for further training for their role; and any implications for the future recruitment of Care Managers. The focus group was followed by individual telephone interviews with each Care Manager. They believed firmly in the positive benefits of the programme for patients, but showed some concern that their own role was somewhat imprecise and potentially left them vulnerable to abuse or burnout.

Structured telephone interviews or email dialogue with twelve stakeholders, depending on their personal choice and availability were sought to understand this groups' opinions of how the programme had impacted on: patients receiving the service; those involved in setting up

and delivering it and healthcare professionals working in the local breast and prostate cancer service. Stakeholders' views on the programme were mixed, with some feeling the programme to be a new and original innovation that was meeting a high level of unmet need and promoted patient empowerment, whilst others were concerned that it might be a duplication of service and encouraged patient dependency. Challenges were perceived in terms of the potential operational difficulties in establishing the programme and achieving effective working relationships with existing services. There is a risk it complicates rather than enhances care. If the programme was to be continued, it would be essential to consider how best to develop communication and referral pathways with existing cancer services to ensure effective working partnerships and agreed referral pathways.

c) Group Follow-Up

The NCSI Assessment and Care Planning work stream are currently exploring the concept of a post-treatment clinic. There are some similarities between this idea and the post-treatment support conference (Brighton and Sussex University Hospitals NHS Trust). This is being considered as an adjunct to or alternative to current approaches to cancer follow-up, with a strong emphasis on helping to inform and support people after cancer treatment to resume as normal a life as possible. Taking place around six weeks post-completion of the initial treatment phase, those patients who meet the criteria and have been assessed as clinically and holistically suitable for this model of follow-up by their consultant clinician and specialist nurse will be given the option of attending a half day group delivered programme. The programme for this visit will mainly focus upon: Informing and educating patients about their ongoing management/care requirements; strategies for managing the early effects of their diagnosis and treatment; opportunities available for promoting their own health, exercise, weight maintenance, healthy eating options; agreeing and finalising the survivorship care plan with the individual cancer survivor; ensuring the end of treatment summary record is initiated and forwarded to the GP; and ensuring that patients have received or are given the relevant forms or instructions relating to their ongoing monitoring/screening requirements and appointments. The main focus of this clinic will be to inform and educate the patient about the clinical aspects of their ongoing management and care and signpost the relevant supportive care opportunities available to them. It is not intended that attendance at this clinic will replace or be able to deliver all the elements of a self-management, exercise or rehabilitation programme. Information about the opportunities to access these programmes locally or who to contact for further information should be provided to the patient and/or carer either during the session or as part of an information pack (*Stephen Hindle, Cancer Survivorship Programme Lead, Macmillan Cancer Support*).

d) Alternative models (nurse-led telephone; patient-initiated; group)

In 2008, NHS Improvement commissioned the Picker Institute Europe (Sheldon, Davis, and Parsons, 2008) to conduct a focus group study exploring the views of cancer patients on health and social care services following their treatment. Patients and carers were recruited through local support groups, voluntary agencies and networks, providing five separate focus groups: women who had experience of follow-up care for gynaecological and breast

cancer (n = 9); men who had experience of follow-up care for prostate cancer (n = 8); carers of people who had experience of follow-up care for a range of cancers (n = 8); people who had experience of follow-up care that included invasive procedures (n = 6); and, people who were living with the side-effects of cancer treatment (n = 7). Each group was facilitated by a senior researcher from the Picker Institute Europe, using a topic guide developed in collaboration with the project steering group. Groups lasted approximately one and a half hours.

The final report demonstrated that most patients received their follow-up appointments with a specialist at the hospital, though in the later stages some patients saw their GP for all or some of their care. A positive experience of follow-up care was expressed by the majority, with the exception of patients living with long-term side-effects. The most common problems with follow-up care in all groups related to access, in particular stemming from a lack of co-ordination, lack of local provision, lack of integrated and holistic care, and lack of either local or national specialised services. There was also a general lack of information about what to expect following treatment, with there being particular gaps in the provision of written information. Help with returning to work, advice about benefits, the provision of psychological support, and support for carers were all areas focus group members would like to see included in follow-up services.

When asked to comment on three alternative models of aftercare (e.g. nurse-led telephone; patient-initiated; and, group follow-up), participants in all but the side-effects group were resistant to the suggested new models as replacements for existing models of follow-up care. This reticence was mainly based on concerns surrounding these alternatives not offering a specialist service, as well as anxiety about access to hospital care if needed. However, there was some support for all three models as additional services to supplement gaps in current aftercare.

A limitation to this study is the fact that the women with experience of breast and gynaecological cancer aftercare and the men with experience of prostate aftercare were all members of support groups and thus were in receipt of a support network that might counteract any deficits in the aftercare received. Indeed, the men were all from the same support group and had all been treated at the same hospital. The follow-up care available at this particularly hospital might be particularly good. Nevertheless, this study has highlighted poor aftercare experiences among patients living with the long-term side-effects of treatment, as well as reticence among most cancer survivors in regard to models of follow-up other than that which is traditionally received from the hospital. On the other hand, the provision of such models alongside traditional follow-up was generally supported, indicating a potential avenue for introducing alternative models of aftercare. Furthermore, lack of information, a problem cited in this study, might have contributed to this reticence if patients were not fully informed of how these alternative models would work.

Summary of Findings

Across cancers, the use of internet adjunct symptom monitoring via two-way computer systems is currently being assessed in the UK (Wright et al., ongoing). Patients who have completed treatment could be given self-management training around consequences of treatment and issues about getting back to everyday life, and access to the website. This could reduce the need for some hospital follow-up, be a source of information and support, relieve pressure on overstretched services, and would be a systematic method to collect long-term outcomes from the growing number of survivors. These studies look promising in terms of enhancing patient/provider partnership and the recommended use of patient-reported outcome measures (PROMs) in routine data collection (DH, 2009).

Group sessions in the form of group delivered programmes aimed at informing and educating the patient about the clinical aspects of their ongoing management and care offer innovative quality improvement. Evidence from group follow-up for other chronic conditions shows improved patient satisfaction, increased understanding of symptom management (Jaber, Braksmajer, and Trilling, 2006; Vieira et al., 2007) and cost-effectiveness (Escobar, 2001). Given the current drivers for change, such as resource limitations and the economic stress on the healthcare system, group follow-up requires further exploration, especially in terms of integrating self-management and patient-initiated models of post-treatment care.

The report by the Picker Institute Europe (Sheldon, Davis, and Parsons, 2008) highlights the potential challenges to introducing alternative models of aftercare to that which is traditionally offered in secondary care. At the same time, the report also provides insight into possible ways of introducing alternative methods alongside traditional follow-up in a way that informs and educates patients, thus reducing any concerns surrounding a change in service provisions

Conclusions

This has been an update of the evidence for 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*' (CRD; 2007), which was undertaken to inform the Cancer Reform Strategy.

The aim of this review was to update the CRD evidence as well as to identify studies and initiatives highlighting current alternative approaches to follow-up. In achieving this aim, six types of follow-up were identified for breast cancer (i.e. intensive; GP-led; nurse-led (sub-sets: routine; automated; telephone; patient-initiated); patient-initiated (terminology: patient-triggered; point of need access; symptom-led); radiographer-led mammographic; and educational), four for colorectal cancer (i.e. intensive; primary care; routine imaging; and patient-initiated with routine imaging), two for lung cancer (i.e. PET; and nurse-led), four for prostate cancer (i.e. long-term; internet adjunct; nurse-led; and group), and three for all cancers (i.e. patient-initiated with internet support; telephone; and group).

This review has included studies which were not included as part of the CRD review because we feel they added to the debate around cancer follow-up practices. The search terms have reflected those of the CRD review, however, where these terms may not have been sufficient to capture relevant records, subsequent searches were conducted on PubMed.

In addition, we have included work in progress, as well as accounts of service driven projects and initiatives where they reflect strong current trends aimed at addressing pressing concerns of the quality of cancer aftercare, rising survivor numbers, and resource issues. This is most evident in breast cancer follow-up.

Overall, as reported in the CRD review, there is a paucity of good quality evidence for most cancer sites. There are a number of ongoing trials which may address some of the evidence gaps (Dunn et al 2008; Wille-Jorgensen, 2009; Primrose et al., ongoing).

Breast cancer

One further systematic review was identified (Montgomery Krupa & Cooke 2007). This review investigated alternative approaches to breast cancer follow-up. It concluded that there is insufficient good quality evidence on acceptable frequency/duration of follow-up, and no evidence to confirm the safety of alternative methods, including by GP, patient-initiated, and routine contact by specialist nurses. Routine clinic visits are an inefficient way of detecting recurrent disease, and for many patients there is doubt they address their psychosocial and practical needs (Renton et al., 2002; Oltra et al., 2007).

Recent trials have attempted to compare traditional follow up with alternatives, and their acceptability and satisfaction to patients, on their quality of life, and on the lack of disadvantage in detection of locoregional recurrence (Beaver et al., 2009; Sheppard et al., 2009). Beaver et al. (2009) demonstrated that routine telephone follow-up with specialist

nurses were well received by women with low/moderate risk of recurrence after breast cancer, with no psychological or physical disadvantage. Telephone contact significantly improved satisfaction and produced no excess anxiety compared with usual hospital follow-up. This study focused less on survival. An economic evaluation is yet to be published for this study. However, the intensity of this follow-up model (consultation length) and its provision by specialist nurses, is unlikely to lead to a more cost-effective approach.

Giving patients the option to trigger their contact with specialist nurses (as an alternative to other models of follow-up) based on self-assessed need is a growing trend (Chapman et al., 2009; Sheppard et al., 2009; Maher, unpublished; Dent and Allinson, ongoing; Koinberg, 2009; Wright, ongoing). Sheppard et al. (2009) compared 'point of need access' to specialist nurses via telephone, with routine hospital-based clinical review for patients 2-years after diagnosis. Self-initiated follow-up was acceptable to two thirds of patients, with a third opting to maintain regular clinical review. There was no evidence to indicate that 2-years post-diagnosis clinical review improves psychological morbidity or general quality of life, nor does it compromise these outcomes for women not attending such review. Moreover, 95% of patients in the 'point of need access' group chose not to return to regular review, indicating satisfaction with their experience, as well as confidence in their own ability to self-manage.

Similar outcomes have been found in services redesigned to allow patient-led follow-up (Chapman et al., 2009; Maher, unpublished) for women at low/moderate risk of recurrent disease. In the main, there is high satisfaction with patient-led follow-up by such women, 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 concerns arise. The conclusions by Chapman et al. (2009) is that patient-led follow-up should be considered by all breast units in the UK.

With the growing trend in patient-led follow-up, there are studies which are investigating the question as to 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 (Dunn and Allinson, ongoing; Wright, ongoing; Koinberg, 2009). For example, Chapman et al. (2009) found that a number of patients had concerns about access to psychological support and desired advice about treatment side-effects. Interventions of interest include a tailored self-management course integrated and 'prescribed' as part of post-treatment preparation and self-triggered follow-up (Dunn and Allinson, ongoing), a self-management course offered as a choice after treatment (Maher, unpublished), self-management advice and support provided by specialist nurses as part of post-treatment consultations (Koinberg 2009), and psycho-educational strategies (Mandelblatt et al., 2008). Wright et al. (ongoing) are testing the accessibility and utility of a web-based support and information tool which could be part of an aftercare and surveillance model and which could also include an educational programme and provide a platform for the collection of routine standardised monitoring data from patients. This could support a range of alternative approaches to follow-up, including patient-initiated. At this point there is a paucity of evidence available as to the types of preparation and support which would best equip patients to confidently undertake self-management, and which would make a beneficial impact on the effectiveness of recovery of health and well-being and a return to a new normal life.

The range of projects and initiatives which have been described in this review also reflects the growing awareness of the range of challenges patients experience as cancer survivors, and where in the main, services do not currently exist. Post-treatment clinics (e.g. Brighton and Sussex University Hospitals NHS Trust; Macmillan Cancer Support) and telephone-based care management (e.g. Surviving Cancer, Living Life) are two examples of projects which are aimed at improving the quality of aftercare and support for cancer survivors. The qualitative study of the impact of the telephone support (Richardson et al 2009) indicates that patients find this an acceptable and valuable aid to regaining their health and well-being after cancer treatment. There is less evidence that the approach, which aimed to support patient self-management, is actually achieving this goal.

There is evidence through the studies, pilot initiatives, and service changes, that alternatives to current follow-up models are being tested and replacing current practice. However, this is limited. A number of the interventions reviewed were modelled on conventional hospital follow-up, with few (but increasing) numbers incorporating patient education/self-management training, which would enable patients to take responsibility for their own care and contact the breast clinic if any concerns arise. It is also considered that GPs can provide safe care and take responsibility for providing support to women on long-term treatment with tamoxifen or other hormone-modifying drugs, and for stopping such treatment after 5-years. There should be an open access policy to enable GPs to make rapid referrals to the breast care team when recurrent cancer is suspected or problems arise related to treatment. A further consideration is that at the end of primary treatment, the patient and specialist agree a written care plan and locally agreed measures are developed to support transition from treatment. The study by Grunfeld et al. (ongoing) aims to provide evidence to support the effective transition from specialist to general practitioner care, supported by guidelines for the patients and practitioners, a comprehensive care plan, and educational input from nurses.

In turn, action is being taken to create a more personalised health service, where the patient becomes partnered with their healthcare provider (Coulter and Ellins, 2006), contributing to the management of their condition as well as any healthcare decisions. The focus of follow-up has been shifting from not only the risk of recurrence, but also towards the management of acute and chronic survivorship issues, including consequences of treatment and psychosocial and practical issues. If the emphasis on cancer care and its 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.

Colorectal Cancer

The aim of colorectal cancer follow-up has primarily been to detect as early as possible resectable recurrences, often resulting in a model of intensive follow-up comprising biochemical and imaging tests (e.g. CEA tests, CT scans, and FOBTs). However, intensive follow-up for colorectal cancer is extremely costly and far from cost-effective when investigating patients who would never develop detectable recurrences. For example, the provision of 181,352 CEA tests and 79,695 CT scans over 5-years has been estimated to

cost £15.6 million on patients who would never develop detectable recurrence (Macafee, Whynes, and Scholefield, 2007).

For this reason, current trials and initiatives have, in the main, attempted to identify safe alternatives to 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. The general consensus is that intensive follow-up after curative resection does improve overall survival and resection rates for recurrent colorectal cancer, but that there was no significant improvement in cancer-related mortality, and the survival benefit is not related to earlier detection and treatment of recurrent disease (CRD, 2007).

If the most reliable and cost-effective combination of blood tests for tumour markers and other examinations can be determined, then risk stratification has been offered as a possible method of ascertaining which patients might benefit from a more costly intensive programme of aftercare (Macafee, Whynes, and Scholefield, 2007; Primrose et al., ongoing). The COLOFOL study might be able to answer some of the questions surrounding the most reliable and cost-effective combination of blood tests for tumour markers and other examinations (Wille-Jørgensen, 2009). It is an ongoing large-scale international multicentre RCT being conducted within eighteen surgical departments, and is anticipated to provide insight into two different time schedules for a follow-up programme in patients operated for colorectal cancer with curative intent ($n =$ approx. 2,500): 1) CT-scan of liver and lungs (or CT of liver + plain X-ray of lungs) + CEA after 6, 12, 18, 24, and 36 months, or 2) CT-scan of liver and lungs (or CT of liver + plain X-ray of lungs) + CEA after 12 and 36 months. The acceptability of these two models are promising, with few eligible patients (6.4%) refusing to take part in the RCT.

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 (Primrose, ongoing). Besides self-referral, GP-led or nurse-led follow-up offer potential alternatives, with visits to GPs and oncology specialists being recommended above visits to only one since preventive care services have been reported to be more accessible if both professionals are consulted (Snyder et al., 2008).

Overall, there is a clear need to reduce the high variability of follow-up services and support available for colorectal cancer survivors, and to enhance consistency of service availability across individuals and cancer networks. There also needs to be more emphasis on other aspects of patient need as a cancer survivor, such as quality of life, self-management, coping, and lifestyle advice. The latter is a particularly important information need for colorectal cancer survivors, with evidence suggesting that lifestyle changes can reduce risk of recurrence (Quadriatero and Hoffman-Goetz, 2003). At present, there is a paucity of work being conducted within the area of lifestyle aftercare, and ideally this needs to be addressed promptly.

Lung Cancer

In the main, trials have compared intensive follow-up with alternatives such as PET imaging or nurse-led follow-up. It has been found that intensive follow-up (e.g. thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy were performed every 6-months after surgery for two years) is an efficacious model, but that PET imaging does not result in a lower overall survival rate (Melloni et al., in press).

An RCT comparing the acceptability and feasibility of nurse-led clinic and telephone follow-up in patients with lung cancer expected to survive for at least 3 months, which did not meet the inclusion criteria for the CRD (2007) review, was included in this review (Moore et al., 2002). The study was included in this review due to the fact that it addresses previously neglected outcomes such as quality of life. It was concluded that a nurse-led model of follow-up can be used to make aftercare more responsive to individual needs, increase patient satisfaction, and reduce the burden of hospital visits and clinical investigations.

Overall, there was a paucity of evidence pertaining to lung cancer follow-up, as well as a paucity of initiatives aimed at addressing this lack of evidence. Thus, a number of drivers for change remain unaddressed such as a need to evaluate the efficiency of FDG-PET scanning, symptom-led follow-up, care planning, involvement in decision-making, and the most appropriate duration of follow-up. More research is clearly required to establish the most efficacious and feasible model of lung cancer follow-up.

Prostate Cancer

Internet adjunct and web-based follow-up is becoming increasingly popular for prostate cancer, such as the STAR program in the US, which is based on the National Cancer Institute Common Terminology Criteria for Adverse Events schema (Basch et al., ongoing). The system is being further developed for symptom monitoring during survivorship. These web-based patient-reporting systems are often accessible from desktop computers in outpatient clinics and from home computers, as well as being augmented with risk-stratification, self-referral, and nurse-led follow-up (Basch et al., ongoing; McFarlane, ongoing). In terms of technology-based nurse-led follow-up, such as the 'PSA Tracker' being utilised at the Urology Department of the Royal United Hospital Bath, such strategies allow patient-reported assessment via questionnaires, PSA testing in primary care, and treatment history to be captured by nurses on the PSA Tracker, which automatically triggers routine postal follow-up or recall to an outpatient clinic based on clinically established algorithms for PSA (McFarlane, ongoing). This system is being planned at Worcester Royal Hospital, to be run by a urology nurse specialist (Hopcroft et al., ongoing). This pilot, however, is planned to include an annual conference like the one provided to breast cancer survivors at Brighton and Sussex University Hospital NHS Trust (Huff et al., ongoing), covering self-management topics such as diet, complementary therapies, psychosexual problems, and benefits, as well as an 'information prescription.' Such methods are anticipated to save consultation slots and to be more cost-effective than routine clinical follow-up, as has already been demonstrated with the PSA Tracker (McFarlane, ongoing).

Along the same lines of support conferences are group follow-up models. One study not included in the CRD (2007) review, but which has been included in this review due to its testing of a more cost-effective model of aftercare is that of Fletcher et al. (2006). Fletcher et al. (2006) offer a group teaching follow-up model, or 'drop-in group medical appointments.' This study not only indicated the acceptability and feasibility of a group model of follow-up for prostate cancer survivors, but also demonstrated that such models need not necessarily be condition-specific. Whilst most diagnoses were prostate cancer or benign prostatic hyperplasia, group members also included men with incontinence, neurogenic bladder and chronic discomfort syndromes. Patient satisfaction was as high as with individual follow-up, indicating that a gender-specific group of people with urological chronic conditions might offer sufficient, cost-effective aftercare.

Conversely, a specialised model of long-term follow-up for prostate cancer survivors, the 'Prostate Cancer Survivorship Programme', is underway in Canada (Landier, ongoing) and would increase secondary care appointments. The goal of the programme, which is carried out in collaboration with each patient's primary treatment team, is to help each survivor stay as healthy as possible, and to prevent problems from happening or catch them early, when they are most easily treated. Patients enrolled on the programme will be seen in a long-term follow-up clinic every 6-months for the first five years after diagnosis, and then yearly thereafter. The follow-up includes a combination of medical tests and examinations, as well the provision of a 'Survivorship Care Plan,' and access to specialists (e.g. psychologists, dieticians). This is an ambitious programme, likely to be extremely costly, but results as yet remain unpublished.

Overall, the most promising model of aftercare offered thus far is the internet adjunct model, which facilitates the reduction of unnecessary investigations, whilst also increasing patient involvement and optimising the use of health care resources. There is, however, still a paucity of evidence on which to base the development of alternative approaches to the aftercare of men who are living with and beyond prostate cancer. In particular, more research is needed into effective follow-up care for men on hormone therapy, which often occurs unplanned and informally (NCSI, 2009), as well as into the psychological and emotional needs of this population.

All Cancers

Across cancers, the use of internet adjunct symptom monitoring systems is currently being assessed in the UK (Wright et al., ongoing), and if successful, patients will be able to remain connected to their oncology service by way of a specially designed website providing information and the collection of comprehensive standardised clinical and psychological information for the purpose of monitoring patient outcomes and service quality.

Nurse-led telephone follow-up has shown promise with breast and prostate cancer survivors, whereby each survivor is allocated a nurse who contacts them by telephone at pre-arranged times to provide individualised advice, support, and self-management guidance (Richardson et al., 2009). Qualitative feedback has been encouraging, but there is as yet no evidence

pertaining to the success of the self-management aspect of the model. Furthermore, since this service is provided in addition to other healthcare services, the long-term feasibility and cost-effectiveness of such a model might prove difficult. Indeed, neither nurse-led telephone follow-up or patient-initiated follow-up has been found to have a significant effect on the workload or satisfaction of GPs relative to conventional follow-up (Lewis et al., 2009). On the other hand, evidence pertaining to nurse-led follow-up is limited due to small sample sizes and lack of trials assessing long-term outcomes (Lewis et al., 2009).

In the main, telephone contact is generally viewed as being advantageous over face-to-face contact, particularly in terms of convenience, confidentiality and continuity of care. However, potential challenges surrounding establishing such a model will need to be addressed prior to any roll out.

Group sessions in the form of group delivered programmes aimed at informing and educating the patient about the clinical aspects of their ongoing management and care offer innovative quality improvement. For example, the NCSI Assessment and Care Planning work stream are currently exploring the concept of a post-treatment clinic (Hindle, ongoing) similar to the post-treatment support conference at Brighton and Sussex University Hospitals NHS Trust (Huff et al., ongoing). This is being considered as an adjunct to alternative approaches of cancer follow-up, with a strong emphasis on helping to inform and support people after cancer treatment to resume as normal a life as possible. Indeed, evidence from group follow-up for other chronic conditions shows improved patient satisfaction, increased understanding of symptom management (Jaber, Braksmajer, and Trilling, 2006; Vieira et al., 2007) and cost-effectiveness (Escobar, 2001). Evidence is now needed on the clinical implications of such a model, if it is to be more firmly integrated into routine follow-up care.

Overall, evidence obtained that is not site-specific does not offer much more than has been gained from the site-specific evidence. It does, however, highlight a shift towards patient empowerment via individualised and group education programmes aimed at increasing survivors 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.

Further evidence for group follow-up, risk-stratification, and patient-reported outcome measures can be found in appendix 4.

Appendix 1: Search Strategy

a) Systematic Review Searches

Cochrane Library 2007 to 2009

Date searched: 19/08/09

CDSR - 262 records

DARE - 0 records

NHS EED - 0 records

#1 MeSH descriptor Neoplasms explode all trees

#2 (cancer* or precancer* or (pre next cancer*) or neoplas* or tumor* or tumour* or malignan* or premalignan* or (pre next malignan*) or oncolog* or carcinoma*):ti,ab

#3 (#1 OR #2)

#4 (followup* or surveillance):ti,ab

#5 follow*-up*:ti,ab

#6 follow* next up:ti,ab

#7 follow next ups:ti,ab

#8 (#4 OR #5 OR #6 OR #7)

#9 (#3 AND #8), from 2007 to 2009

MEDLINE / EMBASE

- searches required to cover delay in records being made available on MEDLINE / EMBASE and appearing on DARE on the Cochrane Library.

- update date range covered: June 2008 – September 2009.

MEDLINE

Date searched: 19/08/09

31 records

1. exp *neoplasms/

2. (cancer\$ or precancer\$ or pre cancer\$ or neoplas\$ or tumor\$ or tumour\$ or malignan\$ or premalignan\$ or pre malignan\$ or oncolog\$ or carcinoma\$).ti,ab.

3. 1 or 2

4. (followup\$ or follow\$-up\$ or follow\$ up or follow ups or surveillance).ti.

5. 3 and 4

6. review.ab.

7. review.pt.

8. meta-analysis.ab.

9. meta-analysis.pt.

10. meta-analysis.ti.

11. or/6-10

12. 5 and 11

13. letter.pt.

14. editorial.pt.

15. comment.pt.

16. or/13-15

17. 12 not 16

18. 17

19. limit 18 to yr="2008 - 2009"

20. (200606\$ or 200607\$ or 200608\$ or 200609\$ or 200610\$ or 200611\$ or 200612\$ or 2007\$).ed.

21. 19 and 20

EMBASE

Date searched: 19/08/09

20 records

1. exp *Neoplasm/
2. (cancer\$ or precancer\$ or pre cancer\$ or neoplas\$ or tumor\$ or tumour\$ or malignan\$ or premalignan\$ or pre malignan\$ or oncolog\$ or carcinoma\$).ti,ab.
3. 1 or 2
4. (followup\$ or follow\$-up\$ or follow\$ up or follow ups or surveillance).ti.
5. 3 and 4
6. exp meta analysis/
7. meta-analys\$.ti,ab.
8. metaanalys\$.ti,ab.
9. meta analys\$.ti,ab.
10. review\$.ti.
11. overview\$.ti.
12. (synthes\$ adj3 (literature\$ or research\$ or studies or data)).ti,ab.
13. pooled analys\$.ti,ab.
14. ((data adj2 pool\$) and studies).mp.
15. (medline or medlars or embase or cinahl or scisearch or psychinfo or psycinfo or psychlit or psychlit).ti,ab.
16. ((hand or manual or database\$ or computer\$) adj2 search\$).ti,ab.
17. ((electronic or bibliographic\$) adj2 (database\$ or data base\$)).ti,ab.
18. ((review\$ or overview\$) adj10 (systematic\$ or methodologic\$ or quantitativ\$ or research\$ or literature\$ or studies or trial\$ or effective\$)).ab.
19. or/6-18
20. (case\$ adj2 review\$).ti,ab,sh.
21. (record\$ adj2 review\$).ti,ab,sh.
22. (patient\$ adj2 review\$).ti,ab,sh.
23. (patient\$ adj2 chart\$).ti,ab,sh.
24. (peer adj2 review\$).ti,ab,sh.
25. (chart\$ adj2 review\$).ti,ab,sh.
26. (case\$ adj2 report\$).ti,ab,sh.
27. (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep).ti,ab,sh.
28. or/20-27
29. 19 not 28
30. 5 and 29
31. ("200631" or "200632" or "200633" or "200634" or "200635" or "200636" or "200637" or "200638" or "200639" or "200640" or "200641" or "200642" or "200643" or "200644" or "200645" or "200646" or "200647" or "200648" or "200649" or "200650" or "200651" or "200622" or "200652" or "200623" or "200624" or "200625" or "200626" or "200627" or "200628" or "200629" or "200630").em.
32. 2007\$.em.
33. 31 or 32
34. 30 and 33
35. 34
36. limit 35 to yr="2008 - 2009"

b) Ongoing Trials Searches

International Cancer Research Portfolio

<http://www.cancerportfolio.org/index.jsp>

Searched: 19/08/09

'follow up' in title

10 records

'follow-up' in title

4 records

ClinicalTrials.gov

<http://www.clinicaltrials.gov/>

Searched: 19/08/09

(cancer OR neoplasm OR neoplasms OR tumor OR tumours OR malignancy OR oncology OR carcinoma) AND (follow up OR follow-up OR followup)

3 records

mRCT (Current Controlled Trials)

<http://controlled-trials.com/>

- All active registers, excluding NIH records from ClinicalTrials.gov

Searched: 21/08/09

(cancer OR neoplasm OR neoplasms) AND (follow up OR follow-up OR followup)

21 records

c) RCT Searches

Additional RCT searches were run for the specific cancer sites and group follow-up.

Cancer Site

PUBMED

Date searched: 21/08/09

345 records

Search ("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance AND breast"[Title/Abstract] OR "prostate"[Title/Abstract] OR "colorectal"[Title/Abstract] OR "bowel"[Title/Abstract] OR "lung"[Title/Abstract]) AND ("2007"[Publication Date] : "3000"[Publication Date]) Limits: only items with links to full text, Humans, Randomized Controlled Trial, English, Cancer, All Adult: 19+ years.

Group Follow-Up

PUBMED

Date searched: 21/08/09

481 records

Search (("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance AND breast"[Title/Abstract] OR "prostate"[Title/Abstract] OR "colorectal"[Title/Abstract] OR "bowel"[Title/Abstract] OR "lung"[Title/Abstract]) AND ("2007"[Publication Date] : "3000"[Publication Date])) AND (((("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance"[Title/Abstract] OR "cluster visits"[Title/Abstract] OR "in-group medical appointments"[Title/Abstract] OR "shared medical appointments"[Title/Abstract] OR "drop-in group medical appointments"[Title/Abstract]) AND ("2007"[Publication Date] : "3000"[Publication Date])) AND (((("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance AND lung"[Title/Abstract] OR "breast"[Title/Abstract] OR "prostate"[Title/Abstract] OR "colorectal "[Title/Abstract]) AND ("2008"[Publication Date] : "3000"[Publication Date])) AND (((("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance"[Title/Abstract]) AND ("2008"[Publication Date] : "3000"[Publication Date])) AND (((("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance"[Title/Abstract]) AND ("2007"[Publication Date] : "3000"[Publication Date])) AND ((("cancer"[Title/Abstract] OR "neoplasm AND follow-up"[Title/Abstract] OR "surveillance"[Title/Abstract]) AND (cancer OR neoplasm AND follow-up OR surveillance)))))) Limits: only items with links to full text, Humans, Randomized Controlled Trial, English, Cancer, All Adult: 19+ years.

Appendix 2: Data Extraction for Published Studies of Cancer Aftercare

Breast Cancer

Authors: Beaver (2009)

Title: Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial.

Aims: To compare traditional hospital follow-up with telephone follow-up by specialist nurses after treatment for breast cancer.

Participants: 374 women treated for breast cancer, meeting the following inclusion criteria: completion of primary treatment (surgery, radiotherapy, chemotherapy); no evidence of recurrent disease; low to moderate risk of recurrence (determined by the NPI; HER² status); access to a telephone; and adequate hearing.

Outcomes: Psychological morbidity (state-trait anxiety inventory, general health questionnaire (GHQ-12), participants' needs for information, participants' satisfaction, clinical investigations ordered, and time to detection of recurrent disease.

Methods: A two centre randomised equivalence trial in which women remained in the study for a mean of 24 months. Breast care nurses underwent four half day training sessions on the administration of the telephone intervention with subsequent feedback and debriefing sessions throughout the study period. Seven nurses received training, although one nurse at the district general hospital and three nurses at the specialist breast unit conducted most telephone appointments. To monitor the integrity of the intervention, all telephone consultations were recorded with consent of the women.

Randomisation: 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).

Response Rates: 110 of 121 women (91%) agreed to participate. Seventy-five patients (71%) completed follow-up using the new automated system 1 year later.

Results: Uptake of the intervention was 60%; those who refused to take part differed from participants in study site, social class, and follow-up status. Patients at the specialist breast unit (71%) were more likely to want to participate than those at the district general hospital (61%), participants from higher social classes (professional occupations) were more likely to want to participate than those from lower social classes, and participants with three to 12 months between visits (67.7%, 70.6%) were more likely to participate than those on six monthly follow-up (58.1%). Time from diagnosis did not differ significantly for those who did or did not take part. Differences between groups in state-trait score were not significant at the start, middle, or end of the trial under intention to treat or adjusted treatment received analyses, although means were consistently lower for the telephone group. Mean score did not significantly improve during the trial, the mean reduction from the start to the end of the trial being 0.33. Differences in GHQ-12 scores at the start, middle, or end of the trial were not significant, nor were differences between time points. Although the percentage of cases (scores ≥ 4) was consistently higher in the hospital group at the start, middle, and end of the trial, differences between the groups at each time point were not significant. Initially, 22% were GHQ-12 cases compared with 17% at the end of the trial. Participants clearly indicated their specific information needs with, initially, the highest need relating to information about genetic risk and the lowest for information on sexual attractiveness. Within both randomised groups, information needs reduced over time for all items. There was little difference between

the groups in information needs, apart from information on sexual attractiveness in the middle of the trial, where 15% of the hospital group compared to 7% of the telephone group required information on this. The need for information on genetic risk remained the highest at the end of the trial, with 31% of respondents still requiring information. There were no significant differences between randomised groups initially regarding satisfaction with information received. The telephone group showed significantly more satisfaction at the middle and end of the trial. Participants were asked if they had thought that the appointment had been helpful in dealing with their concerns. There was no difference between groups initially, but 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 44% in the hospital group) and few with negative responses. Contacts between appointments for both groups were relatively few, but were primarily with breast care nurses, GPs, and lymphoedema nurses. There were no significant differences between groups in terms of contact at any time point. There were no differences between groups in whether clinical investigations were ordered for participants as a result of appointments at the start (hospital 29% v telephone 24%), middle (36% v 34%), or end of the trial (40% v 43%, $\chi^2=0.32$). 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.

Conclusion: 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 and decreases the burden on busy hospital clinics. However, the intensity of this intervention (frequency of contact and length of consultations) and its provision by specialist nurses, it is unlikely to prove more cost-effective than the current provision by junior doctors in outpatient clinics.

Strengths and Limitations: Randomisation was employed, and the analyst was blind to study group allocation. Breast care nurses had no involvement in randomisation or data collection procedures. Validated measures used. However, the study provides limited information about time to detection of recurrent disease

Authors: Chatfield and Simcock (2008)

Title: Follow-Up in Breast Cancer

Aims: To assess the acceptability and feasibility of providing early discharge to low risk breast cancer survivors.

Participants: 28 low risk breast cancer patients.

Outcomes: The primary outcome was patient perceptions of how helpful this model of follow-up is, as well as any changes in healthcare utilisation resulting from the model.

Methods: On completion of treatment, patients were 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. Patient-initiated follow-up was implemented, initially for low risk patients and supported by a conference which aimed to provide a holistic overview of issues facing cancer survivors, including a discussion of self-examination, endocrine therapies, financial issues, diet (by Consultant Dietician), sexual health, and psychological well-being. The purpose of the conference was to provide all patients with expert opinion and knowledge as well as empowering them with the knowledge required to actively self-manage. The conference Patients continue to have rapid access to the BCN and continue with regular mammograms.

Response Rates: Ninety-two patients were invited to the conference, 43% replying that they would attend and 31% actually attending.

Results: Feedback from attendees (75% response rate) was 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 routine clinical follow-up, equating to 30 scheduled appointments and up to a further 240 appointments collectively.

Conclusion: Despite the time required to organise a successful conference (i.e. venue and programme planning; speaker and delegate administration) being cited as a potential barrier, this model of follow-up is now firmly established for low risk breast cancer patients at BSUH, with roll out to medium and appropriate high risk patients being considered. There is a need to explore alternative resources for the conferences if this initiative is to be expanded.

Strengths and Limitations: Small sample size, no randomisation, and limited outcome measures. Nevertheless, a reasonable foundation for further research

Authors: Chapman et al. (2009)

Title: Patient-led breast cancer follow up.

Aims: The audit aimed to assess patient satisfaction and GP workload following the introduction of patient-led breast cancer follow up (PLFU).

Participants: to 217 patients at low risk of recurrence or death following breast cancer treatment and 302 GPs. All patients (female or male) met the following inclusion criteria: Any age (pre- or post-menopausal); All cases of ductal carcinoma in situ (DCIS); All invasive breast cancer with Nottingham Prognostic Index < 4.4

Outcomes: Patient satisfaction and GP workload.

Methods: Patient-led breast cancer follow-up (PLFU), comprising regular mammographic surveillance and easy access self-referral to the breast clinic if required, was introduced to the service. Patients were selected for PLFU by the multidisciplinary team and were discharged either following surgery or three months after completion of radiotherapy. Each patient underwent an exit interview, where symptoms and signs of recurrence were discussed, and given contact details for specialist nurses to allow rapid self-referral to the breast clinic if concerns arose. Regular clinical examination, either by the GP or breast unit clinicians, did not form part of routine follow up. All local GPs were informed by letter at the start of the PLFU programme. All patients had regular mammographic surveillance, either annually following breast conserving surgery or biannually following mastectomy, for a five-year period. Mammograms were booked on the Computerised Radiology Information System (CRIS) for each of the years of follow-up until entry into the NHS Breast Screening Programme (NHSBSP). Each patient's appointments were recorded on a mammography "season ticket" which was posted to them. Following each mammogram a report was sent to the patient and their GP and if abnormal the patient was recalled for further assessment, in a similar fashion to women in the NHSBSP. In April 2008 a questionnaire was sent to 217 patients who had entered the PLFU programme to assess patient satisfaction and the effectiveness of this discharge protocol. In addition a questionnaire was sent to 302 GPs to assess their knowledge about PLFU and any impact of reduced clinical follow up on their workload.

Response Rates: From 217 patients there were 130 respondents (60%).

Results: 97% patients had a clear idea of how to contact the breast unit, and only 5 of 130 patients (4%) required a breast clinic appointment. All 106 respondents (100%) were satisfied with the process to contact the breast unit. Only 10 of 277 GP respondents (3.6%) referred a patient on PLFU back to the breast unit during the study period. GP responses indicated that only 4% had re-referred a patient back to the breast unit during the study period. A further 71 GPs reported no consultations and 27 reported 1–2 patient consultations for their patients in the follow-up programme. The remaining 13 GPs had seen patients 3–5 times or more than 5 times.

Conclusion: PLFU has been well received by patients following breast cancer treatment with little increase in GP workload. The use of risk stratification allows low risk patients to undergo five-year mammographic surveillance without regular breast examination but with access to clinical input if necessary. It also allows time to be spent with new referrals and those patients at higher risk of recurrence. A potential problem is that such a model of follow-up will lead to an initial increase in workload for GPs as patients seek additional clinical follow-up in primary care.

Strengths and Limitations: No validated instruments. An audit as opposed to a randomised study with rigorous controls.

Authors: Koinberg et al. (2009)

Title: A health economic evaluation of follow-up after breast cancer surgery: Results of an RCT Study

Aims: The aim was to evaluate the cost-effectiveness of two different models of follow-up for stage I and II breast cancer patients: routine follow-up with a physician or 'on-demand' (i.e. patient-initiated) follow-up with a nurse al., 2009). The primary outcome was cost-effectiveness.

Participants: Stage I and II breast cancer patients (n = 254) were randomised to a routine follow-up with a physician (PG; n = 131) or 'on-demand' (i.e. patient-initiated) follow-up with a nurse (NG; n = 133)

Outcomes: The primary outcome was cost-effectiveness.

Methods: Routine follow-up with a physician involved a specialist in oncology or surgery examining the patients four times per year during the first two years after surgery, followed by bi-annual examinations for up to five 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 of the breasts, chest wall and regional lymph nodes was carried out. Mammography was carried out at one-year intervals. Blood tests, chest x-ray or other imaging techniques were only performed on clinical indication. Patient-initiated follow-up with a nurse was introduced during a visit to the physician that took place following radiotherapy and after randomisation. Patients were given an appointment to meet with an experienced nurse approximately three months after surgery. In the course of this meeting, the patient received information about how to recognise a recurrence in breast, skin, axilla and scar. The nurse arranged mammography at one-year intervals and informed the patient of the result of the mammography by telephone or letter. After three years, the 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 took time to talk to the patient about her psychosocial situation. The patient was instructed to contact the nurse at any time if she had any questions or symptoms that she perceived could be related to breast cancer. The nurse co-ordinated the healthcare resources and consulted a physician or a physiotherapist when needed.

Randomisation: Stage I and II breast cancer patients (n = 254) were randomised to a routine follow-up with a physician (PG; n = 131) or 'on-demand' (i.e. patient-initiated) follow-up with a nurse (NG; n = 133).

Results: The cost per person year of follow-up differed between the groups, with 630 euro per person year in the PG compared to 495 euro per person year in the NG. Thus, specialist nurse intervention with check-ups on demand was 20% less expensive than routine follow-up visits to the physician. The main difference in cost between the groups was explained by the numbers of visits to the physician in the respective study arms. There were 21% more primary contacts in the PG than the NG.

Conclusion: The authors concluded that the difference in cost per year and patient by study arm is modest, but transforms to nearly 900 euro per patient over a 5-year period, offering a substantial opportunity for reallocating resources.

Strengths and Limitations: Randomisation was used, but a limitation is the relatively small sample size and thus a lack of generalisability of findings.

Authors: Mandelblatt et al. (2008)

Title: Economic evaluation alongside a clinical trial of psycho-educational interventions to improve adjustment to survivorship among patients with breast cancer.

Aims: To collect data alongside a randomised trial to compare the costs and benefits of three psycho-educational strategies to improve transition to cancer survivorship.

Participants: Women were eligible if they had received surgery for invasive breast cancer of any size or nodal status. Exclusion criteria included use of neoadjuvant chemotherapy, high-dose chemotherapy with bone marrow or stem-cell rescue or protracted reconstructive surgery, and inability to read and write in English. Exactly 418 women completed the original trial; 396 women returned calendar data; 389 women were available for the economic analyses.

Outcomes: The outcomes for this analysis were changes in distress and energy 6 months post-intervention, as measured by the Revised Impact of Events Scale (IES-R) and the SF-36 vitality scale, respectively. The vitality scale captures energy level and fatigue. Because of skewness in the IES-R score distribution, a logarithmic transformation was performed to produce a relatively normal distribution of IES scores; the scores were retransformed for cost-effectiveness analysis. Higher change scores for the SF-36 represent more energy and a higher IES change score represents less distress pre- to post-intervention. There were some baseline imbalances in the study arms, so baseline depression was controlled for in calculating outcomes. Costs stratified by baseline level of preparedness for transition were also calculated. Preparedness was defined by responses to two items ("Overall, I feel very well prepared about what to expect during recovery; Overall, I feel the medical team has done a great deal to prepared me for what to expect during my recovery."). Overall 12-month health care costs were assessed by study arm.

Methods: Women completed a baseline survey 4 to 6 weeks after primary treatment; the survey was repeated at 6 and 12 months after the intervention. The research staff used weekly logs to record the time and resources used to deliver the interventions. Finally, participants were mailed calendars every 3 months to document all health services used; those not returning calendars were provided mail and telephone reminders. Three strategies for improving survivorship transitions were compared. The least expensive approach (a booklet control condition) was compared with the next most expensive (an educational video plus the control booklet); the video was compared incrementally to the most expensive option (counselling plus the video plus the booklet). 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." This 23-minute film was designed to address re-entry challenges in physical health, emotional well-being, interpersonal relations, and life perspectives. The video includes peer modelling of active coping approaches to fatigue and other survivorship concerns. The last arm included psycho-educational counselling (one individually conducted in-person session and one telephone session) plus the video and booklet.

Randomisation: Women were randomised to one of three conditions: a booklet control group; educational video plus the control booklet; and counselling plus video plus control booklet.

Response Rates: Exactly 418 women (74.9%) completed the original trial; 396 women (94.7%) returned calendar data. Seven women were missing treatment or other information, leaving 389 women (69.7%) for economic analyses. There were no significant differences between those completing economic data and those not doing so.

Results: 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; among women who were the least prepared for transition, the video was more effective, resulting in even lower costs. The video cost \$7,275 per unit change in distress versus control, but costs were lower in the subgroup least prepared for transition (\$355). The counselling arm was more expensive and less effective than the video for virtually all end points. However, in one group, women more prepared for transition, counselling cost \$1,066 per unit decrease in distress compared with the video. Health care costs tended to increase as intervention intensity increased.

Conclusion: In this trial, 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.

Strengths and Limitations: The patients included in this trial had high education and income. It is possible that less advantaged women might be more vulnerable to poor adaptation and might benefit more from intervention or require different or more costly types of interventions. The study was limited to volunteers for a randomised controlled trial in three geographic regions and may not be generalisable to all breast cancer survivors. The study arms were unbalanced for baseline depression and although depression was controlled for, it is possible that there are residual unmeasured differences between the groups. Although the video produced benefits at the lowest costs, this benefit was for a defined, limited period of time: the 6 months after active treatment ended. The video tended to produce continued positive effects at 12 months, but this trend was not statistically significant. The findings are further limited by self-report of health care use. However, the use of randomisation and validated outcome measures adds strength to results.

Authors: Montgomery, Krupta, and Cooke (2007).

Title: Alternative methods of follow up in breast cancer: a systematic review of the literature.

Aims: To investigate alternative follow-up methods that have undergone a controlled trial, in order to establish evidence to inform and clarify guidelines for breast cancer follow-up.

Methods: Systematic review - Using MEDLINE, Embase, CancerLit, Web of Sciences and EBM reviews as data sources, they reviewed all RCTs meeting the following inclusion criteria were: patients included had been treated for primary operable breast cancer and were free of distant metastases outside the breast or axilla at the time of initial treatment; and, the study was a randomised controlled trial comparing routine clinical and mammographic follow-up with an alternative, or comparing different frequencies or durations of clinical follow-up. All outcome measures addressed in the trials were analysed.

Search Strategy: 2248 titles were examined in MEDLINE, 944 in EMBASE, 225 in EBM reviews, 2882 in CancerLit and 331 in Web of Sciences; 20 abstracts were obtained. In total, seven RCTs were found in the literature, all of which were eligible for inclusion.

Results: A total of seven records were included in the review: two trials compared follow-up in hospital clinics with that provided by a GP (Grunfeld et al, 1996, 2006); two compared traditional follow-up with 'on-demand' (i.e. patient-initiated) follow-up by contacting a BCN (Brown et al, 2002; Koinberg et al, 2004); one compared routine follow-up by doctors with routine follow-up by BCNs (Baildam et al, 2004). Two trials compared different frequencies of follow-up within a traditional model of follow-up (Gulliford et al, 1997; Kokko et al, 2005).

Conclusion: The authors found that all trials were of inadequate power or duration to establish ideal frequency of clinic visits or safety of alternative follow-up methods. 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, larger and higher quality trials are required to establish whether these alternative models are as safe as clinical examination.

Strengths and Limitations: The inclusion criteria did not include blinding to randomisation and the RCTs reviewed were not of sufficient quality to provide any valuable guidance on breast cancer follow-up. However, this review has highlighted gaps in knowledge, as well as the need for larger, more rigorous RCTs within the area of cancer follow-up.

Authors: Montgomery et al. (2008)

Title: Automated telephone follow-up after breast cancer: an acceptability and feasibility pilot study.

Aims: To assess the acceptability and feasibility of remote, automated telephone follow-up after breast cancer.

Participants: All patients with a history of breast cancer treated with curative intent who had completed their adjuvant chemo-radiotherapy and who attended a routine follow-up clinic between 1 May 2006 and 31 August 2006 were asked to participate. The following exclusion criteria were applied: The presence of local or distant disease at time of clinic. (Successfully treated previous locoregional relapse was not an exclusion criterion); Inability to complete the questionnaire on paper independently; No access to a telephone; and Inability to consent to participation.

Outcomes: An initial seven questions were designed to encourage self-examination and allow the reporting of symptoms that may be associated with relapse, either locoregional or metastatic. The FACT-B questionnaire with endocrine and arm subscales was used to assess QoL.

Methods: A prospective cohort study, where the follow-up questionnaire was administered on paper at baseline. In place of a clinic visit the following year, the women completed the same questionnaire using an automated telephone system. All patients were given mammograms. A semi-structured interview was then conducted to assess the acceptability. 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 telephone in and complete the questionnaire using an ordinary touch tone telephone. The answers generated are recorded within an individual patient record. The system can be programmed to calculate scores according to the answers given in the questionnaire and undertake specific actions in the event of certain answers being given or scores being achieved. An acceptable score can result in a reassuring letter being generated by the system and a request for a routine mammogram being sent to radiology. Poor scores or deterioration from the last-recorded score can result in an email being sent to a designated person to ensure that the low score is followed up.

Response Rates: 110 of 121 women (91%) agreed to participate. Seventy-five patients (71%) completed follow-up using the new automated system 1 year later.

Results: 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 part of their follow-up, whilst 16% were not

Conclusion: Automated telephone follow-up also allows the generation of not only outcome data, but also far 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.

Strengths and Limitations: Randomisation was not employed. One questionnaire was highly validated whilst the other was not. The validated FACT was used as a screening instrument within this study, which it was not designed for, but which complements recent moves towards computer-assisted health consultations. Associations between this model of aftercare and QoL were not assessed.

Authors: Oltra et al. (2007)

Title: Cost-benefit analysis of a follow-up program in patients with breast cancer: a randomized prospective study.

Aims: To compare the cost-benefit of intensive follow-up versus standard clinical follow-up in the early detection of relapses in patients with breast cancer.

Participants: One hundred and twenty-one stage I, II and III breast cancer patients, who had completed treatment with curative intent were randomised to standard clinical follow-up (n = 63) or to an intensive follow-up (n = 58)

Outcomes: Outpatient appointments kept; relapse; overall cost of follow-up.

Methods: In the standard clinical follow-up arm, the patients had a careful history and physical examination; no complementary tests were undertaken if the clinical symptoms at the time did not require them. In the intensive follow-up arm, in addition to the anamnesis and physical examination, biochemistry, hematogram, and the markers carcinoembryonic antigen (CEA) and CA15.3 were assessed at every outpatient visit together with an annual hepatic echography, chest x-ray, and bone scan. All patients, irrespective of their 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. Surveillance followed the guidelines of the American Society of Clinical Oncology (ASCO) currently in operation at the time of the study.

Randomisation: After initial treatment, those patients consenting to be randomised were either randomised to intensive or standard follow-up.

Results: The number of scheduled outpatient appointments kept was 359 in the standard clinical follow-up and 355 in the intensive follow-up group. After a median of 3 years of follow-up, there were 28 relapses, 11 in standard clinical follow-up, and 13 in the intensive follow-up group. The overall cost of follow-up was 24,567 euros in the standard clinical follow-up group and 74,171 euros in the intensive follow-up group.

Conclusion: Performing complimentary investigations in breast cancer follow-up is associated with higher costs without difference in early detection of relapses; 69% of the relapses in the intensive follow-up group were diagnosed in the interval between scheduled visits, when patients initiated clinic visits because of the appearance of symptoms. The authors recommend that follow-up programs that encourage the patients to have easy and rapid access to the health care system when symptoms or signs of relapse become evident are the most efficient system of care.

Strengths and Limitations: Primarily objective outcomes with limited assessment of subjective outcomes. No mention of whether researchers were blind to randomisation. Indeed, very little detail is provided in terms of research methodology.

Authors: Pinto, Goldstein, and Papandonatos (2009)

Title: Promoting physical activity in follow-up care for breast cancer patients.

Aims: To examine the effectiveness of integrating health promotion into follow-up care.

Participants: One hundred and ninety-two breast cancer patients (13% Cancer Stage 0, 38% Stage 1, 41% Stage 2, 8% Stage 3-4; mean years since diagnosis = 2.9 years); 14 Oncologists and surgeons (mean years in practice = 15.6 years).

Outcomes: The primary outcomes were physical functioning (SF-36), mood (SF-36), and fatigue (FACIT), as well as satisfaction with the intervention.

Methods: In *Moving Forward with Life*, a theoretically-based physical activity RCT designed for breast cancer survivors who have completed treatment in the past 2-years, Oncologists and surgeons were trained to provide brief physical activity (PA) advice for 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 PA (extended advice) or contact control (brief advice). Assessments of patients' PA, physical functioning, mood and fatigue were completed at baseline, 3, 6, and 12 months. Healthcare providers completed questionnaires on PA counselling at baseline and provided feedback at study end.

Randomisation: After initial treatment, those patients consenting to be randomised were either randomised to extended advice or brief advice.

Results: 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 PA 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. Moderate intervention effects were also obtained for physical functioning and small effects for fatigue. **Conclusion:** These promising results suggest that effective health promotion can be integrated into follow-up care for cancer survivors.

Strengths and Limitations: Randomisation of participants, as well as the utilisation of well-validated measures adds strength to this study. A relatively large sample is used. However, no reference is made to the blinding of researchers to participant randomisation.

Authors: Vaile, Donovan and Barrett-Lee (2006)

Title: Breast cancer follow-up with the Velindre model: a mammography-based approach.

Aims: To assess the feasibility of radiographer-led mammographic follow-up.

Participants: 1,210 breast cancer patients.

Outcomes: Healthcare utilisation and patient/provider relationships.

Methods: Radiographers are trained in implementing this new system. At the patients' annual mammography visit the radiographer completes an Online health questionnaire on the patient database, the main aim of questions being to determine if patients have: experienced any new breast problems; developed any signs of lymphoedema; developed shoulder stiffness on the treated side; discovered any significant new, unexplained health problems; or whether they have been taking Tamoxifen /Arimidex™/ Femara™ for treatment of breast cancer and for how long.

As well as an abnormal finding at mammography triggering referral to a specialist BCN, certain problems identified via the electronic questionnaire also trigger such a referral: new breast problems including mild pain, swelling, skin rash; recent onset of shoulder stiffness on treated side; or recent onset of lymphoedema. Referral takes the form of a paper referral to the BCN, who then contacts the patient by telephone or letter. Similarly, answers to the hormone treatment questions inform radiologists of whether referral to a specialist oncology nurse is necessary. For those patients who have completed more than five-years hormone treatment, this is reviewed regarding discontinuation or change from Tamoxifen™ to an aromatase inhibitor licensed for extended adjuvant use (i.e. Femara™). *Adjuvant Online*, an online risk stratification tool for professionals, is used to determine the benefit of extended use of an aromatase Inhibitor and the GP is informed of any hormone therapy decisions via an electronically-generated result letter. Referral to a Consultant Oncologist takes place if the patient reports: nipple discharge or bleeding, new breast lump, severe persistent breast pain, new breast distortion; chronic, severe bone pain; severe headaches; persistent nausea or unexplained weight loss; or persistent chest pain or shortness of breath.

Results: The Velindre model has demonstrated a reduction in clinic visits (i.e. typically, patients need only one hospital visit each year) and improvement in the consistency of established relationships with radiographers and specialist nurses. Other benefits include that electronic sign-off of Radiology reports alerts the Consultant Oncologist to any abnormal mammogram reports. In the year from 1 August 2007 to 31 July 2008, 1,210 patients attended mammographic follow-up, 80% requiring no further input from the breast team; 9% requiring further input from a CNS; 2% requiring a referral to the outpatient clinic; 5% discharged from care; and 4% of questionnaires had no outcome recorded.

Conclusion: Following presentations at two national conferences there has been interest from several other NHS Trusts who wish to operate a similar follow-up model.

Strengths and Limitations: This study was not randomised and measured limited outcomes. However, the study provides a successful example of the feasibility of risk-stratification and the involvement of healthcare providers other than nurses and Oncologists. This is a novel approach in need of further testing.

Authors: Sheppard et al. (2009)

Title: Breast cancer follow up: a randomised controlled trial comparing point of need access versus routine 6-monthly clinical review.

Aims: To examine a model of care for breast cancer patients based on the concept of point of need access and investigate the effectiveness of this model compared to routine 6-monthly clinical reviews.

Participants: A total of 237 patients were recruited to the study.

Outcomes: Outcome measures at baseline, 9 and 18 months included psychological morbidity using the GHQ12 questionnaire, quality of life using the FACT-B plus endocrine subscale, fear and isolation. Recurrences and methods of detection were recorded as secondary outcome measures.

Methods: A parallel randomised controlled trial was used to examine point of need access to specialist care via the nurse specialist, compared to routine hospital based 6-monthly clinical review at year two post breast cancer diagnosis. Outcome measures at baseline, 9 and 18 months. An analysis of covariance was used to detect changes over time.

Randomisation: A parallel randomised controlled trial, whereby patients were exposed to one condition only.

Response Rates: Two hundred and fourteen patients completed the study, a response rate of 90%.

Results: Overall patients were not exposed to risks of increased psychological morbidity ($p = 0.767$) or decline of quality of life ($p = 0.282$) when routine review was discontinued, and no significant differences were detected during an 18-month period. Patients not receiving regular review did not feel isolated, and at the end of 18 months did not wish to return to 6-monthly clinical reviews. The presentation of recurrences and short symptom history demonstrate that the recurrences observed were unlikely to have been detected at a routine visit.

Conclusion: Point of need access is acceptable to the majority of patients. Although a third of patients may wish to maintain a regular review, patient choice is important. Findings suggest that after 2 years following the diagnosis of breast cancer 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.

Strengths and Limitations: Randomisation was employed, but blinding of researchers or participants was not. Validated outcome measures were used, as were rigorous statistical analyses.

Colorectal Cancer

Authors: Macafee et al. (2007)

Title: Risk-stratified intensive follow up for treated colorectal cancer - realistic and cost saving?

Aims: This paper aims to calculate the additional resource and cost implications of intensive follow up post-CRC resection, examine the possibility of risk-stratifying this follow-up to those at highest risk of recurrence and investigating the impact that population screening might have on the future cost and outcomes of follow-up.

Outcomes: Detection of recurrence, frequency of appointments, cost-effectiveness.

Methods: Two follow-up regimens were constructed: the 'standard' follow-up protocol used the principles of the British Society of Gastroenterology (BSG) guidelines whilst the 'intensive' follow-up protocol used the most intensive arm of the follow-up after colorectal surgery (FACS) trial. Using ONS data, the number of CRC diagnosed in a given year was calculated 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. Risk stratifying entry to follow-up and the introduction of population CRC screening were then considered.

Results: For the 2003 cohort, an intensive follow-up program would detect 853 additional resectable recurrences over 5 years with 795 fewer subjects 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 subjects who would never develop detectable recurrences was £15.6 million. The cost per additional resectable recurrence was £18 077, a figure also found for a nonscreened population in 2016. An identical intensive follow-up policy with biennial FOBT screening in 2016 saw the cost per additional resectable recurrence rise to £36 255.

Conclusion: Intensive follow up will detect considerably more resectable recurrences but at considerable cost and it is unclear if such follow up will be achievable in an already over-stretched NHS. If population-based CRC screening increases the number of Dukes A cancers this may offer the possibility of risk-stratifying future follow-up to those at highest risk of recurrence; minimising tests on those who will never have recurrent disease and better utilising scarce resources.

Strengths and Limitations: Consideration of current government priorities, but questionable as to whether findings can be utilised within present economic climate.

Authors: Snyder et al. (2008)

Title: Trends in follow-up and preventive care for colorectal cancer survivors.

Aims: 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.

Participants: Twenty thousand sixty-eight survivors diagnosed with stage 1–3 colorectal cancer between 1997 and 2001.

Outcomes: Using the SEER-Medicare database, the mean number of visits to different physician types, the percentage of survivors receiving preventive services, how receipt of preventive services related to physician types visited, and trends over time in physician visits and preventive care.

Methods: Retrospective cross-sectional study of 5 cohorts of cancer survivors in survivorship year 1.

Results: There was a trend over time of increased visits to all physician types, which was statistically significant for oncology specialists and other physicians ($p < .001$) but not PCPs. The percentage of survivors receiving preventive services remained relatively stable across the 5 cohorts, except for an increase in bone densitometry ($p < .05$). Survivors who visited both a PCP and oncology specialist were most likely to receive each preventive care service ($p < .05$).

Conclusion: 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.

Strengths and Limitations: Error due to confounding and bias is a potential limitation with retrospective studies.

Lung Cancer

Authors: Moore et al. (2002)

Title: Nurse-led follow-up and conventional medical follow-up in management of patients with lung cancer: randomised trial.

Aims: To assess the effectiveness of nurse led follow-up in the management of patients with lung cancer.

Participants: 203 patients with lung cancer, who had completed their initial treatment and were expected to survive for at least 3 months.

Outcomes: QoL (EORTC QLQ C30) was assessed at baseline and at monthly intervals and patients' satisfaction at baseline and at three, six, and 12 months. Secondary endpoints included overall survival, symptom-free survival, and progression-free survival. Data on use of services at three, six, and 12 months was collected for analyses of patterns of use of services and cost-effectiveness of nurse led follow-up. Costs of visits by GPs and nursing staff were calculated on the basis of information provided by third parties, calculated costs of hospital treatment with reference to standard costs reported by the DH, and obtained costs of tests and procedures from third parties. Unit costs derived from these sources were used to calculate the total cost per patient for each period of follow-up.

Methods: The trial took place in a specialist cancer hospital and three cancer units in south-eastern England. Patients were randomised to either conventional medical follow-up or nurse led follow-up. The care of patients randomised to conventional medical follow up remained unchanged and consisted of routine outpatient appointments (one post-treatment appointment, then appointments at two or three month intervals) for medical assessment and investigations to monitor disease progression. Patients were also seen on the basis of need. Patients randomised to nurse led follow-up were allocated to one of two clinical nurse specialists in lung cancer and were assessed monthly by protocol over the telephone or in a nurse led clinic to identify signs of disease progression, symptoms warranting intervention, or serious complications. Additional contacts were made as necessary: patients had access to the clinical nurse specialists in the nurse led clinic or by telephone without an appointment. Clinical nurse specialists focused on providing information and support and coordinating input from other agencies or services. The clinical nurse specialist was responsible for the entire care of patients in the nurse led follow-up group, unless the patient needed further treatment. The clinical nurse specialists were prepared for the role by observing outpatient lung cancer clinics and shadowing medical consultants. Medical consultants and nurse academics gave regular clinical supervision sessions for the clinical nurse specialists.

Randomisation: This was a randomised controlled trial, where patients were randomised to either conventional medical follow-up or nurse led follow-up.

Response Rates: Of 271 patients approached, 203 (75%) agreed to participate.

Results: Patient acceptability of nurse led follow-up was high, as demonstrated by response rates. Patients who received the intervention had less severe dyspnoea at 3 months ($P=0.03$) and had better scores for emotional functioning ($P=0.03$) and less peripheral neuropathy ($P=0.05$) at 12 months. Intervention group patients scored significantly better in most satisfaction subscales at 3, 6, and 12 months ($P<0.01$ for all subscales at 3 months). No significant differences in GPs overall satisfaction were seen between the two groups. No differences were seen in survival or rates of objective progression, although nurses recorded

progression of symptoms sooner than doctors ($P=0.01$). Intervention patients were more likely to die at home rather than in a hospital or hospice ($P=0.04$), attended fewer consultations with a hospital doctor during the first 3 months ($P=0.004$), had fewer radiographs during the first 6 months ($P=0.04$), and had more radiotherapy within the first 3 months ($P=0.01$). No other differences were seen between the two groups in terms of the use of resources.

Conclusion: Nurse led follow-up was acceptable to lung cancer patients and GPs, leading to positive outcomes.

Strengths and Limitations: Randomisation was employed to allocate participants to follow-up. Validated instruments were used and the study used both subjective and objective outcomes. Replication at other centres in the UK, with a range of nurse specialists and outside the context of a research study, is essential to confirm the generalisability of the findings. The rate of attrition was high because of death or disability. The authors' note that the number of outcomes analysed in this study would imply that some findings may have occurred by chance.

Prostate Cancer

Authors: Fletcher et al. (2006)

Title: An improved approach to follow-up care for the urological patient: drop-in group medical appointments.

Aims: To explore the hypotheses that drop-in group follow-up will result in 1) efficiency could be improved by seeing 6 to 14 patients at 1 appointment, 2) access to appointment times would increase and 3) patient satisfaction would be enhanced with 60 minutes of didactic contact and discussion with the urologist.

Participants: A heterogeneous sample of urological patients. Of the patients 287 were surveyed, including 177 at drop-in group medical appointments and 110 at solo appointments.

Outcomes: Patient satisfaction

Methods: Patients were invited to participate in a drop-in group medical appointment. Appointments were made based on sex and not on diagnosis, although the majority had prostate cancer. A 60-minute group teaching session was followed by a private 2 to 5-minute physical examination or further testing, as indicated. Confidential satisfaction surveys were administered to drop-in group medical appointment participants and patients seen at traditional individual appointments.

Results: Patient satisfaction with the drop-in group medical appointment format was as high as that of solo patients, with 87% of drop-in group medical appointment patients rating their experience as excellent or very good vs 88% by solo patients.

Conclusion: 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.

Strengths and Limitations: Randomisation was not employed and neither was blinding of researchers or participants. The questionnaire was not highly validated. Measuring satisfaction alone offers little practical utility.

Appendix 3: Data Extraction for Ongoing Studies/Initiatives

Breast Cancer

Criteria	Details
Study/Primary Investigator	Patient Education Programme plus Patient-Initiated Self-Referral to Nurse (Dr Jo Dent and Veronica Allinson of Calderdale and Huddersfield NHS Foundation Trust Hospital Trust).
Aims	The aims are to test the feasibility and acceptability of a model of follow-up based on an education programme followed by patient-initiated follow-up.
Design	<p>This is a single-centre open, pilot RCT. Eligible patients will attend a specifically designed Breast Cancer Care (BCC) course on <i>Living with Breast Cancer</i> comprising four half-day sessions running over four consecutive weeks. All patients who consent will attend the course and upon completion of the course, patients will be debriefed by the BCN before being randomised to either the trial arm (n = 40) where there is no routine follow-up or the standard arm (n = 40) where they will undergo routine follow-up in out-patients. Random permuted variable blocks will be used to ensure treatment groups are well-balanced. Block sizes will not be revealed to investigators or other study staff. All patients in the trial arm are given contact details and helpline telephone numbers to allow open access back into the service if required.</p> <p>Patients in the trial group will be provided with written information concerning the issues covered in the course and details of how to get back into contact with breast surgical services (a telephone Helpline run by the BCN's) should they have any concerns about their breast cancer. If required, they will have direct access back into the breast surgical service without the need for a lengthy re-referral process, but they will not be followed up routinely in outpatient clinics.</p> <p>At the end of the study, patients will be offered the option of continuing with the study model or to transfer to follow-up in outpatients.</p>
Population	Newly diagnosed breast cancer patients, who have been treated with curative intent and are at low risk of recurrence.
Sample Size	80 breast cancer patients; 40 per arm.
Variables to be Assessed	The primary outcome is the assessment of feasibility, process and acceptability of introducing the new model, as assessed, in the main, by descriptive analysis (i.e. satisfaction with the model, attendance at the course, an evaluation of the financial costs). At 12 and 24 months a member of staff will undertake a telephone patient satisfaction interview. Secondary outcomes will be QoL, psychosocial and lifestyle issues, as measured with the EORTC QLQ-C30 plus breast module, HADS and Concerns Checklist. Outcomes will be measured at 0, 6, 12, 18 and 24 months. They will also be asked to keep patient diaries

	for the duration of the trial, entering any comments about their experiences and contacts that they make over the following two years.
Study Duration	Two years; last course of the pilot is in October 2009.
Site	Calderdale and Huddersfield NHS Foundation Trust.
Preliminary Data	Ongoing evaluations of the course content have been excellent; the patients have enjoyed the programme and the process of self-referral, despite initial reservations
Strengths and Limitations	Randomisation; Validated outcome measures; Small sample size.

Criteria	Details
Study/Primary Investigator	A proposed large-scale multicentre phase III prospective RCT of hospital-based specialist versus risk-adjusted breast cancer follow-up (Prof. Janet Dunn; Peter Donnelly, South Devon Healthcare NHS Foundation Trust).
Aims	The trial has been designed to determine whether innovative alternative follow-up methods without clinical examination are equivalent to traditional specialist hospital-based follow-up with clinical examination in terms of survivorship and patient perception of living with cancer.
Design	<p>A large-scale multicentre (n = 200) phase III prospective RCT. The alternative methods of follow-up to be tested include: radiographer-led follow-up; nurse-led telephone follow-up; and GP/patient-initiated follow-up. Newly diagnosed patients have been registered for the trial, as well as patients 'flagged' at follow-up clinics. Patients were risk stratified into groups at diagnosis: Low risk (NPI<3.4) - randomise 1-year post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by specialist hospital based consultant with clinical examination up to 5-years post-diagnosis; Moderate risk (NPI ≥3.4 and ≤5.4) - randomise 2-years post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by specialist hospital based consultant with clinical examination up to 5-years post-diagnosis; High risk (NPI >5.4) - randomise 3-years post-diagnosis to immediate discharge to alternative follow-up versus continuing to be followed up by specialist hospital based consultant with clinical examination up to 5-years post-diagnosis followed by an agreed care plan and follow-up contract. Patients completing their randomised follow-up phase within the hospital setting will be then offered discharge to the alternative follow-up protocol. All patients will be followed up by annual questionnaire and annual mammography up to 10 years post diagnosis. Patients will be flagged for long-term survival (i.e. up to 20 years) with the Office of National Statistics.</p> <p>Training packages for radiographer- led and patient- led follow-up are available as well as training for provision of a nurse-led telephone service.</p>
Population	iBreast is open to breast cancer patients with either invasive or non-invasive disease treated with curative intent that are dischargeable from consultant led follow up. The trial is risk-adjusted to include patients up to 3 years post-diagnosis, depending on their risk.
Sample Size	8,000 participants from 200 centres; 4,000 per arm.
Variables to be	Primary outcomes include disease-free survival, recurrence (time to

Assessed	recurrence and severity of recurrence), psychological assessments and QoL (EORTC QLC-C30 plus breast module, EUROQOL, HADS and GHQ-12), and health economics. Secondary outcomes include compliance with guidelines (e.g. bone health, adjuvant hormone blocking therapy and breast imaging), number of referrals back into the hospital system, satisfaction with follow-up strategies, acquisition of outcome data, molecular pathology of breast cancer and molecular biomarkers (ER, PgR, HER2, CK5/6, EGFr to select luminal A vs B, HER2 & Basal cancers), and long-term survival.
Study Duration	The study will start in December 2009 and the first 6 months will also involve setting up the trial at each centre (n = 200 centres). The recruitment phase will be 3 years with an additional 5 year follow-up
Strengths and Limitations	<p>The project has been through an intensive design phase, with engagement of breast and primary care research communities and evaluation of alternative methods of follow- up.</p> <p>This is a large-scale RCT necessary to produce more credible evidence than is currently available, on whether clinical examination is needed in breast cancer follow-up.</p>

Colorectal Cancer

Criteria	Details
Study/Primary Investigator	A study to assess the frequency of surveillance tests after curative resection in patients with stage I and II colorectal cancer; ClinicalTrials.gov identifier: NCT00225641 (Peer Wille-Jørgensen, MD, Dr. Med. Sci., Associate Professor Chair of the COLOFOL Steering Group).
Aims	The aims are to evaluate two different time schedules for a follow-up programme in patients with colorectal cancer.
Design	An international multicentre RCT. 576 patients have been randomised to one of two models of follow-up: 1) CT-scan of liver and lungs (or CT of liver + plain X-ray of lungs) + CEA after 6, 12, 18, 24, and 36 months, or 2) CT-scan of liver and lungs (or CT of liver + plain X-ray of lungs) + CEA after 12 and 36 months. If recurrence is detected, the patient will be offered the best available treatment either as repeated surgery with curative intent or palliative treatment. Data will be collected electronically via the internet to an already constructed database.
Population	Patients operated, with curative intent, for stage I and II colorectal cancer.
Sample Size	2,500; 576 recruited at present.
Variables to be Assessed	The primary outcomes are overall survival and disease-free survival, and secondary outcomes are QoL and cost-effectiveness.
Study Duration	Launched in 2002, with the first patient being recruited in 2005, it is anticipated that recruitment of patients will take 2 years.
Site	Eighteen surgical departments in Denmark, Sweden, Poland, Uruguay, and Ireland.
Preliminary Data	Eight of the participating departments have been able to report on recruitment. In total 1309 patients were operated on for colorectal cancer in the eight departments in the period since the beginning of the study up to 1 September 2007. Of these 241 patients were randomised, which is only 18.4% of the total population. Reasons for not being randomised included not meet the inclusion criteria, having previous or other malignancies, being involved in other trials, or refusing randomisation. Only 32 patients who comprise 6.4% of eligible patients directly refused randomisation.
Strengths and Limitations	This is a large-scale RCT, with a rigorous design and a combination of both clinical and patient-reported outcomes.

Criteria	Details
Study/Primary Investigator	PET Interest in the Follow Up of Colorectal Cancer Stage II and III: Phase III Randomised Study; ClinicalTrials.gov identifier: NCT00199654 (Nicole Tubianna-Mathieu, University Hospital, Limoges).
Aims	The primary objective is to evaluate PET performance in the earlier detection of colorectal cancer relapse in comparison with conventional control (including CEA levels and other radiological exams).
Design	Diagnostic, randomised, open-label, uncontrolled, parallel trial comparing two arms of colorectal cancer patients: PET versus conventional controls.
Population	Stage II and III colorectal cancer patients.
Sample Size	376; 188 per arm
Variables to be Assessed	The primary outcome is time to colorectal cancer relapse and the secondary outcome measures include evaluation of overall survival in the two groups, evaluation of the rate of curative surgery, and comparison of the medical cost in the two detection strategies.
Study Duration	3-years, but has over-run; started in February 2004 – recruitment anticipated to be complete by March 2010.
Strengths and Limitations	This study is uncontrolled and appears to have confronted a number of delays.

Criteria	Details
Study/Primary Investigator	A randomised controlled trial to assess the cost-effectiveness of intensive versus no scheduled follow-up in patients who have undergone resection for colorectal cancer with curative intent - main trial; NCT00560365, http://clinicaltrials.gov/ct2/show/NCT00560365 . (John Primrose, Southampton General Hospital).
Aims	To examine 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 colorectal cancer patients treated surgically with curative intent.
Design	An RCT whereby all patients who have undergone curative treatment for primary colorectal cancer (R0 resections, Dukes A-C are being randomised to one of four arms: 1) symptomatic follow-up in primary care; 2) a single CT at 12-18 months plus CEA in primary care, 3-monthly for two years and 6-monthly for another three years; 3) hospital based imaging with CT 6-monthly for two years and annually for another three years; and 4) a combination of 2 and 3. All groups are given a patient handbook detailing symptoms suggestive of recurrence, as well as a colonoscopy at trial end (5-years) and ongoing contact with the CNS. Groups 3 and 4 receive an additional colonoscopy at year two.
Population	All patients who have undergone curative treatment for primary colorectal cancer (Stage I, II, III).
Sample Size	Unknown.
Variables to be Assessed	The primary outcome is number of recurrences treated surgically with curative intent by intention-to-treat analysis. The secondary outcomes are overall survival, QoL, cost of NHS services utilised, and NHS cost per life-year saved.
Study Duration	A pilot study was completed between 2002 and 2004, with the main trial being planned as 4.5 years recruitment and a median of 5-years follow-up. December 2013 is the anticipated final data collection date for primary outcome measure.
Preliminary Data	Recruitment has been completed, but no results can be obtained until the 5-year follow-up period. Baseline data is to be published soon, which will show that if a patient is well staged at the outset then the relapse rate is actually quite low.

	<p>The low relapse rate in this group means that follow-up cannot be too intensive otherwise it cannot be cost effective. Correspondence with the primary investigator reveals the anticipated conclusion to be that single CT at 12-18 months in primary care, 3-monthly for two years and 6-monthly for another three years (arm 2) is a sufficient model of follow-up for colorectal cancer survivors.</p>
<p>Strengths and Limitations</p>	<p>An RCT with both clinical and patient outcomes. Rigorous design and will fill gap in knowledge.</p>

Lung Cancer

Criteria	Details
Study/Primary Investigator	Follow-up of Patients with Curative-Intent Surgical Resection for NSCLC: CT Scanning Versus 18 FDG Imaging; ClinicalTrials.gov identifier: NCT00199615 (Boris Melloni, University Hospital, Limoges).
Aims	The aim of this study was to compare follow-up by conventional methods versus PET.
Design	Diagnostic, randomised, open-label, uncontrolled, parallel trial where patients are randomly assigned to two arms. In the first arm, thorax CT with liver and adrenal gland sections, abdominal ultrasonography and nuclear bone scintigraphy were performed every 6-months after surgery for two years. In the second arm, only PET scanning was received. For brain metastasis detection, CT was performed in the two arms. Recurrences were detected during scheduled or unscheduled procedure in asymptomatic patients. PET and CT were interpreted separately by two nuclear physicians and two radiologists.
Population	All patients who underwent resection for NSCLC.
Sample Size	120; 60 per arm.
Variables to be Assessed	The primary outcomes were disease-free survival from the date of operation to the date of recurrence or censored at the date of last follow-up visit or date of the death. Secondary outcomes were overall survival from the date of the operation to the death, specificity, sensibility and accuracy of PET to detect recurrence, and direct cost of follow-up.
Study Duration	5-years.
Preliminary Data	This study demonstrated that intensive follow-up after curative-intent surgery for NSCL cancer is an accurate technique for detecting recurrent disease, but that PET imaging compared to CT imaging follow-up did not change overall survival in this population. The data is currently in press, as confirmed by the primary investigator.
Strengths and Limitations	This study is randomized, but uncontrolled. It also has a relatively small sample size.

Prostate Cancer

Criteria	Details
Study/Primary Investigator	Patient online self-reporting of toxicity symptoms (Ethan Basch, Memorial Sloan-Kettering Cancer Centre, USA).
Aims	The aim of this study is to develop and assess the feasibility of introducing online symptom monitoring into cancer follow-up.
Design	<p>A Symptom Tracking and Reporting for Patients (STAR) program to facilitate follow-up consultations. 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, which is 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 follow-up consultations or to confirm that a consultation is not required.</p> <p>The next generation of these patient adverse symptom items for the U.S. National Cancer Institute, which are currently called PRO-CTCAE items but will ultimately be called PROTECT items, are underway. These items cover 77 different symptoms with about 122 different items. They were developed in the context of measuring acute toxicities of cancer treatments, but with an eye towards monitoring symptoms during survivorship. The items are still undergoing validation and are being tested by a taskforce who are creating a web-based open-source technology platform for administration of these items.</p>
Population	Prostate cancer patients.
Sample Size	Unknown.
Variables to be Assessed	Acceptability and feasibility.
Study Duration	Unknown.
Preliminary Data	Improvements in attrition are anticipated with the integration of prompts to complete the online questionnaires.

Strengths and Limitations	There is a large task force of experts working towards developing an online symptom monitoring device, which is consistent with current government objectives in terms of introducing electronic PROMs into healthcare.
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Criteria	Details
Study/Primary Investigator	PSA Tracker in prostate cancer follow-up (Mr Jonathan McFarlane, Consultant Urologist Royal United Hospital Bath).
Aims	The aim of this study is to free Consultant time with the use of symptomatic software that can assist CNS' with follow-up.
Design	Instead of seeing a Consultant for every follow-up, routine follow-up is overseen by a CNS, as assisted by a new piece of software called 'PSA Tracker.' Patients receive a postal questionnaire asking them about their general state of health, whilst bloods for PSA testing are taken in primary care. The PSA levels and treatment history are captured on the computer software, 'PSA Tracker,' which automatically triggers routine postal follow-up or recall to an outpatient clinic, based on clinically established algorithms for PSA.
Population	Prostate cancer patients with slow-growing tumours.
Sample Size	Unknown.
Variables to be Assessed	The primary outcomes being assessed are healthcare utilisation, and cost-effectiveness.
Study Duration	Unknown.
Preliminary Data	Findings so far suggest that the new care pathway is suitable for the majority of patients with slow-growing tumours who are willing and able to complete the health questionnaire. As a result, there has been 100 Consultant slots saved per annum (estimated around 80% of eligible patients will take up the questionnaire service) and the cost of follow-up has reduced from £88,200pa to £30.063pa.
Strengths and Limitations	There is little information available on the design and methodology of this study. However, it does seem promising in terms of moving towards technology-based symptom reporting.

	Details
Study/Primary Investigator	A randomized trial of a patient-centred strategy to facilitate transition of breast cancer survivors' routine follow-up from specialist to primary care (Eva Grunfeld, Dalhousie University and Nova Scotia Cancer Centre).
Aims	The primary objective of the study is to evaluate a survivorship care plan intervention with the breast cancer survivorship population throughout nine specialist cancer care centers in Canada.
Design	<p>A pragmatic multi-centre RCT of a patient-centered strategy to facilitate transition of breast cancer survivors' routine follow-up from specialist to primary care. Patients (n = 400) will be randomised to receive usual care or to receive the care plan intervention. They will also be stratified into 2 groups: 1) diagnosed <24 months previously and 2) diagnosed ≥24 months previously. Patients will be followed for 24-months, with outcome measures being completed at baseline, 3, 6, 12, 18, and 24 months.</p> <p>The care plan comprises a binder of documents important to a patient's follow-up care, and is delivered through an educational session with a study nurse before the patient is discharged to their family physician. The documents within the care plan binder include: a personalised record of care (diagnosis, tumour characteristics, treatment received, plan for initiating aromatase inhibitor, oncologist's recommendations, etc.); a survivorship care plan (summary of "what to expect," i.e. frequency and type of visits as well as important contact information for patient); a patient version of the Canadian Medical Association Journal (CMAJ) guidelines for the care and treatment of women with breast cancer ("Questions and answers on follow-up after breast cancer"); and a follow-up care reminder table. The study nurse will add additional documents that are locally available based on the meeting with the patient and an assessment of their particular needs (i.e. information about menopause, physical activity, nutrition, etc.). Family physicians of the patients in the intervention arm also receive a copy of the patient's care plan, a user-friendly version of the CMAJ guidelines, the full CMAJ guidelines, and a reminder table to keep track of their patient's visits and tests.</p>
Population	Breast cancer patients identified by their oncologist as medically ready for transition from specialist care to primary care for routine follow-up will be included in the trial.
Sample Size	400
Variables to be Assessed	The primary outcome will be the specific health-related QoL domain of adjustment to breast cancer at 12-months, as measured by the Impact of Events Scale, Profile of Mood States, and SF-36. Secondary outcomes will be adjustment at 24-months, patient satisfaction (Medical Outcomes Study-Patient Satisfaction Questionnaire), and

	health service outcomes (e.g. adherence, visits with multiple practitioners, coordination of care, and awareness of which physician is responsible for various aspects of care). An economic evaluation will be conducted alongside the clinical trial, using the SF-6D and assessing the costs of travel, follow-up visits and tests.
Study Duration	The study has reached its target accrual goal and final analysis is expected to begin in 2011. It is anticipated that preliminary analysis might be completed during the Spring of 2010.
Strengths and Limitations	This large-scale study incorporates a variety of follow-up methods, including care plans, nurse-led education, and physician-led follow-up, in an attempt to provide breast cancer survivors with tools that will ease transition to primary care. Such trials, which measure long-term outcomes, are needed within the field of cancer follow-up.

Criteria	Details
Study/Primary Investigator	Nurse-led follow-up using the PSA Tracker and a patient information prescription (Vernon Hopcroft, Worcester Royal Hospital).
Aims	The aim of this study is to become more patient-centred and to reduce workload.
Design	A pilot study is currently being planned at Worcestershire Royal Hospital to integrate the PSA Tracker, demonstrated to be successful in Bath, into the follow-up of prostate cancer patients who have had curative treatment. The proposal is for the pathway to be run by a urology nurse specialist who will measure PSA levels; a trigger will be activated if recurrence is found and the patient would then be recalled. An annual conference would be held once a year with suggested topics for speakers: diet, complementary therapies, psychosexual problems, benefits, new treatments. A patient information prescription is also proposed to be included in this model of follow-up, the aim being to reduce CNS workload via electronically prescribing information
Population	Prostate cancer patients who have been treated with curative intent.
Sample Size	Unknown.
Variables to be Assessed	Unknown.
Study Duration	Unknown.
Strengths and Limitations	There is little information available on the design and methodology of this study. However, collaboration with Bath will provide further evidence of the utility of the PSA Tracker in prostate cancer follow-up.

Criteria	Details
Study/Primary Investigator	The Prostate Cancer Long-Term Follow-Up Programme; http://clinicaltrials.coh.org/specific_result.aspx?pers=177298 . (Wendy, Landier, City of Hope, Comprehensive Cancer Center in California, US).
Aims	The goal of the programme is to help each survivor stay as healthy as possible, and to prevent problems from happening or catch them early, when they are most easily treated.
Design	<p>Patients who participate in this program are seen every 6 to 12 months in a clinic specially designed to meet the follow-up needs of prostate cancer survivors. Care is provided by a healthcare provider with expertise in prostate cancer care and survivorship issues. Patients in this program receive careful monitoring for possible recurrence of their cancer and have the opportunity to discuss their cancer treatment, its impact on their health, and ways to stay as healthy as possible. Each patient receives a Survivorship Care Plan, which is a personalised record of the details of their cancer treatment, with guidelines for continued monitoring, including recommendations for preventive care and information regarding available resources and services.</p> <p>Patients enrolled on the programme will be seen in a long-term follow-up clinic every 6-months for the first five years after diagnosis, and then yearly thereafter. The clinic is provided by a healthcare professional with expertise in prostate cancer care and survivorship issues, who works in collaboration with the patients' primary treatment team. During each visit, medical history and any symptoms will be reviewed and a physical examination provided, including a PSA blood test. Digital rectal examinations will be done yearly. Additional testing or referrals may be recommended, if needed, based on the results of health history and physical examination. Patients will then be given the opportunity to discuss their diagnosis, treatment history, and ways to stay as healthy as possible, before being given their "Survivorship Care Plan," which includes a written record of the patients' treatment and follow-up recommendations based on treatment history and specific circumstances. If needed, patients will also receive additional information about any treatment-related health problems they might be experiencing, along with recommendations for management of these problems. A summary of each long-term follow-up visit will be sent to the patients' primary healthcare provider and primary treatment team. In addition, referrals are available to a social worker, dietician, psychologist, or physical therapist if appropriate.</p>
Population	Prostate cancer patients who have completed surgical treatment for localised prostate cancer at least one year from diagnosis, and who present with no current evidence of prostate cancer and no history of recurrence, progression, or metastasis.

Sample Size	Unknown.
Variables to be Assessed	Unknown
Study Duration	Ongoing – long-term.
Strengths and Limitations	This is a novel follow-up programme, merging the follow-up pathway with research, thus benefiting the patient whilst expanding knowledge in this area.

Appendix 4i

Group Follow-Up

This review demonstrates internet adjunct and group-oriented models as being educationally focused precursors to patient-initiated follow-up. Indeed, in terms of self-management, evidence suggests that the more economic option is group follow-up, as is being initiated via the NCSI Big Clinic Visit (BCV) and as has proved feasible with breast cancer patients who have completed primary therapy (Ruud et al., 2007) and prostate cancer survivors presenting with post-treatment urological symptoms (Fletcher et al., 2006). Group follow-up has also proved successful with other chronic conditions (Vieira et al., 2007; Escobar, 2001) and researchers examining group follow-up for diabetes have concluded it to be a promising approach to chronic care management for motivated patients (Jaber, Braksmajer, and Trilling, 2006; Trento et al., 2004).

As an example of group follow-up in chronic illness, the Diabetes Cooperative Care Clinic (DCCC) is a 'cluster visit model' of care management. A RCT among patients with diabetes of Kaiser Permanente's Pleasanton center, CA, who had either poor glycemic control or no test performed during the previous year compared usual care with a GP to multidisciplinary outpatient diabetes care management delivered by a diabetes nurse educator, a psychologist, a nutritionist, and a pharmacist in groups of 10–18 patients for 6-months. After the intervention, HbA1c levels (i.e. the average blood glucose level over the past month) declined significantly more in the intervention group versus the control group. Several self-care practices and several measures of self-efficacy improved significantly in the intervention group. Satisfaction with the program was high, and both hospital and outpatient utilisation were significantly lower for intervention subjects (Sadur et al., 1999).

A similar approach has been adopted by the Florida Diabetes Master Clinician Program, where the benefits of group follow-up have been reported to include: the curriculum for a group visit is driven by the patient's questions and concerns; increased trust in their physician; setting attainable goals; and increased confidence in ability to self-manage (Shahady 2006). Models such as these, which increase patient input and decrease healthcare service utilisation, are recommended for low to moderate risk patients in particular, with more intensive, clinical, hospital-based models being available for patients being stratified as high risk.

There are three well-known group visit models in the US, designed to provide one-to-one medical consultations on an 'as needed' basis to all patients:

1. The Drop-In Group Medical Appointment (DIGMA) model (Noffsinger, 1999; 2008)
2. The Cooperative Health Care Clinics (CHCC) model
3. The Physicals Shared Medical Appointment (Physicals SMA) model

The DIGMA model is cited as being especially well suited for routine follow-up care in people with chronic conditions. The CHCC model was designed specifically for elderly patients. The Physicals SMA consists of a series of privately conducted examinations run

concurrently with group interaction among rotating groups of patients, followed by a small DIGMA with all patients in attendance.

The DIGMA model, which is the most appropriate for cancer follow-up, works on the basis that the physician invites patients to the follow-up session, doing so in a positive manner that emits a belief in the programme. The DIGMAs are facilitated by the healthcare provider (i.e. physician, nurse), a behaviourist (i.e. psychologist), and a nurse or medical assistant to take vital signs and assess health status. The appointments can be homogenous (i.e. only open to people with the same condition), heterogeneous (i.e. open to all patients within the practice), or mixed (i.e. a different topic each week).

DIGMAs are designed for 12 to 16 patients seen over a 90-minute period. Patients register in the physician's office, where they are provided with a 'patient package' and are asked to sign a confidentiality agreement. Before the group begins, a nurse starts seeing patients one at a time to take vitals, immunise, and carry out other nursing functions. The nurse continues to see the patients once the group starts, until they are all seen. Before the group begins, the behaviourist writes down on flip chart paper next to the patient's name, the one or two concerns they would like the doctor to address. The flip chart with the patients' concerns is posted on the wall opposite the doctor. The doctor uses the information on the flip chart as a cue to a patient's presenting problem. The behaviourist facilitates group discussion when the physician is working with patients.

There are several potential benefits of DIGMAs, including improved access; increased patient satisfaction; increased professional satisfaction; efficiency in meeting clinical guidelines; greater attention to psychosocial issues; and the provision of support from other patients. Limitations include the fact that patients who need detailed examinations are better seen individually and that 10 to 20% of patients who have experienced group follow-up prefer individual consultations.

In the four pilot studies of DIGMA, the uptake was 81% of all patients who pre-registered. During the 5.5 hours of physician time that the four pilot DIGMAs occupied each week, these same physicians would on average have only been able to see 16 patients during individual office visits compared to 42 patients seen during a comparable amount of time in the initial sessions of the pilot DIGMA program. For the four pilot physicians combined, this corresponds to an average increase in efficiency of 256% during the time spent running the DIGMAs. Both patients and physicians were highly satisfied with the sessions (Noffsinger and Atkins, 2001).

However, despite the vast benefits offered by group follow-up, as demonstrated via many of the pilot studies cited in this review, a process of risk stratification is required in order to ensure that patients at high risk continue to receive the care they need.

Appendix 4ii

Risk Stratification

The NCSI has, in fact, noted a desire for a system of prioritisation (i.e. risk stratification), where patients who are most at risk are given more support but that everyone is supported to the level that they need (Hindle, 2009). Reassuringly, the issue of risk stratification was a primary trend identified from this review of evidence pertaining to current models of follow-up. Risk stratification was primarily conducted on the basis of clinical factors, such as risk of recurrence, as assessed via clinical tools such as the Nottingham Prognostic Index (NPI; Galea et al., 1992) and the Preoperative Endocrine Prognostic Index (PEPI; Ellis et al., 2008). Uniquely, personality (i.e. non-disruptive, willingness to comply) has also been used to stratify patients to group follow-up (Molokhia, 2006).

The NPI has been utilised in a number of the evaluated studies as a form of risk stratification for follow-up decisions. The NPI is specific to breast cancer and consists of a formula that assesses the three factors known to give an indication of how successful treatment might be: the size of the cancer; whether or not the cancer has spread to the lymph nodes (otherwise known as lymph glands) under the arm (and if so, how many nodes are affected); and the grade of the cancer (this is based on the appearance of the tumour under the microscope and is an indication of how aggressive the cancer is). Applying the formula gives scores which fall into three bands: less than 3.4 suggests a good outcome with a high chance of a cure; between 3.4 to 5.4 suggests an intermediate level with a moderate chance of cure; and more than 5.4 suggests a worse outlook with a smaller chance of cure. The NPI was based on information from a group of patients treated some time ago and as a result of improvements in treatment it may underestimate prognosis. So, although the NPI is a useful guide it is not absolutely reliable and it is likely that many people's NPI predictions do not match the reality of their individual outcomes. The NPI, however, remains a useful guide for risk stratification when used alongside clinical expertise. Indeed, there is a wealth of evidence supporting the utility of the NPI in risk stratification (Blamey et al., 2007; Williams, 2006) and it has been recommended alongside patient-reported outcomes (Williams, 2006).

The PEPI, another tool specific to breast cancer, bases a patient's score on tumour size, node status, tumour cell proliferation marker levels, and estrogen receptor status (Ellis et al., 2008). In their study validating the PEPI score, women with a score of 0 had 3% relapse risk at three years whereas those with a score of 4 or more had 17% relapse risk. The authors suggest the model may be useful for making clinical decisions. Indeed, data from one of their studies demonstrates that relapse rates corresponded with PEPI risk scores (3% for low; 5% for intermediate; and 17% for high risk at 37 months). Together, a low pathological stage and a PEPI score of 0 were associated with 100% relapse-free survival at five-years. However, prospective validation studies in larger samples are needed to confirm the reliability of this risk stratification tool for clinical decisions.

On investigating other clinical risk stratification tools, the THEROS Breast Cancer Index was identified. This index refines and improves risk stratification in patients with estrogen receptor (ER)-positive, lymph node-negative breast cancer, providing independent and complementary prognostic information useful for treatment decisions. The index assesses

recurrent risk beyond current parameters such as age, size, grade, etc., stratifying the 'Intermediate Risk' group whilst identifying subgroups with 'Low Risk' and 'High Risk' features, and refining the Low Risk group by identifying subgroups with Intermediate and High Risk features. In a recent study, of 86% of patients identified by St. Gallen Risk Criteria (recommendations for the indication of post-operative adjuvant therapy for node-negative breast cancer; Goldhirsh et al., 1998) as intermediate risk, only 26.5% were actually intermediate risk according to the THEROS Index: 42.5% were low risk and 31% were high risk (bioTheranostics, 2008). Using only the St. Gallen Criteria, 42.5% in the intermediate group would potentially have been over-treated and 31% significantly under-treated, emphasising the need for multidimensional risk assessment, such as the integration of PROMs.

In prostate cancer, risk stratification is traditionally carried out via pre-operative PSA value, Gleason score, and clinical stage (Maffezzini, 2008). Patients with a PSA level of <10 ng/ml, a Gleason score of <6, and T1 or T2a (tumour stage) disease usually have low risk of prostate cancer recurrence. Patients with a PSA level of 10-20 ng/ml, a Gleason score of 7, and T2b disease are usually at intermediate risk. A PSA level of >20 ng/ml, a Gleason score of >8, and T2c disease defines high risk. Recurrence rates after local treatment for patients with low-risk disease are estimated at 6-20% compared with over 50% for individuals with high-risk cancer.

Risk stratification for colorectal and lung cancer are more complex, usually involving gene expressions. Nevertheless, regardless of cancer type, risk stratification clearly requires a holistic framework involving all dimensions of well-being (i.e. physical, psychological, social, and functional) (NCSI, 2008), particularly when considering governmental moves towards measuring the patient experience as an outcome (DH, 2009).

Appendix 4iii

Patient-Reported Outcome Measures (PROMs)

The feasibility of utilising PROMs for risk stratification in cancer follow-up is not new. The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983), an instrument for rating psychological morbidity, has been frequently used to assess cancer patients and is an internationally accepted tool for doing so (Montazeri et al., 2003; Nordin et al., 2001; Katz et al., 2004). The measure is highly acceptable to patients and providers (Herrmann, 1997), comprising 14-items (seven for anxiety and seven for depression) designed to assess affective states independent of physical symptoms. Each subscale is scored from 0 to 21: 0-7 indicates no clinical anxiety or depression, 8-10 indicates borderline clinical anxiety or depression, and 11-21 indicates clinical anxiety or depression

The Symptom Checklist (SCL-90-R) (Derogatis, 1994) has also been utilised in the psychological screening of cancer patients (Derogatis, 1994; Derogatis et al., 1983; Recklitis, O'Leary, and Diller, 2003). The instrument measures the severity of a broad range of psychological symptoms and can facilitate risk stratification and treatment/follow-up planning. By providing an index of symptom severity, the assessment helps facilitate treatment decisions and identify psychological morbidity before problems become acute. Results from one study demonstrate that routine psychological screening can be successfully integrated into cancer survivor clinics and might be effective in identifying those survivors with significant distress who require further evaluation (Recklitis, O'Leary, and Diller, 2003).

Current initiatives using PROMs to risk stratify survivors include the Symptom Tracking and Reporting for Patients (STAR) programme (Basch et al., 2005), which assesses symptoms via the National Cancer Institute Common Terminology Criteria for Adverse Events schema. There is also '*The Living Well After Cancer Program*' (LWAC), set up in 2001 at the LIVESTRONG™ Survivorship Center of Excellence, at the Abramson Cancer Center, US. This program includes the completion of a questionnaire (*OncoLink*) designed to monitor for recurrence as well as establishing an individual risk profile based on the potential effects that prior treatment may have on long-term health (Jacobs et al., 2002). In both initiatives, PROMs are utilised to inform personalised assessment and care planning.

Given the holistic approach being recommended for risk stratification in cancer follow-up, it could be argued that risk stratification requires the use of PROMs as well as clinical screeners such as the NPI, PSA tests, etc. Psychological risk is evidently being recognised via the use of instruments such as the HADS, but in order for social and functional indicators to also be incorporated in a feasible way, evidence within this review indicates that the measurement of symptom impact or generic and condition-specific QoL might prove effective. For example, Velikova et al. (2004) have been exploring the use of routine computerised patient-reported QoL data in guiding follow-up consultations using the EORTC QLQ-C30 (Aaronson et al., 1993). Such data can be used to risk stratify and produce appropriate and individualised care plan.

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