



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Follow-up of cancer in primary care versus secondary care: systematic review

Citation for published version:

Lewis, RA, Neal, RD, Williams, NH, France, B, Hendry, M, Russell, D, Hughes, DA, Russell, I, Stuart, NSA, Weller, D & Wilkinson, C 2009, 'Follow-up of cancer in primary care versus secondary care: systematic review' British Journal of General Practice, vol 59, no. 564, pp. 525-532. DOI: 10.3399/bjgp09X453567

Digital Object Identifier (DOI):

[10.3399/bjgp09X453567](https://doi.org/10.3399/bjgp09X453567)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

British Journal of General Practice

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Follow-up of cancer in primary care versus secondary care: systematic review

Ruth A Lewis, Richard D Neal, Nefyn H Williams, Barbara France, Maggie Hendry, Daphne Russell, Dyfrig A Hughes, Ian Russell, Nicholas SA Stuart, David Weller and Clare Wilkinson

ABSTRACT

Background

Cancer follow-up has traditionally been undertaken in secondary care, but there are increasing calls to deliver it in primary care.

Aim

To compare the effectiveness and cost-effectiveness of primary versus secondary care follow-up of cancer patients, determine the effectiveness of the integration of primary care in routine hospital follow-up, and evaluate the impact of patient-initiated follow-up on primary care.

Design of study

Systematic review.

Setting

Primary and secondary care settings.

Method

A search was carried out of 19 electronic databases, online trial registries, conference proceedings, and bibliographies of included studies. The review included comparative studies or economic evaluations of primary versus secondary care follow-up, hospital follow-up with formal primary care involvement versus conventional hospital follow-up, and hospital follow-up versus patient-initiated or minimal follow-up if the study reported the impact on primary care.

Results

There was no statistically significant difference for patient wellbeing, recurrence rate, survival, recurrence-related serious clinical events, diagnostic delay, or patient satisfaction. GP-led breast cancer follow-up was cheaper than hospital follow-up. Intensified primary health care resulted in increased home-care nurse contact, and improved discharge summary led to increased GP contact. Evaluation of patient-initiated or minimal follow-up found no statistically significant impact on the number of GP consultations or cancer-related referrals.

Conclusion

Weak evidence suggests that breast cancer follow-up in primary care is effective. Interventions improving communication between primary and secondary care could lead to greater GP involvement. Discontinuation of formal follow-up may not increase GP workload. However, the quality of the data in general was poor, and no firm conclusions can be reached.

Keywords

long-term care; neoplasms; outpatients; primary health care; systematic review.

INTRODUCTION

Following completion of treatment, most cancer patients are followed up regularly in hospital outpatient clinics. The perceived benefit of this is to facilitate diagnosis of recurrent disease, monitor the effectiveness and side-effects of treatment, manage comorbidity, and identify and treat psychosocial problems.¹⁻⁴ There is also evidence that patients value the psychological and social support that cancer follow-up provides,⁵⁻⁸ and find it reassuring.⁹⁻¹¹ Conversely, hospital follow-up might also prompt unnecessary tests, raise anxiety, provide false reassurance, and delay the patient's return to full function. For some cancer sites, such as breast and colorectal cancer, there is good evidence that routine follow-up does not provide survival benefit or lead to earlier diagnosis of recurrences, other than in terms of detecting locoregional recurrence or contralateral new primaries.¹²⁻¹⁶

RA Lewis, MSc, BSc, lecturer; **RD Neal**, PhD, FRCGP, senior clinical lecturer; **NH Williams**, PhD, FRCGP, senior clinical lecturer; **B France**, research assistant; **M Hendry**, BA Research fellow; **C Wilkinson**, MD, FRCGP, Department of Primary Care and Public Health, North Wales Clinical School, School of Medicine, Cardiff University, Wrexham. **D Russell**, PhD, senior research fellow/trial statistician, Institute for Medical and Social Care Research; **NSA Stuart**, DM, FRCP, North Wales Clinical School; **DA Hughes**, PhD reader, Centre for Economics and Policy in Health, Bangor University, Bangor, Bangor. **I Russell**, PhD, FRCGP, FRCP(Ed), professor, School of Medicine, Swansea University, Swansea. **D Weller**, PhD, MRCP, FRCP, professor, Department of General Practice, University of Edinburgh, Edinburgh.

Address for correspondence

Ruth Lewis, Cardiff University, Department of Primary Care and Public Health, School of Medicine, North Wales Clinical School, Gwenfro Building Unit 6/7, Wrexham Technology Park, Wrexham, LL13 7YP. E-mail: lewisr17@cf.ac.uk

Submitted: 3 November 2008; **Editor's response:** 6 January 2009; **final acceptance:** 6 February 2009.

©British Journal of General Practice

This is the full-length article of an abridged version published in print. Cite this article as: *Br J Gen Pract* 2009; DOI: 10.3399/bjgp09X453567.

Follow-up of cancer accounts for a substantial burden of outpatient activity. Financial and other drivers are putting downward pressure on 'routine' secondary care follow-up, and new models of care are developing, often through cancer collaboratives.¹⁷ In the UK, primary care, with its universal system of patient registration, generalist skills, and high satisfaction ratings, may be well placed to undertake some of this work. The UK general medical services contract encourages the review of cancer patients by including this within the Quality and Outcomes Framework. Some low-risk follow-up is already done in primary care, notably in prostate cancer, and more is advocated.¹⁸⁻²⁰ However, this seems to be happening without rigorous evaluation. There is some disagreement between specialists and GPs about where care should be delivered, and debate about patient preference.²¹

A systematic review was conducted to compare the effectiveness and cost-effectiveness of primary versus secondary care follow-up of cancer patients. The study also evaluated the impact on primary care of discontinuing formal follow-up or replacing it with patient-initiated follow-up, as well as interventions integrating primary and secondary care for cancer follow-up. Qualitative studies were also included, but their findings are reported separately.²² (The review also looked at nurse-led follow-up as indicated in Figure 1, the findings of which are reported elsewhere.²³)

METHOD

The following databases were searched (from inception to February 2007) using strategies designed specifically for each database: MEDLINE, MEDLINE in process, EMBASE, CINAHL, PsychINFO, AMED, BIOSIS, Index to Scientific and Technical proceedings, Science Citation Index, Social Science Citation Index, Cochrane Central Register of Controlled Trials, Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews, Health Technology Assessment database, NHS Economic Evaluation database, System for Information on Grey Literature, British Nursing Index, Health Management Information Consortium, National Research Register, and other trial registries ($n = 7$) available via the internet. No language restriction was used.

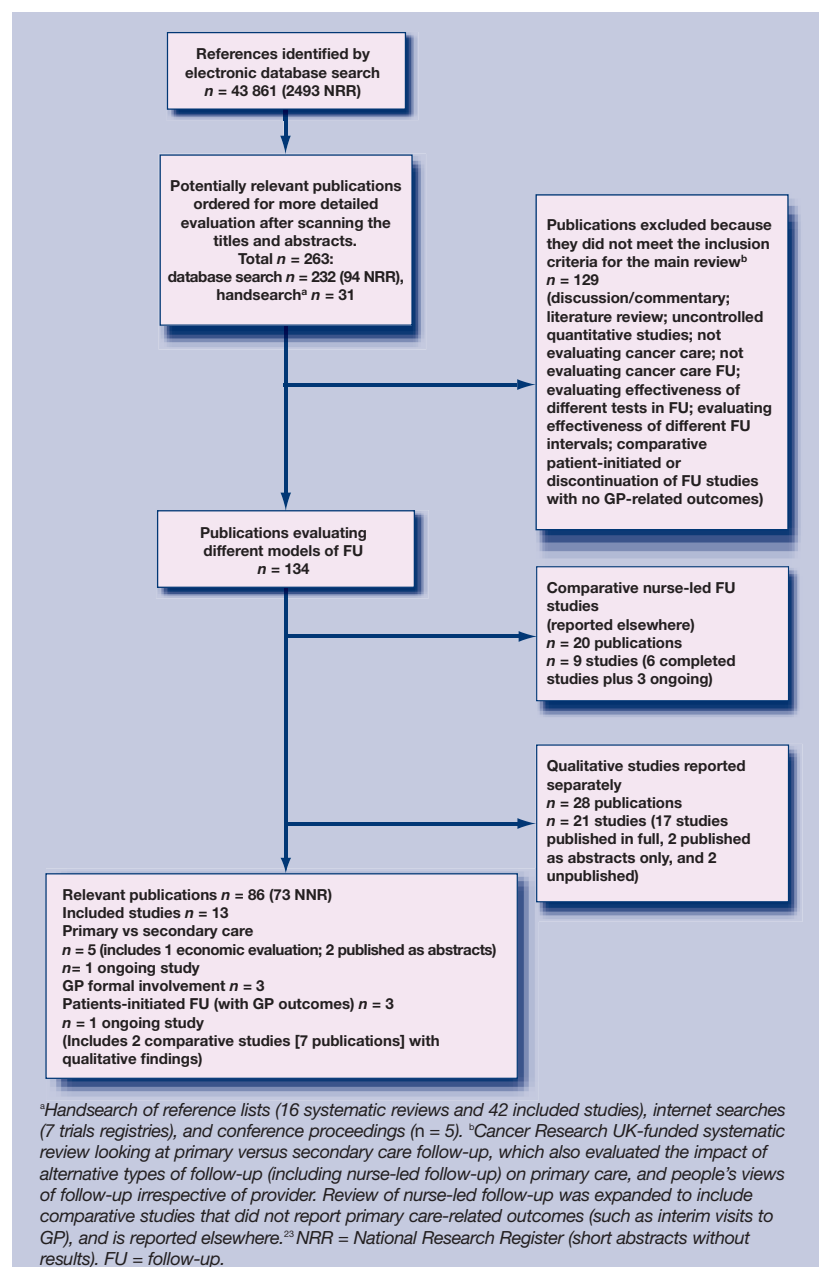
Each cancer site was searched separately, and full details of the search strategy are available on request and described elsewhere (R Lewis *et al*, unpublished data, 2007). (An example of the search strategy used for breast cancer is presented in Appendix 1.) Additional references were identified through reviewing the bibliographies of 16 retrieved systematic reviews and 42 included studies, and hand searching five conference proceedings.

How this fits in

Amid increasing debate, cancer follow-up is being shifted to primary care settings without rigorous evaluation. GP follow-up for breast cancer may be effective. A more formal involvement of primary care in routine hospital follow-up could lead to improved communication between primary and secondary care and more patients using GPs for support. Discontinuation of formal routine hospital follow-up does not appear to have an impact on primary care workload.

The search included any type of study or economic evaluation that compared cancer follow-up in primary care with that in a secondary setting. It also included studies that examined any type of intervention that involved formal primary care input in

Figure 1. Flow diagram showing the number of references identified, retrieved, and included in the review.



routine hospital follow-up. Any type of outcome measure was included. Studies that compared follow-up with no follow-up or patient-initiated follow-up were also considered, but only if they reported data on primary care-related outcomes. The population of interest included patients of any age who had received treatment for any type and stage of cancer. Only studies that examined the follow-up of patients who were free of active disease or no longer receiving treatment for the following purposes were included: to identify recurrent tumours of new primary disease; to provide support for complications or delayed side-effects of treatments; or to identify patients who may require additional help or treatments (for example, for functional or psychological problems). Studies that examined patients who were still receiving hospital-based treatment (for example, radiotherapy) or treatment after care, rehabilitation, or specialist palliative care were excluded. Patients in cancer follow-up but receiving long-term therapy, such as hormonal treatment for breast or prostate cancer, who did not require frequent or routine hospital visits and who were free of active disease were included.

Two reviewers independently assessed the results of each cancer site-specific literature search and the relevance of retrieved studies. Data were extracted by one reviewer, using a predefined form, and checked by a second independent reviewer. Quality assessments were conducted independently by two reviewers. Disagreements were resolved by discussion and, when necessary, a third reviewer was consulted.

The quality of effectiveness studies was assessed using the checklist developed by Downs and Black,²⁴ modified according to the suggestions made by Deeks *et al*,²⁵ and adapted for use on cancer follow-up studies. Economic evaluations were assessed using an updated version of the checklist developed by Drummond and Jefferson.²⁶

Due to variation in the way the outcome data were reported and analysed, a meta-analysis was not feasible, even for the same outcome measures within each follow-up group. A narrative synthesis was therefore conducted.

RESULTS

The electronic searches identified 43 861 references of which 232 papers were retrieved in full. Thirty-one additional studies were identified by hand searching (Figure 1).

Primary versus secondary care

Five studies compared primary versus secondary care follow-up,^{3,27-30} but two were only reported in abstract form (a non-randomised study of patients

who had undergone haematopoietic stem cell transplantation for malignant haematologic disorders²⁸ and a randomised controlled trial [RCT] of patients with cutaneous melanoma²⁹). The three published RCTs examined follow-up for breast cancer^{3,27} and colon cancer³⁰ (Table 1, part a). One of the breast cancer studies was a non-inferiority trial,²⁷ and the other incorporated a cost analysis.³ Two studies recruited patients who had recently completed primary treatment,^{27,30} and one study recruited women who were already receiving follow-up.³ The percentages of eligible participants who declined to be randomised to primary or secondary care follow-up were fairly high (33%,³ 40%,³⁰ and 55%²⁷), especially for studies that recruited patients who had just completed treatment.^{27,30} Only one study (breast cancer) incorporated a pre-trial education session of cancer follow-up for GPs, who were also given a handbook and discharge summary information.³ In the remaining two studies, GPs were provided with a brief summary of the current follow-up guidance.

The three RCTs that examine primary care versus secondary care follow-up^{3,2,30} were well conducted (Table 2, part a). All used an adequate randomisation method with allocation concealed from patients and clinicians. An attempt was made to blind those measuring the main outcomes in all three studies. The sample size was fairly small in two studies (range $n = 203^{30}$ to 296^3), and large in the non-inferiority trial ($n = 968$).³⁰ The length of follow-up ranged from 18 months³⁰ to a median of 3.5 years.²⁷

There were no statistically significant differences between the intervention groups in terms of patient wellbeing (psychological morbidity and quality of life), recurrence rate, or survival, but this may be due to lack of statistical power and the short duration of the studies (Table 3 and Table 4). The non-inferiority trial found no statistically significant difference between the groups for the main outcome of recurrence-related serious clinical events (defined as spinal cord compression, pathological fracture, hypercalcaemia, uncontrolled local recurrence, brachial plexopathy, or poor functional status at the time of diagnosis of recurrence), and was unable to demonstrate statistically significant non-inferiority.²⁷ Although the absolute difference between the intervention groups was small (1.9%), the observed lower band of the confidence interval (95% CI = -2.26 to 2.65) crossed the non-inferiority margin of 1.5%. The patient population included women with early-stage breast cancer (69% had stage I-II disease) for whom a serious clinical event is a rare outcome, and in whom the length of follow-up (median 3.5 or 4.5 years post diagnosis; 31% had five-year follow-up) may not have been sufficient to

Table 1. Characteristics of (a) primary versus secondary care follow-up studies and (b) GP involvement in conventional follow-up studies.

Study	Participants	Interventions	Length of follow-up	Outcomes
(a) Studies of GP follow-up				
Grunfeld <i>et al.</i> , 1996. ³ UK, RCT	296 women with stage I-III breast cancer in remission (completed treatment ≥ 3 months previously). Mean age 61 years. Mean time since diagnosis: 3.4 years	GP follow-up, $n = 148$ Conventional hospital follow-up, $n = 148$	18 months	Diagnostic delay; SF-36; HADS; EORTC; mean number of visits; mean length of each visit; mean total time for follow-up visits; tests ordered; costs
Grunfeld <i>et al.</i> , 2006. ²⁷ Canada Non-inferiority RCT	968 patients with early-stage breast cancer in remission. Mean age 61 years. Time since diagnosis: 9-15 months	GP follow-up, $n = 483$ Conventional hospital follow-up, $n = 485$	Median 3.5 years. Patients observed until 5 years after randomisation or until 30 June 2003, whichever came first; 32% observed for 5 years	Death (all causes); recurrence related serious adverse event; recurrence rate; SF-36, HADS
Wattchow <i>et al.</i> , 2006. ³⁰ Australia, RCT	203 patients with colon cancer (Dukes A, B, or C). 58% were male, 13% were under 60 years of age, and 19% over 80 years. Mean time since diagnosis was not stated; patients recruited and randomised after completing treatment	GP follow-up, $n = 97$ Conventional hospital follow-up, $n = 106$	24 months	Death rate (per 1000 months on trial); recurrence rate (per 1000 months on trial); time to detection of recurrence (median); SF-12; HADS; patient satisfaction; number of follow-up visits (mean); number and type of investigations (blood tests, FOB tests, colonoscopies, and radiological investigations)
(b) Studies examining formal involvement of GPs in conventional hospital follow-up				
Holteidahl <i>et al.</i> , 2005. ³¹ Norway, RCT	91 cancer patients diagnosed with primary ($n = 78$) or relapsing ($n = 13$) cancer; 77 treated with curative intent. Mean age 62 years; 44% male. Patients were invited to participate after completing therapy	Increased contact with the patients' GPs soon after cancer treatment (invitation to two consultations with their GP and advised to contact GP with any problems). Also received routine hospital follow-up, $n = 41$; conventional hospital follow-up, $n = 50$	6 months (from diagnosis)	EORTC QLQ C-23; GP consultation
Johansson <i>et al.</i> , 2001. ³² Sweden, RCT	527 newly diagnosed cancer patients. Included sites: breast, prostate, colorectal, and gastric. Only 510 followed-up; 16 discontinued before receiving information about randomisation and 1 died. For those who completed the trial ($n = 416$) the age was 63 years and 34% were male	Individual support starting at diagnosis: intensified primary healthcare (IPH), nutritional support, and psychological support. IPH extended information from specialist for GPs, and home-care nurses. Patients were referred by the project team to a home-care nurse and the GP informed of the referral, $n = 260$. Standard care, $n = 250$	Utilisation of specialist care: 3 months (from diagnosis). Frequency of contacts with home-care nurse: 6 months (from diagnosis; intervention, $n = 178$; control, $n = 178$). (Note: study published in multiple publications)	Number of patients who had contact with home-care nurse (at 6 months); hospital admissions (at 3 months); days in hospital (at 3 months); visits to outpatient (at 3 months); acute hospital admissions (at 3 months); acute outpatient visits (at 3 months); frequency of contact with home-care nurse (at 6 months)
Nielsen <i>et al.</i> , 2003. ³³ Denmark, RCT	248 newly diagnosed cancer patients; 183 had local/locoregional disease. Cancer site: breast, gastrointestinal, germinal cell, head and neck, bladder and kidney, ovarian and cervix, sarcoma, malignant melanoma, brain, lung, and miscellaneous. 32% were 18-49 years of age and 36% were male	Shared care programme: transfer of knowledge from the oncologist to the GP (discharge summary letters according to study guidelines), improved communication between parties (provision of name and contact details of hospital doctors and nurses), and active patient involvement (patients advised to visit GP with problems), $n = 127$. Conventional hospital care: no usual procedure of informing GPs of newly diagnosed patients, discharge summary letter (not following guidelines) sent at end of treatment period, $n = 121$	6 months	HRQL/performance status; contact with GP; information from GP; care from GP; GPs' knowledge; global assessment of the GP; intersectoral cooperation (primary sector and department of oncology); global assessment of intersectoral cooperation; feeling of not being left in limbo; global assessment of perception of 'not being left in limbo'

EORTC = European Organisation for Research and Treatment for Cancer. EORTC QLQ-C23 = EORTC Quality of Life Questionnaire Core 23. FOB = faecal occult blood tests. HADS = Hospital Anxiety and Depression Scale. HRQL = Health related quality of life. RCT = randomised controlled trial. SF-12 = Short Form 12-Item General Health Questionnaire. SF-36 = Short Form 36-Item General Health Questionnaire.

Table 2. Quality of included studies comparing primary- versus secondary-care follow-up.

	Part a			Part b		
	Grunfeld <i>et al</i> , 2006, ²⁷ breast cancer	Grunfeld <i>et al</i> , 1996, ³ breast cancer	Wattchow <i>et al</i> , 2006, ³⁰ colon cancer	Holtedah <i>et al</i> , 2005, ³¹ multiple site cancer	Johansson <i>et al</i> , 2001, ³² multiple site cancer	Nielsen <i>et al</i> , 2003, ³³ multiple site cancer
Downes and Black ²⁴ item score (maximum score)						
Reporting						
Is the aim of the study clearly described? (1)	1	1	1	1	1	1
Are the outcomes to be measured clearly described? (1)	1	1	1	1	1	1
Are the characteristics of participants clearly described? (1)	1	1	1	1	1	1
Are the interventions clearly described? (1)	1	1	1	1	1	1
Are the distributions of principal confounders in each group described? (2)	2	2	1	1	1	2
Are the main findings clearly described? (1)	0	1	1	0	1	1
Can the reader calculate estimates of variability in data for the main outcomes? (1)	1	1	1	1	0	0
Have all important adverse effects been reported? (1)	1	1	1	1	1	0
Have the characteristics of participants lost to follow-up been described? (1)	1	1	1	0	1	0
Have confidence intervals or exact significance levels been reported? (1)	1	1	1	0	0	1
External validity						
Were those who were asked to participate, representative of their population? (1)	1	1	1	0	0	1
Were those who agreed to participate representative of their population? (1)	0	1	0	0	0	1
Were the staff/setting/facilities representative of those the majority receive? (1)	1	1	1	1	1	1
Internal validity: bias						
Was there an attempt to blind those measuring the main outcomes? (1)	1	1	1	1	0	1
If any results were based on 'data dredging', was this made clear? (1)	0	1	1	0	0	0
Do analyses adjust for different lengths of follow-up? (1)	0	0	1	1	1	1
Was the length of follow-up adequate? (1)	1	1	1	0	1	1
Were the statistical tests used appropriate? (1)	1	1	1	1	1	0
Was non-compliance reported appropriately? (1)	1	1	1	1	1	1
Were the main outcome measures used valid and reliable? (1)	1	0	1	1	1	1
Internal validity: confounding (selection bias)						
Were control and intervention participants recruited from the same population? (1)	1	1	1	1	1	1
Were participants recruited over the same time period? (1)	1	1	1	1	1	1
Were study participants randomised to intervention groups? (2)	2	2	2	2	2	2
Was randomisation concealed from participants and staff until after recruitment? (1)	1	1	1	0	0	0
Was there adjustment for confounding in the analyses? (2)	1	0	1	0	1	0
Were losses to follow-up taken into account? (1)	1	1	1	0	0	1
Power						
Has an estimate of clinically important difference been specified? (2)	1	1	1	0	1	0
Is the sample size adequate? (3)	1	1	2	0	2	1
Total score (maximum 34)	26	27	29	17	22	22

Numbers in brackets indicate highest possible score.

measure the serious effects of recurrent disease. Although patients remained in the trial until death, assessment for serious clinical outcomes was only done until a recurrence was detected or the trial ended.

Only two studies examined patient satisfaction.^{3,30} One found that satisfaction with breast cancer follow-up was higher in the GP group (6 of 12 items) than the hospital group at 9 months (mid trial),³ but did not report satisfaction at 18-month follow-up (end of trial). The second study reported no statistically significant difference between the groups at 2 years for colon cancer follow-up.³⁰ Two studies also evaluated resource use.^{3,30} Hospital doctors and GPs were found to differ in the type and number of diagnostic tests ordered,^{3,30} as well as the length and

frequency of visits.³ A comprehensive cost analysis (cost year 1994) found that breast cancer follow-up by the GP was less costly than routine hospital follow-up, by a mean of £130 per patient (95% CI = £112 to £149). This was due to a difference in physician cost and not because of the variation in diagnostic tests ordered.³

Formal involvement of GP in cancer care follow-up versus conventional care

Three RCTs examined formal involvement of primary care in routine hospital follow-up.³¹⁻³³ No economic evaluations were identified. All three studies included patients with cancer originating from multiple sites (Table 1, part b). The study by Holtedah *et al* examined an intervention that involved patients being

Table 3. Results of survival and recurrence.

Study details	Survival	Recurrence
Grunfeld <i>et al</i> , 1996. ³ Cancer site: breast. Length of follow-up: 18 months. Sample size: $n = 296$; GP $n = 148$, hospital $n = 148$	Not reported	Diagnostic delay: GP $n = 22$ versus hospital $n = 21$; mean difference 1.5 (95% CI = -13 to 22). Assessed at a single date: recurrence rate GP $n = 10$ (6.8%) versus hospital $n = 16$ (10.8%). No comprehensive review at end of trial to identify missed recurrences
Grunfeld <i>et al</i> , 2006 ²⁷ Cancer site: breast. Length of follow-up: median 3.5 years. Sample size: $n = 968$; GP $n = 483$, hospital $n = 485$	Deaths (all cause): GP 29 (6.0%), versus hospital 30 (6.2%); difference: 0.18% (95% CI = -2.90 to 3.26)	Recurrence-related serious clinical events: GP $n = 17$ (3.5%) versus hospital $n = 18$ (3.7%); difference: 0.19% (95% CI = -2.26 to 2.65). Recurrence or new contralateral breast cancers: GP $n = 54$ (11.2%) versus hospital $n = 64$ (13.2%); difference: 2.02% (95% CI = -2.13 to 6.16). Comprehensive review at end of trial found no missed recurrence
Wattchow <i>et al</i> , 2006 ³⁰ Cancer site: colon. Length of follow-up: 24 months. Sample size: $n = 203$; GP $n = 97$, hospital $n = 106$	Death rates (per 1000 months on trial): GP $n = 6.6$ versus hospital $n = 5.4$; $P = 0.67$, Fisher's exact test. Median survival (months): GP 31 versus hospital 20; $P = 0.69$, log rank test	Recurrence rate (per 1000 months on trial): GP $n = 7.1$ versus hospital 8.0; $P = 0.92$, Fisher's exact test. Median time to detection (months): GP $n = 9.5$ versus hospital 8.0; $P = 0.76$, log rank test. Recurrence rate obtained from state-based cancer registries

invited to attend two 30-minute consultations with their GP: one soon after completing treatment and the other 6 months later.³¹ During the consultation, patients were asked about their wellbeing and their experience of having cancer (open-ended questions provided by researchers). Patients were also advised to contact their GP if they had any cancer-related queries or problems. In addition, patients received routine hospital follow-up; the control group received routine hospital follow-up only.

The study by Johansson *et al* examined an intervention that was part of the Support-Care-Rehabilitation project, which involved individual patient support in terms of intensified primary health care, nutritional support, and psychological support.³² The intervention was implemented as soon as possible after randomisation, and patients were referred to a home-care nurse, who contacted the patient and suggested follow-up contacts during the period of primary treatment and rehabilitation or palliative care. GPs of these patients were informed of the cancer diagnosis and the referral to the home-care nurse. Intensified primary health care involved extended information from the specialist clinics (GPs and home-care nurses received copies of the medical records each time the patient was discharged from hospital after a period of inpatient care or attended outpatient clinic); education (in diagnostics and treatments of cancer, pain and diet management, psychosocial support, and palliative care); and supervision in cancer care for GPs and home-care nurses. The control included standard care, which routinely did not include follow-up contacts made by home-care nurses.

Nielsen *et al* examined an intervention which involved the use of discharge letters that followed

predefined guidelines, which were developed for the study.³³ These included details of the investigations, treatment, and information the patient had received; described in detail which physical, psychological, and social problems the patient had or might expect to get; contained information about what the oncologist expected the GP to do; and provided information about the patient's type of cancer, treatment plans, and prognosis as well as information about treatment of common side effects and pain. The names and phone numbers of the hospital doctors and nurses who were responsible for the patient were also attached to the discharge letters. Patients received both oral and written information about the information package given to their GPs, and were advised to contact their GP if they had any problems they thought could be solved in this setting. The control group received routine hospital care, where the GP was rarely informed of the patient's cancer diagnosis, and summary discharge letters did not follow any guidelines.

The interventions were complex and, in two studies, involved educating GPs^{32,33} and/or home-care nurses³² about cancer. The unit of randomisation was the patient in both of these studies, although a type of cluster randomisation was used in one.³³ In one study, once a patient from a practice was randomised, all subsequent patients from the same practice were automatically assigned to the same group.³³ In the second study patients in the control group could have a GP (or home-care nurse) who had received the educational component of the intervention, or a GP who had not, but this was not taken into account in the analysis.³² Two studies included newly diagnosed patients and the intervention was initiated prior to the follow-up

Table 4. Results of psychological morbidity, quality of life, and patient satisfaction.

Study	Psychological morbidity	Quality of life	Patient satisfaction
Grunfeld <i>et al</i> , 1996. ³ Cancer site: breast. Length of follow-up: median 18 months. Sample size: <i>n</i> = 296; GP <i>n</i> = 148, H <i>n</i> = 148. Questionnaire response rates after denominators adjusted for those who died or gone away (<i>n</i> = 2): GP 137/141 (97%), H 119/135 (88%)	Mean change from baseline for HADS score; difference in means (95% CI): Anxiety GP 0.3 vs H 0.1; 0.4 (0.3 to 1.2) Depression GP 0.6 vs H 0.2; 0.4 (0.2 to 1.1)	Mean change from baseline for SF-36 score; difference in mean change from baseline (95% CI): Physical functioning GP -1.6 vs H -4.7; 3.1 (-1.1 to 7.5) Pain GP -0.6 vs H -4.4; 3.8 (-1.5 to 9.2) Social GP -4.8 vs H -3.0; -1.8 (-7.2 to 3.5) Role functioning GP 5.2 vs H 1.0; 4.1 (-5.6 to 13.9) — physical Role functioning GP 1.9 vs H 0.1; 1.8 (-7.3 to 10.8) — emotional General health perception GP -2.0 vs H -2.6; 0.6 (-3.6 to 4.8) Mental health GP -1.6 vs H -2.1; 0.5 (-4.1 to 5.1) Vitality GP 1.3 vs H -2.5; 3.8 (-0.7 to 8.3) Mean change from baseline for EORTC symptom scale score; difference in mean change from baseline (95% CI): Fatigue GP 1.5 vs H 3.7; -2.2 (-6.5 to 2.2) Pain GP 0.1 vs H 2.7; -2.6 (-8.0 to 2.8) Dyspnoea GP 3.0 vs H 7.6; -4.6 (-9.8 to 0.6) Sleep disturbances GP -1.7 vs H 2.0; -3.7 (-10.4 to 2.9) Appetite loss GP 1.4 vs H 4.1; -2.7 (-7.4 to 2.3)	Number of patients who 'agreed' or 'sometimes agreed' vs 'can't say' 'disagree' and the difference between groups (95% CI): Service delivery if urgent you can see Dr GP 116/138 vs H 61/120; 33.2 (22.4 to 44.1) Usually seen by Dr GP 134/138 vs H 111/122; 6.1 (0.3 to 11.9) Not enough time to discuss problems with Dr GP 38/136 vs H 56/119; -19.1 (-30.8 to -7.4) The consultation Get good advice on how to keep healthy GP 112/138 vs H 77/121; 17.5 (6.8 to 28.3) Sometimes difficult to discuss concerns with the Dr GP 39/136 vs H 48/121; -11.0 (-22.6 to 0.57) Dr explains clearly what is wrong GP 126/138 vs H 103/120; 5.5 (-2.3 to 13.3) Dr examines you thoroughly when necessary GP 136/138 vs H 119/121; 0.2 (-2.8 to 3.2) Sometimes think Dr should listen more to what you say GP 38/136 vs H 52/119; -17.2 (-28.8 to -5.6) Dr should tell you more about problem and treatment GP 63/135 vs H 76/119; -17.2 (-29.3 to -5.1) Dr encourages you to talk about problem and treatment GP 126/137 vs H 91/120; 16.1 (7.2 to 25.0) See a Dr that knows you well GP 124/138 vs H 65/121; 36.1 (25.9 to 46.3) Have to wait too long for an appointment with Dr you want GP 54/136 vs H 31/118; 13.41 (2.0 to 24.9)
Grunfeld <i>et al</i> , 2006. ²⁷ Cancer site: breast. Length of follow-up: median 3.5 years. Sample size: <i>n</i> = 968; GP <i>n</i> = 483, H <i>n</i> = 485. Questionnaire response (at 60 months) after denominators adjusted for those who died: GP 106/480 (22%), H 104/483 (22%)	Using a growth model, there were no statistically significant differences between the groups over time for mean SF-36 physical or mental component scores. (Mean response profiles were presented but no raw data given. SF-36 measured during interval the patient was recurrence free)	—	
Wattchow <i>et al</i> , 2006. ³⁰ Cancer site: colon. Length of follow-up: 24 months. Sample size: <i>n</i> = 97, H <i>n</i> = 106. Questionnaire response after denominators adjusted for those who died: GP 76/89 (85%), hospital 79/95 (83%)	Using a growth model, there were no statistically significant differences between the groups over time for mean SF-36 physical or mental component scores. (Mean response profiles were presented but no raw data given. SF-36 measured during interval the patient was recurrence free)	Median (interquartile range) SF-12 score; <i>P</i> adjusted analysis for baseline differences: Physical GP 48.5 (17.7) vs H 50.4 (14.4); <i>P</i> = 0.28 ^a Mental GP 54.4 (17.7) vs H 55.9 (14.4); <i>P</i> = 0.47 ^a Depression GP 4.0 (5.0) vs H 3.0 (4.0); <i>P</i> = 0.80 ^a	% of patients rating 'excellent' or 'very good'; GP <i>n</i> = 76 vs surgeon <i>n</i> = 81: Wait for an appointment GP 82 vs H 82, <i>P</i> = 0.69 ^b Convenience of location GP 84 vs H 78, <i>P</i> = 0.18 ^b Reaching Dr by phone GP 69 vs H 62, <i>P</i> = 0.26 ^b Time in waiting room GP 56 vs H 59, <i>P</i> = 1.00 ^b Average time with Dr GP 77 vs H 69, <i>P</i> = 0.12 ^b Explanation given GP 84 vs H 81, <i>P</i> = 0.33 ^b Technical skills of Dr GP 89 vs H 90, <i>P</i> = 0.50 ^b Personal manner of Dr GP 97 vs H 95, <i>P</i> = 0.08 ^b Overall satisfaction with Dr GP 96 vs H 92, <i>P</i> = 0.06 ^b

... continued

Table 4 continued. Results of psychological morbidity, quality of life and patient satisfaction.

Study	Psychological morbidity	Quality of life	Patient satisfaction
Holtehdahl <i>et al</i> , 2005. ³¹ Cancer site: multiple sites. Length of follow-up: 6 months. Sample size: Int <i>n</i> = 41, H <i>n</i> = 50. Questionnaire response rate was Int: 88%, H: 90%	—	Mean change from baseline for EORTC QLQ-C30; estimate for differences between groups (95% CI): Functional scales Physical Int 2.6 vs H 4.0; -1.4 (-7.62 to 4.82) Role Int 3.3 vs H 12.6; -9.3 (-20.41 to 1.81) Cognitive Int 3.2 vs H 1.8; 1.40 (-8.04 to 10.84) Emotional Int 2.4 vs H 4.3; -1.90 (-9.52 to 5.72) Social Int 0.0 vs H 11.4; -11.40 (-22.90 to 0.10) Global QoL Int 2.3 vs H 2.3; 0.00 (-7.16 to 7.16) Symptom scales/items Fatigue Int -1.9 vs H -4.9; 3.00 (-7.21 to 13.21) Nausea/vomiting Int 0.0 vs H -2.6; 2.60 (-5.07 to 10.27) Pain Int -7.4 vs H -4.0; -3.40 (-14.32 to 7.52) Dyspnoea Int 8.3 vs H 0.7; 7.60 (-4.45 to 19.65) Sleep disturbances Int 0.9 vs H -7.4; 8.30 (-4.52 to 21.12) Appetite loss Int 1.9 vs H -2.9; 4.80 (-4.58 to 14.18) Constipation Int 0.9 vs H -0.8; 1.70 (-10.02 to 13.42) Diarrhoea Int -4.6 vs H 3.0; -7.60 (-19.76 to 4.56) Financial impact Int 2.8 vs H -0.8; 3.60 (-4.64 to 11.84)	—
Nielsen <i>et al</i> , 2003. ³³ Cancer site: multiple sites. Length of follow-up: 6 months since diagnosis. Sample size: Int <i>n</i> = 121, H <i>n</i> = 127. Questionnaire response rate was Int: 78%, H: 64%	—	Mean EORTC QLQ-C30 scores: Functional scales Physical Int 80.92 vs H 81.32; <i>P</i> = 0.621 ^c Role Int 73.42 vs H 72.71; <i>P</i> = 0.781 ^c Cognitive Int 81.88 vs H 84.98; <i>P</i> = 0.357 ^c Emotional Int 75.42 vs H 78.14; <i>P</i> = 0.665 ^c Social Int 84.17 vs H 83.70; <i>P</i> = 0.744 ^c Global QoL Int 69.79 vs H 69.11; <i>P</i> = 0.933 ^c Symptom scales/items Fatigue Int 29.31 vs H 31.14; <i>P</i> = 0.874 ^c Nausea/vomiting Int 8.13 vs H 8.15; <i>P</i> = 0.843 ^c Pain Int 19.38 vs H 21.80; <i>P</i> = 0.345 ^c Dyspnoea Int 15.00 vs H 14.49; <i>P</i> = 0.921 ^c Insomnia Int 22.50 vs H 24.28; <i>P</i> = 0.729 ^c Appetite loss Int 15.00 vs H 15.22; <i>P</i> = 0.591 ^c Constipation Int 12.50 vs H 10.26; <i>P</i> = 0.502 ^c Diarrhoea Int 11.25 vs H 13.55; <i>P</i> = 0.564 ^c Financial impact Int 11.39 vs H 16.85; <i>P</i> = 0.1110 ^c	Mean patients' attitudes (high score = more positive attitude): Intersectoral cooperation Int 59.22 vs H 51.71 (<i>n</i> = 62); <i>P</i> = 0.055 ^c Global assessment of intersectoral cooperation Int 63.73 (<i>n</i> = 71) vs H 58.55 (<i>n</i> = 76); <i>P</i> = 0.142 ^c Feeling of not being left in limbo Int 65.49 (<i>n</i> = 66) vs H 58.55 (<i>n</i> = 77); <i>P</i> = 0.055 ^c Global assessment of the feeling of not being left in limbo Int 57.64 (<i>n</i> = 72) vs H 52.71 (<i>n</i> = 83); <i>P</i> = 0.324 ^c Information from GP Int 74.27 (<i>n</i> = 43) vs H 68.59 (<i>n</i> = 38); <i>P</i> = 0.377 ^c Care from the GP Int 79.22 (<i>n</i> = 45) vs H 77.50 (<i>n</i> = 36); <i>P</i> = 0.542 ^c GPs' knowledge Int 64.84 (<i>n</i> = 32) vs H 66.67 (<i>n</i> = 27); <i>P</i> = 0.588 ^c Global assessment of the GP Int 68.89 (<i>n</i> = 45) vs H 64.02 (<i>n</i> = 41); <i>P</i> = 0.438 ^c

^aAnalysis of covariant ranks. ^bFisher's exact test. ^cMann-Whitney U test. Dr = Doctor. EORTC = European Organisation for Research and Treatment for Cancer. EORTC QLQ-C30 = European Organisation for Research and Treatment for Cancer Quality of Life Questionnaire Core 30 (a high score on functional scale represents healthy level of function; a high global health status score represents high quality of life; a high score of symptoms scale represents a high level of symptoms/problems). GP = GP follow-up group. H = routine hospital follow-up group. HADS = Hospital Anxiety and Depression Scale (higher scores indicate greater level of anxiety and depression). Int = intervention group, involving the integration of primary and secondary care. SF-12 = Short Form 12-Item General Health Questionnaire (higher scores indicate better quality of life). SF-36 = Short Form 36-Item General Health Questionnaire (higher scores indicate better quality of life). QoL = Quality of life. Note: Johansson *et al*³² did not include any relevant outcomes for this table.

Table 5. Results relating to primary care consultations.

Study details	Number of patient contacts with primary care	Frequency of patient contact with primary care
Holtedahl <i>et al</i> , 2005. ³¹ Cancer site: multiple sites. Length of follow-up: 6 months. Sample size: Int <i>n</i> = 41, H <i>n</i> = 50	Number of consultations with GP — patient reported: Int 13 (<i>n</i> = 31) versus H 28 (<i>n</i> = 46); (RR 0.69, 95% CI = 0.43 to 1.11)	Frequency of GP consultations — reported by GPs: mean number of consultations in the intervention group was 1.68 (ranged 0–8); number of patients not stated. Data for control group not reported. Mean number of consultations — patient reported: Int 1.26 (<i>n</i> = 31; range 1–7 per patient) versus H 1.04 (<i>n</i> = 46; range 1–5 per patient)
Johansson <i>et al</i> , 2001. ³² Cancer site: multiple site. Length of follow-up: 6 months since diagnosis. Sample size: Int <i>n</i> = 260, H <i>n</i> = 250	Contact with home-care nurse — patient reported: Int 86 (<i>n</i> = 203) versus H 11 (<i>n</i> = 178); <i>P</i> < 0.05, χ^2 test (RR 6.86, 95% CI = 3.78 to 12.42)	Contact with home-care nurse — patient reported: frequency of contact with nurse was greater in the intervention group than control (number of patients not stated; <i>P</i> < 0.001, Mann-Whitney <i>U</i> test)
Nielsen <i>et al</i> , 2003. ³³ Cancer site: multiple site. Length of follow-up: 6 months since diagnosis. Sample size: Int <i>n</i> = 121, H <i>n</i> = 127	Contact with GP — patient reported: Int 46 (<i>n</i> = 77) — versus H 40 (<i>n</i> = 91); <i>P</i> = 0.046, χ^2 test (RR 1.36, 95% CI = 1.01 to 1.83)	
Brown <i>et al</i> , 2002. ³⁵ Cancer site: breast. Length of follow-up: 12 months. Sample size: <i>n</i> = 62; PI 30, H 31 (one patient did not return questionnaires)	Breast-related GP referral (to hospital): PI 4 versus H 3; (RR 1.38, 95% CI = 0.34 to 5.64)	—
Gulliford <i>et al</i> , 1997. ³⁶ Cancer site: breast. Length of follow-up: median 16 months. Sample size: <i>n</i> = 193; PI 97, H 96	—	Total number of GP visits — patient reported (number of visits/patient not reported): PI 53 (4 cancer related) versus H 53 (7 cancer related)
Kjeldsen <i>et al</i> , 1999. ³⁷ Cancer site: colorectal. Length of follow-up: not stated. Sample size: <i>n</i> = 320; PI 161, H 159. Data based on a subgroup of 50 patients who were included in a RCT of frequent versus virtually no follow-up during 1983–1994 ⁴⁷	—	Median number of GP visits — patient reported: data on GP visits based on a random sample of 50 patients selected from the two intervention groups, PI 4 (<i>n</i> = 24) versus H 2 (<i>n</i> = 26), <i>P</i> = 0.33, Mann-Whitney <i>U</i> test (no visit due to symptom problem)

H = routine hospital follow-up group. Int = intervention group. PI = patient-initiated. RCT = randomised controlled trial. RR = relative risk.

period, after completing cancer treatment.^{32,33} The study by Holtedahl *et al* included patients with primary or relapsing cancer who had completed treatment.³¹ The percentages of eligible patients included in the trials were low and ranged from 41%³¹ to 47%.³³

Study quality ranged from poor³¹ to moderate,^{32,33} and all three were poorly reported (Table 2, part b). In the study by Holtedahl *et al*, patients were randomised to intervention or control using sealed envelopes based on a table of random numbers, but it was not clear when and how envelopes were allocated; therefore, allocation concealment could not be assured.³¹ Although randomisation by Johansson *et al* was based on a computer-generated allocation schedule and was stratified for diagnosis and stage, allocation concealment was not reported.³² More patients with advanced breast cancer were randomised to the intensified primary healthcare group than the control. A type of cluster randomisation was used by Nielsen *et al*.³³ Patients in

the intervention group were younger (*n* = 47, 39%, aged 18–49 years) than those in the control group (*n* = 32, 25%, aged 18–49 years) and more patients in the intervention group (*n* = 99, 82%) were treated with curative intent than in the control group (*n* = 94, 74%).

Blind data collection and analysis of outcomes were not reported by Johansson *et al*.³² Blinding of outcomes assessment was also not reported by the remaining two studies. The main outcomes were based on data from questionnaires completed by the patient, and it was unclear whether researchers handling data were blinded to treatment allocation.^{31,33} Sample size ranged from small (*n* = 91)³¹ to moderate (*n* = 527).³² Thirteen (14%) patients in the study by Holtedahl *et al* had relapsing cancer.³¹ The length of follow-up in all three studies was 6 months, although only 3-month data were reported for most outcomes from the study by Johansson *et al*.³²

There were no statistically significant differences between the intervention groups in terms of patient wellbeing,^{31,33} or patient satisfaction relating to GP

contact, intersectorial cooperation, and patients' feelings of being left in limbo³³ (Table 4). Two studies found that the intervention was associated with a statistically significant increase in the contact with either the GP³³ or home-care nurse³² at 6 months (Table 5). However, the Holtedahl *et al* study found that an intervention comprising two pre-arranged formal consultations with the GP did not result in a significant increase in additional GP visits at 6 months.³¹ There was no statistically significant difference between the intervention groups for hospital admissions and outpatient visits.³²

Effect of hospital-based patient-initiated or minimal follow-up on primary care

Three RCTs evaluated the effect of patient-initiated or (virtually) no follow-up on primary care. Two studies included women with breast cancer, and patients in the intervention group were advised to either telephone the nurse,³⁴ or request an immediate appointment³⁵ if they had any problems. Women received an annual mammogram in both studies. One study included patients who had received treatment for colorectal cancer, and were advised to see their GP if they had any abdominal pain or change in bowel habits lasting more than two weeks.³⁶ The quality ranged from poor³⁵ to good.^{34,36} There were no important differences between the groups for the number of GP visits^{35,36} or cancer-related GP referrals.³⁴

DISCUSSION

Summary of main findings

There were no statistically significant differences between primary and secondary care follow-up of cancer patients (breast or colon) in terms of patient wellbeing, psychological morbidity, and patient satisfaction. However, this may be due to the duration of follow-up and sample size rather than the interventions being equivalent. The findings did not demonstrate any harmful effects of GP-led follow-up. GP-led follow-up for breast cancer was less costly than routine hospital follow-up, due to a difference in physician costs (cost year used 1994). Some interventions that involved improved integration between primary and secondary care resulted in an increase in patient contact with primary care. There were no significant differences between the groups in terms of patient wellbeing and satisfaction. However, these findings are based on poorly reported studies with a short duration of follow-up. The discontinuation of routine hospital follow-up or patient-initiated follow-up did not appear to have an impact on primary care, but this was based on three small RCTs. Overall, the quality of the data was generally poor, and no firm conclusions can be made.

Strengths and limitations of the study

A strength of the review was the comprehensive literature search. However, to make it manageable, separate searches were carried out of the electronic databases for each cancer site, and a general search was not undertaken using the term 'cancer' (or tumour) alone. Although the searches did identify studies evaluating multiple cancer sites, it is not possible to be certain that none were missed. However, database searches were supplemented by a search of conference proceedings and reference lists of included studies and other reviews, which were not narrowed by cancer site.

The review concentrated on the use of primary care as an alternative setting for cancer follow-up and did not address any other issues relating to follow-up.

Because of the small number of relevant studies, it was not possible to assess for any publication bias. The inconsistent methods used to analyse and report most outcome measures meant that no data could be pooled in a meta-analysis.

There are limitations of the available evidence relating to primary- versus secondary-care follow-up, as it is small and only covers two cancer sites: the breast^{33,27} and colon.³⁰ Limitations of the included non-inferiority RCT meant that the evidence for assessing the equivalence of the primary and secondary care settings for breast cancer follow-up was lacking. There is also a paucity of economic evidence on primary versus secondary care follow-up. Further evidence relating to the effectiveness and cost-effectiveness of primary care follow-up may be provided by an RCT of primary care follow-up for cutaneous melanoma,²⁹ and an ongoing RCT of symptomatic follow-up of colorectal cancer in primary care augmented with monitoring of tumour markers or intensive imaging in hospital (<http://www.facs.soton.ac.uk/>).

The length of follow-up and sample size were insufficient to measure delayed diagnosis of recurrences or survival rates, which means that the impact of various types of follow-up on such outcomes is not clear. Duration of follow-up is also likely to affect the outcome of patient satisfaction, as patients are likely to have a different perspective of their follow-up needs during the first 2 years after completing treatment, than later in their cancer journey.³⁷

The data-collection tools used for psychological morbidity, health-related quality of life, and patient satisfaction were limited. Although the Hospital Anxiety and Depression Scale and Short Form-36 are good instruments to measure global function, they are not designed to measure cancer survivor symptoms. On the whole, patient satisfaction

questionnaires were not well developed, and the response rates were poor, making the findings potentially unreliable.

The patient population evaluated in the comparative studies may not have been representative of the population attending cancer follow-up as a whole, because patients who did not want primary care follow-up may not have been randomised.

Comparison with existing literature

Other reviews of cancer follow-up have included comparisons between different models of follow-up, providers, and location. Only one other systematic review looking at primary versus secondary care follow-up has been identified.³⁸ This review evaluated RCTs of alternative methods of follow-up in breast cancer, including reduced frequency of visits. It included seven RCTs: two that compared primary with secondary care follow-up,^{3,27} two that evaluated nurse-led patient-initiated follow-up,^{34,39} one that evaluated nurse-led routine follow-up,⁴⁰ and two that examined different frequencies of follow-up.^{35,41} The authors concluded that all trials were of inadequate power or duration to establish the ideal frequency of appointments or safety of alternative models of follow-up, but the alternative methods of follow-up had no detrimental effect on satisfaction or outcome. Two further reviews evaluating the effectiveness of breast cancer follow-up found that patient survival and quality of life were not affected by location of care.^{12,14} A systematic review of follow-up for cutaneous melanoma found no studies that examined differences between different providers or locations of follow-up.¹⁶

Previous systematic reviews found that the only effective follow-up procedures in breast cancer were mammography and physical examination.^{12,13,42} Systematic reviews of colorectal cancer found that intensive hospital follow-up led to an overall survival benefit of about 20% when compared with less-intensive follow-up.^{43,44} The survival benefit appeared to be associated with the measurement of carcinoembryonic antigen combined with liver imaging. A systematic review of follow-up for cutaneous melanoma found no evidence to support high-intensity follow-up. Only medical history and physical examination appeared to be cost-effective.¹⁶ However, new technological developments in follow-up methods may change the picture of what to do.

Implications for future research and clinical practice

With further training for GPs, rapid access to hospital specialists, and annual mammography, breast cancer follow-up would be feasible in primary care.

However, further psychosocial studies are needed to determine its acceptability. The follow-up of colon cancer might also be feasible, but the evidence base is limited. Results of research in progress are awaited (<http://www.facs.soton.ac.uk/>). Primary-care follow-up for breast cancer might also be cost-effective. However, it is dependent on the unit cost of GP care, and would require additional funding as it is not a core activity. The willingness of primary care to undertake this additional work is unknown, but interventions that improved communication between primary and secondary care were found to increase GP involvement in cancer care.³¹⁻³³ Poor communication between primary and secondary care was seen as a barrier in the current authors' joint publication of qualitative studies,²² and improved communication is a key recommendation of the National Institute for Health and Clinical Excellence guidelines on breast and colorectal cancer.^{45,46} The willingness of GPs to undertake this role may also be hampered by a perceived lack of specialist knowledge.²² Only one study of primary care follow-up (breast cancer) incorporated a pre-trial education session of cancer follow-up for GPs.³ Continued professional education in oncology will be needed if this role is to be extended.

Further RCTs are needed of primary versus secondary care follow-up in cancer where the ideal hospital-based follow-up is transferable to a primary care setting. The studies need to be of sufficient size and duration to ensure that important differences between the intervention groups are identified. They should also include robust psychosocial outcome measures. Future research should include a health-economic analysis that takes into account the current cost of general practice and the additional funding required for this non-core activity.

Funding body

Cancer Research UK (Ref C8350/A4543). The funding source had no involvement in the study

Ethical approval

Not applicable

Competing interests

The authors have stated that there are none

Acknowledgments

We would like to thank Stephen Duffy for his advice on searching databases and developing the search strategy, Bernadette Coles and Hilary Kitcher for checking some of the original search strategies, Madeline Pasterfield and Jennifer Wilkinson for technical support including carrying out the update searches, and Alison Eastwood for peer reviewing the protocol and draft final report. We would also like to thank the following people for sending us further information about the studies they had conducted: Kinta Beaver, Gillian Knowles, Karen Cox, Christine McIlvenney, and Stephen Barclay. Thanks also to Richard Bailey and his staff at the John Spalding Library for their help in retrieving manuscripts.

Discuss this article

Contribute and read comments about this article on the Discussion Forum: <http://www.rcgp.org.uk/bjgp-discuss>

REFERENCES

- Donnelly P, Hiller L, Bathers S, *et al.* Questioning specialists' attitudes to breast cancer follow-up in primary care. *Ann Oncol* 2007; **18**(9): 1467–1476.
- Pascoe SW, Neal RD, Allgar VL, *et al.* Psychosocial care for cancer patients in primary care — recognition of opportunities for cancer care. *Fam Pract* 2004; **21**(4): 437–442.
- Grunfeld E, Mant D, Yudkin P, *et al.* Routine follow up of breast cancer in primary care: randomised trial. *BMJ* 1996; **313**(7058): 665–669.
- Campbell N, MacLeod U, Weller D. Primary care oncology: essential if high quality cancer care is to be achieved by all. *Fam Pract* 2002; **19**(6): 577–578.
- Koinberg IL, Holmberg L, Fridlund B. Breast cancer patients' satisfaction with a spontaneous system of check-up visits to a specialist nurse. *Scand J Caring Sci* 2002; **16**(3): 209–215.
- Rozmovits L, Rose P, Ziebland S. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *J Health Serv Res Policy* 2004; **9**(3): 159–164.
- Bradburn J, Maher J, Adewuyidalton R, *et al.* Developing clinical-trial protocols — the use of patient focus groups. *Psychooncology* 1995; **4**: 107–112.
- Cox K, Wilson E, Heath W, *et al.* Preferences for follow-up after treatment for lung cancer. *Cancer Nurs* 2006; **29**(3): 176–187.
- Beaver K, Luker K. Follow-up in breast cancer clinics: reassuring for patients rather than detecting recurrence. *Psychooncology* 2005; **14**(2): 94–101.
- Pennery E, Mallet J. A preliminary study of patients' perceptions of routine follow-up after treatment for breast cancer. *Eur J Oncol Nurs* 2000; **4**(3): 138–145.
- Allen A. The meaning of the breast cancer follow-up experience for the women who attend. *Eur J Oncol Nurs* 2002; **6**(3): 155–161.
- Rojas MP, Telaro E, Russo A, *et al.* Follow-up strategies for women treated for early breast cancer. *Cochrane Database Syst Rev* 2000; **(4)**: CD001768.
- Somerfield MR, Schapira DV, Davidson NE, *et al.* Recommended breast cancer surveillance guidelines. *J Clin Oncol* 1997; **15**: 2149–2156.
- Collins RF, Bekker HL, Dodwell DJ. Follow-up care of patients treated for breast cancer: a structured review. *Cancer Treat Rev* 2004; **30**(1): 19–35.
- Botteman MF, Pashos CL, Redaelli A, *et al.* The health economics of bladder cancer: a comprehensive review of the published literature. *Pharmacoeconomics* 2003; **21**(18): 1315–1330.
- Francken AB, Bastiaannet E, Hoekstra HJ. Follow-up in patients with localised primary cutaneous melanoma. *Lancet Oncol* 2005; **6**(8): 608–621.
- Kerr D, Bevan H, Gowland B, *et al.* Redesigning cancer care. *BMJ* 2002; **324**(7330): 164–166.
- National Institute for Health and Clinical Excellence. *Improving outcomes for people with skin tumours including melanoma — the manual*. London: NICE, 2006.
- National Institute for Health and Clinical Excellence. *Prostate cancer: diagnosis and treatment*. London: NICE, 2008. <http://www.nice.org.uk/guidance/index.jsp?action=download&o=39687> (accessed 17 Feb 2009).
- Neal RD. NICE prostate cancer clinical guideline: implications for primary care. *Br J Gen Pract* 2008; **58**(554): 607–608.
- Weller D, McGorm K. GP vs hospital follow-up for cancer patients. *Aust Fam Physician* 1999; **28**: 356–359.
- Lewis RA, Neal RD, Hendry M, *et al.* Patients' and healthcare professionals' views of cancer follow-up: systematic review. *Br J Gen Pract* 2009; **59**(559): 533–540.
- Lewis R, Neal RD, Williams NH, *et al.* Nurse-led vs conventional physician-led follow-up for patients with cancer: systematic review. *J Adv Nurs* 2009; **65**: 706–723.
- Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *J Epidemiol Community Health* 1998; **52**(6): 377–384.
- Deeks JJ, Dinnes J, D'Amico R, *et al.* Evaluating non-randomised intervention studies. *Health Technol Assess* 2003; **7**(27): iii–x, 1–173.
- Drummond MF, Jefferson TO. Guidelines for authors and peer reviewers of economic submissions to the BMJ. *BMJ* 1996; **313**(7052): 275–283.
- Grunfeld E, Levine MN, Julian JA, *et al.* Randomised trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol* 2006; **24**(6): 848–854.
- Loberiza FR, Villaneuva MH, *et al.* Effect of follow-up provider source on outcomes of patients with haematologic malignancies receiving haematopoietic stem cell transplantation [abstract]. *J Clin Oncol* 2006; **24** (Suppl 18S): 6112.
- Murchie P, Hannaford PC, Nicolson MC, *et al.* Attending the general practitioner for routine melanoma follow-up: the practical experiences of participants in an RCT. In: *The Society for Academic Primary Care 35th Annual Scientific Meeting*; 2006 12–14 July 2006, Keele University, UK.
- Wattchow DA, Weller DP, Esterman A, *et al.* General practice vs surgical-based follow-up for patients with colon cancer: randomised controlled trial. *Br J Cancer* 2006; **94**(8): 1116–1121.
- Holtedahl K, Norum J, Anvik T, Richardsen E. Do cancer patients benefit from short-term contact with a general practitioner following cancer treatment? A randomised controlled study. *Support Care Cancer* 2005; **13**(11): 949–956.
- Johansson B, Holmberg L, Berglund G, *et al.* Reduced utilisation of specialist care among elderly cancer patients: a randomised study of a primary healthcare intervention. *Eur J Cancer* 2001; **37**(17): 2161–2168.
- Nielsen JD, Palshof T, Mainz J, Jensen AB, Olesen F. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Care* 2003; **12**(4): 263–272.
- Brown L, Payne S, Royle G. Patient initiated follow up of breast cancer. *Psychooncology* 2002; **11**(4): 346–x5.
- Gulliford T, Opomu M, Wilson E, *et al.* Popularity of less frequent follow up for breast cancer in randomised study: initial findings from the hotline study. *BMJ* 1997; **314**(7075): 174–177.
- Kjeldsen BJ, Thorsen H, Whalley D, Kronborg O. Influence of follow-up on health-related quality of life after radical surgery for colorectal cancer. *Scand J Gastroenterol* 1999; **34**(5): 509–515.
- Adewuyi-Dalton R, Ziebland S, Grunfeld E, Hall A. Patients' views of routine hospital follow-up: a qualitative study of women with breast cancer in remission. *Psychooncology* 1998; **7**(5): 436–439.
- Montgomery DA, Krupa K, Cooke TG. Alternative methods of follow up in breast cancer: a systematic review of the literature. *Br J Cancer* 2007; **96**(11): 1625–1632.
- Koinberg IL, Fridlund B, Engholm GB, Holmberg L. Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study. *Eur J Oncol Nurs* 2004; **8**(2): 109–117.
- Baildam A, Keeling F, Noblet M, *et al.* Nurse led follow up clinics for women treated for primary breast cancer: a randomised controlled trial. *Eur J Cancer* 2002; **38**: S136.
- Kokko R, Hakama M, Holli K. Follow-up cost of breast cancer patients with localized disease after primary treatment: a randomized trial. *Breast Cancer Res Treat* 2005; **93**(3): 255–260.
- Edelman MJ, Meyers FJ, Siegel D. The utility of follow-up testing after curative cancer therapy: a critical review and economic analysis. *J Gen Intern Med* 1997; **12**(5): 318–331.
- Jeffery GM, Hickey BE, Hider P. Follow-up strategies for patients treated for non-metastatic colorectal cancer. *Cochrane Database Syst Rev* 2007; **(1)**: CD002200.
- Renahan AG, Egger M, Saunders MP, O'Dwyer ST. Impact on survival of intensive follow up after curative resection for colorectal cancer: systematic review and meta-analysis of randomised trials. *BMJ* 2002; **324**(7341): 813–816.
- National Institute for Clinical Excellence. *Improving outcomes in colorectal cancers — the manual update*. London: National Institute of Clinical Excellence, 2004.
- National Institute for Clinical Excellence. *Improving outcomes in breast cancer — the manual update*. London: National Institute of Clinical Excellence, 2002.
- Kjeldsen BJ, Kronborg O, Fenger C, Jorgensen OD. A prospective randomized study of follow-up after radical surgery for colorectal cancer. *Br J Surg* 1997; **84**(5): 666–669.

Appendix 1. Search strategy.

Search strategy

The following search strategy for breast cancer was used in MEDLINE (using the OVID interface), and subsequently translated and adapted for use in other databases (and for other cancer sites).

1. Patient discharge/
2. ((followup\$ or follow-up\$ or follow up or follow ups) adj4 (discharg\$ or discontin\$)).ti,ab.
3. ((checkup\$ or check-up\$ or check up\$) adj4 (discharg\$ or discontin\$)).ti,ab.
4. ((followup\$ or follow-up\$ or follow up or follow ups) adj4 (stop or stops or stopping or stopped)).ti,ab.
5. ((followup\$ or follow-up\$ or follow up or follow ups) adj4 (cease or ceases or ceasing or ceased or cessation)).ti,ab.
6. ((checkup\$ or check-up\$ or check up or check ups) adj4 (cease or ceases or ceasing or ceased or cessation)).ti,ab.
7. ((followup\$ or follow-up\$ or follow up or follow ups) adj4 (end or ends or ending or ended)).ti,ab.
8. ((checkup\$ or check-up\$ or check up or check ups) adj4 (end or ends or ending or ended)).ti,ab.
9. ((followup\$ or follow-up\$ or follow up or follow ups) adj4 terminat\$).ti,ab.
- 10.((followup\$ or follow-up\$ or follow up or follow ups) adj4 finish\$).ti,ab.
- 11.((followup\$ or follow-up\$ or follow up or follow ups) adj4 withdraw\$).ti,ab.
- 12.((followup\$ or follow-up\$ or follow up or follow ups) adj4 (cut-off or cut off)).ti,ab.
- 13.continuity of patient care/
- 14.((minimal or conventional) adj2 (surveillance\$ or followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 15.(routine adj2 (followup\$ or follow-up\$ or follow up or follow ups or visit\$)).ti,ab.
- 16.(routine adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 17.(surveillance\$ adj2 (recur\$ or relaps\$ or protocol\$ or routine\$ or regular\$ or followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 18.(surveillance\$ adj2 (test or tests or testing or tested or hospital or outpatient\$ or out-patient or out patient\$ or standard\$)).ti,ab.
- 19.((intensive or frequent or aggressive) adj2 (surveillance\$ or followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 20.active\$ monitor\$.ti,ab.
- 21.(routine adj2 exam\$).ti,ab.
- 22.(routine adj2 review\$).ti,ab.
- 23.(routine\$ adj2 (test or tests or testing or tested)).ti,ab.
- 24.(outpatient\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 25.(outpatient\$ adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 26.(systematic adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 27.(scheduled adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 28.(scheduled adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 29.(regular\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 30.(regular\$ adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 31.(specialist\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 32.(hospital\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 33.(hospital\$ adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 34.((clinic or clinics) adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.

... continued

Appendix 1 continued. Search strategy.

- 35.((clinic or clinics) adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 36.(initiated adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 37.(initiated adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 38.((general practitioner\$ or GP\$ or practice or physician) adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 39.((general practitioner\$ or GP\$ or practice or physician) adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 40.((telephone or phone\$) adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 41.((telephone or phone\$) adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 42.((followup\$ or follow-up\$ or follow up or follow ups) adj2 (secondary or primary)).ti,ab.
- 43.((checkup\$ or check-up\$ or check up or check ups) adj2 (secondary or primary)).ti,ab.
- 44.(nurse\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 45.(nurse\$ adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 46.(standard\$ adj2 (followup\$ or follow-up\$ or follow up or follow ups)).ti,ab.
- 47.(standard\$ adj2 (checkup\$ or check-up\$ or check up or check ups)).ti,ab.
- 48.((followup\$ or follow-up\$ or follow up or follow ups) adj2 regime\$)).ti,ab.
- 49.((followup\$ or follow-up\$ or follow up or follow ups) adj2 (postsurgery or post-surgery or post surgery or postsurgical\$ or post-surgical\$ or post surgical\$ or postoperat\$ or post-operat\$ or post operat\$)).ti,ab.
- 50.((checkup\$ or check-up\$ or check up or check ups) adj2 (postsurgery or post-surgery or post surgery or postsurgical\$ or post-surgical\$ or post surgical\$ or postoperat\$ or post-operat\$ or post operat\$)).ti,ab.
- 51.((followup\$ or follow-up\$ or follow up or follow ups) adj2 appointment\$)).ti,ab.
- 52.((checkup\$ or check-up\$ or check up or check ups) adj2 appointment\$)).ti,ab.
- 53.or/1-52
- 54.exp Breast Neoplasms/
- 55.((breast or breasts or mammar\$) adj3 (cancer\$ or neoplas\$ or malignan\$ or carcinoma\$ or sarcoma\$ or oncolog\$ or tumo?r\$ or adenocarcinoma\$ or infiltrat\$ or medullary or intraductal)).ti,ab.
- 56.((breast or breasts or mammar\$) adj3 (duct or ducts or ductal)).ti,ab.
- 57.((breast or breasts or mammar\$) adj3 (lobule\$ or lobe or lobes or lobular)).ti,ab.
- 58.((breast or breasts or mammar\$) adj3 (metastas\$ or metastatic\$)).ti,ab.
- 59.54 or 55 or 56 or 57 or 58
- 60.53 and 59

The strategy is based on the one used for an unpublished scoping review (looking at follow-up for breast cancer) undertaken by the Centre for Reviews and Dissemination, University of York as part of a project with the National Cancer Research Network Coordinating Centre.