BMJ OPEN Gynaecological cancer follow-up: national survey of current practice in the UK

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ABSTRACT

Objective: To establish a baseline of national practice for follow-up after treatment for gynaecological cancer. **Design:** Questionnaire survey.

Setting: Gynaecological cancer centres and units. Geographical location: UK.

Participants: Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions: A questionnaire survey.

Outcome measures: To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results: A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular followup appointments. Two involved general practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 responses (25%) and patient-initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital-based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient-initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents (76/ 117 (65%)) provided routine tests, of which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Patients were usually discharged after 5 years (82/117 (70%)), whereas three (3%) were discharged after 4 years, nine (8%) after three years and one (1%) after 2 years.

Conclusions: Practice varied but most used a standard hospital-based protocol of appointments for 5 years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse-led or telephone follow-up. General practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

INTRODUCTION

Traditionally, patients who have had treatment for cancer are kept on regular review in

ARTICLE SUMMARY

Article focus

- Follow-up after treatment for cancer is a resource-intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse-led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- This is the first study to report the extent of patient-initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- Four UK cancer networks did not respond; there were variations of responses within networks and the response rate could not be calculated.

hospital outpatient clinics for a period between 5 and 10 years after completion of their treatment.¹ The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer.^{2–4} The assumption behind this approach is that early detection of recurrence will be of benefit to patients^{5 6} and that monitoring side effects and anxieties will allow helpful interventions that will improve the quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital every year at an NHS tariff of £118 per visit.⁷ In Wales alone, we estimate that the cost of this follow-up is in excess of £1 m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for

breast cancer reported most recurrences presenting between scheduled clinic appointments.^{8–13} This is also seen with patients having had treatment for early stage endometrial and cervical cancers.¹⁴ ¹⁵ Gynaecological patients may wait for their next routine appointment to disclose their symptoms.¹⁶ There is no prospective randomised evidence to suggest that follow-up improves survival for ovarian cancer⁴ or for cervical cancer.¹⁷ Also, there is no evidence that intensive follow-up improves survival for endometrial cancer.14 18-23 A cost-benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations.²³ In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival.²⁴ As around 20% of all female cancer survivors have had gynaecological malignancy, a cost-effective form of surveillance is important.²⁵

In clinical practice, there appears to be no rationale available for any particular follow-up protocol.²⁶ As there is a lack of any demonstrable survival benefit for the follow-up of gynaecological cancer patients, other schedules of care could be considered. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital-based nurse-led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare, the benefits of routine follow-up following treatment for gynaecological cancer have received little scrutiny and have rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the UK, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

MATERIALS AND METHODS

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. BOS is an easy-to-use survey tool which allows surveys to be developed, deployed and analysed via the internet. The data set was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data were anonymised and then exported to the databases held in SPSS (V.18.0; SPSS, Chicago, Illinois, USA). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the UK. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 441 members of the British Gynaecological Cancer Society (BGCS) and all 71

members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

Investigators, in consultation with BGCS and a patient representative, designed the questionnaire which was organised around three themes (see questionnaire in the online supplementary appendix). The first comprised questions related to practice setting (ie, organisation and hospital) and respondent characteristics (ie, profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different cancers. We listed four possible types of follow-up appointments: clinician-led (traditional), nurse-led, telephone follow-up and patientinitiated follow-up. Telephone follow-up appointments were defined as a prearrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient-initiated follow-up was defined as a practice where the patient is not followed up in secondary care but seen only if the patient requests or initiates a contact, for example, if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/ no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data were collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped by also calculating responses on a network basis, grouping all answers from respondents within their cancer networks. Any positive response within the group was accepted as a positive network response. Textual answers were categorised and counted.

RESULTS

Sample size and respondent characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of BGCS and NFGON. Because the survey was conducted online with the request to take part being distributed widely by email, it is impossible to state how many had the opportunity to take part but did not. Therefore, the response rate has not been calculated. Nonetheless, we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two) and Northern Ireland (one). Each responding cancer network provided between 1 and 14 responses. One response was received from a surgical oncologist based in Greece who was excluded from the study as the objective was to assess the current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) respondents specialised in surgical oncology. Fifteen (13%) specialised in clinical oncology and six (5%) in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents, with the exception of one surgical oncologist (116/117 (99%)), had a standard follow-up protocol after completion of treatment. However, all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, while only two respondents (from different English cancer networks) reported that visits to primary care were part of their follow-up routine.

Most of the respondents (87/116 (75%)) reported using different follow-up protocols for different tumour sites (eg, cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types

Table 1 Characteristics of respondents (N=117)			
	N (%)		
Region			
England	102 (87)		
Wales	7 (6)		
Scotland	5 (4)		
Northern Ireland	3 (3)		
Organisation			
Cancer centre	71 (61)		
Cancer unit	32 (27)		
Cancer unit and cancer centre	12 (10)		
Other*	2 (2)		
Specialty			
Surgical oncology	73 (62)		
Medical oncology	6 (5)		
Clinical oncology	15 (13)		
Surgical and medical oncology	6 (5)		
Surgical and clinical oncology	1 (1)		
Surgical, medical and clinical oncology	8 (7)		
Other†	8 (7)		
Profession			
Medical	83 (71)		
Nursing	32 (27)		
Other‡	2 (2)		

*Gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).

†Clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology and surgical oncology (n=1) and pathology (n=1). ‡Consultant radiographer (n=1) and missing response (n=1). (eg, well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks.

Composition follow-up appointments

All respondents in our sample reported that they followed up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient could be discharged if she remained disease-free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 responses (25%) and patient-initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these, 18/54 (33%) reported that patients have an opportunity to attend either a medical-led or a nurse-led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For patientinitiated appointments, 10/38 (26%) did not have a protocol with contact details (eg, a secretary, Macmillan nurse or general practitioner) for self-referrals. A total of 80/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg, combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than 2 weeks. Seven (6%) respondents from five different cancer networks answered that their practices scheduled urgent appointments in a period of 2–4 weeks, from which two of them also scheduled urgent patient-initiated appointments in the same time frame.

Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and 63% for patient-initiated appointments), while telephone follow-up care was provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they performed any type of routine surveillance test during follow-up. Routine tests were requested by 65% (76/117) respondents, of which 87% (66/76) requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and 9% (7/76) for endometrial cancer. In addition, respondents were asked to provide details of when these tests were performed but only a few responses were obtained. Table 3 shows the distribution of the different type of tests employed during follow-up.

CA125 measurement was the most frequently used test $(60/66 \ (91\%))$ during the follow-up of ovarian cancer patients. Other blood tests $(8/66 \ (12\%))$, for example, α -fetoprotein, carcinoembryonic antigen, CA19.9 and

	Regular	Telephone	Patient initiated 38/117 (32%)	
Positive responses	115/117 (98%)	29/117 (25%)		
Urgent follow-up bookings (wee	ks)			
<2	108/115 (94%)	29/29 (100%)	35/38 (92%)	
2–4	7/115 (6%)	0 (0%)	2/38 (5%)	
Responsible for follow-up				
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)	
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)	
Doctors and nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)	
Other*	2/115 (2%)	1/29 (3%)	1/38 (3%)	

missing response (n=1) for patient-initiated appointments.

inihibin were also requested. The routine use of CT and MRI scans for ovarian cancer was reported by 9/66 (14%) respondents (one respondent used both CT and MRI). Eight respondents stated that the CA125 test was performed at each visit. Another seven reported that CA125 was performed every 3 months during the first year after completion of treatment, of which two reported that they carried on with routine testing during the second year and four up to the fifth year every 6 months.

The use of MRI (15/35, (43%)) was the most common investigation employed in the follow-up of cervical cancer with cervical or vaginal cytology being the second most common method (14/35, (40%)). A wide variety of tests (8/35, (23%)) were reported in the follow-up of this type of cancer. Two of the respondents stated that they performed vault cytology for cervical cancer patients annually over a period of 5 years following hysterectomy, while three specialists reported carrying out the test at 6 and 18 months post-treatment.

Most respondents discharged their patients after 5 years of follow-up $(82/117 \ (70\%))$, three (3%) after 4 years, nine (8%) after three years and one (1%) after 2 years, whereas $22/117 \ (19\%)$ respondents did not answer this question.

DISCUSSION

The current survey is the first evidence reporting the extent of patient-initiated, specialist nurse or telephone

follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. While we know the membership of the professional societies invited to respond, we do not know whether the entire membership received or read their invitations to participate in our survey. Nonetheless, a low-response rate could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined specialty follow-up clinics were reported more often from network responses than for individual responses because positive network responses included respondents with at least one positive response in each network. Unfortunately, we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error as such responses may not accurately reflect local practice. We did not review the content of the follow-up protocols, and so we cannot verify if these variations represent locally approved practice within each network. Network guidelines may be adapted for local use or not followed exactly, so variations within networks could be expected. Our survey shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by

Table 3 Frequency of surveillance tests reported by type of test and cancer type								
	Ultrasound†	CA125	Other blood tests*	СТ	MRI	Cytology	Other‡	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

*Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

†Ultrasound includes: abdominal and transvaginal ultrasound.

‡Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

CA125, cancer antigen 125.

doctors in secondary care. Patient-initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient-initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for 5 years. Few routine tests are undertaken during follow-up to detect recurrence and they show no consistency, particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. However, cervical cytology is recommended for the follow-up of early-stage cervical cancer if the cervix is conserved and is based on expert opinion rather than on evidence.²⁷ Variation in the routine use of tests during follow-up is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not provide a survival benefit with early treatment of relapse.²⁸ Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%), whereas 67% of networks recommended such testing in an earlier survey by Kew and Cruickshank.¹ Respondents were asked not to include tests requested during treatment, but tests could have been included as part of the trial protocols. Vistad *et al*^{\circ} also published the results of a web-based survey of practice among gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with general practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up.²⁹ Furthermore, knowledge of recurrence, whether treatable or not, appears to be useful to patients³⁰ and information should be provided to detail the scope and limitations of follow-up.³ Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments.^{14 31} Knowing that different schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be to other carers.⁶ Follow-up may be in primary care, a hospital-based nurse-led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include risk stratification, where there are effective interventions for physical, psychological and social issues, as well as needs assessments, which are clearly patient-centred, as defined by the National Cancer Survivorship Initiative.³² Follow-up has to be multidisciplinary, designed for detection of morbidity as well as recurrence and with good communication

between professional groups. Informed patient choice regarding the mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand on unnecessary patient-initiated extra hospital appointments and patients may prefer fewer appointments.³¹ The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up, which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health, in collaboration with several leading gynaecological oncologists, has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: randomised controlled trial (RCT) for Endometrium or FIGURE). The proposal was for a multicentre randomised trial comparing standard (hospital) follow-up with a patient-initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree on the level of funding to allow the study to proceed. The Endometrial Cancer Telephone Follow-up Trial (ENDCAT)³³ has started recently. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again, this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer-Treated Patients (TOTEM)³⁴ is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression-free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of the practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al*¹⁵ reported no randomised studies on this subject. A trial similar to an early version of FIGURE should be revisited, which included follow-up for more than one gynaecological cancer site. In the present constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A multicentre RCT could assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for

most gynaecological cancers. The current survey may inform design of such a trial by providing data from the UK concerning national practice.

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Contributors RW conceived the idea for the survey and all authors designed the questionnaire and the method of the survey. RW, YS, NS and SL interpreted the data. All authors provided the text and reviewed the draft script and SL provided modifications as requested. All authors critically reviewed the script modifications.

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