

Title: Endometrial cancer patients' preferences for follow-up after treatment: a cross-sectional survey

Abstract

Purpose: Alternatives to hospital follow-up (HFU) following treatment for cancer have been advocated. Telephone follow-up (TFU) and patient-initiated follow-up are being implemented but it is unclear if these approaches will meet the preferences and needs of patients. This study aimed to explore the preferences of endometrial cancer patients and their levels of satisfaction with HFU and nurse-led TFU.

Methods: A cross-sectional survey design was utilised and a questionnaire was administered to 236 patients who had participated in a randomised controlled trial comparing HFU with TFU for women diagnosed with Stage I endometrial cancer (ENDCAT trial).

Results: 211 (89.4%) patients returned the questionnaire; 105 in the TFU group and 106 in the HFU group. The TFU group were more likely to indicate that appointments were on time ($p < 0.001$) and were more likely to report that their appointments were thorough ($p=0.011$). Participants tended to prefer what was familiar to them. Those in the HFU group tended to prefer hospital-based appointments while the TFU group tended to prefer appointments with a clinical nurse specialist, regardless of locality.

Conclusions: To provide patient centred follow-up services we need to ensure that patient preferences are taken into account and understand that patients may come to prefer what they have experienced. Patient initiated approaches may become standard and preferred practice but TFU remains a high-quality alternative to HFU and may provide an effective transition between HFU and patient-initiated approaches.

Highlights

Participants tended to prefer what they had experienced in terms of follow-up

Overall, high levels of satisfaction with information and service were reported

The telephone group were more likely to indicate that appointments were on time

The telephone group were more likely to report that their appointments were thorough.

Keywords:

Clinical nurse specialists

Endometrial cancer

Follow-up

Oncology

Patient preferences

Patient satisfaction

Telephone follow-up

Survey

Cross-sectional

1. Background

In 2018 there were 43.8 million people worldwide living with a cancer diagnosis (Cancer Atlas, 2019). It is predicted that there will be four million cancer survivors in the United Kingdom (UK) by 2030 (Maddams et al., 2012). Mortality rates are falling globally, and not just in high income countries (Hashim et al., 2016). However, the incidence of endometrial cancer is rising, associated with the global problems of obesity and diabetes (Arnold et al., 2015; Nagle et al., 2018). Since the early 1990s, endometrial cancer incidence rates have increased by 56% in women in the UK (Cancer Research UK, 2019a). Although incidence is rising, most (75%) endometrial cancers are diagnosed at an early stage. Five year survival for Stage 1 disease (confined to the uterus) is over 70% (Baekelandt and Castiglione, 2009). Similar survival rates are reported across Europe (Cancer Research UK, 2019b). The risk of recurrence is low (3% or less) for early stage disease and most recurrences are symptomatic (Fung-Kee-Fung et al., 2006, Jeppesen et al., 2017). Hence, increasing numbers of women treated for endometrial cancer will require information and support following treatment.

Providing follow-up services following treatment for increasing numbers of cancer survivors puts added pressure on health care providers. The traditional medical model of follow-up comprises attendance at hospital-based clinic appointments at regular intervals over a number of years to monitor progress. This approach is unsustainable from a practical and economic perspective but replacing hospital follow-up (HFU) with models of care that are clinically effective, cost effective and meet patients' needs is challenging.

For gynaecological cancers, the intention of HFU is to detect recurrence of cancer at an early stage and thereby improve survival (Nordin, 2006). Indeed, patients with gynaecological

cancers rank detection of recurrence as the most important reason for attending follow-up (Kew et al., 2009). However, regular scheduled hospital consultations for patients treated for gynaecological cancers do not bring a survival benefit and early detection of recurrence does not improve outcomes (Baekelandt and Castiglione, 2009; Kew et al., 2005; Tjalma et al., 2004). Despite the lack of evidence to support a clinical benefit, HFU remains common practice for gynaecological cancers (Leeson et al., 2013).

Providing follow-up services for patients treated for endometrial cancer may be particularly problematic in terms of health care resources, given the number of survivors. A number of clinical trials are taking place across Europe that investigate different strategies for follow-up of endometrial cancer patients (Leeson et al., 2017). So far, findings from two trials have been reported.

The ENDCAT trial, carried out in the UK, compared HFU with nurse-led telephone follow-up (TFU) for 259 women diagnosed with Stage 1 endometrial cancer (Beaver et al., 2017). In the TFU arm, clinical nurse specialists administered a structured telephone intervention intended to provide patients with the information they needed. High levels of satisfaction were evident for both study arms with no physical or psychological detriment reported from foregoing face-to-face consultations and clinical examinations. An economic evaluation indicated that the TFU service was no more costly to the National Health Service (NHS) than hospital-based follow-up (Dixon et al., 2018). Telephone appointments were convenient for patients, who appreciated the continuity of care provided by clinical nurse specialists (Williamson et al., 2018).

The OPAL study, carried out in Denmark, compared patient initiated follow-up with HFU for 156 women with Stage 1 endometrial cancer (Jeppesen et al., 2018). There were no scheduled hospital visits for patients randomised to patient-initiated follow-up, but patients were provided with information on signs and symptoms of recurrence and were given instructions on how to self-refer if they experienced any problems. While patient-initiated follow-up reduced health care use, fear of recurrence was slightly higher in the patient-initiated follow-up arm. Fear of recurrence has been reported as the main reason for cancer patients wanting regular surveillance (Lewis et al., 2009).

Although different approaches to cancer follow-up are being evaluated, it is not clear what patients prefer and preferences may not align with policy shifts away from hospital-based approaches. Gynaecological cancer patients may prefer specialist follow-up as hospital-based specialists are perceived as having higher levels of competence and providing more reassurance (Fidjeland et al., 2018). A Norwegian study reported that detection of recurrence was rated by 93% of gynaecological cancer patients (n=239) as being very important, with follow-up for late effects being more important for younger age groups (<50 years) and the clinical examination being more important for those who had experienced follow-up (Fidjeland et al., 2018). This implied that patients were not well informed as to the likely outcomes of hospital-based appointments and had an unrealistic view of what follow-up was about (Fidjeland et al., 2018). A systematic review also reported that cancer patients were not aware of the limitations of HFU and were not aware of the lack of effectiveness of examinations and tests (Lewis et al., 2009).

Patients may prefer more intensive hospital-based follow-up (Brandenburg et al., 2017) but may not be offered this service due to resource constraints. If new strategies are being proposed (including TFU and patient-initiated follow-up) it is important to understand the preferences and needs of patients. However, asking individuals who have only experienced HFU what they prefer may not be a reliable indicator of preference. Patients may prefer what they know and what is familiar to them (Frew et al., 2010; Salkeld et al., 2000).

Patient-initiated follow-up is being recommended for the more common types of cancer, especially for those at low risk of recurrence (NHS England, 2018) but it is unclear if this approach will meet the needs of patients. For example, Jeppesen et al. (2018) found that patients allocated to patient-initiated follow-up can experience an increased fear of recurrence. The Independent Cancer Taskforce in England proposed a strategy for providing holistic support from diagnosis onwards, including a consideration of patients' physical, psychosocial, financial, information and support needs (Independent Cancer Taskforce, 2015). The Taskforce reported that stratified follow-up pathways, including needs assessment, supported self-management, remote monitoring and re-entry pathways could be more effective approaches to follow-up than traditional medical models of follow-up.

Promotion of patient centred care that meets the needs of patients is central to current thinking on health care service delivery (NHS England, 2019). There has been a decisive shift away from hospital-based models of follow-up, on completion of treatment for cancer, to alternative approaches such as TFU and patient-initiated approaches. However, it is unclear what patients prefer and whether their needs are met by alternative models of follow-up. The current study aimed to establish preferences for follow-up service provision for patients

who had experienced HFU and/or TFU after treatment for endometrial cancer and their levels of satisfaction with information and service. It was anticipated that familiarity with an alternative approach to HFU may result in different preferences to those reported for patients who had not experienced alternative approaches. This study was carried out as part of the ENDCAT trial and was conducted on completion of the trial.

2. Aim

The aim of the study was to investigate preferences for type of follow-up, and satisfaction with information and service, for patients who had been treated for endometrial cancer and had experienced HFU and/or TFU by specialist nurses.

Methods

3.1 Design

A survey design was used to address the aims of the study, focused on patients who had participated in the ENDCAT trial (Beaver et al., 2017). The ENDCAT trial was a randomised controlled trial that compared HFU with TFU. The current study is a cross sectional survey that was conducted on completion of the ENDCAT trial and included all those participants who had been randomised. Although this was a cross sectional survey, we took account of randomised group when carrying out the analysis to make comparisons between groups.

3.2 Sample

Women had been eligible to participate in the ENDCAT trial if they had been diagnosed and treated for Stage 1 endometrial cancer, were attending hospital clinics for routine monitoring, had no clinical signs of recurrence and no hearing impediment that would negate the use of a telephone. A preference and satisfaction questionnaire was sent to 236

of the original 259 participants. Questionnaires were not sent to those who had indicated that they did not want to complete further questionnaires (n=10), had experienced a recurrence of disease (n=10), had been withdrawn from the study at their own request (n=2) or had died from unrelated causes (n=1). Socio-demographic data was collected at the time of recruitment. At the study end point, participants had been in the ENDCAT trial for a mean of 25 months (range 11 to 35 months). Participants had been randomised to either HFU, delivered primarily by medical doctors but also by specialist nurses, or TFU delivered by specialist nurses. All participants had received HFU prior to recruitment but only those randomised to TFU received this service. Questionnaires were sent to patients in November 2014 and data collection continued through to March/April 2015 as reminders were sent to those who did not return the questionnaire. Participants were asked to reflect on their experiences across the ENDCAT study period.

3.3 Access and Recruitment

Participants in the ENDCAT trial had been recruited across five hospitals in the North West of England. Clinical staff had identified eligible patients in hospital outpatient clinics where women had been attending for routine surveillance post treatment. Telephone follow-up had been introduced at the five hospitals specifically for the ENDCAT trial and had not been in operation prior to the study. Additional details on procedures followed in the trial have been reported elsewhere (Beaver et al., 2017).

3.4 Patient Preference and Satisfaction Questionnaire

The questionnaire was divided into five main sections. Questions were derived from previous questions used in a study on nurse-led telephone follow-up for women with breast (Beaver et al., 2009) and the ENDCAT trial (Beaver et al., 2017). Section 1 asked participants about their current follow-up status. That is, if they were still having follow-up appointments or not. An 'other' option was also included for participants to add further comment if their experience did not fit with the question.

Section 2 asked participants to consider their levels of satisfaction with their appointments (hospital or telephone) and their overall satisfaction with information received. There were four questions in this section asking about levels of satisfaction with hospital appointments with a doctor, hospital appointments with a specialist nurse, telephone appointments with a specialist nurse, and overall levels of satisfaction. Each item was scored on a numeric rating scale ranging from 1 (very unsatisfied) to 10 (very satisfied). A 'not applicable' option was also available as those participants who had been randomised to HFU should not have received telephone appointments. Some participants in the TFU arm of the study did receive hospital based follow-up appointments (n=14 at 6 months post randomisation, n=17 at 12 months post randomisation; Dixon et al., 2018) if the specialist nurse had any concerns that warranted a face to face consultation, usually to view a reported problem. Therefore, it was considered likely that some participants in the TFU arm would give a rating to HFU, based on their experiences prior to randomisation or as a result of being asked to attend a hospital consultation during the study period.

Section 3 focused on seven specific aspects of the follow-up appointments; I felt able to ask questions at my follow-up appointment, I had my questions answered, my appointments were always on time, I felt anxious before my appointments, I felt reassured after my appointment, and my appointments were very thorough. Participants were asked to score each item on a four-point Likert type scale, including 'always', 'most of the time', 'sometimes' and 'never'. A 'not applicable' option was also available.

Section 4 presented participants with a choice of eight different types of follow-up (Box 1). An 'other' option was also available and those who indicated 'other' were asked to explain what follow-up they would prefer. Participants were asked to indicate their top three choices by placing a 1, 2 or 3 next to the options that matched their favoured preferences. If participants had no preference, they could tick a 'no preferences' option and were not required to rate the preferences.

Insert Box 1 here

Section 5 was an open question asking participants if they had any comments to add concerning their follow-up care.

3.5 Data Collection

Ethical approval was obtained from the National Research Ethics Service in the UK (NRES reference number 11/NW/0648). Personal contact details for patients in the ENDCAT trial had been retained, with participant consent, for contact throughout the study (e.g. sending outcome measures and reminders). The satisfaction and preference questionnaire was sent

by post with a pre-paid return envelope. Written consent had been obtained from all study participants and completion and return of the questionnaire was taken as consent for continued participation.

3.6 Analysis

Descriptive statistics were used to describe the characteristics of the participants. Mean values and standard deviations (SD) were used to present the numeric rating scale data that measured the participant's levels of satisfaction with their appointments and information received and independent-samples t-tests were used to compare group differences in means, using the Satterthwaite approximation for the degrees of freedom when the group variances appeared to differ. Higher scores indicated higher levels of satisfaction.

Categorical data were reported in proportions (percentage) and differences between groups were tested using the Chi-Square test; Fisher's exact test was used if any expected cell frequency was <5. P-values <0.05 were considered statistically significant.

To obtain a rank order score for the follow-up preference data, first choice was awarded three points, second choice was awarded two points and third choice was awarded one point. For each preference option, the points were summed, and the total score used to rank participant's preferences across the groups, with a higher score indicating a stronger preference. All the statistical analyses were performed using SPSS version 25 (SPSS Inc., Chicago, IL, USA).

The qualitative data from the responses to the open-ended question were uploaded into NVivo 11 and analysed using content analysis procedures (Saldaña, 2009). All comments

were transferred verbatim and were read and re-read independently by two researchers (KB, SW). Comments were considered separately for the HFU and TFU groups and were initially coded according to whether they presented general comments in relation to follow-up or more specific comments on aspects of follow-up. The general comments were then coded as to whether they presented a favourable or unfavourable view of follow-up while the specific comments were coded according to the precise element of follow-up that was mentioned.

3. Results

Questionnaires were sent to 236 eligible women and a total of 211 (89.4%) participants returned the questionnaire; 105 in the TFU group and 106 in the HFU group. Most of the participants in the TFU (n=77, 73.3%) and HFU (n=82, 77.4%) groups were still attending follow-up appointments. The participant characteristics at the time of original recruitment are shown in Table 1. The mean age was 64.8 years (ranging from 36 to 88 years). Those in the HFU group were, on average, younger than in the TFU group (63.5 vs 66.2 years). The majority self-defined as White British and over half of the participants had retired from work (n=125, 59.2%). All the participants had undergone surgery, and six received radiotherapy.

Insert Table 1 here

Both groups expressed high levels of satisfaction with the follow-up service they received, evidenced by mean scores ranging from 8.46 to 9.51 (Table 2). Although participants in the HFU arm did not receive TFU, 13 participants rated this service rather than indicating 'not

applicable' or leaving the questions blank. It is not known why these 13 participants decided to rate TFU, as they were asked to comment on their follow-up consultations during the ENDCAT trial, but they may have been referring to ad-hoc telephone contact with a specialist nurse that was initiated by participants. Hospital appointments with a specialist nurse and overall satisfaction with information received were ranked more highly by the TFU group (Table 2). Given the difference in age between groups, we investigated, using linear modelling, whether the effect of treatment arm on overall satisfaction was confounded by age. The difference in satisfaction between trial arms was not confounded by age (unadjusted difference = 0.61, $p=0.023$; adjusted difference = 0.58, $p=0.032$, with age effect $p=0.45$).

Insert Table 2 here

The TFU group were more likely to indicate that follow-up appointments were always on time compared to the HFU group ($p < 0.001$) (Table 3). In addition, the TFU group were more likely to report that their appointments were thorough compared to the HFU group ($p=0.011$). There were no statistically significant differences between groups in terms of being able to ask questions, having questions answered, feeling anxious prior to appointments and feeling reassured (Table 3).

Insert Table 3 here

Participants were asked to indicate their follow-up preferences across nine options. Table 4 presents scores and rank ordering for preferences across the two groups. The top three

preferences for the HFU group were 'I would prefer appointments at the hospital with a doctor', 'I would prefer my first hospital appointment with a doctor and then hospital appointments with a specialist nurse' and 'I would prefer appointments at the hospital with a specialist nurse', with hospital appointments as a common denominator. The top three preference for the TFU group were 'I would prefer my first hospital appointment with a doctor and then telephone appointments with a specialist nurse', 'I would prefer telephone appointments with a specialist nurse' and 'I would prefer appointments at the hospital with a specialist nurse', with specialist nurses as a common denominator. There were 20 (9.5%) participants who expressed no preference. Two participants indicated 'other', although one of these participants made a comment about their follow-up rather than suggesting an alternative ("I feel it is important to have an examination"). One individual indicated that "I would prefer the first 5 appointments at the hospital, the rest on the telephone and the last at the hospital".

Insert Table 4 here

The majority of participants (n= 148, 70.1%) provided a response to the open-ended question with comments evenly distributed across the HFU (n=75) and TFU (n=73) groups. Comments were overwhelmingly positive, regardless of group allocation. Most comments were general in nature and related to high levels of satisfaction with health care staff and experiences of care and service.

For the HFU group, more specific positive comments related to feeling reassured by hospital appointments, knowing who to contact if they developed a problem and knowing that any

problem would be dealt with. Negative comments related primarily to needing more information on specific aspects of care, seeing different doctors at each appointment, long travelling distances and difficulties with car parking. Participants who needed more information identified the following information needs: symptoms of recurrence, information on support groups, and explanations for various symptoms being experienced. Being seen by different doctors at each hospital appointment was a cause for concern as participants perceived that each new doctor had little knowledge of their case.

'The quality of care from the doctors varied with each one. Some were 'good' others were not so good – one seems to have a poor knowledge of my case in spite of her assurance that she had read the notes!' (ID66, HFU)

'Perhaps more information about possible reoccurrence of the cancer and symptoms to look for would have been helpful.' (ID18, HFU)

For the TFU group, more specific positive comments related to knowing who to contact if they had a problem, the convenience of TFU, and being reassured by the consultation.

Negative comments related to a preference for face to face contact, missing the reassurance of a clinical examination, feeling isolated/unsettled and administrative problems with the organisation of telephone appointments.

'This study has showed me that I would prefer to be seen at the hospital although the phone calls are thorough. I would feel more settled seeing someone than talk over a telephone.'
(ID116, TFU)

'Happy with nurse follow-up but missed the reassurance of internal examinations.' (ID158, TFU)

4. Discussion

This study focused on women who had been treated for Stage 1 endometrial cancer and aimed to investigate preferences for type of follow-up and satisfaction with information and service. Participants had experienced HFU and/or TFU by clinical nurse specialists. Both groups expressed high levels of satisfaction with service but the TFU group were more satisfied with the information received. This is perhaps not surprising as the nurse-led telephone intervention was intended to provide patients with the information they needed. Although there were differences in mean age between groups, the estimated difference in satisfaction between groups was not confounded by the age differences. Competence and knowledge, through access to information, are key components of patient empowerment and a sense of control over health care decision making (Jørgensen et al., 2018). Although some patients may prefer less information to others or prefer different sources of information, engaging in positive communication with health care professionals and having access to information are key facilitators to patient empowerment (Jørgensen et al., 2018). A key part of clinical nurse specialists' role in cancer follow-up is to provide information and support to promote self-management and enable independence (Macmillan Cancer Support, 2014). Hence, interventions that are focused on information provision are likely to enable self-management and patient empowerment.

The TFU group were more likely to indicate that follow-up appointments were always on time compared to the HFU group. In the TFU arm, the clinical nurse specialists were handling their own case load of follow-up patients. In a hospital gynaecology oncology outpatient clinic there are both new and follow-up patients with differing diagnoses, stages of disease and treatment regimens. Keeping appointments to time is challenging in a busy hospital environment. We did not explore if patients were concerned about waiting times in hospital clinics but patients in an Australian study attributed waiting times to a 'problem of the system' and did not attribute blame to hospital staff; waiting times did not impact on trust in health care professionals (Ward et al., 2017). If patients are concerned about waiting times, the shift away from hospital-based approaches should be advantageous for patients.

The TFU group were more likely to report that their appointments were thorough compared to the HFU group and this may relate to the nature of the telephone intervention, which was designed to elicit and discuss information needs. Hospital clinic appointments are brief, especially for follow-up patients, with little time to focus on both physical and psychological issues. However, over 90% of both groups indicated that their appointments were thorough 'always' or 'most of the time'. This is a positive finding but we did not explore in detail how 'thorough' was defined by participants or their expectations of follow-up. A Canadian study reported that a large majority of endometrial cancer survivors were not aware of their risk for recurrence or how to monitor for this and were not provided with clear information in this regard (Jones et al., 2012). Participants in the Canadian study were also unclear about the late effects of cancer treatment, few had been told about the resources available to them and were not provided with information about self-management tools that could aid recovery (Jones et al., 2012).

In the UK, a Recovery Package is advocated for all patients treated for cancer by the UK's Department of Health, which includes holistic needs assessments, treatment summaries, patient education and wellbeing events and cancer care reviews in primary care (Department of Health, Macmillan Cancer Support & NHS Improvement, 2013). In theory, the Recovery Package should meet the information and support needs of patients and enable self-management. The Recovery Package is intended to be in place for all patients diagnosed with cancer by 2020, as indicated in the NHS England Five Year Forward View and the Cancer Taskforce Strategy (NHS England, 2014; Independent Cancer Taskforce, 2015), but it is not clear if all the elements of the Recovery Package are in place as yet at a national level.

Participants in this study tended to prefer the approach to follow-up that was familiar to them. This is encouraging for the implementation of alternative follow-up strategies as any new approach may not be favoured at the outset but, once patients have experienced it, views and preferences may alter. It would seem prudent to discuss the follow-up strategy to be implemented at an early stage in order that patient's expectations of follow-up can be managed effectively and patients can be provided with the information and sources of support they will need throughout the recovery process to enhance the ability to self-manage. The recent trend towards patient-initiated follow-up advocates a strong self-management and empowerment component to follow-up care (Kirshbaum et al., 2017; Jeppesen et al., 2019). A recent UK study reported high levels of satisfaction when patient-initiated follow-up was introduced for early stage endometrial cancer patients at a hospital in England (Kumarakulasingam et al., 2019). More contact with clinical nurse specialists was

made in the first six months of the scheme, primarily the reporting of physical symptoms, and younger women and women from ethnic minority groups were more likely to make contact, indicating that they needed greater levels of support (Kumarakulasingam et al., 2019). If there is an initial discomfort in transferring from HFU to patient-initiated follow-up, then TFU may provide a stepping stone for those who require psychological support and reassurance for a while longer.

Follow-up by a General Practitioner (GP) in primary care was not highly preferred by either group. Participants were more likely to prefer discharge from follow-up in preference to GP follow-up. This is an interesting finding as cancer care reviews in primary care are a key element of the Recovery Package advocated for all patients treated for cancer by the UK's Department of Health (Department of Health, Macmillan Cancer Support & NHS Improvement, 2013). We did not explore if participants had experienced a cancer care review and it may be that participants did not prefer GP follow-up because they were not familiar with this type of follow-up. Patients who have received GP follow-up on completion of treatment for melanoma have reported higher levels of satisfaction, when compared to patients who received HFU, and have appreciated the convenience of GP follow-up as well as reporting more thorough consultations (Murchie et al., 2010a; Murchie et al., 2010b). A systematic review has advocated a greater role for GP's in cancer follow-up care provision but also noted that patients may only feel comfortable accessing their GP for follow-up if they already have an established relationship (Meiklejohn et al., 2016). Participants in our study may have felt able to self-manage their condition and not require regular structured appointments with a GP. More work is still required to determine how primary care practitioners can meet the follow-up care needs of patients treated for cancer.

Overall, participants expressed their satisfaction with both HFU and TFU, although responses to the open-ended question indicated that there were differing reasons between groups for the levels of satisfaction reported. Participants in both groups were overwhelmingly positive about their experiences with staff and service. However, some participants in the HFU group lacked information and this may reflect the short duration of clinic appointments and lack of time available to discuss concerns. Some participants in the TFU group missed the reassurance of clinical examinations and felt more isolated, reflecting a lack of understanding on the likely outcome of the clinical examination. The responses to the open question cannot be considered akin to detailed and in-depth qualitative data but qualitative interview studies on TFU have indicated that patients treated for cancer appreciate the convenience of TFU and the continuity of care provider (Beaver et al., 2010, Cox & Faithfull, 2015; Williamson et al., 2015, Williamson et al., 2018).

Increased provider continuity of care can lead to increased levels of patient satisfaction and better health outcomes (van Walraven et al., 2010). Maintaining continuity of care provider in a hospital clinic environment is challenging as junior doctors rotate on a regular basis, although clinical nurse specialists have more permanence. From an organisational perspective, continuity of care from a clinical nurse specialist is more realistic and feasible. This is reflected in our findings as patients who had experienced clinical nurse specialist led TFU tended to prefer contact with a nurse specialist. Clinical nurse specialists have been reported as key facilitators of supportive follow-up care (Davies and Batehup, 2011). Studies on TFU for patients treated for different types of cancer have utilised the skills of specialist nurses in providing information for patients (Beaver et al., 2009; Beaver et al.,

2012; Cox et al., 2008; Kimman et al., 2010; Shaida et al, 2007). However, clinical nurse specialists are a scarce resource (Macmillan Cancer Support, 2014) and it is unlikely that they could provide TFU for all cancer survivors. Although patient-initiated follow-up approaches do not involve scheduled appointments with health care professionals, the success of patient-initiated follow-up is dependent on patients being provided with the information they need to self-manage (David and Batehup, 2011) and specialist nurses will continue to have a key role as providers of information on alarm symptoms and self-referral processes. Hence, the involvement of clinical nurse specialist in the implementation of any new follow-up approach is key to meeting the needs of patients.

No studies on alternative approaches to endometrial cancer follow-up have focused on survival as a primary outcome and it is not known if any of the approaches evaluated to date would prolong life. In the absence of such evidence it is important to focus on patient needs and preferences. A consideration of patients' physical, psychosocial, financial, information and support needs has been advocated (Independent Cancer Taskforce, 2015). Stratified follow-up pathways that include holistic needs assessment, supported self-management, remote monitoring and re-entry pathways have been indicated as the way forward (Independent Cancer Taskforce, 2015), and early indications are that self-management approaches for those at low risk of recurrence can meet patients' needs for information and support (Dickinson et al., 2014; Kirschbaum et al., 2017; Koinberg et al., 2004). Although we do not yet have a body of evidence on the clinical and cost effectiveness of self-management approaches, this is unlikely to prevent implementation as resources are currently not available to provide hospital-based care to all cancer survivors. There is still a valuable place for nurse-led TFU within the self-management models. Patients who have

only experienced HFU may have a strong preference for continued hospital contact and may feel that patient-initiated follow-up is too drastic a step at a time when they feel vulnerable and continue to have concerns and information needs. TFU could provide a useful stop gap to meet patients' needs but reduce the burden on hospital-based services.

5. Limitations.

Participants had taken part in a trial and therefore had agreed to undergo randomisation; they were all willing to experience either HFU or TFU. Hence, they did not have strong preferences to remain on HFU at the outset. This can be considered both a strength and a weakness; a strength in that participants were open to trying a new approach and were not biased towards one approach or another but a weakness in that they may have been happy to report satisfaction with whatever approach they had been allocated. Patient satisfaction measures can be prone to ceiling effects, with patients tending to report high levels of satisfaction (Voutilainen et al., 2016). A further limitation is that we asked participants to report preferences for services they had received but also services they had not received (GP follow-up and patient-initiated follow-up). Participants may have been reluctant to state a preference for a service they had not experienced. The study sample were predominantly white British, which does not reflect the UK's ethnic diversity or the inclusion/exclusion criteria for the ENDCAT trial as non-English speakers were not excluded from the study. It is not known why there was a lack of ethnic diversity within the sample but this may reflect the global challenge of ensuring representation of minority groups in cancer clinical trials (Chen et al., 2014, Symonds et al., 2012). Hence, more work is needed in this area to explore the information and support needs and follow-up preferences of different minority communities.

6. Conclusion

To provide truly patient-centred follow-up services for patients who have been treated for endometrial cancer we need to ensure that patient preferences are taken into account. However, this needs to be tempered with the knowledge that patients may come to prefer what they have experienced. Although the introduction of patient-initiated follow-up approaches may become standard and preferred practice for patients treated for different types of cancer, TFU remains a high-quality alternative to HFU and may provide an effective transition between HFU and patient-initiated follow-up.

Conflict of interest

None declared

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References

- Arnold, M., Pandeya, N., Byrnes, G., Renehan, A.G., Stevens, G.A., Ezzati, M. et al. 2015. Global burden of cancer attributable to high body-mass index in 2012: a population-based study. *Lancet Oncology*. 16 (1), 36-46
- Baekelandt, M.M., Castiglione, M. 2009. On behalf of the ESMO Guidelines Working Group. Endometrial carcinoma: ESMO clinical recommendations for diagnosis, treatment and follow-up. *Annals of Oncology*. 20 (4), 29–31
- Beaver, K., Campbell, M., Williamson, S., Procter, D., Sheridan, J., Heath, J., Susnerwala, S. 2012. An exploratory trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Disease*. 14 (10), 1201-1209
- Beaver, K., Tysver-Robinson, D., Campbell, M., Twomey, M., Williamson, S., Hindley, A., Susnerwala, S., Dunn, G., Luker, K. 2009. Comparing hospital and telephone follow-up after treatment for breast cancer: a randomised equivalence trial. *British Medical Journal*. 338; a3147
- Beaver, K., Williamson, S., Sutton, C., Hollingworth, W., Gardner, A., Allton, B., Abdel-Aty, M., Blackwood, K., Burns, S., Curwen, D., Ghani, R., Keating, P., Murray, S., Tomlinson, A., Walker, B., Willett, M., Wood, N., Martin-Hirsch, P. 2017. Comparing hospital and telephone follow-up for patients treated for Stage I endometrial cancer (ENDCAT Trial): a randomised, multicentre, non-inferiority trial. *BJOG: An International Journal of Obstetrics and Gynaecology*. 124(1), 150-160
- Beaver, K., Williamson, S., Chalmers, K. 2010. Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing*. 19(19), 2916-2924
- Brandenburg, D., Berendsen, A.J., de Bock, G.H. 2017. Patients' expectations and preferences regarding cancer follow-up care. *Maturitas*. 105, 58-63
- Cancer Atlas. 2019. Cancer Survivorship

<https://canceratlas.cancer.org/the-burden/cancer-survivorship/>

Accessed 17.12.19

Cancer Research UK. 2019a. Cancer Statistics: Uterine Cancer.

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/uterine-cancer#heading-Zero>

Accessed 22.07.19

Cancer Research UK. 2019b. Cancer Statistics: Uterine Cancer

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/uterine-cancer/survival#heading-Five>

Accessed 22.07.19

Chen, M.S., Lara, P.N., Dang, J.H.T., Paterniti, D.A., Kelly, K. 2014. Twenty years post-NIH Revitalization Act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual. *Cancer*. 120(Suppl 7), 1091–6

Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C., Faithfull, S. 2008. Nurse led telephone follow up in ovarian cancer: a psychosocial perspective. *European Journal of Oncology Nursing*. 12(5), 412-417

Cox, A., Faithfull, S. 2015. Aiding a reassertion of self: a qualitative study of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up. *Supportive Care in Cancer*. 23,2357–2364

Davies, N.J., Batehup, L. 2011. Towards a personalised approach to aftercare: a review of cancer follow-up in the UK. *Journal of Cancer Survivorship*. 5, 142-51

Dickinson, R., Hall, S., Sinclair, J.E., Bond, C., Murchie., P. 2014. Using technology to deliver cancer follow-up: a systematic review. *BMC Cancer*. 14, 311

Department of Health, Macmillan Cancer Support & NHS Improvement, 2013. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf Accessed 22.07.19

Dixon, P., Beaver, K., Williamson, S., Sutton, C., Martin-Hirsch, P., Hollingworth, W. 2018. Economic evaluation alongside a randomized controlled trial of hospital versus telephone follow-up after treatment for endometrial cancer. *Applied Health Economics and Health Policy*. 16 (3), 415–427

Fidjeland, H.L., Brekke, M., Stokstad, T., Vistad, I. 2018. Gynecological cancer patients' attitudes toward follow-up care after cancer treatment: Do preferences reflect patients' experience? A cross-sectional questionnaire study. *Acta Obstetrica et Gynecologica Scandinavica*. 97, 1325-1331

Frew, G., Smith, A., Zutshi, B., Young, N., Aggarwal, A., Jones, P., Kockelbergh, R., Richards, M., Maher, E.J. 2010. Results of a quantitative survey to explore both perceptions of the purposes of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. *Clinical Oncology*. 22, 874-884

Fung-Kee-Fung, M., Dodge, J., Elit, L., Lukka, H., Chambers, A., Oliver, T. 2006. Follow-up after primary therapy for endometrial cancer: a systematic review. *Gynecologic Oncology*. 101, 520-529

Hashim, D., Boffetta, P., La Vecchia, C., Rota, M., Bertuccio, P., Malvezzi, M., Negri, E. 2016. The global decrease in cancer mortality: trends and disparities. *Annals of Oncology*. 27, 926–933

Independent Cancer Taskforce. 2015. Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020.

https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf. Accessed 22.07.19

Jeppesen, M.M., Jensen, P.T., Hansen, D.G., Christensen, R.D., Mogensen, O. 2018. Patient-initiated follow-up affects fear of recurrence and healthcare use: a randomised trial in early-stage endometrial cancer. *BJOG: An International Journal of Obstetrics and Gynaecology*. 125(13), 1705-1714

Jeppesen, M.M., Mogensen, O., Hansen, D.T., Bergholdt, S.H, Jensen, P.T. 2019. How do we follow up patients with endometrial cancer? *Current Oncology Reports*. 21,57

Jeppesen, M.M., Mogensen, O., Hansen, D.T., Iachina, M., Korsholm, M., Jensen, P.T. 2017. Detection of recurrence in early stage endometrial cancer – the role of symptoms and routine follow-up. *Acta Oncologica*. 56(2), 262-269

Jones, J.M, Ferguson, S., Edwards, E., Walton, T., McCurdy, N., Howell, D. 2012. Experiences of care delivery: endometrial cancer survivors at end of treatment. *Gynecology Oncology*. 124, 458-464

Jørgensen, C.R., Thomson, T.G., Ross, L., Dietz, S.D., Therkildsen, S., Groenveld, M., Rasmussen, C.L., Johnsen, A.T. 2018. What facilitates “patient empowerment” in cancer patients during follow-up: a qualitative systematic review of the literature. *Qualitative Health Research*. 28(2), 291-304

Kew, F., Galaal, K., Manderville, H. 2009. Patients’ views of follow-up after treatment for gynaecological cancer. *Journal of Obstetrics and Gynaecology*. 29(2), 135–142

Kew, F.M., Roberts, A.P., Cruickshank, D.J. 2005. The role of routine follow-up after gynecological malignancy. *International Journal of Gynecological Cancer*. 15, 413-9

Kimman, M.L., Bloebaum, M.M.F., Dirksen, C.D., Houben, R.M.A, Lambin, P., Boersma, L.A. 2010. Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC Cancer*. 10, 174

Kirshbaum, M.N., Dent, J., Stephenson, J., Topping, A.E., Allinson, V., McCoy, M., Brayford, S. 2017. Open access follow-up care for early breast cancer: a randomised controlled quality of life analysis. *European Journal of Cancer Care*. 26, e12577

Koinberg, I.L., Fridlund, B., Engholme, G.B, Holmberg, F. 2004. Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study. *European Journal of Oncology Nursing*. 8, 109-117

Kumarakulasingam, P., McDermott, H., Patel, N., Boulter, L., Tincello, D.G, Peel, D., Moss, E.L. 2019. Acceptability and utilisation of patient initiated follow-up for endometrial cancer amongst women from diverse ethnic and social backgrounds: a mixed methods study. *European Journal of Cancer Care*. 28, e12997

Leeson, S.C., Beaver, K., Ezendam, N.P.M., Maćuks, R., Martin-Hirsch, P.L., Miles, T., Jeppesen, M.M., Jensen, P.T., Zola, P. 2017. The future for follow-up of gynaecological cancer in Europe. Summary of available data and overview of ongoing trials. *European Journal of Obstetrics and Gynecology and Reproductive Biology*. 210, 376–380

Leeson, S., Stuart, N., Sylvestre, Y., Hall, L., Whitaker, R. 2013.. Gynaecological cancer follow-up: national survey of current practice in the UK. *BMJ Open*. 3, e002859

Lewis, R.A., Neal, R.D., Williams, N.H., France, B., Hendry, M., Russell, D., Hughes, D.A., Russell, I., Stuart, N.S.A., Weller, D., Wilkinson, C. 2009. Follow-up of cancer in primary care versus secondary care: systematic review. *British Journal of General Practice*. 59, e234-47

Macmillan Cancer Support. 2014. A Competence Framework for Nurses – Caring for Patients Living with and Beyond Cancer. [www.macmillan.org.uk/ images/competence-framework-for-nurses_tcm9-297835.pdf](http://www.macmillan.org.uk/images/competence-framework-for-nurses_tcm9-297835.pdf). Accessed 22.07.19

Macmillan Cancer Support. 2014. Working together: challenges, opportunities and priorities for the UK's cancer workforce.

https://www.macmillan.org.uk/_images/workforcediscussiondoc_tcm9-295356.pdf.

Accessed 22.07.19

Maddams, J., Utley, M., Møller, H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 107, 1195–1202

Meiklejohn, J.A., Mimery, A., Martin, J.H., Bailie, R., Garvey, G., Walpole, E.T., Adams, J., Williamson, D., Valery, P.C. 2016. The role of the GP in follow-up cancer care: a systematic literature review. *Journal of Cancer Survivorship*. 10, 990-1011

Murchie, P., Nicolson, M.C, Hannaford, P.C., Raja, E.A., Lee, A.J., Campbell, N.C. 2010a. Patient satisfaction with GP-led melanoma follow-up: a randomised controlled trial. *British Journal of Cancer*. 102, 1447-1455

Murchie, P., Delaney, E.K., Campbell, N.C., Hannaford, P.C. 2010b. GP-led melanoma follow-up: views and feelings of patient recipients. *Supportive Care in Cancer*. 18, 225-233

Nagle, C.M., Crosbie, E.J., Brand, A., Obermair, A., Oehler, M.K., Quinn, M., Leung, Y., Spurdle, A.B., Webb, P.M. for the Australian National Endometrial Cancer Study group. 2018. The association between diabetes, comorbidities, body mass index and all-cause and cause-specific mortality among women with endometrial cancer. *Gynecologic Oncology*. 150, 99-105

NHS England. 2019. Developing patient centred care.

<https://www.england.nhs.uk/integrated-care-pioneers/resources/patient-care/>. Accessed 20.12.19

NHS England. 2018. Supporting people to live better with and beyond cancer.

<https://www.england.nhs.uk/cancer/living/>. Accessed 22.07.19

NHS England. 2014. Five year forward view. <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>. Accessed 22.07.19

Nordin, A.J. on behalf of the National Group of Gynaecology NSSG leads. 2006. Mode of detection of recurrent gynaecological malignancy: does routine follow-up delay diagnosis and treatment? *International Journal of Gynecological Cancer*. 16, 1746-1748

Saldaña, J. 2009. *The Coding Manual for Qualitative Researchers*. Sage Publications Ltd: London, UK

Salkeld, G., Ryan, M., Short, L. 2000. The veil of experience: do consumers prefer what they know best? *Health Economics*. 9, 267-270

Shaida, N., Jones, C., Ravindranath, N., Das, T., Wilmott, K., Jones, A., Malone, P.R. 2007. Patient satisfaction with nurse-led telephone consultation for the follow-up of patients with prostate cancer. *Prostate Cancer and Prostatic Diseases*. 10, 369–373

Symonds, R.P., Lord, K., Mitchell, A.J., Raghavan, D. 2012. Recruitment of ethnic minorities into cancer clinical trials: experience from the front lines. *British Journal of Cancer*. 107, 1017–21

Tjalma, W.A.A., Vandam, P.A., Makar, A.P., Cruickshank, D.J. 2004. The clinical value and cost-effectiveness of follow-up in endometrial cancer patients. *International Journal of Gynecological Cancer*. 14, 931-937

van Walraven, C., Oake, N., Jennings, A., Forster. 2010. The association between continuity of care and outcomes: a systematic and critical review. *Journal of Evaluation in Clinical Practice*. 16, 947-956

Voutilainen, A., Pitkäaho, T., Kvist, T., Vehviläinen-Julkunen, K. 2016. How to ask about patient satisfaction? The visual analogue scale is less vulnerable to confounding factors and ceiling effect than a symmetric Likert scale. *Journal of Advanced Nursing*. 72(4), 946-957

Ward, P.R., Rokkas, P., Cenko, C., Pulvirenti, M., Dean, N., Carney, S.A. 2017. Waiting for' and 'waiting in' public and private hospitals: a qualitative study of patient trust in South Australia. *BMC Health Services Research*. 17,333

Williamson, S., Beaver, K., Gardner, P., Martin-Hirsch, P. 2018. Telephone follow-up after treatment for endometrial cancer: A qualitative study of patients' and clinical nurse specialists' experiences in the ENDCAT trial. *European Journal of Oncology Nursing*. 34, 61-67

Williamson, S., Chalmers, K., Beaver, K. 2015. Patient experiences of nurse-led telephone follow-up after treatment for colorectal cancer. *European Journal of Oncology Nursing*. 19(3), 237-243

Box 1. Preferences for follow-up

- I would prefer appointments at the hospital with a doctor
- I would prefer appointments at the hospital with a specialist nurse
- I would prefer telephone appointments with a doctor
- I would prefer telephone appointments with a specialist nurse
- I would prefer my first hospital appointment with a doctor and then telephone appointments with a specialist nurse
- I would prefer my first hospital appointment with a doctor and then hospital appointments with a specialist nurse
- I would prefer to have my follow-up appointments with my General Practitioner (GP)
- I would prefer to be discharged from follow-up after treatment as long as I know who to contact if I have a problem
- Other (please explain)
- No preferences

Table 1. Characteristics of the study sample (n=211)

	Total (n=211)		TFU (n=105)		HFU (n=106)	
Age (years): Mean (SD)	64.8 (8.8)		66.2 (8.3)		63.5 (9.2)	
	n	%	n	%	n	%
Marital Status						
Married/co-habiting/civil partnership	163	77.3	78	74.3	85	80.2
Divorced/separated	14	6.6	7	6.7	7	6.6
Widowed	21	10.0	12	11.4	9	8.5
Never married	13	6.2	8	7.6	5	4.7
Employment Status						
Working full time	40	19.0	15	14.3	25	23.6
Working part time	38	18.0	20	19.0	18	17.0
Retired from work	125	59.2	65	61.9	60	56.6
Unemployed	1	0.5	0	0.0	1	0.9
Long term sick	3	1.4	2	1.9	1	0.9
Never worked	4	1.9	3	2.9	1	0.9
Educational level						
No formal qualifications	27	12.8	14	13.3	13	12.3
Certificate/diploma/vocational	171	81.0	84	80.0	87	82.1
Degree	13	6.2	7	6.7	6	5.7
Ethnic group						
White	209	99.0	104	99.0	105	99.1
Indian	1	0.5	1	1.0	0	0.0
Polish	1	0.5	0	0.0	1	0.9

TFU: Telephone follow-up. HFU: Hospital follow-up

Table 2. Satisfaction with service provider and information received

	Group	n	mean	SD	T	p
Hospital appointments with a doctor	HFU	99	8.78	2.23	-1.49	0.139
	TFU	57	9.21	1.40		
Hospital appointments with a specialist nurse	HFU	63	8.83	2.12	-2.11	0.037
	TFU	49	9.51	1.29		
Telephone appointments with a specialist nurse	HFU	13	8.46	2.79	-1.30	0.216
	TFU	102	9.48	1.17		
Overall, satisfaction with information received	HFU	102	8.79	2.39	-2.29	0.023
	TFU	102	9.40	1.20		

HFU: hospital follow-up; TFU: Telephone follow-up

Table 3. Satisfaction with service received

		HFU		TFU		χ^2	df	p
		n	%	n	%			
I felt able to ask questions at my follow-up appointments	Always/Most of the time	99	95.2	102	98.1	1.33	1	0.445*
	Sometimes/Never	5	4.8	2	1.9			
I had my questions answered	Always/Most of the time	99	96.1	103	99.0	1.87	1	0.212*
	Sometimes/Never	4	3.9	1	1.0			
My follow-up appointments were always on time	Always/Most of the time	74	71.2	99	99.0	30.68	1	<0.001
	Sometimes/Never	30	28.8	1	1.0			
I felt anxious before my appointments	Always/Most of the time	23	22.1	15	14.7	1.88	1	0.170
	Sometimes/Never	81	77.9	87	85.3			
I felt reassured after my appointments	Always/Most of the time	96	91.4	95	95.0	1.03	1	0.311
	Sometimes/Never	9	8.6	5	5.0			
My appointments were very thorough	Always/Most of the time	95	91.3	100	99.0	6.49	1	0.011
	Sometimes/Never	9	8.7	1	1.0			

*Fisher's Exact test as minimum expected cell frequency <5. HFU: hospital follow-up; TFU: telephone follow-up

Table 4. Preferences for follow-up

Preference	HFU		TFU	
	Rank	Score	Rank	Score
I would prefer appointments at the hospital with a doctor	1	171	5	50
I would prefer my first hospital appointment with a doctor and then hospital appointments with a specialist nurse	2	107	4	53
I would prefer appointments at the hospital with a specialist nurse	3	92	3	65
I would prefer to be discharged from follow-up after treatment as long as I know who to contact if I have a problem	4	50	6	41
I would prefer my first hospital appointments with a doctor and then telephone appointments with a specialist nurse	5	40	1	151
I would prefer telephone appointments with a specialist nurse	6	22	2	149
I would prefer to have my follow-up appointments with my GP	7	18	8	17
I would prefer telephone appointments with a doctor	8	14	7	23

HFU: hospital follow-up; TFU: Telephone follow-up