West Midlands Cancer Alliance

Personalised Follow Up Guidelines for people with an Endometrial Cancer Diagnosis

Audience: Healthcare staff supporting people diagnosed with endometrial cancer

Version number: 1.0

1. **Date:**
2. **First published:**
3. **Update:**

Created by: West Midlands Cancer Alliance, Gynaecology Expert Clinical Advisory group.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact WMCA on

Document Control:

Version	Date	Details/provenance/comments	Status	Revision Author	Sent to
0.1	Aug 2024	Based on standardised guidance updated for endometrial cancer	Draft	SSm	SS/ DP
0.2	Sept 2024	Amendments from DP accepted	Draft	SSm	
0.2	Sept 2024	Presented to Gynaecology EAG to be taken for clinical approval at Gynaecology EAG	Draft	SSm	
0.3	Oct 2024	Updated comments from SS accepted	Draft	SSm	Gynae EAG
0.4	Nov 2024	Gynae EAG membership	Draft	SSm	Gynae EAG
0.4	Dec 2024	Gynae EAG membership	Draft	SSm	Gynae EAG

Approval by

Governance	Description	Who	Date
Chair of Gynaecology Expert Clinical Advisory Group	Document signed off and approved	Gynae EAG membership	17 December 2024
WMCA Board	Document signed off and approved	WMCA Board Membership	29 January 2025

Contents

1. Introduction and Purpose of this Guideline

This guideline is for personalised follow up for people with an endometrial cancer diagnosis. It spans primary and secondary care and covers the care of the individual who has completed their treatment for endometrial cancer.

The purpose of this document is to provide best practice details specific to endometrial cancer and should be read in conjunction with '**Personalised Stratified Follow Up Guidelines for people with a cancer diagnosis'** which provides more detailed general guidelines on the WMCA website.

This document is intended as a flexible resource to help Trusts implement the Personalised Stratified Follow-Up pathway for patients with primary endometrial cancer.

Context

In 2015, there were an estimated 2.5 million people living with cancer across the UK. By 2030, that number is estimated to reach around four million. There is increasing evidence that the current arrangements for follow-up do not meet all the needs of those living with the consequences of their cancer, and its treatment. Support for patients living with a cancer diagnosis should be centred on the individual to address their specific needs and delivered at the right time, in the right way to both support and empower. There is a fundamental difference between living with a cancer diagnosis and living well.

Cancer Research UK report that Endometrial cancer is the 4th most common cancer in women in the UK (2017) and the majority can expect to survive their disease.

Improving cancer pathways through implementation of Personalised Stratified follow-up pathways for all clinically appropriate cancers is identified as a priority within the NHS Long Term Plan, including improving access to personalised care of patients diagnosed with cancer through ongoing needs assessment, robust care planning and provision of support (2021).

The increasing incidence of endometrial cancer and the improvement in treatment options has positively impacted upon the survival rate for women affected. However, Trusts are witnessing an increase in demand for cancer services. The NHS Long Term Plan and Planning and Operational Guidance has placed a strong emphasis on improving the cancer waiting time recovery particularly for the 62-day referral to treatment waiting time standard. The introduction of Personalised Stratified Follow Up (PSFU) will enable the reduction in outpatient activity freeing up clinical capacity to focus on timely patient treatment and care, patient quality outcomes and NHS efficiency.

Many publications and research papers including The British Gynaecological Cancer Society supports ‘patient initiated follow up’ recognising that the historical model of 5-10 years follow up after diagnosis and treatment no longer meet the aims of follow up although the long-term oncological outcomes of reduced clinical follow-up have yet to be confirmed.

Original aims of follow up were to:

- Detect asymptomatic recurrences with the assumption it will improve prognosis.
- Detection and management of side effects of treatment
- Improve quality of life
- Identification and treatment of patient concerns and anxieties around their cancer diagnosis

Now:

- There is no evidence that intensive follow up improves survival.
- Women often find clinical examination uncomfortable (especially vaginal examination)
- Many experience increased anxiety before their appointment
- Overall survival when a recurrence is symptomatic at detection or asymptomatic is not significantly different [1, 2].
- The majority (up to 90%) of recurrences present with symptoms, with an asymptomatic recurrence being identified in only 2.3% of the total population [3].
- There is the concern that a proportion of patients who are symptomatic while on hospital follow-up, delay presentation until their next scheduled appointment rather than seeking an earlier appointment [4].
- A cost analysis of patient initiated follow up demonstrated significant savings in resources – based on 187 women with a median of 37 months follow up after primary surgery, a 93.5% reduction in costs for hospital follow up and a 95.6% reduction in patient related costs [5].
- Luqman[5] notes that many studies report that the majority of endometrial cancer recurrences occur within the first 3 years, categorizing cases by risk shows that the peak incidence of low-risk endometrial cancer relapse appears to be later, namely 4–6 years after diagnosis as compared with 1–3 years with intermediate- and high-risk endometrial cancer[6]. “However, the low recurrence rate in the low-risk endometrial cancer population, would mean that extending hospital follow-up would incur increasing costs with very few recurrences detected”[5].

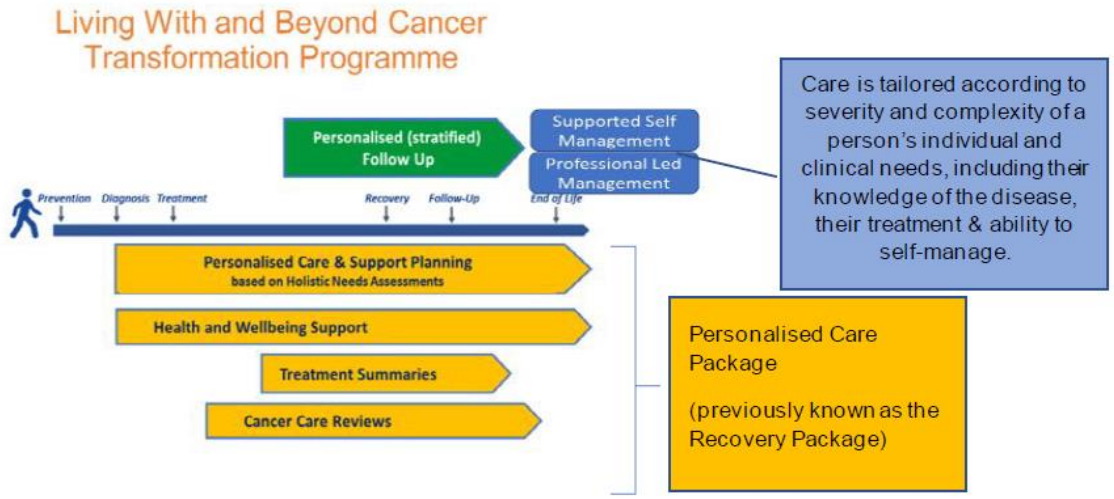
It should also be borne in mind that:[6].

- This low-risk group is associated with a 10-year overall survival rate of 94.1% and a low risk of recurrence of 6%[6] and up to 90% (all risk levels) present with symptoms[3].

Background to Personalised Follow Up

Personalised Stratified Follow-Up (PSFU) is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that we are providing world class services. The implementation of PSFU pathways tailored to individual needs offers huge benefits to patients and the NHS. Furthermore, stratified follow-up improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

Personalised follow-up is for people diagnosed with cancer to be able to access help and empower them to self-manage and live well with and beyond cancer with a greater emphasis on quality of life and responsibility to the individual. It is beneficial to the individual and as a way to address capacity issues within the NHS. The diagram below illustrates the programme driving this.



Levels of follow-up support

This document describes the pathway for people with an endometrial cancer diagnosis. It defines the levels of follow-up support available to them:

- Supported self-management follow up.
- Professional led follow up (including best supportive care)
- All individuals diagnosed with cancer, irrespective of their risk of recurrence receive co-ordinated supportive care with rapid re-entry (open access) to the specialist cancer team as required.

Personalised Follow Up Pathways
Types of Personalised Follow Up

The follow up schedule broadly revolves around two central tenets:

I. Oncological risk of recurrence (pathological / radiological staging)

• Low risk
- Intermediate risk
- High Risk
- Radiotherapy
- Metastatic Disease

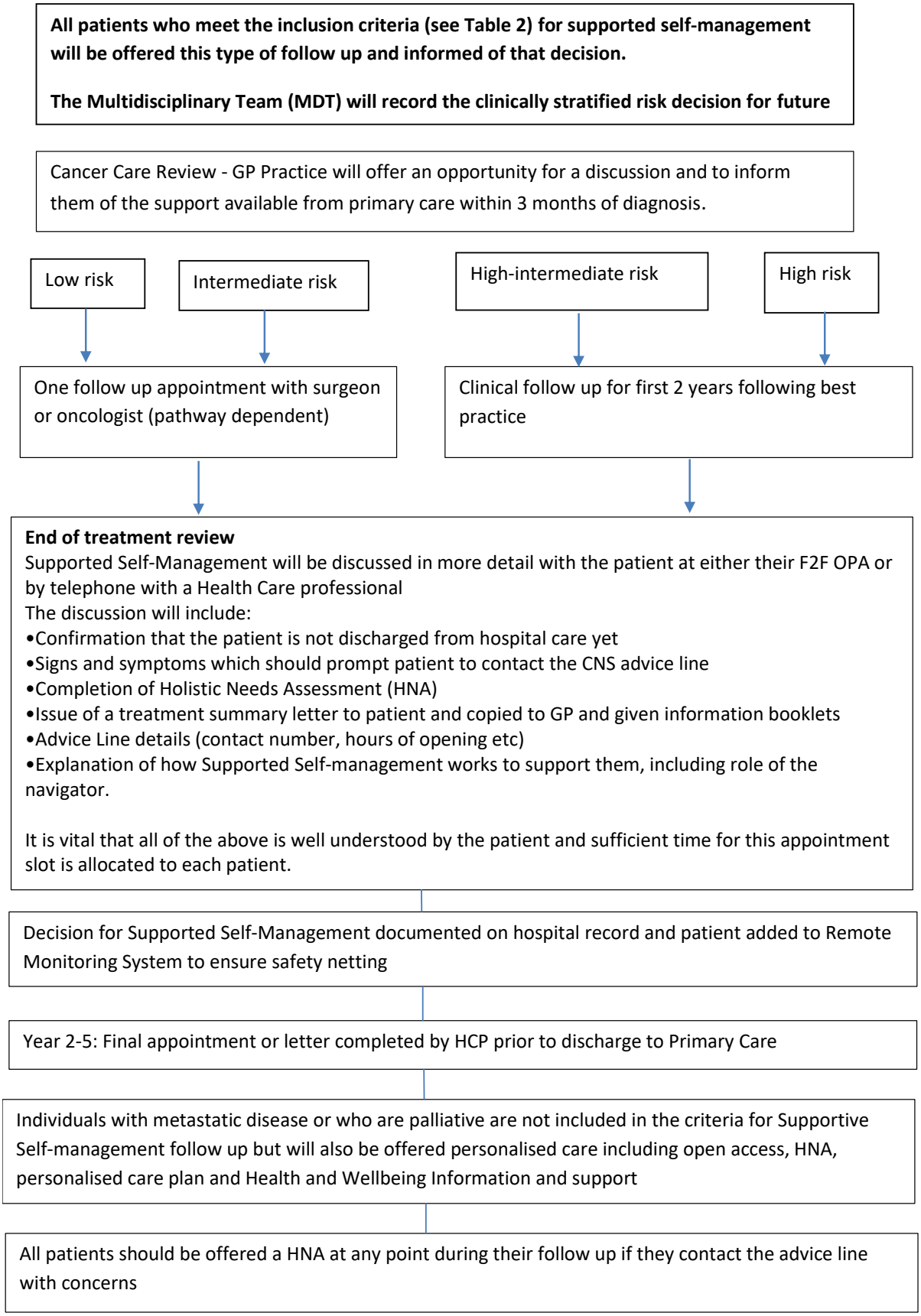
II. Method of Delivery (See Table 2)
- Supported self-management.
- Professional led (includes best supportive care)

Personalised Follow Up: The Pathway
WMCA Endometrial Cancer Personalised Care Pathway

The care pathway route for all individuals with endometrial cancer is shown below in Figure 1

Figure 1 – Endometrial Cancer follow up pathway

Stratified Follow up Algorithm for Endometrial Cancer



Diagnosis and Treatment

There are four elements to the personalised care package:
This document recommends all women with an endometrial cancer diagnosis, including secondary cancer, receive or are offered a personalised care package made up of:

Personalised Care Package

- Personalised Care and support plan (PCSP) based on a Holistic Needs Assessment (HNA)
- Health and wellbeing support and information (HWBSI)
- Treatment Summary (TS)
- Cancer Care Review (CCR)

At diagnosis, individuals will be informed, at a suitable time for them, about supported self-management and professional-led follow up pathways; Open Access; and Health and Wellbeing support and information.
Individuals with secondary cancer will be offered personalised care based around the professional-led pathway follow up model.
The Multidisciplinary Team (MDT), following the decision on treatment recommendation, will record the clinically stratified decision in the individuals notes as defined in the **(Appendix A)**

Personalised Care and Support Plan including Holistic Needs Assessment

A Holistic Needs Assessment (HNA) is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues. It informs the development of a Personalised Care and Support Plan (PCSP) for the woman following discussions with their specialist gynaecology nurse (often a Clinical Nurse Specialist) or key worker, highlighting the most important issues at that time that need to be addressed during or after treatment.

Health and Wellbeing Support and Information (HWBS&I)

All individuals will have access to health and wellbeing support and information at suitable points in the pathway. (See **Appendix G** for further information)

Treatment Summary (TS)

A Treatment Summary (TS) is a document produced by a healthcare professional after a significant phase of an individual's cancer treatment. It is designed to be shared with the person living with cancer and their primary care team, to enable them to manage their health and wellbeing.
TSs are essential for good quality and safe open access follow up and effective Cancer Care Reviews. Personalised follow up should not be undertaken without treatment summaries being completed. Key information that needs to be included in these important documents include.

- Symptoms Checklist – This is particularly important for women with endometrial cancer as there are no routine surveillance tests for recurrence at present, so it is detected mainly through symptoms. It is recommended a

checklist is given to all women diagnosed with cancer as a means of highlighting symptoms that should trigger obtaining advice from the specialist CNS. Much of this can be assessed over the phone, some may necessitate an outpatient appointment or signposting to late effects service or their GP.

NB: People living with cancer and clinicians may differ as to what constitute significant symptoms. People who experience these symptoms may require follow up by trained staff to support them.

Key symptoms that require urgent re-access to the specialist secondary care team include:

1	Vaginal bleeding	5	Change in bowel or bladder habit which persists for 2 weeks or more
2	Persistent vaginal discharge	6	Persistent loss of appetite, nausea or weight loss
3	New unilateral or bilateral leg swelling	7	New persistent breathlessness
4	New persistent low abdominal pain or discomfort which persists for 2 weeks or more	8	New back pain which persists or progresses over 2 weeks or more

Possible treatment toxicities/consequences of disease and/or treatment and late effects which can impact women living with endometrial cancer may include:

- Bladder & bowel symptoms:
- Changes in bowel habits such as diarrhoea or constipation
- Cramps or spasms in the bowel
- Bleeding from the back passage
- Needing to pass urine more frequently
- Unable to wait to empty the bladder
- Blood in urine
- Shortening and / or narrowing of the vagina
- Lymphoedema of the legs (fluid swelling)
- Menopausal symptoms
- Sexual or psychosexual problems

National Pelvic Radiation Disease Association **https://www.prda.org.uk/**

Other information to include:

- Contact name, phone number and working hours of the specialist team.
- Include whether the individual is eligible or not for free prescriptions

- Information that the individual will receive a national ‘quality of life’ survey 18 months after their cancer diagnosis
- Encourage women to take up invitations to participate in both breast and bowel national screening programmes as there are some shared lifestyle risk factors with endometrial cancer

A copy of the Treatment Summary from the end of treatment review will be sent to the individual and their GP as soon as possible following their review.

Treatment summary codes shown below are recommended to go at the top of Treatment Summaries when people diagnosed with cancer have finished an active treatment (e.g.: Surgery, radiotherapy) to assist primary care:

Table 1: Treatment Summary Codes

Snomed code: 413737006	Cancer hospital treatment completed (situation)
Read code: 8BCF.00	Cancer hospital treatment completed

Cancer Care Review (CCR)

The CCR is a holistic conversation between the individual and their healthcare professional in their GP practice and gives an opportunity for:

- the woman to raise any concerns that may be affecting their quality of life
- takes into account their existing conditions and medication
- discuss their cancer experience
- support to manage their own health and wellbeing.
- Offer an opportunity for a discussion and to inform them of the support available from primary care within 3 months of diagnosis.

It is aided by the HNAs, PCPS and TS and provides access to Cancer Care Co-ordinators and Social Prescribers in Primary Care Networks who may be able to assist women in finding support specific to their needs.

Table 2: British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU) (same follow up principles apply for PSFU)[19]

Endometrial cancer	Clinic-based follow-up	Telephone follow-up ± blood test	PIFU
Low risk (<10%ROR)	If patient declines PIFU (for maximum of 2 years from end of treatment)	If patient declines PIFU (for maximum of 2 years from end of treatment)	Offer from end of treatment (after holistic needs assessment at 3 months)
Intermediate risk	Can be offered if patient declines PIFU for 2 years from end of treatment	Can be offered if patient declines PIFU for 2 years from end of treatment	Offer from end of treatment or after 2 years for all
High-intermediate risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up
High risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up

Equality and Health Inequalities Impact Assessment

There is an impact assessment within the general PSFU guidelines.
In the context of endometrial cancers specialist teams should be aware that research studies have shown that:

- Women with increased socioeconomic deprivation (unemployed, non-skilled occupational class or lower levels of education) were more likely to decline to participate in telephone follow up, suggesting that patient acceptability needs to be further assessed in these groups[11].
- Women who are non-English speakers are at particular risk of being marginalised [17] (Kumarakulasingham et al 2019), Kumarakulasingam goes on to indicate this can be reduced through:
  - education sessions with their family/carers and
  - availability of interpreting services can enable women to participate in PSFU.
- knowledge of the local community and its demographics can be helpful in planning services. Each Trust should have available language support in place.

- South Asian endometrial cancer patients are reported to have twice the rate of self-reported depressive symptoms and five times the incidence of severe depression as compared to British White cancer patients[18] (Lord et al.,2013).
- South Asian endometrial cancer patients[18] also used more maladaptive coping strategies, such as helplessness/ hopelessness and fatalism and experienced a heavier physical symptom burden as compared to White patients.
- Younger women had greater CNS contact indicating that they may benefit from a greater level support[17].

Table 3: Types of Personalised Follow-Up Pathways – Method of delivery

Low / Intermediate Risk	**High Risk / Radiotherapy / Metastatic Disease**
Supported Self-Management Pathway	**Professional Led Pathway**
Individuals will not have scheduled outpatient appointments after initial post-operative follow up appointment with the surgeon. HNA can be offered throughout the pathway	Individuals will have scheduled outpatient appointments: At these appointments/reviews there will be a review of: • Test and other scan results as appropriate and available • Medication review where appropriate • HNA can be offered.
At the end of Open Access, individuals will be discharged to the care of their GP. A letter from the specialist gynaecology team will be sent to the individual and their GP confirming this.	At the end of Open Access, following a review, individuals will be discharged to the care of their GP. A letter from the specialist gynaecology team will be sent to the individual and their GP confirming this.
Individuals may move to professional led follow-up if it is appropriate and mutually agreed at any point.	Individuals may move to supported self-management follow-up if it is appropriate and mutually agreed at any point.
All Personalised Follow Up Pathways	
All individuals should have a Cancer Care Review undertaken with their GP practice within 12 months from diagnosis and offered the opportunity for discussion and informed of the support available in primary care within 3 months of diagnosis.	
Individuals will have re-entry to secondary care Open Access (appointment within 2 weeks if clinically urgent) for the length they are on remote monitoring with the specialist gynaecology team from diagnosis (E.g.: 5 years) for both Supported Self-Management pathway or Professional Led pathway. An individual can contact their specialist gynaecology team as needed with any concerns via a dedicated contact number and or e-mail address advised in the Treatment Summary.	
At any point during the secondary care Open Access individuals may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.	

If recurrent or metastatic disease is found at any time along the pathway the persons results will be discussed with the consultant, referred to the MDT meeting and referred as appropriate.

The gynaecology MDT will decide the frequency and responsibility of follow ups for the professional led pathway.

Whilst there are currently no routine surveillance tests for endometrial cancer in order to ensure effective personalised follow up systems are in place each NHS Trust will have **Remote Monitoring Systems** to safety net this group of patients. This will enable appropriate audit of the self-management pathway and for individuals to be contacted and discharged at the correct time and no individual will be 'lost to follow up'. Cancer Navigators have proven to play a key role in this service delivery.

Personalised Supported Self-Management Pathway

Non-Scheduled Appointments

Individuals on the supported self-management pathway will not have scheduled outpatient appointments after their end of treatment review as shown in **Figure 1** and **Appendix A**. They will continue to be supported by the personalised care package, open access service.
An appointment may be subsequently scheduled (face to face or virtually) because the individual has contacted the open access service with symptoms of concern.

A discharge letter or review (virtual or face to face) may take place when the individual is discharged from personalised follow up to inform both the individual and their GP that follow up is complete and they have been discharged from secondary care.

Professional Led Follow Up Pathway

Scheduled Review Appointments

The Gynaecology MDT will decide the frequency and responsibility of scheduled follow up appointments including individuals who have moved from a supported self-management pathway.
Those on the professional led pathway will also be supported by the personalised care package, open access service.
At discharge individuals have a review, virtual or face to face, with a healthcare professional.
There needs to be a safe, robust system in place to ensure all individuals are booked appropriately onto a virtual review at the appropriate time.
The purpose of the review is:

- To identify and inform individuals that their treatment is complete.
- To define when the individual is discharged from professional led follow-up care and open access so both the individual and their GP are notified that the follow up is complete and they have been discharged from secondary care.

Individuals will receive confirmation of the outcome, with a copy sent to their GP.

Best Supportive Care

Some individuals may decline treatment, or their clinical condition means it is inappropriate to offer treatment. Appointments with a member of the specialist team may be appropriate to review and support the individuals before offering transfer to their GPs care or if they have symptoms to palliative care. Their GP may then involve community palliative care at a suitable time for the person.

Discharge from Supported Self-Management Follow Up Pathway to Primary Care

Between 2-5 years individuals, on a supported self-management follow up pathway, and their GP, will be informed by letter that they are being discharged from the secondary care open access service to their GP with recommendations for their long-term plan.
The letter will include advice on what to do if the individual has any new endometrial cancer treatment related problem, including late effects (self-referral available), so they can see their GP who can refer them back to the relevant hospital service.

Table 9 lists **Appendix D** some resources available to help clinicians with possible cancer symptoms and long-term consequences. Table 7 **Appendix B** lists some support to help individuals around health and wellbeing support and information. Good practice would be to remind individuals of the support available to them nationally and locally.

Discharge from Professional Led Follow Up Pathway to Primary Care

Individuals within the professional led pathway will have a final review scheduled appointment. This appointment may be face to face or virtual with a member of the specialist gynaecology cancer team.
Individuals on the professional led follow up pathway, following the final review, and their GP, will be informed by letter of the outcome and recommendations for their long-term plan.

Outcomes include:

- Individuals are discharged from the secondary care open access service to their GP with recommendations for their long-term plan and any queries around their endometrial cancer in future can be discussed with their GP practice. This will include advice on what to do if the individual has any new endometrial cancer treatment related problem, including late effects (self-referral available), so they can see their GP who can refer them back to the relevant hospital service.

Table 6 **Appendix D** lists some resources available to help clinicians with possible cancer symptoms and long-term consequences.

Table 7 **Appendix B** lists some support to help individuals around health and wellbeing support and information.

Open Access in Secondary Care

All women can continue to access their GP practice in primary care as before as well as having Open Access to their secondary care specialist gynaecology team (without necessarily involving the GP). Open Access may have a triage process to enable clinical prioritisation.

Experience has shown that the majority of queries can be resolved over the telephone. If someone needs to be seen (face to face or virtually) and are clinically urgent, they should be seen within 2 weeks of contacting the open access service.

During Open Access run by secondary care the clinical governance responsibility for the individual lies with the specialist team. The clinical responsibility moves to primary care once the individual is discharged to the care of their GP.

Open Access is generally for 2-5 years from diagnosis unless specified otherwise for individuals by the specialist team. After Open Access finishes, people will be discharged to primary care for ongoing support and would be referred back to secondary care if there are red flag symptoms or side effects of treatment that require specialist support as outlined in their Treatment Summary.

The overall aim of the self -management follow-up pathway is to have a low impact on the primary care workload therefore it is important to ensure women living with

cancer are aware of potential symptoms or side effects of their treatment so they can contact the Open Access service or self-refer to a late effects service.

End of Treatment Review

This is a **key decision point** as shown in the personalised follow up pathway flowchart in figure 1 and **Appendix A**.
At the end of treatment, all women, newly diagnosed and secondary cancer, will receive an end of treatment review with a clinician. **A Treatment Summary** will be generated following this end of treatment review meeting and be sent to the individual, their GP and held within the individual's hospital notes.
This end of treatment review may be an individual or group appointment (E.g. a health and wellbeing information and support event).

Each person will have the opportunity:

- to meet with a healthcare professional individually
- receive personalised information about their planned follow-up and surveillance and invited to complete a Holistic Needs Assessment.
- Have their personalised care and support plan be updated accordingly.
- To receive information about their diagnosis, treatment options and subsequent follow-up pathway at the end of treatment.
- Including a description of the re-entry process, the support, and tools available to enable self -management
- All individuals will be transferred onto the jointly agreed follow-up pathway, supported self - management or professionally led, at the end of treatment.

During this appointment, it is expected that the individual will be provided with verbal information, and have access to either on-line or printed information, regarding the following:

- how long their recovery might take
- how, when and where to seek help if side effects become problematic.
- E.g.: lymphoedema, management of menopausal symptoms, sexual or psychosexual dysfunction and bladder or bowel symptoms related to pelvic radiotherapy
- Symptoms checklist – especially important as there is no routine surveillance testing.
- Health promotion benefits: weight management, physical activity, and healthy lifestyle choices specific to endometrial cancer is evidenced table 8:

Surveillance Pathway

Currently there are no routine surveillance tests for recurrence of endometrial cancer with only 2.3% being identified through asymptomatic recurrence[3] whilst over 90% of recurrences in all endometrial cancers present with symptoms[4]
However, going forward research is indicating the potential of a simple regular blood test (ctDNA) could be used to remotely monitor women for recurrence combined with personalised follow up.

Circulating tumour DNA (ctDNA) to monitor endometrial cancer activity appears to have very high sensitivity for identifying recurrent disease, detected in 8/8 (100%)

recurrences, and with a lead-time compared with radiology of up to 10 months and up to 18 months compared with patient symptoms.
Our study suggests that ctDNA analysis could become a useful biomarker for early detection and monitoring of Endometrial Cancer recurrence. However, further research is needed to confirm these findings and to explore their potential implications for patient management.

Source: Moss EL, Gorsia D, Collins A, et al. Utility of circulating tumour DNA for detecting and monitoring of endometrial cancer recurrence and progression (2020)[9]

However remote monitoring surveillance systems are required to ensure no woman on supported self-management is lost to follow up and has Open Access back to the specialist team for up to 5 years after diagnosis.

References

1 Gadducci A, Cosio S, Fanucchi A, *et al*. An intensive follow-up does not change survival of patients with clinical stage I endometrial cancer. *Anticancer Res* 2000;20:1977–84.
2 Shumsky AG, Stuart GC, Brasher PM, *et al*. An evaluation of routine follow-up of patients treated for endometrial carcinoma. *Gynecol Oncol* 1994;55:229–33.]
3 Jeppesen MM, Mogensen O, Hansen DG, *et al*. Detection of recurrence in early-stage endometrial cancer - the role of symptoms and routine follow-up. *Acta Oncol* 2017;56:262–9.
4 Aung L, Howells REJ, Lim KCK, *et al*. Why routine clinical follow-up for patients with early stage endometrial cancer is not always necessary: a study on women in South Wales. *Int J Gynecol Cancer* 2014;24:556–63.
5 Luqman..et al Patient-initiated follow-up for low-risk endometrial cancer: a cost-analysis evaluation | International Journal of Gynaecological Cancer (bmj.com) 2020
6 Ignatov T, Eggemann H, Costa SD, *et al*. Endometrial cancer subtypes are associated with different patterns of recurrence. *JCancer Res Clin Oncol* 2018; 144:2011–7.
7 Parkin, D. M., Boyd, L., & Walker, L. C. (2011). 16. The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010. British Journal of Cancer, 105(Suppl 2), S77–S81. https://doi.org/10.1038/bjc.2011.489
8 Evans T, Sany O, Pearmain P, *et al*. Differential trends in the rising incidence of endometrial cancer by type: data from a UK population-based registry from 1994 to 2006. *Br J Cancer* 2011; 104:1505–10
9 Macmillan (2019) How to Overcome Problems Effectively. https://learnzone.org.uk/courses/course.php?id=111
10 Moss EL, Gorsia D, Collins A, *et al*. Utility of circulating tumour DNA for detecting and monitoring of endometrial cancer recurrence and progression. *medRxiv* 2020:10.1101/2020.03.04.20030908.
11 Collins et al (2021) Innovative Follow-up Strategies for Endometrial Cancer - ScienceDirect
12 Courneya KS, Karvinen KH, Campbell KL, Pearcey RG, Dundas G, Capstick V, et al. Associations among exercise, body weight, and quality of life in a population-based sample of endometrial cancer survivors. Gynecol Oncol 2005;97: 422e430
13 Smits A, Lopes A, Bekkers R, Galaal K. Body mass index and the quality of life of endometrial cancer survivorship systematic review and meta-analysis. Gynecol Oncol 2015;137: 180e187.
14 Lauver D, Connolly-Nelson K, Vang P. Health-related goals in female cancer survivors after treatment. Cancer Nurs 007; 30:9e15.
15 von Gruenigen V, Frasure H, Kavanagh MB, Janata J, Waggoner S, Rose P, et al. Survivors of uterine cancer empowered by exercise and healthy diet (SUCCEED): a randomized controlled trial. Gynecol Oncol 2012; 125:699e704.
16 McCarroll ML, Armbruster S, Pohle-Krauza RJ, Lyzen AM, Min S, Nash DW, et al. Feasibility of a lifestyle intervention for overweight/obese endometrial and breast cancer survivors using an interactive mobile application. Gynecol Oncol 2015; 137:508e515.
17 Kumarakulasingam et al (2019) Acceptability and utilisation of patient-initiated follow-up for endometrial cancer amongst women from diverse ethnic and social backgrounds: A mixed methods study - PubMed (nih.gov)
18 Lord, K., Ibrahim, K., Kumar, S., Mitchell, A. J., Rudd, N., & Symonds, R.P. (2013). Are depressive symptoms more common among British South Asian patients compared with British White patients with cancer? *A cross-sectional Survey. BMJ Open*, *3*(6), e002650. https://doi.org/10.1136/bmjopen-2013-002650
19 The British Gynaecological Cancer Society recommendations and guidance on patient initiated follow-up (PIFU)British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU) (bgcs.org.uk)

Bibliography

Alfano, C., *et al* (2019) Implementing Personalized Pathways for Cancer Follow-Up Care in the United States: American Cancer Society-American Society of Clinical Oncology Summit, *CA: A Cancer Journal for Clinicians. 69*(3) https://doi.org/10.3322/caac.21558.

British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (2020) British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU) (bgcs.org.uk)

Cancer Research State of the Nation (2019) https://www.cancerresearchuk.org/sites/default/files/state_of_the_nation_april_2019.pdf

Department of Health – Quality Health (2012) Quality of life of cancer survivors in England, report on a pilot survey using Patient Reported Outcome Measures (PROMS). Department of Health.

Department of Health, Macmillan Cancer Support and NHS Improvement (2013) *Living with & Beyond Cancer: Taking Action to Improve Outcomes.* Department of Health.

East Midlands Cancer Alliance Personalised Follow Up Guidelines for people with an Endometrial Cancer Diagnosis

ESGO/ESTRO/ESP guidelines for the management of patients with endometrial carcinoma | International Journal of Gynaecologic Cancer (bmj.com)

Innovation to Implementation: stratified pathways of care for people living with or beyond cancer. A “How to Guide”. London: NCSI. Access - https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf NHS England (2014).

Macmillan Cancer Support: Cancer Statistics in England https://lci.macmillan.org.uk/england/all/Bowel

Macmillan: The burden of cancer and other Long-Term Health Conditions (April 2015) https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf

Macmillan Cancer Support: Throwing Light on the Consequences of Treatment (July 2013) Throwing light on the consequences of cancer and its treatment (macmillan.org.uk)

Maddams J et al. (2012) ‘projections of cancer prevalence in the United Kingdom, 2010-2040. Br. J. Cancer 107:1195-1202 (2012) https://www.ncbi.nlm.nih.gov/pubmed/22892390

Moss E L, Gorsia D, Collins A et al (2020) Utility of circulating tumour DNA for detecting and monitoring of endometrial cancer recurrence and progression Utility of Circulating Tumour DNA for Detection and Monitoring of Endometrial Cancer Recurrence and Progression. - Abstract - Europe PMC

National Cancer Survivorship Initiative (2011) *Evaluation of adult cancer aftercare services.* Ipsos MORI.

NHS England (2016) *Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer*. NHS.

NHS Improvement Cancer (2012) Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A ‘how to guide’. NHS.

NHS Living with and Beyond Cancer – Implementing Personalised Stratified Follow Up Pathways. A Handbook for local health and care systems. March 2020

Sussex and Surrey Cancer Alliance Guidance for the Implementation of Endometrial Cancer Personalised Stratified Follow-Up Pathways

Abbreviations

ANP	Advance Nurse Practitioner
CCR	Cancer Care Review
CNS	Clinical Nurse Specialist
CPES	National Cancer Patient Experience Survey
CSW	Cancer Support Worker
EBRT	External Beam Radiotherapy
ECAG	Expert Clinical Advisory Group
WMCA	West Midlands Cancer Alliance
ESGO	European Society of Gynaecological Oncology
ESP	European Society of Pathology
ESTRO	European Society for Radiotherapy and Oncology
HCP	Healthcare Professional
HNA	Holistic Needs Assessment
HWBSI	Health and Wellbeing and Support Information
HOPE	How to Overcome Problems Effectively
MDT	Multidisciplinary Team
NICE	National Institute of Clinical Excellence
OAFU	Open Access Follow Up
OPFA /OPFU	Outpatient Follow Up Appointment
PCSP	Personalised Care and Support Plan
PIFU	Patient Initiated Follow Up
PSFU	Personalised Stratified Follow Up
TS	Treatment Summary
VBT	Vault Brachytherapy
VR	Virtual Review

APPENDICES

APPENDIX A Clinical Criteria

Table 2: British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU) (same follow up principles apply for PSFU)[19]

Endometrial cancer	Clinic-based follow-up	Telephone follow-up ± blood test	PIFU
Low risk (<10%ROR)	If patient declines PIFU (for maximum of 2 years from end of treatment)	If patient declines PIFU (for maximum of 2 years from end of treatment)	Offer from end of treatment. (after holistic needs assessment at 3 months)
Intermediate risk	Can be offered if patient declines PIFU for 2 years from end of treatment	Can be offered if patient declines PIFU for 2 years from end of treatment	Offer from end of treatment or after 2 years for all
High-intermediate risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up
High risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up

APPENDIX B

The listed resources are recommended, WMCA are not responsible for the content of the listed resources

Table 6 Online support resource information

www.cancercaremap.org/	www.macmillan.org.uk/
Living with womb cancer | Cancer Research UK	www.macmillan.org.uk/
www.eveappeal.org.uk/	Womb Cancer Support UK – Home
https://www.prda.org.uk/	

Table 7 Health and Wellbeing information and support and how to access relevant services. This may include any local self-help groups and useful phone numbers E.g.

www.cancercaremap.org/	www.macmillan.org.uk/
Living with womb cancer | Cancer Research UK	Womb Cancer Support UK - Home
www.eveappeal.org.uk/	www.gogirlssupport.org/contact
https://www.prda.org.uk/	Local Late Effects Services ??

APPENDIX C

Table 8: Evidence of the benefits of health promotion for women living with Endometrial Cancer

An increased body mass index has been negatively correlated with quality of life in endometrial cancer survivors, including reduced physical, social and role functionality [12, 13]
Cardiovascular disease remains the leading cause of death in endometrial cancer survivors[11]
Evidence suggests that endometrial cancer survivors are motivated to make lifestyle changes[14]
Health promotion interventions should be an integral part of survivorship programmes.
The SUCCEED trial showed that endometrial cancer survivors participating in a 6-month lifestyle intervention programme were able to sustain weight loss and increase physical activity at 6- and 12-months post-intervention with 84% adherence [15].
Similar results have been shown in a feasibility study using a virtual web-based or mobile application intervention[16]*, which may provide a more cost-effective and less resource-intensive option for survivorship programmes.*

APPENDIX D

Table 9 Resources for clinicians to help with possible cancer symptoms

Gateway C	https://www.gatewayc.org.uk/gwc-cancer-map/ https://courses.gatewayc.org.uk/mod/page/view.php?id=6030 2 relevant modules – 'Managing Physical effects' and a webinar – 'Supporting your patients'
QCancer	https://qcancer.org/10yr/female/ 10-year risk calculator works out risk of developing various cancers by answering simple questions
RCGP Toolkit – Consequences of Cancer	https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit.aspx
CRUK interactive Desktop Easel	https://www.cancerresearchuk.org/health-professional/diagnosis/suspected-cancer-referral-best-practice/nice-cancer-referral-guidelines#NICE_implementation1
CRUK Infograph Poster	https://www.cancerresearchuk.org/sites/default/files/nice_infographic_poster_march2016.pdf Or can be ordered: https://publications.cancerresearchuk.org/search?p=7)
Macmillan Rapid Referral Guidelines	https://www.macmillan.org.uk/_images/rapid-referral-toolkit-desktop_tcm9-291864.pdf Also versions for desktop/ mobile/ laptop or can order in print)

Macmillan Clinical Decision Support	https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/prevention-early-diagnosis-programme/cancer-decision-support-tool.html#280141
Womb Cancer UK	Womb Cancer Support UK - Home (weebly.com)
The Eve Appeal	Home | Gynaecological Cancer Research Charity | The Eve Appeal
Go Girls Support Group	Contact Us | Go Girls Support Group
Pelvic Radiation Disease Association	https://www.prda.org.uk/

APPENDIX E

Table 10: National Resources for individuals around health & wellbeing support

Good practice: Remind individuals of health and wellbeing support and information available nationally such as websites, and in their local community including support groups in addition to local GP practice resources E.g.: Social prescriber	
Cancer Care map directory	https://www.cancercaremap.org/ Can help individuals living with cancer to find local cancer care services in their area.
Macmillan Cancer Support	https://www.macmillan.org.uk/ Provides advice and patient information on gynaecological cancers. Includes an online community and support line.
Womb Cancer UK	Womb Cancer Support UK - Home (weebly.com)
The Eve Appeal	Home | Gynaecological Cancer Research Charity | The Eve Appeal
Go Girls Support Group	Contact Us | Go Girls Support Group
Pelvic Radiation Disease Association	https://www.prda.org.uk/

APPENDIX F Embed sample of a gynae care plan.

To be inserted

APPENDIX G Examples of wellbeing events delivered face to face or virtually:

To be inserted

APPENDIX H Examples of a Treatment Summary are shown below.

To be inserted

APPENDIX I Examples of a Cancer Care Review are shown below.

To be inserted