East Midlands Cancer Alliance

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Personalised Follow Up Guidelines for people with an Endometrial Cancer Diagnosis

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Audience: Healthcare staff supporting people diagnosed with endometrial cancer

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Version control

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0.1	Aug 21	Sally Picken	DRAFT	
0.2	Sept 21	Esther Moss	DRAFT	Ethnicity update, clinical criteria update for 'advanced' cancer
0.3	Sept 21	Sally Picken	DRAFT	Remote Monitoring System clarification
0.4	Sept21	Mike Ryan / Sally Picken	ECAG APPROVED	Revision to 3.3.3; Treatment Summary; Key symptoms that require urgent re-access
0.5	Sept 21	Pawan Randev		Additions to late effects information, primary care and patient support tools. Removal of 'Stratified' to leave term 'Personalised Follow Up'
FINAL	Sept 21	Sally Picken	LWC and Primary Transformation Chairmen APPROVED	Approved

Approved by:

Chairman of Gynaecology Expert Clinical Advisory Group	**Appendix A** Gynaecology Expert Clinical Advisory Group membership	Mr Viren Asher	10/09/21
Chairman of EMCA Living with Cancer/Personalised Care Steering Group		Dr Heetan Patel	29/09/21
Chairman of EMCA Primary Care Transformation Group		Drs Pawan Randev / Ben Noble	30/09/21

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 EMCA website.

Thank you to the Gynaecology Expert Clinical Advisory Group (Appendix A) particularly Miss Esther Moss, University Hospitals Leicester and the ECAG Gynaecology Clinical Nurse Specialist subgroup who have developed these personalised follow-up guidelines in line with national guidance including the British Gynaecological Cancer Society guidance and the European Society of Gynaecological Oncology (ESGO), the European Society for Radiotherapy and Oncology (ESTRO), and the European Society of Pathology guidelines for the management of patients with endometrial cancer.

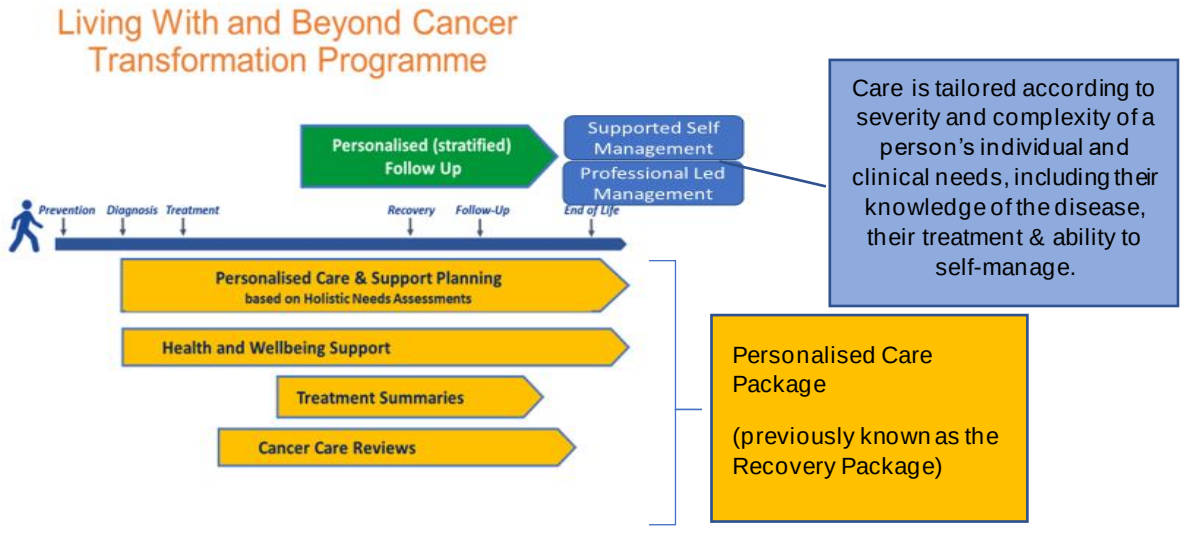
The document includes risk stratification of women diagnosed with endometrial cancer from low risk to high risk of recurrence according to agreed clinical criteria. A pathway flowchart illustrates the stratification process and the personalised care package required to support women living with endometrial cancer.

Note that whilst there are no routine surveillance test schedules included based on existing best practice for endometrial cancer, to ensure no woman is 'lost to follow up' remote monitoring systems are required to maintain a register of those on supported self-management with Open Access back to the specialist team.

Endometrial cancer is sometimes referred to elsewhere as uterine cancer or womb cancer (94% of uterine cancers are endometrial).

2. Background to Personalised Follow Up

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.



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

- Supported self-management follow up
- Professional led follow up
    - Including best supportive care

This document recommends all women with an endometrial cancer diagnosis, including secondary cancer, receive a personalised care package made up of:

- 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) in primary 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.

Context

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.
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:

- 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

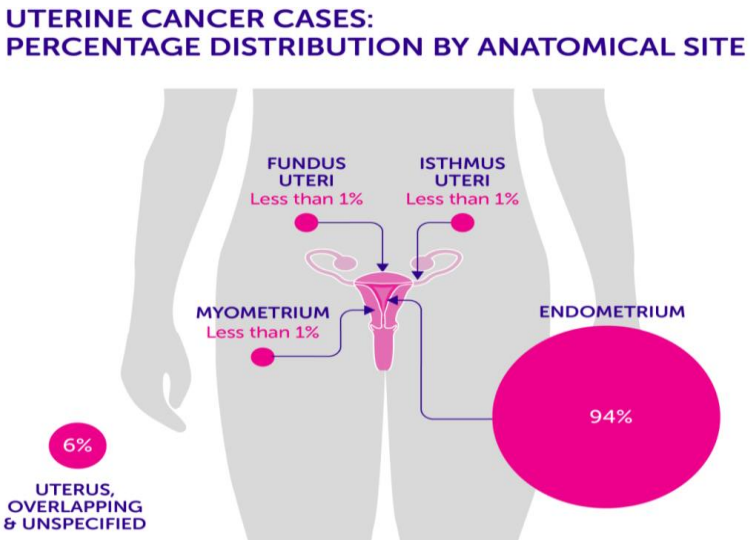
Now:

- 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:

- 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]

2.1 Increasing Incidence and survival

The diagram below gives an overview of endometrial cancer by anatomical location. Endometrial cancer accounts for 94% of uterine cancer cases (2010- 12). The data below is for uterine cancer.

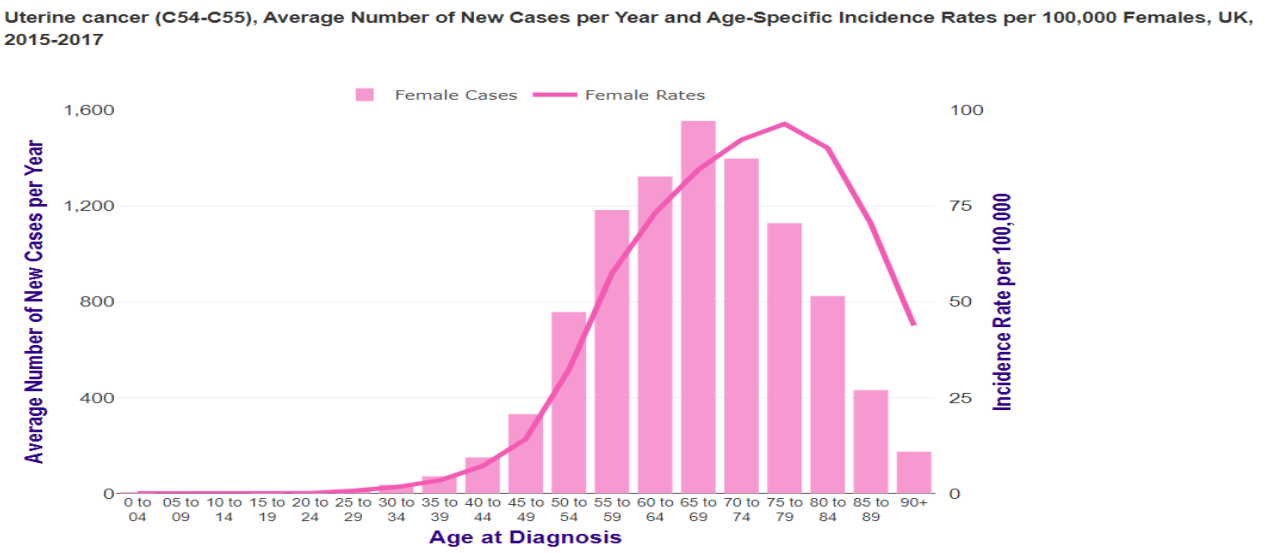


Source: Uterine cancer incidence statistics | Cancer Research UK

There has been a 55% increase in uterine cancer incidence rates in women since the early 1990s. In the UK there were 9,377 new cases between 2015-2017. By 2035 this is projected to rise to 11,576.

Age: The highest incidence rates of diagnosis are in older women with, on average, each year 27% of new cases in the UK were in women aged 75 and over in 2015-2017. However, age-specific incidence rates rise steeply from around age 45-49 before dropping in the oldest age groups – this is a slightly different pattern from most cancers.

TABLE 1: Number of new cases per year, age specific Incident rates /100,000 females, UK 2015-17



Source: Uterine cancer incidence statistics | Cancer Research UK

Deprivation: Uterine cancer incidence rates in England in females are 17% higher in the most deprived quintile compared with the least deprived 2013-2017. It is estimated that there are around 640 more cases of uterine cancer each year in England than there would be if every deprivation quintile had the same age-specific crude incidence rates as the least deprived quintile.

Ethnicity: There are reported differences in women and their tumour characteristics in different ethnic groups. Research is ongoing to investigate these differences further and their impact on diagnostic pathways and personalised treatment

Prevention: In the UK 34% of uterine cancer cases are preventable due to links to being overweight and obesity. It is a cancer that typically affects older women with over a quarter of new cases being in women on 75 years old at diagnosis who can also have co-morbidities, in particular obesity, diabetes and cardio-vascular disease [7]

TABLE 2: Staging and Diagnosis – Uterine Cancer

Staging	% Diagnosed at this stage	Survival 5 years or more after diagnosis
Stage I	74-75% of women are diagnosed with endometrial cancer at stage I (with a known stage)	More than 90% Most of these women will have been cured
Stage II	81-83% are diagnosed at stage I or II	Around 75%
Stage III	18-19% are diagnosed at stage III or IV (late stage)	Almost 50%
Stage IV	7% - 8% of uterine cancer patients have metastases at diagnosis - stage IV	Around 15% The outcome depends on how far the cancer has spread. E.g. to the bowel and bladder, or perhaps to the lungs, liver, or brain.
Source of Data	Uterine cancer incidence statistics | Cancer Research UK	Cancer survival by stage at diagnosis for England, 2019 Office for National Statistics

It is estimated that between 20% and 40% of endometrial cancers in the UK fall within the low-risk endometrial cancer category and thus could be considered for supported self-management. This proportion could potentially rise as high as 56% of the total endometrial cancer population [8]

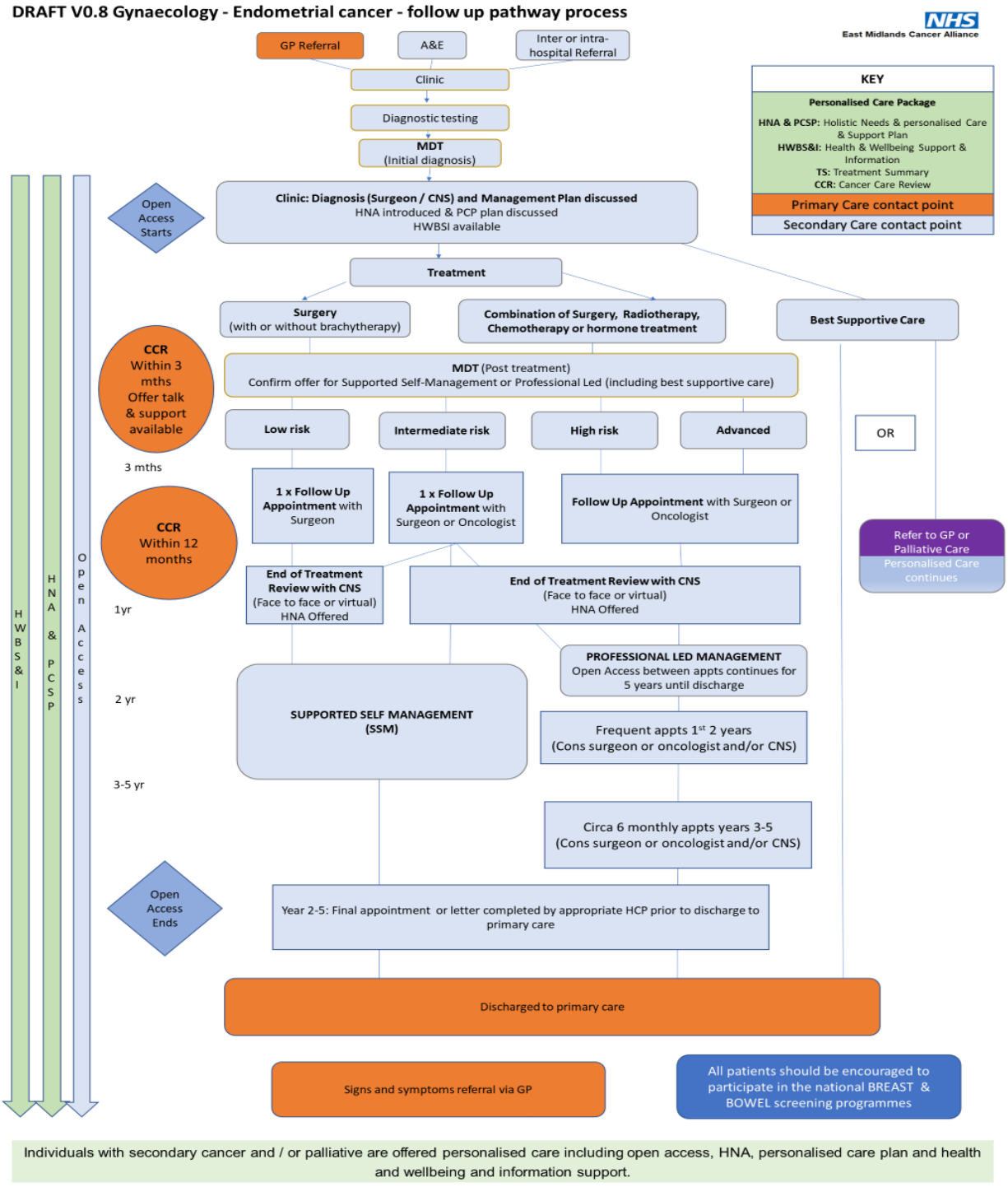
This low risk group is associated with a 10-year overall survival rate of 94.1% and a low risk of recurrence of 6% [6]
This means that increasing numbers of women are living with a variety of supportive care needs such as coping strategies for symptoms and late effects such as psycho-sexual, physical and psychosocial as well as broader emotional, practical and social aspects of the impact of their diagnosis and treatment.

3. Personalised Follow Up: The Pathway

3.1 EMCA Endometrial Cancer Personalised Care Pathway

The referral routes for all individuals with either suspected or secondary endometrial cancer is shown below in Figure 1 and in **Appendix B**

Figure 1



3.2 Diagnosis and Treatment

All individuals will have a personalised care package, they will be offered:

- 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 Table 3. **(Appendix B)**

Table 3: EMCA Defined Clinical Risk Stratification Decision for Follow Up

RISK	CLINICAL CRITERIA / TREATMENT	SUPPORTED SELF MANAGEMENT	PROFESSIONAL LED
LOW RISK	**Stage 1a G1/2** Usually surgery only	From 3 months for 2 years Open Access for up to 5 years	
INTERMEDIATE RISK	**Stage 1b G1/2** Usually surgery with vault brachytherapy	From 3 months for 2 years Open Access for up to 5 years	
HIGH RISK	**Stage 1a, b, G3** Usually surgery with vault brachytherapy if nodes negative, with EBRT =/- chemo if nodes not done	Can consider offering from 2 years in place of professional led	For 5 years including Open Access Frequent follow up first 2 years then circa 6 monthly visits for years 3-5 Open Access 5 years
ADVANCED DISEASE	**Individualised treatment** Surgery +/- radiotherapy, chemotherapy, immunotherapy.		For 5 years including Open Access or timing to be determined by clinician

Women who are diagnosed with early endometrial cancer in the low risk group are most suitable to be offered **supported self-management pathway <u>unless</u>**:

- There is mutual agreement not to enter the self-managed follow up pathway.
- The individual is unable to self-manage due to physical, cognitive, communication or emotional reasons.
- The individual has co-morbidities that may require closer monitoring.
- The individual is deemed inappropriate by the MDT because of oncological concerns.

Women at intermediate or high risk of recurrence or have complex needs are cared for on the **professional led pathway**.

Women are on '**a best supportive care' pathway** because their cancer is non curative or too frail are most suited for their personalised care to be offered via the **professional-led follow-up** pathway. They are supported by their oncology team, palliative care / enhanced supportive care as appropriate.

Women may move to between supported self-management or professional led follow-up pathways if it is appropriate and mutually agreed at any point.

3.3 Personalised Care Package

There are four elements to the 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)

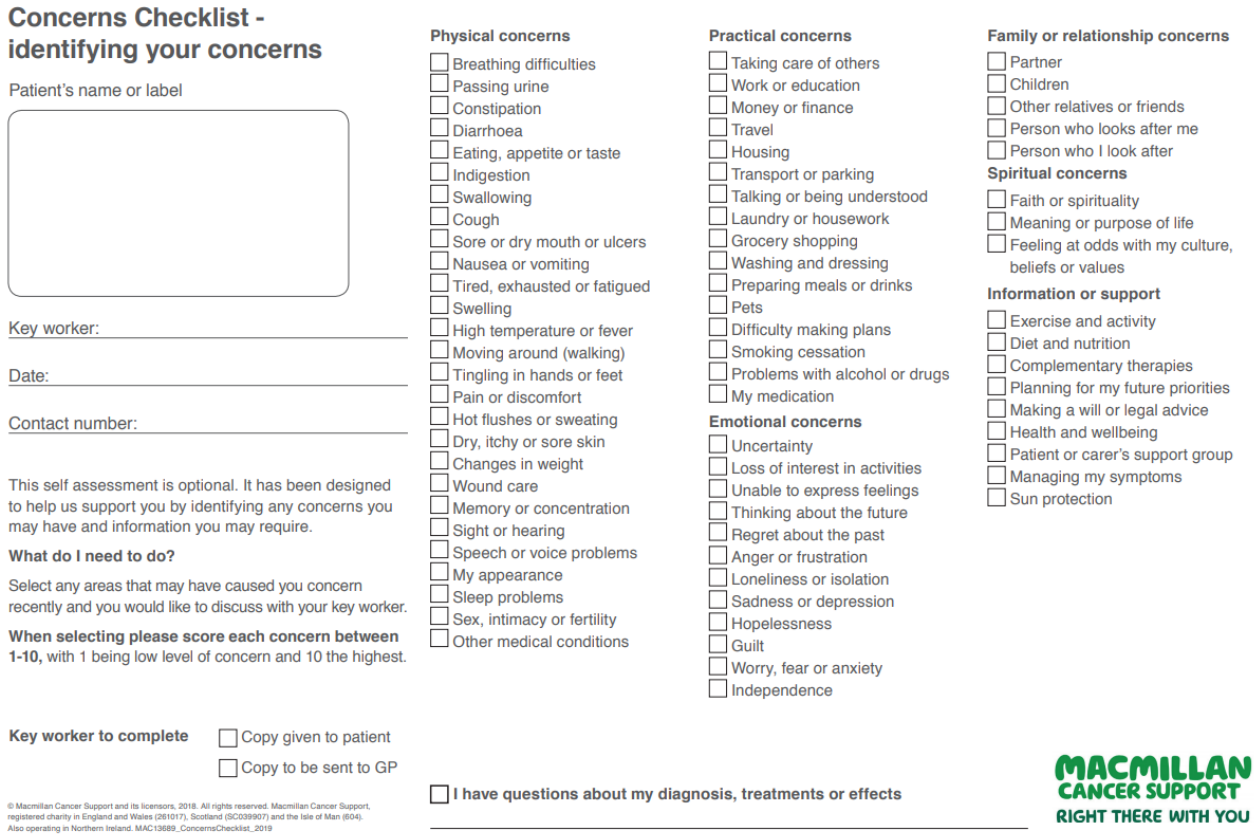
3.3.1 Personalised Care and Support Plan including Holistic Needs Assessment

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.

Common areas of concern identified through HNA's by individuals diagnosed with gynaecological cancers including endometrial cancer include:

1. Physical such as sex, intimacy, and fertility
2. Emotional such as worry, fear and anxiety, anger or frustration, depression, loneliness or isolation
3. Practical such as taking care of others
4. Information such as exercise and activity, diet

Table 4: HNA (concerns checklist)



Concerns Checklist - identifying your concerns

Patient's name or label

Key worker:

Date:

Contact number:

This self assessment is optional. It has been designed to help us support you by identifying any concerns you may have and information you may require.

What do I need to do?

Select any areas that may have caused you concern recently and you would like to discuss with your key worker.

When selecting please score each concern between 1-10, with 1 being low level of concern and 10 the highest.

Physical concerns

- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating, appetite or taste
- ☐ Indigestion
- ☐ Swallowing
- ☐ Cough
- ☐ Sore or dry mouth or ulcers
- ☐ Nausea or vomiting
- ☐ Tired, exhausted or fatigued
- ☐ Swelling
- ☐ High temperature or fever
- ☐ Moving around (walking)
- ☐ Tingling in hands or feet
- ☐ Pain or discomfort
- ☐ Hot flushes or sweating
- ☐ Dry, itchy or sore skin
- ☐ Changes in weight
- ☐ Wound care
- ☐ Memory or concentration
- ☐ Sight or hearing
- ☐ Speech or voice problems
- ☐ My appearance
- ☐ Sleep problems
- ☐ Sex, intimacy or fertility
- ☐ Other medical conditions

Practical concerns

- ☐ Taking care of others
- ☐ Work or education
- ☐ Money or finance
- ☐ Travel
- ☐ Housing
- ☐ Transport or parking
- ☐ Talking or being understood
- ☐ Laundry or housework
- ☐ Grocery shopping
- ☐ Washing and dressing
- ☐ Preparing meals or drinks
- ☐ Pets
- ☐ Difficulty making plans
- ☐ Smoking cessation
- ☐ Problems with alcohol or drugs
- ☐ My medication

Emotional concerns

- ☐ Uncertainty
- ☐ Loss of interest in activities
- ☐ Unable to express feelings
- ☐ Thinking about the future
- ☐ Regret about the past
- ☐ Anger or frustration
- ☐ Loneliness or isolation
- ☐ Sadness or depression
- ☐ Hopelessness
- ☐ Guilt
- ☐ Worry, fear or anxiety
- ☐ Independence

Family or relationship concerns

- ☐ Partner
- ☐ Children
- ☐ Other relatives or friends
- ☐ Person who looks after me
- ☐ Person who I look after

Spiritual concerns

- ☐ Faith or spirituality
- ☐ Meaning or purpose of life
- ☐ Feeling at odds with my culture, beliefs or values

Information or support

- ☐ Exercise and activity
- ☐ Diet and nutrition
- ☐ Complementary therapies
- ☐ Planning for my future priorities
- ☐ Making a will or legal advice
- ☐ Health and wellbeing
- ☐ Patient or carer's support group
- ☐ Managing my symptoms
- ☐ Sun protection

Key worker to complete

- ☐ Copy given to patient
- ☐ Copy to be sent to GP

☐ **I have questions about my diagnosis, treatments or effects**

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An example of a personalised care and support plan is embedded below

UHL Sample Gynae Care plan.pdf

3.3.2 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. This support may be in the form of an event, face to face or on line, where there is education and support sessions aimed to provide individuals with the information and reassurance to build the confidence they require to enable them to lead as normal and active life as possible after their cancer treatment.

A national checklist of health and wellbeing services is available so healthcare systems can identify gaps in provision across cancer pathways and thus to support them in providing consistent information across the health system in different formats.

Examples of health and wellbeing events are embedded below

LLR Online HWBSI.pdf

SFHFT H&WBIS Sample Agenda.pdf

Examples of wellbeing events delivered face to face or virtually:

- 1:1 appointments
- Rolling programmes - E.g. The 6-weekly Macmillan HOPE Programme [9] also delivered as an iHOPE course.
- **Group events** which are scheduled at regular intervals, face to face or online, throughout the year, open invitations, may be specific to a gynaecological cancer diagnosis or open to all who have had a cancer diagnosis. Signposting and access to local services for cancer as a long-term condition health and wellbeing management.
- Online support groups
- Online tools and support– national examples are shown in table 5

Table 5: Online support

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/	

3.3.3 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

Support for Late Effects (also known as Side Effects): Some secondary care sites provide late effects service for chemotherapy and radiotherapy including symptoms relating to pelvic radiotherapy and bowel complications. These are listed b

Late effects service for chemotherapy and radiotherapy: Nottingham University Hospitals Trust and University Hospitals of Derby and Burton NHS Foundation Trust

Late effects service specific for people with bowel complications: United Hospitals of Lincolnshire

All the above offer self-referral as well as healthcare professional referral. Details are below.


NUH Late Effects Clinic.pdf


UHDB Late Effects Services.pdf


ULHT Late Effects Service.pdf

UHDB You Tube video about Late Effects Service at Royal Derby Hospital site

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 and discharge letter 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 (eg: Surgery, radiotherapy) to assist primary care:

Table 5: Treatment Summary Codes

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

Examples of a Treatment Summary are shown below.

UHL Treatment Summary Endometrial

UHDB End of treatment summary-g

3.3.4 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.

It is aided by the HNAs, PCPS and TS. It allows Social Prescribers in Primary Care Networks may be able to assist women in finding support specific to their needs.

Primary care can be commissioned through the National Quality Outcome Framework indicators in 2021/22 for people diagnosed with cancer which specify that an individual's GP practice offers those diagnosed with cancer:

- An opportunity for a discussion and to inform them of the support available from primary care within 3 months of diagnosis.
- Offers a Cancer Care Review (CCR) within 12 months of diagnosis.

Examples of a Cancer Care Review are shown below

LLR CCR Oct 19.pdf

Lincs Arden CCR template.pdf

Macmillan CCR Template.pdf

3.4 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.

Examples of information on Open Access services in secondary care for women are shown below.

UHL PIFU leaflet 2019.pdf

3.5 End of Treatment Review

This is a **key decision point** as shown in the personalised follow up pathway flowchart in figure 1 and Appendix B.

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** (Section 2.3.3) 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.
- 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.
  Eg: 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 6:

Table 6: 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.*

- 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 (see

3.6 Personalised Follow Up Pathways

3.6.1 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 6)
- Supported self-management
- Professional led (includes best supportive care)

Table 6: 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 It may be valuable for the individual to have an annual review with their GP Practice team.	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 (Eg: 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 to ensure effective personalised follow up systems are in place each NHS Trust will have **Remote monitoring systems** to enable the following to happen:

- There should be a designated member of the specialist gynaecology team who is responsible for ensuring the following takes place:
    - Scheduling systems to ensure appropriate individuals are contacted and no individual is 'lost to follow up'

a Eligibility for Entry - Personalised Supported Self-Management Pathway

All individuals with endometrial cancer who have completed treatment will be considered for entry onto the supported self-management pathway. This empowers individuals with the knowledge and skills to self-manage their condition.

Individuals suitability for entering the supported self-management pathway will be considered at the **end of treatment review**, if not before at the Gynaecology MDT, according to the clinical criteria in Table 3 in Section 3.2. Those eligible will be recorded as appropriate for supported self-management follow-up on their MDT proforma within the cancer IT system. A copy will be placed in the individuals notes as appropriate.

For those individuals on the supported self-management follow up pathway no further scheduled follow up appointments in secondary care are required after the end of treatment review.

b Eligibility for Entry - Personalised Professional Led Pathway

Individuals suitability for entering professional led pathway will be considered at the **end of treatment review**, if not before, at the Gynaecology MDT, according to the clinical criteria in Table 3 in Section 3.2.

Some individuals identified was low / intermediate risk may not be appropriate for supported self-managed care and will join the professional led pathway. These can include:

- The individual who is unable to self-manage due to physical, cognitive, communication or emotional reasons.
- The individual who has co-morbidities that may require closer monitoring.
- Following discussion between the individual and the healthcare professional there is mutual agreement not to enter the self-managed follow up pathway.
- The individual is deemed inappropriate by the MDT because of oncological concerns.
- The individual is in a clinical trial

NB: Any need for the provision of language services for people diagnosed with endometrial cancer whose first language is not English will need to be considered locally depending upon the demographic served by each hospital to enable them to have access to a self-managed option.

Individuals who are not eligible will be recorded as not appropriate for self-managed follow-up on their MDT proforma within the cancer IT system and will continue on the professional led follow-up pathway. A copy will be placed in the individuals notes as appropriate.

3.6.3 Clinical Trials

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocol.

It is recommended that at any point during the follow-up pathway in secondary care, patients may be contacted to be offered access to any relevant clinical trials that may become available.

All individuals taking part in trials will still access and benefit from personalised care including open access to secondary care.

3.7 Personalised Supported Self-Management Pathway

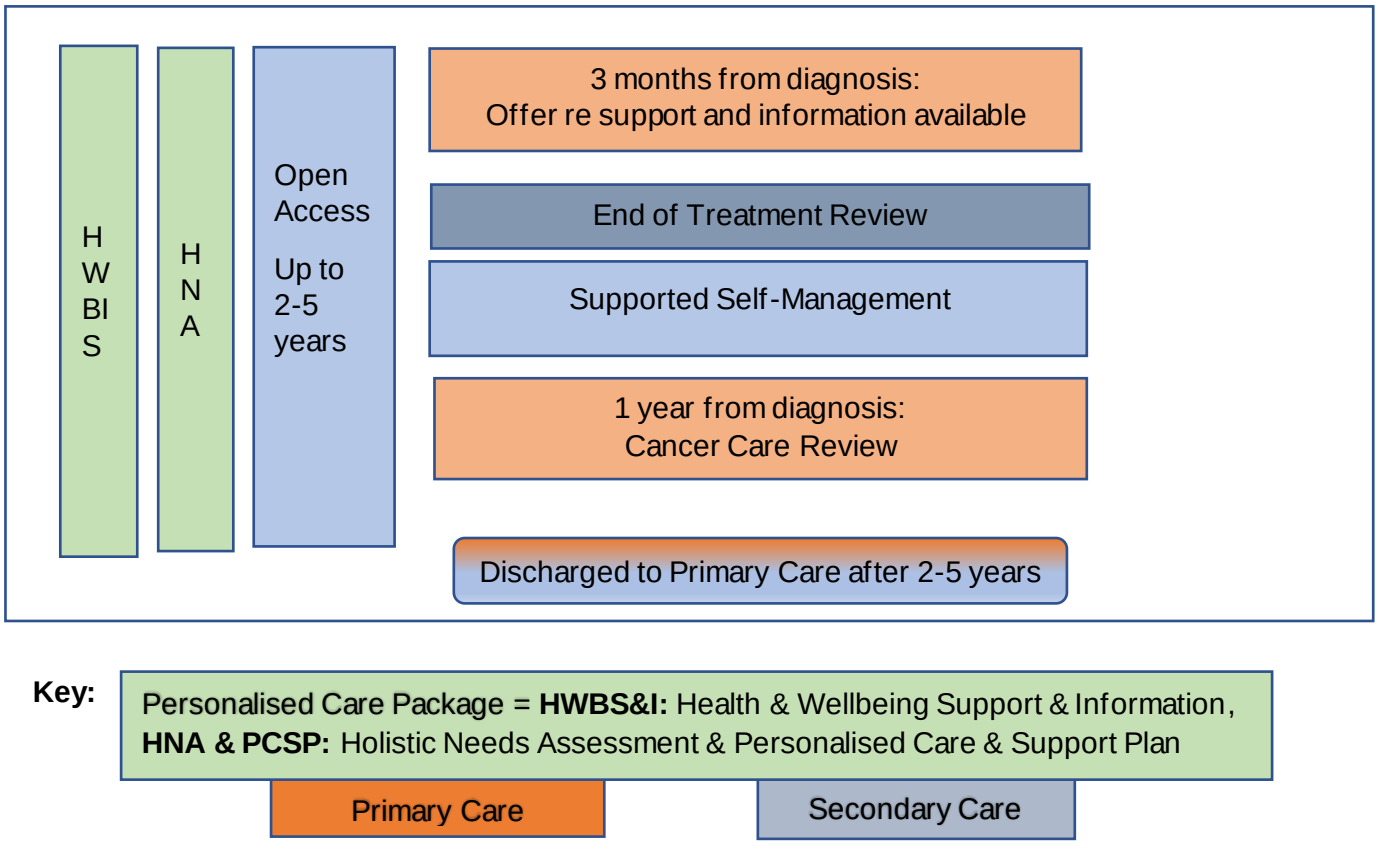
Non-Scheduled Appointments

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 B. 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.

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.

Table 7: **Supported Self-Management model**



3.8 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.

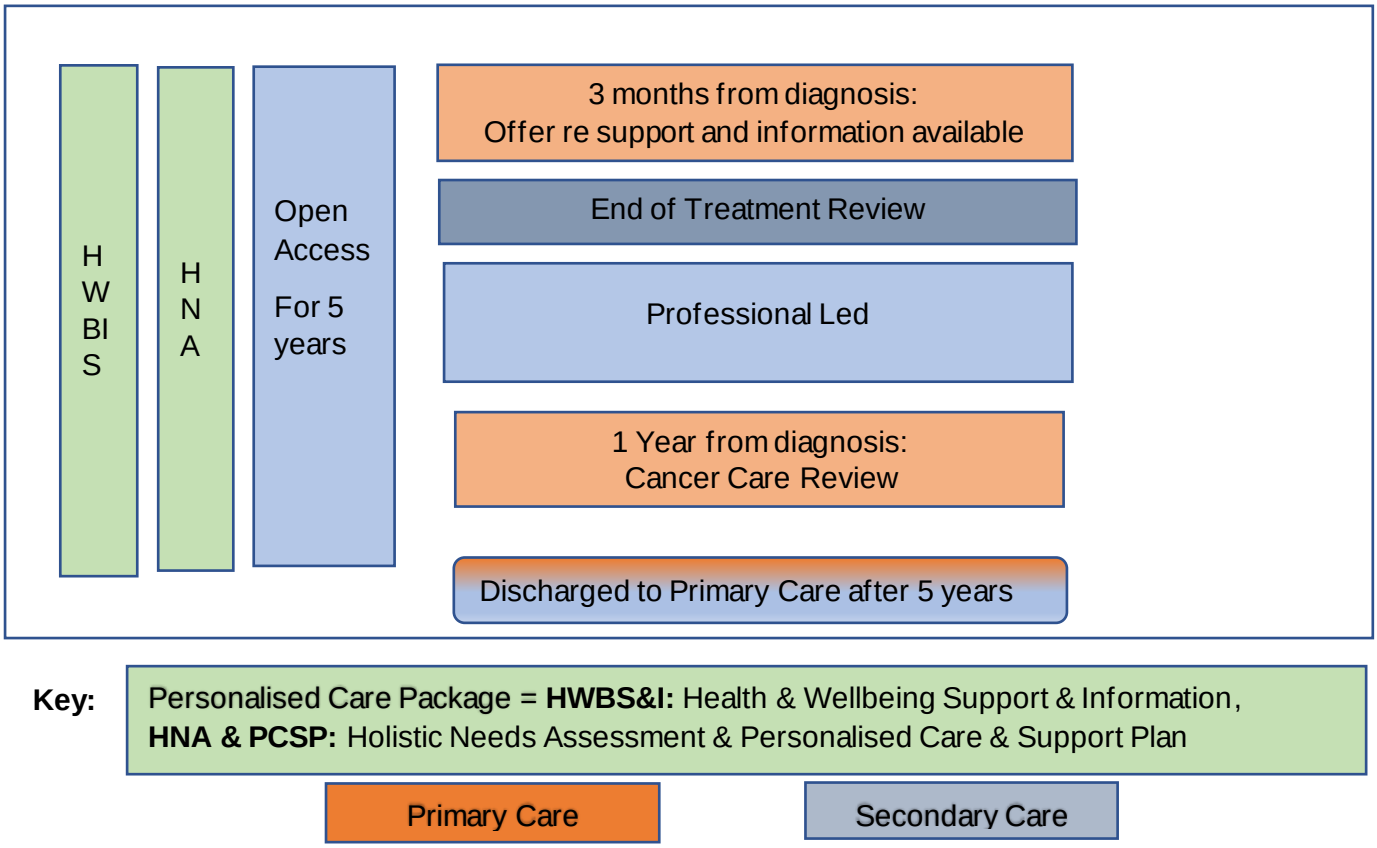
There needs to be a safe, robust system in place to ensure all individuals are booked appropriately onto a virtual review at the appropriate time.

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.

Table 8: **Professional Led model**



3.8.1 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.

3.9 Discharge from Personalised Follow-up Pathways to Primary Care

After 5 years from diagnosis individuals on supported self-management and professional led review are eligible for discharge from the secondary care open access service unless the specialist clinical team agree to continue follow up.

3.9.1 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 some resources available to help clinicians with possible cancer symptoms and long-term consequences. Table 10 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.

3.9.2 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 9 lists some resources available to help clinicians with possible cancer symptoms and long-term consequences. Table 10 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.

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/

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/

4. 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 tumor 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)

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.

5 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
    - 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 E.g. Leicester has a high South Asian population who are predominantly Gujarati speaking and one of the CNS is a fluent Gujarati/Hindi speaker thereby enabling non-English speakers to access the scheme [17]
- 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]

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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
EMCA	East 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

6 APPENDICES

APPENDIX A EMCA Gynaecology ECAG Membership

Appendix A Gynae Membership Sept 21

APPENDIX B Endometrial Cancer Personalised Care Pathway & Clinical Criteria

Gynae Endo pathway v0.8.pptx