Guidelines for Personalised Stratified Follow-Up (PSFU) following Endometrial Cancer treatment

University Hospitals of Leicester NHS
NHS Trust

Trust Ref no: C26/2018

1. Introduction and who the guideline applies to:

The incidence of endometrial cancer has increased by 55% over the past 20 years and it is now the fourth most common malignancy in women in the UK[1]. The major risk factors for low-risk endometrial cancer are increasing patient age, diabetes and obesity, however the number of cases in patients under the age of 55 years is also increasing[2]. The patient population is therefore very mixed with a wide range of post-treatment survivorship issues and future treatment options.

Developments in the understanding of endometrial cancer subtypes has led to the risk-stratification of cases, which can better identify patients who are at very low-risk of recurrence, and therefore can be safety discharged from routine clinical follow-up, and those at higher risk of recurrence, where regular clinical follow-up is advised. New developments in the treatment of recurrence, including the role of secondary surgery, are changing the focus of follow-up with the aim now being on identifying recurrence earlier at lower tumour volume to enable more cases to be amenable to surgery, or salvage radiotherapy.

Personalised stratified follow-up (PSFU) is the overarching term to describe the process of individualising cancer follow-up depending on a patient's tumour characteristics and personal needs. The aim is that people diagnosed with cancer are 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 also as a way to address capacity issues within the NHS.

These guidelines apply to all staff working within the endometrial cancer patient pathway and their patients. The Gynaeoncology MDT has a decision-making role in the selection of patients for the different pathways and all staff involved will implement the pathway thereafter.

Related documents:

East Midlands Cancer Alliance Personalised Follow Up Guidelines for people with an Endometrial Cancer Diagnosis 2021

Abbreviations:

CNS	Clinical Nurse Specialist
eHNA	electronic Holistic Needs Assessment
GP	General Practitioner
HFU	Hospital Follow-Up
MDT	Multi-disciplinary Team
MUST	Malnutrition Universal Screening Tool
PSCP	Personalised Care and Support Plan
PSFU	Personalised stratified follow-up
RCR	Royal Collage of Radiologists
RMS	Remote Management System

SSM Supported Self-Management
TFU Telephone Follow-Up

1.1. Follow up models:

Within PSFU there are different follow-up models, including patient-initiated follow-up (PIFU), remote monitoring, telephone follow-up (TFU) and face-to-face hospital follow-up (HFU), and different durations[3].

Endometrial cancer is known to recur many years after diagnosis and therefore patients and clinicians should remain vigilant even after discharge to primary care[4]. The British Gynaecological Cancer Society[5] and East Midlands Cancer Alliance[6] support PSFU and have given structured guidance on the risk classification and follow-up models that are advised.

At the centre of the guidance is that patients should continue to have a voice on which follow-up pathway they are placed on and be able to change pathways if they wish. The need for open access to the Clinical Nurse Specialists (CNS) and access to urgent investigations and clinical review/appointments is essential for a successful PSFU scheme, and patients who have communication challenges or lack the confidence to telephone the CNS need to be assessed to see whether it is safe for them to be placed on this pathway[7]

Supporting patients to self-manage their own health and wellbeing can meet unmet needs and reduce demand on services[8], where appropriate. This can be done in the following ways:

- Stratifying patients to an appropriate pathway based on clinical and individual needs.
- Organising needs assessments and care plan reviews at key points in the pathway – for example, at the end of treatment or when problems arise.
- Providing a treatment summary that is a succinct record of diagnosis, treatments, potential side effects of treatment, contact details and other key information.
- Improving access to clinical and non-clinical support services.

'Stratified' means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and the person (whether they have other illnesses or conditions, and how much support they feel they need).

Safety issues have been considered. This guidance has been produced in line with the BGCS PIFU guidance. Regular audits will be performed to ensure patient acceptability and accessibility[9]. Future developments for endometrial cancer PSFU include the creation of multi-lingual information materials, a messaging platform for patients to contact the CNS, an endometrial cancer specific survivorship course and biomarker monitoring.

2. PSFU pathways

2.1. Supported Self-Management (SSM)

- Patients suitable for the SSM will be identified from MDT
- The patient will have a follow-up clinic appointment at approx. 6-8 weeks post-treatment with the surgical team the SSM pathway will be discussed

- The surgical team will confirm the suitability of the patient for SSM with the CNS/RMS team. A dedicated email mailbox has been created to facilitate contact. The mailbox is 'Gynaecology Cancer Remote Monitoring Mailbox'
- An appointment with the Gynaecology CNS will be arranged within 4 weeks following the patient's post operative clinic appointment or final decision to place into SSM. An initial face-to-face or telephone appointment will be offered to the patient.
- At the CNS appointment, a further electronic Holistic Needs Assessment (eHNA) offered including a PSCP, along with a Malnutrition Universal Screening Tool (MUST) and menopause signposting along with an assessment once developed. Also an end of treatment summary.
- A printed patient information leaflet (Appendix A) explaining the SSM will be given to the patient along with a copy of their eHNA. When developed a link/QR code to the information video will also be provided.
- The RMS team will send a reminder letter (Appendix B) at 6 months and then annually for 5 years, reminding the patient that they are on SSM scheme. Supported by an Accurx message. A future development will contain a link/QR code to the SSM information video (Video 1).
- After 5 years the patient will be notified through a RMS letter (Appendix C) that they will be discharged to primary care, supported by an Accurx message. A future development aims to contain a link/QR code to an information video explaining pathways for re-referral (Video 4) within the discharge letter.

2.2. Telephone Follow-Up (TFU

For patients with language issues or concerns that they may not contact with CNS team if placed on SSM, the TFU pathway may be suitable.

- Patients suitable for the TFU will be identified from MDT
- The patient will receive a follow-up clinic appointment at approx. 6-8 weeks post-treatment with the surgical team the TFU pathway will be discussed
- The surgical team will confirm the suitability of the patient for TFU with the CNS team. A dedicated email mailbox has been created to facilitate contact. The mailbox is 'Gynaecology Cancer Remote Monitoring Mailbox'.
- An appointment with the Gynaecology CNS will be arranged within 4 weeks following the patient's post operative clinic appointment or final decision to place into SSM. A face-to-face or telephone appointment will be offered to the patient.
- At the CNS appointment, a eHNA offered including a PSCP, along with a MUST and menopause signposting along with an assessment once developed. Also an end of treatment summary
- A printed patient information leaflet (Appendix D) explaining the different follow-up models (SSM, TFU and HFU) will be given to the patient along with a copy of their eHNA. A future development will be to send a link/QR code to an information video explaining TFU (Video 2)
- The patient will receive a telephone call from the CNS at set time points. The patient will be informed of the time/date of the appointment.
- The CNS will cover a list of questions (CNS TFU question list - Appendix E) to elicit signs/symptoms of recurrence, before asking about any unmet meets
- A DICT3 letter will be dictated by the CNS following the appointment to record the appointment findings. A copy will be sent to the patient's GP, the patient and added to the patient medical records
- In cases of language barriers, Language Line can be used to facilitate the consultation

2.3. Hospital Follow-Up (HFU)

Patients at risk of cancer recurrence or with specific complex needs will remain under regular clinical follow-up. The duration of HFU and the possibility of transferring to TFU or SSM will be discussed with the patient at appropriate times in their pathway. The majority of patients on the HFU pathway will have received radiotherapy, chemotherapy and or immunotherapy and therefore will have a greater likelihood of late-treatment effects.

- After completing primary treatment, the patient will be seen by a consultant to discuss PSFU and the optimum plan for their personal follow-up
- An appointment with the Gynaecology CNS will be arranged within 4 weeks following the patient's post operative clinic appointment or final decision to place into SSM. An initial face-to-face or telephone appointment will be offered to the patient.
- At the CNS appointment, a eHNA offered including a PSCP, along with a MUST and menopause signposting along with an assessment once developed. Also an end of treatment summary
- A printed patient information leaflet (Appendix D) explaining the different follow-up models (SSM, TFU and HFU), which includes the signs and symptoms of recurrence, will be given to the patient along with a copy of their eHNA. A future development is that a link/QR code to an information video explaining HFU (Video 3) can be included and/or sent to patients.
- The patient will attend face-to-face clinic appointments for clinical examination and assessment of treatment-related effects. Imaging may be organised if there is suspected recurrence or in keeping with national guidance (RCR guidelines)
- At the end of the follow-up period the patient will be discharged from routine follow-up. An Accurx message will also be sent to the patient. A future development aims to have a link/QR code to an information video explaining pathways for re-referral (Video 4) within the discharge letter.

3. Procedure/process for Registered Nurse in Clinic

- The Nurse-led clinic will run on a Friday morning from 10:00 – 13.00 hrs and there will be 4 x face to face or telephone call, 45mins slot for the CNS.
- The clinic code will be GONCNF.
- If the appropriate CNS is not available to run the clinic, the clinic must be cancelled
- The administrative team will prepare the clinic and ensure that all the relevant information that is needed is available
- The CNS will inform the patient of the reasons for the clinic appointment and discuss their diagnosis and treatment they have completed.
- The CNS will undertake an eHNA and PCSP along with a MUST as part of the end of treatment process.
- The CNS will discuss the PSFU pathway and explain the signs and symptoms to look out for and how to contact the CNS team and offer written information to the patient.
- 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.

- If a patient requires a prescription of medication this will be written by an available Consultant or Doctor.
- The patient remains the responsibility of the Consultant who has undertaken the treatment/ surgery.
- The CNS will dictate a letter on DICT3 and a copy of this will be sent to the patient, GP, and patient's medical record.
- The CNS will email the remote monitoring mailbox to place the patient onto the Somerset Remote Monitoring system (RMS).
- The CNS will document a record of the consultation in the patient's medical record and on Somerset Cancer information System.

4. Pathway for patient contacts

If a patient contacts the CNS they will be assessed, triaged and appropriate investigations or clinical review will be arranged:

- Collection of details by support worker/CNS – using the Triage question sheet (Appendix F)
- The patient will be triaged by a CNS, contacting them if more information is needed
- Patients reporting symptoms suspicious for recurrence will be discussed with their consultant or the follow-up lead and a management plan determined
- In cases of suspected recurrence, patients should be seen in a clinic within 2 weeks of contact for clinical examination and appropriate investigations organised
- If the patient needs to return to clinic, the CNS will contact the Admin Team Leader to book the patient into the next available clinic and notify them accordingly
- A copy of the completed Triage question sheet (Appendix F) will be added to the patient's medical record and the Somerset/RMS system updated to state: checklist completed, XX is main symptoms of concern, refer to patients notes.
- Cases of recurrence should be discussed in the MDT to determine their further management.

5. Patient selection

The follow-up pathway advised for patients will be based on the BGCS guidance[5] a flow chart from the EMCA PSFU guideline is in Appendix G. Suitability will be determined by the MDT, the patient's clinical team and CNS team.

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

- There is a mutual agreement not to enter the self-managed follow up pathway
- The individual is unable to self-mange 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

(Based on the EMCA Endometrial Cancer PSFU guideline)

Risk	If suitable for SSM	If not suitable for SSM
Low Risk	SSM for 5 years	TFU 6 monthly for 2 years, annually years 3-5
Intermediate Risk	SSM for 5 years	HFU at 6 months and 18 months; TFU 12 and 24 months After 24 months either SSM or TFU annually years 3-5
High-Intermediate Risk	N/A	HFU at 6 months and 18 months; TFU 12 and 24 months After 24 months either SSM or TFU annually years 3-5
High-risk	N/A	Year 1: HFU at 3, 6, 9 and 12 months Year 2: HFU at 4, 8 and 12 months Year 3 and 4: HFU at 6 and 12 months Year 5: HFU at 12 months

6. Ongoing audit and pathway review

All cases of endometrial cancer recurrence will undergo review to identify and investigate any issues with the PSFU pathways.

Patients will be requested to complete quality-of-life measures and symptom measures at times in their pathway to enable the identification of unmet needs and areas for further service development.

The trialling on new developments in clinical practice will follow Good Clinical Practice and research governance guidelines.

7. Education and Training

No new skills are required to implement the guideline however, there does need to be awareness training of the PSFU pathway model and SSM pathway. At the outset a communication plan will be devised which will include both Gynaecology and Oncology Services and GPs. The aims of this will be in order that staff support the revised approach should patients raise unfounded concerns and more importantly, ensure that patients can make a timely return into the hospital processes should signs and symptoms dictate.

It is the responsibility of the CNS to ensure they regularly update their knowledge and skills in line with continuing professional development in line with the NMC Code (October 2018). The CNS has undergone adequate preparation for the development of this practice, supported by the Clinical Lead (Appendix H).

On an on-going basis, new staff joining the MDT will need to be aware of the guidelines in the context of the revised service model.

8. Monitoring and Audit Criteria

Key Performance Indicator	Method of Assessment	Frequency	Lead
Time between patent contact and clinical assessment	Somerset	3 monthly	RMS Team
Number of endometrial cancer cases, patient contacts	Somerset	Annually	RMS Team
Time from contact with symptoms to diagnosis of recurrence	Patient's medical notes and CNS records	6 monthly	RMS Team
CNS contacts	Somerset	6 monthly	CNS Team
Patient experience	Patient survey	Annually	CNS Team
Top concerns identified by patients	My Care Plan Portal	Annually	RMS Team

9. Appendix

A. SSM patient information sheet
B. RMS reminder letter
C. RMS discharge letter
D. PSFU PIL
E. CNS TFU question list
F. Triage question sheet
G. Training and assessment required for the CNS clinic

10. Patient information videos (In development)

1. SSM
2. TFU
3. HFU
4. After discharge from FU

11. References

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12. Key words

Gynaecology, Malignancy, Oncology, Personalised Stratified Follow-Up (PSFU), Nurse-led

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The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

Contact and review details			
Guideline Lead (Name and Title) Louise Boulter - Macmillan Gynaecology Oncology Clinical Nurse Specialist Nafisa Patel - Macmillan Gynaecology Oncology Clinical Nurse Specialist Miss Esther Moss – Consultant			**Executive Lead** Miss Esther Moss – Consultant
Details of Changes made during review:			
Date	**Issue Number**	**Reviewed By**	**Description Of Changes (If Any)**
December 2023	**4**	Jane Pickard, Macmillan Lead Cancer Nurse Kristy Link – Project Manager Cancer Centre	Amended to reflect introduction of PSFU, changes in terminology, restructuring, adding in RMS, Accurx and revised appendix versions Merged CNS guideline and PSFU guideline together

Appendix A: SSM Patient Information Leaflet

Information about supported self-management after treatment for endometrial cancer

Appendix B: RMS reminder letter

Hospital Number: <<HospitalNumber>>

University Hospitals of Leicester NHS
NHS Trust
Caring at its best

Gynaecology Department

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

We are sending you this letter to remind you of the signs and symptoms to be aware of as part of the supportive self-management follow up.

You haven't been discharged from our care, but you are on a different way of follow up – if you have any symptoms that are new or anything that concerns you – please call us on 0116 2584840 – we have an answerphone available out of hours - and we can speak to you and discuss your concerns and if needed make an appointment in one of our clinics for you to be seen swiftly, rather than go back to your GP.

The signs and symptoms you should seek further advice about include:-

- Vaginal bleeding
- Vaginal discharge that does not go away
- New leg swelling – in one or both legs
- New low abdominal pain or discomfort which lasts for two weeks or more
- Change in bowel or bladder habit which lasts for two weeks or more
- Loss of appetite, nausea or weight loss
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

If you are concerned about any symptoms you are experiencing, please contact us so we are aware of changes and we can maintain our records of your symptoms if they occur.

Kind Regards

Louise Boulter & Nafisa Patel

Macmillan Gynae/Oncology Clinical Nurse Specialist

Appendix C: RMS discharge letter

Hospital Number: <<HospitalNumber>>

University Hospitals of Leicester NHS
NHS Trust
Caring at its best

Gynaecology Department

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

You have now completed your 5 years of follow up since your diagnosis and have finished our Supportive Self-management programme.

We will now discharge your care back to your GP.

If you have any symptoms that are new or anything that concerns you please see your GP and they will review you and if necessary refer you back to the Gynaecology Department.

The signs and symptoms you should seek further advice about include:-

- Vaginal bleeding
- Vaginal discharge that does not go away
- New leg swelling – in one or both legs
- New low abdominal pain or discomfort which lasts for two weeks or more
- Change in bowel or bladder habit which lasts for two weeks or more
- Loss of appetite, nausea or weight loss
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

Kind Regards

Louise Boulter & Nafisa Patel

Macmillan Gynae/Oncology Clinical Nurse Specialist

Appendix D: PSFU Patient Information Leaflet

Your patient initiated follow up (PIFU) pathway

Appendix E: CNS TFU questions list

Endometrial cancer Telephone Follow-Up (TFU) Appointment checklist (Appendix E)	University Hospitals of Leicester NHS NHS Trust

Patient Name:		**Date of Call:**	
DOB:		**Time of Call:**	
Hospital Number:		**Personal taking Call:**	
Telephone number:			

General Health including and changes with existing medical conditions

Checklist (Ref: EMCA PSFU Guidelines for people with an Endometrial Cancer Diagnosis)			
Symptoms	**Yes**	**No**	**Details**
Vaginal bleeding			
Persistent Vaginal discharge			
New unilateral or bilateral leg swelling			
New persistent low abdominal pain or discomfort which persists for 2 weeks or more Abdominal/pelvic pain			
Change in bladder habit which persists for 2 weeks or more symptoms			
Change in bowel habit which persists for 2 weeks or more symptoms			
New persistent breathlessness			
New back pain which persists or progresses over 2 weeks or more			
Persistent loss of appetite, nausea or weight loss			

Psychological Health/Sexual Health:

CNS Review/Plan:

CNS Name		**Date**	
Added to RMS/Somerset		**Added to Patients notes**	

Appendix E: Endometrial Cancer Telephone Follow-Up (TFU) Appointment Checklist v1.0, August 2023
Guidelines for PSFU following Endometrial Cancer Treatment

Appendix F: Triage question sheet

Endometrial cancer Telephone Triage Checklist (Appendix F)	University Hospitals of Leicester NHS

Patient Name:		**Date of Call:**	
DOB:		**Time of Call:**	
Hospital Number:		**Personal taking Call:**	
Telephone number:			

Reason for calling

Checklist (Ref: EMCA PSFU Guidelines for people with an Endometrial Cancer Diagnosis)			
Symptoms	**Yes**	**No**	**Details**
Vaginal bleeding			
Persistent Vaginal discharge			
New unilateral or bilateral leg swelling			
New persistent low abdominal pain or discomfort which persists for 2 weeks or more Abdominal/pelvic pain			
Change in bladder habit which persists for 2 weeks or more symptoms			
Change in bowel habit which persists for 2 weeks or more symptoms			
New persistent breathlessness			
New back pain which persists or progresses over 2 weeks or more			
Persistent loss of appetite, nausea or weight loss			

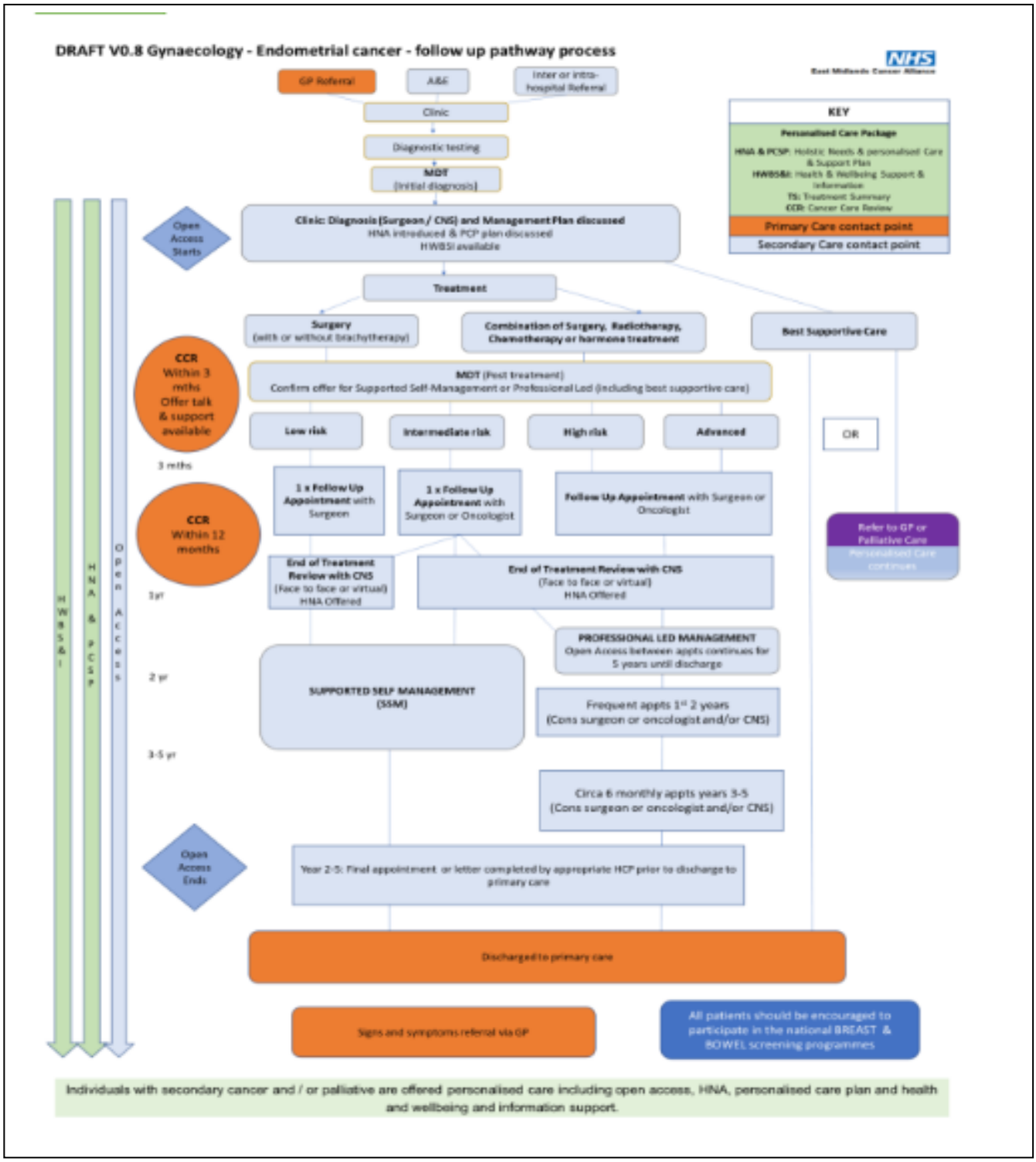
Action plan:

CNS Review:

CNS Name		**Date**	
Added to RMS/Somerset		**Added to Patients notes**	

Appendix F: Endometrial Cancer Telephone Triage Checklist v1.0, August 2023
Guidelines for PSFU following Endometrial Cancer Treatment

Appendix G: Flow diagram for PSFU



Appendix H: Training and assessment required for the Clinical Nurse Specialist for clinic

CNS wishing to see patients as part of the clinic must complete the appropriate training and assessments:

- The registered nurse must have an in-depth understanding of relevant two week wait cancer pathways as per NG12 NICE guidance
- The registered nurse must have completed advanced communication skills training.
- If appropriate, the registered nurse must arrange and co-ordinate any further tests / appointments which are indicated following discussion with the relevant senior clinician at the MDT
- The nurse must be familiar with all relevant National Guidelines and keep up to date with any changes and recommendations

Training and Assessment Proforma for the CNS:

Record of Diagnosis Support Clinical Nurse Specialist Competence

Demonstrate in depth knowledge in assessing / triaging referrals through discussion and reflective learning for a minimum of 10 individual cases (depending on individual level of competence) which includes:

No.	Competence	CNS Sign / Date	Lead CNS Sign / Date
1	Review referral of patients that are referred via the pathway discussed at the MDT		
2	Discuss in detail with patient that they understand their diagnosis and treatment prior to PSFU follow up		
3	Advanced communication skills training completed		
4	Interpreting outcomes, (blood tests as per the referral criteria) and explaining the proposed pathway for onward referral		
5	Escalating where appropriate with a clear rationale		
6	Communicating with a patient in an appropriate and sensitive manner when explaining PSFU over the telephone		
7	Documenting clearly the patients plan on Somerset under CNS activities		
8	Adhering to the NMC Code (2018) and recognising their level of competence and any limitations and working appropriately.		

Number of reflective clinical discussion held …….

This is to confirm, that ……..…… is competent to triage referrals as the Clinical Nurse Specialist as defined within the boundaries of these guidelines.

Signature …… (Clinical Lead)

Print …….

Date ……