CLINICIANS GUIDE TO GYNAECOLOGICAL CANCER PERSONALISED STRATIFIED FOLLOW UP (PSFU)

Updated 30/11/2022

This document was adapted from the LSC Clinicians Guide for Breast, Colorectal and Prostate SSMFU.

Executive Summary

The number of people living with and beyond cancer is increasing by 3% every year, with an estimated 4 million living with a diagnosis of cancer by 2030 (Macmillan, 2019). There is increasing evidence to suggest that the traditional follow up model does not meet the needs of patients and their families dealing with the consequences of treatment (NHS 2016).

Recognising that a clinical setting is not necessarily the most appropriate environment in which to meet the individual needs of patients has promoted the development of an exciting new model of cancer follow up: Personalised Stratified Follow Up - PSFU **(previously known as Supported Self-Managed Follow Up – SSMFU or Risk Stratified Follow Up - RSFU).** By transforming the gynaecological cancer follow up pathways we will empower patients and provide them with the essential tools and education required for them to take ownership of their follow up care, hence taking a step towards personalised care and support planning, as prioritised in the NHS Long Term Plan (LTP).

Effective delivery of PSFU will require all patients to have access to the elements of the LTP personalised care interventions (formerly Macmillan Recovery Package) i.e. Personalised Care and Support Plan based on Holistic Needs Assessment (HNA), Treatment Summaries, Health and Wellbeing Information and Support, or similar, and a primary care Cancer Care Review.

Effective PSFU is dependent upon *all* stakeholders working collaboratively to embrace this cultural shift and present it as a positive alternative for patients.

Principles that underpin supported self-management:

- An agreed stratification criterion to identify those patients suitable for supported self-management considering both risk of recurrence and the individual needs of the patient.
- A reliable, safe, remote surveillance digital software system to track and monitor investigation requests and results.
- Access to timely education and support for the patient in the form of workshops (online, telephone or face to face), supported by written material which can be assessed online or in printed format.
- Follow up criteria will remain in line with national guidelines.
- A Cancer Support Worker (CSW, band 4) will manage the database and be the first point of contact for patients.
- Rapid re – access into traditional follow up if required at any point in the journey.

Personalised Stratified Follow-Up (PSFU)

The patient will be identified as suitable for PSFU when they attend their appointment with their health care professional: using the Stratification Criteria (Appendix 1)**.** All patients entering onto this pathway will have been diagnosed with a gynaecological cancer and completed or started their initial treatment or management.

When a patient is selected for PSFU, the criteria consider individual needs alongside the staging and grading of the cancer. Please refer to Staging for Risk Groups (Appendix 2). Patients must have a good understanding of PSFU and be willing to self-manage along with an agreement to attend the PSFU patient education workshop (online or face to face). Patients who are non-compliant, socially isolated, or with complex needs will not be eligible for PSFU.

Any patients requiring vault smears following surgery will be identified by their consultant and this will initiate a separate appointment from the PSFU follow up.

Lynch syndrome patients will be followed up in a national surveillance programme in addition to Risk stratified follow up.

Entry onto the Database

The CSW will input the patient's details onto the remote surveillance database based upon current British Gynaecological Cancer Society guidelines. See also the Gynaecology Cancer PSFU Aftercare Pathways (Appendix 3)

Depending on local policy, providers may input additional investigations manually.

Pending database capabilities, the Treatment Summary **(**Appendix 4**)** will be populated and ready for use in the Post-Operative Appointment.

An appointment letter will be generated for the next available Supported Self-Management Patient Education Workshop (either face to face or virtual online workshop). This letter will be given to the patient at their Post-Treatment Appointment or sent out to the patient after the appointment at a later date.

Post-Operative Appointment

If the appointment is face to face, the Consultant, Gynaecology Clinical Nurse Specialist (CNS) and the ideally the CSW will be present. However, it is recognised that this will not be possible for appointments undertaken by telephone.

The patient's histology will be discussed, and Treatment Summary (Appendix 4) completed with the Consultant/CNS.

The Consultant and/or CNS responsible for stratification (Network or Local level) will discuss the 3/5 year follow up programme and provide the patient with patient information on Supported Self-Management (Appendix 5).

The CSW will be introduced as the main point of contact and contact details given. The CSW will provide the patient with the appointment letter for the Health and Wellbeing Workshop and an information leaflet (Appendix 5).

A HNA (Appendix 6) will be offered by the CSW at this appointment.

The Treatment Summary (Appendix 4) and Information for GPs (Appendix 7) will be sent to GP. This will be done separately for each patient. A copy of the HNA/Care Plan will be sent to GP to inform their Cancer Care Review.

Supported Self-Management Patient Education Workshop

Pre- Workshop

Every patient will be required to attend a 'Supported Self-Management Education Workshop', at their local Trust, approximately 3-4 months post treatment. There will be one of these held a month for 1-2 hours and will cater for no more than 12 patients. The frequency of these workshops may need to be increased as

confidence in the pathway grows and the eligibility criteria expand. An online version or 1:1 education will also be provided if required.

The workshop will be organised by the CSW including arranging the agenda and speakers, venue and refreshments.

During the Workshop

The appointment will be a group educational session with an aim to provide patients with the information and education (Appendix 9) that will allow them to transfer into a supported self-management programme as safely and as positively as possible.

Content to include:

- Gynaecological cancer information
- Explain the concept of PSFU and rapid access back to clinic
- Details of how to log-in to Mi-PRES system – when available.
- Completion of compulsory Health Concerns Questionnaire (red flag symptoms) (Appendix 8)
- Signs and symptoms of recurrence
- Methods of contact if patient has any concerns
- Health and wellbeing advice (e.g. diet, exercise and emotional support)
- Late effects of treatment
- Questions and answers

Once implemented in the Trust, patients will receive their log in details for the patient portal (Mi-PRES) at this workshop.

Post workshop

1 week post workshop the CSW will ring the patient. During this call they will confirm the following:

- Patient understands the concept of PSFU and is happy to remain in PSFU
- The patient has successfully logged onto the Mi-PRES system -if applicable.
- The patient understands their FU protocol.

If the patient agrees to remain in PSFU the CSW will send out a confirmatory letter to patient and GP explaining their personal FU protocol and next steps (Appendix 10).

If patients wish to opt for 'traditional follow-up' or are not suitable for PSFU, then an appointment will be made for the patient to be seen back in a consultant or CNS clinic.

The Supported Self-Management Patient Education Workshop will be reviewed by the CNS and CSW with regard to the following:

- Patient evaluation forms completed during the session (Appendix 11)
- Number of patients that failed to attend the Supported Self-Management Patient Education Workshop.

They will also regularly monitor the number of patients that:

  - Failed to comply with the routine surveillance questionnaires.
  - Contacted the helpline.

The above results will be presented 6 monthly to clinical governance meetings locally and updates will be provided at Clinical Reference Group (CRG).

Surveillance Investigations (see Gynae Aftercare pathway (Appendix 3)

Gynaecology Annual Health Concerns Questionnaire (Appendix 8)

Alert B Questionnaire for patients who have received pelvic radiotherapy (every 6 months) (Appendix 12)

Ovarian Cancer PSFU - CA125 6 monthly

Surveillance Questionnaires

The digital surveillance system will enable the CSW to track when the next investigation/questionnaire is due.

The CSW will send the Health Concerns Questionnaire (Appendix 8) (Local Trust Equality of Access considerations to be applied where appropriate (i.e. language/BSL/literacy etc.) to the patient or complete over the telephone or the patient can complete this directly via Mi-PRES.

The CSW will check if any concerns have been raised on the Health Concerns Questionnaire. If the patient doesn't complete the Health Concerns Questionnaire, the CSW will contact the patient and go through the questionnaire with them. If the patient does not comply with completion of the compulsory Health Concerns Questionnaire/investigations they will be removed from PSFU and put back into traditional follow-up.

- **No Concerns on the Health Concerns Questionnaire**
  - Questionnaire result to be reviewed in Virtual clinic (weekly administrative clinic led by the CNS and supported by the CSW).
  - Patient to continue on protocol
  - "Questionnaire normal letter" to be sent to the patient and GP with date for next questionnaire due

- **Concerns identified on the Health Concerns Questionnaire**
  - Questionnaire to be reviewed in Virtual clinic (weekly administrative clinic led by the CNS and supported by the CSW).
  - CSW/CNS to contact the patient for more information – if appropriate
  - CNS to seek advice from consultant directly or book into clinic appointment

Virtual Clinics

These will be held 'virtually once a week. The CSW/CNS will populate the clinic list with patients whose investigation (where appropriate) and/or questionnaire results are available. Patients are not in attendance.

All Surveillance investigations and Health Concerns Questionnaires will be reviewed. If the results are normal and there are no concerns raised on the Health Concerns Questionnaire, the patient will receive a generic letter stating this. This letter will be sent by post and uploaded onto the patient portal (once available). If the results are abnormal the CNS will contact the patient to discuss further and agree next steps. The CNS will inform the patient and the Consultant.

The virtual clinic will also be used to review any completed HNAs, or additional questionnaires. Any appropriate onward referrals will be actioned.

Rapid Re access to clinic

The patient will be able to re access a face to face or virtual clinic appointment at any point in their pathway.

If disease recurrence is indicated as a result of surveillance questionnaire patients will be put onto MDT for review as per pathway. The CNS will contact the patient to inform them they will be seen in a Consultant/CNS clinic at the earliest opportunity.

If a patient has red flag symptoms from a phone call, appropriate investigations will be requested, and consultant informed or brought back to MDT, if necessary.

Did Not Attend

If a patient fails to complete the mandatory health concerns questionnaire or attend for investigations, the CSW will contact the patient and alert the CNS. If a patient fails to complete/attend on a second occasion, the CSW will attempt to contact them and a letter will be sent to the patient informing them to contact the CSW to discuss why. If the patients do not make contact or cannot be readily contacted they will be transferred back to traditional follow-up.

Questionnaires

Personalised Care and Support Plan based Holistic Needs Assessment (HNA) - **(Appendix 6)**

This should be completed if the patient identifies that they have a worry or concern they wish to address on the mandatory Health Concerns Questionnaire. Patients can also request to complete/review their personalised care and support plan (HNA and care plan) at any point throughout their 3/5 year follow-up. A personalised care and support plan should be developed with the patient to address the unmet needs/concerns.

Alert B Questionnaire – (Appendix 12)

This questionnaire is used to detect chronic gastrointestinal symptoms after pelvic radiotherapy and will only be sent to patients who have received radiotherapy. Local Trust Equality of Access considerations to be applied where appropriate (i.e. language/BSL/literacy etc.) This will be 'optional' for patients to complete along with the compulsory Health Concerns Questionnaire. This questionnaire will be sent to the patient via the patient portal if available, or sent by post if the patient is not registered to use portal. If the patient doesn't complete the questionnaires, it will be assumed the patient has declined. The Questionnaire will be sent on a 6 monthly basis for 5 years. This will not only be used to pick up recurrence but also to manage any side effects from the radiotherapy treatment.

References

Macmillan. (2019) *Statistics Fact Sheet.* ***https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf***

NHS England. (2016) *Risk Stratified Follow up- A how to Guide.* ***https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf***

British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU)

Appendix 1 – Stratification Criteria (Based on BGCS Recommendations)

RISK LEVEL TO BE DETERMINED AT MDT

Protocol	PSFU for 3/5 years post treatment	Remote telephone FU	Clinic based FU
Endometrial Cancer	Low risk (<10% risk of recurrence ROR) from end of treatment HNA by 3/12;	If patient declines PSFU (for maximum of 2 years from end of treatment)	If patient declines PSFU (for maximum of 2 years from end of treatment)
	Intermediate risk (10-20% ROR) offer from end of treatment or 2yrs for all;	Intermediate risk up to 2 years in place of traditional clinic based follow up	Intermediate risk up to 2 years in place of remote FU
	High risk (>20% ROR) offer from 2 years from end of treatment.	High risk up to 5 years in place of traditional clinic based follow up	High risk up to 5 years in place of remote FU
Ovarian Cancer	Low risk (<10% ROR, Stage 1A/B fully staged) from end of treatment (surgery ± chemotherapy). Excluding fertility sparing surgery. Offer from end of treatment (after holistic needs assessment at 3 months)	Can be offered if declines PSFU for 2 years from end of treatment.	Can be offered if declines PSFU for 2 years from end of treatment. The intermediate group (stage 1C and 2) should still have F2F routine follow up at least for the first 3 years. For ovarian cancer any pt led should only be for the FU early ovarian cancer and should definitely not include stage 3 or stage 4 pts. It should also not include any pts on maintenance treatments (which currently will be stage 3 and 4
	FIGO stages 1C-4. Not suitable for PSFU	Can be offered for years 4-5 from end of treatment.	For 3 years from end of treatment.
Cervical Cancer	Excluding fertility sparing Surgery or LLETZ; Low risk (<10% ROR. FIGO < STAGE 1B) offer PSFU from 2 yrs from end of treatment	Not suitable for remote telephone follow-up	5 years post completion of treatment.
	Intermediate risk – Not suitable for PSFU	Not suitable for remote telephone follow-up	5 years post completion of treatment

	High Risk – (>stage 1B2) Not suitable for PSFU	Not suitable for remote telephone follow-up	5 years post completion of treatment
Vulva/Vaginal			Follow up including clinical inspection for at least 5 years from last treatment
	CSP (Clinical Symptomatic Progression): **In case of RT, advise recall for troublesome pelvic symptoms including:** • **Rectal bleeding** • **PV bleeding/discharge (vulva/vagina/bleeding after sex)** • **Change in urine/bowel habit** • **Getting up at night to open bowels** • **Bowel urgency or incontinence affecting quality of life** • **Night sweats** • **Abdominal bloating/reduced appetite** • **Persistent Pain** • **UTI symptoms** • **Reduced energy levels** • **New lumps or swellings** • **Itching down below**		
	The following patients must remain with traditional face to face follow up Patients who are unable to self-manage due to physical, cognitive or emotional reasons. Patients on clinical trials incorporating specialised follow up requirements Patients who are experiencing treatment related side effects Patients with disease recurrence or maintenance/active treatment Patients with non-epithelial ovarian cancer Patients with rare tumours with uncertain or higher recurrence risk		

Those patients that are not eligible will be recorded as not appropriate and offered traditional face to face follow up. Patients on traditional face to face attended follow up will have appointments that are individualised to their diagnosis and ongoing needs. The final decision regarding entry into PSFU Personalised Stratified Follow Up is conducted in collaboration with the patient.

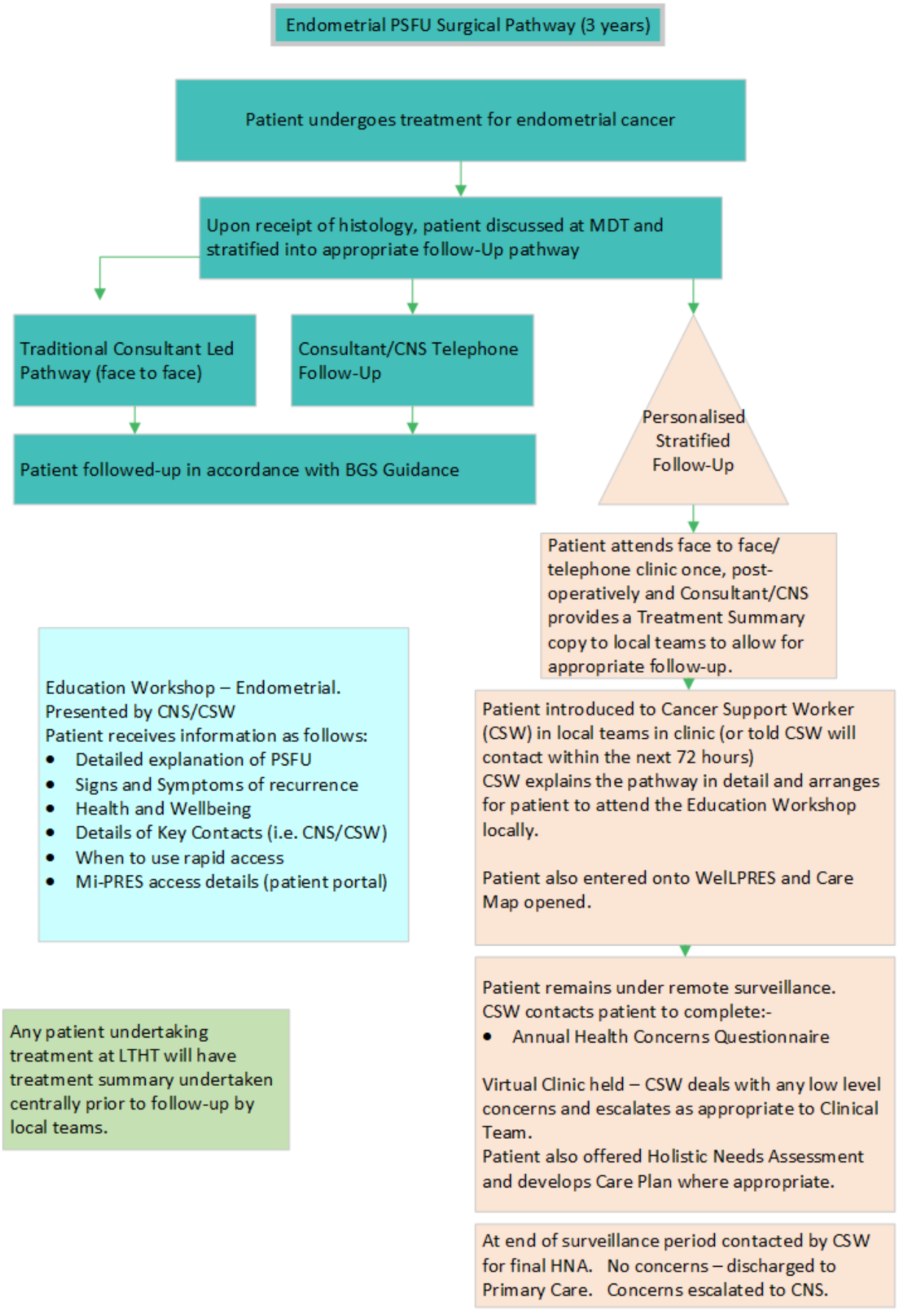
Appendix 2 Staging for Risk Groups

Risk group	2014 ESMO-ESGO-ESTRO Consensus	Molecular classification unknown	Molecular classification known
Low	· Stage IA endometrioid +low grade* +LVSI negative	· Stage IA endometrioid + low-grade* + LVSI negative or focal	· Stage I-II *POLE*mut endometrial carcinoma, no residual disease · Stage IA MMRd/NSMP endometrioid
Intermediate	· Stage IB endometrioid + low grade* + LVSI negative	· Stage IB endometrioid + low-grade* + LVSI negative or focal · Stage IA endometrioid + high-grade* + LVSI negative or focal · Stage IA non-endometrioid** without myometrial invasion	· Stage IB MMRd/NSMP endometrioid carcinoma + low-grade* + LVSI negative or focal · Stage IA MMRd/NSMP endometrioid carcinoma + high-grade* + LVSI negative or focal · Stage IA p53abn and/or non-endometrioid** without myometrial invasion
High-intermediate	· Stage IA endometroid + high grade*, regardless of LVSI status · Stage I endometrioid + low grade* + LVSI unequivocally positive, regardless of depth of invasion	· Stage I endometrioid + substantial LVSI, regardless of grade and depth of invasion · Stage IB endometrioid high-grade*, regardless of LVSI status · Stage II	· Stage I MMRd/NSMP endometrioid carcinoma + substantial LVSI, regardless of grade and depth of invasion · Stage IB MMRd/NSMP endometrioid carcinoma high-grade*, regardless of LVSI status · Stage II MMRd/NSMP endometrioid carcinoma
High	· Stage IB endometrioid + high grade* regardless of LVSI status · Stage II · Stage III endometrioid with no residual disease · Stage I-III non-endometrioid** with no residual disease	· Stage III-IVA with no residual disease · Stage I-IVA non-endometrioid** with myometrial invasion, and with no residual disease	· Stage III-IVA MMRd/NSMP endometrioid carcinoma with no residual disease · Stage I-IVA p53abn endometrial carcinoma with myometrial invasion, with no residual disease · Stage I-IVA NSMP/MMRd serous, undifferentiated carcinoma, carcinosarcoma with myometrial invasion, with no residual disease

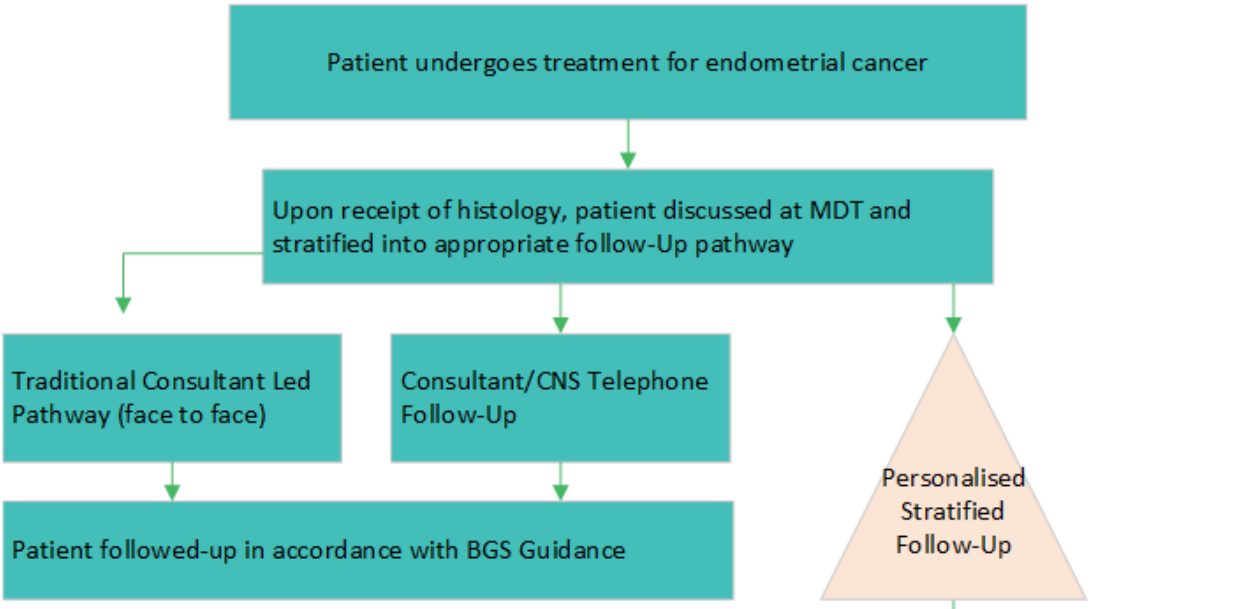
As per binary FIGO classification (Grade 1/2 = low; Grade 3 = high); ** includes serous, clear cell, undifferentiated carcinoma, carcinosarcoma, mixed

Intermediate group suitable for PIFU/ PSFU after first 3 month review following treatment.

Appendix 3 – Gynaecology Cancer PSFU Aftercare Pathways



Endometrial PSFU Radiotherapy Pathway (5 years)



Patient attends face to face/telephone clinic once, post-operatively and Consultant/CNS provides a Treatment Summary

Education Workshop – Endometrial.
Presented by CNS/CSW
Patient receives information as follows:

- Detailed explanation of PSFU
- Signs and Symptoms of recurrence
- Health and Wellbeing
- Details of Key Contacts (i.e. CNS/CSW)
- When to use rapid access
- Mi-PRES access details (patient portal)

Patient introduced to Cancer Support Worker (CSW) in local team in clinic (or told CSW will contact within the next 72 hours)
CSW explains the pathway in detail and arranges for patient to attend the Education Workshop.

Patient also entered onto WelLPRES and Care Map opened.

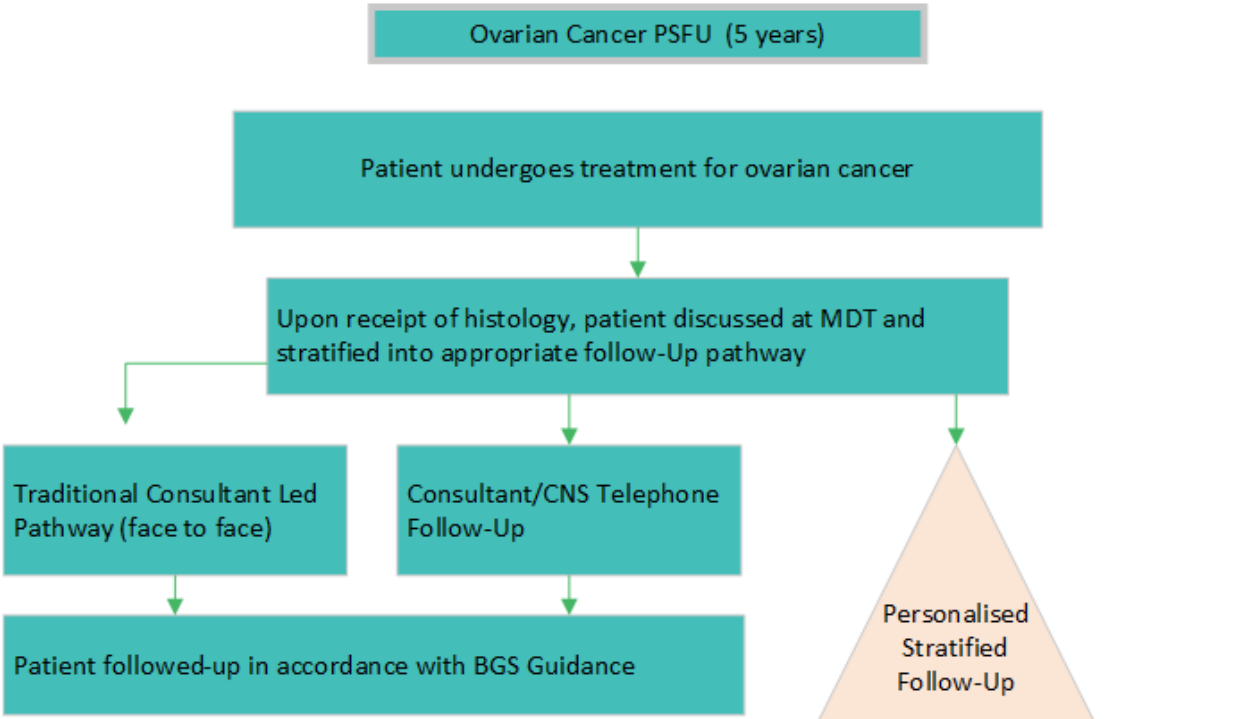
Patient remains under remote surveillance.
CSW contacts patient to complete:-

- Annual Health Concerns Questionnaire
- Alert B Questionnaire for patients who have received pelvic radiotherapy (every 6 months)

Virtual Clinic held – CSW deals with any low level concerns and escalates as appropriate to Clinical Team.
Patient also offered Holistic Needs Assessment and develops Care Plan where appropriate.

Any patient undertaking treatment at LTHT will have treatment summary undertaken centrally prior to follow-up by local teams.

At end of surveillance period contacted by CSW for final HNA. No concerns – discharged to Primary Care. Concerns escalated to CNS.



Patient attends face to face/telephone clinic once, post-operatively and Consultant/CNS provides a Treatment Summary

Patient introduced to Cancer Support Worker (CSW) in local team in clinic (or told CSW will contact within the next 72 hours)
CSW explains the pathway in detail and arranges for patient to attend the Education Workshop.

Patient also entered onto WelLPRES and Care Map opened.

Health and Wellbeing Information Workshop – Ovarian.
Presented by CNS/CSW
Patient receives information as follows:

- Detailed explanation of PSFU
- Signs and Symptoms of recurrence
- Health and Wellbeing
- Details of Key Contacts (i.e. CNS/CSW)
- When to use rapid access
- Mi-PRES access details (patient portal)

Patient remains under remote surveillance.
CSW contacts patient to complete:-

- Annual Health Concerns Questionnaire
- CA125 (6 monthly)

Virtual Clinic held – CSW deals with any low level concerns and escalates as appropriate to Clinical Team.
Patient also offered Holistic Needs Assessment and develops Care Plan where appropriate.

Any patient undertaking treatment at LTHT will have treatment summary undertaken centrally prior to follow-up by local teams.

At end of surveillance period contacted by CSW for final HNA. No concerns – discharged to Primary Care. Concerns escalated to CNS.

Cervical Cancer PSFU entered after 2 years and followed up on PSFU for a further 3 years

Patient undergoes treatment for cervical cancer

Upon receipt of histology, patient discussed at MDT and stratified into appropriate follow-Up pathway

Traditional Consultant Led Pathway (face to face)

Consultant/CNS Telephone Follow-Up

Patient followed-up in accordance with BGS Guidance at local Trust for 2 years post treatment.

Traditional Consultant Led Pathway (face to face)

Consultant/CNS Telephone Follow-Up

Personalised Stratified Follow-Up

Education Workshop – Cervical
Presented by CNS/CSW
Patient receives information as follows:

- Detailed explanation of PSFU
- Signs and Symptoms of recurrence
- Health and Wellbeing
- Details of Key Contacts (i.e. CNS/CSW)
- When to use rapid access
- Mi-PRES access details (patient portal)

Any patient undertaking treatment at LTHT will have treatment summary undertaken centrally prior to follow-up by local teams.

After 2 years patient attends face to face/telephone clinic and Consultant/CNS provides a Treatment Summary if not already done.

Patient introduced to Cancer Support Worker (CSW) in local team in clinic (or told CSW will contact within the next 72 hours)
CSW explains the pathway in detail and arranges for patient to attend the Education Workshop.

Patient also entered onto WelLPRES and Care Map opened.

Patient remains under remote surveillance.
CSW contacts patient to complete:-

- Annual Health Concerns Questionnaire

Virtual Clinic held – CSW deals with any low level concerns and escalates as appropriate to Clinical Team. Patient also offered Holistic Needs Assessment and develops Care Plan where appropriate.

At end of surveillance period contacted by CSW for final HNA. No concerns – discharged to Primary Care. Concerns escalated to CNS.

Appendix 4- Treatment Summary

Dear Patient

Treatment Summary

You have now completed your initial treatment for your endometrial cancer. A summary of your diagnosis, treatment and on-going management plan are outlined below. Your GP will have a copy of this:

Diagnosis: Endometrial Carcinoma
Date of Diagnosis:
FIGO staging:
Treatment:
Surgery Date:

Treatment Aim: Curative Intent Other: Comments

Adjuvant treatment YES/ NO
Comments:

Possible Treatment Effects:

- Infertility
- Lethargy, fatigue, poor concentration and low stamina – these should all improve after treatment ends; regular exercise speeds up recovery
- Emotional problems/ anxiety/ depression –advice from Gynaecology CNS
- Team, patient support groups and counselling services are available

New signs and symptoms: (free text)

Symptoms that may require referral back to the specialist team:

- Bleeding/discharge vulva/vagina/bleeding after sex
- Rectal bleeding
- Persistent pain, tummy swelling/bloating/reduced appetite
- Change in urine/bowel habit
- New lumps or swellings
- Reduced energy levels
- Itching down below

Prescription charge exemption

In England, prescriptions are free for people with cancer. The exemption certificate lasts for 5 years.

Signposted to GP/CNS for FP92A form.

- Yes
- No

Referrals made:
District Nurse
Social Worker
Dietitian
Clinical Nurse Specialist
Psychologist
Macmillan Information Centre
Continence Service
Other

Additional information including issues relating to lifestyle and support needs:

Summary of information given to the patient about their cancer and future progress:

- Patient aware of histology (results of operation)
- Patient has a copy of the agreed care plan
- The patient is fully aware of the signs and symptoms of recurrence

Patient is aware they can contact the CNS team on xxx should any concerns arise.

Recommended GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)

The patient is suitable for self-supported follow up: y/n

Patient's comments:

Your follow up plan

Endometrial Cancer Surgical 3 Year Follow-Up Grid

	1 Year	*2 Years*	*3 Years*
Annual Health Questionnaire	*X*	*X*	*X*

Endometrial Cancer Radiotherapy 5 Year Follow-Up Grid

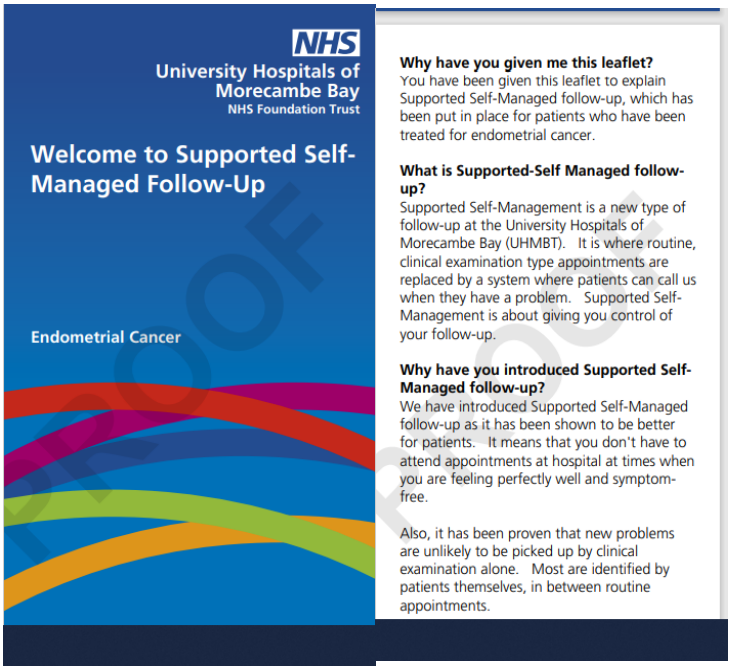
	6M	*1 Yr*	*1 ½ Yrs*	*2 Yrs*	*2 ½ Yrs*	*3 Yrs*	*3 1/2 Yrs*	*4 Yrs*	*4 1/2 Yrs*	*5 Yrs*
Annual Health Questionnaire		*X*		*X*		*X*		*X*		*X*
Alert B Questionnaire only be sent to patients who have received radiotherapy - 'optional' for patients to complete.	*X*	*X*	*X*	*X*	*X*	*X*	*X*	*X*	*X*	*X*

Contacts for queries:

Specialist Nurse:
Cancer support worker:

Consultant/CNS Signature: Date:

Appendix 5 – Patient Information Leaflet



NHS
University Hospitals of Morecambe Bay
NHS Foundation Trust

Welcome to Supported Self-Managed Follow-Up

Endometrial Cancer

Why have you given me this leaflet?
You have been given this leaflet to explain Supported Self-Managed follow-up, which has been put in place for patients who have been treated for endometrial cancer.

What is Supported-Self Managed follow-up?
Supported Self-Management is a new type of follow-up at the University Hospitals of Morecambe Bay (UHMBT). It is where routine, clinical examination type appointments are replaced by a system where patients can call us when they have a problem. Supported Self-Management is about giving you control of your follow-up.

Why have you introduced Supported Self-Managed follow-up?
We have introduced Supported Self-Managed follow-up as it has been shown to be better for patients. It means that you don't have to attend appointments at hospital at times when you are feeling perfectly well and symptom-free.

Also, it has been proven that new problems are unlikely to be picked up by clinical examination alone. Most are identified by patients themselves, in between routine appointments.

Why have you given me this leaflet?
You have been given this leaflet to explain Supported Self-Managed follow-up, which has been put in place for patients who have been treated for endometrial cancer.

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Supported Self-Management is a new type of follow-up at the University Hospitals of Morecambe Bay (UHMBT). It is where routine, clinical examination type appointments are replaced by a system where patients can call us when they have a problem. Supported Self-Management is about giving you control of your follow-up.

Why have you introduced Supported Self-Managed follow-up?
We have introduced Supported Self-Managed follow-up as it has been shown to be better for patients. It means that you don't have to attend appointments at hospital at times when you are feeling perfectly well and symptom-free.

Also, it has been proven that new problems are unlikely to be picked up by clinical examination alone. Most are identified by patients themselves, in between routine appointments.

Are there any regular tests that I need to have?
No. All we ask is that you complete and return a health concerns questionnaire at various intervals.

Will I still be able to access the Gynaecology Team in the event of concerns?
Yes. You can still call the **Gynaecology Team** if you have any queries or problems, and you are encouraged to do so. Please see below for details of the numbers.
Cancer Support Worker - 07815464693
Clinical Nurse Specialist (RLI) - 07779423602
Clinical Nurse Specialist (FGH) - 07779423761

How the Helpline works
During the Health and Wellbeing Information and Support Workshop you will be given information on how to contact the team with any symptoms or concerns.

If you need to use these numbers please leave a short message including your name, hospital number, and telephone number on the answerphone. These are checked regularly from Monday to Friday 9am until 4pm and you will be phoned back by a member of the Gynaecology Team within 2 working days.

Appendix 6 – Holistic Needs Assessment (HNA)

Dear

Additional Support for People Affected by Cancer

We understand that every person's experience of living with a cancer diagnosis will be different. We can help tailor the care and support you feel you need by offering you a Holistic Needs Assessment (HNA).

Holistic care is caring for every person as an individual and considers the physical, emotional, social and spiritual needs of each person. You can take as much as you need from the assessment, it will be led by you.

How We Can Help You

Our role is to work with you to address any concerns and questions you may have, we work closely with your wider specialist cancer team and where needed, we can refer you to relevant professionals that can answer any questions you may have that we can't.

To complete your HNA we can meet at your next clinic appointment, at a separate arranged time within the hospital or via the telephone, whichever you find most suitable to you. A copy of the HNA can be found on the back of this letter.

If you do not want to have a HNA but still want information and advice or information about local support services available to you please contact our Macmillan Information and Support Service on xxxx or email xxxxx

If you would like to arrange an appointment to carry out the HNA please get in touch with us.

Yours sincerely

Holistic Needs Assessment: Identifying your concerns

Practical Concerns

- ☐ Caring responsibilities
- ☐ Preparing meals/drinks
- ☐ Grocery Shopping
- ☐ Talking or Being Understood
- ☐ Smoking Cessation
- ☐ My medication
- ☐ Washing and dressing
- ☐ Transport or Parking
- ☐ Money or Finance
- ☐ Taking Care of Others
- ☐ Pets
- ☐ Difficulty Making Plans
- ☐ Travel
- ☐ Work or Education
- ☐ Laundry or Housework
- ☐ Housing
- ☐ Problems with Alcohol or Drugs

Family/Relationship Concerns

- ☐ Children
- ☐ Person who looks after me
- ☐ Partner
- ☐ Person who I look after
- ☐ Other Relatives/friends

Emotional Concerns

- ☐ Anger or Frustration
- ☐ Worry, Fear or Anxiety
- ☐ Difficulty making plans
- ☐ Unable to Express Feelings
- ☐ Independence
- ☐ Guilt
- ☐ Loss of Interest/Activities
- ☐ Sadness or Depression
- ☐ Thinking about the future
- ☐ Loneliness or Isolation
- ☐ Hopelessness
- ☐ Uncertainty
- ☐ Regret about the past

Spiritual or religious concerns

- ☐ Faith or Spirituality
- ☐ Not being at Peace or Feeling Regret about the Past
- ☐ Meaning or purpose of life

Physical concerns

- ☐ My appearance
- ☐ Constipation
- ☐ Tired/Exhausted or Fatigued
- ☐ Hot Flushes/Sweating
- ☐ Memory or Concentration
- ☐ Pain or Discomfort
- ☐ Sleep Problems
- ☐ Wound Care
- ☐ Swallowing
- ☐ Breathing difficulties
- ☐ Diarrhoea
- ☐ Swelling
- ☐ Moving Around (Walking)
- ☐ Sore or Dry Mouth or Ulcers
- ☐ Sex/Intimacy/Fertility
- ☐ Speech or Voice Problems
- ☐ Changes in Weight
- ☐ Cough
- ☐ Passing urine
- ☐ Eating, Appetite or Taste
- ☐ High temperature or Fever
- ☐ Indigestion
- ☐ Nausea or Vomiting
- ☐ Dry, itchy or Sore Skin
- ☐ Tingling in Hands/Feet
- ☐ Sight or Hearing
- ☐ Other Medical Conditions

Information or Support

- ☐ Complementary Therapies
- ☐ Sun Protection
- ☐ Managing my symptoms
- ☐ Diet and Nutrition
- ☐ Making a will or legal advice
- ☐ Patient or carer's support groups
- ☐ Exercise and Activity
- ☐ Planning for my future priorities
- ☐ Health and Wellbeing

Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for Gynaecological Cancer Patients

Date:
Patient Name: DOB: Hospital Number: NHS Number:

Dear Dr .....
I am writing to you to let you know that your patient, after having completed or started treatment for gynaecological cancer at Trust Name, has been transferred onto our PSFU follow up programme.

They have had a consultation which covered the following topics:

- Their diagnosis and prognosis
- The treatment they have had, any ongoing treatment or management, and possible side effects
- Signs and symptoms to report
- Being aware of changes to their body
- Where to find further help and support – including how to contact the dedicated helpline if they have any concerns

Please find enclosed a copy of their treatment summary which outlines what was discussed with them. Your patient also has a copy of this.

Your patient has been added onto a digital remote surveillance system that will be managed by our Cancer Support Worker (CSW). From the database the CSW will generate a reminder approximately 4 weeks before the next investigation is due and xxxx will receive the relevant information. Along with this, the patient will receive a copy of a Health Concerns Questionnaire (red flag symptoms) providing them with a regular opportunity to highlight any concerns. There will be access to an online patient portal where xxxx can view their surveillance (questionnaire) schedule, information from the Supported Self-Management Patient Education Workshop, their treatment summary and an opportunity to complete a holistic needs assessment.

At any point during the 3/5-year follow-up pathway, patients may be contacted to be offered access to any relevant clinical trials that may become available.

At the end of 3/5 years, insert patient name will be contacted via telephone and offered a Health Concerns Questionnaire (red flag symptoms) to ensure any unmet needs are addressed. There will be no end of pathway hospital appointment with the consultant. Any plans from this review will be actioned and a letter will be sent to both you and the patient to provide information regarding any changes and to discharge them from the Hospital Trust supported self-management pathway.

For any queries, please contact our Gynaecological cancer team on insert specialist team number

Signed: ..... Contact Tel no. .....

Name (please print) .....

GYNAECOLOGY PSFU FOLLOW UP HEALTH CONCERNS QUESTIONNAIRE

If you answer yes to any question, please give further details.

1	Have you experienced any vaginal bleeding/discharge?	Yes/No
2	Have you noticed any bleeding after sexual intercourse?	Yes/No
3	Have you developed night sweats?	Yes/No
4	Have you developed any new and persistent abdominal pain (that is different from normal)?	Yes/No
5	Do you have any problems with abdominal bloating?	Yes/No
6	Have you noticed any problems with rectal bleeding?	Yes/No
7	Have you experienced any significant change in your bowel or bladder habit that has lasted more than 2 weeks including getting up at night to open your bowels/bladder?	Yes/No
8	Have you experienced recurrent urinary tract infections?	Yes/No
9	Have you noticed any new lumps or swellings?	Yes/No
10	Have you experienced reduced energy levels?	Yes/No
11	Are there any practical, emotional or relationship concerns that you would like to discuss?	Yes/No
12	Are there any other issues you wish to discuss with one of our Clinical Nurse Specialists?	Yes/No

If you have answered yes to any of these questions you will be contacted by telephone by your gynaecology cancer team. You will also be offered the opportunity to create or review a personalised care and support plan/holistic needs assessment.

Appendix 9 – Patient Education Workshop Leaflet

EXAMPLE OF PATIENT LEAFLET – TO BE DEVELOPED FOR EACH TRUST.

Front cover

Gynaecological cancer personalised stratified follow up – PSFU (supported self-managed follow up for gynaecological cancer SSMFU)

Your guide to supported self-management and surveillance of gynaecological cancer

Contents to cover

Introducing supported self-managed follow-up (SSMFU)
What is supported self-management?
Attending the workshop (or receiving virtual information)
What will the workshop cover?
Surveillance Questionnaires
Holistic needs assessment and care planning
How do I arrange a review?
Finding support
Further information and contacts

- Surgical consultant:
- Oncology consultant:
- Clinical nurse specialist:
- Cancer support worker:

Introducing PSFU Personalised Stratified Follow up or supported self-managed follow-up (SSMFU)

In the past, patients living with or after gynaecological cancer have been seen at regular intervals by their clinical team for follow-up care. Some patients find these pre-arranged appointments useful and reassuring, however many more find them a source of great anxiety and not particularly helpful, unless they have something specific they wish to discuss.

There is strong evidence that symptoms and concerns are addressed more quickly if patients report them as and when they occur, rather than waiting for a routine appointment. We have therefore changed the way we manage the care of patients and this new system is called Personalised Stratified Follow up or supported self-managed follow-up (SSMFU). This booklet explains what SSMFU (a combination of supported self-management and a personal surveillance plan) is and how it works. It contains details about your cancer and the treatment you have received so far, as well as the tests that you will need in the future (your surveillance plan). It also contains all the information you need to contact your team and arrange to be seen if you are worried.

What is supported self-management?

Supported self-management puts you in control of your care and allows you to take an active and leading role in your recovery with help from your specialist cancer team. There are lots of things you can do to look after your own health during and after cancer treatment. Many of which can be done without the involvement of your clinical team, such as physical activity and healthy eating. During your treatment and care, a member of your team will discuss supported self-management with you. Once you and your doctor have agreed this is the right option for you, you will no longer have routine follow-up appointments at the hospital. Instead you

will be able to contact your team at the hospital directly to arrange a follow-up appointment, if you have any concerns.

Attending the workshop

To take part in SSMFU, you will be invited to come to a one-off education workshop. This will be run by a member of our gynaecological cancer nursing team. This will provide you with the skills and confidence to self-monitor for symptoms and signs of recurrence, manage lifestyle change, and set your own goals for recovery and rehabilitation. At the workshop you will learn about how surveillance is planned for you.

What will the workshop cover?

- Introduction to supported self-management
- WelLPRES demonstration and training
- What is surveillance?
- Coping with the physical and emotional effects of gynaecological cancer
- Healthy lifestyles - healthy eating, physical activity/exercise and bone health
- Fear of recurrence and stress
- Moving forward and goal setting

Where face to face attendance is not available at the education workshop, this information will be available virtually and you will be provided with a link to access this. Alternatively, we can provide you with a hard copy of the information.

Surveillance / Health Concerns questionnaires

At appropriate times, you will be asked to complete a Health Concerns questionnaire. This is to determine if you have any problems that may require further investigation. This questionnaire will also offer the opportunity to discuss any other concerns you may have (such as emotional, relational, financial etc.) with a member of the team, this is sometimes referred to as a Holistic Needs Assessment.

Holistic needs assessment and care planning

At any time you can request a holistic needs assessment (HNA). This is a way of identifying any concerns or problems you may have living with or after gynaecological cancer. These might include practical issues such as work, or dealing with the physical and emotional effects of gynaecological cancer, or concerns relating to your relationships or family life. The HNA will reflect your individual needs with a clear care or action plan. This can help you to manage your care or identify when other help or resources could be useful.

How do I arrange a review?

Emails sent at the weekend will be replied to the next working day. Alternatively you can call the Gynaecology team on <insert telephone number>.

You can leave a message on the answer machine, which is checked every working day (please note: it is not an emergency phone line). One of the team will aim to contact you within one working day.

Finding support

You may have already found that people have different ways of living with gynaecological cancer. There is no right or wrong way, just what works for you. Some people prefer not to talk about it, while others find it helps to discuss their experience. Your gynaecological cancer nursing team is there to help you with support so ask them if you would like details of local support groups.

National contacts

Cancer Research UK
Cancer Research UK's patient information resources
Helpline: 0808 800 4040
www.cancerresearchuk.org

Macmillan Cancer Line
Free information, practical and emotional support.
Telephone: 0808 808 2020
Email: cancerline@macmillan.org.uk

NHS Choices
Includes all NHS online services and information, to help you make choices about your health.
www.nhs.uk

Citizens Advice Bureau
www.citizensadvice.org.uk

RADAR national key scheme
Offers access to more than 6000 locked public toilets for disabled people in the UK. Keys can be obtained from 020 7944 2046, and often from local social services offices, district council offices and some branches of Age Concern.
www.radar.org.uk

Eve Appeal
Home | Gynaecological Cancer Research Charity | The Eve Appeal

Ovacome
Ovacome ovarian cancer

Target Ovarian Cancer
Target Ovarian Cancer | The ovarian cancer charity

Jo's Cervical Cancer Trust
Jo's Cervical Cancer Trust | Cervical Cancer Charity (jostrust.org.uk)

Menopause Matters
Menopause Matters, menopausal symptoms, remedies, advice

Local contacts

<Insert local support available> MCISS Teams, Cancer Care Teams plus local support groups.

INSERT TRUST LOGO

Appendix 10 (Sample letters)

PATIENT DETAILS

Date:

Introduction to Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway)

Dear (insert name) RXR (insert RXR number)

As your gynaecological cancer is stable at the moment, you have been placed on our PSFU (Supported Self-Managed Follow-Up Programme). This means that we will organise for you to receive a Treatment Summary and attend an education workshop. You will complete an annual health concerns questionnaire. This questionnaire will be reviewed and if you have raised any concerns our gynaecological cancer nurse specialist team will contact you. You will also be able to contact a member of our Gynaecological Cancer Support Team at any time between these questionnaires if you have noticed any problems.

The advantage of this programme is that we will be able to closely monitor your gynaecological cancer, without you having to attend the hospital regularly. However, if you do have any problems we will be able to see you urgently. There is strong evidence that symptoms and concerns are assessed more quickly if patients report them as and when they occur, rather than waiting for a routine appointment.

If you have any questions or problems before then you should call us on **(INSERT TELEPHONE NUMBER).** If you reach the answerphone then please leave a short message with your name, date of birth and contact number. We will aim to call you back within one working day.

We would also like to hear from you if you have any of the following symptoms;

- **Bleeding/discharge**
- **Vulval/vagina/bleeding after sex**
- **Persistent pain, tummy swelling/bloating/reduced appetite**
- **Change in urine/bowel habit**
- **New lumps or swellings**
- **Reduced energy levels**
- **Itching down below**

Kind Regards, Gynaecological Cancer Support Team **(TELEPHONE NUMBER)**

ENTER TRUST LOGO

GP DETAILS

Doctors Address:

Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) and remote surveillance

Dear Dr (name),

RE: (Patient name and NHS number)

This patient's cancer is stable at the moment and they are now registered on our PSFU programme. We will organise for the patient to have any appropriate regular investigations and complete a Health Concerns Questionnaire about any issues they may be having and will then contact the patient with the outcomes. We will also inform you of the result and if any further actions are needed.

- If the result is acceptable and there are no issues on the questionnaire, we will notify the patient and let them know. We will also write to you with the results.
- If there have been any concerns highlighted on the questionnaire, we will contact the patient to discuss matters further.

The advantage of this programme is that the patient will not have to attend clinics at the hospital so often and their condition will be remotely monitored by the Gynaecological Cancer Support Team.

We would also like to hear from you if you have any of the following symptoms;

- **Bleeding/discharge**
- **Vulval/vagina/bleeding after sex**
- **Persistent pain, tummy swelling/bloating/reduced appetite**
- **Change in urine/bowel habit**
- **New lumps or swellings**
- **Reduced energy levels**
- **Itching down below**

There is strong evidence that symptoms and concerns are addressed more quickly if patients report them as and when they occur rather than waiting for a routine appointment. As part of this programme the patient will be invited to a one–off Supported Self-Management Patient Education Workshop delivered by the Gynaecological cancer support team. This will provide the patient with the confidence to self-monitor symptoms and signs of recurrence, manage lifestyle changes and set their own goals for recovery and rehabilitation. ONCE SYSTEM LIVE ADD IN: The patient will be provided with secure and confidential access to an online resource called Mi-PRES. Through this system, they can track their own results and complete a health questionnaire (holistic needs assessment) as well as accessing information and support on living with and after gynaecological cancer.

Kind Regards,

Gynaecological Cancer Support Team **(TELEPHONE NUMBER)**

INSERT TRUST LOGO

GP DETAILS

Dear Dr **(name)**

RE: Patient name + NHS number

This patient is on Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for their gynaecological cancer. The latest (appropriate investigation) shows XXX. We have therefore asked the patient to have a further test on **(date)** which is slightly earlier than usual and will contact you again following this.

Kind Regards,

Gynaecological Cancer Support Team

FOLLOW UP

Throughout your follow up you can contact the Cancer Support Worker (CSW) or Cancer Nurse Specialist at any time if you or your family are concerned about your health and after effects of your Gynaecological Cancer Treatment.

Should you develop any of the symptoms below, which persist for more than a month, you can contact your GP or Gynaecological Specialist Nurse:

XXX

XXX

XXX

If you have any worrying symptoms, your gynaecological nurse or Consultant will see you in clinic.

Cancer Support Worker Tel: xxxxxxx

Gynaecological Clinical Nurse Specialist Tel: xxxxxxxxx

INSERT TRUST LOGO

(INSERT DATE)

GP DETAILS

Dear Dr **(name),**

RE: Patient name + NHS number

This patient is on Gynaecological Stratified Follow Up – PSFU (supported self-managed follow up pathway) for their gynaecological cancer. The patient has raised some queries or concerns on their latest Health Concerns Questionnaire so we will contact them about these. Hopefully we will be able to deal with these but will keep you informed and may need your assistance with some matters.

Kind Regards,

Gynaecological Cancer Support Team

INSERT TRUST LOGO

Date (insert)

Dr (name)

Address

Dear **Dr (name),**

RE: (PATIENT NAME) **NHS: (INSERT)**

This patient is on Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway)) for their gynaecological cancer. The latest XXX on **(date)** was satisfactory at **(level).** The patient also raised no concerns on their Health Concerns Questionnaire. We have asked the patient to have a further test on **(date)** and will contact you again following this.

Kind Regards,

Gynaecological Cancer Support Team

If you have answered yes to any of these questions you will be contacted by telephone from your gynaecology cancer team. You will also be offered the opportunity to create or review a personalised care and support plan/holistic needs assessment.

Appendix 11 – Patient Evaluation for Supported Self-Management Patient Education Workshop

Patient Evaluation

Supported Self-Management Education Clinic Feedback Form

1. **Were you provided with a letter and an information leaflet?**

   ☐ Yes
   ☐ No

2. **Understanding Supported Self-Managed Care.**

   a. **Importance**

   ☐ High
   ☐ Medium
   ☐ Low

   b. **Useful, Relevant & Met your needs**

   ☐ Yes
   ☐ Not sure
   ☐ A little
   ☐ No

3. **Managing side effects from treatments**

   a. **Importance**

   ☐ High
   ☐ Medium
   ☐ Low

   b. **Useful, Relevant & Met your needs**

   ☐ Yes
   ☐ Not sure
   ☐ A little
   ☐ No

4. **Signs and symptoms to look out for**

   a. **Importance**

   ☐ High
   ☐ Medium
   ☐ Low

   b. **Useful, Relevant & Met your needs**

   ☐ Yes
   ☐ Not sure
   ☐ A little
   ☐ No

5. **Exercise**

   a. **Importance**

   - [ ] High
   - [ ] Medium
   - [ ] Low

   b. **Useful, Relevant & Met your needs**

   - [ ] Yes
   - [ ] Not sure
   - [ ] A little
   - [ ] No

6. **Diet**

   a. **Importance**

   - [ ] High
   - [ ] Medium
   - [ ] Low

   b. **Useful, Relevant & Met your needs**

   - [ ] Yes
   - [ ] Not sure
   - [ ] A little
   - [ ] No

7. **Adjusting and adapting to life after breast cancer**

   a. **Importance**

   - [ ] High
   - [ ] Medium
   - [ ] Low

   b. **Useful, Relevant & Met your needs**

   - [ ] Yes
   - [ ] Not sure
   - [ ] A little
   - [ ] No

8. **Do you think you were invited to the Education Clinic:**

   - [ ] Too early in your follow-up
   - [ ] Too late in your follow-up
   - [ ] At the right time in your follow-up

9. **The workshop itself**

   a. **What was useful?**

   b. **What could be improved?**

   c. **Was the venue suitable?**

   ☐ Yes
   ☐ No

10. **Would you like to be involved in patient voice/involvement projects?**

   ☐ Yes
   ☐ No

Assessment of Late Effects of Radiotherapy – Bowel
Alert-B Screening Tool

Name: Date:
Hospital Number:

Your specialist has asked you to complete this screening tool to puck up any bowel or tummy problems you may have developed following radiotherapy treatment.
Please answer 'Yes' or 'No' to the following questions:

1. Do you have difficulty in controlling your bowls (having a poo), such as:

   - Having to get up at night to poo Yes No
   - Having accidents, such as soiling or a sensation of wetness ("wet wind") Yes No

2. Have you noticed any blood from your bottom recently? (any amount or frequency) Yes No

3. Do you have any bowel or tummy problems that affect your mood, social life, relationships or any other aspect of your daily life? Yes No

   (e.g., do you avoid any activities or situations – travel, work, social life, hobbies? Do you take continence supplies or spare clothing with you when you go out? Have you made any dietary changes? Do you need to allow for frequency or urgency of needing the toilet?)

4. If you have any other worries or concerns, please write them in the box below.

If you have any other problems, your Clinical Nurse Specialist Team will contact you.