Royal Cornwall Hospitals
NHS Trust

Patient Initiated Follow Up (PIFU) Gynaecology Oncology Standard Operating Procedure

V2.0

October 2025

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Data Protection Act 2018 (UK General Data Protection Regulation – GDPR) Legislation

The Trust has a duty under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 to ensure that there is a valid legal basis to process personal and sensitive data. The legal basis for processing must be identified and documented before the processing begins. In many cases we may need consent; this must be explicit, informed, and documented. We cannot rely on opt out, it must be opt in.

Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 is applicable to all staff; this includes those working as contractors and providers of services.

For more information about your obligations under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 please see the Information Use Framework Policy or contact the Information Governance Team

Royal Cornwall Hospital Trust rch-tr.infogov@nhs.net

1. Introduction

1.1. The decision to offer patient initiated follow up (PIFU) is at the discretion of the managing clinician.

1.2. Patient initiated follow-up is a shared decision between the clinician and the patient.

1.3. The patient should understand the process and know when and how to get in touch.

1.4. PIFU is not to be used where patients would otherwise have been discharged.

1.5. This version supersedes any previous versions of this document.

2. Purpose of this Standard Operating Procedure

2.1. **Patient cohort/selection criteria:**

There are no absolute inclusion or exclusion criteria, as decisions surrounding follow-up are centered on the situation and needs and wishes of the individual patient. Clinicians may wish to take into consideration the following factors when considering offering PIFU:

- When the patient completed treatment.
- The risk of recurrence, and the likelihood of any recurrence being salvageable.
- If there are any treatment toxicities that require ongoing monitoring/management.
- If the patient been treated for recurrence and when.
- If the patient can communicate any concerns, for example without a significant language barrier, psychological co-morbidity, cognitive issues, or safeguarding concerns.

2.2. **Exclusion criteria:**

- The patient should not be on a clinical trial where follow-up schemes are defined and limited to hospital-based follow/up.
- It is necessary to see the patient on a fixed timescale, although a blend of PIFU and timed follow-up can be offered.
- The patient is on medication that requires monitoring in secondary care.

2.3. **Timeframe for patient to stay on PIFU pathway:**

- Most patients will remain on PIFU for five years after completion of treatment.
- The time frame may need to be extended for certain pathologies e.g. adult granulosa cell tumour of the ovary may be offered 20 years follow-up.

2.4. **PIFU review date**

Once the patient has completed their specified time for PIFU (usually five years), their case is reviewed by the CNS (Clinical Nurse Specialist) and the patients is discharged with advice to contact their GP if they have any new concerns in future.

2.5. **Key symptoms that should trigger a follow-up appointment request**

For gynae-oncology patients, trigger symptoms are contained in the “CNS-led telephone clinic” patient information leaflet that all patients are given when the schedule of follow-up is being discussed.

For vulval patients the information is contained in the “self-examination” leaflet that all vulval patients receive, and in their clinic correspondence.

2.6. **The patient will trigger their follow-up appointment by**

- For gynae oncology patients: Telephoning the Gynae-oncology CNS office.
- For Vulval clinic patients: Telephoning the Consultant’s secretary.

2.7. **Admin Process when a patient initiates their follow-up**

- For Gynae oncology patients: seek advice from CNS team.
- For Vulval clinic patients: seek advice from the managing consultant.

2.8. **Waiting time between activation of PIFU by patient and review by a clinician:**

- For gynae oncology patients this will depend on the assessment by the CNS. Some patients may benefit from going “straight to test” (e.g. an immediate Ca125 or CT (computed tomography) scan) before coming to clinic. If investigations are not required prior, then a consultation should take place within two weeks of patient contact.
- For vulval clinic patients: at the discretion of the managing consultant, but generally within four weeks.

2.9. **When triaged as requiring an appointment the patient will be seen in**

Either telephone slots or face to face with the managing Consultant, or appropriate colleague in their absence.

2.10. **Clinicians who can list patients for management by PIFU:**

- Consultants.
- Associate Specialists.
- Gynae-oncology Fellows.
- Clinical Nurse Specialists.

2.11. **Equality considerations for this patient group that may necessitate amendments to the PIFU protocol:**

PIFU can be activated by either the patient or significant others (family, friends and carers) where the patient is able to consent to information sharing.

3. Ownership and Responsibilities

3.1. Role of the Clinicians

The clinician is responsible for:

- Ensuring the patient is aware of when and how to get in contact.
- Ensuring the patient and their GP are given the appropriate written information.
- Ensuring the outcome instruction given at the point of transfer to the PIFU service is ‘add to FU pending’. The RTT (referral to treatment) code should be I – decision to commence a period of waiting.

3.2. Role of the Clinical Administration Lead

The clinical administration lead will be responsible for:

- Ensuring the correct FU (follow up) waiting lists are established on PAS. Each clinician offering a PIFU service should have a ‘PIF’ FU waiting list established prior to offering the service to ensure the patients are appropriately excluded from reporting. All naming conventions should be consistent with the Trust standards– list code PIF.
- Ensuring the specialty specific outcome form is updated to include ‘add to PIFU’ as an option.
- Ensuring all relevant clerical and administration staff involved in the service are aware of what a PIFU service is and how to administratively manage patient enquiries relating to activating an appointment.
- Monitoring, using the FU Analysis Tool on Radar, patients who have gone past their ‘to be seen by date’ in conjunction with the responsible clinician.
- Once a month the admin team will forward the list of patients past their “to be seen by date” (the end of the PIFU period) to the CNS team, who will confirm suitability for discharge and which standard letter is to be sent to the patient (see Appendix 3 and 4 for letter templates).

3.3. Role of the Reception Team

The reception team (or those responsible for making FU appointments) will be responsible for:

- Ensuring demographic patient details, including contact telephone number and email address is up to date.

- Ensuring the correct outcome of ‘added to FU pending list’ is recorded at the point of transfer to the PIFU service.
- Ensuring the correct RTT code is recorded – it should be a STOP code.
- Ensuring the patient details are added to the correct Consultant’s PIFU waiting list, and the ‘to be seen by date’ is recorded as detailed on the outcome form.
- Making a follow-up appointment as directed by the clinician for PIFU patients activating a review.
- Irrespective of time elapsed between appointments; the appointment will always be booked as a follow-up.
- The coded comment PIF must be added to field ten when making the appointment on PAS to enable PIFU patients to be monitored.

4. Standards and Practice

As per section two and three above.

5. Dissemination and Implementation

This document will be shared with the relevant staff via the Cervical Screening Provider Lead Meeting. Updates on new documents are also automatically shared Trustwide. No additional training is required for staff in order to implement this procedure.

6. Monitoring compliance and effectiveness

Information Category	Detail of process and methodology for monitoring compliance
Element to be monitored	Compliance with this procedure.
Lead	Miss Sophia Julian, Lead Consultant Gynaecological Oncologist.
Tool	Monitoring incident reports where procedure has failed (Datix).
Frequency	As dictated by frequency of incident reports.
Reporting arrangements	Reporting via Datix.
Acting on recommendations and Lead(s)	Gynaecology risk management process.
Change in practice and lessons to be shared	Required changes to practice will be identified and actioned within 3 months, immediately if required. A lead member of the team will be identified to take each change forward where appropriate. Lessons will be shared with all the relevant staff/stakeholders.

7. Updating and Review

This document will be reviewed no less than every three years.

8. Equality and Diversity

8.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the Equality Diversity And Inclusion Policy or the Equality and Diversity website.

8.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.

Appendix 1. Governance Information

Information Category	Detailed Information
Document Title:	Patient Initiated Follow Up (PIFU) Gynaecology Oncology Standard Operating Procedure V2.0
This document replaces (exact title of previous version):	Patient Initiated Follow Up (PIFU) Gynaecology Oncology Standard Operating Procedure V1.0
Date Issued/Approved:	October 2025
Date Valid From:	October 2025
Date Valid To:	October 2028
Directorate /Department responsible (author/owner):	Miss Sophia Julian, Lead Consultant Gynaecological Oncologist.
Contact details:	Via Secretary - 07385 397 950.
Brief summary of contents:	Local guidance for the management of Gynaecology Oncology patients when transferring them to a PIFU pathway.
Suggested Keywords:	Patient Initiated Follow-Up, PIFU, Gynaecology, Oncology.
Target Audience:	**RCHT:** Yes **CFT:** No **CIOS ICB:** No
Executive Director responsible for Policy:	Chief Medical Officer
Approval route for consultation and ratification:	Gynaecology Speciality Meeting
Manager confirming approval processes:	Caroline Chappell
Name of Governance Lead confirming consultation and ratification:	Michael Cross
Links to key external standards:	https://www.bgcs.org.uk/wp-content/uploads/2020/04/IJGC-British-Gynaecological-Cancer-Society-recommendations-and-guidance-on-patient-initiated-follow-up-PIFU.pdf
Related Documents:	None

Information Category	Detailed Information
Training Need Identified?	None
Publication Location (refer to Policy on Policies – Approvals and Ratification):	Internet and Intranet
Document Library Folder/Sub Folder:	Clinical/Gynaecology

Version Control Table

Date	Version Number	Summary of Changes	Changes Made by
September 2022	V1.0	Initial issue	Miss Sophia Julian, Lead Consultant Gynaecological Oncologist
October 2025	V2.0	Full review, no amendment required.	Jane Borley; Gynaecology Oncology Consultant

All or part of this document can be released under the Freedom of Information Act 2000.

All Policies, Strategies and Operating Procedures, including Business Plans, are to be kept for the lifetime of the organisation plus 6 years.

This document is only valid on the day of printing.

Controlled Document.

This document has been created following the Royal Cornwall Hospitals NHS Trust The Policy on Policies (Development and Management of Knowledge Procedural and Web Documents Policy). It should not be altered in any way without the express permission of the author or their Line Manager.

Appendix 2. Equality Impact Assessment

Section 1: Equality Impact Assessment (EIA) Form

The EIA process allows the Trust to identify where a policy or service may have a negative impact on an individual or particular group of people.

For guidance please refer to the Equality Impact Assessment Policy (available from the document library) or contact the Equality, Diversity and Inclusion Team rcht.inclusion@nhs.net

Information Category	Detailed Information
Name of the strategy /policy /proposal /service function to be assessed:	Patient Initiated Follow Up (PIFU) Gynaecology Oncology Standard Operating Procedure V2.0
Directorate and service area:	Gynaecology
Is this a new or existing Policy?	New
Name of individual completing EIA (Should be completed by an individual with a good understanding of the Service/Policy):	Miss Sophia Julian, Lead Consultant Gynaecological Oncologist
Contact details:	Via Secretary - 07385 397 950

Information Category	Detailed Information
1. Policy Aim - Who is the Policy aimed at? (The Policy is the Strategy, Policy, Proposal or Service Change to be assessed)	This is a local guidance for staff in the management of Gynaecology Oncology patients when transferring them to a PIFU pathway.
2. Policy Objectives	To improve the well-being of patients by offering the appropriate management of patients.
3. Policy Intended Outcomes	To improve the well-being of patients by offering the appropriate management of patients.
4. How will you measure each outcome?	Audit/Multidisciplinary team weekly discussion/incidents/risk management.
5. Who is intended to benefit from the policy?	Staff and patients.

Information Category	Detailed Information
6a. Who did you consult with? (Please select Yes or No for each category)	• Workforce: Yes • Patients/visitors: No • Local groups/system partners: No • External organisations: No • Other: No
6b. Please list the individuals/groups who have been consulted about this policy.	**Please record specific names of individuals/groups:** Gynaecology Specialty Meeting.
6c. What was the outcome of the consultation?	Approved.
6d. Have you used any of the following to assist your assessment?	**National or local statistics, audits, activity reports, process maps, complaints, staff or patient surveys:** No.

7. The Impact

Following consultation with key groups, has a negative impact been identified for any protected characteristic? Please note that a rationale is required for each one.

Where a negative impact is identified without rationale, the key groups will need to be consulted again.

Protected Characteristic	(Yes or No)	Rationale
Age	No	
Sex (male or female)	No	
Gender reassignment (Transgender, non-binary, gender fluid etc.)	No	
Race	No	Any information provided should be in an accessible format for the patient /carer's needs- i.e. available in different languages if required/access to an interpreter if required.

Protected Characteristic	(Yes or No)	Rationale
Disability (e.g. physical or cognitive impairment, mental health, long term conditions etc.)	No	Those patient/carers with any identified additional needs will be referred for additional support as appropriate- i.e. to the Liaison Team or for specialised equipment. Written information will be provided in a format to meet the family's needs e.g. easy read, audio etc.
Religion or belief	No	All staff should be aware of any beliefs that may impact on the decision to treat and should respond accordingly.
Marriage and civil partnership	No	All staff should be aware of any marital arrangements that may have an impact on care (for example: separated families, domestic abuse).
Pregnancy and maternity	No	
Sexual orientation (e.g. gay, straight, bisexual, lesbian etc.)	No	

A robust rationale must be in place for all protected characteristics. If a negative impact has been identified, please complete section 2. If no negative impact has been identified and if this is not a major service change, you can end the assessment here.

I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.

Name of person confirming result of initial impact assessment: Miss Sophia Julian

If a negative impact has been identified above OR this is a major service change, you will need to complete section 2 of the EIA form available here:
Section 2. Full Equality Analysis

Appendix 3. PIFU letter One: For Gynae-oncology Patients

Dear Patient,

As you will recall, your name has been on our “patient-initiated follow-up list” since you completed your treatment.

I am writing to let you know that your period of post-treatment surveillance with us at the hospital has now ended. As you have not reported any concerns to us, your name has been removed from the patient-initiated follow-up list and you have been discharged back to the care of your GP.

It remains important to monitor yourself for symptoms. If you have any concerns in the future, please make an appointment with your GP.

With very best wishes for the future,

Yours sincerely,

Consultant.

Cc GP

Appendix 4. PIFU letter One: For Vulval Clinic Patients

Dear Patient,

As you will recall, your name has been on our “patient-initiated follow-up list” since you completed your treatment.

I am writing to let you know that your period of post-treatment surveillance with us at the hospital has now ended. As you have not reported any concerns to us, your name has been removed from the patient-initiated follow-up list and you have been discharged back to the care of your GP.

It remains important to monitor yourself for symptoms, and self-examine regularly. If you have any concerns in the future, please make an appointment with your GP.

With very best wishes for the future,

Yours sincerely,

Consultant.

Cc GP