
CLINICIANS GUIDE TO PROSTATE CANCER PERSONALISED STRATIFIED FOLLOW UP (PSFU) - SUPPORTED SELF MANAGEMENT

This document was adapted from the LSC Clinicians guide for Colorectal SSMFU and LSC Clinicians guide for Breast SSMFU.

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LANCASHIRE AND SOUTH CUMBRIA CANCER ALLIANCE v9

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 prostate cancer follow up pathway 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 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 prostate cancer and completed or started their initial treatment or management.

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

ENTRY ONTO THE DATABASE

The CSW will check with CNS regarding suitability for PSFU. If CNS confirms appropriateness, CSW to input the patients' details onto the remote surveillance database. The database will populate the five year follow up as per PSFU follow up protocol, based on NICE guidelines.

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

Pending database capabilities, the treatment summary (**Appendix 3**) will be populated and ready for use when treatment complete/decision made regarding ongoing treatment or watchful wait/active surveillance

An appointment letter will be generated for the next available Supported Self-Management Patient Education Workshop.

POST INITIATION OF TREATMENT/MANAGEMENT APPOINTMENT

Patients on active surveillance (AS), watchful waiting (WW) or androgen deprivation therapy (ADT).

Patients are to be seen at their local hospital. The health care professional (+/-) CSW will be present.

The patient's diagnosis will be discussed, and treatment summary completed with the health care professional. The treatment summary (**Appendix 3**) will be sent to GP.

The healthcare professional (+/-) CSW will discuss the 5 year follow up programme and provide the patient with a follow up grid (**Appendix 6**) and patient information on PSFU (**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 Supported Self-Management Patient Education Workshop, if face to face, or link to relevant online resources and information leaflets if required.

A HNA (**Appendix 8**) will be offered by the CSW at this appointment and will form part of a personalised care and support plan. A copy of the HNA will be sent to GP to inform their cancer care review.

If the CSW is not present at this appointment, they will check suitability for PSFU with the CNS and if appropriate, contact the patient at a later date to introduce themselves and send out the appointment letter for the Supported Self-Management Patient Education Workshop, if face to face, or link to relevant online resources and information leaflets if required.

Patients following Robotic Assisted Radical Prostatectomy (RARP) or Radiotherapy

ELHT and LTHT patients

Patients to be seen approximately 6 weeks post treatment.

The Consultant +/- Urology Nurse Specialist and CSW will be present where possible.

The patient's treatment and histology (in the case of prostatectomy) will be discussed, and treatment summary completed by the Consultant, advising the length and type of adjuvant treatment if required. The treatment summary (**Appendix 3**) and Information for GP's (**Appendix 4**) will be sent to GP.

The concept of PSFU will be discussed with the patient during this appointment.

The Consultant and CNS and/or CSW will discuss the 5 year follow up programme and provide the patient with a follow up grid (**Appendix 6**) patient information on PSFU (**Appendix 5**)

The CSW will be introduced as the main point of contact and contact details given. The CSW will check suitability for PSFU with the CNS and if appropriate, provide the patient with an appointment letter for the Supported Self-Management Patient Education Workshop, if face to face, or link to relevant online resources and information leaflets if required.

A HNA (**Appendix 8**) will be offered by the Cancer Support Worker at this appointment. A copy of the HNA will be sent to GP to inform their cancer care review.

BTH and UHMBT patients

Patients to be seen approximately 6 weeks post treatment at the tertiary centre. The Consultant +/- CNS will be present.

The patient's treatment and histology, in the case of prostatectomy, will be discussed, and a treatment summary completed with the Consultant, advising the length and type of adjuvant treatment if required. The treatment summary (**Appendix 3**) and Information for GP's (**Appendix 4**) will be sent to GP.

The concept of PSFU will be introduced to the patient during this appointment and the patient will be referred back to local trust for follow-up (with a copy of the treatment summary).

Approximately 6 weeks later (ie: 3 months after surgery or completing radiotherapy) the patient will be seen back at the local Trust. An extended clinic appointment may be required for this appointment. The Consultant +/-CNS and/or CSW (where possible) will discuss the 5 year follow up programme and provide the patient with a follow up grid (**Appendix 6**) and patient information on PSFU (**Appendix 5**).

The CSW will be introduced as the main point of contact and contact details given. The CSW will check suitability for PSFU with the CNS and if appropriate, provide the patient with the appointment letter for the Supported Self-Management Patient Education Workshop, if face to face, or link to relevant online resources and information leaflets if required.

A HNA (**Appendix 8**) will be offered by the CSW at this appointment. A copy of the HNA will be sent to GP to inform their cancer care review.

If the CSW is not present at the local Trust post-treatment appointment, they must contact the patient at a later date to introduce themselves and send out the appointment letter for the Supported Self-Management Patient Education Workshop, if face to face, or link to relevant online resources information leaflets or 1:1 education if required.

SUPPORTED SELF-MANAGEMENT PATIENT EDUCATION WORKSHOP

Pre- Workshop

Every patient will be required to attend a Supported Self-Management Education Workshop/one to one Education appointment or sent virtual resources as per local protocol.

During the Workshop

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

Content to include:

- Prostate cancer information
- Explain the concept of PSFU and rapid access to back to clinic
- Details of how to log-in to the Patient Portal (when available).
- Completion of compulsory EPIC Questionnaire (**Appendix 10**)
- Explain the different FU protocols
- 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, including ED information
- Questions and Answers

Once implemented in the Trust, patients will receive their log in details for the patient portal at this workshop.

Post workshop

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 9)**.

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 Cancer support worker with regard to the following:

- Patient evaluation forms completed during the session **(Appendix 7)**
- Numbers 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 investigations.
- Contacted the helpline.

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

SURVEILLANCE INVESTIGATIONS

PSA

The Remote Monitoring System will enable the CSW to track when the next PSA is due.

The CSW will send 'PSA due letter' and request for completion of the EPIC Questionnaire **(Appendix 10)** to the patient and request bloods as per local protocol.

The patient will be encouraged to have their PSA taken within the first two weeks of the month due.

The CSW will check for the PSA results during the last two weeks of the month due. The CSW, supported by the Remote Monitoring System) will track the PSA result against the recall criteria and check if any concerns raised on the EPIC Questionnaire. If the patient doesn't complete the EPIC Questionnaire, the CSW/CNS will contact the patient and go through the questionnaire with them over the telephone. If the patient does not comply with completion of the compulsory EPIC, they will be taken off PSFU.

- **No Concerns (ie: PSA within protocol range and no concerns on the EPIC Questionnaire.**
 - Patient to be reviewed in Virtual clinic (weekly administrative clinic led by the CNS and supported by the CSW).
 - Patient to continue on protocol
 - "PSA normal letter" to be sent to the patient and GP with date for next PSA due.
- **Concerns identified (ie: PSA breached protocol range or concerns raised on the EPIC Questionnaire**

- Patient to be reviewed in Virtual clinic (weekly administrative clinic led by the CNS and supported by the CSW).
- CSW to request repeat PSA if required
- CNS to seek advice from consultant directly or book into clinic appointment
- If second PSA is still abnormally raised and/or health concerns persist then stop protocol and discuss at MDT or with an appropriate clinician.
- Rectal Bleeding - To be managed as per local protocol. This may include referral back to GP for 2ww colorectal referral.

VIRTUAL CLINICS

These will be held once a week. The CSW will populate the clinic list with patients whose results are available; a Urology CNS and the CSW will be present.

All test results and EPIC Questionnaire will be reviewed. If the investigation results are normal and there are no concerns raised on the EPIC Questionnaire, the patient will receive a generic letter stating this. This letter will be sent by post. If the results are abnormal - these will be actioned as per Aftercare Pathway (**Appendix 2**). The CNS will inform the patient and the Consultant.

The virtual clinic will also be used to review any completed HNAs or EPIC 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 investigations patients will be discussed at MDT or with an appropriate clinician for review as per pathway. The CNS will contact the patient to inform them they will be seen in a Consultant clinic at the earliest opportunity.

If a patient has red flag symptoms from a phone call, appropriate investigations will be requested, and consultant informed.

DNA – DID NOT ATTEND

If a patient fails to have a PSA blood test or complete the EPIC questionnaire, the CSW will contact the patient and alert the CNS to re-request. If a patient fails to have a PSA blood test on a second occasion, the CSW/CNS 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

Frequency and repetition of questionnaires – discussion at Urology CRG 2/3/23 agreed to reduce use of questionnaires to EPIC (as Nationally agreed questionnaire for prostate patients) with the addition of HNA.

PERSONALISED CARE AND SUPPORT PLAN BASED ON HOLISTIC NEEDS ASSESSMENT (HNA) – (APPENDIX 8)

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

EPIC QUESTIONNAIRE – (APPENDIX 10)

This questionnaire is designed to evaluate patient function and quality of life after prostate cancer treatment and patients will complete at the time of their PSA checks. This questionnaire will be sent to the patient via the patient portal, or sent by post if the patient is not registered to use the patient portal. If the patient doesn't complete the questionnaires, it will be assumed the patient has declined.

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>

APPENDIX 1 -STRATIFICATION CRITERIA

PSFU- PERSONALISED STRATIFIED FOLLOW UP (SUPPORTED SELF-MANAGED FOLLOW UP) – IS ONLY SUITABLE FOR PATIENTS THAT HAD A PSA THAT WAS REPRESENTATIVE OF THEIR GRADE AND STAGE OF DISEASE AT DIAGNOSIS).

Protocol	Eligibility	Monitoring	Recall
Radical Prostatectomy RALP/LRP	<ul style="list-style-type: none"> Consider at 3 months FU PSA<0.05 	<ul style="list-style-type: none"> Year 1, PSA test every 3/12 Year 2-5 PSA test every 6/12 EPIC questionnaire alongside PSA test every 3/12 during Year 1, then every 6/12 during Years 2-5 Discharge to primary care after 5 years, advise PSA annually. Primary care to refer back if meets recall criteria 	<ul style="list-style-type: none"> If PSA > 0.05, repeat after 3mths and if increased further, for review. New onset LUTS, visible haematuria, bone pain
Radiotherapy Alone (with neoadjuvant and concurrent ADT only)	<ul style="list-style-type: none"> Consider at 6 wks to 3 months following completion of radiotherapy for low or intermediate risk disease PSA<2 	<ul style="list-style-type: none"> Year 1, PSA test every 3/12 (with optional testosterone*) Year 2-5, PSA test every 6/12 EPIC questionnaire alongside PSA test every 3/12 during Year 1, then every 6/12 during Years 2-5 Discharge to primary care after 5 years, advise PSA annually. Primary care to refer back if meets recall criteria <p>*testosterone until level recovered or plateau's</p>	<ul style="list-style-type: none"> If PSA> 2, repeat after 3 mths and if still >2, for review. Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain.
Radiotherapy + adjuvant hormones (ongoing ADT after completion of radiotherapy. Oncology Consultant to document clear plan for duration of ADT and if duration of 1-3 years needs to be determined depending on assessment of tolerability, oncology consultant to	<ul style="list-style-type: none"> Consider at 6 wks to 3 months after completion of radiotherapy PSA<2 	<ul style="list-style-type: none"> Year 1 PSA test (with optional testosterone test) every 3/12 Year 2 onwards (5 years after stopping ADT) PSA test (and optional testosterone test*) every 6/12 EPIC questionnaire alongside PSA test every 3/12 Year 1 then 6/12. Discharge to primary care 5 years after completion of ADT, advise PSA annually. 	<ul style="list-style-type: none"> If PSA> 2, repeat after 3 mths and if still >2, for review. If PSA doubles refer to Oncologist. Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain.

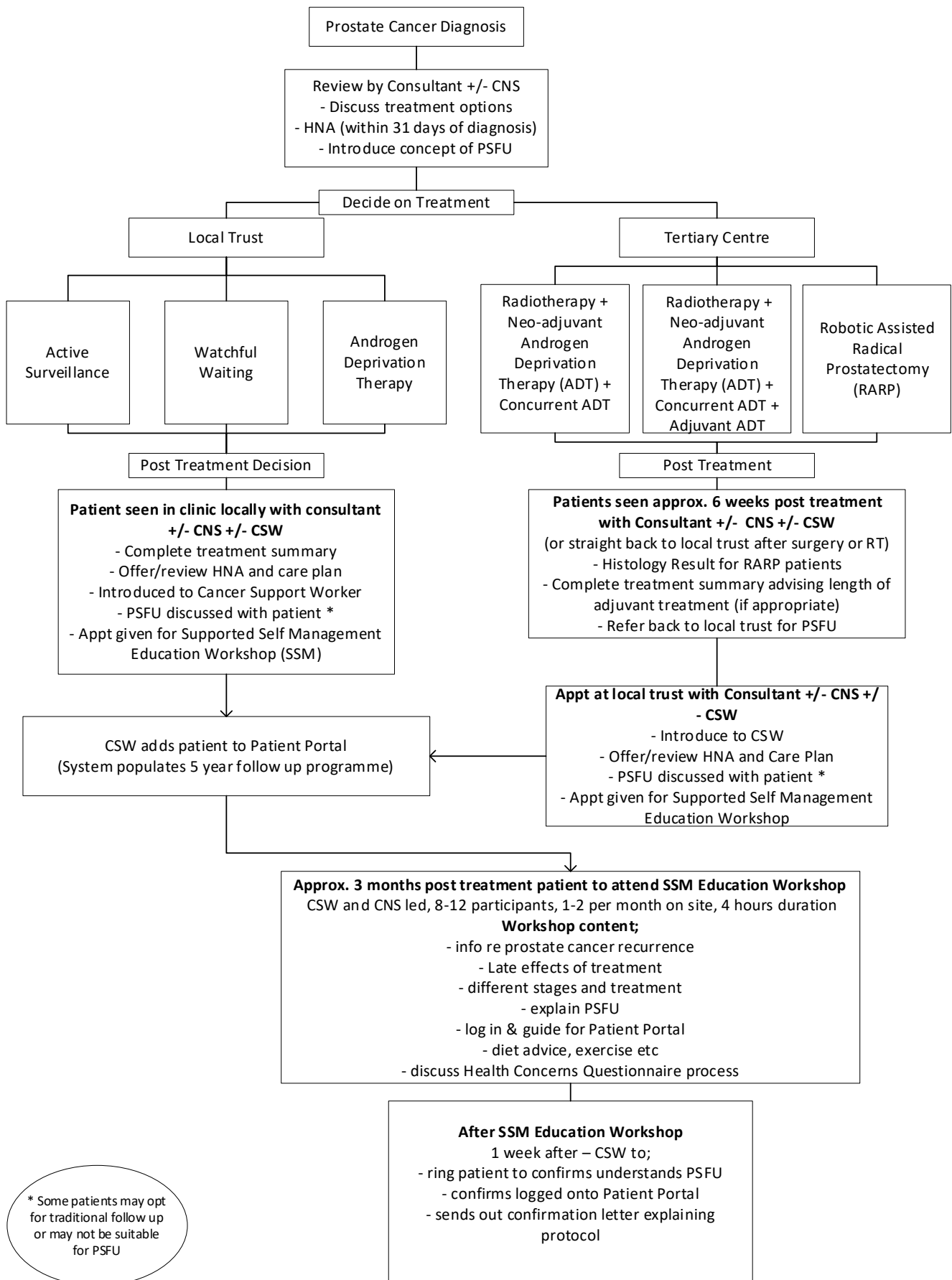
<p>request pre-planned review in oncology at end of ADT).</p>		<ul style="list-style-type: none"> • Primary care to refer back if meets recall criteria *testosterone until level recovered or plateau's In welcome letter advise GP to "monitor annual renal and liver function whilst on adj hormones as to the risk of nephrotoxicity". 	
<p>Salvage Radiotherapy</p>	<ul style="list-style-type: none"> • Consider at 6 wks to 3 months after completion of radiotherapy • PSA 0.5 	<ul style="list-style-type: none"> • Year 1, PSA test every 3/12 (Year 2-5, PSA test every 6/12 • EPIC questionnaire alongside PSA test every 3/12 during Year 1, then every 6/12 during Years 2-5 • Discharge to primary care after 5 years, advise PSA annually. • Primary care to refer back if meets recall criteria 	<ul style="list-style-type: none"> • If PSA > 0.5, repeat after 6 weeks and if still >0.5, for review. • Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain.
<p>Stable patients on Hormones alone for Locally Advanced or Metastatic disease (if not suitable for systemic oncological therapy).</p>	<ul style="list-style-type: none"> • PSA < 4.0, • Satisfactory clinical/biochemical response • Full testosterone suppression ie: <0.5 	<ul style="list-style-type: none"> • Blood tests every 6/12: • PSA • U&Es • FBC • Alkaline phosphatase • LDH • EPIC questionnaire with each PSA test • Discharge to primary care after 5 years. Advise PSA annually. • Primary care to refer back if meets recall criteria 	<ul style="list-style-type: none"> • If PSA > 20 or if clinically symptomatic which is indicated below. • Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain. • Consider testing Testosterone • Hormone holidays only to be instigated by secondary care
<p>Watchful Waiting</p>	<ul style="list-style-type: none"> • Stable PSA or PSA <20 (can be individualised PSA level), • PSA doubling time > 1 yr 	<ul style="list-style-type: none"> • PSA every 6/12 • EPIC questionnaire with each PSA test • Discharge to primary care after 5 years. Advise PSA annually. • Primary care to refer back if meets recall criteria 	<ul style="list-style-type: none"> • PSA above 20, • Clinical Symptomatic Progression* <p>May have to be individualised at the time of discharge.</p>
<p>Active surveillance For adoption by individual Urology Departments as they see fit – to follow NICE Guidelines</p>	<ul style="list-style-type: none"> • Low risk PSA <10, GI 6, CI<T2b • Intermediate risk PSA 10-20 or GI 7 or CI T2b+ 	<ul style="list-style-type: none"> • PSA every 3 months for 1 year, DRE and MRI (or re-biopsy) at 1 year then PSA every 6 months with DRE every year. • EPIC questionnaire alongside every PSA test 	<ul style="list-style-type: none"> • PSA rise greater than 50% over 2 months • Clinical Symptomatic Progression*

		<ul style="list-style-type: none"> • Discharge to primary care after 5 years. Advise PSA annually. • Primary care to refer back if meets recall criteria 	
	<p>CSP (Clinical Symptomatic Progression):</p> <ul style="list-style-type: none"> • Visible haematuria • New onset LUTS • Bone pain • Intractable back pain and symptoms of spinal cord or cauda equine compression • Perineal pain <p>In case of RT, advise recall for troublesome bowel symptoms including:</p> <ul style="list-style-type: none"> • Rectal bleeding • Getting up at night to open bowels • Bowel urgency or incontinence affecting quality of life 		
	<p>The following patients must remain with traditional face to face follow up via their Access Plan:</p> <p>Patients who are unable to self-manage due to physical, cognitive or emotional reasons.</p> <ul style="list-style-type: none"> • Patients on clinical trials incorporating specialized follow up requirements • Patients with low PSA producing tumours 		

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 & ongoing needs. The final decision regarding entry into PSFU Personalised Stratified Follow Up is conducted in collaboration with the patient.

APPENDIX 2 - PROSTATE PSFU AFTERCARE PATHWAY

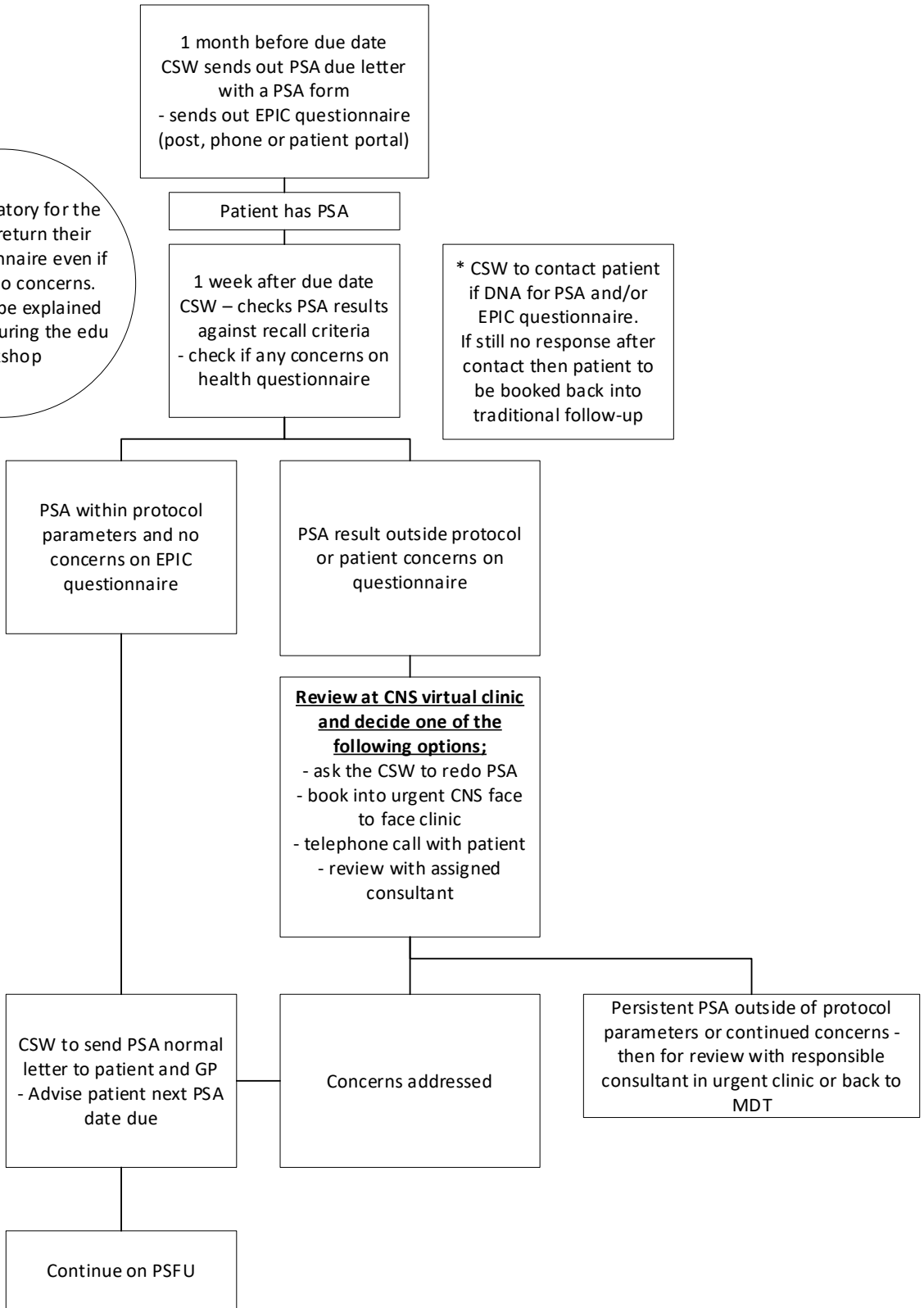
Personalised Stratified Follow Up (PSFU): Prostate Cancer
V2.2 11/03/20 PART 1



* Some patients may opt for traditional follow up or may not be suitable for PSFU

Personalised Stratified Follow Up (PSFU): Prostate Cancer
 V2.2 11/03/20 PART 2

* It is mandatory for the patient to return their EPIC questionnaire even if they have no concerns. This should be explained to patients during the edu workshop



* CSW to contact patient if DNA for PSA and/or EPIC questionnaire. If still no response after contact then patient to be booked back into traditional follow-up

APPENDIX 3- TREATMENT SUMMARY

GP Name GP Address

Dear Dr

Re: Add in patient name, address, date of birth and record number

Your patient has now completed or started on their initial treatment/management for prostate cancer and has been transferred onto a Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway). A summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.

Diagnosis:	Date of Diagnosis:	Organ/Staging: Local/Distant:
Summary of Treatment and relevant dates:		Treatment Aim:
Possible treatment toxicities and / or late effects:		Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contact for queries:

APPENDIX 4- GP INFORMATION

Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for Prostate 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 prostate 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
- Their planned surveillance tests
- 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 either a blood form with a list of blood clinics and/or a letter reminding them a PSA surveillance investigation is due. Along with this, the patient will receive a copy of a EPIC Questionnaire providing them with a regular opportunity to highlight any concerns. At any point during the 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 5 years, insert patient name will be contacted via telephone and offered an EPIC Questionnaire to ensure any unmet needs are addressed. 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 Urology Team on insert specialist team number

Signed: Contact Tel no.

Name (please print)

APPENDIX 5- PATIENT INFORMATION LEAFLET

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

Front cover

Prostate cancer personalised stratified follow up – PSFU (supported self-managed follow up for prostate cancer SSMFU)

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

Contents

Page 3	Your personal details
Page 4	Introducing supported self-managed follow-up (SSMFU)
Page 4	What is supported self-management?
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Page 6	PSA tracking and surveillance
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Page 6	How do I arrange a review?
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Your personal details and summary of your treatment

Name:

Hospital number:

Date you were diagnosed:

PSA level when you were diagnosed:

PSA stands for prostate specific antigen, which is a protein found in the blood

Gleason Score:

this gives an indication of how aggressive the cancer is likely to be

Tumour Staging:

this shows how far the cancer has spread

T – Stage:

this shows how far the cancer has spread in and around the prostate

N – Stage:

this shows whether the cancer has spread to the lymph nodes

M – Stage:

this shows whether the cancer has spread to any other areas of the body

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 prostate 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.

Patient Portal (when available)

To help you self-manage you will be provided with secure and confidential access to a patient portal. You can access this via the internet to share information between you and your clinical team in order to support the management of your healthcare. The patient portal can also be used to access information on living with or after prostate cancer. If you choose not to register to use the patient portal, you can continue to take assessments and receive information in paper format.

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 prostate 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 we will keep track of your prostate specific antigen (PSA) level and how surveillance is planned for you.

What will the workshop cover?

- Introduction to supported self-management
- Patient portal (when available) demonstration and training
- What is PSA tracking and surveillance?
- Coping with the physical and emotional effects of prostate cancer
- Healthy lifestyles - healthy eating, physical activity/exercise and bone health
- Fear of recurrence and stress
- Moving forward and goal setting

PSA tracking and surveillance

PSA stands for prostate specific antigen, which is a protein found in the blood. A PSA blood test is a very effective way of monitoring your progress during or after treatment. You will be notified when your blood test is required via the patient portal (when available) or via post. The test can be carried out at your GP surgery and your clinical team at the hospital will be notified of the result. If you have any concerns about your PSA result you can contact the team by telephone or send a message to the team via the patient portal (when available) The hospital will contact you directly if they need to discuss your PSA result with you.

EPIC questionnaire

At each PSA check you will be asked to complete an EPIC 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.

If you are registered to use the patient portal this will be sent to you electronically. If you are not using the patient portal this will be sent to you in the post or the team will contact you via telephone to complete.

We would also like to invite you to complete some additional questionnaires that look in a little more detail into health and well-being issues that may have been affected by your cancer or treatment. This will provide vital information for patients coming after you, so that they will have a clearer idea of what to expect.

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 prostate cancer. These might include practical issues such as work, or dealing with the physical and emotional effects of prostate 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?

You will be given contact details for the CSW and if you need to leave an answerphone message, the Team will respond within 48 hours. Emails sent at the weekend will be replied to the next working day. 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 48 hours.

Finding support

You may have already found that people have different ways of living with prostate 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 prostate cancer nursing team is there to help you with support so ask them if you would like details of local support groups.

National contacts

Prostate Cancer UK

Telephone: 0800 0748383

www.prostatecancer.org

Movember

<http://uk.movember.com>

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

Local contacts

<Insert local support available>

APPENDIX 6-FOLLOW UP GRID

5 Year Follow Up Plan

	3M	6M	9M	1 year	1.5 year	Year 2	2.5 year	3 year	3.5 year	4 year	4.5 year	5 year
PSA Test												
Other bloods												
DRE												
EPIC												
HNA												

You will be informed by letter of the results of your PSA test .

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 Prostate Cancer Treatment.

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

- **Blood** in the urine
- **Rectal bleeding**
- **Increased difficulties** in passing urine
- **Aches and pains** in the bones lasting more than 6 weeks

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

Cancer Support Worker Tel: xxxxxxxx

Urology Nurse Specialist Tel: xxxxxxxxxx

APPENDIX 7- PATIENT EVALUATION FOR SUPPORTED SELF-MANAGEMENT PATIENT EDUCATION WORKSHOP

Patient Evaluation

Was the venue suitable for the Supported Self-Management Patient Education Workshop?

Please comment:

Please comment on how useful you found each topic?

I found the topic very useful	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Follow up Investigations					
Database (Patient facing Portal)					
Patient questionnaires					
Role of the cancer care coordinators					
Adapting to a new normal					
Side effects of treatment					
Dietary advice					
Exercise					
Question and answer session					
Signposting to written information					

INSERT YOUR WORKSHOP AGENDA/SPEAKERS

Have you learnt anything new?

Please comment

Would you have preferred more time or a different structure to the workshop?

Please comment

Are there any other topics you would have liked to include?

Please comment

Thank you for taking the time to complete this questionnaire

APPENDIX 8- HOLISTIC NEEDS ASSESSMENT

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		
<u>Practical Concerns</u>		
<input type="checkbox"/> Caring responsibilities	<input type="checkbox"/> Washing and dressing	<input type="checkbox"/> Travel
<input type="checkbox"/> Preparing meals/drinks	<input type="checkbox"/> Transport or Parking	<input type="checkbox"/> Work or Education
<input type="checkbox"/> Grocery Shopping	<input type="checkbox"/> Money or Finance	<input type="checkbox"/> Laundry or Housework
<input type="checkbox"/> Talking or Being Understood	<input type="checkbox"/> Taking Care of Others	<input type="checkbox"/> Housing
<input type="checkbox"/> Smoking Cessation	<input type="checkbox"/> Pets	<input type="checkbox"/> Problems with Alcohol or Drugs
<input type="checkbox"/> My medication	<input type="checkbox"/> Difficulty Making Plans	
<u>Family/Relationship Concerns</u>		
<input type="checkbox"/> Children	<input type="checkbox"/> Partner	<input type="checkbox"/> Other Relatives/friends
<input type="checkbox"/> Person who looks after me	<input type="checkbox"/> Person who I look after	
<u>Emotional Concerns</u>		
<input type="checkbox"/> Anger or Frustration	<input type="checkbox"/> Guilt	<input type="checkbox"/> Loneliness or Isolation
<input type="checkbox"/> Worry, Fear or Anxiety	<input type="checkbox"/> Loss of Interest/Activities	<input type="checkbox"/> Hopelessness
<input type="checkbox"/> Difficulty making plans	<input type="checkbox"/> Sadness or Depression	<input type="checkbox"/> Uncertainty
<input type="checkbox"/> Unable to Express Feelings	<input type="checkbox"/> Thinking about the future	<input type="checkbox"/> Regret about the past
<input type="checkbox"/> Independence		
<u>Spiritual or religious concerns</u>		
<input type="checkbox"/> Faith or Spirituality	<input type="checkbox"/> Not being at Peace or Feeling Regret about the Past	<input type="checkbox"/> Meaning or purpose of life
<u>Physical concerns</u>		
<input type="checkbox"/> My appearance	<input type="checkbox"/> Breathing difficulties	<input type="checkbox"/> Passing urine
<input type="checkbox"/> Constipation	<input type="checkbox"/> Diarrhoea	<input type="checkbox"/> Eating, Appetite or Taste
<input type="checkbox"/> Tired/Exhausted or Fatigued	<input type="checkbox"/> Swelling	<input type="checkbox"/> High temperature or Fever
<input type="checkbox"/> Hot Flashes/Sweating	<input type="checkbox"/> Moving Around (Walking)	<input type="checkbox"/> Indigestion
<input type="checkbox"/> Memory or Concentration	<input type="checkbox"/> Sore or Dry Mouth or Ulcers	<input type="checkbox"/> Nausea or Vomiting
<input type="checkbox"/> Pain or Discomfort	<input type="checkbox"/> Sex/Intimacy/Fertility	<input type="checkbox"/> Dry, itchy or Sore Skin
<input type="checkbox"/> Sleep Problems	<input type="checkbox"/> Speech or Voice Problems	<input type="checkbox"/> Tingling in Hands/Feet
<input type="checkbox"/> Wound Care	<input type="checkbox"/> Changes in Weight	<input type="checkbox"/> Sight or Hearing
<input type="checkbox"/> Swallowing	<input type="checkbox"/> Cough	<input type="checkbox"/> Other Medical Conditions
<u>Information or Support</u>		
<input type="checkbox"/> Complementary Therapies	<input type="checkbox"/> Diet and Nutrition	<input type="checkbox"/> Exercise and Activity
<input type="checkbox"/> Sun Protection	<input type="checkbox"/> Making a will or legal advice	<input type="checkbox"/> Planning for my future priorities
<input type="checkbox"/> Managing my symptoms	<input type="checkbox"/> Patient or carer's support groups	<input type="checkbox"/> Health and Wellbeing

APPENDIX 9 (SAMPLE LETTERS)

INSERT TRUST LOGO

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 prostate 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 have a regular PSA blood test and complete a quick EPIC Questionnaire. We will then let you know the results of your PSA test and contact you to discuss any queries that you may have raised on your EPIC Questionnaire. You will also be able to contact a member of our Prostate Cancer Support Team at any time between these regular checks if you have noticed any problems.

For your regular PSA blood tests, please can we ask that you attend your GP surgery, local clinic or blood room, located in the hospital, for a blood test (using the form provided by the hospital). Can we also request that for 3 days prior to your blood test that you don't do any vigorous exercise (especially heavy lifting or riding a bicycle) or ejaculate. The result of this test is sent back to us, and we will contact you within 1 month of the test to let you know the result.

- If the result is ok, we will notify you, and also let you know when you should have your next test done. **ONCE SYSTEM IS LIVE PLEASE ADD:** You can also check your PSA result via the patient portal. We will always inform your GP of your result.
- If the PSA level has gone up a little, we may ask you to have your PSA checked sooner than usual, or we will send you an appointment for our outpatient clinic to discuss this.

Your next PSA test is due within 2 weeks following **(INSERT DATE)**. We also request that you complete your EPIC Questionnaire at this time. (We would also be grateful if you could complete the additional voluntary questionnaires if you could). You do not need to have any other PSA tests done before then, unless your GP instructs you otherwise.

The advantage of this programme is that we will be able to closely monitor your prostate 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;

- **Blood** in the urine
- **Increased difficulties** in passing urine
- **Aches and pains** in the bones lasting more than 6 weeks

Kind Regards, Prostate 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 PSA surveillance

Dear Dr (name),

RE: (Patient name and NHS number)

This gentleman's prostate cancer is stable at the moment and he is now registered on our PSFU programme. We will organise for him to have regular PSA blood tests and complete an EPIC questionnaire about any issues he may be having and will then contact him with the outcomes. We will also inform you of the PSA result and if any further actions are needed. His next PSA test is due within 2 weeks following (DATE). He does not need to have any other PSA tests done before then.

- If the result is acceptable and there are no issues on his questionnaire, we will notify him and let him know when he should have his next PSA test and questionnaire done. We will also write to you with the results.
- If the PSA level has gone up above the acceptable range for him, we will ask him to have his PSA checked sooner than usual or we will send him an appointment for our outpatient clinic to discuss this. If he has highlighted any concerns on his questionnaire, we will contact him to discuss matters further.

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

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

- **Blood** in the urine
- **Rectal bleeding**
- **Increased difficulties** in passing urine
- **Aches and pains** in the bones lasting more than 6 weeks

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 he will be invited to a one-off Supported Self-Management Patient Education Workshop delivered by the Urology cancer support team. This will provide him with the confidence to self-monitor symptoms and signs of recurrence, manage lifestyle changes and set his own goals for recovery and rehabilitation. **ONCE SYSTEM LIVE ADD IN:** He will be provided with secure and confidential access to an online patient portal. Through this system, he can track his own PSA results and complete a health questionnaire (holistic needs assessment) as well as accessing information and support on living with and after prostate cancer.

Kind Regards,

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

ENTER TRUST LOGO

(Insert date)

Your PSA Blood Test Result

Dear **(NAME)**

NHS number or Hosp number: **(Insert)**

Your recent blood test showed that the PSA level in your blood has increased slightly. Although this isn't a cause for immediate concern, we think it is sensible for you to have a repeat test a little sooner than usual. Your next test needs to be within 2 weeks following (DATE). Before this test please can you ensure that you don't do any vigorous exercise (especially heavy lifting or riding a bicycle) or ejaculate for 3 days.

You should not have any other PSA tests before this time, unless your GP instructs you otherwise. Please could you also complete your quick Health Questionnaire when you next have your blood test and return it to us.

If you have any questions or problems before then you should **INSERT WHEN SYSTEM IS LIVE either message us via the patient portal or** call us on: **INSERT TELEPHONE NUMBER** If you reach an 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.

INSERT WHEN SYSTEM IS LIVE: Remember you can check your blood test dates, view you results and email us any time by logging in to the patient portal. If you are not registered and would like further support to register, please contact us.

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

- **Blood** in the urine
- **Rectal bleeding**
- **Increased difficulties** in passing urine
- **Aches and pains** in the bones lasting more than 6 weeks

Kind Regards,

Prostate Cancer Support Team.

INSERT TRUST LOGO

GP DETAILS

Dear Dr **(name)**

RE: Patient name + NHS number

This gentleman is on Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for his prostate cancer. His latest PSA is at **(level)** and has increased slightly. We have therefore asked him to have a further test on **(date)** which is slightly earlier than usual and will contact you again following this.

Kind Regards,

Prostate Cancer Support Team

INSERT TRUST LOGO

(INSERT DATE)

GP DETAILS

Dear Dr **(name)**,

RE: Patient name + NHS number

This gentleman is on Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for his prostate cancer. He has raised some queries or concerns on his latest EPIC Questionnaire so we will contact him 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,

Prostate Cancer Support Team

INSERT TRUST LOGO

Date (insert)

Dr (name)

Address

Dear **Dr (name)**,

RE: (PATIENT NAME) NHS: (INSERT)

This gentleman is on Personalised Stratified Follow Up – PSFU (supported self-managed follow up pathway) for his prostate cancer. His latest PSA on **(date)** was satisfactory at **(level)**. He also raised no concerns on his EPIC Questionnaire. We have asked him to have a further test on **(date)** and will contact you again following this.

Kind Regards,

Prostate Cancer Support Team

INSERT TRUST LOGO HERE

(Insert Date)

Your PSA Blood Test Result

Dear Mr **(name)** NHS number or Hospital number **(INSERT)**

I am pleased to say that your latest PSA test on **(date)** was satisfactory at **(levels)**. You should have your next PSA test within 2 weeks following **(date)**. Please find enclosed a blood test form for this. You should not have any other PSA tests before this time, unless your GP instructs you otherwise.

Please could you complete your quick EPIC Questionnaire when you next have your blood test and return this to us. If you raise any issues on this, we will contact you to see if you would like to discuss matters further.

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

Remember you can check your blood test dates, view your results and message us any time by logging in to your patient portal. If you are not registered and would like further support or to register, please contact us.

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

- **Blood** in the urine
- **Rectal bleeding**
- **Increased difficulties** in passing urine
- **Aches and pains** in the bones lasting more than 6 weeks

Kind Regards,

Prostate Cancer Support Team.

Trust Logo

Address etc

Dear Pt name

As you have now completed 5 years of Self Supported Management follow up following your (delete as appropriate) treatment for prostate cancer and you remain well, we are now discharging you to the care of your GP.

The annual surveillance of your PSA blood test can continue with your GP. Your next PSA will be due one year from the date of this letter.

You should see your GP if you have any new signs or symptoms that persist such as:

- Blood in the urine
- Rectal bleeding
- New or worsening incontinence
- Changes in passing urine- hesitancy or slow flow
- Blood in your stools
- Bowel problems- constipation or diarrhoea
- Aches and pains in the bones lasting more than 6 weeks
- A raised PSA

Please remember however, that all these symptoms can also be caused by other conditions that are completely unrelated to prostate cancer.

If you have any queries regarding your discharge, please do not hesitate to contact us on xxxxxxxxxxxxxxxx.

Kind Regards

Prostate Self Supported Management Team

Appendix 11 EPIC questionnaire

EPIC QUESTIONNAIRE – UHMB

1. **How big a problem, if any, has each of the following been for you during the last 3 months? Circle one number on each line**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Dripping or leaking urine	0	1	2	3	4
b. Pain or burning on urination	0	1	2	3	4
c. Bleeding with urination	0	1	2	3	4
d. Weak urine stream or incomplete emptying	0	1	2	3	4
e. Need to urinate frequently during the day	0	1	2	3	4

2. **How big a problem, if any, has each of the following been for you? Circle one number on each line**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Urgency to have a bowel movement	0	1	2	3	4
b. Increased frequency of bowel movements	0	1	2	3	4
c. Losing control of your stools	0	1	2	3	4
d. Bloody stools	0	1	2	3	4
e. Abdominal/ Pelvic/Rectal pain	0	1	2	3	4

3. **Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 3 months? Circle one number.**

No problem	1
Very small problem	2
Small problem	3
Moderate problem	4
Big problem	<input type="checkbox"/> 5
I do not wish to answer	Please tick if relevant

4. **How big a problem during the last 3 months, if any, has each of the following been for you? Circle one number on each line**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Hot flashes	0	1	2	3	4
b. Breast tenderness/enlargement	0	1	2	3	4
c. Feeling depressed	0	1	2	3	4
d. Lack of energy	0	1	2	3	4
e. Change in body weight	0	1	2	3	4

5. **Do you have any other concerns as a result of the treatment of your Prostate Cancer that require support from a clinician?**

Please circle either Yes No

If yes - we can arrange a telephone call from your specialist nurse. Please list dates and times when it is convenient for us to ring you.

THANK YOU VERY MUCH