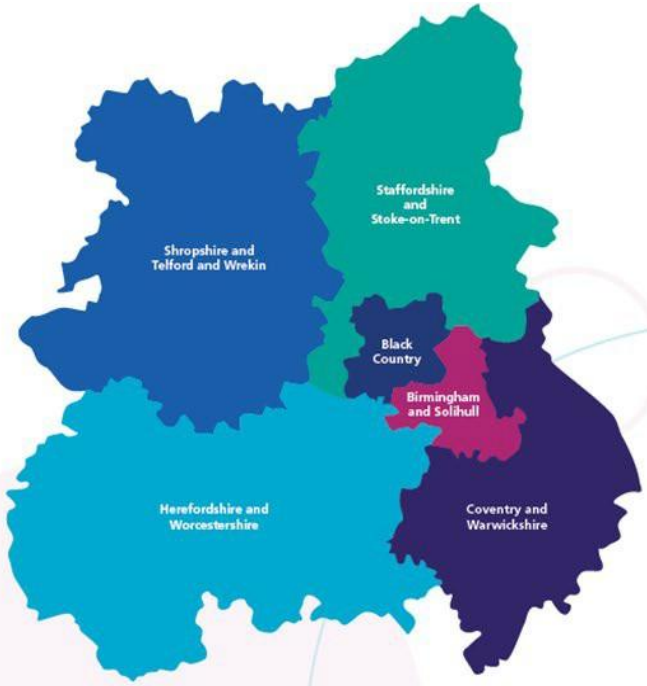
West Midlands Cancer Alliance: Prostate Cancer Personalised Stratified Follow-up Pathway Guidelines December 2025



Document Management

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Document Title	West Midlands Cancer Alliance Prostate Cancer Personalised Stratified Follow Up (PSFU) Pathway Guidelines	
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Document Purpose	To provide clinical guidance and support to Trust Urology Clinical Teams for the management prostate patients following diagnosis or completing treatment as appropriate. To support the delivery of the national priorities and objectives for cancer.	
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Approval Signatures:	**Chair Urology EAG** Altan Omar 	**Clinical Director, West Midlands Cancer Alliance** 

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Approved by

This document must be approved by the following people:

Governance	Description	Who	Date
WMCA Urology EAG Chair	Approved	EAG chair	10.12.2025
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Executive Summary

These guidelines are to assist all members of the multi-disciplinary team (MDT) to understand the Personalised Stratified Follow Up (PSFU) process and ensure optimum follow-up care is provided to the identified cohort of prostate patients following diagnosis or completing treatment as appropriate:

The clinical team and the person affected by cancer shall decide about the best form of follow-up through shared decision making. Care is tailored according to the severity and complexity of a person's individual and clinical needs, including their knowledge of the disease, their treatment, and their ability to manage the identified follow up pathway.

Principles underpinning Personalised Stratified Follow Up

- People living with cancer and professionals work collaboratively to form personalised care plans that enable them to live actively and well from diagnosis.
- There is a programme of appropriate education for people living with and beyond cancer, supported by written information, signposting and access to a range of online portals for those who are IT enabled.
- All clinical evidence-based surveillance investigations continue unchanged.
- Robust systems are in place for surveillance, to ensure tracking and monitoring of investigation requests and results and to facilitate timely recall if necessary.
- End of Treatment Review and End of Treatment Summary are provided to people living with and beyond cancer and their GPs to support good quality Cancer Care Reviews
- There are fast track re-entry (Open Access) pathways that facilitate specialist clinical review if required.
- There is consistent implementation of self-management support interventions.

This protocol has been co-designed with the West Midlands Cancer Alliance, the West Midlands Cancer Alliance Prostate Expert Advisory Group, representatives from local Integrated Care Systems and Primary Care as well as patient and carer involvement throughout.

1. Introduction and Purpose of this Guideline

This guideline is for PSFU for people with a prostate cancer diagnosis. It spans primary and secondary care and covers the care of the individual who has completed their treatment for prostate cancer.

The purpose of this document/guideline is to:

- Provide best practice details specific to prostate cancer and should be read in conjunction with the PSFU guidelines for people with a cancer diagnosis' which provides more detailed general guidelines. This document is on the WMCA website.
- Provide best practice guidance for Trusts, commissioners, clinicians and all others involved in providing person centred follow up after treatment for prostate cancer.
- Assist all members of the prostate MDT in understanding the process, ensuring optimum follow up care is provided to all prostate cancer patients completing treatment.

This document is intended as a flexible resource to help Trusts implement the PSFU pathway for patients with prostate cancer.

Improving cancer pathways through the implementation of PSFU pathways for all clinically appropriate cancers is identified as a priority within the NHS Long Term Plan, including improving access to personalised care of patients diagnosed with cancer through ongoing needs assessment, robust care planning and provision of support. (Long Term Plan 2021).

The NHS Long Term Plan and Planning and Operational Guidance has placed a strong emphasis on improving the cancer waiting time recovery particularly for the 62-day referral to treatment waiting time standard. The introduction of PSFU will support and enable the reduction in outpatient activity freeing up clinical capacity to focus on timely patient treatment and care, patient quality outcomes and NHS efficiency.

The Prostate PSFU Guidelines has been in place since April 2019 and has now been reviewed and updated in 2025.

This model of follow-up should enable individuals who have completed their treatment for prostate cancer to be on self- supported follow-up pathway.

Five groups of men diagnosed with prostate cancer have been identified as suitable for risk stratified follow up, this includes patients have had or are continuing:

I. Radical Prostatectomy
II. Radical Radiotherapy
III. Active surveillance

IV. Watchful Waiting
V. Hormone Therapy
VI. Focal Therapy

With rising rates of prostate cancer and improved survival outcomes, there's a growing need for innovative follow-up models that prioritise patients' quality of life and encourage greater personal responsibility. This approach will enhance patient experience and also help alleviate capacity pressures within the NHS. This transformation requires investment in IT and staffing to ensure a safe, quality service and a positive redistribution of resources and facilities.

This document describes the pathway for prostate cancer patients. It defines the two levels of follow-up support available to this cohort of patients – professional led and self- managed.

The document provides guidelines to recommend:

All individuals diagnosed with prostate cancer receive a Holistic Needs Assessment (HNA) and care plan as well as personalised information and appropriate health and well-being support to encourage them to live actively and well following the end of their cancer treatment.

A safe, robust, user-friendly system is available to enable PSFU, which includes appropriate surveillance with timely reporting and recall if required to facilitate a positive patient experience.

- Every individual is provided with additional information and signposting to enable them to self-manage and live well with and beyond cancer.
- Every individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.
- Every individual and their GP will receive a Treatment Summary outlining the care and treatment received plus any key information regarding consequences of disease and/or treatment required for Primary Care to facilitate continuity of care and support as required
- Timely, safe and appropriate open access back into specialist prostate services is in place should they be required.

2. Prostate Cancer Context

Prostate cancer remains the most commonly diagnosed cancer among males in the UK, with approximately 55,100 new cases annually—equating to around 150 diagnoses each day (2017–2019). It accounts for 28% of all new male cancer cases and 14% of all new cancer cases across both sexes.

Incidence is highest among men aged 75 to 79, with one-third (34%) of diagnoses occurring in those aged 75 and over. Since the early 1990s, rates have surged by 53%, and in the past decade alone, they've risen by 9%. Projections suggest a further 15% increase between 2023–2025 and 2038–2040, potentially reaching 85,100 new cases annually by 2040.

Socioeconomic and ethnic disparities persist. Men in the most deprived areas of England have 17% lower incidence rates compared to those in the least deprived quintile, with around 3,100 cases annually linked to lower deprivation. Ethnic variation is also notable: incidence is lower among Asian and mixed-ethnicity males, but higher in Black males compared to their White counterparts (2013–2017). For more details see Cancer Incidence by Broad Ethnic Group. (Prostate cancer statistics Cancer Research UK).

As of 2010, an estimated 280,500 men previously diagnosed with prostate cancer were living in the UK, underscoring the importance of long-term, tailored follow-up care. PSFU models are well-positioned to address these trends by offering stratified pathways that reflect individual risk, stage at diagnosis, and personalised support improving outcomes for patients and enabling resource efficiency.

For more details also see Early Diagnosis Data Hub (link is external) for statistics on stage at diagnosis for prostate cancer. (Prostate cancer statistics Cancer Research UK).

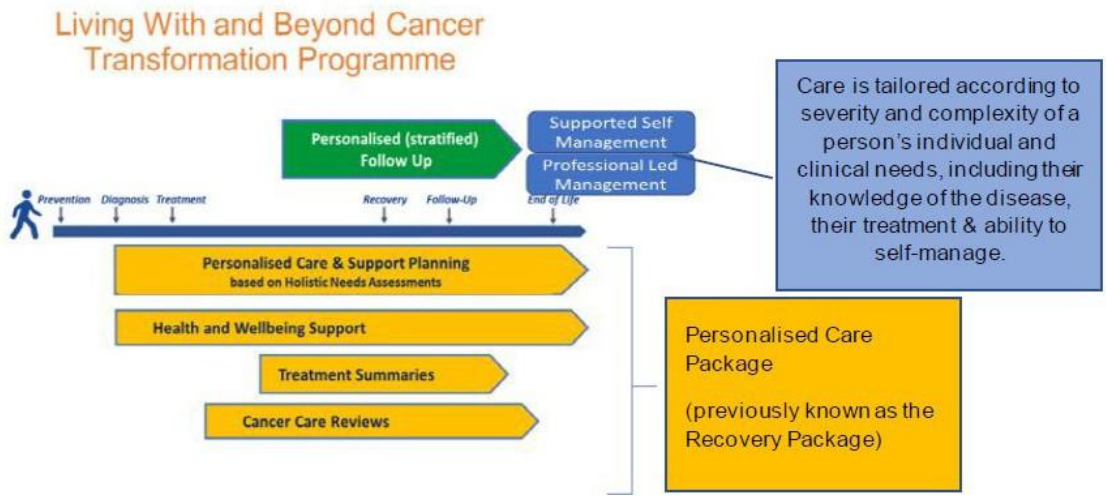
3. Background to Personalised Stratified Follow Up

PSFU is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that the NHS is providing world-class services. The implementation of PSFU pathways tailored to individual needs offers huge benefits to patients and the NHS. Furthermore, stratified follow-up improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

PSFU supports individuals diagnosed with cancer by providing accessible help and empowering them to self-manage their health and wellbeing. It focuses on enhancing quality of life and encourages personal responsibility, enabling people to live well with and beyond cancer.

Personalised care diagram below illustration that supports and enables PSFU. See appendix 1 figure 5 for the benefits of PSFU.

Figure 1



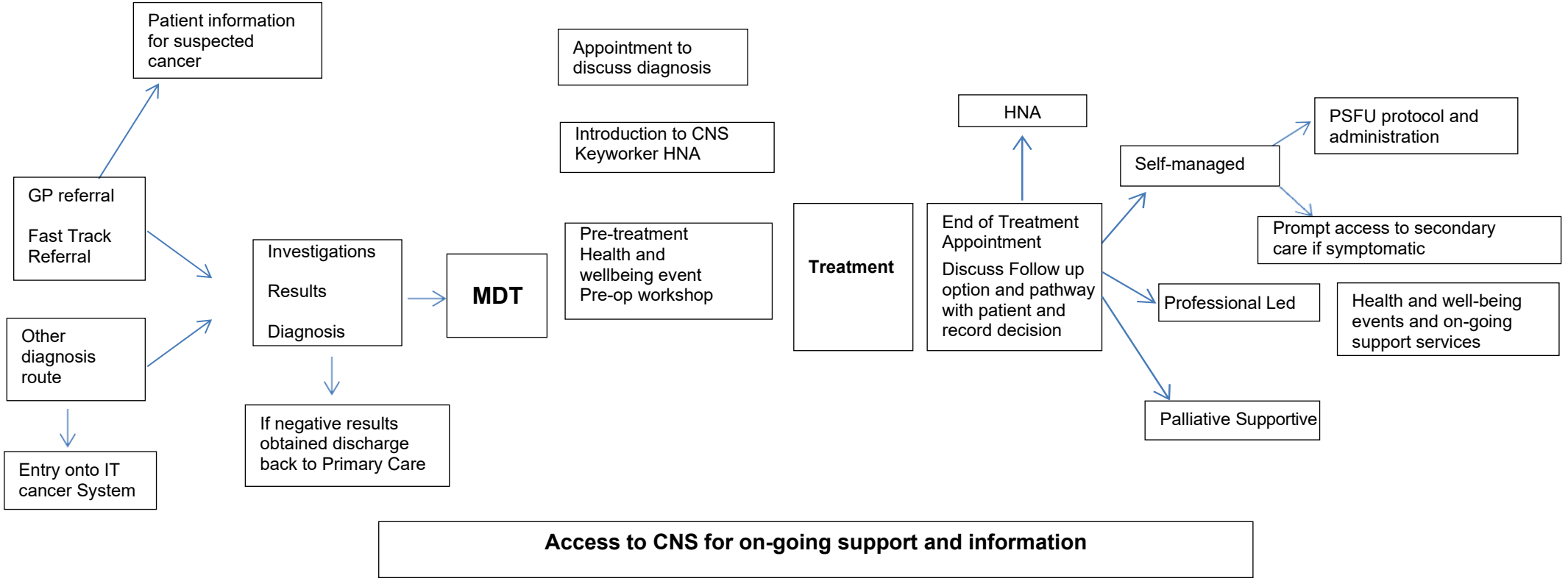
4. Implementing the Prostate Personalised Stratified Follow Up Pathway

For patients with prostate cancer entering a PSFU pathway, the following key components must be in place to ensure safety, support, and empowerment:

Personalised care diagram below illustration that supports and enables PSFU. See appendix 1 figure 5 for the benefits of PSFU.

- **Holistic Needs Assessment (HNA) and Care Planning**
  All patients should receive a comprehensive HNA and personalised care and support plan (PCSP). This should be accompanied by tailored information and access to appropriate health and wellbeing support services to empower patients to live actively and well following the completion of their cancer treatment. All patients will have an HNA embedded as part of the assessment process; Ideally a patient should be offered an HNA at diagnosis (after the patient has been informed of their diagnosis).
  The HNA will inform the development of a short-term care plan following discussions with their Urology CNS or key worker at the point of diagnosis, highlighting the most important issues at that time that need to be addressed during treatment; the GP will receive a copy of the HNA care plan.
- **End of Treatment Summary (EoTs)** All patients should receive an EoTs prior to transitioning onto a PSFU pathway. These tools ensure that care remains tailored to individual needs and supports patients in taking an active role in their recovery and ongoing health.
- **Robust and Accessible Follow-Up System**
  A safe, reliable, and user-friendly system must be in place to support PSFU. This should include appropriate surveillance protocols with timely reporting and recall mechanisms to ensure a positive and reassuring patient experience, including details of any required scans or tests and how these will be arranged. All patients will be transferred onto the jointly agreed follow-up pathway at the end of treatment following discussion between the clinician and patient.
- **Support for Self-Management**
  Patients should be provided with additional information and signposting relevant services and resources that enable them to self-manage and maintain wellbeing with and beyond cancer. Personalised care and support planning, including resources for self-management to promote long-term health and wellbeing.
- **Clear Communication Channels**
  Patients must receive both verbal and written guidance detailing when and how to seek help, including specific contact points within the urology team for any future concerns. Patients should receive clear written information about signs and symptoms that may indicate recurrence or progression of disease. They should also receive guidance on surveillance, including details of any required scans or tests and how these will be arranged. All newly diagnosed Prostate cancer patients will receive information about their diagnosis, treatment options and subsequent follow-up pathway at the end of treatment. This will include a description of the re-entry process, the support and tools available to enable self-management and explanation of the ongoing surveillance and screening that will occur during follow up period up to 5 years;

Figure 2: Urology Cancer Pathway Model



5. Workforce Planning

Workforce planning is essential to the implementation and delivery of a successful PSFU pathway. Departments planning to implement PSFU should undertake a workforce planning exercise to ensure successful delivery of this pathway. This is to ensure that patients can be fully supported remotely and have ease of access to advice or to be seen when required

The safety and quality of the service is dependent upon a dedicated cancer coordinator and deputy to organise and manage aspects of the pathway. This role is designed to release and appropriately realign Clinical Nurse Specialist (CNS) clinical time and will require specific support, training and development. It is expected that this role will require some underpinning clinical knowledge, coordinating the re-entry process and any other contact point within the service. Urology CNS team will need to have the appropriate time agreed in their job plans to allow the necessary time to undertake HNAs, care plans and end of treatment reviews.

6. Levels of Follow-up Support

PSFU should be discussed, explained at the time of planned treatment discussion. The preparation for seamless adoption and understanding of the transition to living with and beyond cancer should start as early as possible. This will demonstrate the message that care is not just about treating the disease, but considering the individual's physical and psychological needs before, during and after treatment.

This document describes the pathway for people with a prostate cancer diagnosis. It defines the levels of follow-up support available to them:

- Supported self-management follow up
- Professional led follow up (including best supportive care- to be referred to primary care; MacMillan team via the prostate cancer navigator)
- All individuals diagnosed with cancer, irrespective of their risk of recurrence receive coordinated supportive care with rapid re-entry (open access) to the specialist cancer team as required.

Levels of Follow-up Support

The follow up schedule broadly revolves around two central tenets:

I. Oncological risk of recurrence (pathological / radiological staging)
   - Low risk
   - High Risk

II. Method of Delivery (see Appendix 4, Figure 6)
   - Supported self-management.
   - Professional led (includes best supportive care)

   See Appendix 4 for further information.

Diagnosis and Treatment

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

- Personalised Care and support plan (PCSP) based on a Holistic Needs Assessment (HNA)
- Health and wellbeing support and information (HWBSI)
- Treatment Summary (TS)
- Cancer Care Review (CCR)

At diagnosis, individuals (with curative intent) will be informed (at a suitable time for them) about supported self-management and professional-led follow-up pathways; Open Access; and Health and Wellbeing support and information.

Individuals with secondary cancer will be offered personalised care based around the professional led pathway follow up model.

The Multidisciplinary Team (MDT), following the decision on treatment recommendation, will record the clinically stratified risk decision in the individuals notes as stable or requires further review as defined in Figure 1.

End of Treatment and Follow-up

- At the end of treatment (surgery, chemotherapy, radiotherapy, hormone treatment), all individuals will receive a single end of treatment review with a clinician. At this appointment the patient will receive personalised information about their planned follow-up and surveillance. A Treatment Summary will be generated following this meeting and be sent to the patient, their GP and held within the individual's hospital notes.
- On conclusion of the end of treatment review, patients will be transferred onto either the professional led or self-managed pathway.
- During this appointment it is expected that the patient be provided with verbal information, and that they have access to either on-line or printed information, regarding the following:
- Possible treatment toxicities/consequences of disease and/or treatment;
- A personal plan for future surveillance, scans and blood tests. This will include an explanation of the process for receiving appointments for scans, other tests and results;
- Key symptoms that require re-access to the specialist team;
- Contact name, phone number and working hours of the Urology specialist team;
- Exercise, Nutrition and weight management;
- Health and Wellbeing support and how to access relevant services;
- Any local self-help groups and useful phone numbers
- The Urology Multi-Disciplinary Team will decide the frequency and responsibility of follow ups on the professional led pathway.
- Most patients will be discharged at the end of year five

Personalised Stratified Follow Up Pathways

I. Self-Managed Pathway

These patients:

- Can contact their Urology Specialist Team as needed with any concerns via a dedicated contact number;
- Are provided with lifestyle advice to reduce the risk factors (smoking cessation, weight management)
- Will not have annual outpatient appointments.
- Will be issued with a specific plan for follow up; this will be specified in the individualised End of Treatment review (prior to a patient moving onto a self-managed pathway).
- May move to professional-led follow-up at any point in time if it is appropriate and mutually agreed;

Some patients who are under the policy of watchful waiting or active surveillance may be suitable to move to the self-managed pathway.

During the 2 to 5-year self-managed follow up pathway, patients may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.

II. Professional led Pathway

Individuals who are on the professional-led follow-up pathway:

- Will have follow up surveillance with appointments that are individualised to their diagnosis/needs.
- May be subsequently transferred to a self-managed pathway at any point if appropriate and mutually agreed.

III. Health and Wellbeing Intervention

- All patients will have access to health and wellbeing support.
- This support may be in the form of an event where there is education and support sessions aimed to provide individuals with the information and reassurance to build the confidence they require to enable them to lead as normal and active life as possible after their cancer treatment.
- These sessions may also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families.
- All patients will be offered the opportunity to attend a health and wellbeing event within two months of their end of treatment consultation.
- Signposting to other existing known local health and wellbeing support services for Cancer and other Long-Term Conditions can also be offered as health and wellbeing interventions and will promote collaboration between service providers to ensure sustainability of this essential element of supported self-care.
- Health and Wellbeing intervention may be delivered as:
  - 1:1 appointments;
  - Rolling programmes (such as the 6-weekly Macmillan HOPE Programme);

- Group events which are scheduled at regular intervals throughout the year and which individuals may have an open invitation to attend if they choose to do so. These give opportunity for interaction between patients and carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapist.
- These might also include market stalls of local health promotion services or voluntary agencies i.e. financial, late effects, living well, physical exercise
- Signposting and access to local services for Cancer or Long-Term Condition health and wellbeing management;
- Online tools and support.

7. Eligibility for Entry onto the Self-Managed Follow Up Pathway

- There is an impact assessment within the general PSFU guidelines. In the context of urology cancers specialist teams should be aware that research studies have shown that: All prostate cancer patients who have completed treatment will be considered for entry onto the self-managed follow up pathway. This empowers individuals with the knowledge and skills to self-manage their condition. They will not receive any further outpatient appointments unless further investigation or support is required.
- Some patients may not be appropriate for self-managed care for the reasons listed below:
  - The individual is unable to self-manage due to physical, cognitive, communication or emotional reasons;
  - Patients with treatment related morbidities that may require further monitoring and treatment;
  - Following the shared decision, there is mutual agreement not to enter the self-managed follow up pathway;
  - Patients deemed inappropriate by the MDT because of oncological concerns or non-engagement.

- For individuals participating in clinical trials, follow-up will be determined by a clinical trial protocol. All individuals taking part in trials will still access and benefit from the end of treatment review and health and wellbeing interventions.
- Patients will have their suitability for entering the self-managed follow-up pathway considered by the clinical team. Those who are not eligible will be recorded as not appropriate for self-managed follow-up within the cancer IT system and will continue on the professional led follow-up pathway at a frequency determined by the clinical team. A copy will be placed in the patient notes as appropriate.
- For certain patient groups mentioned above; the professional-led follow up, as per the local unit protocol, may be more appropriate. Patients in this group should also have access to health and wellbeing events and other primary care services as required. If at any point in follow up the patient, no longer requires a regular clinical review they could transfer to a self-managed pathway.

Figure 3 WMCA Defined Clinical Risk Stratification Decision

Low/ Intermediate risk	Complex/ High Risk
Radical Prostatectomy Undetectable PSA *<0.1 mcg/L;* No complications and reversible complications	
Radical Radiotherapy Stable PSA < PSA Nadir + 2 Supporting Info: **ASTRO Phenix Criteria**	Individual with ongoing clinical issues with individuals needs identified through a HNA and PCSP, general fitness, functional problems, psycho-social issues and men completing treatment with unstable PSA and/or symptoms requiring ongoing professional led support
Watchful Waiting (Also known as deferred hormones) Asymptomatic – not for radical treatment.	
	Hormone Therapy Clinical Judgement based on PSA and symptom indicators (LUTS, bone pain)
Individual moves to supported self-management follow up pathway (subject to criteria and individual choice)	Individual moves to professional led follow up pathway

GIFT Urology Towards a better diagnosis
https://gettingitrightfirsttime.co.uk/wp-content/uploads/2024/04/GIRFT-Urology-Towards-Better-Diagnosis-Management-of-Suspected-Prostate-Cancer-FINAL-V1-April-2024-1.pdf

Low/ intermediate risk denotes an individual is suitable for the supported self-management if:

- Some patients may not be appropriate for self-managed care for the reasons listed below:
- There is mutual agreement to enter the self-managed follow up pathway.
- The individual does not have co-morbidities that may require closer monitoring.
- The individual is deemed appropriate by the MDT.

All other patients will continue under professional-led follow up.

Complex/high risk denotes an individual most suited for the professional-led follow-up pathway. A member of the MDT will record the follow-up pathway agreement in the clinical notes for the individual. Individuals with secondary cancer are on a professional led pathway supported by their oncology team and palliative care as appropriate. Their personalised care will be based around the professional-led pathway model.

Eligibility Criteria

All other patients will continue under professional-led follow up. The decision to offer patients a self-managed pathway is at the discretion of the MDT and should be considered on a patient-by-patient basis.

Changes to patient's circumstances may change their suitability for PSFU during their surveillance period. This should be reviewed and actioned as appropriate by the clinical team.

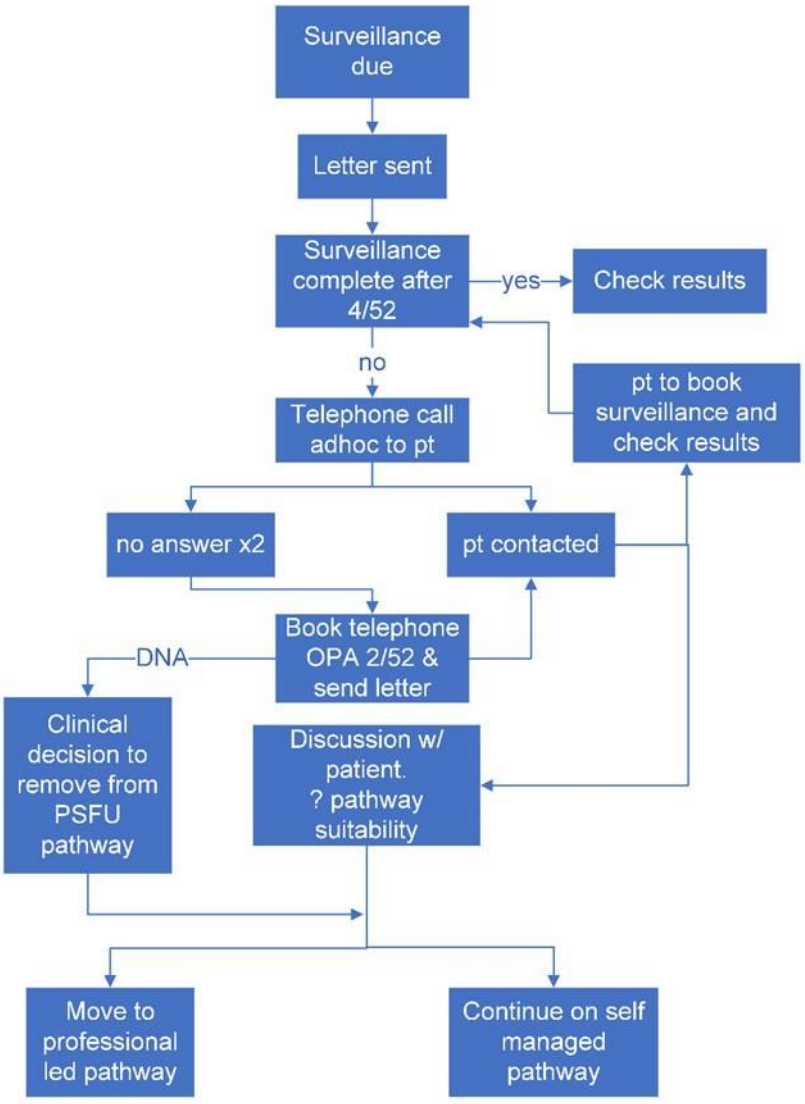
This list of inclusion and exclusion criteria is provided as a guide for the clinical team to make their decision. A patient may be offered PSFU despite not meeting these criteria, if deemed appropriate by the MDT.

Inclusion	Exclusion
Post Prostatectomy	Metastatic Cancer
Active Surveillance	Long term Hormone Therapy
Post radiotherapy	Lynch Syndrome
Consents to surveillance testing	Low level patient activation*
Appropriate level of literacy to read and understand information provided, or appropriate support in place to assist.	Clinical Trial participation
	Treatment/ Cancer related morbidities requiring referral, treatment or face to face management
	Frailty precluding surveillance tests
	Suspected/ confirmed substance abuse affecting patients' ability to self-manage
	Physical, cognitive, communication, emotional or psychological needs likely to preclude self-management and no appropriate support in place to assist.
	History of non-compliance with the service

Non-compliance and Escalation

In the event that a patient demonstrates non-compliance with the self-managed pathway reasonable effort should be made to support the patient in improving compliance and, if possible a discussion should take place between the patient/carer and a member of the clinical team on how this can be achieved. The following process provides guidance on escalating non-compliance with the pathway.

Figure 4



8. Discharge from the Prostate Cancer Follow-up Pathway

At the end of their surveillance period, the results of Prostate cancer patients will be reviewed by their clinical team. This is so that any ongoing treatment regimens can be updated considering latest evidence. Any plans from this review both the patient and the GP will be informed within the end of treatment summary.

Consider a virtual PSFU discharge MDT at the end of the 5-year follow-up period.

9. Remote Monitoring System

- Some patients may not be appropriate for self-managed care for the reasons listed below:
- All patients will have their surveillance investigations recorded on a remote monitoring system. This system will hold the information required to manage follow-up investigations - ordering, checking and recording of results. It will also record dates of HNAs, end of treatment reviews, Health and Wellbeing Intervention attendance and invitations for each patient.
- The Remote Monitoring System will be developed to include a patient portal to allow patients to directly access their results
- RMS is integral to the running of a self-governed service to minimise the risk of losing patients or missing results.

A remote monitoring system should be:

- Easy to use and compatible with a Trusts current IT system.
- Secure and safe (regularly backed up etc.).
- Accessible throughout a Trusts IT system.
- Able to record and distribute the metrics needed for comparison of other sites. Easily adaptable to future changes in care.
- Suitable for other personalised follow-up cancer programmes in the Trust.

- A safe and secure system of managing surveillance, bookings, attendance and results is required. Results will be reviewed, and unremarkable results will be sent directly to the patient, GP and recorded onto the cancer IT database. Unexpected results will be discussed by the clinical team, to formulate a plan and the patient then contacted.
- A robust system needs to be in place to ensure patients who have died or moved into a new geographical area during their surveillance period are not sent for.
- Patients will be aware of when their surveillance tests are due from their Treatment Summary. Patients will be informed to contact the specialist team if they do not receive a request for their tests or scans by the end of the month that it is due. It is recommended that the trust have a system in place to outline which team members will have the responsibility to resolve issues regarding missed surveillance appointments.

10. Re-accessing the Urology Specialist Team as Required

All patients and their GPs will be aware of how to access the Urology Specialist Team if concerns arise within the surveillance period. Safe robust and sustainable open access systems will be in place to facilitate this.

Re-accessing the pathway via the cancer navigator.

Multiple models:

1. Secondary care monitors disease remotely and automatically recalls patient (direct alert).

2. The GP can advise the patient how to access the secondary care team (the point of access needs to be defined in the EoTs)

Patients and their GPs will have contact numbers and guidance about when and how to access further support. Access will be via the Urology Specialist Team through an open access system.

To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing Urology and oncology clinics.

If a patient is required to have further investigations following their routine surveillance, they will be recalled for further imaging or an outpatient appointment after discussion of the imaging in an MDT and seen within 2 weeks.

After discharge back into the care of the GP, re-entry will be via a urgent referral route into the appropriate pathway.

Open Access in Secondary Care:

All individuals can continue to access their GP practice in primary care as before as well as having open access to the secondary care specialist urology team. Open Access (this could be via telephone, e-mail etc. according to local systems) may have a triage process to enable clinical prioritisation.

Open Access is generally for 2-5 years from diagnosis unless specified otherwise for individuals by the specialist team. After Open Access finishes, people will be discharged to primary care.

During Open Access run by secondary care the clinical governance responsibility for the individual lies with the Urology specialist team.

Safe robust and sustainable Open Access systems will be in place in secondary care to facilitate this.

Any discharge letters and treatment summaries should be shared with the individual and their GP as soon as possible after their last appointment. Contact numbers and guidelines on how to contact the specialist urology team must be made clear in this information.

It is recommended that services such as an open access follow up (OAFU) helpline has an audit trail right from the first call and allows immediate recording of clinical information in an appropriate place.

The individual will be reviewed via secondary care open access (clinical triage) and will receive advice and may either have an appointment made for specific imaging, one-stop clinic,

appointment virtually or face to face with either a urology surgeon, urology care nurse, oncologist or to be recommended to see their GP if not urology related. Once an individual has contacted the secondary care Open Access service, they can expect to receive a response to their query as soon as possible, best practice is that this is within 1 working day however this may be within 2 working days. If someone needs to be seen (face to face or virtually), they are seen within 4-6 weeks (sooner if deemed clinically urgent) of contacting the open access service.

To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing symptomatic and oncology clinics.

It is recommended that:

- All Hospitals identify a triage clinic for these individuals to ensure rapid access when required
- An alternative code is used for OAFU appointments to enable differential data collection for these groups of patients unless alternative methods already capture this data.
- If an individual is required to have further investigations following their routine PSA surveillance, they will be recalled for further imaging or an outpatient appointment and seen within 4-6 weeks. (sooner if deemed clinically urgent)

11. Clinical Governance

For individuals who are on the self-managed follow-up pathway, responsibility lies with the clinical team in secondary care.

- The responsibility for security and the database, and ensuring its suitability, lies with the Caldicott Guardian, Cancer Lead Clinician and Cancer Lead Nurse.

12. Guideline Monitoring

It is recommended that evaluation occurs twelve months following the implementation of these guidelines at Cancer Alliance and Urology Expert Advisory Group level – and then on an annual basis provided there are no significant adjustments required.

13. References

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East Midlands Cancer Alliance Personalised Stratified Follow Up Guidelines for people with a Prostate Cancer Diagnosis

Cancer Research UK Prostate cancer statistics | Cancer Research UK

Wye Valley NHST Trust PSFU SOP for Prostate Cancer

14. Definitions

Cancer IT System: The local cancer database (e.g. Somerset, Infoflex or Dendrite).

Cancer Care Review (CCR): A CCR is a conversation that is carried within Primary Care with the cancer patient.

Co-design: Collaborative method of design engaging with all key stakeholders involved in service provision and those using the service.

Eligibility Criteria: An agreed description of the safety and appropriateness of entry onto the supported self-management pathway for individuals with early prostate cancer.

End of Treatment (EOT): The end of treatment is defined as the conclusion of all active treatment required by an individual following a diagnosis of cancer, this may be after surgery alone or following a combination of therapies (excluding adjuvant endocrine therapy) but precedes the period known as ‘follow-up’. The patient will be presented with a Treatment Summary – see definition below.

Health & Wellbeing Intervention (HWBI): Health and Wellbeing interventions are any support or education events or programmes that enable the transition from treatment for cancer to

supported self-management. They can range from one-to-one information sessions to group sessions on a variety of topics designed to help with the emotional and practical aspects of life with and beyond cancer.

Holistic Needs Assessment (HNA): A Holistic Needs Assessment is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues ensuring each area is addressed and a care plan created for those identified as needing specific support. The care plan offers suggestions to manage the concerns including signposting to other services or information services that can help.
An HNA can be offered at key points during the pathway to meet the needs of the individual.

Personalised Stratified Follow Up (PSFU): A model of follow-up in which the clinical team and the person living with cancer make a decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or self-managed follow up pathway. The Personalised Stratified Follow Up pathway extends 5 years from the point of diagnosis.

Personalised Approach: A personalised approach means that any person that receives care or support will have choice and control in determining the shape of that support based on what is important to and for them. Professional Led Follow Up Pathway: The follow-up pathway in which individuals with cancer continue to have face to face, phone, or email contact with the specialist team as part of continuing follow up.

Self-managed Follow Up Pathway: The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests, and how to contact the specialist prostate team if they have any concerns. They do not receive any further OPA unless further investigations or support is required.

Shared Decision Making: Shared decision making is a collaborative process that allows the individual and the responsible health care professional to make health care decisions together in the person's best interest, based on evidence-based practice – taking into account the person's values and preferences

Stratified Follow Up: A model for managing how individuals are followed up after completion of treatment; depending on their risk of disease recurrence.

Treatment Summary (TS): A Treatment Summary is a document produced by the
Doctor or Specialist Nurse at the end of active treatment for cancer. The Treatment Summary details the diagnosis, stage and any relevant pathology information. It also includes any surgery, chemotherapy, radiotherapy or any other therapies that the person may have received during the treatment phase. It is followed by specific information on signs and symptoms of recurrence

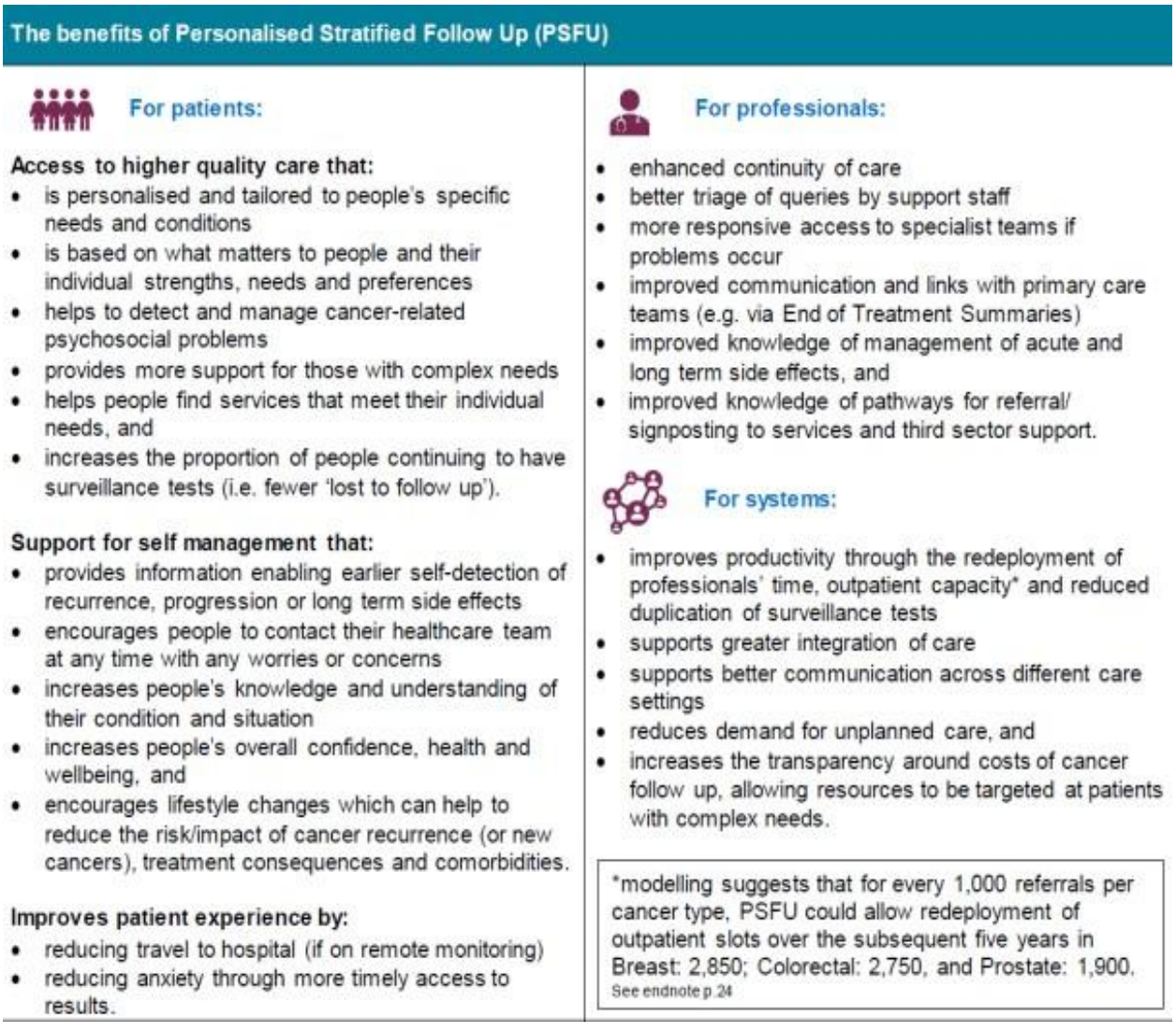
as well as significant consequences of disease and/or treatment. This is important as this information may be needed at a later date by long term survivors who may develop issues. A treatment summary and an HNA supports the Cancer Care Review.

The document is shared with the Patient and the Primary Care team to facilitate ongoing supported self-management.

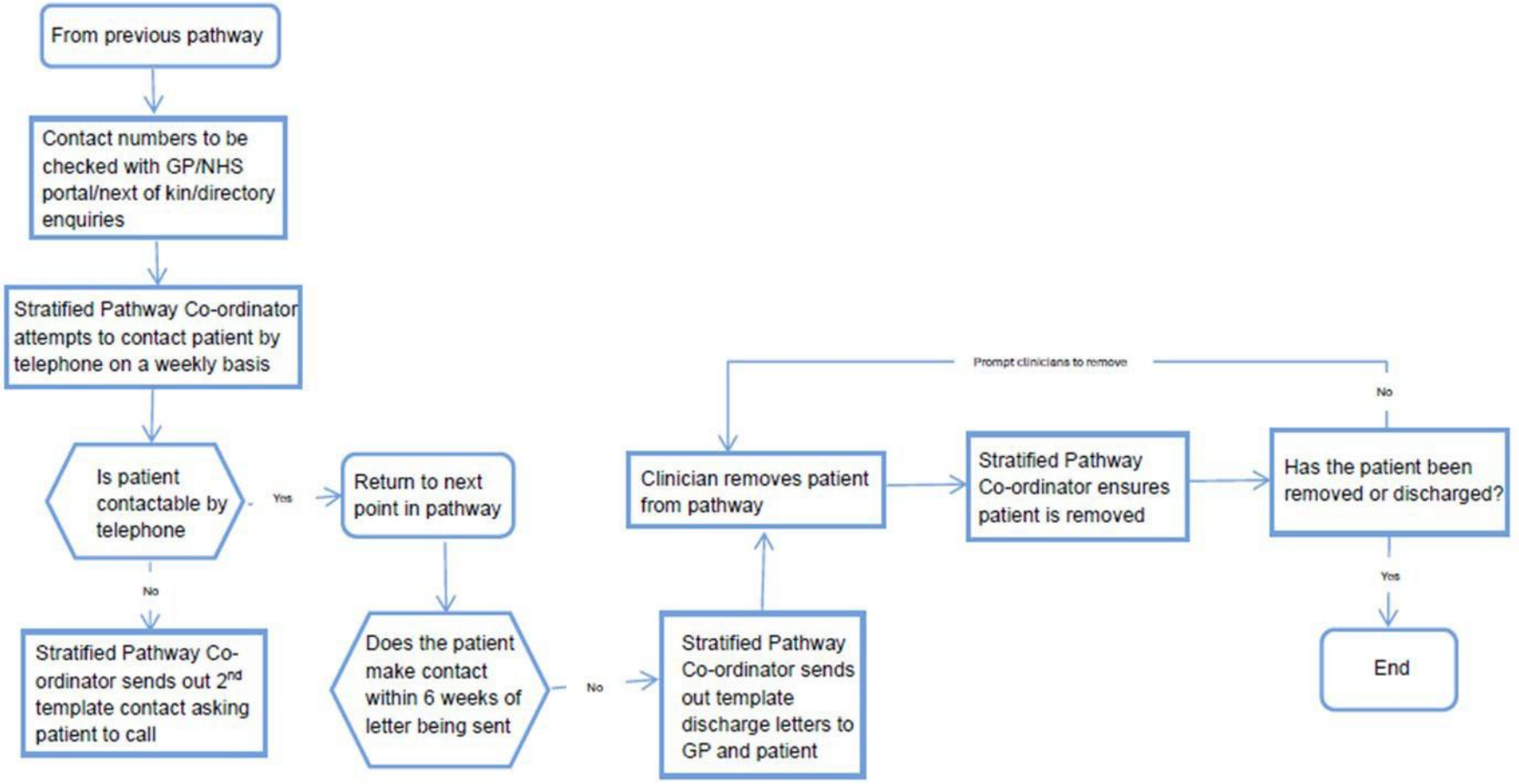
15. Appendices

Appendix 1: Personalised Follow Up Pathways

Figure 5: The Benefits of Personalised Stratified Follow Up



Appendix 2: Pathway for Those Patients who are “Uncontactable”



Appendix 3: Example Content for Trust PSFU Patient Information

To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing symptomatic and oncology clinics.

N.B. Each Leaflet will include WMCA & Trust Logo

Why have you given me this leaflet?

You have been given this leaflet to explain Personalised Follow-Up which **Trust Name** has put in place for patients who have been treated for prostate cancer.

What is Self-managed Follow-Up?

Self-managed follow-up is being introduced at all hospitals. It is where routine, clinical examination appointments are replaced by a system where patients can call us when they have a problem so that they don't have to come to hospital at times when they are feeling well and symptom-free.

Why has Self-managed Follow-Up been introduced?

We have introduced Self-managed Follow-Up as it has been shown to be better for patients in lots of ways.

It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well and just want to concentrate on living your life.

Patients often find traditional clinical appointments can lead to anxiety and delay reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it's been proven that new problems are unlikely to happen in line with your appointment time and are identified by patients themselves, in between routine appointments.

It will also mean that you can access support and advice quickly from the right people when you need it, allowing you peace of mind.

You will also get back into the system quickly should this be necessary.

Communication between all of the people involved in your care will be better, those in the hospital and outside, such as your GP. This will mean everyone can support you or signpost you on to others who can support you at the right time for you.

What information will I be given?

In addition to this leaflet, you will have an End of Treatment Review with your xxxxx Nurse and will be taught about specific symptoms you should report without delay to your xxxxx Nurse.

You will also be given written information in a Treatment Summary on:

Your diagnosis and medication:

- The treatment you have had and the possible side effects;
- Signs and symptoms to report;
- Arrangements for scans and other tests
- How to use the Helpline which gives you fast access to your xxxx Nurse if you need it
- Advice on Exercise and Nutrition
- Health and Wellbeing support
- Any local support groups and useful contact numbers

Will I still be able to access the Urology service if I have concerns?
Yes. You can call the Urology Team on the dedicated **Helpline telephone number (xxxx)** if you have any queries or problems, and you will be encouraged to do so. The helpline is monitored between **0900 and 1700 Monday to Friday** and if you leave a message, with your name, hospital number and telephone number, in the evening or over the weekend you will be called back by the team on the next working day. If they feel that it would be appropriate for you to come back to clinic to be seen, you will be offered a clinic appointment, or if necessary, an appropriate diagnostic test within 14 days of your telephone call.

Will I continue to have routine tests?
Yes. Unless it has been otherwise specified at the end of your treatment, you will continue to receive appointments and reminders to attend for tests or monitoring.

Appendix 4: Types of Personalised Follow Up

There are two types:
Supported self-management and professional led.

Figure 6: Types of Personalised Follow-Up Pathways

Stable Cancer of the Prostate Supported Self-Management Pathway	Complex / High risk cancer of Prostate Professional Led Pathway
Individuals will not have scheduled outpatient appointments. It may be valuable for the individual to have an annual review with their GP Practice team.	Individuals will have scheduled outpatient appointments: At these appointments/review there will be q review of: Test and other scan results as appropriate and available Medication review where appropriate HNA if appropriate for the individual
At the end of open access, individuals will be discharged to the care of their GP. A letter from the urology team will be sent to the individual and their GP confirming this.	At the end of open access, following a review, individuals will be discharged to the care of their GP. A letter from the urology team will be sent to the individual and their GP confirming this.
Individuals may move to more professional led follow-up if it is appropriate and mutually agreed at any point.	Individuals may move to more self-supported management follow-up if it is appropriate and mutually agreed at any point.
All Personalised Stratified Follow Up Pathways	
To optimise outcomes both to patients and the healthcare system, GP practices should consider the wider benefits of offering Cancer Care Reviews (CCRs) as best practice. WMCA recommend that Practices continue to provide patients with the opportunity to have a conversation within 12 months of a cancer diagnosis, with the aim to increase their awareness of the support available to them at the practice, as well as signposting/referring them to additional support within the wider local community.	
Individuals will have re-entry to secondary care open access (appointment within 4 to 6 weeks if required) for however long they are on remote monitoring with the specialist team from diagnosis if on the supported self-management SSM pathway or a professional led pathway. An individual can contact their specialist Urology Care Team as needed with any concerns via a dedicated contact number and/or email address.	
Individual will be invited to have PSAs, by their specialist urology team. This will be clearly documented in the treatment summary clearly stating who is responsible for ordering and reviewing the investigation and when they should be started and stopped. GIRFT recommends discharging patients back to GP after 5 years from radical treatment if PSA undetectable and patients are asymptomatic, with a clear protocol of follow up. This should be offered where local ICBs have an agreed protocol with Primary Care to offer post-treatment surveillance.	
At any point during the secondary care open access individuals may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.	

The Urology MDT will decide the frequency and responsibility of follow up for the professional led pathway. To ensure effective personalised follow-up systems are in place each NHS Trust will have remote monitoring systems to enable the following to take place:

There should be a designated member of the specialist urology care team who is responsible for ensuring the following takes place:

The scheduling, monitoring and communication of surveillance tests and subsequent results of scheduling systems to ensure appropriate individuals are contacted with the test results and no individual is 'lost to follow up'

Appendix 5

PSFU Protocol development outline pathway

NHS England and Improvement Implementing Personalised Stratified Follow Up Pathway A hand book for local Health Care Systems March 2020 (https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf)

Appendix 6: Acknowledgements

Thank you to all the West Midlands Cancer Alliance Urology Expert Advisory Group/Primary Care Expert Advisory Group, patient advocates and sub-group members who assisted in the development of this guidelines document. The Cancer Alliance acknowledges the input and expertise of all the members of these groups who have participated in the development process.