

**West Midlands Cancer Alliance:
Prostate Cancer Personalised Stratified
Follow Up Pathway Guidelines
December 2019**



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1. Introduction and Purpose of this Guideline

The independent Cancer Taskforce set an aim for the NHS to make improvements in reducing preventable cancers, increasing cancer survival and improving patient experience and quality of life by 2020. Personalised follow-up and support to help empower people to self-manage and live well with and beyond cancer is one of the key aims in delivering world class cancer services.

Because of increasing incidence and improved survival rates from prostate cancer, the introduction of new models of follow-up with greater emphasis on quality of life and responsibility for the individual are beneficial both for the patient and for the system as a way of addressing capacity issues 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.

Cancer Alliances are leading transformational programmes to deliver the Personalised Care Package and Personalised Stratified Follow Up (PSFU), previously termed stratified follow-up, for patients across England. In the West Midlands some patients have been benefiting from a personalised approach to care and support for several years in some areas; in others, roll out is still in its infancy. It is important that all patients benefit from these changes and the current variation in service provision that exists across the West Midlands is reduced to ensure equity of access to high quality, safe and sustainable services.

The purpose of this document is to provide best practice guidance to Trusts, CCGs and any other respective users of the document, on delivering person centred follow-up following treatment for prostate cancer. This new model of follow-up is to be in place by March 2020 and these guidelines are to assist all members of the Urology multi-disciplinary team in understanding the process to ensure optimum follow-up care is provided to all prostate cancer patients completing treatment.

PSFU should be discussed, explained and planned at the time of diagnosis. 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 redesigned 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 that:

- 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 Personalised Follow Up, 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 sign posting 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 in the form of a Cancer Care Review (CCR);
- Timely, safe and appropriate open access back into specialist prostate services is in place should they be required.

This Personalised Stratified Follow Up pathway meets the expectations of the five-year Cancer strategy, NHS England. It has been co-designed with the West Midlands Cancer Alliance, the West Midlands Cancer Alliance Urology Expert Advisory Group, representatives from local Clinical Commissioning Groups and Primary Care, as well as strong patient involvement throughout.

2 Personalised follow up Model and Process for the West Midlands

2.1 Workforce Planning

Workforce planning is essential to the implementation and delivery of a successful Personalised Stratified Follow Up pathway. The nature of the work will change for all members of the Urology team. The impact on staff health and wellbeing should not be underestimated as a result of this transformational shift. Organisations should demonstrate an understanding of the potential increase in emotional labour that this change will bring, ensure workforce planning is prioritised and opportunities for staff to build resilience are embedded within their work.

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.

2.2. Diagnosis and Treatment

- All patients will have an HNA and care plan embedded as part of the normal assessment process at diagnosis and at the end of treatment;
- 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;
- All patients will be transferred onto the jointly agreed follow-up pathway at the end of treatment following discussion between the clinician and patient.

2.3 Holistic Needs Assessment

- A HNA is a simple questionnaire completed by the person affected by cancer that assesses the physical, practical, emotional, spiritual and social needs of the individual and ensures these needs are met in a timely and appropriate way;
- All patients will have an HNA embedded as part of the normal assessment process within 31 days of diagnosis and at the end of treatment;
- This requires consideration of the timing of the assessment in relation to the patient's journey, enough time to reflect and consider their own needs and feelings and an appropriate environment to undertake the questionnaire;
- 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;
- A review of the care plan will occur following the HNA at the end of treatment;
- It is recognised that an HNA should be done at any point in the pathway where there is a change in treatment or issues identified by the patient or healthcare professional, with a care plan generated and acted upon;
- It is recognised that the HNA can be done by any member of the MDT. Appropriate time should be allocated to staff to complete HNAs and managing the findings;
- If a care plan is required it should be completed by the CNS in communication with the patient;
- There needs to be real time recording of the time (in relation to patient journey) and number (% of all patients diagnosed) of HNAs undertaken as this will be used to compare units and will possibly in developing a structure for funding of this service;
- GP will receive a copy of the HNA care plan.

2.4 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 MDT 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.

2.5 Living Beyond Cancer

- Individuals who are on the self-managed pathway: Defined as non-metastatic prostate cancer patients who have had radical treatment with no sign of recurrence at 2 years.
These patients:
 - Can contact their Urology Specialist Team as needed with any concerns via a dedicated contact number;
 - Will not have annual outpatient appointments;
 - A specific plan for follow up 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.
- 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.

2.6 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.
- In summary, 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 therapists.

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.

3 Eligibility for Entry onto the Self-Managed Follow Up Pathway

3.1 All early and locally advanced 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 out patient appointments unless further investigation or support is required.

3.2 Some patients may not be appropriate for self-managed care:

- 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.

3.3 If deemed unsuitable for the self-managed pathway, then a professional led follow-up pathway is prescribed. Individuals will continue to have face to face, phone, or email contact with the specialist team.

3.4 For individuals participating in clinical trials, follow-up will be determined by the 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.

3.5 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 clinician-led follow up, as per 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 regular clinical review they could transfer to a self-managed pathway.

4. Discharge from the Prostate Cancer Follow-up Pathway

At the end of their surveillance period, 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 will be actioned and both the patient and the GP will be informed of any recommendations for ongoing treatment and monitoring, or that the patient has been discharged from the hospital's care.

5 Remote Monitoring System

- 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
- It is expected that the remote monitoring system will require initial investment and on-going finance, however it 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.

6. 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.

7. 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.
- 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 new patient GP referral into the appropriate pathway.

8. Evaluation

- It is expected that the Quality of Life and Living with and Beyond metrics will be used to evaluate the implementation of Personalised Stratified Follow Up. These metrics are currently under development by the national team so an addendum to these guidelines will be published in April 2020.
- Comparison of previous and subsequent evaluation from the National Cancer Patient Experience Survey (CPES) will be reviewed in relation to aspects of the Personalised Care Package.

9. Guideline Monitoring

It is recommended that auditing 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.

10. References

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11. Appendices

Appendix 1: Definitions

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

Cancer Care Review (CCR): The Cancer Care Review is currently a conversation that is carried out 6 months from diagnosis as part of QOF. It is envisaged that it should ideally be revisited after the end of treatment by the GP or Practice Nurse in Primary Care and is based on the Treatment Summary and HNA. This holistic discussion ensures the person can discuss their cancer experience and it will continue to facilitate supported self-management. It reinforces the messages given via the Treatment Summary and allows an opportunity to raise any concerns that may be affecting the quality of life of the person living with and beyond cancer.

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 breast 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 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 breast team if they have any concerns. They do not receive any further OPA unless further investigations or support is required.

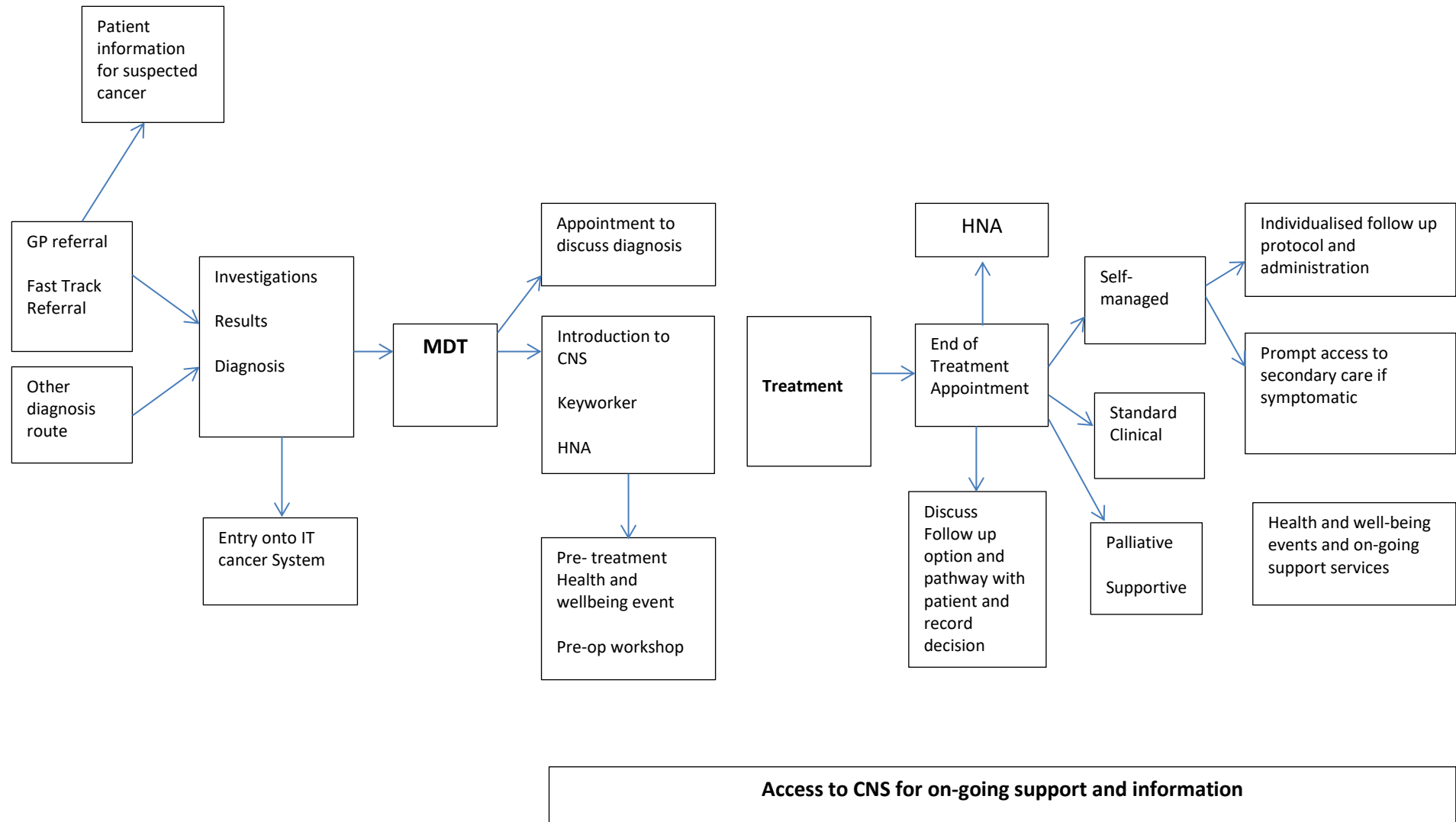
Shared Decision Making: Shared decision making is a collaborative process that allows the individual and the responsible health care professional to make health care decisions together in the person's best interest, based on evidence-based practice – taking into account the person's values and preferences

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

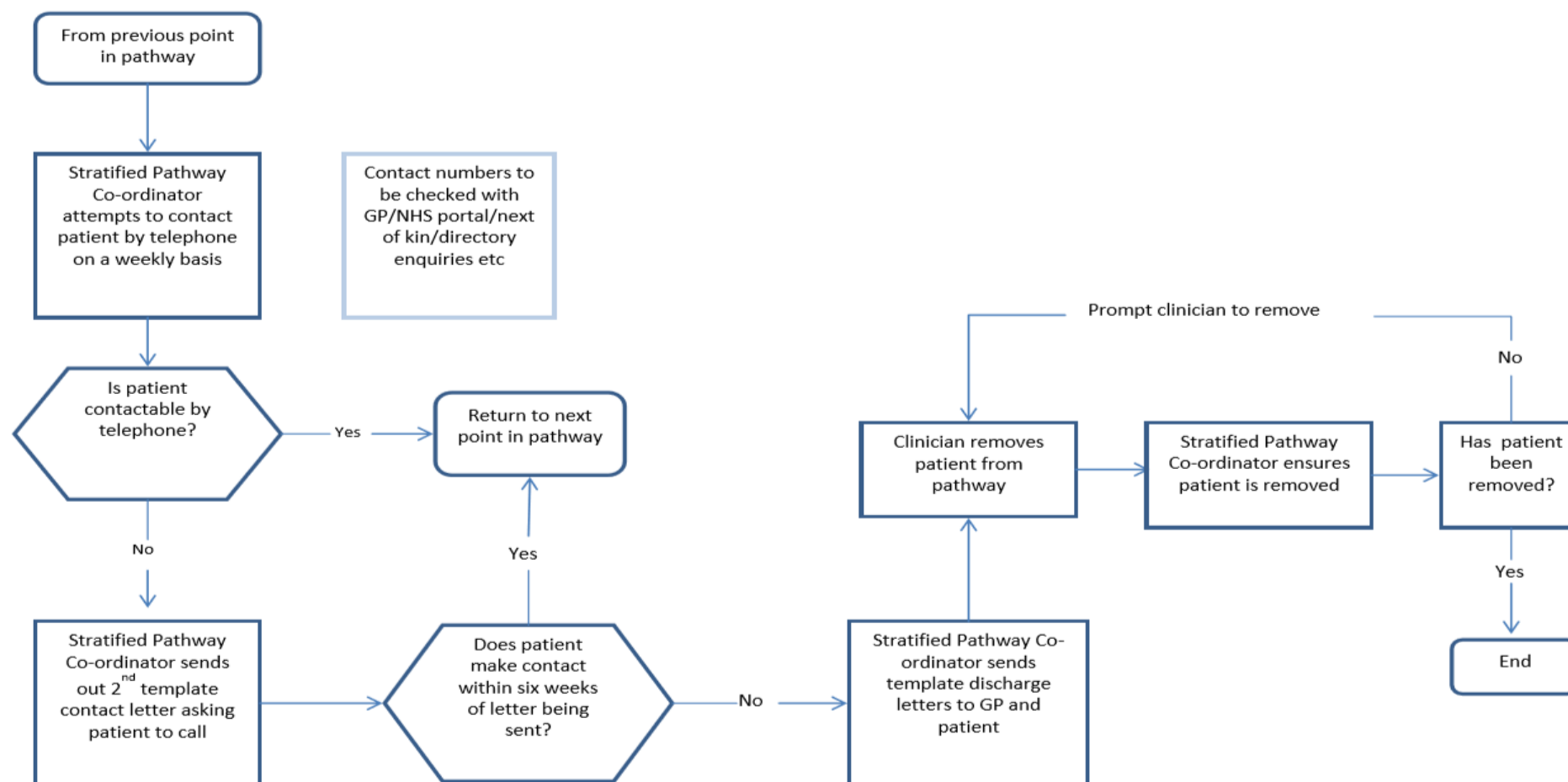
Treatment Summary (TS): A Treatment Summary is a document produced by the Doctor or Specialist Nurse at the end of active treatment for cancer. The Treatment Summary details the diagnosis, stage and any relevant pathology information. It also includes any surgery, chemotherapy, radiotherapy or any other 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 develop the Cancer Care Review.

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

Appendix 2. Urology Cancer Follow Up Pathway Model



Appendix 3. Pathway for those patients who are “uncontactable”



Appendix 3. Example Content for Trust PSFU Patient Information

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.

Acknowledgements

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