London Cancer:
Prostate Cancer Stratified Follow–Up
Implementation Resource Pack

March 2016
FINAL
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1. Background & Introduction

A key London Cancer priority is to reduce variation in order to improve patient experience and outcomes for individuals living with or beyond cancer. Across London Cancer, there are currently considerable differences in follow-up policies to support individuals who have completed their cancer treatment. The Living with and Beyond programme is collaborating with our pathway boards and partner trusts to drive and support the shift from clinician-led and largely hospital-based models of follow-up to an evidence based, stratified model that addresses the unique needs of the individual living after a cancer diagnosis.

In 2011, a stratified follow-up model for individuals with cancer was developed and successfully tested by NHS Improvement as part of the National Cancer Survivorship Initiative (NCSI). The model has been recommended for implementation by the NCSI in the ‘Living with and Beyond Cancer: Taking Action to Improve Outcomes’ document published in March 2013. Stratified follow-up is an approach to steering individuals onto the best follow-up pathway to address their specific needs. It has a focus on promoting wellbeing, recovery and empowerment to provide individuals with the information and confidence to have an active role in their care. The overall aim of the approach is to improve patient experience and outcomes, and quality of care, by tailoring aftercare and embedding supported self-management within the cancer pathway.

The move toward stratified follow-up is consistent with The Model of Care for Cancer Services (Commissioning Support for London, 2010) which recommends a transition to personalised assessment, information provision and care planning. The rationale for this shift is that there is no evidence that traditional follow-up, consisting of regular appointments in secondary care, provides the most effective care or best means to detect disease recurrence. In addition, longer life expectancy combined with more intensive treatments are resulting in increasing numbers of individuals living with consequences of treatment, which may manifest years after treatment ends (Macmillan 2013). These consequences of cancer need to be addressed by an effective model of aftercare.

This document is a resource to assist trusts to plan and implement prostate cancer stratified follow-up at local level. The templates contained within the appendices may be sourced as word documents on the London Cancer website: http://www.londoncancer.org/cancerprofessionals/urological/urological-pathway-documents/

2. Key features of stratified follow-up

The National Cancer Survivorship Initiative advises that individuals are assessed to determine which tier of follow-up would best meet their needs. Individuals deemed at low risk of recurrence and late effects (physical and psychosocial) are encouraged towards supported self-management, those at medium risk receive planned, co-ordinated care and those at high risk receive complex care from specialist services.
Overall key features of stratified follow-up:

- Enables people who are willing and able to undertake self-management to do so in a safe and supported manner.

- Incorporates NCSI Recovery Package interventions (Holistic Needs Assessment, Treatment Summary, Cancer Care Review, Health and Wellbeing Event) to improve outcomes and co-ordination of care.

- Improves patient experience by eliminating anxiety and stress induced by attending unnecessary appointments.

- Rapid re-entry into the specialist cancer service as required. This reassures individuals that they are able to access appropriate, named support quickly should they need it, without having to go via their GP. The ability to re-access services quickly and easily has been shown to be crucial to the confidence of people undertaking supported self-management, and consequently to the long-term success of a supported self-management programme.

- Removal of routine follow-up appointments from the pathway. Routine surveillance tests are still completed at set intervals. However, these do not require the individual to automatically see a hospital doctor or nurse to receive their results. The results will be reviewed by an appropriately qualified trust or primary care health professional and the patient is informed of the results by letter, phone, or in person (as per clinical judgement). Recall back into specialist services is effected via urgent referral.

3. Understanding, evaluating and learning from national pilots

In 2011 NHS Improvement supported, coached and facilitated stratified pathway development and implementation in 14 test communities in England for the National Cancer Survivorship Initiative. Lessons learned from the test sites:

- Staff were supportive of stratification – they thought it was valuable for all patients as it allowed those who were self-managing to be empowered to move on with their lives, while those on professionally led pathways or still in treatment benefited from additional time with Consultants.

- Most staff stated that patients positively received the concept of self-management if it was fully explained and introduced at an appropriate point so that it did not contrast with their expectations for follow-up care. Several nurses advised that only new patients should be moved onto a self-management pathway.
• Monitoring was extremely important for patients as a key safety measure. For those patients on a supported self-management pathway, their greatest concerns were related to their cancer returning, and recognising the signs and symptoms of cancer recurrence.

• Patients reported that the knowledge that an appropriately trained health professional reviewed their scan or blood test results was often the reassurance they needed to enter a supported self-management pathway.

• Cultural barriers – many staff acknowledged that the new stratified pathways required a very different way of working and thinking for all concerned. Self-management requires a shift from a culture of dependency and reliance on professionals towards self-reliance and responsibility.

There were a number of factors that stood out as being particularly important for care coordination within a supported self-management follow-up pathway:

• Remote monitoring reassured patients that problems would get picked up; this served as a welcome safety net.

• Assessment and care planning was seen as crucial to effective care coordination by staff and charity contacts. Patients were less vocal about this, simply because not all of them had gone through this process. However, where it had happened, patients seemed positive about the care plan – they thought it was useful and a comfort to them.

• Equally hand held records didn’t seem to feature strongly for the patients interviewed; however, where they did have them, they could see the benefit for care coordination and for their own peace of mind.

• The central role of the CNS for many patients suggests that even where patients are self-managing, the responsibility for managing whatever care may be needed has not entirely shifted to the patient.

• IT solutions to ensure that individuals don’t ‘fall through the net’.

There are a number of things that require consideration for a fuller shift towards self-management, including:

• The broader cultural changes around how healthcare is provided, part of which is a shift from a traditional medical model, focusing on ill health, towards a model focusing on health and wellbeing. This brings with it broader challenges around how these cultural changes are implemented and operationalised, and how they filter through to staff and individuals with cancer.

• This then has implications for how staff and individuals with cancer see their own role in how care is provided and received. It requires consideration of how attitudes and
awareness may be shifted in moving from a system where treatment and care is done to patients to a system where care is delivered in partnership with the individual.

- The challenges around this cultural shift towards self-management were particularly pertinent during the transition from treatment to aftercare, requiring patients to adjust from “being taken care of” to taking on responsibilities themselves. Therefore, it is essential that patients’ expectations be managed early on in the assessment and care planning process to increase their confidence in self-managing once they complete treatment.

- Clear communication around new approaches to care and what this means for all involved is important. As part of this, being more explicit about the respective roles and responsibilities will ensure that each party is aware of what is expected of them. However, making patients’ responsibilities clear to them needs to go hand in hand with building their confidence to handle their own condition. Similarly, further training with staff to build their own confidence in this changing role may prove beneficial.

- Longer-term implementation of the programme assists the transition – so key principles that will enable self-management (including needs assessment, care plans, education and learning etc.) are embedded further.

- Finally, staff identified a need for a different approach to resourcing – nurses in particular suggested that resources may need to be moved around the system.

4. Progress with developing stratified pathways within London Cancer

The Living with and Beyond Cancer workstream is supporting the breast, colorectal and urology pathway boards and our partner trusts to develop and implement a stratified model of follow-up. Each board has developed a subgroup which is taking forward development of a stratified pathway and resource pack on a tumour-specific basis.

5. The Prostate Cancer Stratified Pathway

In February 2015, the Urology Pathway Board convened and tasked a sub-group to take this work forward. A stratified follow-up pathway and guidelines have subsequently been developed. (Appendix A). In addition to the development of the pathway, the group developed a suite of documents to provide to trusts as a resource to implement locally. Please refer to the appendices below for the following:

- Appendix B: Draft business case for developing stratified follow-up
- Appendix C: Patient information leaflet on supported self-management
- Appendix D: GP information leaflet on supported self-management
- Appendix E: IT Functionality Requirements and Options Appraisal document
- Appendix F: GP clinical template letter – includes treatment summary
The subgroup is also in the process of identifying two beacon sites to pilot the introduction of the prostate cancer stratified pathway.

6. References


Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*


NHS Improvement Cancer (2011) *Effective follow up: testing risk stratified pathways*


National Institute for Excellence (2014) *Prostate cancer: diagnosis and treatment*

7. Acknowledgements

Thank you to all of the sub-group members who assisted in the development of this new stratified follow-up pathway. We acknowledge the input and expertise of all the members of this sub-group and the Urology Pathway Board whom participated in the development process.

We also acknowledge Helen Liles, London Cancer Alliance Stratified Follow up Project Manager who kindly shared relevant London Cancer Alliance documentation for our group to review and adapt as needed.
Appendix A: Prostate Cancer Stratified Follow-Up Pathway Guidelines
London Cancer:
Prostate Cancer Stratified
Follow-up Pathway Guidelines

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1. Contents

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2. Introduction and Purpose of this Guideline

The London Cancer Urology Pathway Board formed a sub-group to develop a stratified follow-up pathway for the future delivery of prostate cancer. The sub-group met during the period between February 2015 and May 2015 and delivered its final proposed pathway to the Urology Pathway Board on 14th May 2015. The pathway board, as the ultimate source of prostate cancer expertise and leadership for London Cancer ratified the stratified follow-up pathway on 4th February 2016.

This guidance describes a secondary care led follow-up process but it can be adapted for a primary care led solution. It is anticipated that trusts will engage with local Clinical Commissioning Groups (CCGs) to discuss if a secondary or primary care led model is best for their local population and services. For definitions, please refer to Appendix I.

These guidelines have been produced to ensure that:

- All individuals diagnosed with prostate cancer receive personalised information and appropriate support to enable them to live actively and well following the end of their cancer treatment.
- A safe, robust and transparent system is utilised to manage prostate cancer surveillance and ongoing care/support.
- Timely, safe and appropriate systems back into specialist services are in place in the event that a concern arises.
- Each individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.

This stratified pathway meets the expectations of the National Cancer Survivorship Initiative, NHS Improvement (Cancer) and NICE guidance for the management of prostate cancer. It is an accompanying document to the London Cancer Pathway Specification for Urological Cancers document.

3. Stratified Follow-Up: Overview of the pathway

The redesigned stratified follow-up pathway for individuals with prostate cancer is outlined in Appendix II. The pathway is described from the point of diagnosis, through treatment until living with and beyond the disease or the transition to end of life care.

The pathway has 3 strata of follow-up:

- **Supported self-management pathway (SSMP):** Patient led follow-up where the individual receives support and interventions to empower them to self-manage their health. They receive surveillance tests but do not have routine clinic appointments.
• **Personalised clinical follow-up:** Clinician led follow-up. Clinic appointments are scheduled as per individual need

• **Supportive/end of life care services:** Clinician led with palliative care input as required.

The individual will receive personalised clinical follow-up until their disease is deemed stable. If they have unstable or advanced disease, they will continue to have personalised clinical follow-up or will transition to supportive/end of life care (as per their clinical/individualised needs).

Once an individual has stable disease they will be reviewed by the clinical team and stratified onto the supported self-management pathway – or remain on the personalised clinical follow-up pathway if they are unable to self-manage. Detail of the ‘Stratified Pathway for Stable Prostate Cancer’ pathway is provided in Appendix III. They will be monitored on this pathway for approximately three years. Those who are on the SSMP will then be discharged into primary care.

Individuals receiving personalised clinical follow-up will be reviewed and their needs for ongoing support by secondary care will be reviewed by the Multidisciplinary Team (MDT).

### 4. Eligibility for Entry onto Supported Self-management Pathway

All stable prostate cancer patients will be considered for entry onto the prostate supported self-management pathway unless the individual:

- Is unable to self-manage due to physical, cognitive or emotional reasons
- Chooses not to enter the supported self-management pathway
- Is on active surveillance
- Is being treated with brachytherapy
- Is at high risk and has had radical radiotherapy or surgery

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocols. All individuals taking part in trials will still access and benefit from the end of treatment clinical OPA (outpatient appointment), and health and wellbeing events.

Definitions of stable have been developed and agreed per treatment. They are as follows:

1. **Localised Prostate Cancer – Watchful Waiting:** All patients who are willing and able are to be considered for self-management.

2. **Patients who have had curative radical prostatectomy:** All patients 1 year after treatment and PSA is <0.1 ng/ml above nadir.

3. **Patients who have radical radiotherapy – aim PSA <0.1:** All patients 2 years after treatment and PSA is <2 ng/ml above nadir and no complications.

4. **Patients being treated with hormonal treatment only for locally advanced disease with or without metastases:** All patients 1 year after treatment whose PSA is less than 4 ng/ml.

5. **Patients who have received focal treatment:** All patients 1 year after treatment and no complications. Consultant will set individualised ceiling for PSA at this time.
Patients will have their suitability for entering the supported self-management pathway considered in the MDT. Those who are not eligible will be recorded as not appropriate for SSMP on their MDT proforma within the cancer IT system and will receive personalised clinical follow-up. A printed copy will be placed in the patient notes as appropriate.

5. Stratified Follow-Up: The Process

5.1 Diagnosis and treatment:

- All men diagnosed with prostate cancer will receive information about the treatment they will receive and how they will be supported:
  - During and following the end of treatment
  - Once their disease and PSA are stable

- This will include a description of both personalised clinical and supported self-management follow-up options with emphasis placed on the fact that they may move between pathways if their needs change during the follow up period.

- Individuals will receive a holistic needs assessment around diagnosis. This will be reviewed whenever their needs change.

5.2 End of treatment

- At the end of first definitive treatment or at the end of a defined set of treatments, all individuals will receive an 'end of treatment clinical outpatient appointment’. This is an appointment between the patient and the Consultant in which the individual will have their holistic needs reviewed and they will receive personalised information to support them at this transitional point in the pathway. It is recommended that the patient be provided with verbal and/or written information regarding the following:
  - Explanation of their personal plan for future surveillance tests. This will include a description of the process for having blood tests and receiving results
  - Alert symptoms that require contacting the specialist team to discuss
  - Possible treatment toxicities/consequences of treatment
  - Contact name and phone number of the urology specialist team and trust helpline
  - Advice on healthy eating
  - Advice on physical activity – keeping active
  - Upcoming Health and Wellbeing Events
  - Any local self-help groups and useful phone numbers (e.g. Macmillan Cancer Support, Prostate Cancer UK)

- A treatment summary will be generated by the medical team and placed in the individual’s written/electronic hospital notes. Copies of the treatment summary will also be sent to the patient if they have opted to receive clinical documents.
• It is recommended that the GP is sent copies of the same information that is given to the patient. This will enable the GP to support the individual in the primary care setting.

• A schedule of personalised future clinical appointments will be booked and dates will be given to the individual.

5.3 Living with or Beyond Cancer – Stratification

Once the individual has stable disease, their eligibility for entry onto supported self-management pathway (SSMP) is to be established. The final decision regarding the most appropriate pathway for the individual is conducted in collaboration with the patient. Therefore if they are eligible, it is advised that a ‘stratified follow-up OPA’ is arranged to discuss follow-up options – with a focus on encouraging entry onto the SSMP.

During this appointment, the individual will also receive:

- A review of their holistic needs assessment
- A personal plan for future surveillance tests - including an explanation of the process for having blood tests and receiving results
- Alert symptoms that require contacting the specialist team to discuss
- Possible treatment toxicities/consequences of treatment
- Contact name and phone number of the urology specialist team and trust helpline
- Advice on active and healthy living – nutritional advice and physical activity
- Information on upcoming Health and Wellbeing Events
- Contact details on any local or national support groups or information services (e.g. Macmillan Cancer Support, Prostate Cancer UK)

Individuals who are eligible and choose the supported self-management pathway:

• Can contact their Urology CNS as needed with any concerns
• Will have six-monthly PSA tests for 3 years with the results sent to them
• If on hormone therapy, they will have six-monthly PSAs on an ongoing basis and will receive bone health monitoring as per national and local guidelines
• Will not have routine outpatient appointments

At any point during the follow-up pathway, individuals may be contacted and offered access to any relevant clinical trials that may become available.

The individuals who choose the personalised clinical pathway or who are not eligible for the supported self-management pathway:

• Will receive follow up surveillance tests and outpatient appointments as per their clinical and individual needs
• During each OPA, the individual’s eligibility for entry onto SSMP to be revisited
5.3.1 Health and Wellbeing Events

All patients will be offered a health and wellbeing event. Health and wellbeing events are patient education and support sessions which aim to provide individuals with the information and confidence they require to lead as normal and active life as possible after their cancer treatment. They also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families.

The Health and Wellbeing events may be delivered as:

- **1:1 appointments** conducted with individuals at the end of treatment
- **Rolling programmes** (such as the 6-weekly Macmillan HOPE events)
- **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. They 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

It is recommended that the core content of Health and Wellbeing events is as follows:

- **Expert advice on health promotion** – to minimise risk of recurrence and support healthy living. Specifically this will include: being physically active, nutrition, healthy weight management, and smoking cessation. To include information/support to effect behavioural change
- **Support** to ensure that individuals have the confidence and skills to manage their condition themselves as far as possible – i.e. referral to rehabilitation and psychological support services and signposting to local groups or buddy services
- **Advice on adjusting to life after treatment** – addressing fears of cancer recurrence
- **Information on signs and symptoms of recurrence and potential consequences of treatment.** All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease
- **Information and access to financial and benefits advice**
- **Specific issues relevant to the individual’s type of cancer.** For example continence issues – early detection and management, body image & sexual functioning
- **Vocational rehabilitation**

The end of treatment appointment with the Consultant/CNS may be tailored to fulfil the function of a health and wellbeing event. However, evidence from National Cancer Survivorship Initiative health and wellbeing pilot sites revealed that many patients benefited from group sessions. Specifically the pilots demonstrated that:

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• The informal atmosphere of group events enhanced the delivery of the Health and Wellbeing messages
• The combination of using professionals and volunteers at the Health and Wellbeing group sessions was effective
• Participants valued the group discussions – this assisted to address issues of isolation and to validate what is ‘normal’ to experience and feel for a person affected by cancer. This differentiates the clinics from traditional forms of follow-up such as outpatient appointments

5.3.2 Discharge from the Stratified Follow-up Pathway

At the end of 3 years from the point of entry onto the stratified follow-up pathway, it is recommended that the individuals on the:

• Self-management pathway – are reviewed in a virtual MDT to update any ongoing treatment regimes in light of latest evidence. Discharge into primary care to be effected as appropriate.
• Personalised clinical follow-up pathway – are reviewed every three years in a virtual MDT meeting to establish suitability of being discharged to primary care or moved to self-management pathway.

Any plans from the virtual MDT review will be actioned and a letter will be sent to both the patient and the GP to inform them of any recommendations for ongoing treatment or stating that the individual has been discharged from the trust stratified follow-up pathway. Patients will continue to have annual PSA measurements for the length of time indicated by their Consultant.

6. Surveillance Investigations

All patients will have their surveillance investigations recorded on the cancer IT database. This database will hold the information required to manage follow up investigations – ordering of tests and results recording/checking. From a clinical perspective, it is recommended that the IT system provides data that demonstrates PSA results numerically and graphically over time as increases in PSA levels, even if levels are within tolerance, can indicate recurrence of disease.

6.1 PSA tests will be conducted on a six monthly basis unless otherwise indicated by the consultant. PSA surveillance requests will be recorded and scheduled on the cancer IT database.
6.2 A safe and robust system of checking PSA tests needs to be implemented. It is recommended that the electronic database generates a monthly list of patients requiring a PSA test. The PSA requests will then be made and an appointment sent to the patient.
6.3 Results will be reviewed by a clinician and recorded on the cancer IT database. They will then be sent directly to the GP. If the results are normal, a letter will be sent to the patient informing them of this. If the results indicate further investigations required, the patient will be recalled into an OPA within 2 weeks of the results being reviewed.
6.4 Other surveillance such as for bone health will be recorded and managed on an individual basis.

6.5 Patients will be aware of due date for their PSA tests from information included within their end of treatment clinical OPA and on their treatment summary. Individuals will be advised to contact the specialist team if they do not receive a request for the PSA test by the end of the month that it is due.

6.6 It is recommended that the trust has a system in place to outline which team members will have the responsibility to resolve issues regarding missed PSA results or to follow up DNAs.

6.7 After 3 years of being on the SSMP, patients on the self-management pathway will be discharged to primary care. It is recommended that PSA testing responsibilities transfer to primary care at this point.

7. Clinical Governance

Over the 3-year duration of the stratified follow-up pathway, the clinical governance responsibility for patients on the personalised clinical follow up and supported self-management pathways lie with the Urology MDT. Clinical governance responsibility for those on the SSMP will then move to primary care once they are discharged into the care of their GP.

8. Re-accessing Specialist Services as required

All patients and their GP’s will be aware of how to access the specialist team if concerns arise. Safe robust systems will be in place to facilitate this.

8.1 Patients and their GP’s will have written contact numbers and guidelines about when and how to access further support. Access will be via the Urology CNS whilst the individual is on either of the stratified pathways and thereafter via a GP referral.

8.2 If a patient is on the SSMP and is required to have further investigations following their routine PSA testing, they will be recalled for an urgent OPA within two weeks of their investigations being reported. It is recommended that trusts identify a clinic for these patients to attend to ensure rapid access when required. Patients will be informed of this possibility at their end of treatment clinical appointment. Patients on the personalised clinical follow-up pathway will be seen in clinic for a review within 2 weeks and further investigations ordered as required.

8.3 Triggers for re-referral (by treatment)

Localised Prostate Cancer – Watchful Waiting: 2 consecutive rises in PSA is predominant trigger. A member of the Urology MDT should review men with localised prostate cancer who have chosen a watchful waiting regime and who have evidence of significant disease progression (rapidly rising PSA or bone pain) as per NICE guidance (2014)
Patients who have had curative radical prostatectomy: PSA > 0.1 ng/ml, or 2 consecutive rises in PSA, or PSA of Nadir + 1

Patients who have radical radiotherapy - aim PSA < 0.1 ng/ml: PSA of Nadir +2

Patients being treated with hormonal treatment only for locally advanced (or metastatic) disease: 3 consecutive rises in PSA, or PSA of Nadir +2

Patients who have received focal treatment: 2 consecutive rises in PSA, or if PSA ceiling reached

9. Evaluation

9.1 It is recommended that user feedback is conducted by postal questionnaire which is sent to all patients 3 months post the stratified follow-up OPA. The aim of the questionnaire is to establish if the patients’ needs have been met. (Refer to Appendix IV for an example of a patient questionnaire)

9.2 Baseline measures/process mapping: Establishing baseline measures prior to implementation is critical to enable measurement of improvements at a later date. Recommended data for collection includes:
- New cancer diagnosis: Follow up ratios for prostate patients
- Number of Surgical outpatient clinics per week
- Number of Oncology outpatient clinics per week
- Number of cancer patients seen at each outpatient clinic
- Average number of new cancer patient slots per clinic
- Average number of follow up cancer patient slots per clinic
- Number of telephone clinics to follow up cancer patients. Average number of cancer patients reviewed at each telephone clinic.
- Number of virtual clinics to follow-up cancer patients. Average number of cancer patients reviewed at each virtual clinic.
- Readmission rates for cancer patients

9.3 On-going measures: Establishing the data collection and measures to be utilised to demonstrate effectiveness also needs to be agreed prior to implementation. Data on all or some of the following would be useful:
- Reduction in outpatient attendances
- Patient Reported Experience Measures (PREMS)
- Patient Reported Outcome Measures (PROMS)
- No. of calls to helpline or Clinical Nurse Specialist from patients being followed up on the SSMP
- No. of Holistic Needs Assessments completed
- Cancer waiting times
- Number/ % of patients with a care plan
- Number/\% of patients who receive a Treatment Summary at end of treatment
- Number of patients enrolled onto the supported self-management pathway
- Patients’ narratives/stories

9.4 It is recommended that measurement of the health related quality of life and wellbeing of prostate cancer patients is assessed approximately one year post entry onto the stratified model of follow-up. PROMS tools to consider:

- **EORTC QLQ-C30**
  
  **Description:** A questionnaire which assesses the quality of life of cancer patients. It comprises 30 questions which focuses upon functional (physical, cognitive, emotional, and social); specific symptom (fatigue, pain, and nausea and vomiting); global health and quality-of-life domains. A tumour specific module is also available as required.
  
  **Permissions/Licencing:** Permission required. There is no fee for academic use. Permissions obtained via the EORTC website.
  
  **Website:** [http://groups.eortc.be/qol/eortc-qlq-c30](http://groups.eortc.be/qol/eortc-qlq-c30)

- **FACT G**: A general quality of life instrument intended for use with a variety of chronic illness conditions. It assesses the functional status of patients with specific cancer diagnosis. The sub-scales included within the questionnaire are as follows: physical, social/family, emotional, and functional well-being. Originally validated in a general cancer population, it has condition-specific subscales to complement it, including one for prostate cancer (**FACT-P**).
  
  **Permissions/Licencing:** Permission for use is obtained by completing a user agreement on the FACIT website. There is no fee for use of the tool.
  
  **Website:** [http://www.facit.org/](http://www.facit.org/)

- **EQ-5D-5L**: A standardised instrument for use as a measure of health-related quality of life and of health outcome. The measure has 5 dimensions: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression. The instrument comprises 2 parts: respondents rate their health on the dimensions/levels as well as record an overall assessment of their health on a visual analogue scale. Results able to be utilised to calculate quality adjusted life years (QALYs) to inform economic evaluation.
  
  **Permissions/Licencing:** Requires written consent of the EuroQol Executive Office. Registration form able to be completed electronically via the EuroQol website.
  
  **Website:** [http://www.euroqol.org/](http://www.euroqol.org/)
10. Guideline Monitoring

It is recommended that auditing occur three months following the implementation of these guidelines at trust level – and on an annual basis provided there are no significant adjustments required.
11. References


National Institute for Clinical Excellence (2002) Improving outcomes in urological cancers (the manual)

National Institute for Health and Care Excellence (2014) Prostate cancer: diagnosis and management

NHS Improvement Cancer (2011) Effective follow up: testing risk stratified pathways


12. Acknowledgements

Thank you to all of the sub-group members (named in Appendix V) who assisted in the development of this new stratified follow-up pathway. We acknowledge the input and expertise of all the members of this sub-group and the Prostate Pathway Board whom participated in the development process.
Cancer IT System: The local cancer database (Somerset or Infoflex).

CNS: Clinical Nurse Specialist

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

OPA: Outpatient appointment

Personalised clinical follow-up pathway: The follow-up pathway in which individuals with cancer have face to face, phone, or email contact with the specialist team as part of individualised continuing follow up.

PSA: Prostate specific antigen. A test for PSA may be used to screen for cancer of the prostate and to monitor treatment of the disease.

Supported self-management pathway (SSMP): 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.

Stratified Follow-up: 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 personalised clinical follow-up pathway or a supported self-management pathway. The stratified follow-up pathway extends 5 years from the point of diagnosis.

Treatment Summary: The NCSI treatment summary template is completed by the medical team at the end of primary treatment. It includes information on possible treatment toxicities and /or consequences of treatment, signs and symptoms that require referral back to a specialist team, an ongoing management plan, and a summary of information given to the individual about their cancer and future progress and any required GP actions to support the patient. Copies are sent to the GP and provided to the patient when they are discharged.
The treatment summary can be automatically generated on the two main cancer information systems Somerset and InfoFlex.
Appendix II: Stratified Follow up Pathway for Prostate Cancer
Stratified Follow up Pathway for Prostate Cancer

Area within the green lines is expanded in the 'Stratified follow-up pathway for stable prostate cancer' diagram overpage
Appendix III: Stratified Follow up Pathway for Stable Prostate Cancer
Stratified follow-up pathway for stable prostate cancer

Diagnosis and Treatment
- Entry onto cancer IT system and remote monitoring database
- Decision recorded on IT cancer system
- MDT
  - Treatment decision / Treatment / End of treatment clinical OPA with: discussion of future surveillance tests, support information and healthy living advice
  - Treatment summary completed
- Investigations and diagnosis
  - Patient info. describes follow-up options
- Patient actively engaged as a partner in their care throughout pathway.

End of treatment & living beyond cancer
- Prep. Of treatment summary and invitation to aftercare appointment
- If abnormal result, patient recalled for review
- If normal result
  - Scheduled PSA blood tests
  - Results to GP & Patient
  - Continue remote monitoring
- Personalised Clinical Follow-up: Clinician led follow-up. Frequency of secondary care appointments determined by need
  - Patient moves between these as per their individual needs

Supported Self management: Patient led F-up / support determined by need
- Hormone therapy review and bone health monitoring as per National Guidelines. Virtual MDT at end of five years.
- Ongoing support and helpline for patients

GP Support - Includes cancer care review within 6 months of diagnosis and referral back to specialist team, as required
- Health and well-being events AND additional support services (sexual functioning, continence, psychological/emotional support, rehab, diet and nutrition, physical activity, peer support)

* Stable prostate cancer patients stratified as per London Cancer recommended eligibility criteria:
  All stable prostate cancer patients will be considered for entry onto the stable prostate supported self management pathway unless:
  - The individual is unable to self-manage due to physical, cognitive or emotional reasons
  - The individual chooses not to enter the supported self-management pathway

Refer patient (2WW)
- Holistic Needs Assessment
- Discuss F-up options with patient
- Holistic needs assessment reviewed as needed
- Health and well-being events AND additional support services (sexual functioning, continence, psychological/emotional support, rehab, diet and nutrition, physical activity, peer support)
Patient Questionnaire about follow up, after treatment ends, for prostate cancer patients cared for by insert trust name

At the insert trust name, we are changing how we care for individuals who have prostate cancer once they have completed their treatment. These changes are in line with national guidelines (NHS Improvement Cancer and the National Cancer Survivorship Initiatives) and with what cancer patients have reported best meets their needs. It is important to us that we receive feedback from you to determine if we are meeting your needs - and what we need to do to continue to improve the care we give.

Please could you take a few minutes to complete this questionnaire?

Your answers will remain anonymous and will only be used by the trust to guide service improvements.

1. Do you have the contact details for your Urology Clinical Nurse Specialist (CNS)?
   Yes □       No □

2. After your end of treatment clinical review outpatient appointment with the doctor or Prostate CNS, did you receive a letter detailing your diagnosis, treatment and what scans or treatment you will need in the future?
   Yes □       No □

3. Do you feel you were given an adequate explanation of this letter by the doctor?
   Yes □       No □

4. Have you had the opportunity to discuss this letter in your aftercare appointment with your Urology CNS?
   Yes □       No □
5. Please comment about the contents of this letter below, if you feel able to.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

6. Did you receive a holistic needs assessment with your Urology CNS at your aftercare appointment?  
   Yes □   No □ don’t know □

7. Do you feel the holistic needs assessment was useful for you?  
   Yes □   No □ don’t know □   not applicable □

8. Please comment about the holistic needs assessment below, if you feel able to.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

9. Over the past six months, how many times have you contacted your GP practice for advice or support with issues relating to your cancer, or your treatment for cancer?  
   Not at all □   1-2 times □   3-5 times □   6-10 times □   More often □

10. How confident do you feel about managing your health?
   
   Very Confident □
11. Do you have all the information, advice or support you need to help you manage your health?
   Yes □   No □   not sure □

12. What other information, advice or support do you need to help you manage your health?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

13. Do you have all of the information and advice that you need about the effects of your treatment?
   Yes □   No □   not sure □

14. How confident do you feel about who to contact if you have a query or concern, if at all?
   Very Confident □
   Fairly Confident □
   Not very confident □
   Not at all confident □
   Don’t know □
15. Were you offered the opportunity to be on the supported self-management pathway?
   Yes □  No □  I don’t know □

16. If yes to question 15 then did you choose to go on the supported self-management pathway?
   Yes □  No □  I don’t know □  not applicable □

If you feel able, please could you share any further comments or thoughts you have about the end of treatment information and appointment with your Urology CNS?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Thank you for taking the time to complete this questionnaire, we value your comments and they will be used to guide service improvement in the future.

(Questionnaire adapted from Parapet Breast Unit at Heatherwood and Wexham Park Hospitals NHS Foundation Trusts)
Appendix V: Prostate Cancer Stratified Follow-Up Subgroup Members
• Sharon Cavanagh (Chair) – Living with and Beyond Cancer and AHP Lead, London Cancer
• John Hines – London Cancer Urology Pathway Director and Consultant Urologist, Barts Health NHS Trust
• John Sandell – Patient Representative
• Jane Smith – Patient Representative
• Katie Sutton - Macmillan Project Lead-Cancer Follow-Up Redesign, University College of London Hospital NHS Foundation Trust
• John O’Neill – Prostate Cancer Nurse, Whipps Cross Hospital
• Kate Kavanagh - Cancer Commissioning Manager (BHR & West Essex) NEL Commissioning Support Unit
• Alex Clayton-Jolly - Consultant Radiologist, Barking, Havering and Redbridge University Hospitals NHS Trust
• Paula Wells – Consultant Clinical Oncologist, University College London Hospitals NHS Foundation Trust
• Ros Crooks – Consultant Prostate Radiologist, Whittington Hospital NHS Trust
• Philip Lunn - Divisional Operations Director, Homerton Hospital
• Wade Norcott, Assistant Service Manager, Princess Alexandra Hospital
• Karen Sennett, GP/CCG Islington Board member, Islington Cancer Lead, Islington CCG
• Christine Moss, Epping GP and Clinical Director of west Essex CCG
Draft Business Case

Self-management pathway  Cancer Services

Executive Summary

The primary purpose of follow-up is to detect for cancer recurrence and identify and treat late effects of treatment. The traditional model follows a standard regime of outpatient appointments and surveillance tests over several years. Patients can be seen by any member of the clinical team.

Increasing incidence of cancer (currently 3% per year) alongside increased survival rates are putting huge pressure on outpatient resources and impacting on the quality and efficiency of services provided. Both patients and professionals have identified that many appointments are unnecessary, add no value and incur unnecessary costs for patients.

The (insert team) have reviewed their current clinical pathways and propose the introduction of a self-management or open access pathway option for low risk patients, offered soon after the completion of treatment and when the short term effects of treatment have subsided. Key enablers to support this pathway are an effective assessment process to identify and manage individual needs and a remote monitoring system to ensure surveillance tests are safely monitored.

A number of options were considered to support this approach:

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do nothing</td>
</tr>
<tr>
<td>2</td>
<td>Supported self-managed pathway - specialist monitors surveillance tests</td>
</tr>
<tr>
<td>3</td>
<td>Self-managed pathway - primary care monitors surveillance tests</td>
</tr>
<tr>
<td>4</td>
<td>Self-managed pathway - external provider monitors surveillance tests</td>
</tr>
</tbody>
</table>
Option 2 is the preferred option. This option is favoured over other models because:

- It offers higher patient safety. A robust IT solution built specifically for this purpose ensures no patient slips through the net;
- Higher rates of referral to open access pathway are expected as patients remain under specialist watch rather than in primary care or external service;
- There will be easier access to MDT or specialist advice for equivocal or abnormal results;
- Patients are more likely to accept the self-management pathway choice if remaining under ‘specialist supervision’;
- The ‘do nothing’ option will rapidly need new resources (Consultant sessions and outpatient space) as demand exceeds capacity.

Benefits of a specialist led open access pathway:

**To patients:**
- Follow-up model based on choice;
- Reduced personal costs associated with outpatient attendances;
- More rapid re-access/recall to specialist if needed

**For providers:**
- Improved access times for new referrals;
- Increased time in clinic for those with complex needs;
- Fewer overbooked clinics; and
- Released outpatient capacity.

**For commissioners:**
- More effective use of local outpatient capacity;
- Improved quality of service for local population;
- Improved communication between specialist and community teams;
- Safer service - fewer patients ‘lost to follow up’; and
- Monitoring surveillance tests remains under ‘specialist watch’.

This solution is expected to take 6 months to implement. Investment in a remote monitoring system and other qualitative initiatives are required to safely implement this option. The pathway will offer a return on investment within (insert time).

The capital costs of set up is (insert year 1 capital costs) and has (£ insert) on-going revenue implications.

This proposal has the full support of (insert directorate and or commissioning group).

1. Introduction

This business case proposes the introduction of a supported self-management pathway within (insert cancer specialty areas). This solution requires investment in a remote monitoring solution and a more formalised approach to needs assessment and care planning to ensure that patients offered this pathway are informed and confident to manage their condition without regular face to face contact with the specialist team. The solution enables the release of outpatient capacity and aligns
with the local strategy to improve the efficiency and effectiveness of outpatient services.

2. Background Information

There are estimated to be around 2 million (2008) people in the UK living following a diagnosis of cancer. This number is rising by approximately 3% per annum and expected to reach 3 million by 2030 as incidence increases and survival rates improve.

Locally as the number of (insert specialty) cancer survivors increase, so does the number of patients requiring follow up. Without a change in approach further significant investment in resources (clinical, space, support teams) will be required.

The quality, innovation, productivity and prevention agenda calls upon all organisations within the health service to identify and implement more efficient ways of working. Providers and commissioners are required to work across health systems to reduce unnecessary use of resources.

With regard to cancer follow up, while some appointments are clinically indicated, a large proportion are not required and alternative models of care can be delivered whilst still complying with NICE Guidance (Insert reference). Supporting patients to self-manage develops their ability to actively participate in their follow-up care empowering and building confidence so they have the ability to make decisions concerning their recovery within a supported environment. Patients on an open access pathway are more likely to act promptly to report concerns than those on traditional follow up who often wait for an appointment before reporting abnormal signs.

3. Current position

(Insert trust) sees approximately (insert no:) new referrals per annum. Following treatment the follow up regime involves (insert number) follow up attendances over (insert number) years. There are approximately (insert number) patients in follow up. The annual cost to commissioners of follow up within this specialty is (insert).

On-going surveillance tests (insert) are timed to coincide with follow up appointments where the results are shared with the patient. The health care professional discusses the result with the patient and confirms when the next test and follow up appointment is due. After (insert number) years, surveillance tests cease and the patient is discharged to primary care.
4. Proposed service change

Studies within NHS Improvement test sites¹ and elsewhere have found that with appropriate investment in quality initiatives such as needs assessments and care plans, information and education, approximately (75% prostate, 45% colorectal, 30% prostate) of patients are suitable for a supported self-management pathway.

The (insert directorate) proposes the same approach. At the end of treatment or at each follow up appointment patients will be triaged, based on agreed criteria, to either a supported self-management pathway or continue to be followed up by the specialist team. For patients stratified to a self-managed pathway, surveillance tests will be scheduled and monitored remotely with results conveyed to the patients and their GP without the need for a face to face appointment.

At the time of decision to transfer to a self-management pathway the patient will be ‘enrolled’ to a remote monitoring system. Patient dataset and diagnostic data will be drawn into the remote monitoring solution from trust existing IT systems. The health care professional will ensure information such as diagnosis, treatment history and other relevant information such as co-morbidity or social circumstances are recorded. They will enter the date/s that the surveillance test is next due setting individual upper limits where appropriate to do so. The next test due date is reset each time a test is completed.

Operationally the responsibility for managing this group of patients rests with the (insert specialty) MDT with delegated responsibility under protocol to the (insert role e.g. Clinical Nurse Specialist) for the day to day management of patients.

5. Option Appraisal

The following options for offering a self-managed pathway have been considered

<table>
<thead>
<tr>
<th>Option</th>
<th>Description and key issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do nothing</td>
</tr>
<tr>
<td>2</td>
<td>Specialist led open access</td>
</tr>
</tbody>
</table>

¹ NHS Improvement - Stratified Pathways of Care from Concept to Innovation. Executive Summary. May 2012
Primary care led follow up

Low risk patients are assessed at end of treatment are referred to primary care who schedule and monitor all test results. Requires on-going investment in education as treatment and salvage options change. Potential for patients to be ‘lost to follow up’. Often lacks consensus amongst GPs, patients and specialist teams. Capacity issues in primary care.

6. Preferred non-financial option

Based on the following criteria the preferred non-financial option is *(insert preferred option).* Options were scored 1-5 *(as a team insert your own assessment scores and weightings).*

<table>
<thead>
<tr>
<th>Key Criteria</th>
<th>Weighting</th>
<th>Option 1 Do Nothing</th>
<th>Option 2 Specialist led</th>
<th>Option 3 GP led</th>
<th>Option 4 Other provider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Score</td>
<td>weighted score</td>
<td>Score</td>
<td>weighted score</td>
<td>Score</td>
</tr>
<tr>
<td>Clinical safety</td>
<td>35</td>
<td>3</td>
<td>105</td>
<td>etc.</td>
<td></td>
</tr>
<tr>
<td>Impact on cancer waits</td>
<td>25</td>
<td>1</td>
<td>25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient experience</td>
<td>20</td>
<td>1</td>
<td></td>
<td>etc.</td>
<td></td>
</tr>
<tr>
<td>Access to specialist</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient choice</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. Benefits appraisal

The following is an example only. The same cost benefits analysis is required for each option. Seek help from local finance to complete.

7.1 Option 2

<table>
<thead>
<tr>
<th>Year</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IT set up*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£10,000.00</td>
</tr>
<tr>
<td>IT interface*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£5,000.00</td>
</tr>
<tr>
<td>Licenses and server</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£2,000.00</td>
</tr>
<tr>
<td>IT maintenance and development</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£5,000.00</td>
</tr>
<tr>
<td>Remote Monitoring - CNS band 7 (2.5 hrs. per week)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£2,500.00</td>
</tr>
<tr>
<td>Needs assessment and care planning - CNS grade 7 (4hrs per week)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£3,500.00</td>
</tr>
</tbody>
</table>
Admin and clerical support - Band 3 (2 hours per week) | £1,400.00 | £1,400.00 | £1,400.00 | £1,400.00
---|---|---|---|---
Lost income through reduced OP tariff cost | £0.00 | £3,000.00 | £4,000.00 | £5,000.00
---|---|---|---|---
Total Costs | £24,400.00 | £15,400.00 | £16,400.00 | £17,400.00
---|---|---|---|---
Benefits (to providers) |  |  |  | 
Opportunity costs - released slots for new activity | £0.00 | £10,400.00 | £15,000.00 | £20,000.00
---|---|---|---|---
Total benefits | £0.00 | £10,400.00 | £15,000.00 | £20,000.00
---|---|---|---|---
Net Cash Flow |  | -£5,000.00 | -£1,400.00 | £2,600.00
---|---|---|---|---
PV | 1 | 0.96 | 0.93 | 0.90
---|---|---|---|---
NPV | -£24,400 | -£4,800.00 | -£1,302.00 | £2,340.00
---|---|---|---|---

NB. The IT costs will depend on the remote monitoring solution selected for which a separate Business case may be required.

7.2 Assumptions (draft examples)

- The current follow up regime is consistent across all specialty clinicians;
- There is 80% take up of needs assessment at end of treatment;
- ....% of total new patients are stratified to self-management pathway in year 1;
- Released OP capacity is available to offer new services/opportunities;
- Some released capacity used to extend clinic times for complex patients;
- No medical staff savings (through released OP slots) transferred to nursing budget;
- Surveillance tests costs covered through block contract not within OP tariff;
- Commissioners wish to purchase new activity; and
- No costs have been included for education events or self-management programmes.

The introduction of a specialist led self-managed pathway supported by remote monitoring systems offers quality, safety and efficiency benefits for patients and commissioners. Whilst there will be a consequent reduction in income to provider organisations there will also be opportunity costs arising from released capacity to the wider benefit of the local population.

7.3 Funding source – (if applicable) either known or suggested should be identified and an indication of the certainty of funding being made available when required.

7.4 Other benefits of the specialist led self-management pathway

Patient experience and quality:
- Longer appointment times available for those with complex needs;
- Reduced personal cost to patients associated with outpatient appointments (average £350/5 years); and
- Personalised information and education, written care plans and treatment summaries support self-management and increase self-confidence.

Operational Efficiency:
- Released capacity will improve access times for new referrals;
• Potential for application within other specialties in future

Staff benefits:
• Fewer overbooked clinics with less pressure on staff;
• Increased capacity and satisfaction to deliver high quality care to those with complex needs; and increased training opportunities for junior medical staff in managing complex patients.

8. Risks Analysis

The following risks and mitigating actions have been identified

<table>
<thead>
<tr>
<th>Ref</th>
<th>Risk</th>
<th>Probability</th>
<th>Impact</th>
<th>Risk score</th>
<th>Mitigation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No new activity is commissioned as outpatient capacity is released.</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>Demand for new services increasing. Unless capacity released additional Consultant post required within 3 years</td>
</tr>
<tr>
<td>2</td>
<td>Commissioners will transfer monitoring of tests to primary care in the future</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>Investment in IT will be utilised to support other specialties where primary care monitoring is not suitable</td>
</tr>
<tr>
<td>3</td>
<td>Etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. Project management arrangements

Once business case approval is agreed a small project team will be established led by (insert named project lead). Members will reflect the IT component of the project as well as clinical and operational staff representatives. Patients will be co-opted to advise on process and documentation to support system. The project will report to (insert appropriate steering group) group.

Baseline data and on-going measures will be collected to ensure the changes proposed have made an improvement to the patient experience and efficiency of services. A project initiation document will be developed. (Insert high level plan with key components and milestone dates as appendix)

The new pathway will be operational within (insert time based on resources available) of approval to proceed.

10. Conclusions and recommendations

The introduction of self-management pathways will improve the efficiency and effectiveness of follow up care for cancer patients. Enabled by a robust remote monitoring solution it will release significant outpatient capacity. The recommendation for a specialist led self-management pathway is cost effective and meets the needs of commissioners.
Why you have been selected for supported self-management
Your Consultant has selected you for supported self-management because they believe this is the best way of keeping a close eye on your recovery following your treatment for prostate cancer. Results of your regular PSA tests will be monitored by the hospital and you will be recalled quickly if there are any concerns. This gives you the freedom to get on with your life, but with the reassurance that there is a clinician monitoring your progress and a fast way back into the hospital should you need it.

At the end of your prostate cancer treatment, you will have an appointment with your Consultant/Clinical Nurse Specialist, who will review your diagnosis, treatment and any possible side-effects.

You will have a discussion about any signs and symptom you need to watch out for and the arrangements for regular PSA tests. Your Consultant will tell you exactly how often you need to have these done, but it will usually be every 6 to 12 months, depending upon the treatment you have had and your progress beyond this point.

Monitoring your test results
Your Consultant/CNS will monitor your PSA blood test results and your results will be fed back to you by letter, text or telephone (delete as appropriate) you will only be called back to hospital if it is felt you need further tests or investigations. PSA levels are recorded and monitored and if the PSA level rises above what is normal for you, the Consultant or CNS will contact you to discuss these results and, if necessary, ask you to return to hospital for a clinic appointment.

You will continue to have regular blood tests, but will only be brought back in to hospital for an appointment if your PSA level shows a sustained or worrying rise or you have symptoms which require further investigation. If you have any concerns, please contact the Helpline on XXXXXXXX which is available Monday-Friday 9am-5pm.

When your PSA test is due, you will receive a letter from your Consultant/CNS with a blood form (this will vary from Trust to Trust) asking you to book yourself a blood test with your hospital.
About PSA (Prostate Specific Antigen) levels
The best way of identifying that you may need more treatment for your prostate cancer related problems is through a ‘PSA test’. This is a simple blood test which can be taken at your GP surgery or Trust Name. PSA is a protein made by the prostate gland, which naturally leaks out into the blood. The PSA test measures the level of PSA in your blood. Sometimes a raised PSA level can be a sign of prostate cancer or its return. However, it can be caused by something less serious like:

- an infection
- exercise
- ejaculation

Following the PSA test, your blood sample is sent to the Trust Name pathology laboratory for checking and the results will be reviewed by the Consultant/CNS. If the PSA results are within the range that is normal for you, you will receive a letter from the Consultant/CNS confirming this and telling you when your next PSA test will be due. You will not be routinely called for a follow-up appointment at the hospital if your PSA levels are normal and you are symptom-free.

If your Consultant/CNS is concerned about your PSA level, they will telephone you to discuss this with you and will send you a letter offering the first available clinic appointment.

Exercise, such as long-distance running or cycling, or sex may raise PSA levels and patients should not have:

- prolonged exercise 48 hours before the PSA test or
- sex 48-72 hours before the PSA test

**Signs and Symptoms to report:**
The following is a list of the signs and symptoms which you need to keep in mind following your treatment for prostate cancer. These symptoms could indicate a return or spread of the disease and need further investigation. If you experience any of these or have any concerns, please contact the Helpline on XXXXXXXXX. Your CNS will phone you back within 2 working days of you leaving your message. The Helpline is available Monday to Friday, 0900-1700.

- Stiffness or frequent soreness in areas such as the lower back, hips and thighs
- Swelling in the legs or pain in the pelvic region.
- Bone pain that doesn't stop.
- Unexplained weight loss

Obviously everyone is different and it is you who knows your body best, so we would much rather you telephoned the Helpline with a concern that turned out to be nothing, than have you sitting at home worrying. The sooner you share your symptoms or concerns with us, the quicker we can resolve the problem.

**Helpline: XXXXXXXXX**
There is a dedicated Helpline (XXXXXXXXX), which you can telephone and leave a message if you have any concerns about your prostate cancer or are suffering from one or more of the symptoms listed below. Please do not wait until your next PSA test is due before contacting the Helpline. Often patients delay reporting symptoms or problems until their next clinic appointment, particularly if this is not too far away. It is much better to investigate symptoms as soon as they are noticed.

The Helpline is checked for messages between 0900 to 1700 Mondays to Fridays and your CNS will phone you back within 2 working days of you leaving your message. If, as a result of this discussion with you, your CNS thinks that you need to come back into clinic, you will be offered the first appointment available.

**Benefits of supported self-management**

- You will not have to make unnecessary trips to the hospital at times when you are symptom-free and getting on with your life.
- You can phone the Helpline at **Trust Name** (Monday-Friday 9am-5pm) with any concerns or symptoms relating to your prostate problems in between appointments and receive a call back from your CNS within 2 working days.
- You no longer have to take time off from work or pay travelling or parking charges for out-patient appointments that you don’t need.
- You should receive an improved experience of care, with the advantage of a Helpline you can ring.

**Please remember**

- If you are experiencing any of the symptoms listed above, please phone the Helpline as soon as possible on XXXXXXXX.
- If you are asked to return for a clinic appointment and are unable to make the date and time given, please telephone the **Name of Trust** outpatient department on xxxxxx to rearrange the appointment.
- Telephone messages to the Helpline will be monitored Monday to Friday 9am to 5pm. They will not be picked up at weekends or on bank holidays. If you have a prostate-related emergency occurring at the weekend or on a bank holiday, you will need to contact your out of hours GP service or your local Accident and Emergency (A&E) Department.

Created:
Review date:
Appendix D: GP information leaflet on supported self-management
Why have I received this leaflet?
You have been sent this leaflet to explain the Stratified Pathway Follow-up model which Trust Name are introducing for patients who have completed treatment for prostate cancer and will be supported to self-manage their health. They will have PSA tests to monitor their condition.

What is supported self-management?
Patients are stratified according to the staging of their cancer, risk of recurrence, late effects and their ability to self-manage their follow up care. Men with stable prostate cancer can be monitored without coming back to the hospital for follow up appointments.

How does supported self-management work?
1. When a patient has completed their treatment at Trust Name and their PSA is stable, they will have a consultation with the Consultant or CNS. They will be provided with information about future tests and the signs and symptoms to report.
2. A letter will be sent to the patient and his GP telling him when to have his PSA blood test—with/without a blood form.
3. Bloods will be taken at the hospital.
4. Results will be communicated back to you and your patient.
5. Depending on the results and underlying PSA trend, the patient will either continue on remote follow-up, or be recalled to a Consultant clinic for further investigation within 14 working days.

What other support is available?
There is a dedicated telephone helpline to enable patients or their GPs to report any symptoms of concern and receive prompt telephone triage and advice from the Consultant. Patients are guaranteed a Consultant clinic appointment within 14 working days of phoning the helpline, if their symptoms require urgent investigation.

What are the benefits of this follow-up model?
- Significant reduction in the number of unnecessary follow-up appointments freeing up clinic time for new prostate cancer patients
- Removes the need for patients to make unnecessary trips to hospital
- Dedicated support line for prostate cancer patients and their GPs, with Consultant/CNS telephone triage.
- Fast-track recall process for those patients who need to be seen back in hospital
- Improved care experience for patients
- Improved clinical governance around the monitoring of prostate cancer patients’ PSA levels, enabling problems to be identified and responded to earlier.

When will the model be introduced?
The model will be introduced within Trust Name from XXXX for those patients who have completed treatment for prostate cancer.

From XXXXX, the programme may be extended to other groups of prostate cancer patients who attend Trust Name for follow-up purposes.

Is further information available on this programme?
Yes. This is simply a brief introduction to the new follow-up programme. We have developed detailed guidelines in support of the programme. If you would like to receive any of this information, please email Trust contact/Project Manager.
Signs and Symptoms to report:

The following is a list of the signs and symptoms which you need to keep in mind when treating patients who have previously had prostate cancer. These symptoms could indicate a return or spread of the disease and need further investigation.

- Stiffness or frequent soreness in areas such as the lower back, hips, and thighs
- Swelling in the legs or pain in the pelvic region.
- Bone pain that doesn't stop, bone fractures and spinal compression.
- Unexplained weight loss

Information for GPs:

Supported self-management Follow-Up for prostate cancer

Please note: This will not change what you are already doing as a GP, but is a major improvement to patient safety.
Living with and Beyond Cancer Board

IT Remote Monitoring System: Functionality requirements and options appraisal

Sharon Cavanagh
December 2015
Introduction

Integral to the successful implementation of stratified model of follow-up is the setting up of a robust IT remote monitoring system. Remote monitoring assists the specialists to schedule and review surveillance tests for patients who have completed treatment for cancer, without the need for a face to face outpatient appointment to convey the result. Its primary role is to support low risk patients treated with curative intent who are suitable to be supported on a self-managed pathway. Therefore, a key enabler for testing and implementing stratified pathways of care is access to a safe reliable IT system that enables clinicians to schedule and monitor surveillance tests (such as mammograms, CT scans, colonoscopies).

Functionality requirements of the remote monitoring system

Stratified follow-up national pilot sites have identified the required functionality of IT systems to ensure that remote monitoring can effectively take place. The system needs to house sufficient information to enable the clinician to manage the patient without the need to access case notes.

Other functions of the system are as follows$^2$:

1. To pull patient data set information from PAS via the local cancer information system
2. To pull test results from local diagnostic IT systems
3. To store key diagnostic and key patient history data
4. To log any relevant treatment history during monitoring period including a log of patient contacts
5. To set individual patient range/tolerances for specific tests
6. To schedule tests based on user definable follow up schedules
7. To hold a range of template letters to enable communication of results to patients and GPs by post or electronically
8. To include an alert system that identifies test results for review, due dates exceeded or test result that exceed tolerance
9. To provide a summary history and treatment page with test results shown numerically and graphically to record the outcome of any event or test
10. To provide standard and ad hoc reporting and routine monitoring function and be amenable to clinical audit
11. To be NHS and HL7 compliant with secure access
12. To use a common file format for all data export to be able to import the data into local IT systems if required

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Options Appraisal

In addition to defining the functionality, NHS Improvement developed an options appraisal for services to make local decisions with regards to how to best take this forward. This information was published in 2013 in a document titled “Innovation to implementation: Stratified pathways of care for people living with or beyond cancer - A ‘how to guide’”. We have outlined these options below.

Option 1 - Use functionality within existing IT systems

Many IT systems have scheduling and monitoring systems available within them and may only require small adjustments to accommodate the needs for remote monitoring. IT leads or system providers will be able to provide advice on the local system capability. For example, CIMS (Clinical Information Management Systems) who supply InfoFlex have developed remote monitoring capability within their system.

Pros
- Existing familiarity of use with staff.
- Fewer interface requirements than other options.
- On-going support through existing service contracts.
- Send and receive data capability.
- Flexibility to suit local needs, e.g. audit.
- Speed of implementation.
- Less likely to require business case approval.

Cons
- May require additional licenses.
- Existing staff often do not utilise local IT system.
- System provider consultancy costs to support implementation.

Option 2 – Develop a bespoke remote monitoring solution

This suits organisations where there is local IT development team skill and capacity or local restrictions on use of external software.

Pros
- Local ownership and development.
- Fit with existing IT architecture.
- No external maintenance costs.

Cons
- Long lead in time for development (allow three months from approval and three months to test and implement).
- Existing IT workload can delay development and implementation.

Option 3 – National Cancer Survivorship Initiative (NCSI) solution

NHS Improvement, North Bristol NHS Trust (NBT), Royal United Hospital Bath and national clinical advisors have developed a remote monitoring solution to support prostate and colorectal cancer. Both modules are designed to interface with the local cancer registry and diagnostic systems such as pathology, radiology and endoscopy systems. Within each module the specialist can view all their patients with a diagnosis of prostate or colorectal cancer. Once selected for enrolment to...

a self-managed pathway, the specialist enters diagnostic details, treatment and relevant drug therapy, comorbidity and any other relevant information. Test results are automatically drawn into the modules and displayed numerically, graphically or as text. Standard outcome letter templates are generated from the system to send to the patient and the GP. Maintenance and development of the NCSI system is available to sites through a service level agreement (currently £5,000 per annum) with North Bristol NHS Trust. Assistance with local installation is also available on request.

Pros
- Available to any NHS organisation.
- Capable of interface with any IT system.
- No license issues.
- Remote installation of system including any future upgrades.
- Recent upgrade (March 2013).

Cons
- Importing external solutions may not align with local IT strategy.
- Requires server capacity.
- ‘Virtual clinics’ are still required on PAS to capture activity data.
- Annual cost of £5000.

Option 4 – Primary care solution

Examples exist of primary care based IT systems for monitoring surveillance tests. Whilst these have not been tested by the NCSI there are systems available as an option for those considering a primary care based solution.

Pros
- Care transferred closer to home.
- Potential reduction in cost to commissioners.
- Releases maximum capacity within secondary care.

Cons
- Not viable by individual practice due to the small patient numbers. A clinical commissioning group option might be feasible.
- Professional education required to establish and maintain disease knowledge base.
- Reaching GP consensus to manage surveillance tests.
- Less immediate access to specialist for advice on abnormal or equivocal results.
- Manual entry of enrolment data.

Option 5 – National breast screening system (NBSS) – mammography only

Set up a parallel recall system for breast cancer patients who require annual mammograms. This is the same as, but separate to, the national breast screening programme and mirrors the model set up for managing high risk familial patients who require annual rather than three yearly mammograms.

Pros
- Excellent clinical governance.
- Very low risk of patients being missed as processes, system and staff involved are the same as those delivering the national breast screening service.

Cons
- Limited use as does not link to radiology information systems.
- Set up and license costs.
- Implementation more difficult for non-screening sites.
- System cannot be adapted without NBSS approval.
• Unsuitable for use through mobile units.

Contact: David Soloman at Temenos for further information on this option dsolomon@temenos. Temenos are the IT suppliers for the national breast screening system.
Supported Self-management Follow-Up for Prostate Cancer Patients

Today’s Date:

Patient Name: DOB:

Hospital Number: NHS Number:

Dear Dr ..........................................................

After having treatment for prostate cancer at Trust Name, insert patient name has stable prostate cancer and has now transferred onto our supported self-management 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, and possible side effects
- Signs and symptoms to report
- 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.

As part of your patient’s ongoing care, they will need:

☐ Annual/six monthly PSA tests for a period of 5 years. The patient will be contacted directly with an appointment and results fed back to you and the patient.

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

At the end of 3 years, insert patient name will be discussed in a virtual MDT in order to update any ongoing treatment regimes in light of latest evidence. 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 trust supported self-management pathway.

For any queries, please contact our Prostate Cancer Team on insert specialist team number.

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

Name (please print) ..................................................................

55
Dear Dr X

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

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Date of Diagnosis:</th>
<th>Organ/Staging</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Local/Distant</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Summary of Treatment and relevant dates:</th>
<th>Treatment Aim:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Possible treatment toxicities and / or late effects:</th>
<th>Advise entry onto primary care palliative or supportive care register</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DS 1500 application completed</th>
<th>Prescription Charge exemption arranged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alert Symptoms that require referral back to specialist team:</th>
<th>Contacts for re referrals or queries:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In Hours:</td>
</tr>
<tr>
<td></td>
<td>Out of hours:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Care Ongoing Management Plan: (tests, appointments etc.)</th>
<th>Other service referrals made: (delete as nec)</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>District Nurse</th>
<th>AHP</th>
<th>Social Worker</th>
<th>Dietician</th>
<th>Clinical Nurse Specialist</th>
<th>Psychologist</th>
<th>Benefits/Advice Service</th>
<th>Other</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Recommended GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Summary of information given to the patient about their cancer and future progress:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Additional information including issues relating to lifestyle and support needs:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Completing Doctor:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

GP READ CODES FOR COMMON CANCERS (For GP Use only). Other codes available if required. (Note: System codes are case sensitive so always ensure codes are transcribed exactly as below).
<table>
<thead>
<tr>
<th>System 1 (5 digit codes)</th>
<th>All other systems</th>
<th>Version 3 five byte codes (October 2010 release)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Lung Malignant Tumour</td>
<td>XaOKG</td>
<td>Malignant neoplasm of bronchus or lung</td>
</tr>
<tr>
<td>Carcinoma of Prostate</td>
<td>X78Y6</td>
<td>Malignant neoplasm of prostate</td>
</tr>
<tr>
<td>Malignant tumour of rectum</td>
<td>XE1vW</td>
<td>Malignant neoplasm of Rectum</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78gK</td>
<td>Malignant neoplasm of Colon</td>
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<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female prostate</td>
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<tr>
<td>Female Malignant Neoplasia</td>
<td>B34..</td>
<td>Malignant neoplasm of male prostate</td>
</tr>
<tr>
<td>Male Malignant Neoplasia</td>
<td>B35..</td>
<td></td>
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<td><strong>Histology/Staging/Grade:</strong></td>
<td><strong>Histology/Staging/Grade:</strong></td>
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<tr>
<td>Histology Abnormal</td>
<td>4K14.</td>
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<tr>
<td>Tumour grade</td>
<td>X7A6m</td>
<td>Tumour staging</td>
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<tr>
<td>Dukes/Gleason tumour stage</td>
<td>XaOLF</td>
<td>Gleason grading of prostate Ca</td>
</tr>
<tr>
<td>Recurrent tumour</td>
<td>XaOR3</td>
<td>Recurrence of tumour</td>
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<tr>
<td>Local Tumour Spread</td>
<td>X7818</td>
<td>Metastatic NOS</td>
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<td>Mets from 1°</td>
<td>XaFr.</td>
<td>Osteoporosis</td>
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<td>Palliative Radiotherapy</td>
<td>5149.</td>
<td>Radiotherapy tumour palliation</td>
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<tr>
<td>Curative Radiotherapy</td>
<td>XalpH</td>
<td>Radiotherapy</td>
</tr>
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<tr>
<td><strong>Treatment</strong></td>
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<tr>
<td>Curative procedure</td>
<td>Xallm</td>
<td>Curative treatment</td>
</tr>
<tr>
<td>Palliative procedure</td>
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<td>Palliative treatment</td>
</tr>
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<td><strong>Treatment toxicities/late effects:</strong></td>
<td><strong>Treatment toxicities/late effects:</strong></td>
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<td>Osteoporotic #</td>
<td>Xa1TO</td>
<td>At risk of osteoporosis</td>
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<td>XaELC</td>
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<tr>
<td>Infection</td>
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<tr>
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<td><strong>Ongoing Management Plan</strong></td>
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<td>Follow up arranged (&lt;1yr)</td>
<td>8H8..</td>
<td>Follow up arranged</td>
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<td>Follow up arranged (&gt;1yr)</td>
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<td>No follow up arranged</td>
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<td>Tumour marker monitoring</td>
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<tr>
<td>----------------------------</td>
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<tr>
<td>New medication started by specialist</td>
<td>XEOhn</td>
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<tr>
<td>Advice to GP to stop medication</td>
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<tr>
<td>Unaware of prognosis</td>
<td>XaVzE</td>
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<tr>
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<td><strong>Miscellaneous:</strong></td>
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<td>On GSF Palliative Care Framework</td>
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