



# **Desktop review of Prostate Cancer UK Funded Projects in London**

A report by Transforming Cancer Services Team for  
London, with support from Prostate Cancer UK

January 2016

<b>Contents</b>	<b>Page</b>
1. Executive summary	3
2. Introduction	6
3. The projects	9
4. Headline findings	11
5. Discussion	11
6. Recommendations	25
7. Conclusion	26
8. References	28
9. Appendix 1: Headline findings	31

## 1. Executive summary

This report provides an overview of projects that have been funded by Prostate Cancer UK in London as part of the Health and Social Care Professionals Programme. The programme, funded by Royal Mail and The Movember Foundation, provides funding for nurses and allied health care professional roles to test new models of care. The programme builds on the National Cancer Survivorship Initiative and aims to ensure that men affected by prostate cancer have access to the specialised care they need across primary, secondary and tertiary care.

Prostate cancer is the most common cancer in men in the United Kingdom (Office for National Statistics, 2013) and with improved treatments there are increasing numbers of men surviving (Cancer Research UK, 2015). In London there are 28,110 men living with prostate cancer (Macmillan/NICN, 2015) and the largest numbers of men are 5-10 years post treatment. With this in mind providing effective aftercare for an increasing number of men will be challenging unless alternative models of care are developed.

The national initiative to provide alternative pathways for follow-up after treatment rather than traditional hospital outpatient care aims to improve the quality of care whilst also freeing up secondary capacity for diagnosis and treatment of new patients (National Cancer Survivorship Initiative 2013). The recovery package is an important part of this process with the provision of holistic needs assessment, health and wellbeing events treatment summaries and cancer care review in primary care (NHS improvement 2012).

The development of a number of differing follow-up pathways across London therefore provides commissioners (Clinical Commissioning Groups and Strategic Planning Groups) with an increased choice of possible pathways to commission for their patients with prostate cancer. The purpose of this report is to provide information to commissioners about the PCUK funded projects in London, which in turn can be used to support commissioning of prostate cancer follow up pathways locally. Components of an ideal pathway are outlined on page 24.

This report reflects on these different models and provides available outcome data at the time of publication (January 2016).

## Findings

There are a number of innovative projects which are testing a range of interventions that provide evidenced based and high quality care to men before, during and after treatment for prostate cancer. All of the projects were able to deliver some or all of the aspects of the recovery package. For example, the provision of holistic needs assessments is far higher in the project sites than in current traditional secondary care follow-up.

Patient satisfaction with the pathways, from the data that has so far been made available, is positive. There is good outcome data from the projects. Improvements have been demonstrated in quality of life scores, as well as improvements in reducing some of the side effects of treatment as a consequence of targeted interventions. This is demonstrated by the integrated rehabilitation service at Bart's Health NHS Trust and St Joseph's Hospice.

There are risks to developing new models of follow-up. The Croydon primary care project identified the risks of transferring care out of secondary care without properly planning the pathway (patients lost to follow-up, misinterpretation of PSA values).

Conversely the same project is demonstrating that care can be safely transferred when structures and processes are put in place. Other risks include continuation of projects when pilot phases end.

## Recommendations

- CCGs to consider their local population's need, service provision, local commissioning arrangements and workforce issues, when making decisions regarding models of follow-up care for patients with prostate cancer
- Transforming Cancer Services Team (TCST) to fully cost an enhanced follow-up pathway that encompasses good practice demonstrated in the Prostate Cancer UK funded projects. This includes the provision of all aspects of the recovery package, access to rehabilitation services when required, and a local incentive scheme for primary care to ensure on-going delivery of high quality care.
- Providers and commissioners need to consider the transfer to primary care for the majority of the patients in follow-up after treatment for prostate cancer. The timing of

this will vary depending on local agreement and treatment modality, but it is essential that this is planned for to ensure the smooth and safe transition of patients.

## Limitations

Following discussions with the Prostate Cancer UK funded projects and commissioners in London; the need for information on the differing models of follow-up was identified as a priority before 2016/2017 commissioning decisions were made. This desktop review was therefore conducted **before** the completion of all the funded projects across London and therefore full evaluation data was not available for all projects. Data used for the review was provided by Prostate Cancer UK.

Provisional / early outcome data was therefore used in these instances to make the comparisons.

## 2. Introduction

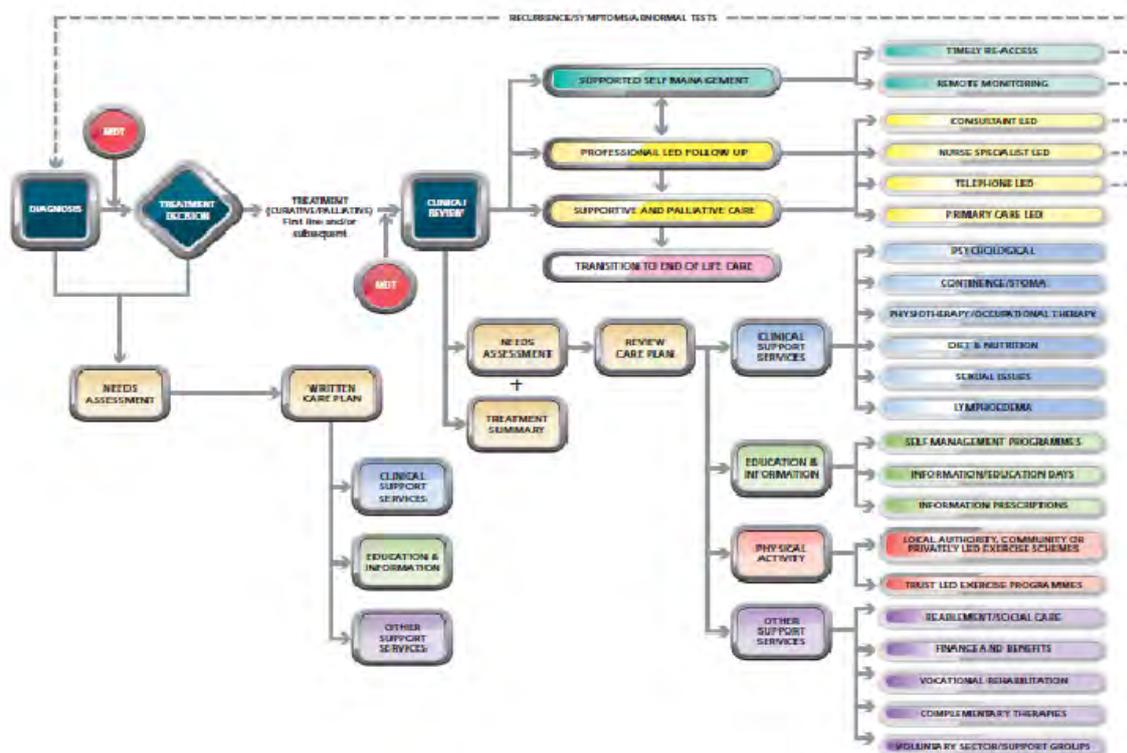
Prostate cancer is the most common cancer in men in the United Kingdom (Office for National Statistics 2013) and with improved treatments, there are increasing numbers of men surviving this disease (Cancer Research UK 2015). In London there are 28,110 men living with prostate cancer (Macmillan/NICN 2015) and the largest number of men are five – ten years post treatment Yip et al (2014) confirm that the majority of men in the United Kingdom with prostate cancer are in the post treatment, monitoring phase and conclude that providing effective aftercare will be challenging unless alternative models of care are developed.

A national initiative to provide alternative pathways for follow-up after treatment to traditional hospital outpatient care aims to improve the quality of care whilst freeing up secondary capacity for diagnosis and treatment of new patients (National Cancer Survivorship Initiative 2013). The initiative to develop alternative models of care for follow-up is supported by NICE (2014) who advise that patients can be managed outside of the hospital setting if they are stable 2 years post radical treatment or on a watchful waiting pathway.

The development of a number of differing follow-up pathways across London provides commissioning groups with an increased choice of possible pathways to commission for their patients with prostate cancer. The NCSI risk stratified options are shown in Figure 1 and include remote surveillance, consultant led care, nurse led care, telephone follow-up and primary care led follow-up.

This desktop review was prompted by a request from commissioners for more information about the differing models of follow-up.

Figure 1 NCSI Stratified pathway: Prostate cancer



The problem of unmet needs in patients living with and beyond cancer is well evidenced. Macmillan estimates that 500,000 people in the United Kingdom have one or more physical or psychosocial consequence of their cancer or treatment that affects their lives on a long term basis (Macmillan 2013). Addressing these unmet needs is therefore an integral consideration when redesigning services.

Figure 2 below depicts principles for commissioners to adopt in order to address Supportive / holistic needs.

**Figure 2: General recommendations to everyone involved in redesigning services and support for people living with and beyond cancer:**

- **Prevent** or minimise consequences of cancer and its treatment where possible, through healthier lifestyle choices, better surveillance, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
- **Inform** patients of potential consequences of cancer and its treatments, with simple strategies for self-management, and the value in taking early action and how to seek appropriate help.
- **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential consequences so they can be easily anticipated, recognised and monitored in primary care.
- **Assess** potential consequences through regular Holistic Needs Assessment, the use of 'power' questions and Patient-Reported Outcome Measure (PROM) tools at regular time points.
- **Support** patients through local care pathways for the consequences of cancer and its treatment, which include support for self-management and referral to appropriate specialist services.

Macmillan (2013)

### Prostate Cancer UK health and social care professional programme

Prostate Cancer UK with support from the Movember Foundation and Royal Mail have funded nurses and allied health professionals through the NHS and other health organisations to test new models of care. This builds on the work of the National Cancer Survivorship Initiative and aims to ensure that men affected by prostate cancer have access to the specialised care they need across primary, secondary and tertiary care

Transforming Cancer Services Team for London and Prostate Cancer UK have worked together to develop this desktop review of the London Projects with the aim of demonstrating their key features. The projects cover a range of models which match the NCSI descriptions of secondary care nurse led; telephone follow-up, remote monitoring, primary care led, as well as AHP led models which focus on rehabilitation and survivorship.

The Health and Social Care (HSCP) programme is a national programme with 59 professionals funded working on 45 projects. This report focuses on the London based project, for more information for projects in other areas please visit - [prostatecanceruk.org/healthroles](http://prostatecanceruk.org/healthroles)

### 3. The Projects

#### North West London Hospitals Trust (NWL)

##### **Community Clinical Nurse Specialist**

Working with an established team of Specialist Nurses, the role of the community CNS was developed to ensure that risk stratification and revision of follow-up will become an embedded process. The project also focused on the review of the information and support needs of patients at key stages of the cancer pathway with particular attention to end of treatment and rehabilitation after cancer.

***Project theme: new pathway; risk stratification; survivorship***

#### Transforming Cancer Services Team for London, South East CSU (TCST/Croydon)

##### **Clinical Nurse Specialist, GP with special interest**

Working in partnership with primary care, the CNS has developed and tested a holistic-needs based follow-up service for prostate cancer patients who are stable at two years after radical surgery and those who are undergoing 'watchful waiting'. This new follow-up model has shifted care from secondary to primary care and improved patient experience and outcomes by embedding the holistic needs assessment as part of the follow-up service. Training and development for primary care professionals within the prostate follow-up system has been provided.

***Project theme: new pathway; GP engagement; health professional education***

## Royal Marsden NHS Foundation Trust (RMH)

### Senior Physiotherapist, Clinical Nurse Specialist

The project will transform the clinical follow-up model for patients with localised prostate cancer. It will ensure patients have access to health and well-being events and webinars streamed through the use of a web-based tool that includes preventative advice for pelvic floor dysfunction and the role of diet, lifestyle and exercise in rehabilitation.

The pathway will ensure men have access to

- Sign-posting to community based supportive services
- Rapid re-access for primary care referrals

There will also be an education programme developed to support practice nurses and primary care to manage post treatment symptoms and to develop a robust follow-up process

***Project theme: new pathway; with a focus on pelvic dysfunction***

## UCL Partners / London Cancer and Barking Havering Redbridge Universities Trust (BHRUT/UCL)

### Prostate Cancer Navigator

A primary care based Prostate Cancer Navigator acted as a key support system for patients and their family/carers from the point of diagnosis. The navigator is a conduit and mainstay between the patient, GP, specialist centre, local hospital, and community social services and has a central role in developing a prostate cancer community practice for patients.

***Project theme: new pathway; survivorship; health professional engagement***

## Bart's Health NHS Trust and St Joseph's Hospice (Bart's)

### Physiotherapist; Rehabilitation Assistant

A comprehensive, integrated rehabilitation service which is tailored to meet the needs of prostate cancer patients throughout the disease pathway has been developed. This includes providing access to information and raising awareness of services available; optimising patients physical functioning and addressing specific problems such as continence, erectile dysfunction and fatigue; and providing holistic palliative support for patients and carers.

***Project theme: new/improved service; patient education; physiotherapy, pelvic dysfunction; African Caribbean***

## **Guy's and St Thomas' NHS Foundation Trust (GSTT)**

### **Clinical Nurse Specialist, GP with special interest**

A shared-care survivorship model has been established to improve the follow-up pathway for patients and ensure a smooth and safe transition of care from primary to secondary care. Patients are offered tailored support and tools to manage their condition after cancer to lead as healthy a life as possible. Pre-treatment and post treatment seminars (information days) provide patients with information as well as peer support.

***Project theme: pathway redesign; survivorship; patient education***

## **The Hillingdon Hospital Trust**

### **Clinical Nurse Specialist**

This CNS has managed the transition of patients onto the new remote monitoring system ensuring that it is clinically robust and staff are trained in its use. The role has coordinated Health and Well Being Days for patients and facilitates meetings with health professionals to improve the services and support men receive on survivorship issues such as erectile dysfunction and incontinence.

***Project theme: remote monitoring/support; survivorship; patient and health professional education***

## **4. Headline Findings**

See Appendix 1 for a table of the headline findings from the projects.

## **5. Discussion**

This report started life as a compare and contrast of the differing models of follow-up across London through the comparison of the Prostate Cancer UK funded projects. Once the process of comparison was underway it became apparent that the projects focused on different parts of the patient pathway with differing outcomes. This made the contrast and comparison difficult. The focus of the report therefore was adjusted to review the differing

models in order to identify the key features of an ideal pathway, following diagnosis and decision on treatment for prostate cancer, in order to guide commissioners.

### **Project Clinical Lead Role**

The majority of services were nurse or allied health professional led. This contrasts with the traditional model of secondary care follow-up led by a Urologist. Nurse led follow-up of stable patients with prostate cancer within secondary care is an established practice in many trusts with a good evidence base for efficacy, safety and acceptability for patients (Cox and Wilson 2003).

Recruitment was noted as a potential barrier by many of the projects when they were in the planning phase. This was in terms of finding an appropriately experienced and skilled clinician to fill the role. Prostate Cancer UK funded research has identified a shortage of Specialist Nurses for prostate cancer with 49% of the current workload due to be eligible to retire over the next 10 years (Prostate Cancer UK 2014). In addition the report highlighted a lack of a formal training route for the role with only 48 of 285 nurses (17%) stated they came in to specialist nursing through a development role. The numbers of Specialist Nurses for prostate cancer in England (Clinical Nurse Specialists) is low compared to other common cancers such as breast (Macmillan 2014).

### **Location of service**

The projects were mostly secondary care based, with the exception of the TCST/Croydon primary care model. Although the other projects were secondary care based there was a focus on community/primary care in a number of the projects. This ranged from involving primary/community colleagues to be involved in health and wellbeing events, to providing outreach or shared care services into the community and having primary care clinicians as part of the team (e.g. Guys and St Thomas's project).

Most patients in secondary care in nurse led follow-up or on remote surveillance will be discharged to primary care at some point. Currently there is no national guidance or consensus on the length of surveillance after treatment and therefore patients are followed up for life after radical treatments unless they default from their follow-up programme. Therefore there needs to be consideration and planning for the smooth transition to primary care follow-up whether this is at year one, two or ten post treatment. All of the secondary

care post projects included the provision of a treatment summary to the GP at the end of active treatment. There was variability in the timing of transfer of care to primary care.

### Remote surveillance tools used

PSA tracker software was used in the Hillingdon project. Tracker software enables trusts (or other providers) to monitor a large cohort of patients with alerts set for rising PSAs. Systems are also available for primary care providers (NHS improvement 2013).

The risk of misinterpretation of results is reduced (Hennessey et al 2013) and it is used in a number of centres in the UK to monitor patients post treatment. There remains the need to keep the database up to date which may be more challenging if there is a transient population. There is a cost consideration to purchasing the software and integrating this with the organisation's electronic patient record system and subsequent software upgrades and maintenance and cleansing of the data needs to be considered. There also needs to be consideration of the administration time required to ensure that the data remains up to date.

### Elements of the recovery package

All of the projects delivered some or the entire recovery package (see headline findings).



Copyright © Macmillan Cancer Support 2013  
Permission granted for use as seen, this notice must remain intact in all cases. All rights reserved.

The rates of HNA completion in London for prostate cancer at end of treatment in 2014 were 2-6% (source: data reported by LC and LCA 2014). There are well evidenced unmet needs for patients living with and beyond prostate cancer from patient reported outcome measures (Quality Health 2013). For example 26 % of patients had urinary symptoms that limited their activity, 62 % could not maintain an erection (5 years after treatment). The offer of a holistic needs assessment as an integral part of a follow-up model/pathway allows identification of unmet needs on an individual basis and referral on to appropriate services/ signposting can be triggered. All the projects offered an HNA assessment as a standard part of the pathway.

The recovery package interventions have been included in London's acute commissioning intentions every year since 2012/13. Acute providers are expected to implement all interventions that relate to their services (Holistic Needs Assessment, Treatment Summaries, and Health and Wellbeing Events) in parallel so that patients receive a package of care without variation.

The patient navigator role piloted by Barking, Havering and Redbridge was able to bring several elements of the recovery package together through the flexibility of the role. HNAs were carried out (mostly outside of the hospital environment) and a local support directory enabled the post holder to direct patients appropriately to relevant services. The sharing of a treatment summary and the HNA outcomes enabled meaningful information to be shared with primary care. Additionally sharing the HNA with primary care at the point of diagnosis improved the quality of information available at the cancer care review in primary care. The assessment and planning process for holistic needs therefore had the potential for being a meaningful process rather than a one off event.

Similarly, the primary care pathway developed in the TCST/Croydon project provides primary care with a tailored 'HNA' tool which may be more useable in a time pressured primary care setting. Again, if there is sharing of the HNA at the point of transfer of care, the assessment / review of unmet holistic needs then becomes an on-going process. Patient experience data from the TCST/Croydon project suggests that patients appreciated the opportunity to discuss their holistic needs rather than only their PSA result within the consultation and the primary care professionals found that the tool added some structure to their consultations.

Two of the projects had a component of rehabilitation (Bart's Health and Royal Marsden projects). Rehabilitation being the restoration, to the maximum degree possible, of an individual's function and/or role, both mentally and physically, within their family and social networks and within the workplace where appropriate (NHS Improving Quality 2014)<sup>i</sup>. There is a growing evidence base to promote exercise as part of recovery and reduction in reoccurrence of cancer (Macmillan, 2012). Findings from two studies indicated a lower risk of prostate-specific mortality of approximately 30% and a lower rate of disease progression of 57% with three hours per week of moderate intensity activity (Macmillan, 2012 and Richman et al, 2011.) There is also a role for rehabilitation services in addressing some of the consequences of prostate cancer treatment, for example fatigue and lower urinary symptoms after prostate cancer treatment (Whitney, 2015). A scoping exercise in North East London (Whitney, 2014) demonstrated a lack of referrals of men with prostate cancer by professionals to local rehabilitation services, and a subsequent lack of specialist provision.

## Outcomes and benefits to patients

At present a full evaluation is available for the Bart's, Guys and Hillingdon projects, a summary of which is outlined below. The Croydon primary care project is currently being evaluated. Patient experience is generally good (Figure 4 below).

### The Bart's Project (Figure 3)

A specialist physiotherapist offering both health and wellbeing clinics and individual physiotherapy sessions for men experiencing physical impairment demonstrates the following outcome data:

- 17% increase in self-reported global health score
- 57% improvement in lower urinary tract symptoms from moderate to mild
- 209% increase in individual physical activity
- 17% decrease in urinary incontinence
- 25% increase in confidence in self-managing side-effects post intervention (and maintained up to six months later)
- 45% decrease in unscheduled GP visits and 100% decrease in hospital admissions over six months
- £3,160 per QALY gained

Source: Whitney 2015

### Hillingdon Project (Figure 4)

- More follow up of patients (with stable PSA) have been moved to nurse led clinics/PSA Tracker which has freed up more clinic slots for patients.
- Over 90% of patients who have been transferred to the new remote monitoring system (PSA Tracker) and the nurse led clinics (face to face/telephone) reported a high satisfaction level
- More patients have been directly referred to LUTS/ED clinics with an immediate positive outcome, and more men are receiving referral to other survivorship services. Of the 29 men assessed who had been referred to LUTS clinics 19 showed improvement and of the 12 referred to ED clinics 10 patients showed improvement.
- Nurse led telephone clinics cost £25.77 per session compared to the £67.43 clinician clinic, which is restricted to only two follow up consultations. The introduction of this service has enabled more men to be followed up in nurse led clinics with access to clinician clinics if required. Full costs savings of the introduction of this service and CNS clinics are being assessed.
- Health and Wellbeing days received a positive evaluation from the men who attended

### **Croydon Project: (Figure 5)**

Patient's comments at the point of transfer to primary care:

"Pleased, Because of feeling as if at home"

"Pleased, because the surgery is closer"

"I was pleased to know my condition would be reviewed on a regular basis"

"The GP continually assessed my PSA which was normal. I was reassured."

"Pleased, I felt I am free of remission for the cancer"

Clinician's comments on the resources to support them in delivering follow up to patients:

81 % of clinicians surveyed found the follow up template for EMIS/VISION very helpful or helpful

"The template is excellent, very useful links to support services/information"

The follow up includes questions about sexual function, urinary symptoms, bowel control, as well as mood, ability to carry out activities of daily living and prompts for lifestyle interventions ( exercise, diet etc.).

84% of clinicians stated that patients did not bring up any subject they found difficult to deal with.

The BHRUT/LC project is due to complete its evaluation early in 2016. They have preliminary patient satisfaction data that is outlined below in figure 5. This demonstrates high rates of patient satisfaction. The majority of patients were seen in a location closer to home and the data demonstrates a significant improvement in quality of life scores for those men using a validated tool.

**Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT)/ London Cancer: (Figure 6)**

## Patient benefits/outcomes

To date, 124 men have been supported by the Survivorship Navigator in the following settings:

- 95% of men have been supported at home or in community drop-in clinics.
- 5% of men have attended the cancer information centre for their assessment.
- All of these men have been offered an HNA and 50% (62) have accepted this offer and received an HNA at end of treatment.

The Survivorship Navigator has shown to have the following impact:

- 80% of those surveyed reported improved communication and access to information following input from the navigator role.
- FACT-P results indicate an increase in Quality of life (QOL) from under 70 to over 100 in 40% of men receiving navigator input and support. Improvements noted particularly in areas of emotional and physical wellbeing.
- Of the 24 men who have attended Health and Wellbeing events, 67% report accessing some form of exercise/physical activity as a result of the event. Others indicated they have benefited from advice on diet, fatigue management, continence and accessing psychology and complementary therapy services.

In addition, the Survivorship Navigator has worked with the acute trust CNS' to ensure all patients are offered an HNA following diagnosis

The projects offering health and wellbeing seminars for men (GSST, Bart's, RMH, BHRUT, and Hillingdon) had good feedback from patients. Figure 6 below indicates data from GSTT project. They provided seminars at: pre-treatment seminar sessions (all treatments), post robotic surgery seminar session (erectile dysfunction and continence), post treatment seminar session (well-being event) and a discharge seminar (all prostate cancer patients). At points in the pathway attendance at the event was mandatory for the patient to proceed to the next phase. This ensured good rates of attendance enabling patients to get the maximum benefit from the intervention.

## **GSTT Project (Figure 7)**

### **ED and Continence Seminar – 354 patients:**

- 72 % felt confident before the clinic in dealing with issues that might arise following treatment
- 98% felt more confident in coping with their recovery after attending the seminar
- 100% were satisfied with the seminar
- 4% would have preferred 3 individual appointments to discuss all of the ED/continence issues
- 97.2% felt comfortable asking any questions in a group setting

### **Discharge Seminar – 36 patients:**

- 85% felt confident before the clinic in dealing with issues that might arise following treatment.
- 100 % felt more confident in coping with their recovery following this seminar
- 100% were satisfied with the seminar
- 93% Felt comfortable asking any questions in a group setting
- 71% were confident being discharged back to their GP prior to the seminar
- 100% were satisfied with the seminar
- 79% felt more confident in coping with being discharged and self-management after
- the seminar
- 1 (7%) did not feel comfortable asking questions in a group setting.

Patient experience feedback and other data collected (e.g. quality of life) suggests that patients are receptive to having alternative models of follow-up. In the secondary care pathway redesign projects (GSTT, Hillingdon, NWL, and RMH) will have been risk stratified onto the new pathways as an integral part of their care. Patients will not therefore have experienced a 'traditional' model of follow-up prior to this for their prostate cancer care (although they may have done for other conditions.) Patients in the Croydon cohort may have been in traditional consultant led follow-up for some time before being risk stratified and transferred, and therefore would have been aware of a change in their care.

## Incidental findings

A number of the projects identified incidental findings. The TCST/Croydon project offered case finding support to practices to identify suitable patients for primary care follow-up. Croydon had a large cohort of patients already transferred to primary care as the CCG had offered a Local Incentive scheme for > 5 years for primary care follow-up. The project clinicians identified a number of patients who had become lost to follow-up in primary care (approx. 10% of the discharged patients.) prior to the service redesign.

The team were able to identify practices that had successfully and safely managed patients that had 0% lost to follow-up. These practices had effective systems in place to track patients, for example a prostate cancer register. The prostate cancer register template was shared with all practices and the maintenance of it is now a requirement for payment under the local incentive scheme.

The TCST/Croydon project also identified an issue with the misinterpretation of PSA results in primary care. An example of this is a patient who was 3 years post radical prostatectomy who had a detectable and rising PSA. The GP had referred to the generic lab reference range when interpreting the result and had therefore mistakenly coded the result as normal. The patient's transfer/discharge summary from secondary care did not give information about PSA rises and when to re-refer/ seek advice. The provision of good quality treatment summaries that clearly outline the management required in primary care and transfer information would help mitigate against such mistakes. Additionally, education for clinicians and a revised wording of lab comments have also been recommended by the project team.

GSTT project noted that previously all patients were referred to andrology, but in the last six months since this pathway has been established no new patients have been referred. This means an extra 230 patients a year can be seen by andrology or continence CNS. They also observed a reduction in telephone calls, emergency admissions and urgent appointments. Patients are discharged back to primary care quicker as ED and continence are being addressed earlier.

RMH initially had the nurses based in primary care. The project team found that the project had more success when the nurse was based in secondary care and the pathway was

reviewed by the MDT. This ensured that the whole pathway was reviewed and had support from the MDT.

## Resources developed by projects

A number of the projects developed resources specifically for their patient group. For example, the Royal Marsden has developed pre-habilitation leaflets for their patients who are undergoing radical prostatectomy. This formed a part of the pre-treatment education for the patients. For more information please contact the RMH team (details in Appendix 1)

Croydon project have developed a number of resources. These include a tool kit for primary care nurses, and a whole range of resources for primary care to support the pathway and patient information that outlines local support services and includes a holistic needs assessment that the patient can bring to subsequent appointments from the discussion. These are available from TCST and enable another CCG to 'lift' the model and implement it into their area. For more information please contact the TCST team (details in Appendix 1).

## Costs

All the projects required posts to lead and implement the pathways. The costs varied depending on number of staff and proposed grading. All the CNS posts were graded at Band 7. This is the average pay band for a CNS in England (Prostate cancer UK 2015.) Projects that required significant pathway development across organisations required a Band 8a clinician (TCST/Croydon and BRHUT).

A full economic analysis is expected for the TCST/Croydon project in January 2016. Preliminary data available suggests a primary care follow-up appointment is approximately £43 compared to £85 in secondary care which demonstrates a cost saving for commissioners (costings from Local Medical Committee and NHS tariffs). Short term investment would be required from CCGs to implement the pathway (project management) but a long term costs saving would be expected. This cost saving is demonstrated in Pearce et al's work (2015). Their work in the Republic of Ireland compared the costs of three follow-up strategies over a ten-year period. These were: hospital based follow until year 5 and then

discharge to a GP; NICE guidance recommends discharge to a GP at 2 years if stable; and European Urology Association guidance with long term hospital based follow-up.

Each follow-up schedule had slight variation in frequency of PSA follow-up but all had yearly PSA and follow-up after year 3. All patients had been treated with curative intent. The cost saving of the NICE guidance cohort was defined as 74% of the current practice cost, versus EAU guidelines which represented 92% of current cost. They show a clear costs saving following NICE guidance discharging to primary care after 2 years.

The Barts' evaluation (Whitney 2015) demonstrates a good economic case for rehabilitation services in prostate cancer follow-up. Participation in the one to one Physiotherapy intervention was linked with a reduced utilisation of other health services with 45% fewer unscheduled GP visits recorded and a 100% reduction in hospital admissions and consequent savings across the health economy. The predicted cost/impact of the specialist prostate cancer Physiotherapist is £3,160 per Quality Adjusted Life Year (QALY) gained. Consequently, very cost efficient when evaluated against the NICE guidance.

Whitney also argues that income generation can be successfully implemented across other tertiary cancer hospitals for oncology. An example is physiotherapy out-patient roles within Barts Health NHS Trust for women with breast cancer. If the large collection of positive outcomes from the prostate pilot is pro-actively utilised and entered into Barts Health's commissioning intentions the development of a dedicated specialist out-patient post open to all patients in Oncology (not just breast cancer) could be self-sustaining thanks to income generation.

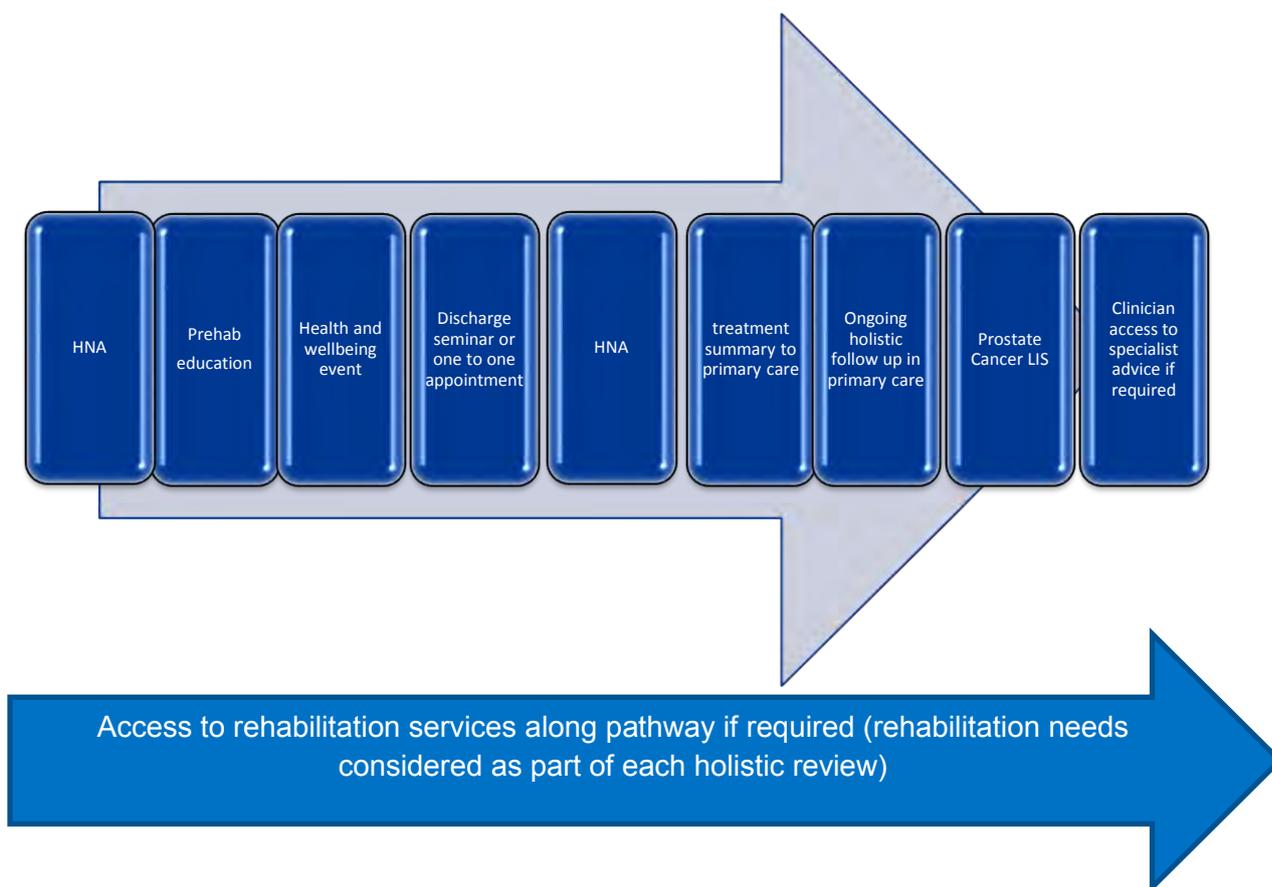
The introduction of the new pathway at GSTT has resulted in costs savings of £44,000 when costs were reviewed during the project (multidisciplinary approach). This was due to how the patients are being managed in the new pathway. Full costs savings for the new pathway are currently being reviewed and will be available early 2016.

### Components of an ideal pathway

The projects spanned the pathway of patients with prostate cancer from the point of treatment starting, initial follow-up and long term follow-up in primary care.

As we have indicated a comparison of the differing models is not possible for that reason. The outcomes available from the projects indicate good patient satisfaction with the recovery package being delivered consistently. Figure 7 below provides a visual guide to components of an ideal pathway.

Figure 7 Components of an ideal pathway



## Limitations of this report

Following discussions with the funded projects and commissioners in London the need for information on the differing models of follow-up was identified as a priority. This report was therefore completed in time for the 2016/17 commissioning decisions but before the completion of all the funded projects across London. Full evaluation data was not available for several of the projects and therefore provisional / early outcome data was used to make the comparisons.

This report was jointly written by TCST and Prostate Cancer UK. The TCST prostate cancer team are one of the Prostate Cancer UK funded projects. There is therefore the potential for bias in the analysis of data received and the conclusions that have been made. Prostate Cancer UK's co-editing of the report has therefore been crucial to mitigate against this risk.

## 6. Recommendations

- CCGs to consider their local population's need, service provision, and work force, when making decisions regarding models of follow-up
- CCGs to ensure that all the components of an ideal pathway are addressed when redesigning existing pathways.
- TCST and Prostate Cancer UK to fully cost an enhanced follow-up pathway that encompasses good practice demonstrated in the projects (provision of all aspects of the recovery package, access to rehabilitation services when required, and a local incentive scheme for primary care to ensure on-going high quality care).
- Providers and commissioners need to consider the transfer to primary care for the majority of the patients in follow-up after treatment for prostate cancer. The timing of this will vary depending on local agreement but it is essential that this is planned for to ensure the smooth and safe transition of patients
- Prostate Cancer UK to review projects across HSCP programme and how learnings contribute to recommendations for the ideal pathway for prostate cancer patients

## 7. Conclusions

There are a number of innovative projects within the HSCP programme which are testing a range of interventions that provide evidenced based and high quality care to men before, during and after treatment for prostate cancer. All of the projects were able to deliver some or all of the aspects of the recovery package. Offer of holistic needs assessment was far higher for example than in traditional secondary care follow-up. This is assumed to be because nurses and other AHPs were leading the care, and because provision of elements of the recovery package was built in to the pathway. Considering the known unmet needs for this patient group from PROM data it is imperative that any pathway developed aims to address these.

Patient satisfaction with the pathways, from the data that has so far been made available, is positive. There is good outcome data from the projects with improvements demonstrated in quality of life scores, as well as improvements in some of the side effects of treatment as a consequence of targeted interventions.

CCGs have a range of pathways that they can commission to suit their local population needs and health care provision. A question that has been asked by commissioners is which one they should choose. Whilst full evaluation data is not available from all of the projects there are now some indicators as to what may meet the needs of patients, what is economically viable and what considerations may be needed when planning aspects of the pathway.

For example, the provision of pre-habilitation improves outcomes post treatment (Silver and Baimer 2013), health and wellbeing events as part of the pathway had good outcomes and were accepted by patients. The point at which to transfer care to primary care will be a local decision but the pathway to primary care needs to be addressed as part of the pathway design and not an add-on. The TCST/Croydon project has identified some of the risks of primary care follow-up if this is not properly planned (patients becoming lost to follow-up, misinterpretation of PSA results) with the risk of variability in practice across GP practices. The provision of a local incentive scheme enables CCGs to ensure consistency in follow-up as well as measuring quality indicators such as patient experience.

The value of PSA tracker software has been identified as another tool to help long term follow-up of this patient group. The software enables patients to be robustly managed in terms of their PSA results. The use of tracker software is therefore a tool that could be adopted in different settings to prevent the risk of losing patients to follow-up. The PSA tracker needs administration and the results need to be conveyed to patients, in addition the supportive needs of patients still need to be addressed.

An alternative answer to the question of which pathway to commission may therefore be components of all the projects. A redesigned pathway in secondary care that provides health and well-being events and holistic needs assessment complements a structured primary care pathway that provides on-going access to rehabilitation services as required. Local needs, service provision and workforce availability are likely to be factors in the decision making.

It is recommended that TCST explore the costs of a redesigned follow-up pathway that encompasses redesigned secondary care follow-up (with delivery of the recovery package elements), access to rehabilitation services, and a local incentive scheme for primary care follow-up once the patient is transferred.

## 8. References

Cox K and Wilson E (2003) Follow-up for people with cancer: nurse-led services and telephone Interventions. Journal of Advanced Nursing. July 2003. 43 (1) 51-61

Hennessey D, Lynn C, Chambers K, and Mulholland C (2013) The PSA tracker: a computerised healthcare system initiative in Northern Ireland. Ulster Medical Journal 2013 Sept; 82 (3): 146-149.

Macmillan (2012): The importance of physical activity for people living with and beyond cancer. A concise evidence review. Available:

<http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Physicalactivityevidencereview.pdf> (last accessed 4.12.15)

Macmillan (2013) Throwing light on the consequences of cancer and its treatment. Available:

[http://www.ncsi.org.uk/wp-content/uploads/MAC14312\\_CoT\\_Throwing-light\\_report\\_FINAL.pdf](http://www.ncsi.org.uk/wp-content/uploads/MAC14312_CoT_Throwing-light_report_FINAL.pdf) (last accessed 9/12/15)

Macmillan (2014) Specialist adult cancer nurses in England: A census of the specialist adult cancer nursing workforce in the UK, 2014.

Available:

<http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Macmillan-Census-Report-England.pdf>

NHS Improvement (2012) Adult Survivorship from concept to innovation. Available:

[http://www.ncsi.org.uk/wp-content/uploads/Concept\\_to\\_Innovation.pdf](http://www.ncsi.org.uk/wp-content/uploads/Concept_to_Innovation.pdf)

NHS Improvement (2013) Innovation to implementation: Stratified pathways of care for people living with or beyond cancer A 'how to guide' Available:

<http://www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf> ( last accessed 4.12.15)

NHS Improving Quality (2014) Improving adult rehabilitation services in England. Sharing the best practice in acute and community care:

[http://www.nhs.uk/media/2487824/improving\\_adult\\_rehabilitation\\_services\\_in\\_england.pdf](http://www.nhs.uk/media/2487824/improving_adult_rehabilitation_services_in_england.pdf)

Pearce A, Ryan F, Drummond F, Thomas A, Timmonds A, Sharp L. (2015) Comparing the costs of three prostate cancer follow-up strategies : a cost minimisation analysis. Supportive Care in Cancer. 2015 Aug 6

Prostate Cancer UK (2014): The specialist nursing workforce caring for men with prostate cancer in the UK Research report 2014. Available:

[http://prostatecanceruk.org/media/2491517/2631-urology-nurse-workforce-research-report\\_web.pdf](http://prostatecanceruk.org/media/2491517/2631-urology-nurse-workforce-research-report_web.pdf) (last accessed 3.12.2015).

Quality Health (2013): Quality of Life of Cancer Survivors in England One Year On from the 2011 Survivorship Survey Pilot. Available:

<https://www.quality-health.co.uk/resources/surveys/cancer-survivorship-survey/503-cancer-surviourship-survey-2012-report/file> (last accessed 4.12.15).

Richman E, Kenfield S, Stampfer M, Paciorek A, Carroll P, and Chan J (2011): Physical activity after diagnosis and risk of prostate cancer progression: data from the cancer of the prostate strategic urologic research endeavour. Cancer Research UK. 2011:71 (11):3889

Silver j, Baima J ( 2013) Cancer Prehabilitation: An Opportunity to Decrease Treatment-Related Morbidity, Increase Cancer Treatment Options, and Improve Physical and Psychological Health Outcomes .American Journal of Physical Medicine & Rehabilitation: August 2013 - Volume 92 - Issue 8 - p 715–727

Whitney (2014): Scoping Needs and Mapping Rehabilitative Services for Men with Prostate Cancer in North East London.

Available: <http://prostatecanceruk.org/media/2492261/scoping-and-mapping-final-report.pdf> (last accessed 4.12.15)

Whitney (2015): Six Month Pilot Analysis: Improving Rehabilitation for Men with Prostate Cancer in North East London.

Available: <http://prostatecanceruk.org/media/2492258/executive-summary-six-month-pilot.pdf>

Yip K, McConnell H, Alonzi R and Maher J (2014): Using routinely collected data to stratify prostate cancer patients into phases of care in the United Kingdom: implications for resource allocation and the cancer survivorship programme. *British Journal of Cancer* 2014, 10.1038

## Appendix1: Headline Findings from the Projects

Project	TCST	Hillingdon	RMH	GSTT	Barts	NWL
<b>Clinical Lead Role</b>	Nurse/GP	Nurse	Nurse	Nurse/GP	Physio	Nurse
<b>Location</b>	Primary care	Secondary care	Secondary care	Secondary care	Secondary care	Secondary care
<b>Pathway phase</b>	Post treatment	End of treatment (post prostatectomy/ radiotherapy)	Pre and post radical prostatectomy and radiotherapy	Pre and post op radical prostatectomy.	Post radiotherapy/ Prostatectomy	Across pathway from diagnosis to follow-up after treatment
<b>Remote surveillance?</b>	No	Yes	No	No	N/A	Yes
<b>Recovery package</b>	HNA On-going holistic assessment	HNA H and W being events Treatment summary	HNA H and W being events Treatment summary	HNA H and E being events Treatment summary	H and W events	HNA Treatment summary
<b>Outcomes</b>	Good patient experience (figure 4) 57/59 practices signed up to LIS. Clinicians generally positive about improved LIS	Increased OPA capacity More pts. ref directly to LUTS/ ED clinics, and more ref to survivorship services	PROMS, ICIQ, IIEF-SHIM data collected at all points of contact (6-10 weeks post surgery, then 3 monthly until 12 months.) To be reported	Positive patient experience and outcomes data available (figure 6)	Positive patient experience and patient outcome data available (figure 3)	Increased rate of HNAs offered as proxy measure of improved outcomes.
<b>Costs</b>	£50 for an initial 30 appt, £43 for 20 minute follow-up appointments (costing agreed with Croydon Local Medical Committee	Cost for remote surveillance software. One band 7 WTE CNS.  Cost for maintenance and software upgrades	Cost of a WTE band 7 for the Specialist Nurse.	Project required one WTE band 7 nurse, one GPwSI (6 hrs / month)	Band 7 physiotherapist and one Band 4 support worker.	One WTE Band 7 CNS

<b>Incidental findings</b>	Risk of patients becoming lost to follow-up identified as part of project case finding. This is mitigated by having a prostate cancer register in each practice.	Issues with remote tracking software which needed upgrading at cost.	The project was originally based in primary care and there were issues with set up. When reviewed and pathway changed at secondary care level it was more successful with pick up and engagement	Numbers of pts. ref to andrology decreased. Reduced emergency admissions/urgent appointments. Patients discharged to primary care quicker as ED and continence are addressed earlier.	Value in physiotherapy input in radiotherapy and surgical pathways by providing bladder training and pelvic floor exercise education.	
<b>Evaluation</b>	Early 2016	Dec 2015	Mid 2016	Dec 2015	Available now	Early 2016
<b>Contact</b>	Sandra Dyer <a href="mailto:Sandra.dyer1@nhs.net">Sandra.dyer1@nhs.net</a> Sarita Yaganti: s.yaganti@nhs.net or Liz Price liz.price4@nhs.net	Mariam Nasser mariam.nasser@thh.nhs.uk	Netty Kinsella 0207 352 8171 ext 4898	paula.allchorne@gstt.nhs.uk or pallchorne@hotmail.co.uk	Helen Whitney helen.whitney@bartsheath.nhs.uk 07949 405814	Mary Cremin mary.cremin@nhs.net 020 8869 3680

---

*Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company 02653887.*