



# Enhanced primary care-led prostate cancer follow-up

Evaluating the quality, safety and financial validity of the Croydon model

February 2016

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## Glossary of terms

**Active surveillance:** Active surveillance (AS) programmes aim to offer men the option of avoiding immediate surgery or radiotherapy and their adverse events, with disease monitoring, so that those whose disease remains stable can avoid intervention and those whose disease progresses can have curative treatment - Wade et al 2015

**Watchful waiting:** Watchful waiting is a method of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to monitor the cancer over the long term, and avoid treatment symptoms develop. The aim of any treatment will be to manage symptoms rather than a curative intent.

**Local Enhanced Service (LES) and Local Incentive Scheme (LIS):** Locally developed primary care services designed to meet local health needs.

**The 'Recovery Package'** is defined by the Cancer Survivorship Initiative as: a combination of different interventions, which when delivered together, will greatly improve the outcomes and coordination of care for people living with and beyond cancer. These are:

- Holistic Needs Assessments (HNA) and care planning at key points of the care pathway,
- A Treatment Summary completed at the end of each acute treatment phase, sent to patient and GP
- A Cancer Care Review completed by GP or practice nurse to discuss the person's needs, and
- A patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, which will include advice on healthy lifestyle and physical activity.

**Stratified pathways:** The transformed pathway of care for cancer survivors is based on a model of care for people with long term conditions. A stratification process will help to identify which care pathway is most suitable for each patient, based on the level of care needed for the disease, the treatment and the patient's ability to manage, and therefore what level of professional involvement will be required.

## Executive Summary

Primary care is fast becoming an obvious choice for alternative models of follow-up care as it enables care to be delivered in a setting where long term conditions are predominantly managed.

The numbers of people living with and beyond a diagnosis of cancer continue to increase as our population ages with four million people expected to survive their cancer by 2030. Consequently, primary care is becoming a suitable alternative to provide long term support for people affected by cancer.

The National Institute of Clinical Excellence states that stable at two years after radical treatment and patients who are undergoing “watchful waiting” should be offered follow-up outside of hospital in an appropriate setting (NICE Prostate Cancer: CG175 2014). Alternative models must to be safe, improve patient outcomes, cost effective and sustainable.

The aim of the enhanced model in Croydon CCG is to develop and test a holistic follow-up service that is catered to the physical *and* emotional well-being of patients. It intended to improve follow-up processes and shift care from secondary to primary care. In addition to delivering test results closer to home, the service ensures that with the right information, patients are fully supported toward self-management.

Between 2008 and 2014, Croydon patients have been followed up by their GP and the practices were remunerated by a local enhanced scheme (LES). The scheme was initiated with 70% GP practice uptake and after 6 months, a £50,000 savings in follow-up appointments was achieved. Although not a major saving the pathway is cost neutral at the very worst and likely to be cost saving. In addition an audit of new referrals to urology showed a 50% decrease in practices who had taken up the pathway. This suggests that those practices that understood the training and started to manage more urology patients felt empowered and managed more in practice than those that did not take part.

In 2014, the service specification was reviewed and revised by the Transforming Cancer services Team and Croydon CCG. The updated specification was launched in December 2014 in the form of a local incentive scheme (LIS). The LIS was developed to include various tools and resources to support the delivery of a holistic follow-up service including a concise information pack for patients, educational resources for clinicians, a clinical template to

provide structure for the follow-up appointment and a route for primary care clinical to access advice from secondary care specialists.

The CCG saw a 100% increase in practice sign up to the revised LIS and this report evaluates the model on patient safety, quality of the service and the economic viability and demonstrates the feasibility of primary care led follow-up for stable prostate cancer.

There are a number of considerations for commissioners when planning a primary care-led and deliver pathway which were identified by this evaluation. A frequently asked questions document for commissioners was produced in September 2015 to support planning for the 2016/17 planning round and can be found in Appendix 6.

The project aimed to improve follow-up processes to shift care from secondary to primary care for prostate cancer. This was ultimately achieved through the development of the local incentive scheme and engagement from secondary care colleagues with initiatives to share best practice and reduce variation. Provision of tools such as an EMIS/VISION template and a prostate cancer register helped to achieve this. 57 patients were identified as lost to follow-up under the old local enhanced scheme and the introduction of the prostate cancer register mitigates the risk of further patients being lost in the system and act as a safety netting tool going forward. At the time of writing this report, 34 (60%) of these patients have been recalled.

The project improved patient experience and access to other services for better outcomes by embedding a supportive/holistic element to needs assessment, as part of the follow-up service. This was achieved through the introduction of the welcome pack, welcome appointment and an emphasis on addressing holistic needs as part of the on-going follow-up. Patient experience was measured as part of the evaluation process. Whilst accepting the limitations of the patient experience survey (in terms of quantity) it provides an assurance that patients are generally happy with their transfer of care to their primary care team.

The provision of the Welcome Letter and revised information for the Welcome Appointment aimed to enhance knowledge of prostate cancer and promote self-management. The extent to which this was achieved was not directly measured in the project. The move towards self-management could be considered for patients who are stable after a period of time following the transfer of their care. Currently there is no evidenced based guidance on how long to monitor patients after treatment and therefore it is generally life-long. The move to self-

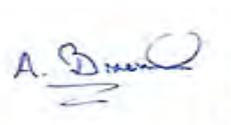
managed care for a proportion of this patient group could be considered when planning and redesigning patient pathways.

Bringing care closer to home was facilitated by the transfer of an additional 70 patients into primary care. The speed of transfer was slower than the project team anticipated and demonstrates some challenges about the identification of patients and engagement of both primary and secondary care in order to achieve this. There remains another 85 patients awaiting transfer and we anticipate that they will gradually move across to primary care. A pathway redesign in progress at the larger trust (RMH) and fuller engagement will help facilitate this as a key aim is to ensure that those patients who meet the NICE criteria (which matched the LIS criteria) will be transferred to primary care.

The results of the financial analysis found that the enhanced primary care pathway and LIS is significantly cheaper than the traditional secondary care pathway. It provides a direct healthcare cost saving of 57% per patient over a five year period. Not all patients who were identified as fulfilling the criteria for discharge from secondary care had moved onto the new care pathway. If all 155 eligible patients had been discharged from secondary care to the new primary care pathway, the savings would have been much greater.

The project also provided training and development for primary care professionals on prostate cancer and the needs of patients living with and beyond prostate cancer. Up skilling primary care to support patient living with and beyond cancer will become a big part of managing prostate cancer as a long term conditions.

Even though this analysis shows that there is a considerable cost saving from introducing the new primary care pathway compared to the secondary care pathway, this was not the sole aim. The new pathway aimed to improve the quality of support provided to prostate cancer patients by providing tailored patient information packs, training modules for GPs and primary care nurses, templates to seek specialist advice and providing more holistic support which includes referring and or signposting patients to support services. Croydon CCG values the changes made in the new care pathway and is pleased to share the evaluation findings in this report.



Anthony Brzezicki, Chair, NHS Croydon Clinical Commissioning Group  
February 2016

## **1. Introduction**

In the UK, the numbers of men living with a diagnosis of prostate cancer will continue to increase as the population ages. The National Institute of Clinical Excellence recommends that patients stable at 2 years after radical treatment and patients who are undergoing “watchful waiting” are offered follow-up outside of hospital in an appropriate setting (NICE Prostate Cancer: CG175 2014).

Primary care is an obvious choice for most as it enables care to be delivered in a setting where other long term conditions are now predominantly managed (Department of health 2010). Stratified follow-up into primary care fits with a national strategy over the last decade to provide care closer to home (Department of health 2006, 2007).

## **2. Background**

The enhanced prostate cancer follow-up is a joint project with Prostate Cancer UK, the Transforming Cancer Services Team (TCST) and Croydon CCG.

The aim was to develop and test a holistic needs-based follow-up service led by primary care for people with prostate cancer who are stable at two years after radical treatment or are undergoing “watchful waiting”. The Project Team supported primary care nurses and GPs to deliver an enhanced care package that is co-ordinated, brings care closer to home and tailored to the emotional and physical well-being of people in their care.

Croydon CCG GP practices were the pilot site for testing the model.

### **Project funding**

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.

In April 2014 the TCST recruited a Band 8a nurse to work alongside a TCST Strategy Implementation Lead. The original plan was to recruit 2 nurses. However as the project

progressed it was evident that a sessional GP would add greater value than another nurse in engaging with GP practices and provide a wider understanding of primary care processes. In October 2014 a Croydon GP was recruited for 3 sessions per week as part of the final project team.

TCST received a Prostate Cancer UK Grant of £143,689. This comprised of:

- £93,939 for the Clinical Nurse Specialist (Band 8a) (including London weighting and on-costs)
- £48,750 for the GP (£250 per session, for a maximum of three sessions a week for a maximum of 15 months/ 65 weeks)
- £1,000 equipment.

Other funds:

£2,000 grant from Macmillan to support launch event

£15,000 from TCST to support extension of Band 8a post for 3 months.

Payment in kind:

TCST and Croydon CCG resources were approximately £22,000-£25,000 per quarter at the start of the project reducing to £6,000 - £8,000 in the final quarter.

### **Stratified pathways of care**

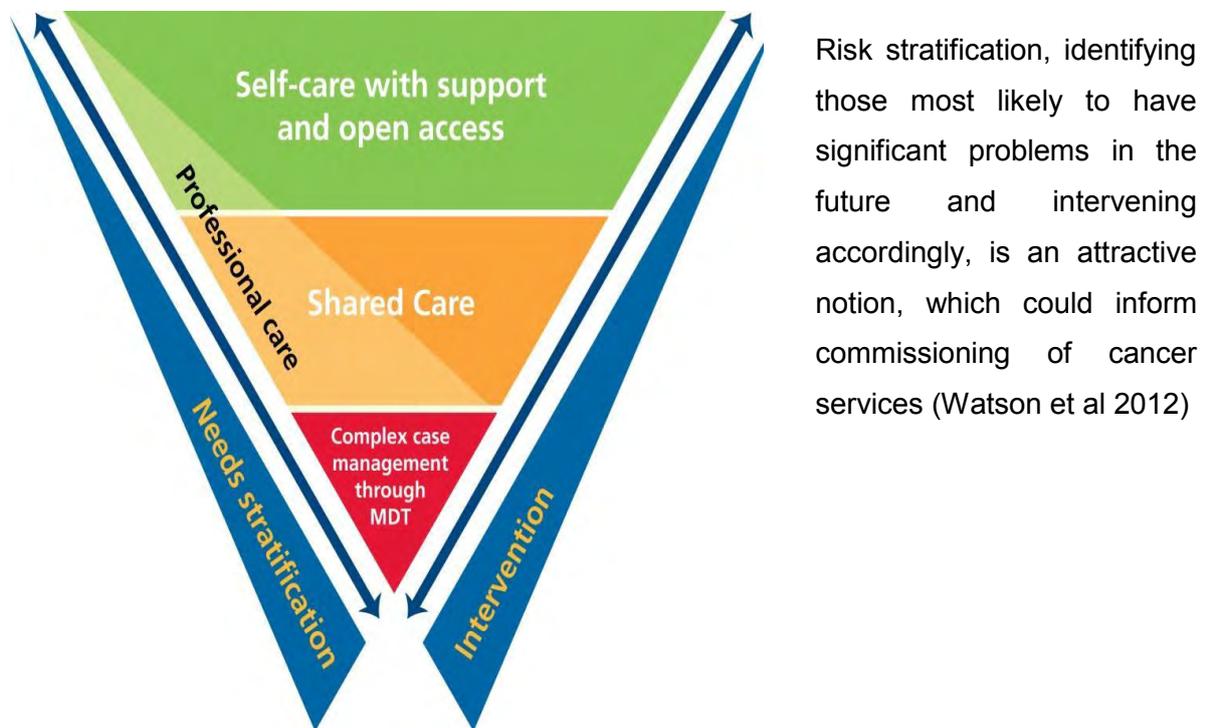
A mapping of the follow-up pathways across London and the rest of the UK showed limited activity of stratified pathways into primary care-based services that were not secondary care-led (e.g. remote monitoring and secondary care nurse-led telephone follow-up). The project team found only a few examples of wholly primary care-led and delivered stratified pathway for stable prostate patients as outlined by NICE. These pathways appeared to be focused on PSA monitoring and did not specify that they intended to meet the holistic needs of patients.

The ten year survival for prostate cancer is 84% (Cancer Research UK 2011). Reoccurrence can be detected through PSA monitoring which can be conducted in either secondary or primary care setting.

The National Cancer Survivorship Initiative developed a [stratification process](#) (NCSI 2013) to help identify which care pathway is most suitable for each patient based on the level of care needed for the disease, the treatment received and the patient's ability to self-

manage, and therefore what level of professional involvement will be required (See Figure 1).

Figure 1: NCSI Stratification process

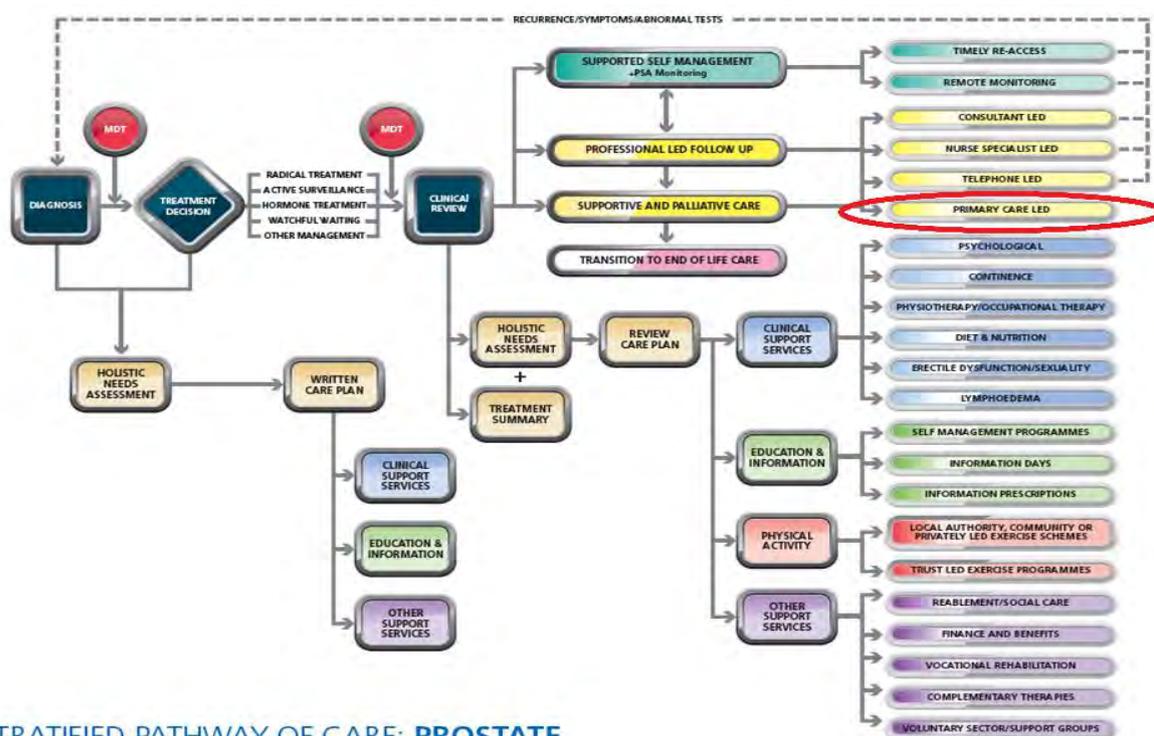


Stratified pathways for follow-up after treatment to traditional hospital outpatient care aims to improve the quality of care whilst freeing up secondary capacity for diagnosis and treatment of new patients (National Cancer Survivorship Initiative 2013). The initiative to develop alternative models of 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 two years post radical treatment or on a watchful waiting pathway.

The NCSI risk stratified options are shown in Figure 2 and include remote surveillance, consultant led care, nurse-led care, telephone follow-up and primary care-led follow-up.

The TCST positioned the enhanced follow-up model as stratified to primary care-led.

Figure 2: NCSI Stratified pathways



## Population profile of Croydon

Croydon has both a growing and ageing population, placing increased pressures on the health and social care system. Over 65s represent nearly 13% of Croydon's total population, and this number is growing - over the next five years, the number of over 65s living in Croydon is expected to increase by 10%. The latest projections for Croydon suggest the number of people aged over 85 will increase by two thirds by 2029.

Croydon is an ethnically diverse borough with 45% of the population defined as non-white (Office of national Statistics 2011). Of these around 33% are defined as Black African/Caribbean. Black men have a higher life time risk of developing prostate cancer (one in four) than white men (one in eight).

## Prostate Cancer in Croydon

Incidences of prostate cancer are a particular challenge for Croydon and the mortality rate from prostate cancer are highlighted as emerging issues (Croydon CCG 2014). Prostate

cancer incidence in Croydon at 179.9 per 100,000 is above the national average of 173.2 per 100,000 (NCIN 2012) and mortality is also higher.

Croydon CCG has identified addressing the increased incidence and emerging issue of increased deaths from prostate cancer as a key priority in their cancer plan (Croydon CCG 2014).

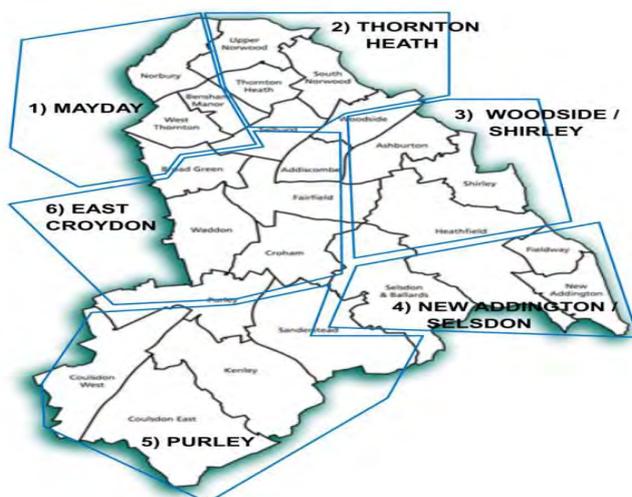
Figure 3

Indicator	Cases	Croydon value	England Average
Prostate Cancer Incidence (2010-2012 age standardised rate per 100,000)	603	179.9	173.2
Prostate Cancer mortality (2010-2012 age standardised rate per 100,000)	148	52.7	50.1
Male life expectancy at birth	n/a	79.2 years	74 – 82.9 years

[http://www.ncin.org.uk/profiles/la\\_profiles/atlas.html](http://www.ncin.org.uk/profiles/la_profiles/atlas.html)

There are now 2 million people in the UK living with cancer and this set to double to 4 million by 2030. Cancers is becoming a long-term condition as more people are surviving cancer but living with the consequences of treatment. These consequences can appear shortly after treatment ends or years later and dramatically alter the lives of these individuals.

### Croydon Clinical Networks



There are six geographical networks within Croydon and these networks were pivotal in engaging with the practices on the ground.

The Project team attended Network meetings at the start of the project in order to understand the reasons for the low uptake of the previous local incentive schemes.

Figure 4 outlines the profile of each Network including the priority areas.

<p><b>Mayday</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• 77% Black, Asian and Minority Ethnic groups</li> <li>• High crime and overcrowded housing</li> <li>• High proportion of lone parent families</li> <li>• High prevalence of obesity and diabetes</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Prescribing indicators</li> <li>• Breastfeeding</li> <li>• Smoking</li> <li>• Diagnosis of CHD, heart failure and hypertension</li> <li>• Care and outcomes for mental health conditions, COPD and CKD</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Patient experience</li> <li>• High A&amp;E attendance rates</li> <li>• High emergency admission rates</li> <li>• Diagnosis of atrial fibrillation and epilepsy</li> <li>• Childhood immunisations</li> <li>• Cancer screening</li> </ul> <p><b>Significantly high referral rates:</b> Endocrinology, direct access ultrasound</p>	<p><b>Woodside / Shirley</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• Demographics similar to Croydon average</li> <li>• 51% Black, Asian and Minority Ethnic groups</li> <li>• High prevalence of smoking, adult obesity, and long-term conditions including depression, AF, COPD, asthma, CKD and rheumatoid arthritis</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Low rates of A&amp;E attendances</li> <li>• Diagnosis rates for adult obesity, diabetes, hypertension, atrial fibrillation, CKD and epilepsy</li> <li>• Care and outcomes for COPD</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Access and overall patient experience</li> <li>• Prescribing indicators</li> <li>• Diagnosis rates for dementia and CHD</li> <li>• Flu vaccine uptake</li> <li>• Childhood immunisations</li> <li>• Care and outcomes for severe mental illness and sexual health</li> <li>• High referral rates</li> </ul> <p><b>Significantly high referral rates (top 3):</b> Orthopaedics / musculoskeletal, ENT, paediatrics</p>	<p><b>East Croydon</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• High proportion aged 25-44</li> <li>• High population growth in future years</li> <li>• 57% Black, Asian and Minority Ethnic groups</li> <li>• Deprived area with high crime rate</li> <li>• High proportion of nursing home residents</li> <li>• High prevalence of smoking, severe mental illness, and drug and alcohol use</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Diagnosis rates for atrial fibrillation, stroke/TIA, CKD and epilepsy</li> <li>• Care and outcomes for atrial fibrillation</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• High rate of A&amp;E attendances and emergency admissions particularly for over 65s</li> <li>• Prescribing indicators</li> <li>• Diagnosis rates for diabetes, depression, dementia and hypertension</li> <li>• Care and outcomes for diabetes, severe mental illness and CKD</li> <li>• Cancer screening</li> </ul> <p><b>Significantly high referral rates:</b> Direct access US</p>
<p><b>Thornton Heath</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• 68% Black, Asian and Minority Ethnic groups</li> <li>• Deprived area with high unemployment</li> <li>• High proportion of lone parent families</li> <li>• High prevalence of smoking, diabetes and severe mental illness</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Patient experience</li> <li>• Diagnosis rate for diabetes</li> <li>• Care and outcomes for atrial fibrillation</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Flu vaccine uptake</li> <li>• High rate of emergency admissions for over 65s</li> <li>• High rate of GP referrals to A&amp;E</li> <li>• Diagnosis rate for depression, CHD, atrial fibrillation, COPD and epilepsy</li> <li>• Care and outcomes for depression and rheumatoid arthritis</li> <li>• Breast and bowel screening; cancer reviews</li> </ul> <p><b>Significantly high referral rates:</b> Physiotherapy, direct access MRI</p>	<p><b>Purley</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• High proportion aged over 55</li> <li>• 31% Black, Asian and Minority Ethnic groups</li> <li>• Affluent area</li> <li>• High proportion of care home residents</li> <li>• High prevalence of long-term conditions including depression, dementia, CVD, cancer and hypothyroidism</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Patient experience</li> <li>• Low rate of A&amp;E attendances and emergency admissions</li> <li>• Primary immunisations uptake</li> <li>• Cervical and bowel cancer screening coverage</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Flu vaccine uptake</li> <li>• Care and outcomes for diabetes and depression</li> </ul> <p><b>Significantly high referral rates (top 3):</b> Physiotherapy, cancer TWW, dermatology</p>	<p><b>New Addington / Selsdon</b></p> <p><b>Population:</b></p> <ul style="list-style-type: none"> <li>• 29% Black, Asian and Minority Ethnic groups</li> <li>• Includes deprived and affluent areas</li> <li>• High proportion of older people living alone</li> <li>• High prevalence of smoking, adult obesity, circulatory diseases, cancer, COPD</li> </ul> <p><b>Achievements:</b></p> <ul style="list-style-type: none"> <li>• Patient experience of access</li> <li>• Flu vaccine uptake (QOF indicators)</li> <li>• Support for stopping smoking</li> <li>• Care and outcomes for circulatory conditions, mental health conditions and CKD</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Breastfeeding; smoking during pregnancy</li> <li>• High emergency admission and A&amp;E attendance rates in New Addington</li> </ul> <p><b>Significantly high referral rates (top 3):</b> Orthopaedics/musculoskeletal, paediatrics, cancer TWW</p>

Source: Croydon CCG Cancer strategy (2014)

Croydon is served by a number of secondary care providers including:

- Croydon University Hospital
- Royal Marsden NHS Foundation Trust
- St Georges NHS Trust
- Epsom and St Helier NHS Trust
- East Surrey Hospital NHS Trust
- Princess Royal University Hospital NHS Trust
- Kings College Hospital NHS Trust
- Guys and St Thomas NHS Foundation Trust

For the purpose of this project, the pilot only included the suitable cohort of patients who were having their follow-up from either the Royal Marsden NHS Foundation Trust or Croydon University Hospital NHS Trust.

### 3. Aims and Objectives of the project

This eighteen month project aimed to develop and test high quality holistic-needs based follow-up service in primary care for prostate cancer patients who are stable at two years after radical treatment and patients who are undergoing “watchful waiting”. It aimed to develop the role of primary care nurses and GPs to deliver an enhanced care package that is co-ordinated, closer to home and tailored to the emotional as well as physical well-being of the patient.

#### Purpose

- Improve follow-up processes to shift care from secondary to primary care for prostate cancer patients who are stable at two years after radical treatment and patients who are undergoing “watchful waiting”.
- Improve patient experience and access to other services for better outcomes by embedding a supportive/holistic element to needs assessment, as part of the follow-up service.
- Bringing care closer to home by facilitating primary care follow-up.
- Review and revise information given to patients about their follow-up care in order to enhance knowledge of prostate cancer and promote self-management where possible.
- Review and revise the current Local Enhanced Scheme in partnership with Croydon CCG.
- Provide Training and development for primary care professionals on prostate cancer and the needs of patients living with and beyond prostate cancer.

#### Objectives

- Work with Croydon GPs, patients, practice nurses, Croydon University Hospital, London Cancer Alliance and Croydon CCG to support the pilot of the best practice primary care-led follow-up model for prostate cancer patients who are stable at two years after radical treatment and patients who are undergoing “watchful waiting”.
- Develop patient and professional surveys to benchmark experiences of the current pathways and to identify areas of improvement. The objective is to embed experience-based design into a service improvement initiative and to support the holistic/supportive needs of people living with and beyond cancer.

- To further develop and test a risk stratified pathway in primary care. The risk assessment being based upon clinical risk of re-occurrence or spread of cancer, or need for health care in a secondary care setting due to consequences or side effects of treatment.
- Primary care teams to be able to identify patients that they believe are suitable for primary care follow-up according to defined parameters agreed with the consultant urologist and in accordance with NICE (2014).
- To assess the available evidence from various follow-up pathways pilots and initiatives that has occurred and is on-going in London, nationally and internationally

#### 4. Methodology

A review of patients followed-up in the community showed that whilst patients were satisfied with their follow-up care, the majority did not receive relevant information regarding the change in their care, the potential side effects and consequence of treatment or signposts to psycho-sexual, social and incontinence services.

The review also highlighted the need for improvements to be made to patient and primary care clinician experiences, access to other services and follow-up processes to shift care from secondary to primary care for suitable patients. Better outcomes can be achieved by embedding a supportive and holistic element to follow-up appointments that includes signposting and referral to local emotional and psychological support or associated wellbeing services.

##### **Development and support for primary care**

Locally arranged GP clinical network meetings provided an opportunity to discuss issues pertaining to the existing pathway, the quality of information provided from the hospital, the opportunities to sustain the enhanced service and GPs' views of a holistic model adapted for primary care. The following points were taken from these discussions:

- The need to increase GPs' awareness of support groups and services and cancer specific charity resources for signposting people affected by cancer
- The need for a primary care based process to help identify suitable patients for primary care follow-up. Produce a template for use in follow-up appointments that review holistic needs.

- To ensure information given to patients about their follow-up care is accurate and relevant
- Ensure the current pathways and processes are appropriate.
- Training required for primary care professionals for managing and supporting people with prostate cancer, including: prostate follow-up systems, explicit PSA referral thresholds, symptomatic and psychological red flags, and safety netting protocols to ensure clinically governed management of referrals and re-referrals between primary and secondary care.

## Outputs

A prostate cancer urology local enhanced scheme (LES) specification was revised in light of the issues raised and launched in December 2014; see Table 6 below for a comparison of the old locally enhanced scheme (LES) and the new local incentive scheme (LIS).

The project team developed a series of tools and resources to support the delivery of the enhanced pathway. These included:

- Patient Identifier tool to help find prostate cancer patients that are suitable for primary care follow-up (see Appendix 4) Letter to secondary care requesting transfer of patient for primary care follow-up
- Information to newly transferred patients: Letter and Welcome Pack for patients that inform them of transfer to primary care and to offer a Welcome Appointment. The Pack includes a service directory of local support services, a glossary of medical terms and a copy of the Holistic Care Plan (HCP) that will be used in the Welcome Appointment and be reviewed in the subsequent follow-up appointment. The HCP can be integrated into VISION/EMIS web.
- Letter to patients already being followed up in primary care which introduces a more holistic follow-up service and includes directory of local support services and a copy of the HCP.
- Urgent referral / advice only template letters to secondary care
- Prostate Cancer follow-up consultation template for EMIS and VISION clinical systems and supporting guide to upload template
- CCG Reporting spread sheet for remuneration
- Prostate Cancer Register to mitigate and reduce risk of patient lost to follow-up
- CDP accredited education modules for GPs, primary care nurses and Allied Health Professionals
- Primary care follow-up protocol designed to assist primary care where there is a lack of guidance in their discharge summary (historical discharges).

Tools and resources are available in Appendix 4.

**Table 6 Comparison of old LES and revised LIS**

Elements of pathway	Identified gaps from 2008 model	Enhanced Prostate cancer follow-up LIS 2015/16
Discharge process / identifying patients suitable for discharge	Ad hoc process from both GP requesting discharge and CUH stratifying patients.	Clear process and clinically revised process including clear re-referral guidelines.
HNA and Discharge summaries	HNAs not routinely conducted in secondary care. Lack of holistic assessment at point of discharge and discharge summaries completed inconsistently.	Negotiated with secondary care, minimum info for discharge summaries including clear re-referral criteria
Patient information (pre-survey of one Croydon practice patients <i>n</i> =13 and feedback from Purley Prostate Support Group <i>n</i> =30)	Little or no information given to patient regarding follow-up process, signposting to support services or symptoms of reoccurrence. Urology CNS signposts within Urology clinics, no info provided by practices	Developed patient information as part of Welcome Letter. Endorsed by PCUK, CUH and Purley Support Group.
Educational gaps and resources for primary care clinicians	None available	Conducted training needs assessment (GPs and Nurses) and compiled accredited Education Resources
On-going holistic review of patients in primary care follow-up pathway	N/A	Holistic Care Plan agreed with GPs for trial. Holistic elements inserted into PSA clinical templates. Welcome Appointments agreed by GPs.
Costs and incentives	£50 per patient per year	1x Welcome Appointment £50 per <u>new</u> patient discharged to primary care. £43 per appointment (LMC rates) for 20 minute PSA follow-up appointment with GP/nurse face-to-face (one-two appointments per year)

### Requirements from Primary Care Teams

Practices that sign up to the new LIS are required to:

- Complete a minimum one hour training session accredited by BMJ Learning to refresh training gaps.

- Use the patient identifier guide to identify suitable patients on practice lists that could be discharged from secondary care follow-up to primary care follow-up. GPs to send the list to the secondary care consultant to formally request discharge and the consultant is to outline follow-up requirements for the patients.
- Offer a 30 minute 'welcome appointment' to all newly discharged patients within four weeks of discharge from secondary care with the primary care nurse or GP. This is an opportunity for the practice to start a holistic care plan developed for the project which should be reviewed at subsequent follow-up consultations.
- Conduct PSA blood tests and relay results to patients via a PSA consultation appointment using the bespoke PSA follow-up template specifically developed and designed for integration into EMIS and VISION clinical systems. This includes the use of validated tools to objectively assess symptoms such as lower urinary symptoms, erectile dysfunction, low mood and anxiety. Resources to promote self-management of other symptoms such as fatigue are also embedded in the template to facilitate signposting to appropriate resources.
- The risk of patients being lost to follow-up in primary care is mitigated by the introduction of a mandatory prostate cancer disease register.
- During the pilot phase, patients, GPs and practice nurses were invited to complete a survey and send directly to the Transforming Cancer Services Team (TCST) as part of a full evaluation process of the entire service.

### **Requirement from secondary care**

To stratify and potentially transfer patients for primary care follow-up on request by Croydon-based GPs. The GP will ensure suitable patients are identified according to criteria set out in the Patient Identifier tool and request formal transfer. Secondary care teams were asked to:

- Stratify patients requested for transfer by Croydon GPs.
- GP is notified of the decision regarding transfer within four weeks of request. The practice then informs patient regarding transfer of care.
- Secondary care to send standardised discharge/transfer letter (LCA-wide template currently in production) clearly outlining follow-up requirements, any consequences of treatment, red flags and re-referral criteria. It is recommended that a summary of the patient's holistic needs is included if available.
- To actively stratify Croydon patients that fit the watchful wait criteria and those stable two years post-surgery when patient attends outpatient/follow-up clinics.

## 5. Literature Scan

A literature scan of the English language literature on primary care follow-up of prostate cancer was carried out. The scope of the search included material from 2000 to date. This limit was set due to the changes in cancer services and survivorship initiatives that have developed in the last decade. The key words for the initial search were “prostate cancer”, “primary care”, “follow-up”, “stratification”, used in combinations using MEDLINE, CINAHL, INTERNURSE and the British Nursing index.

Additional material was also accessed as emerging themes came from the literature. The last electronic search for literature was carried out on 5 January 2016. The following themes were identified as common themes in the literature:

### **Models of follow-up in cancer: role of primary care in prostate cancer follow-up and comparison with traditional models of care**

Lewis et al (2009) conducted a systematic review examining the follow-up of cancer in primary versus secondary care. They include the follow-up of patients with breast and colorectal cancer. They are also then looked at studies involving the formal involvement of GPs in conventional follow-up of a range of cancers including prostate. The GPs involvement ranged from increased contact to a shared care programme but did not include the transfer of care to primary care. They could find no statistical difference in the quality of care of patients who were having primary care follow-up (breast and colorectal) and demonstrated no harmful effects of GP follow-up. It was noted that GP led follow-up was less costly. They also commented that education for GPs was a key consideration if planning for primary care follow-up. Although the systematic review was not looking specifically at prostate cancer it would seem reasonable to assume that the findings may apply to other tumour sites.

Differing models of prostate cancer follow-up are discussed in a number of papers. A Danish project (Lund et al 2013) demonstrates the feasibility of primary care led follow-up and willingness of primary care clinicians to carry out this role. They assert that there are no benefits to patients in remaining in secondary care led services once they are stable after treatment and suggest that their prostate cancer is best managed alongside their other long term conditions in primary care.

Hudson et al (2012) discuss the long term follow-up of prostate and breast cancer patients in an American Study. They focus on the patient's perspective of primary care based follow-up. Whilst this is an American study there are some pertinent points raised about patient's perception of primary care clinicians' lack of knowledge, that primary care clinicians are not experts in cancer care, that their cancer care team knows their history, and that their primary care clinician has not been involved in their cancer care to date. Patients generally felt their care could be transferred to primary care 'when enough time had passed' and some saw this as acknowledgement that their cancer was in remission.

The work of Pearce et al (2015) 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 five and then discharge to a GP; NICE guidance based with discharge to a GP at two years if stable; and European Urology Association guidance with long term hospital based follow-up. Each follow-up schedule had slight variation in the frequency of PSA follow-up but all had yearly PSA and follow-up after year three. 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 the current cost. Pearce et al acknowledge that their cost comparisons did not include comparisons of other models of secondary care follow-up (e.g. nurse-led or remote surveillance) which is a limitation.

McIntosh et al (2009) carried out a systematic review of international guidelines of the follow-up of men with prostate cancer and the role of primary care. They included 18 international guidelines (UK, European, and North American). All of the guidance include the role of PSA blood test but differ in the recommended intervals between the tests. These differences tended to be more in the early stages of follow-up, with reduced variation later on (after five years). There is also a lack of consensus on the use of digital rectal examination both after curative treatment and in watchful waiting. They conclude that there is a lack of evidence to guide the follow-up of prostate cancer and that there is a need for robust primary research to improve the evidence base for prostate cancer follow-up, particularly to guide the best practice models of care.

### **Role of nurses in alternative models of follow-up**

The use of specialist nurses in the follow-up of patients living with cancer is well established in the UK. Cox and Wilson's work (2003) demonstrated nurse led follow-up of stable patients

with prostate cancer was safe and patient satisfaction was good. Macintosh et al (2013) demonstrate the acceptability to patients of nurse led follow-up for breast cancer.

The role of nurses in primary care fulfilling a similar role in cancer follow-up is novel and the literature search revealed no examples. However, in the United Kingdom the role of primary care nurses providing on going follow-up for other long term conditions (asthma, diabetes, COPD etc.) is well established and accepted by patients and other health care professionals (Kendall et al 2010).

### **Supportive needs / consequences of treatment and the role of primary care**

Ream et al (2008) carried out a multicentre study in England looking at quality of life indicators of 749 men with prostate cancer in their first 24 months after treatment. The men had had a range of treatments including radical prostatectomy, radiotherapy, brachytherapy and hormone treatment and no treatment (watchful waiting). They concluded that there were high levels of unmet needs in patients with prostate cancer with a number of predictors for poorer outcomes (these included older age, multiple treatment types, and a pre-existing history of depression). They observe that many men are reticent in expressing unmet needs (especially around sexual function, low mood, and urinary symptoms) and recommend the use of a screening tool to identify individual needs.

Theoretically the wide spread use of Holistic Needs Assessments in secondary care prior to transfer to primary care would ensure that unmet needs were at least identified. The use of such assessment although a part of the recovery package, is not currently universally offered to patients. For example the completion rate of HNA within 30 days of diagnosis of a urological cancer in Croydon is 5.1% and Royal Marsden 80.2% (Transforming cancer Services Team 2015). Across London there is large variation in achievement of the 60% target. Ability to meet this target is likely to depend on local factors such as availability of a Clinical Nurse Specialist, and access to electronic HNA for example.

Khan et al (2011) looked at the role of primary care in meeting the unmet needs of people living with and beyond cancer through a qualitative study. This included patients with breast, colorectal and prostate cancers some of whom remained in secondary care follow-up and some for whom their care had been transferred. They identified a number of unmet needs related to their cancer and reluctance from patients in accessing primary care to meet these needs. The reasons given ranged from feeling the GP did not have the time, GPs not being the experts and lack of continuity of care within the primary healthcare team. In addition this

was compounded by secondary clinicians giving patients 'permission' to contact them directly if they had any concerns even after discharge from their service.

A number of the patients welcomed the idea of their GP raising the cancer diagnosis when they attended for review of other conditions, and welcomed attending a cancer care review where they knew the GP had time to discuss any concerns. The authors also recommend flexibility in appointments systems to allow patients to see the same clinician so that continuity of care can be achieved.

Walter et al (2015) surveyed 500 GPs in England to determine their views regarding survivorship care. In particular they looked at GPs role after recent active treatment and care beyond this. They highlighted a number of issues: firstly, GPs were less likely to consider a patients cancer diagnosis when the diagnosis was more than ten years ago. This was of particular relevance when assessing bone health, cardiovascular risk and consequences of treatment. They conclude that there was an education need for GPs around long term consequences of their cancer treatments, but also that their work demonstrates the importance of communication from secondary care in the form of treatment summaries and sharing of holistic care plans.

Jefford et al (2013) explore the enablers to developing post treatment care in England to address the needs of those living with and beyond cancer. They conclude that redesign of services is needed to promote faster and more comprehensive recovery, fewer patients in routine follow up, increased self-management, better access to services to address the consequences of treatment and they emphasise the importance of on-going care outside of hospital (primary care) in order to reduce the risk of unplanned admissions.

### **Summary of literature scan**

There is evidence to support the follow-up of stable prostate cancer in primary care. The literature demonstrates that this is feasible and economically cost effective

The need for the preparation of clinicians in cancer follow-up in terms of education is apparent.

There are well known unmet needs in this patient group that could be addressed by primary care. The use of holistic needs assessment tools would help patients identify their unmet needs and help facilitate their consultations in primary care.

The role of nurses in cancer follow-up in secondary care is well established but this is a new role in primary care. Primary care nurses have experience in skills in the management of long term conditions as their roles have developed to meet Quality Outcome Frameworks measures. It is hypothesized by the project team that these skills could be transferable to prostate cancer follow-up with support and education.

## **6. Data Collection and Analysis**

At the start of the project, the number of primary care managed patients with prostate cancer was unknown. The data presented below was collected from a number of sources. Initial data was collected by practice visits and case finding by the project team. A search was run to identify all patients with prostate cancer registered with each practice (see Appendix 4 for the patient identifier tool which defines the search terms).

As part of the planning process the project team met with lead secondary care clinicians in order to discuss the transfer of suitable patients. Whilst the lead clinicians in both trusts were committed to transferring patients who met the NICE criteria, they were unable to systematically identify suitable patients. They agreed to consider transfer when patients attended their outpatient appointments. This was dependant on all members of the team being aware of and supportive of the project aim to transfer patients to primary care. This also meant that the transfer of patients would be slow process as patients attended appointments only six monthly or yearly. It was therefore agreed that primary care teams would identify patients who met the NICE criteria and that secondary care clinicians would then risk stratify those patients on request.

The project team worked with the practices to identify suitable patients met the LIS criteria as suitable for primary care follow-up (stable two years after radical treatment or on watchful waiting).

205 patients were identified who were under secondary care but met the LIS criteria as above. The project focused on Croydon University Hospital and the Royal Marsden. 155 patients (76%) were identified who met the criteria and attended those two trusts. The remaining 50 patients were attending other trusts across London.

Croydon GP practices were then asked to request transfer of those suitable patients from secondary care. A template letter was used for this (see Appendix 4 for transfer of care letter). During the project period, 87 transfer letters were sent to secondary care and 48

letters (55%) were received back confirming that the patient was transferred. Primary care teams varied in their efficiency in sending the transfer requests to secondary care which is why 155 letters were not sent at one time. The project team liaised with secondary care at regular times to ensure they had the capacity to respond to the transfer letters in a timely manner.

The reason why primary care received written confirmation for only 55% of patients is because different process for transfer was agreed with the two participating trusts. Croydon University Hospital agreed to transfer suitable patients on receipt of a letter whilst Royal Marsden agreed they would see the patient prior to transfer. The remaining confirmations of transfers will continue to be sent to the practices as those patients are reviewed.

	Start of project	End of project
No of new patients identified all trusts	205	N/A
No of new patients identified CUH/RMH	155	N/A
No. of transfer letters sent	N/A	87
No. of transfers letters back from secondary care	N/A	48
No. of welcome packs sent	N/A	70
No. of welcome appointments	N/A	49
Total number on primary care follow-up	450	527
Lost to follow-up	57*	
Lost to follow-up recalled	n/a	34
Prostate cancer register set up	1	36

*\* 57 patients lost to follow up were identified at the **start** of the project and were historical patients having primary care follow up under the old local enhanced scheme.*

Whilst 48 transfer letters were received back the data collected from the practices, Croydon CCG claim returns indicate that 70 patients were transferred from secondary care during the project period. We have used the number of Welcome Packs sent as a proxy figure for newly transferred patients. This figure differs from the number of transfer letters received, this may be because they are additional patients identified by the trusts as suitable for transfer or they may have been patients at other trusts who had subsequently been transferred

The speed of transfer from secondary to primary care is dependent on a number of factors. In our model, with primary care identifying and subsequently requesting the transfer from secondary care we were dependant on the practices completing this task in a timely manner. No payment was made to the practice until the patient had been transferred and the patient was seen in primary care for their first appointment. In some practices the process of requesting transfer was slow to complete due to competing priorities. Secondly the speed of response from secondary care was variable. The urologist at CUH and oncologist at RMH did not have dedicated time to complete a review of the patient record and respond to the requests. This was a potential barrier to a timely response. In addition the process agreed with RMH involved the patient being seen in clinic before the transfer was agreed. If the patient's next appointment was for example eleven months away (if on yearly review) then a delay was inevitable.

Of those 70 patients who were sent a Welcome Pack, 49 welcome appointments (70%) were carried out. This data was collected from practice returns to the project team and claims to Croydon CCG. Patients receiving Welcome Packs were offered a Welcome Appointment but some patients may not have wanted it, or it may have not been booked during the project period.

The total number of patients identified as already being in primary care follow-up at the start of the project was 450. This data was collected through the case finding completed by the project team or the practices themselves. The project team reviewed the records of all those patients having primary care follow-up to ensure they met the criteria for the LIS, were having their PSA/ regular reviews, and that their PSA result was being appropriately interpreted and acted upon. As a result of the case review a number of issues were identified: patients lost to follow-up, misinterpretation of PSA values, patients on active surveillance released to secondary care. These are explored fully in Section 5.

Of those patients lost to follow-up (n=57), this was defined as patients receiving a delayed PSA result longer than six months. The reasons for patients becoming lost to follow-up are explored in Section 5. They include: the discharge from secondary care being overlooked by the practice, the patient travelling abroad for long periods; patients not attending planned appointments (and having unscheduled contact with primary care only). The project team left advice for the practice clinicians regarding these patients to ensure that they were contacted and attempts were made to recall them. At the end of the project, 34 patients (60%) had been recalled and PSA/review performed. 23 patients remained lost to follow-up. Croydon

CCG has now taken responsibility for writing to those practices to ensure all measures have been taken to attempt to recall the patients.

### **Recommendations**

*Case finding in primary care is a time consuming process. For a list size of 10,000 it could be expected to take around 3-4 hours. In this pilot, the project team were able to provide support with this process. If this resource were not available then payment for this should be considered by the CCG when designing the Local Incentive Scheme.*

*The speed of transfer could be helped by a financial incentive up front to both complete the case finding and send transfer requests to secondary care. This would also help engagement with practices to encourage sign up to the scheme.*

*Alternatively, case finding in secondary care would ensure a more streamlined and faster process provided that secondary care teams were committed to the task and had dedicated time to complete the administration. A standard process could be put in place to ensure patients were aware of the transfer of care and could be prepared for it by their oncologist/urologist/clinical nurse specialist.*

*The speed of transfer should be considered when predicting potential financial savings. Although the project team identified 155 patients in the two trusts that were engaged with, less than 50% were transferred during the project period (12 months). Clearly the faster and smoother the process, the quicker savings can be realised in the local health economy.*

## **7. Patient Safety**

### **Patients lost to follow-up in primary care.**

Case finding by the project team was carried out in 51 out of 59 practices (86%). Case finding support was offered to all practices along with a visit from the project clinicians. 57 practices (96%) were visited. The remaining two practices declined to sign up to the incentive scheme. Six of the practices visited declined support with case finding. Those practices have been asked to supply data to the project team as part of the evaluation process and were directly asked if they had patients that had been lost to follow-up in primary care. We defined lost to follow-up as no PSA following transfer from secondary care OR PSA tests delayed by longer than six months. We identified 57 patients (10.5%) as being lost to follow-up in primary care. This was out of a total of 450 having primary care follow-up.

### **Prostate cancer disease registers**

On commencement of the project only one practice had a prostate cancer disease register in place. This enabled the practice to record of all their registered patients with prostate cancer outlining who was responsible for their follow-up (secondary or primary care) and when their PSA follow-up was due. It also provides a summary of treatment received and threshold for referral back to secondary care (taken from guidance provided by secondary care). This particular practice had no patients lost to follow-up and had a robust system in place to recall patients who did not attend for their follow-up appointments. It also enabled them to identify patients who had defaulted from or been lost to follow-up in secondary care.

The template of a standardised register has now been shared with all practices within Croydon CCG. The project team has helped practices set up their register when they have completed case finding. A discussion also took place with practices as to who would maintain the register once it was set up. Practices that had a disease register in place prior to the commencement of the project had no reported patients lost to follow-up. Having a register therefore seems to be a means of ensuring there is a clear list of patients having primary care follow-up, with a record of when their next prostate cancer appointment and PSA bloods are due. At the point of data collection in December 2015, 36 practices (60%) had disease registers set up. Setting up and maintaining a register is now a requirement for claiming under the Local Incentive Scheme and the CCG will continue to work with practices to implement the register.

For those patients that had been lost in primary care, clear recommendations for action were given by the project team to the GP lead for prostate cancer follow-up in the practice.

The CCG has agreed to follow-up by letter to ensure that these instructions were acted upon and that those patients are now receiving appropriate follow-up care for their prostate cancer.

**Recommendation:**

*The number of patients lost to follow-up is a concern. It is important to note that these patients were lost before the project commenced when there was no standardised process in place to safeguard against this. The use of a disease register for prostate cancer with an identified person responsible for its administration is a means to mitigate against this risk. We have been unable to test this during the project period, however and it is therefore a recommendation that the CCG audits the number of patients lost to follow-up in the year 2015/16.*

*CCGs designing a local incentive scheme for prostate cancer follow-up should consider using a disease register as a method of enabling practices to organise the follow-up of patients. In addition, consideration should be given to the use of software solutions that may be available whilst designing a follow-up service*

*When setting up an incentive scheme, developing and maintaining a register as a condition of payment will help mitigate against the risk of 'losing' patients. In addition the use of read coding a diary entry at month six or month twelve is another safeguard. A search can be performed monthly to see which patients are due their follow-up. This may be more appropriate for larger practices that are following up larger groups of patients.*

*The use of PSA tracker schemes which are managed by primary care may be another safeguard against the risk of losing patients/ having delayed follow-up. There would need to be clear governance arrangements in place for the use of such software (for example who is running the checks, or who is responsible for updating patient information such as change of address).*

## Active surveillance patients transferred from secondary care

Through the process of case finding the project team identified five patients (1.1%) who had been transferred out of secondary care despite their clinic letters indicating that they were on active surveillance. The LIS specifically excludes active surveillance for primary care follow-up. Figure 7 outlines the definitions of active surveillance and watchful waiting.

*Active surveillance (AS) programmes aim to offer men the option of avoiding immediate surgery or radiotherapy and their adverse events with disease monitoring, so that those whose disease remains stable can avoid intervention and those whose disease progresses can have curative treatment (Wade et al 2015)*

NICE (2014) outlines a clear structure for active surveillance follow-up which includes a repeat TRUS biopsy at 12 months, DRE every 6-12 months and PSA monitoring 3-6 monthly. NICE advises that this may be carried out in primary care but only if there are shared care protocols and recall systems in place. In addition an understanding of PSA kinetics, and expertise and confidence in DRE would be required.

There is no local shared care agreement for active surveillance in Croydon. The transfer letters for these patients were not explicit in the follow-up care that the patient required or when to seek advice.

The five practices where the patients were registered were advised that the patients' care needed to be discussed with the lead urologist at the local trust with a view to transfer back there for their care. The lead urologist was made aware of the issue and planned to follow the patients up. Croydon CCG was asked to write to the practices concerned to ensure that these patients were discussed with the urologist to formulate a plan for their future care.

**Recommendation:**

*Locally, patients with active surveillance should remain in secondary care unless there is a robust pathway developed for this patient group whereby care is shared with secondary care. Explicit guidance about the care required and when to seek advice/ transfer back to secondary care also needs to be provided to primary care.*

*The project identified that clinicians confuse the terminology of watchful waiting and active surveillance (including secondary care urologists). Education for primary care clinicians must include clear definitions of the terminology.*

**Misinterpretation of PSA results**

Through the process of case finding, the project team clinicians were able to identify that there were varying skills in interpreting PSA results in primary care.

One issue was the lab comments indicating a 'normal range'. If this is applied to patients who are on 'watchful waiting' or who have had radical treatment then an incorrect 'normal' or 'abnormal' may be applied. For example a patient had a radical prostatectomy and was transferred to primary care with a PSA of 0.03ng/ml, and had subsequent test results of 0.1ng/ml, 0.5ng/ml, 1.0 ng/ml (with six monthly intervals). If the clinician used the lab comments as a reference they would be falsely reassured about the patient's detectable and rising PSA.

The quality of the transfer letter from secondary care will also impact upon decisions made in primary care. If the above patient had a transfer letter that stipulated transfer back to secondary care if their PSA increased over 0.1 (for example), then this would inform decision. If no such guidance existed, the primary care clinician will make a clinical judgement of when to be concerned.

**Recommendation:**

*Lab comments should stipulate that the reference range does **NOT** apply in the context of patients post treatment for prostate cancer or if watchful waiting.*

*Education for primary care clinicians should include interpretation of PSA in the context of prostate cancer treatment.*

*Transfer letters / treatment summaries from secondary care must include a PSA threshold (appropriate for the individual patient) for transfer back to secondary care for all patients who have been treated.*

## Read Coding

Through the process of case finding, the practice team identified that read coding for prostate cancer was inconsistent across practices. There were examples of practices not read coding a prostate cancer diagnosis for several patients, one of whom was receiving Goserelin injections at the practice. In other practices there was the use of both carcinoma in situ and malignant neoplasm of the prostate by different clinicians.

There are obvious safety issues for patients due to poor read coding. In addition, running searches became more complex when there was no uniformity in terms of read coding with the risk of missing patients. With the increasing use of cancer risk tools such as Q-cancer, read coding for both symptoms and diagnosis is an important component to its usefulness as a tool to assist with early detection of cancer. This patient group will be at risk of both reoccurrence and second cancers and therefore this is highly relevant.

**Recommendation:**

*The issue of standardisation of read coding and good practice are beyond the realms of this project. Recent work by London Cancer (Bhuiya 2015) provides some clear guidance that would promote good practice on read coding.*

*In addition, Cancer Research UK provides training to primary care clinicians in London (including Croydon) on safety netting which will include good practice on read coding.*

## 8. Quality

### 9.1 Patient Experience

#### Methodology

A patient experience questionnaire (Appendix 2) was sent to all newly discharged patients as part of their Welcome Pack from primary care. This was a standard questionnaire that was designed by the project team and the Transforming Cancer Services Team's User Involvement and Patient Experience Coordinator. A cover letter was sent with the survey explaining to patients why the survey had been sent and that the results were confidential and would not be identifiable when reported. The results were sent directly back to the TCST team using a stamped, addressed envelope supplied by the GP practice. Patients were asked for permission to contact them for a second survey after their first follow-up appointment.

A second survey (Appendix 2) was sent out after the first follow-up appointment in primary care. This was based on information given in the first survey. The TCST sent the form directly to the patient with a stamped, addressed envelope.

On collation, each respondent was given a code so that the results could be anonymised for evaluation. Information was stored on a secure drive on a password protected computer. The paper copies of the results were stored in a locked cupboard.

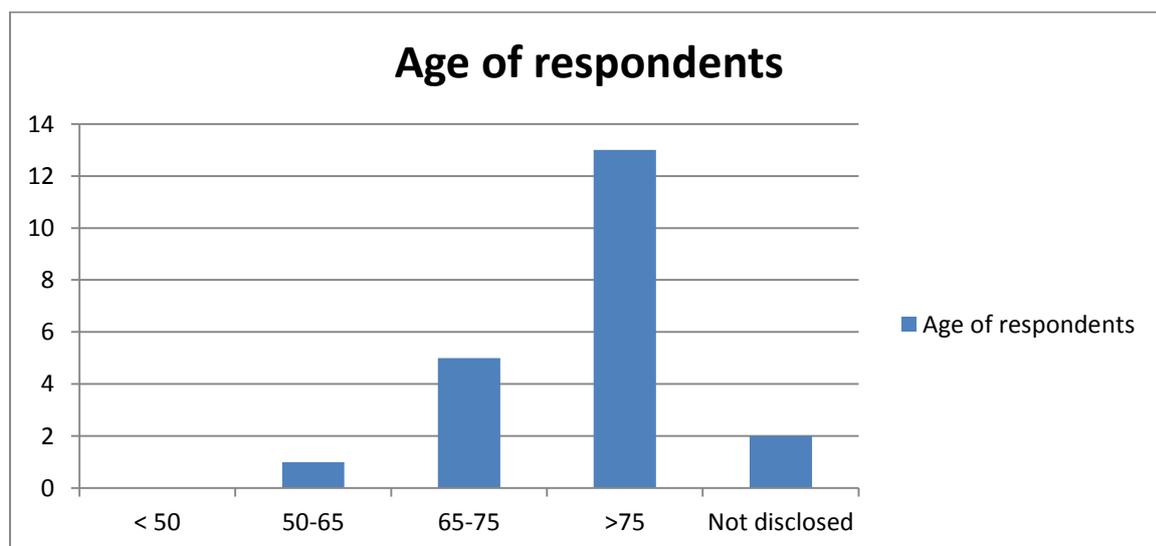
The results from the surveys were analysed by the project team and the findings are presented below.

## Findings

### Survey 1 – at the point of transfer

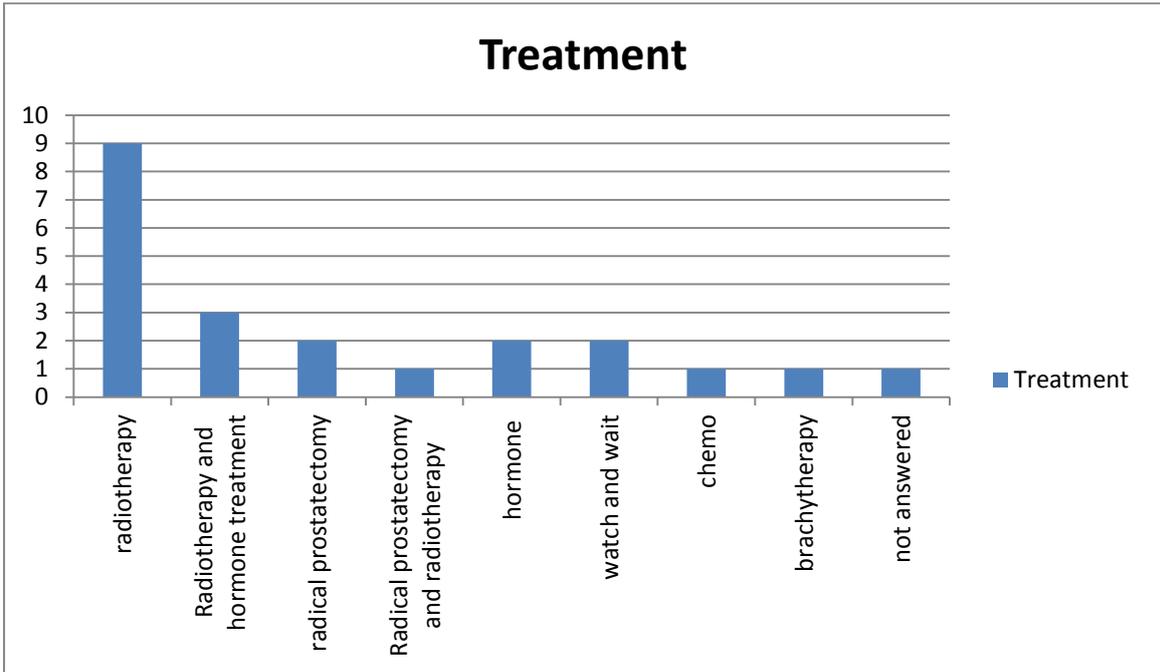
Survey 1 collected data from the patients at the point of transfer from secondary care. They would have received the Welcome Pack at this point that included a welcome letter (Appendix 4), Survey 1 and the prostate cancer care plan (Appendix 4). A total of 22 surveys were received back from patients. As the project data collection indicates that 70 patients were transferred to primary care during the course of the project, this represents a 31% return rate. This rate is recognised in academia as a reasonable level on which to use results.

**Question 1** asked the patient's date of birth. The age of respondents is shown below. The majority of patients were over the age of 75.

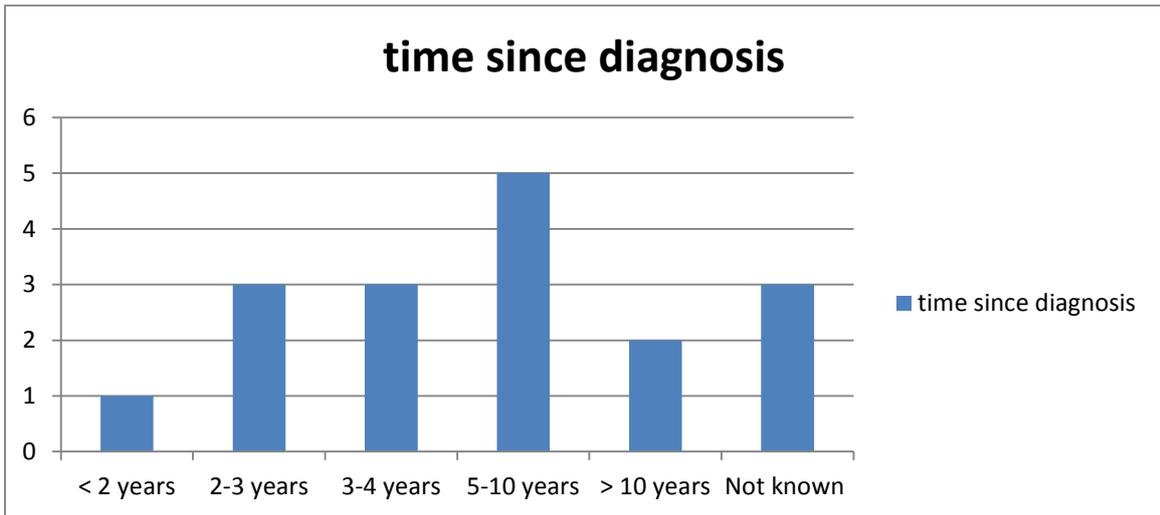


**Question 2** asked the type of treatment the patient had had or was receiving for their prostate cancer. This was left as a free text section.

The majority of patients had radiotherapy treatment. It is assumed that those patients had had only short course hormones, and those who indicated radiotherapy and hormones had a long course of hormones. However as this was not asked in the question, the conclusion is not clear.

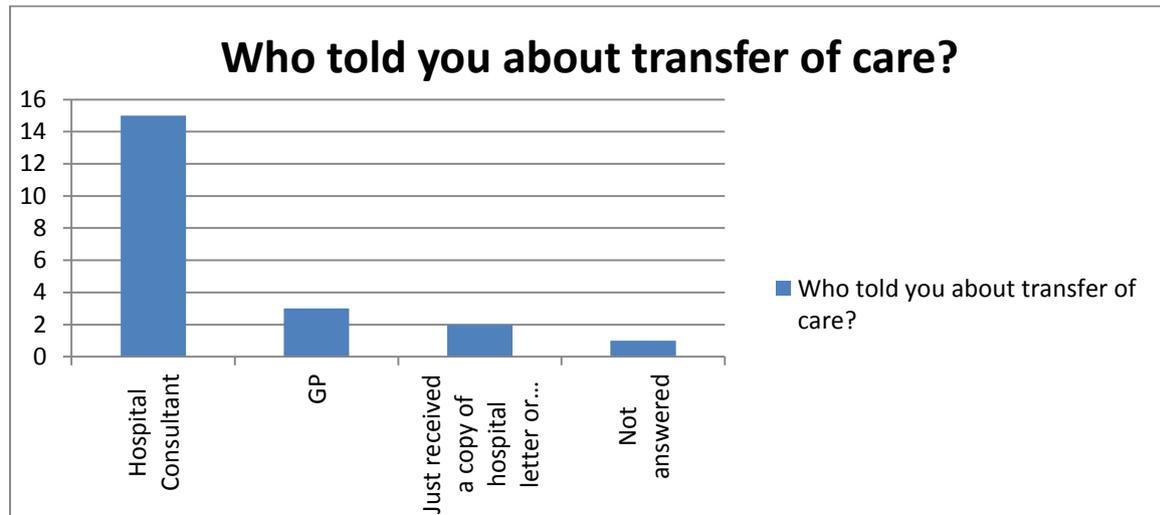


**Question 3** related to the time since diagnosis. Most men had been diagnosed for more than five years. This is significant as this means they had been attending secondary care for a long period of time for their follow-up. The possible move to primary care would not have been planned in the early days of their diagnosis as this is a relatively new development. This may then be expected to have a possible negative effect on the acceptability of the transfer of care.



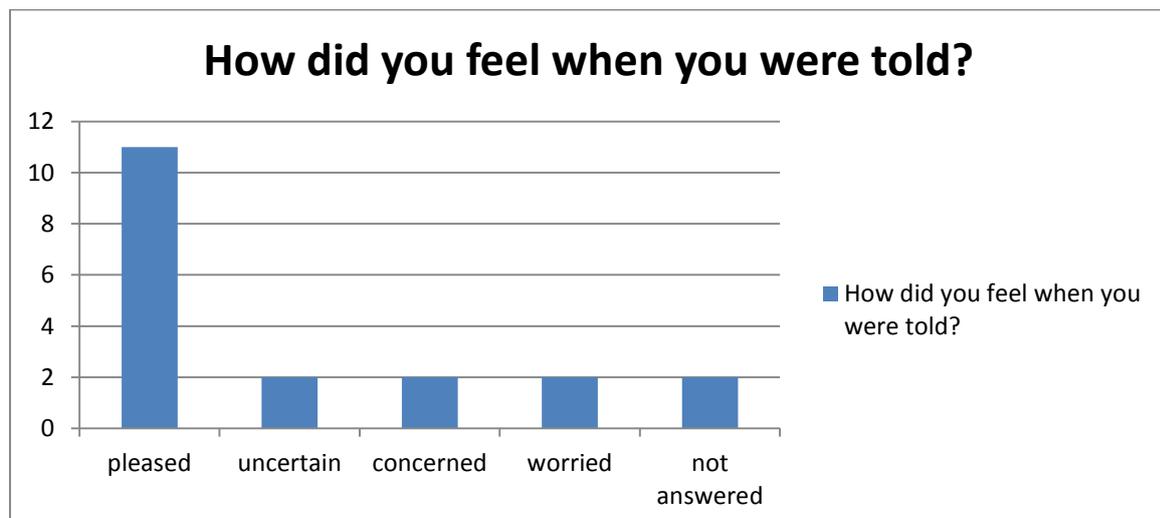
**Question 4:** Who told the patient about their transfer of care?

The majority of patients were told by their hospital consultant about the transfer of their care. A few did not know about it until their Welcome Pack arrived in the post or they were copied into a letter from the secondary care consultant to their GP. This indicates that not all of the GP practices were following the agreed process to let the patient know about the transfer of care in person or by phone before sending out the transfer letter.



**Question 5:** How did the patient feel when they were told?

The next section was free text asking the patient to explain their feelings towards the transfer. Half the respondents were pleased and the remaining half were uncertain, concerned, worried or did not answer this question.



A thematic analysis of answers produced the following:

Those patients who were pleased to be transferred, the common themes include less travel and increased convenience:

*'Feeling as if at home'*

*'Not so far to travel, I don't mind which doctor sees me'*

*Because I have known my GP for over 25 years and their surgery is very local. Furthermore although I am 74 years old I still work full time and when I attend appointments at the outreach dept. of the Marsden at CUH I sometimes waited for over 2 hours whereas I am always seen promptly at GP surgery.'*

Confidence in their GP was also commented on as a positive reason:

*"Because I have great confidence in my GP as he is the one who first noticed I might have a problem and referred me to [a] urologist"*

*"Feeling relieved the treatment was completed and entering the next phase"*

*"I felt I am free or (in) remission for the cancer"*

*'To know the treatment is finish (sic)'*

Those patients who indicated they were uncertain, concerned and worried, the common themes were:

Feeling confused as they had not been told directly:

*"I heard about it in a letter from Prof XXXX on 14th to Dr XXX (GP). I had never heard of Dr XXX and had no further information about the follow-up until receiving this. It seemed rather off-hand".*

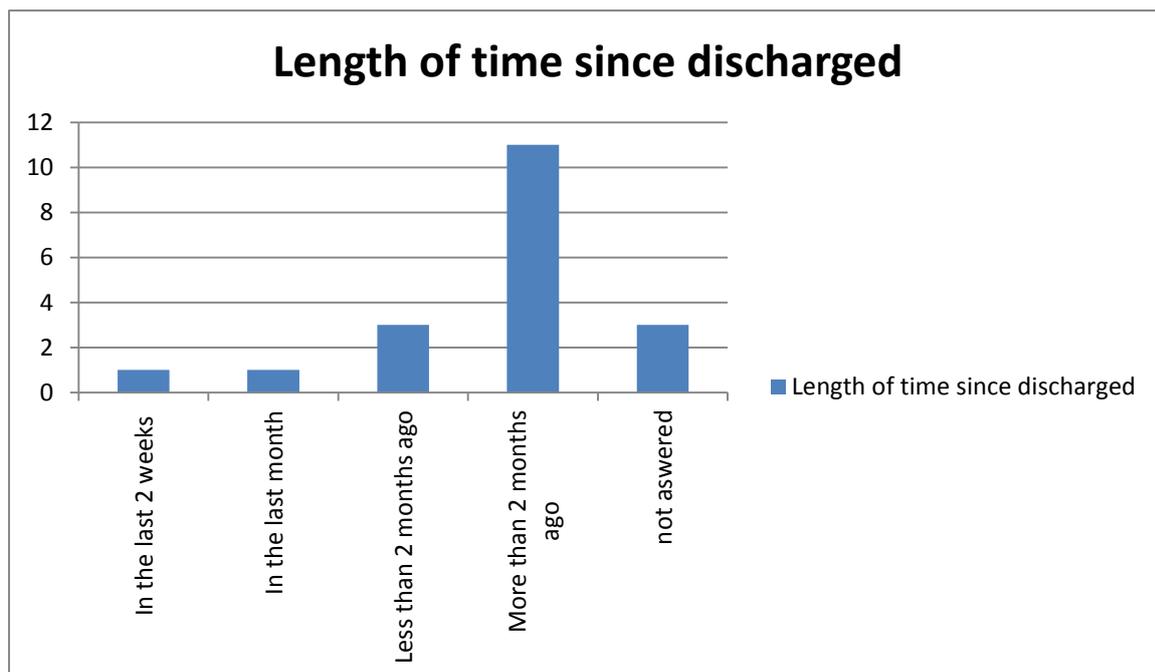
Feeling concerned that the new system would not be as good as secondary care follow-up:

*“when I noticed my hospital ref no on the blood form was wrong. Not a good start to have confidence in the new system. Have always been very pleased with the brilliant service from the Marsden Sutton, over the past 17 yrs”*

Some of the concerned or worried comments seemed to relate to how they were feeling about their cancer rather than to how they felt about the transfer of care:

*“worried about the long term effects of the cancer, although I had been told and assured that the cancer had been removed from my prostate gland”*

**Question 6: When were you discharged from the hospital to your GP?**



Although all these patients are newly transferred patients from secondary care the majority were transferred more than two months ago. This may reflect the time between their hospital clinician telling the patient they were being transferred and their GP practice being informed and the letter sent out.

**Question 7: What do you think about the information you have received from your GP with this survey?**

This was a free text box. It related to the information in the welcome pack (see Appendix 4).

Mostly patients liked the information contained in the welcome letter:

*“Very encouraging and supportive”*

*“Very good”*

*“Great”*

*“It was very constructive and useful”*

Some patients felt they had already been given or knew the information contained in it:

*“It was helpful although much of the content was already known to me”*

*“Nothing new, signs and symptoms and info has already been given. I was not given a prostate cancer care plan.”*

One patient expressed their feelings about the transfer of care;

*“After receiving close personal treatment at Royal Marsden, I suddenly felt abandoned - which is of course ridiculous”*

This comment is of interest as it demonstrates the effects that transfer of care can have on patients and highlights the need for on-going personal treatment outside of hospital. Unfortunately this patient did not respond to an invitation to complete the follow-up survey after his first appointment in primary care.

**Question 8: Do you have any comments about having follow-up for your prostate cancer by your GP?**

This was mainly left blank. One patient was clearly worried about his cancer and the possibility of it returning.

***“Only that I am rather looking forward to it, in particular I am anxious to learn of the possible return of the cancer or if there is any likelihood of having cancer elsewhere.”***

Patients who had treatment were transferred only when they were stable and therefore the risk of reoccurrence is very low. This comment may reflect on the education and information given about the cancer to date.

The following patient was clearly pleased that his care had been transferred and in fact would have liked this earlier in the pathway:

***“I asked RMH to discharge me 2 years ago; I have had a blood test, PSA. I find this more convenient to go to my GP”***

One patient simply said: ***“It makes sense”***

## **Survey 2**

The second survey was sent to those patients who indicated that they were happy to be contacted after their first follow-up appointment in primary care. The aim of the second survey was to get feedback on both their welcome appointment and first follow-up appointment in primary care with their PSA result.

Unfortunately due to the time scales of the project and patients being transferred at varying points only eleven patients were eligible for a second survey. Seven completed surveys (64%) were returned to the team. Due to the low volume, the quantitative data from these questionnaires is therefore difficult to analyse or generalise from. The project team had used the qualitative data below.

A patient comments on his welcome appointment:

***“My doctor was extremely helpful and spent over half an hour talking to me”***

The welcome appointment is funded for 30 minutes and is intended to provide an opportunity to discuss any unmet needs at the point of transfer to primary care. The patient should have received a welcome letter and prostate cancer care plan prior to the appointment. The prostate care plan is completed before this appointment so it can be used as a focus for discussion.

Another patient commented: ***“I brought up lots of things that were concerning me”***

The decision as to which clinician provides the Welcome Appointment is made by the GP practice team. The project team provided guidance that it could be a GP, primary care nurse or allied health professional. Clearly knowledge around the possible issues that may arise in the consultation would inform the decision making about who should carry out the appointment, as will capacity within the team. The recommended educational modules are suitable for GPs, Nurses and AHPs.

One patient was disappointed about his welcome appointment:

***“Nurse pleasant, but said 'refer to your GP' to any queries I had. Did not seem informed...poor - as used to seeing specialist doctors at hospital who always answered any query in full detail with latest knowledge”***

This comment reflects the importance of adequate education for all clinicians carrying out both welcome and follow-up appointments. Clearly patient's confidence in primary care taking on their follow-up will be undermined if they feel the clinician is inadequately prepared or informed.

### **Other Engagement with users**

Additionally the project team also worked with Purley prostate cancer patient support group ([www.sechc.org.uk](http://www.sechc.org.uk)) in order to gain patient feedback on the redeveloped pathway and materials designed to support patients. The project team attended several support group meetings, initially to present the proposed new pathway, and to discuss the welcome letter, and prostate cancer care plan. A number of patients were very keen to meet with the project GP to discuss primary care issues (interpretation of PSA results, PSA testing, communication with their GP and primary health care team). This was arranged and was well received by the patient group.

The comment below is from a patient relating to the welcome letter:

***“Speaking as a patient, I think the letter's excellent: well laid out, and containing a mass of useful information.”***

## Limitations

The initial survey was designed to be sent out to all newly transferred patients with the Welcome Pack. The project team were dependant on the GP practices in sending this out and including a stamped, addressed envelope for the patient to return the survey to the TCST team. It is unknown if a survey was sent to each patient and if a stamped, addressed envelope was included. 22 initial surveys were returned out of a possible 70 giving a response rate of 31%.

The second survey aimed to capture feedback after the Welcome Appointment and first PSA follow-up appointment. The speed of transfer from secondary care to primary care and the limited length of the project meant that a second survey could not be sent to each of the patients who had completed the initial survey. There were seven second surveys received which makes generalisation of the results difficult. Whilst accepting its limitations, the patient experience data provides a valuable insight into the needs of patients at the point of transfer to primary care.

### Recommendations

*The following recommendations are made to CCGs who are redesigning their care pathways for this patient group to provide primary care follow-up:*

- Processes need to be in place to inform patients, in person, about the decision to transfer care. Where this decision is secondary care-led, this may be easier to achieve. Secondary care clinicians should explain to the patient early on in the pathway that their care is likely to be transferred to primary care at some stage (eg watchful waiting or active surveillance).*
- Provide good quality information at the point of transfer. This may be secondary care delivered (e.g. health and well-being event, CNS end of treatment clinic, or discharge seminar) or delivered by primary care. Ideally a redesigned pathway would include this within both settings with uniformity of delivery (e.g. joint logos Secondary care provider/ CCG on behalf of primary care).*
- Clinicians need to have completed the required educational modules and be confident and competent in follow-up of this patient group. Mandatory completion of modules as part of LIS and use of protected learning time events for both GPs and Primary Care Nurses would help facilitate this.*
- Resources developed to support primary care clinicians as part of this project are made available to other CCGs to adopt or adapt to their local needs.*

## 9.2 Clinicians Experience

An initial survey was sent to all clinicians in Croydon at the start of the project in order to understand and identify their understanding and learning/ education needs around prostate cancer and management in primary care.

The survey provided a useful insight into the learning needs of primary care clinicians around the follow-up of stable prostate cancer patients. It identified a number of key areas to be incorporated into the planned education intervention as part of the project. These included:

- An exploration of the terms 'Watchful Waiting' and 'Active Surveillance'.
- Guidance around which groups of patients may be suitable for primary care follow-up.
- Information on the long term side effects of treatment (radical prostatectomy, external beam radiotherapy, brachytherapy, and hormone treatment).
- Guidance on the significance of PSA rises and thresholds for re-referral to secondary care.
- Information on the 'red flags' for this group of patients and when to consider re-referral to secondary care.
- A discussion about the psycho-social and sexual health needs of this patient group and ways in which these needs may be met.

The respondents indicated mixed views on their preference for face to face or on line education. Whilst this was considered in the planning of the educational component of the project the resources available dictated that on line learning was the most viable option.

A number of resources were developed for the project to support clinicians in the follow-up process. These included:

- A template for EMIS/VISION to ensure standardisation of consultations
- A primary care nurses tool kit for primary care follow-up
- A prospectus of recommended online modules for clinicians to complete
- A number of template documents to reduce variation in all aspects of the process of primary care follow-up.

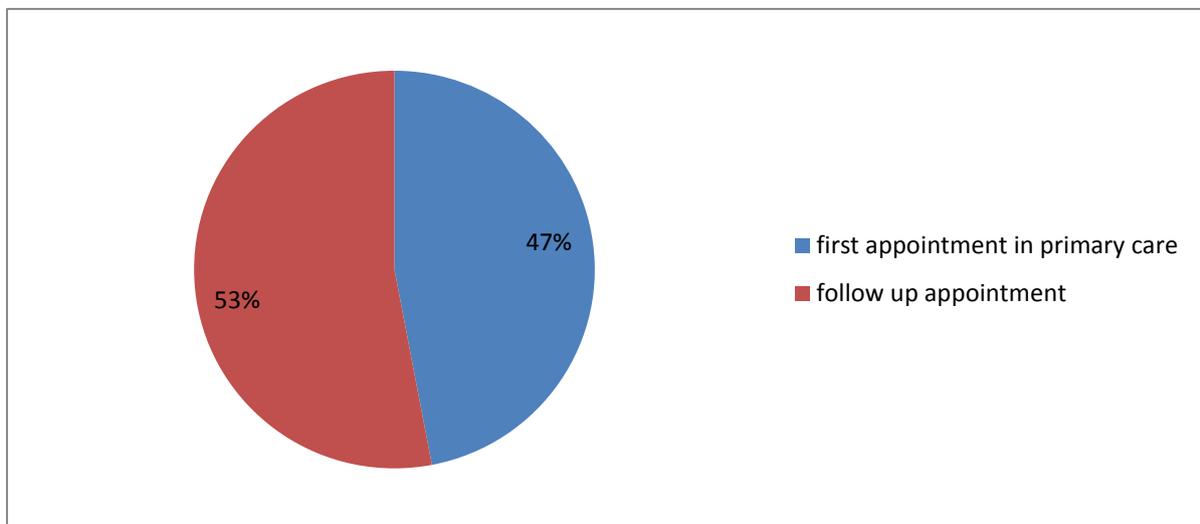
At the end of the survey period all clinicians and practice managers were asked to complete an anonymised on line survey in order to identify any clinical or operational issues, to gauge opinion on the new process and identify any clinical or operational concerns.

## Clinician's survey

A link to an anonymised survey was sent to all clinicians by a number of means (directly from the project team, through the CCG clinical engagement team, and via a CCG newsletter).

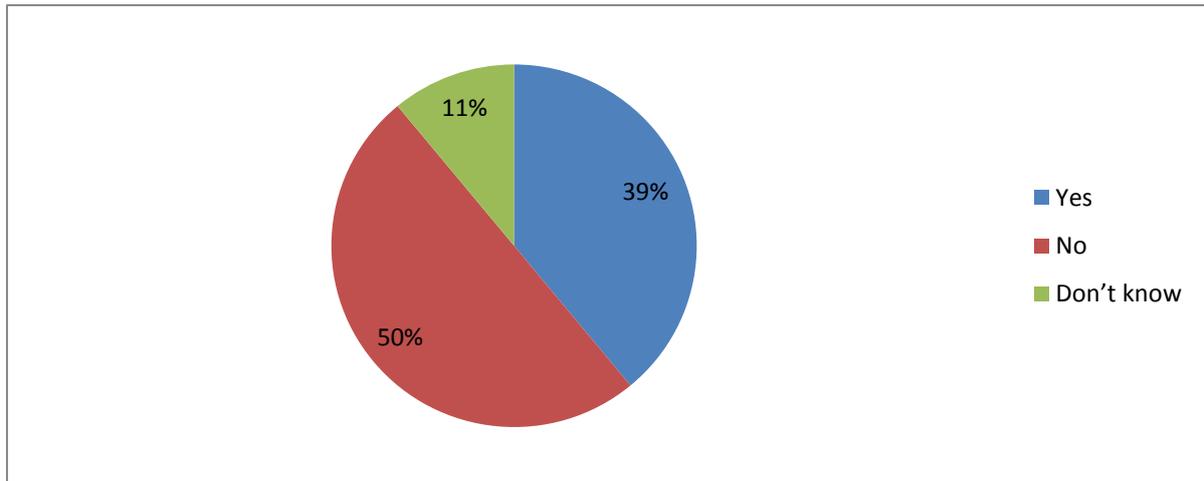
There were 36 responses received from primary care clinicians. 68 % were GPs, 16 % Practice nurses and 16 % Advanced Nurse Practitioners.

**The clinicians were asked about their last consultation with a patient who has/had prostate cancer.**



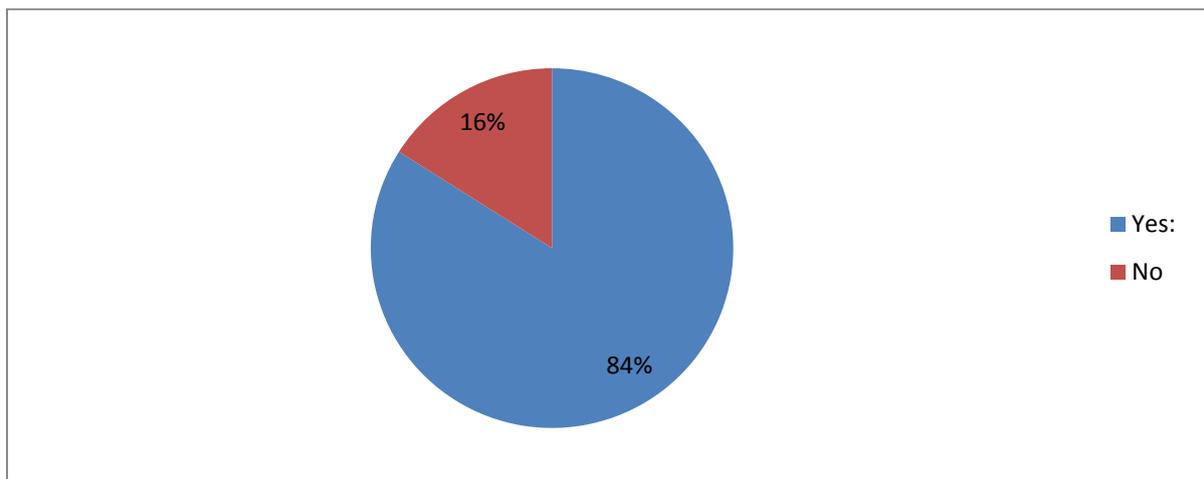
The prostate cancer care plan (Appendix 4) was developed to help patients identify their holistic needs before their initial appointment in primary care. The care plan was based on a tool developed by the Star project in Southampton and the London HNA tool.

### Did the patient bring their prostate cancer care plan?



The care plan template was tailored by the project team for patients living with and beyond prostate cancer in a primary care setting. It is sent to the patient with their Welcome Pack to bring to their initial welcome appointment in primary care so that this can form the basis of the holistic discussion. For those patients who were newly transferred (47%) only 39% brought their care plan. This may have been because they did not receive a welcome pack or because they forgot or declined to bring it to the appointment. Responsibility to bring the documents lies with the patient but theoretically it could be given to the patient at the time of the appointment if they had forgotten it.

### Did you use the EMIS/Vision template?



The template was developed for both EMIS web and VISION which are the two clinical systems used in Croydon. The aim of the template was to standardise the consultation, reducing variability, and as a means to enable clinicians to signpost patients to services/

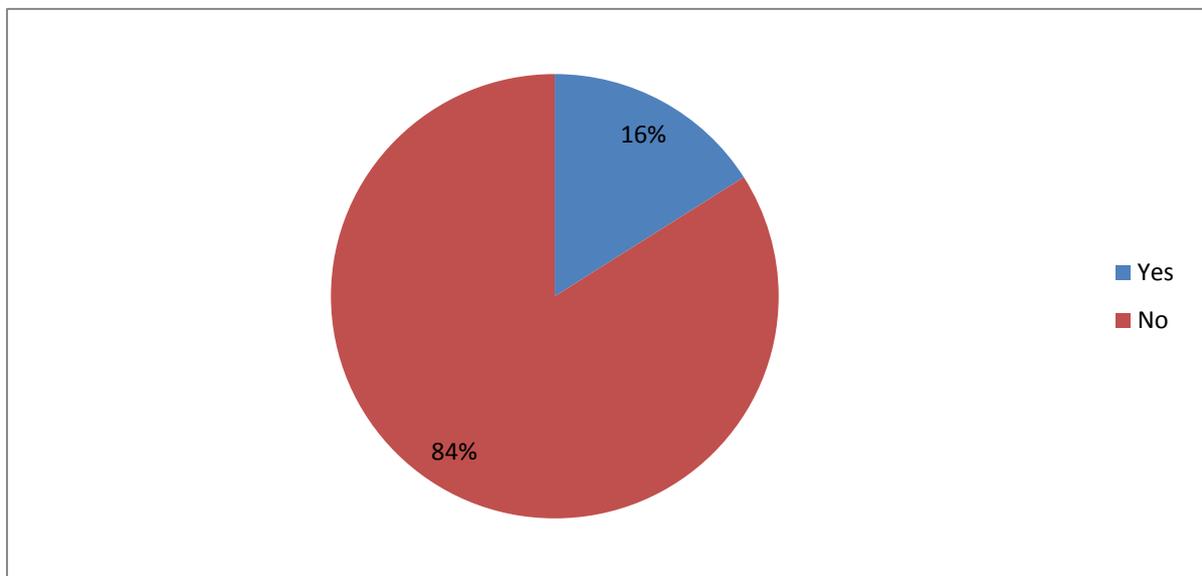
resources. The majority of the clinicians used the template. As a locally designed template it needed to be uploaded manually by the practices. Some practices needed assistance with this process.

### **If you used the template, did you find it useful to structure the consultation?**

Clinicians generally liked the template and felt it was useful to have links to local services. The template contains hyperlinks to support organisations and local pathways.

*“The template is excellent, very useful links to support services.”*

### **Did the patient bring up any subject you found difficult to deal with?**



Comment from GP: *“Sexual function- patient seemed uncomfortable discussing with female clinician.”*

It is positive that clinicians in the main felt comfortable raising issues such as sexual dysfunction and low mood with patients. The template provides clinicians with the link to the local pathway for treatment for erectile dysfunction, and tools to assess anxiety and low mood. The comment above may be of interest to teams planning their follow-up. A patient may be referred to another clinician to address specific needs identified (e.g. erectile dysfunction) according to availability and competence.

Have you received or seen the tools to support you in managing this cohort of patients?

Tool	Received and used	Received but not used	Not received	Not sure	Need clarification on the tools
Template	72%	18%	0%	5%	5%
Prostate care Plan	56%	28%	5%	5%	5%
Educational resources	72%	5%	5%	5%	12%
Prostate cancer register	72%	5%	5%	12%	5%

The resources for the project were distributed to the practices via the project team and via the CCG clinical engagement team. Ensuring that practices were aware of the resources and using them appropriately was a challenge throughout the project.

As discussed in section 5, the use of the prostate cancer register is now a requirement for the LIS.

The project team worked closely with Croydon CCG to ensure that the documents are widely available and they are now available via the DSX interface. This will ensure that clinicians have easy access to all the relevant files on their desk tops with an interface with their clinical system.

**If you have received and used the tools outlined above please rate them in terms of usability and appropriateness**

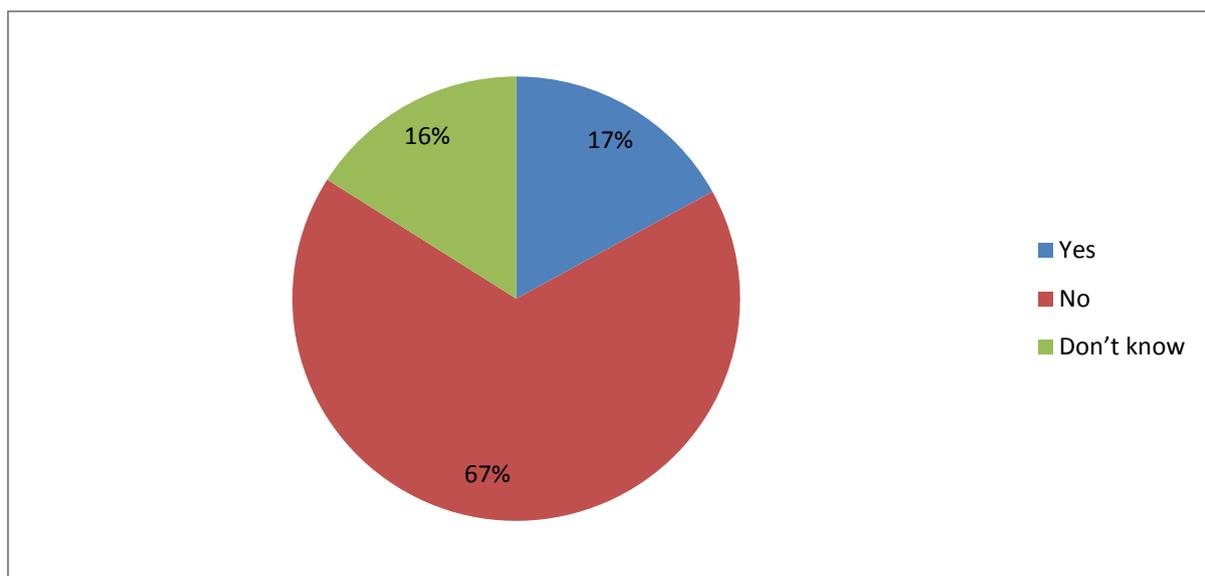
	Very useful	useful	Somewhat useful	Not useful	Have not used	Have not received
Template	44%	28%	17%	0%	11%	6%
Prostate cancer care plan	28%	22%	17%	6%	17%	11%

<b>Prostate cancer register</b>	<b>22%</b>	<b>39%</b>	<b>17%</b>	<b>0%</b>	<b>11%</b>	<b>11%</b>
<b>Educational resources</b>	<b>25%</b>	<b>31%</b>	<b>6%</b>	<b>0%</b>	<b>25%</b>	<b>13%</b>

Summary of above table:

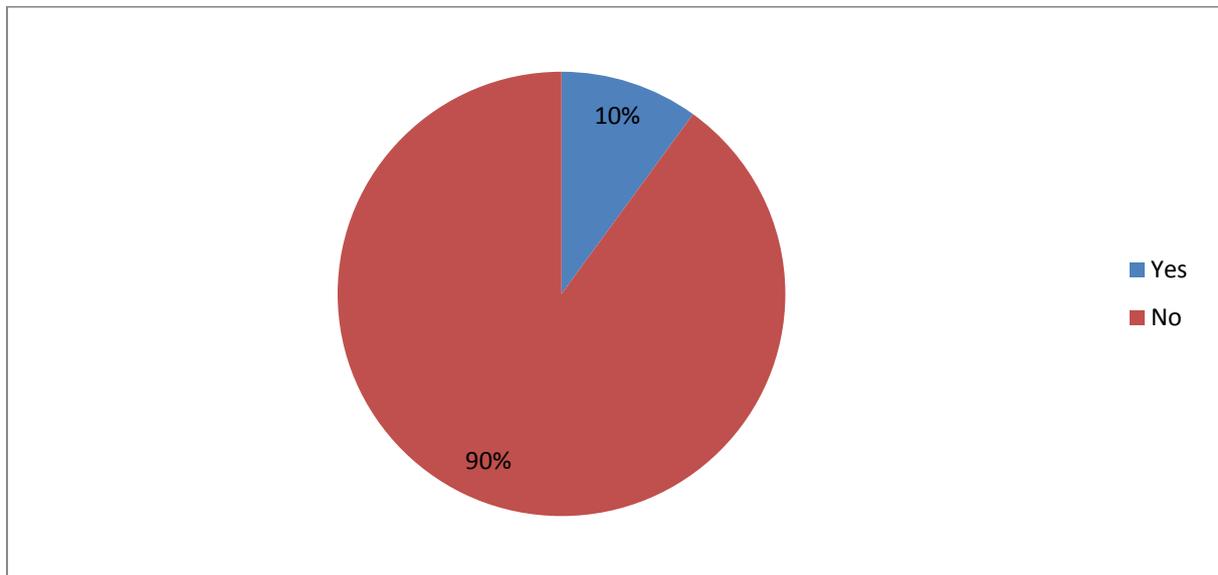
- 72% of clinicians found the template useful or very useful.
- 50% found the prostate cancer care plan useful or very useful
- 61% found the prostate cancer register useful or very useful
- 25% of clinicians did not use the educational resources

**Have you completed any of the BMJ modules that were promoted as part of the educational resources?**



The educational tools comprised of a tool kit for primary care nurses and a prospectus of online modules. The rate of completion of the educational modules is disappointingly low although the majority of respondents had seen the educational resources (previous question). Completion was not a requirement for the LIS.

**Are there any additional resources you would find useful for prostate cancer follow-up?**



**Comment:** *“TIME- we are expected to take on more and more work which leads to significant time constraints .I understand there is funding attached to this piece of work –but in real terms it is insufficient in the current recruitment crisis.”*

This comment is interesting and a familiar message to the project team. This reflects a general feeling amongst clinicians in primary care about current pressures more generally, which impacts upon the ability to take on work that has been traditionally been carried out in secondary care.

### **9.3 Survey for Practice managers and non-clinicians**

A second survey was carried out of practice managers and non-clinicians in order to gain feedback on the processes of the LIS.

**Has your practice signed up to the LIS for prostate cancer follow-up?**

Yes 100%

No 0%

Engagement with practices was a priority for the project team. The sign up for the previous LIS (pre project) had been less than 50%. Data collected by the project team confirms that 57/59 practices had signed up at the end of the pilot period.

**Has the project support team visited your practice?**

Yes: 89%

Don't Know 11%

The project team aimed to go out to every practice to meet clinicians and practice managers and admin staff. 97% of practices were visited but not all staff members were present due to constraints of time available.

**How helpful have you found project support?**

Extremely: 65%

Fairly 35%

*The project nurse lead visited us on more than 1 occasion to train both nurses and myself”*

*The project nurse lead has been to see us twice and has been very supportive”*

*“Very helpful in setting up the register and quality checking data”*

**Have the following documents been uploaded onto your system (welcome letter, letter for existing patient, prostate cancer care plan)**

Yes: 100%

**Is the clinical template for prostate cancer follow-up uploaded onto EMIS/ VISION?**

Yes 83%

No 6%

Don't know 11 %

Using the EMIS/VISION template for follow up consultation is a requirement for claiming under the LIS. There were challenges for the practice team in ensuring the latest versions of the template were uploaded onto each practice's system. The project team did provide support with this where possible and provided a 'how to' guide to practices (Appendix 4)

**Do you have a prostate cancer disease register set up for your practice?**

Yes 95%

No 5%

Before the project only one practice had a register in place, this example of good practice was shared by the project team as a means to ensuring patients did not become lost to follow-up once transferred. The project team recommended that the setting up and maintenance of the register become a requirement for the LIS. The CCG have accepted this and amended the LIS to include this.

**Who is responsible for maintaining the prostate cancer register at your practice?**

Practice Manager 47%

Clinician 42%

Other 5 % (assistant practice manager)

Identifying someone to maintain the prostate cancer register helps ensure that patients are having their follow-ups on time and do not become lost to follow-up.

**How have you communicated about the prostate cancer LIS to the rest of the project team?**

Discussed at practice meeting 50%

Informal discussion with team meetings 55%

Email 11%

Other 16%

**Do you have any other feedback?**

*“Main problem at the moment is that need to get started, change in processes needed. Just not enough time in each day to get everything done”*

*“Not enough time to do the work either. Needs better payment to cover the time or the team to come in and do the work”*

*“Could do with streamlining, lots of different things to do”*

## **Recommendations:**

### **Croydon CCG**

All documentation and resources developed for the project are available via DSX. These will need yearly review to ensure they are up to date and reflect best practice in accordance with revised NICE guidance etc.

Completion of the two essential online modules is made a requirement for a minimum of one clinician in each practice. Lead clinicians would also benefit from attending the Prostate Cancer UK primary care master classes which are free to access (link to PCUK education page).

### **Other CCGs**

Consideration is to be made locally for the willingness and capacity for primary care providers to take on primary care follow-up. CCGs may want to consider the use of networks/federations, where they are established, to provide this service where some practices are reluctant or are unable to proceed with the work in a timely manner.

Given some of the patient feedback about perceived knowledge gaps in primary care, it is recommended that the completion of the two essential online modules is made a requirement for a minimum of one clinician in each practice.

## **9. Financial analysis and sustainability**

ICF Consulting was commissioned by PCUK's Health and Social Care Professionals programme to carry out a short piece of research to analyse the cost of the two care pathways for prostate cancer in Croydon. These two care pathways were for patients to receive their support in either a primary care or secondary care setting.

The aims of the research were to:

- Undertake financial modelling of existing models of care; and
- Undertake financial modelling of the new pathway and models of care.

## Findings

The analysis focussed on patients with prostate cancer within Croydon registered at GP practices. It examined the costs of providing prostate cancer support over a five year period, as examining costs over a longer period reduces the certainty of the estimates.

The basic components of the care pathway were:

- The patient had a PSA test on average twice a year for the first three years of their support programme. This involves attending a phlebotomy clinic or their GP practice to have their blood taken for the test. The patient would then see either their GP in surgery or consultant in secondary care to receive the results of the test.
- After three years of receiving the PSA test on average every six months, patients had a PSA test on average every 12 months, assuming that there were no causes for concern. This test was conducted in the same way as described above.
- If patients were on the primary care pathway and there was a concern about a PSA rise or reoccurrence the primary care clinicians would either request for the patient to be transferred back for secondary care opinion or advice would be sought about management from the secondary care consultant.

Under the old primary care pathway there was an existing LIS in place. This was paid to primary care providers who were providing support for prostate cancer patients. The LIS was £50 per patient per year. This was to encourage GPs to provide prostate cancer support to patients so that the patient did not have to attend secondary care.

Under the new enhanced pathway each appointment has a LIS cost attached.

- The LIS for the welcome appointment, including the holistic needs assessment and care plan (new care pathway) is £50 per appointment (30 minutes).
- The LIS for GP appointments (new primary care pathway) is £43 (20 minute appointment) per patient.

The LIS for GP appointments (old primary care pathway) is £50 per patient per year. This is the equivalent of £25 per appointment for the first three years followed by £50 per appointment for subsequent years.

## Headline costs of old and new care pathways

### Secondary care pathway and new primary care pathway

The cost per patient of receiving follow-up care in a secondary setting and on the new primary care pathway is presented in the table below. This shows that the total discounted direct healthcare cost for a patient receiving follow-up in a secondary care setting is nearly £900 per patient over five years. This includes secondary care appointments and hospital transportation. On the new care pathway, the direct healthcare costs are under £400 per patient. This represents a reduction in cost of £490, or 57%.

The opportunity costs of the new primary care pathway are lower than for the secondary care pathway as well. The opportunity cost per patient for the new primary care pathway is £160, compared to £280 on the secondary care pathway. This represents a reduction of £130, or 45% in the opportunity cost. A patient transferred from secondary care to the new primary care pathway does incur an opportunity cost to GP practices, as GPs and nurses have additional patients to treat. This is estimated at £320 per patient over five years. The total difference in cost between the secondary care and new primary care pathways is estimated to be £300 per patient.

### Cost of secondary care and new primary care pathways per patient, five year period

Type of cost	Secondary care pathway	New primary care pathway	Difference in cost
Direct healthcare costs			
Primary care cost (LIS)	£0	£380	(-£380)
Blood test cost	-	-	-
Secondary care	£640	£0	£640
Hospital transportation	£230	£0	£230
<i>Total direct healthcare costs</i>	<i>£870</i>	<i>£380</i>	<i>£490</i>
Opportunity cost to patients, carers and employers			
Opportunity cost to patient	£130	£60	£70
Opportunity cost to informal carer	£10	£10	£10
Opportunity cost to employer	£140	£90	£50
<i>Total opportunity cost to patients, carers and employers</i>	<i>£280</i>	<i>£160</i>	<i>£130</i>

Change in opportunity cost to GP practices			
Changes due to staffing arrangements	-	-	(-£320)
<b>Total cost</b>	<b>£1,150</b>	<b>£530</b>	<b>£300</b>

*ICF calculations*

### Old primary care pathway and new primary care pathway

The cost per patient receiving primary care follow-up on the old and new primary care pathways is presented in the table below. This shows that due to the increase in the value of the LIS for the new care pathway, the direct healthcare cost per patient increased by £90, or 39% over five years. This is the only direct healthcare cost.

The opportunity cost to individuals, carers and employers is the same on the old and new primary care pathways, as patients attend the same number of appointments at the same location on both care pathways. However, the change in care pathways in primary care does create an opportunity cost saving for GP practices. As practice nurses are able to carry out the follow-up appointments, more GP time is made available to treat other patients. The value of the changes in staffing arrangements is valued at £200 per patient over five years. This means that the total estimated difference in cost between the old and new primary care pathways is estimated to be £110.

### Cost of old primary care and new primary care pathways per patient, five year period

Type of cost	Old primary care pathway	New primary care pathway	Difference in cost
Direct healthcare costs			
Primary care cost (LIS)	£230	£330	(-£90)
Blood test cost	-	-	-
Secondary care	0	0	0
Hospital transportation	0	0	0
<i>Total direct healthcare costs</i>	£230	£330	(-£90)
Opportunity cost to patients, carers and employers			
Opportunity cost to patient	£50	£50	£0
Opportunity cost to informal carer	£10	£10	£0
Opportunity cost to employer	£80	£80	£0

Total opportunity cost to patients, carers and employers	£140	£140	£0
Change in opportunity cost to GP practices			
Changes due to staffing arrangements	-	-	£200
<b>Total cost</b>	<b>£370</b>	<b>£460</b>	<b>£110</b>

*ICF calculations*

## Conclusion of financial analysis

The results of the analysis suggest that the new primary care pathway and LIS is significantly cheaper than the secondary care pathway. It provides a direct healthcare cost saving of 57% per patient over a five year period. This is due to the decrease in both the use of hospital consultant appointments and requirements for hospital transportation in the secondary care pathway.

The direct healthcare costs of the new primary care pathway are 39% more expensive than the previous primary care pathway. This is due to the increased value of the LIS on the new primary care pathway. Therefore, although the cost to primary care increases, the cost per patient overall is still lower than the cost in secondary care pathway.

The opportunity costs for patients, carers and employers on the new primary care pathway are 45% lower than the costs for the secondary care pathway. This is because travel times and waiting times are much lower for primary care than secondary care, therefore the length of time patients and carers spend travelling to or waiting for appointments decreases.

The opportunity cost to GP practices is also lower on the new care pathway than on the old primary care pathway. This is because the value of the time GPs and practice nurses spend supporting prostate cancer patients will actually decrease rather than increase in time spent with the patient. The decrease in the value of time to GP practices is due to some primary care follow-up-appointments being carried out by practice nurses who are properly trained in dealing with prostate cancer patients. Previously these appointments were carried out by GPs, whose time is more expensive.

The results from the sensitivity analysis show that the change in total costs for the cohort (including direct healthcare costs, opportunity costs to individuals, carers and employers and opportunity costs to GP practices) ranges between a saving of nearly £2,000 and £168,000

between the old and new care pathways. In all estimates, the total cohort costs are less expensive with the introduction of the new care pathway than without it. This means that even when using the most pessimistic set of assumptions, there is a cost saving following the introduction of the new care pathway. This gives a high degree of certainty that the cost of the new care pathway is lower than the cost of the old care pathway.

Additionally, not all patients who were identified as fulfilling the criteria for discharge from secondary care had moved onto the new care pathway. If all 155 eligible patients had been discharged from secondary care to the new primary care pathway, the savings would have been much greater.

Even though this analysis shows that there is a cost saving from introducing the new primary care pathway compared to the secondary care pathway, this was not the sole aim. The new pathway is also aiming to improve the quality of support provided to prostate cancer patients by providing tailored patient information packs, training modules for GPs and primary care nurses, templates to seek specialist advice and providing more holistic support which includes referring and or signposting patients to support services. This should be taken into consideration when analysing the value of the new care pathway.

## **10. Lessons learnt/limitations**

### **Patient identification**

The identification of suitable patients for the LIS was carried out in primary care in this project. The project team initially asked the two secondary care providers to fulfil this but they were unable to do so within the time frame of the project. One of the trusts (Royal Marsden Hospital NHS Foundation Trust) is now undergoing a pathway redesign for prostate cancer which will result in patients being transferred to primary care according to NICE 2014 guidance. For patients within Croydon this criterion is identical to the LIS criteria so will result in a seamless pathway for patients. The other provider (Croydon University Hospital NHS Trust) is also committed to the transfer of patients.

### **Timing of the launch of the LIS**

Due to the constraints of the timing of the project, the new LIS was launched close to the final quarter of 2014. This proved challenging in terms of engagement with practices as this coincided with the end of the financial year as their focus was ensuring that Quality Outcome Frameworks (QOF) targets were being met. Both clinicians and practice managers therefore had both less time for meetings with the project team and less time to initiate actions to implement the new LIS.

### **Other priorities in primary care**

Although, the timing of the launch of the project was problematic, there remained a constant message coming from practices that there were too many other priorities within primary care that were taking precedence to the prostate cancer LIS. There were 18 new pathways launched in Croydon in 2014/2015, all of which involved practice teams becoming familiar with new processes.

### **Engagement with primary care**

The project team spent a substantial amount of time engaging with and supporting primary care teams. All except one of the 59 practices in the borough were visited at least once. Feedback from the primary care clinicians and practice managers suggests that this face-to-face contact was appreciated and valued. It may not however, be the most time efficient way of sharing information about the pathway and supporting practices. A webinar or use of a video to launch and explain the pathway would be more time efficient. Alternatively, a presentation per network demonstrating the project tools and resources may also have worked well.

### **Education**

As discussed previously, the project team recommended modules for clinicians to access. These were all accredited modules that were relevant to primary care follow-up. Of those clinicians who completed the online survey, only 17% had completed the modules which was disappointing. Mandatory completion of the modules by at least one GP and one nurse for each practice would improve uptake of the modules and potentially motivate those clinicians in leading the prostate cancer follow-up work within their practice.

The project team did not have the opportunity to present at the regular protected learning time events in Croydon. An event for cancer was scheduled towards the end of the project (October 2015) and the project team attended and used the event to try and capture

clinician's feedback on the project. A time on the agenda earlier in the project period would have helped with engagement, to outline the required process and the opportunity to provide education.

### **Speed of transfer**

The slow speed of transfer was identified as an issue quite quickly in the project once the LIS had been launched. It was apparent from feedback that practices were struggling to find the time for case finding. The project team decided to offer case finding support to enable the practice teams to start requesting patients for transfer. The requests for transfer also took time to be sent and then the project was dependant on a timely response from secondary care. Clinicians in both secondary care providers, though supportive of the project, did not have dedicated time to review records, risk stratify and write letters to transfer patients. This was fitted in between other commitments and feedback from the primary care teams suggested it could take several weeks. As indicated in the data collection, although 155 patients were identified as suitable only 70 were transferred within the project period.

Conversely there was concern amongst primary care teams about large numbers of patients being transferred at once and their capacity to manage them.

A secondary care led process to transfer patients would be more efficient and would bypass the need for primary care teams to identify patients, send transfer requests and chase these up. The speed of transfer to primary care would need to be considered if large numbers of patients were transferred in a short time period in relation to capacity.

For CCGs deciding to commission a LIS, the cost savings that would be anticipated will take time to be realised depending on the speed of transfer.

### **Impact of lack of resources in secondary care**

The difficulty in both the identification of suitable patients in secondary care and time to risk stratify patients (whose transfer is requested by primary care) provided a challenge for the project team. Additionally, little or no access to a clinical nurse specialist in secondary care meant that potentially patients were being transferred without an end of treatment HNA. This meant that there was a greater emphasis required to address these possible unmet needs in primary care.

Primary care clinicians were initially unwilling to carry out a holistic needs assessment for a number of reasons. There were concerns about time and also feedback that the London HNA tool was too broad and not specific enough for prostate cancer. Development of a local tool which was prostate specific helped with engagement and acceptability of addressing holistic needs. The lack of HNA from secondary care at the point of transfer was also cited as a barrier to primary care assessing holistic needs. Increased provision of the recovery package from secondary care providers would ensure a smoother transfer to primary care. The assessment of holistic needs would also be an integrated part of the process for both patients and clinicians.

## **11. Conclusions and recommendations for future commissioning**

The project demonstrates the feasibility of primary care led follow-up for stable prostate cancer. There are a number of considerations for commissioners when planning a primary care pathway which were identified by the project evaluation. A frequently asked questions document for commissioners was produced in September 2015 to support planning for the 2016/17 planning round and can be found in Appendix 6.

The aims of the project were met as outlined below.

The project aimed to improve follow-up processes to shift care from secondary to primary care for prostate cancer patients who are stable at 2 years after radical treatment and patients who are undergoing “watchful waiting”. This was achieved through the development of the local incentive scheme with initiatives to share best practice and reduce variation. Provision of tools such as an EMIS/VISION template and a prostate cancer register will help to achieve this.

The Project also aimed to improve patient experience and access to other services for better outcomes by embedding a supportive/holistic element to needs assessment, as part of the follow-up service. This was achieved through the introduction of the welcome pack, welcome appointment and an emphasis on addressing holistic needs as part of the on-going follow-up. Patient experience was measured as part of the evaluation process. Whilst accepting the limitations of the patient experience survey (in terms of quantity) it provides an assurance that patients are generally happy with their transfer of care to their primary care team.

The provision of the Welcome Letter and revised information for the Welcome Appointment aimed to enhance knowledge of prostate cancer and promote self-management. The extent to which this was achieved was not directly measured in the project. The move towards self-management could be considered for patients who are stable after a period of time following the transfer of their care. Currently there is no evidenced based guidance on how long to monitor patients after treatment and therefore it is generally lifelong. The move to self-managed care for a proportion of this patient group could be considered when planning and redesigning patient pathways.

Bringing care closer to home was facilitated by the transfer of an additional 70 patients into primary care. The speed of transfer, as discussed, was slower than the project team anticipated and demonstrates some challenges about the identification of patients and engagement of both primary and secondary care in order to achieve this. There remains another 85 patients awaiting transfer and we anticipate that they will gradually move across to primary care. A pathway redesign in progress at the larger trust (RMH) and fuller engagement will help facilitate this as a key aim is to ensure that those patients who meet the NICE criteria (which matched the LIS criteria) will be transferred to primary care.

The project also aimed to provide training and development for primary care professionals on prostate cancer and the needs of patients living with and beyond prostate cancer. Whilst the project team provided a prospectus of on-line modules that achieved this aim, the uptake of the education was poor (only 17% of those who responded to the online survey completed these). A specific resource was developed for practice nurses to enable them to carry out both welcome appointments and on-going care. The tool kit was supported by both Prostate Cancer UK and Macmillan Cancer Support and available in both printed and online formats. A launch event was held for the tool kit but attendance was fairly low (one AHP and 12 primary care nurses out of a possible 147 nurses). A requirement to attend an event and/or online module and subsequent audit as part of the LIS would be recommended for consideration by commissioners as part of the planning process.

## 13. Appendices

### Appendix 1: project timescales

Time scale	Work stream	Objective	Lead
March 2014	Project management	Resubmit re-scoped PID, Timescales, R&I log Project Board User involvement Project included in TCST work plan with NHS England (London)	TCST
March / April 2014	Recruitment	Interviews for nurse posts, recruited and orientation complete.	TCST
April / May 2014	Scoping (including review of information to patient and to primary care (e.g. discharge summaries), patient and healthcare professional interviews of PSA follow-up and audit primary care professional's education support needs to conduct holistic PSA consultations in test site and)	Complete detailed scoping of existing services in motion with support from TCST, the provider and commissioning Urology Pathway Group and Prostate UK (if available).	TCST / Band 8a Nurse
		Development of pathways and links with secondary care to enable FU care with specialist nurses	Band 8a Nurse
		Review the process for referring patients from secondary care to Primary Care and the process of readmitting patients from primary to secondary care.	Band 8a Nurse
		Review, develop and implement safety netting protocols with specialist nurses	Band 8a Nurse
		Review information given to patients and the communication between primary and secondary care	TCST User Facilitator / Band 8a Nurse
		Financial data collection. Complete review of activity and funding with the transfer of follow-up	Currently reviewing and evaluating current Local Enhanced Service (LES) contracts for follow-up in North West and South London initially focusing on the LES currently in place in Croydon CCG.

	activity to Primary Care. This schedule of work is in progress and supported by PCUK and GHK		
		Currently conducting a cost comparison of current models against national tariffs and a <u>cost comparison of primary care v secondary care follow-up</u> for prostate patients.	TCST /GHK
	Scoping	Initial findings of scoping and financial analysis of primary care v secondary care follow-up to be presented to North West London and South London CSUs for consideration in CSU/CCG commissioning contract setting.	TCST
April / May 2014	Developing Primary Care (Pilot site: Croydon CCG)	Develop and disseminate training plan for primary care and identification of GPs and practice nurses as future key workers in pilot practices.	Band 8a Nurse / Croydon CCG
July 2014	TCST proposal to PCUK to fund Associate GP to support multidisciplinary support to GP practices. Gap identified through attending local meetings and survey or training needs.		
August 2014	Test pilot service review	Final evaluation of patient and professional experience	Band 8a Nurse / Croydon CCG / Croydon GP practices
September 2014	Recruitment process for sessional Associate GP. Recruitment secured October 2014		
Sept 2014 – Sept 2015 (12 month test period)	SLIPPED to December 2014 Test enhanced Holistic needs-based model in Croydon CCG from Dec 2014,	Project nurse and Assoc. GP to monitor and the on-going engagement of the holistic pathway. Review patient and experience after each PSA consultation	Band 8a Nurse / Assoc GP / Croydon GP practices
Date slipped to	January 2015	Start data collection: establishing baseline patient figures via the Patient Identifier Tool	Band 8a Nurse / Assoc GP /

Dec 1 <sup>st</sup> 2014 due to CCG sign off		then quarterly returns form CCG via LIS Reporting Tool	Croydon GP practices
	January 2015- 31 March 2015	Practice visits including providing support with the patient identification.	Band 8a nurse /Assoc GP/ Croydon GP practices
	<u>May 2015</u> : mid pilot review of patient and professional experience in pilot site.	PSDA review the holistic needs of patients and assess any unmet needs. Focus Group with existing patients to (the focus group of existing patients will act as a control group and help to evaluate the quality improvement initiatives that the project has developed in order to enhance the pathway)	Band 8a Nurse / Assoc GP /Croydon CCG
September 2015 to January 2016	Evaluation	Final data collection	Band 8a Nurse / Assoc GP / Croydon CCG
	Sustainability	Implement contract levers to maintain pathway change.	TCST / Pan London Living with and Beyond Cancer Board
	Final project review pending evaluation by GHK and PCUK	Recommendations on future commissioning of the FU in Primary Care across high impact areas across London	TCST /GHK/ Band 8a Nurse/ Asscoc. GP / Croydon CCG / Croydon GP practices

## Appendix 2: Patient experience surveys

Patient Experience Survey 1 (at point of discharge.)



Final Point of  
Transfer Survey Dec2

Patient Experience Survey 2 (after welcome appointment and first primary care review appointment)

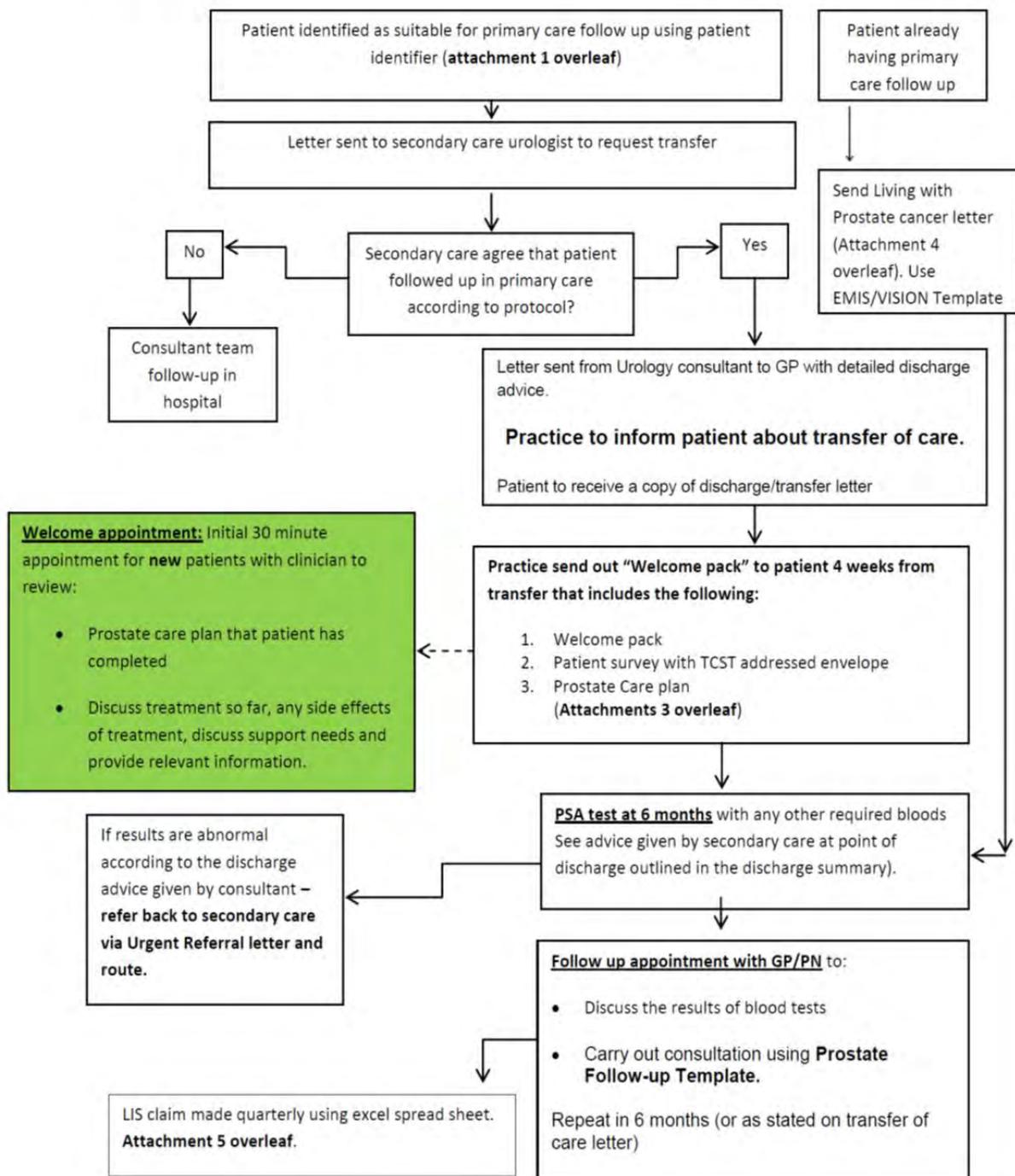


Second Survey 6  
monthv4.pdf

### Appendix 3: Operational flow chart



#### Operational Flowchart Prostate Cancer Enhanced Follow-up



### Appendix 4: Project Outputs / resources

Attachment 1	Patient Identifier tool to help find prostate cancer patients that are suitable for primary care follow-up.	 FINALprimary_care_i dentification_of_stab
Attachment_2	Letter to secondary care requesting transfer of patient for primary care follow-up. Use one letter per patient. For CUH please address to Mark Lynch, for any other trust please address to their consultant urologist/oncologist.	 Transfer of care letter to Secondary C <hr/>
Attachment 3	Welcome pack documents <ul style="list-style-type: none"> <li>• Practice to inform patient if transfer to primary care is agreed by secondary care consultant</li> <li>• Welcome Letter, Survey and Welcome Appointment to be sent 4 weeks from receipt of transfer to practice. Survey to be sent with SAE to : Barbara Gallagher/Sandra Dyer, Transforming cancer Services Team for London , SE CSU, 1 Lower Marsh, London SE1 7NT.</li> <li>• Welcome Appointment to be arranged with patient</li> <li>• Holistic Care Plan to be used in Welcome Appointment and be reviewed in subsequent follow-up appointment. This can be integrated into VISION/EMIS web.</li> </ul>	 Welcome Letter to prostate cancer patik  Survey One Word 2003.doc   Prostate Cancer Care Plan July 2015.c
Attachment 4	Living with prostate cancer letter (for existing patients). Send out when recalling for PSA blood and review.	 Letter to Existing patients July 2015.dc
Attachment 5	Urgent re-referral/ Advice only letter to Secondary Care.	 Urgent follow up letter June 2015.doc <hr/>  Advice only template June 2015.doc

Attachment 6	Guides to upload the Prostate Cancer follow-up consultation templates for EMIS or Vision clinical systems.	 Importing_an_EMIS web template .pdf <hr/>  Vision instructions for downloading and impr <hr/>
Attachment 7	CCG Reporting Spread sheet for remuneration.	 LIS reporting tool.xls <hr/>
Attachment 8	Maintain Prostate Cancer Register to mitigate and reduce risk of patients lost to follow-up/ or delayed PSA and follow-up.	 Prostate cancer Register.xls <hr/>
Attachment 9	CPD accredited educational resources suitable for GPs, practice and primary care nurses and Allied Health Professionals.	 Final July 2014 Prostate_Cancer_Edu  Primary_Care_Nurses_Tool_pdf  <a href="http://prostatecanceruk.org/croydon-toolkit">http://prostatecanceruk.org/croydon-toolkit</a>
Attachment 10	Primary care Follow-up protocol. Designed to assist primary care where there is a lack of guidance in their discharge summary (historical discharges). This does not replace individualised discharge advice. Please note that secondary care recommendations for DEXA for patients on hormone treatment or Sigmoidoscopy post radiotherapy/brachytherapy there are no commissioned pathways currently.	 Follow up in protocol primary care <hr/>

## Appendix 5: Pathway documentation available on the CCGs' referral support system

The screenshot shows the CReSS (Croydon Referral Support Service) website. The header includes the CReSS logo, the tagline "Enabling patients to receive the right care, in the right place, at the right time", and the NHS logo with "Croydon Clinical Commissioning Group". A navigation bar contains links for Patients, Health Professionals, About Us, and Contact Us, along with a search bar. The breadcrumb trail reads: "You are here: Home > Health Professional > Referral Support Directory > C > Prostate Cancer LIS".

### Prostate Cancer LIS

Information | Referral forms

#### Prostate cancer Local Incentive Scheme

In the UK, the numbers of men living with a diagnosis of prostate cancer will continue to increase as the population ages. The National Institute of Clinical Excellence recommends that patients stable at 2 years after radical treatment and patients who are undergoing "watchful waiting" are offered follow-up outside of hospital in an appropriate setting (NICE Prostate Cancer: CG175 2014).

The Local Incentive Scheme (LIS) provides an incentive for primary care to provide follow up to stable patients with prostate cancer or those who are on a watchful waiting pathway. Croydon CCG has been supported by Transforming Cancer services Team for London to develop the pathway and provide resources for clinicians to provide high quality, evidence based care that meets patients holistic needs( through a Prostate Cancer UK grant.)

The attached documents enable the to practice to: identify suitable patients; request their transfer from secondary care; provide information and signposting to both new and existing patients; address patient's holistic needs; provide standardised high quality care; refer back to or seek advice from secondary care if required; and keep a prostate cancer register.

[Operational Flow Chart Prostate Cancer](#)

## Appendix 6: Frequently asked questions for commissioners

  
FAQ for  
commissioners V4.pdf

## Appendix 7: Financial evaluation by ICF Consulting Ltd

  
Final\_report\_Econom  
ic analysis of Prostate

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***TCST is part of the Healthy London Partnership, a collaboration between all London CCGs and NHS England London region to support the delivery of better health in London***

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