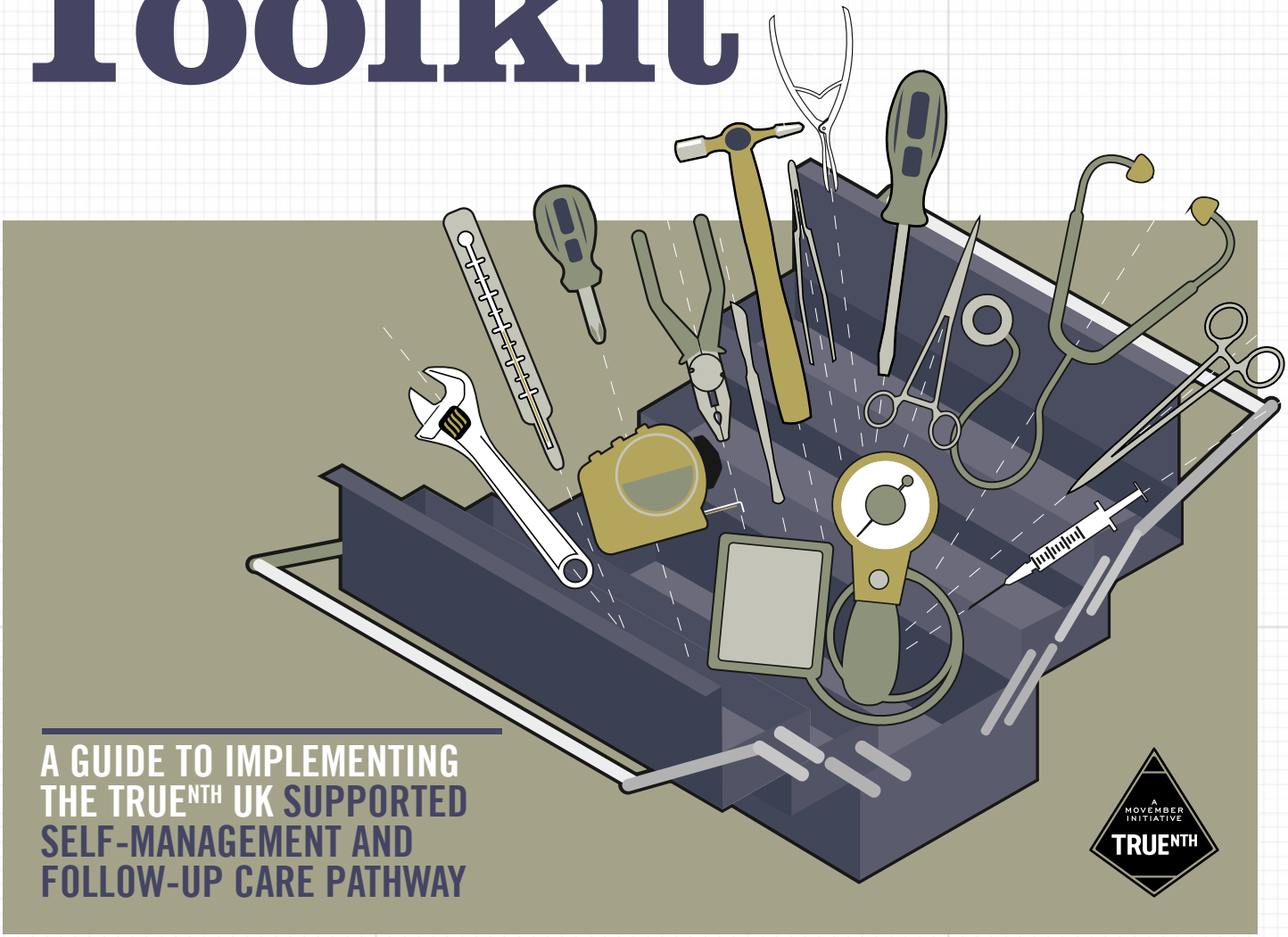
The Toolkit



A GUIDE TO IMPLEMENTING THE TRUE^{NTH} UK SUPPORTED SELF-MANAGEMENT AND FOLLOW-UP CARE PATHWAY

A MOVEMBER INITIATIVE
TRUE^{NTH}

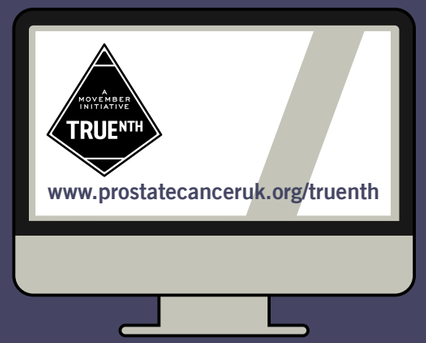
Contents

INTRODUCTION

THE TRUE^{NTH} PROGRAMME

TrueNTH is a global partnership of over 300 healthcare professionals, academics and volunteers from countries around the world that aims to "significantly improve the lives and experiences of men with prostate cancer, as well as the experience of their partners, caregivers and family members."

The Movember Foundation has invested over $41.5 million USD in the TrueNTH Programme. This is the largest ever global investment into prostate cancer care. Participating nations include the UK, the US, Canada, Australia, New Zealand, Singapore, the Hong Kong SAR and Ireland.



In the UK, TrueNTH is delivered in partnership with Prostate Cancer UK. The Supported Self-Management and Follow-Up Care initiative is one of eight TrueNTH projects supported in the UK.

For further information about these projects visit: **www.prostatecanceruk.org/truenth.**

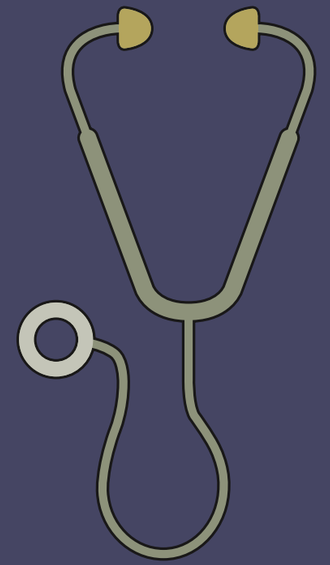
Learning from other TrueNTH projects will be incorporated into future versions of this toolkit.

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

THE SUPPORTED SELF-MANAGEMENT AND FOLLOW-UP CARE INITIATIVE

The TrueNTH UK **Supported Self-Management and Follow-Up Care Initiative**, led by the University of Southampton, commenced in January 2014 with the aim of **designing, introducing** and **evaluating** a new prostate cancer follow-up pathway.

This new care pathway aims to **improve the quality of prostate cancer care** by addressing some of the key challenges faced by contemporary uro-oncology services:



- **High levels of unmet need reported by men**
- **Increasing demands on the system due to year on year increases in prostate cancer prevalence**
- **Workforce challenges, including a chronic shortage of uro-oncology specialist nurses**

The concept of Supported Self-Management recognises that not all men require the same intensity of support from their healthcare professional team and that many men, given the right support, can self-manage aspects of their care.

MEN ENROLLED ON THE TRUE^{NTH} CARE PATHWAY:

Are recalled to clinic within two weeks, if the PSA results or symptoms indicate this would be appropriate

Attend a 4-hour Supported Self-Management workshop with the aim of giving men the knowledge, skills and confidence to self-manage aspects of their prostate cancer

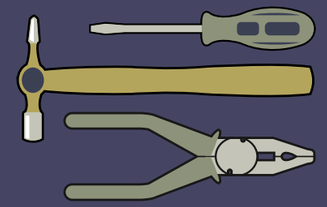
Are given the opportunity to sign up to an Patient Online Service where they can access PSA results and health information, complete Holistic Needs Assessment and use an electronic messaging function to contact their Support Worker

Are introduced to a Support Worker who is their key worker for the duration of their follow-up

No longer need to attend face-to-face clinic appointments to discuss PSA test results that fall within normal limits

This project has been delivered in partnership with the University of Surrey and our five implementation sites: Dartford and Gravesham NHST; Royal Cornwall Hospitals NHST; Royal United Hospitals Bath NHSFT; St Helens and Knowsley Teaching Hospitals NHST and the University Hospital Southampton NHSFT.

HOW TO USE THIS TOOLKIT



This toolkit has been written in collaboration with the **clinical teams and health care providers** involved in the delivery of the new care pathway. It aims to share **practical learning** and **resources** from the project such as job descriptions, examples of business cases, audit guidelines and **prostate cancer monitoring guidelines**.

We understand that every service is unique: all of our project sites used **guidelines developed at project level** and **tailored** them to their local needs. With this in mind, we anticipate that the resources in this toolkit may provide a good starting point for your service, while you will adapt them and build on them locally.

You will find that many of the resources in this toolkit are contained in the appendices (available on the CD-ROM). This is to ensure the main body of the toolkit remains user-friendly and acts as a companion that you can dip into whenever needed. Furthermore, many of the resources are in a format that you can edit to make it easier to tailor them to meet your local needs.

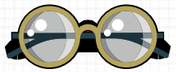
For further information, visit **www.protatecanceruk.org/truenthtoolkit.** You can register to receive information about updated versions of this toolkit via this site. We plan to launch a digital version of the toolkit in 2017.

> The Supported Self-Management and Follow-Up team really hope you find the information and resources contained in this toolkit useful. Based on the learning from our five sites we have developed this toolkit to enable you to rapidly bring about change in the follow-up care pathway. Men with prostate cancer deserve a consistent, effective and person-centred approach to their follow-up care. We hope this toolkit can play a part in helping you achieve this for the men under your care.
>
> **Professor Alison Richardson, Clinical Professor of Cancer Nursing & End of Life Care, University of Southampton**

SECTION **A** INTRODUCING THE CARE PATHWAY

SO WHAT DOES THE CARE PATHWAY LOOK LIKE?

A flow chart detailing steps 1 to 29 of the care pathway is available on pages 14 and 15



This section aims to provide you with an at-a-glance overview. The later sections of the toolkit examine key areas in much more detail.

KEY COMPONENTS OF THE PATHWAY INCLUDE:

Support Worker: Men are introduced to a Support Worker who is their key worker for the duration of their follow-up.

Remote monitoring: Men no longer need to attend face-to-face clinic appointments to discuss normal PSA test results. Nurse-led PSA Tracking Clinics are held using an electronic PSA tracking system. Men are recalled to clinic within two weeks if their PSA results or symptoms warrant further investigation. Clinical monitoring protocols have been developed for each treatment group.

Patient online service: Men are given the opportunity to sign up to a Patient Online Service where they can access PSA results and health information, complete Holistic Needs Assessment and also use an electronic messaging function to contact their Support Worker. This service interfaces with the PSA tracking system.

Workshop: All men are required to attend a four-hour Supported Self-Management workshop. This workshop aims to give men the knowledge, skills and confidence to "self-manage" their condition.

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

SCREENING AND IDENTIFICATION OF ELIGIBLE PATIENTS (STEPS 1 TO 7):

In the days prior to clinic, Support Workers screen clinic lists to identify potentially eligible men. The development of detailed **eligibility criteria (Figure 3, page 27)** has enabled Support Workers to undertake this task independently.

Potentially eligible men are flagged to clinicians prior to clinic (either verbally, on paper notes, or electronically). The Support Workers liaise with clinicians during clinic to ensure that men who are eligible for the care pathway are identified and referred. *Some of our sites found that as the care pathway becomes normal practice, most clinicians require less prompting to refer men and are more likely to do so independently.*

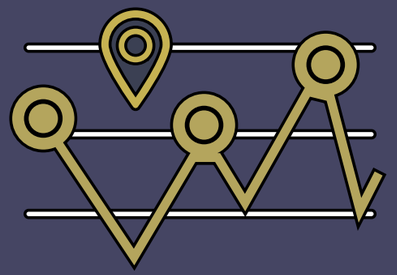
> Royal Cornwall Hospitals NHST deliver urology and oncology clinics across eight different geographical locations. Unlike Trusts that run clinics in one location, it was not possible for our Support Worker to always be physically on site to enrol men to Supported Self-Management. We had to adapt our processes to reflect this. If our Support Worker couldn't attend clinic she would pre-screen the clinic lists remotely and send a list of eligible patients and recruitment packs to the administrator for that particular clinic. The administrator would then prompt clinicians to assess eligible patients and discuss Supported Self-Management with them during the consultation. Our Support Worker would then follow up this consultation up with a telephone call to the patient.
>
> **Debbie Victor, Uro-Oncology Clinical Nurse Specialist, Royal Cornwall Hospitals NHST**

> The concept of Supported Self-Management (SSM) should be introduced at the earliest possibility, ideally when discussing treatment options at the time of diagnosis. This enables SSM to be seen as the 'normal' pathway and not something that is an optional extra.
>
> **Miranda Benney, Macmillan Uro-Oncology Clinical Nurse Specialist, Royal United Hospitals Bath NHSFT**

THE CLINIC APPOINTMENT (STEP 8):

If the man is suitable for Supported Self-Management, the clinician **briefly describes the care pathway** and **introduces the man to his Support Worker**. It is really important that the decision to commence Supported Self-Management, and the proposed monitoring protocol, is **communicated to the Support Worker** and **recorded clearly in the clinic letter**.

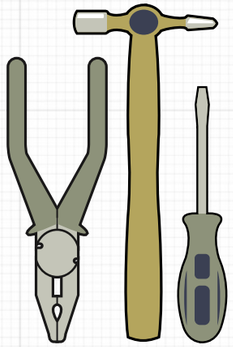
INTRODUCTION TO THE CARE PATHWAY - PATIENT CONSULTATION (STEP 9):



The Support Worker holds **an initial ten-minute consultation** with the man. This consultation can be **face-to-face or over the telephone**. During this consultation the Support Worker describes the man's follow up care in detail and explains what the care pathway comprises. Men are given an **information booklet** (appendix A1) and an **invitation to a Supported Self-Management workshop** (appendix A2). The Support Worker also explains the **Patient Online Service** and asks men if they would like to set up an account. If required, the Support Worker signposts men to local organisations that provide training in IT skills. The Support Worker arranges a username (typically an email address) and password for men who would like to use the Patient Online Service.

PRE-WORKSHOP SUPPORT WORKER ADMIN (STEP 10):

The Support Worker is responsible for adding new patients to the PSA tracking system. This involves entering both demographic and clinical data. Support Workers should **always refer to the clinician's clinic letter** for key information. If the PSA tracking system is integrated with the hospital pathology system and the patient administration system, some of this data can be **automatically added to the PSA tracker**, minimising time spent on manual data entry. It is also the Support Worker's responsibility to **undertake all preparation for the workshop**.



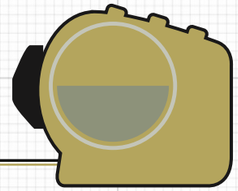
THE WORKSHOP (STEP 11):

All men are required to attend a **four-hour** Supported Self-Management workshop that aims to give men **knowledge, skills and confidence** to **manage aspects of their prostate cancer**. Topics include; Supported Self-Management, PSA testing, important **signs and symptoms**, **assessment** and **goal setting**, physical and emotional wellbeing and the Patient Online Service. Men are asked to complete a **Holistic Needs Assessment** (appendix A3) during the workshop. The workshop usually has between eight and twelve men in attendance and is jointly facilitated by the **Clinical Nurse Specialist** and the **Support Worker**.

FOLLOW UP PHONE CONSULTATION (STEP 12):

Approximately one week following the workshop, the man has a **follow-up phone consultation** with the Support Worker. The aim of this consultation is to ensure that the man has grasped the key points from the workshop and to discuss any issues and questions that the man may have. The call is a good opportunity to ensure men who were less forthcoming at the workshop can ask questions and raise concerns. Some of our project sites have found that **family members often joined the consultation** and asked questions at this point. The Holistic Needs Assessment may be discussed and a care plan established for men who feel this would be helpful.

ONGOING SURVEILLANCE, PSA TRACKING CLINICS, AND RECALL (STEPS 13 TO 28):



Men have their PSA tested regularly (as they would if they were attending clinic-based follow-up). Each treatment group has a separate monitoring protocol. An **electronic PSA tracking system** is used by the Clinical Nurse Specialist to monitor results. Each PSA review takes between **two and ten minutes**, depending on the required action. If the PSA result is within normal limits (specified by the relevant protocol) a **"PSA normal"** letter is issued, and the next PSA due date is set. Men who need to be recalled are booked in for a clinic appointment, which could be **within 2 weeks** if required.

Case study: A 70 year old gentleman was enrolled on the Supported Self- Management pathway three months post Laparoscopic Radical Prostatectomy. He attended a workshop, and also demonstrated good IT literacy in terms of accessing the Patient Online Service and his PSA results. (N.B. The follow-up protocol specified PSA testing every 3 months for this gentleman.)

A rise in PSA was noted by the gentleman when he checked his PSA result online, which prompted him to telephone the urology team. His case was discussed with the urology consultant. As per the clinical protocol, his PSA was rechecked 6/52's later; his PSA had risen again. His case was reviewed by the urology consultant and a bone scan was arranged. The gentleman was seen back in urology clinic within 2 weeks and was referred to an oncology consultant following MDT discussion. The gentleman received EBRT to the prostate bed. His PSA level reduced and he is now back on the Supported Self-Management pathway.

N.B. All PSA results are reviewed by the clinical team. Patients can access their PSA results in "real time" via the Patient Online Service as soon as these results have been entered on the pathology system. As such, there are instances where PSA results are reviewed by patients prior to being reviewed by the clinical team.

Men can raise concerns at any point in their follow-up, by contacting the Support Worker either by phone or by electronic message. Men can also raise concerns by completing a Holistic Needs Assessment (in paper format or online) that will be reviewed by the Support Worker. Care plans can be updated as required by either the man or the Support Worker to reflect on-going concerns. Some of these concerns are triaged to the CNS and can on occasion warrant recall to clinic.

COMMUNICATION WITH PRIMARY CARE:

For every letter sent to the man (introductory letter, results, reminders and recall letters), an accompanying letter is sent to his General Practice. The PSA tracker also has the ability to generate Treatment Summary Records (appendix A4) that can be sent to the GP if this has not been done earlier in the pathway.

Issues requiring GP input (e.g. low mood that might be indicative of depression) can be communicated subject to the man's consent as part of the assessment and care planning process. The Clinical Nurse Specialist will normally dictate a clinic letter in this scenario.

ADMINISTRATIVE PROCESSES:

Our project sites have found a number of existing administrative processes needed to be re-designed to support the care pathway. This issue is examined in more detail in section E.

Open

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

Open

THE OVERVIEW of the care pathway

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

1. Pre-clinic appointment: Support Worker to review patients in terms of PSA stability, treatment modality, or time since treatment completion/commencement.

2. Does the patient meet the eligibility criteria thus far?

NO

3. Record reason for exclusion in notes and continue routine clinic follow-up.

YES

Steps: 1-12 "Transition to the Supported Self-Management pathway"

4. Pre-clinic appointment: Support Worker to record on clinic list "Review patient for Supported Self-Management".

5. In clinic appointment: Clinician to review patient in terms of functional, emotional and disease stability.

For eligibility criteria and clinical management protocols see Figure 3 pg 27.

6. Does the patient meet the eligibility criteria thus far?

NO

7. Record reason for exclusion in notes and continue routine clinic follow-up.

YES

8. In clinic appointment: Clinician to inform patient that they will be enrolled on Supported Self-Management.

9. In clinic appointment:

Support worker to introduce him/herself to patient and:

- Briefly explain Supported Self-Management (providing supporting printed information)
- Explain workshop and give invitation
- Register patient on Patient Online Service (optional)

10. Pre-workshop

CNS/Support Worker to:

- Set up patient on PSA tracker
- Send Introdcution to Supported Self-Management letter and Treatment Summary Record to patient (and copy to GP)

11. At workshop:

Patient to attend a 4-hour workshop that covers:

- Supported Self Management/My follow up
- Physical concerns
- Emotional concerns
- Healthy lifestyles
- Goal setting
- Patient Online Service

12. One week post workshop: Support worker to follow up all patients who attended the workshop via telephone to discuss support needs. Support worker and patient to agree care plan if required.

Steps: 13-29 "Ongoing monitoring"

13. PSA letter:

Send the patient one of the following letters advising him to have a PSA test and complete an HNA in the first two weeks of *z* month:

- Introduction to Supported Self-Management letter (step 10)
- PSA "normal" letter
- PSA "slightly raised"letter

14. Has the patient raised any issues via phone or patient online service prior to *z* month?

YES

NB: "*z* month" is 6 weeks, 3 months, 6 months or 12 months following last PSA test. Refer to clinical management protocol.

15. Contact patient: CNS or Support Worker to contact the patient to discuss. It may be necessary to recall the patient to clinic.

16. Is it necessary to recall the patient to clinic?

YES

17. Recall: Recall patient to clinic. Offer appointment within 2 weeks if urgent.

NO

18. Care Plan: CNS or Support Worker to update care plan with man to address issue. Continue Supported Self-Management.

NO

19. Has the patient had a PSA test by the 14th of *z* month?

YES

20. Reminder letter: Send PSA reminder letter to patient.

NO

21. Has the patient had a PSA test by the 21th of *z* month?

YES

22. Reminder phone call: CNS or Support Worker to telephone patient to remind him to have a PSA test.

NO

23. Has the patient had a PSA test by the end of *z* month?

YES

24. Recall: Unless exceptional circumstances, recall patient for follow up in clinic as patient not adhering to Supported Self-Management.

NO

25. Review PSA/HNA: Review PSA result and HNA (if available) as per the Clinical Management Protocol.

26. Is it necessary to recall the patient to clinic?

YES

27. Recall: Recall patient to clinic. Offer appointment within 2 weeks if urgent.

NO

28. Does the patient have any issues flagged in the HNA that do not require recall?

YES

29. Care Plan: CNS or Support Worker to call man to discuss and agree care plan to address issue.

NO

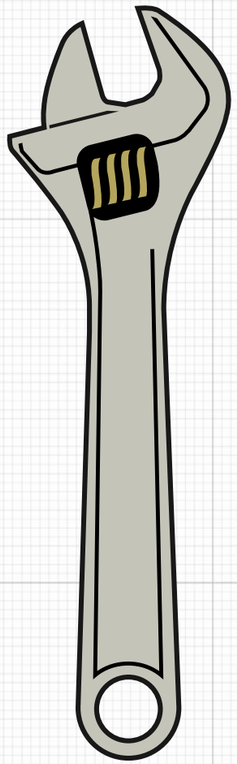
Return to step 13.

SECTION **B**

CLINICAL ROLES AND RESPONSIBILITIES

Section B of this toolkit describes the roles and responsibilities of the core clinical team in delivering the care pathway. The roles of a wider range of stakeholders involved in setting up the pathway, are described in the project management section of this toolkit.

THE SUPPORT WORKER ROLE



At the project outset, only one of our project sites had Support Workers assigned to cancer care, and none of the urology teams had this role in place. Understandably there were lots of questions about this new role:

- **Will anyone apply for the job?**
- **Is it an administrative or a clinical role?**
- **Should Support Workers wear uniforms?**
- **What training do they need?**
- **What tasks should they do?**
- **Do they need to be full time?**

In our project sites, the Support Worker is the only person solely dedicated to the follow-up care pathway and is critical to ensuring its safe and effective delivery.

This person needs excellent communication and interpersonal skills, superb organisational skills and a reasonable level of IT literacy. This is an AfC band 4 role; it encompasses a mixture of administrative and patient-facing work. It is vital that Support Workers are able to follow clinical protocols and can triage men to the Clinical Nurse Specialist as appropriate. Fortunately, all of our project sites had a significant number of high quality applicants for this role.

Appendix B1 includes a number of resources for the Support Worker role including: **job advert**, **job description**, **person specification**; **KSF profile** and **induction plan**.

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

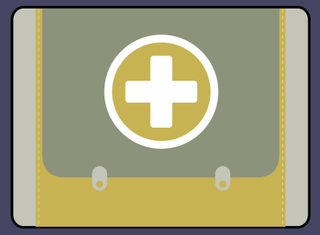
Figure 2 outlines a typical two-week timetable for one of our Support Workers.

Week 1

	Monday	Tuesday	Wednesday	Thursday	Friday
AM					
08:30	• Screening clinics • Recruitment from urology and oncology	• Recruitment from urology • Booking workshop appts • Registering pts for Online Service • Data entry on PSA tracker • Ordering patient literature	• Workshop follow-up calls	• PSA tracking clinic • Sending out paper Holistic Needs Assessment • Data entry on PSA tracker • Phone calls • Online messages	• Oncology recruitment
09:30					
10:30					
11:30			• Online messages • Phone calls • Holistic Needs Assessment		
12:30					
AM					
13:00	• Booking workshop appts • Registering pts for Online Service • Completing data entry	• Recruitment from urology • Booking workshop appts • Registering pts for Online Service • Data entry on PSA tracker • Ordering patient literature	• Workshop follow-up calls	• Oncology recruitment	• Booking workshop appts • Registering pts for Online Service • Completing PSA Tracker data entry
14:00					
15:00					
16:00	• Online messages • Phone calls • Holistic Needs Assessment		• Online messages • Phone calls • Holistic Needs Assessment		
17:00					

Week 2

	Monday	Tuesday	Wednesday	Thursday	Friday
AM					
08:30	• Screening clinics • Recruitment from urology and oncology	• Recruitment from urology • Booking workshop appts • Registering pts for Online Service • Data entry on PSA tracker • Ordering patient literature	• Workshop follow-up calls	• Workshop set-up	• Oncology recruitment
09:30					
10:30					
11:30			• Messages • Phone calls • Holistic Needs Assessments	• Workshop delivery	
12:30					
AM					
13:00	• Booking workshop appts • Registering pts for Online Service • Completing data entry	• Recruitment from urology • Booking workshop appts • Registering pts for Online Service • Data entry on PSA tracker • Ordering patient literature	• Workshop follow-up calls • Workshop prep	• Workshop delivery	• Checking in/out workshop pts • Booking telephone follow up calls • Booking workshop appts • Registering pts for Online Service
14:00					
15:00				• Pack away workshop equipment • Workshop debrief/ supervision with CNS	
16:00	• Online messages • Phone calls • Holistic Needs Assessment				
17:00					



Key Support Worker responsibilities include:

- **Screening clinic lists to identify men potentially eligible for the care pathway and liaising with clinicians to enrol eligible men**
- **Holding an initial consultation to introduce men to the care pathway**
- **Undertaking administrative duties, such as setting men up on the PSA tracker, registering men on the Patient Online Service, and preparation for the Supported Self-Management workshops**
- **Co-facilitating Supported Self-Management workshops**
- **Undertaking duties relating to PSA tracking clinics**
- **Serving as the first point of contact for men via phone call or electronic message**
- **Undertaking Holistic Needs Assessment and developing care plans**
- **Undertaking telephone consultations as required**
- **Triaging men to the wider clinical team, as appropriate**
- **Undertaking audits and reporting**

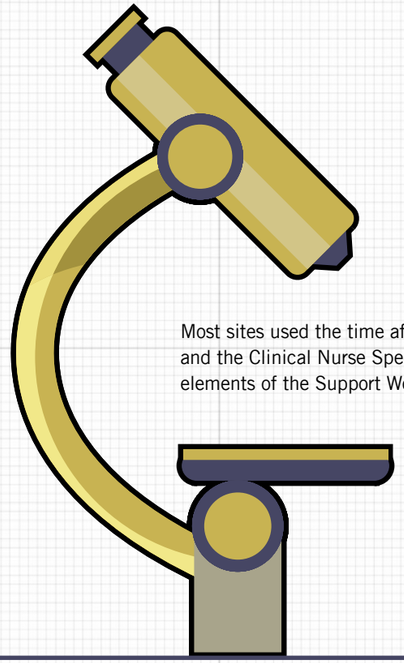
> Shelley (Support Worker) has taken the lead in identifying suitable patient candidates and facilitating a seamless transition to Supported Self-Management. Not only has her role in streamlining this pathway improved patient experience, it has also reduced clinical workloads. She is brilliant!
>
> **Fay Fawke, Lead Uro-Oncology Nurse, Dartford and Gravesham NHST**

Based on our learning so far, we estimate Support Workers need to be appointed between 3 and 5 days per week to support the delivery of this pathway. This will depend on the size of your service and how many men you plan to enrol on the pathway year-by-year.

If you do not feel that delivery of the care pathway in your department can justify the appointment of a full time Support Worker, you may wish to consider how the Support Worker could contribute to other aspects of prostate cancer care.

Our Support Workers have expressed a desire to take on more clinical and patient facing duties. Our sites are currently considering the deployment of Support Workers to:

- **Undertake all Holistic Needs Assessment (not just for men on follow up)**
- **Deliver different workshops, such as "Healthy on Hormones"**
- **Provide diet and exercise prescriptions**
- **Deliver prehabilitation initiatives**



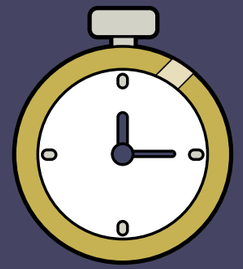
Only one of our Support Workers had previous experience working in cancer services. However, with a robust induction and sufficient support, they have all flourished in their roles. Peer support played an important role, with Support Workers in different sites keeping in regular contact with each other.

Most sites used the time after the workshop for a one-to-one discussion between the Support Worker and the Clinical Nurse Specialist. This time was used to reflect on the workshop delivery and other elements of the Support Worker's daily practice.

A TrueNTH Online Training Programme for Support Workers will be launched in 2017. This will be made available on the Prostate Cancer UK online learning site:

www.prostatecanceruk.org/for-health-professionals/online-learning

The CLINICAL NURSE SPECIALIST



In all of our project sites, one of the Clinical Nurse Specialists took responsibility for appointing and line-managing the Support Worker. This CNS also took a lead in running the PSA tracking clinics and co-facilitating the workshops. It is important that a CNS has protected time to undertake these activities. Our sites found that one day per week was sufficient time, but recognise this will need to be reviewed when caseloads increase. The CNS decides what specific activities are delegated to the Support Worker.

Ideally, more than one CNS should be trained in workshop facilitation and running PSA tracking clinics.

The **Lead CNS** and **Lead Clinician** have a responsibility to ensure Supported Self-Management is discussed at clinical meetings, ensuring the agenda remains fresh in the minds of clinicians, and that referral levels are maintained.

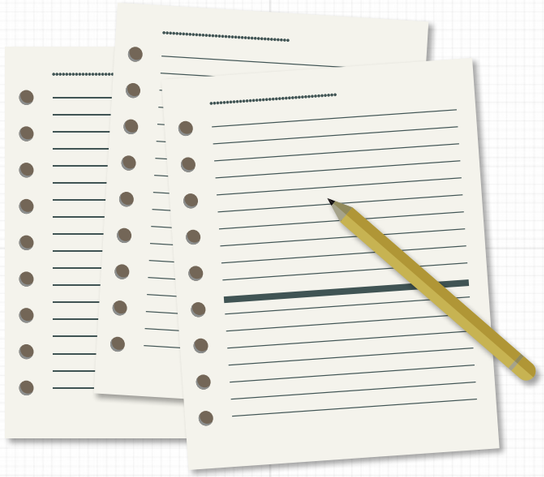
The LEAD CLINICIAN

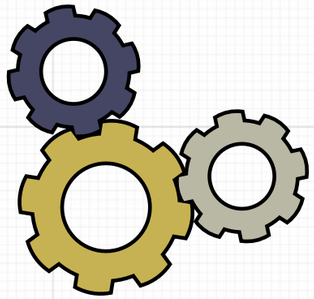
This person is typically a Urologist, but also could be an Oncologist or Clinical Nurse Specialist. From a governance perspective, the lead clinician is the person in the department who is accountable for ensuring the care pathway is delivered in a safe and effective manner. Duties include, but are not limited to:

- **Liaising with Trust Management to gain support for the business case and ongoing support for the pathway**
- **Reviewing service activity and audit reports and escalating any issues or concerns**
- **Promoting the care pathway amongst wider stakeholders, including commissioners and GPs**
- **Leading the development of clinical protocols and guidelines to support the delivery of the pathway**
- **Liaising with Clinical Governance leads to develop and implement monitoring guidelines for the pathway (N.B. this relates to service monitoring and does not relate to the monitoring of individual patients)**
- **Championing the delivery of the pathway amongst colleagues and intervening to address issues as required. For example, if the Support Worker is receiving referrals that do not have sufficient supporting information, then this is a situation where the lead clinician may intervene to resolve the issue**

Referring CLINICIANS

The referring clinician (Urologist, CNS or Oncologist) is the person who is responsible for making the clinical decision to enrol a man on the care pathway. Once the referring clinician identifies a man who is suitable for referral to the care pathway, the clinician briefly introduces the pathway to the man and then refers the man to the Support Worker. It is important that the decision to refer (or not) is recorded in the notes. The referring clinician also decides the monitoring protocol. It is crucially important that this be communicated clearly to the Support Worker and is also documented in the clinic letters.





Administrative & CLERICAL STAFF

In our project sites, the administrative work is undertaken by Support Workers. However, as caseloads increase, our sites may have to explore which of these duties could be taken on by administrative & clerical staff.

SECTION C

CLINICAL GUIDELINES

Section C of this toolkit provides examples of clinical protocols from our project and describes some of the clinical processes involved in the delivery of the care pathway. This section also shares some of our project learning and experiences that you may find useful when creating protocols locally.

DEVELOPING GUIDELINES

At the outset of our project, our clinical teams spent considerable time and effort agreeing on clinical guidelines and protocols to support the delivery of the care pathway. These guidelines aimed to serve a number of purposes, including:

- **Supporting the delivery of safe and effective follow-up care**
- **Reducing variation in practice among clinicians**
- **Enabling Support Workers to take a more active role in follow-up care by providing clear parameters**
- **Maximising the utility of the PSA tracker by enabling the programming of clear parameters and follow-up protocols into the PSA tracking system**

Figure 3 gives an overview of the eligibility, monitoring and recall guidelines, used by sites for men in the following "treatment" groups:

- **Post radical prostatectomy**
- **Post radiotherapy**
- **Receiving primary androgen deprivation therapy**
- **On watchful waiting**

Figure 3

True NTH Supported Self-Management and Follow-Up Care
CLINICAL MANAGEMENT PROTOCOL

NOT FOR IMPLEMENTATION:
This protocol is for example purposes only. It was developed in 2014, and may not be based on the most up-to-date evidence and clinical guidelines.

Protocol	Eligibility		Monitoring		Recall
Radical Prostatectomy	• Consider from 6 weeks post-surgery • PSA ≤ 0.1 • Refer to decision aid 1	Exclude patients with non-PSA producing tumours, patients who are unable to self -manage or are required to attend clinic to manage functional or psychological issues	• YEAR 1: PSA 3/12 • YEARS 2-5: PSA 6/12 • YEARS 6-10: PSA Annually • PROM 6/12	Monitoring and recall criteria may be personalised for individual patients. These criteria should be recorded in the "comments" section of the PSA tracking system.	• PSA > 0.1: telephone, retest 6/52 • PSA > 0.2 or 3 consecutive rises consider recall • New onset LUTS, visible haematuria, bone pain
Radiotherapy	• Consider from 6 weeks post completion of treatment • PSA < 2 • Refer to decision aid 2		EBRT • YEAR 1: PSA 3/12 • YEARS 2-5: PSA 6/12 • YEARS 6-10: PSA Annually Brachytherapy • YEARS 1-2: PSA 3/12 • YEARS 3-5: PSA 6/12 • YEARS 6-10: PSA Annually • NB: late effects		• PSA > nadir + 2 ng/ml, or 3 consecutive rises • NB: In the case of "clinical bounce" consider retest 3/12. • Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain
Primary Androgen Deprivation Therapy	• Consider from 3 months post commencement of treatment • PSA has responded to treatment • PSA < 4 • Refer to decision aid 3		• PSA 6/12 • Creatinine, ALP 6/12		• PSA > 4 • Troublesome LUTS, visible haematuria, weight loss, bone pain • Consider testosterone testing on recall
Watchful Waiting	• PSA < 30 and PSA doubling time of > 1 year • Refer to decision aid 4		• PSA 6/12 • U+E, ALP 6/12 • Consider testosterone, LFT and creatinine 6/12		• PSA > 30 or PSA doubling time < 1 year • Troublesome LUTS, visible haematuria, weight loss, bone pain

Locally sites have also developed guidelines for men who receive Intermittent Hormone Therapy and men on Active Surveillance (appendix C1). We did not develop a centralised active surveillance protocol due to significant variation in practices among sites.

To simplify the referral and follow-up process we kept the number of treatment categories and protocols to a minimum. Project sites found the majority of men fit into one of the defined categories, and for the occasional patient who does not, a bespoke follow-up plan can be detailed on the PSA tracking system.

As with any successful service change it is important that the clinical teams involved in delivery play a key role in the management of this change. When developing these guidelines, we sought to engage all of the referring clinicians, beginning with one-to-one discussions to canvass individual views, which were followed by larger meetings to reach consensus. There was a wide variation in views initially, which presented a challenge.

This was overcome by:

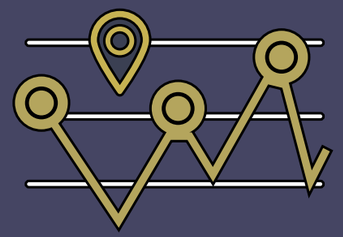
- **The Lead Clinician taking ownership of the protocol documents and signing off on any changes. There were numerous requests for changes and/or additions to the clinical protocols, so strict document-control processes were essential.**
- **Being respectful and understanding of clinician concerns. Is it safe? Is this in the best interest of my patients? are common and legitimate concerns when implementing new clinical protocols. It is important to stress that the guidelines and protocols are not designed to replace clinical acumen, and that clinicians can specify individual protocols for men whose needs did not fit with the local guidelines.**

> We found some clinicians were reluctant to refer men initially, but came on board once the new pathways became established and the benefits became apparent.
>
> Mr Jon McFarlane, Consultant Urological Surgeon, Royal United Hospitals Bath NHSFT

ELIGIBILITY criteria

Once our clinical teams had decided which treatment groups should be considered for referral to the care pathway, we had to develop treatment-specific eligibility criteria for each of these groups. Clinicians agreed that men enrolled on the pathway should have "stable disease" and "be able to self-manage". It was agreed that these concepts needed to be articulated much more specifically. As such, the eligibility criteria encompassed:

- **Men who do not have planned treatment that requires hospital attendance**
- **The time since treatment completion or treatment commencement. This is the earliest time point that the man could be referred to the care pathway**
- **The most recent PSA result should be at a level where additional treatment is not currently being considered. N.B. Men who had tumours that did not produce PSA were deemed ineligible for the care pathway**
- **Functional stability in terms of issues such as Lower Urinary Tract Symptoms, sexual dysfunction, and other acute and long-term treatment effects**



It is important to remember that men on the care pathway are still being monitored closely by the urology team.

Determining functional stability can be very subjective. Sometime men may have an issue that cannot be resolved in the urology clinic, or steps have been taken to resolve the issue and it's "as good as it's going to get". Men may not want intervention. A good test to apply is asking the question, "What is the benefit of inviting this man back into clinic?"

How do we know if someone is able to self-manage?

Asking the following key questions can help to assess this:

- **Could this man arrange to have his PSA tests done in response to reminder letters? (The answer to this should be "yes" for most men, as men have to do this for their regular clinic-based follow up.)**
- **Do you think that following the Supported Self-Management workshop, this man would be able to recognise important signs and symptoms of disease progression and get in contact with his clinical team? This is less critical than the first question, as PSA changes are likely to predict disease progression long before symptoms manifest themselves**

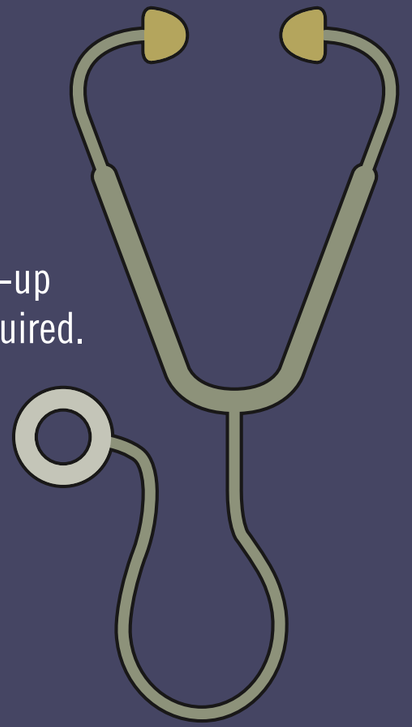
Patient case studies relating to eligibility are available in appendix C2.

Which protocol?

When assessing patient eligibility at the initial screening stage, some of our Support Workers found it challenging if patients had received multiple treatments. For example, if a man had undergone Radical Prostatectomy, then years later received salvage EBRT and adjuvant hormones, there was sometimes confusion as to whether the man should be assessed using the radical prostatectomy protocol, the radiotherapy protocol, or the hormone therapy protocol. To overcome this, we developed decision aides (appendix C3) and clinicians were required to communicate clearly which protocol each patient should be managed under.

PATIENT consent

Do men need to give their consent to be enrolled on a Supported Self-Management follow-up pathway? If this method of follow-up is standard practice, then consent isn't required.



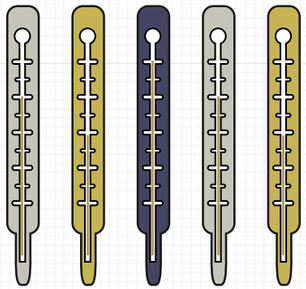
You would, however:

- **Ensure men understand what their care involves**
- **If men are reluctant to go on Supported Self-Management, explore their underlying concerns**
- **Address the concerns and reassure as appropriate**
- **Stress the benefits of Supported Self-Management**

If the man is still anxious after the clinical team have taken the above steps, you may wish to see how he feels about Supported Self-Management after attending a Supported Self-Management workshop. In very exceptional occasions some men have been deemed unsuitable for Supported Self-Management due to anxiety.

Consent may be required to register men on the Patient Online Service. Your Information Governance Team will be able to provide advice on this matter.

MONITORING protocols



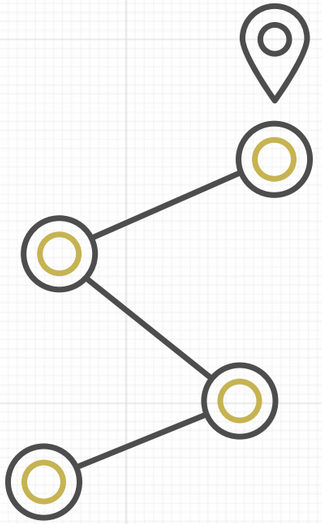
There are a number of measures that can be incorporated into monitoring protocols:

- **PSA tests, which will usually be set at the same intervals as men receiving clinic-based follow-up**
- **Additional blood tests, such as testosterone and creatinine, that were included in the initial monitoring protocol as optional extras**
- **Patient Reported Outcome Measures (PROMS) for the assessment of surgical and radiotherapy outcomes at both a service level and an individual level**
- **Holistic Needs Assessment, to identify wider unmet needs**

Implementing Holistic Needs Assessment (HNA)

At the project outset, our clinical teams agreed that men should be asked to complete regular HNA at the same intervals as their PSA tests. However, the uptake of HNA on a periodic basis was poor (less than 10 percent). All of our clinical teams agree on the value of a comprehensive HNA at the end of treatment, however there is still significant debate as to the value of asking men to complete them on a periodic basis. All men on the care pathway can complete an HNA at any point, indicating on the assessment if they would like input from their clinical team. Some of the project clinical teams take no action if men choose not to complete an HNA, whereas others will put more effort into sending reminders prompting men to complete an assessment.

RECALL criteria

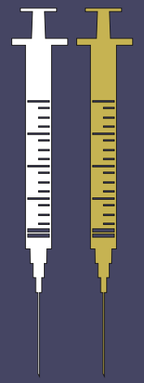


Recall thresholds are set at the point where further intervention may be necessary. For example, in the protocol outlined in figure 3, the suggested recall threshold for post-surgery patients is 0.2ng/ml or 3 consecutive PSA rises. This is because radiotherapy may be explored as an option at this point.

Many of our clinicians felt that there is no point in setting it lower, for example, at 0.05ng/ml, as further intervention would not be considered at this point, and recall may only cause unnecessary anxiety and distress to the patient.

The suggested recall parameter for radiotherapy was higher. It was set at nadir+2ng/ml, as this is the level at which further intervention (usually androgen deprivation therapy) would be considered.

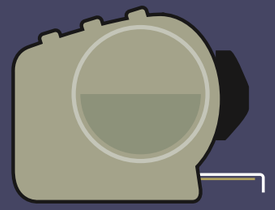
The protocols provided in this toolkit were developed at the outset of our project in 2014, and may not be based on the most up-to-date guidelines. It is important that your service develops and agrees on local protocols based on the most up-to-date treatments and clinical evidence.



Men who are recalled may need additional blood tests. For example, men on hormones may have their testosterone levels tested.

Certain symptoms may justify recall. These should be specified in the protocol:

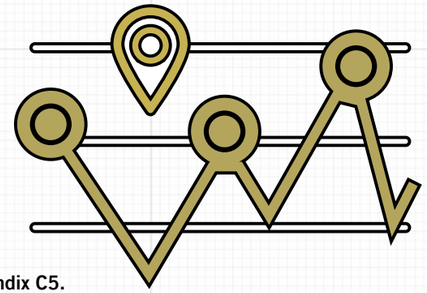
- **Haematuria**
- **Bone pain**
- **Unplanned weight loss**
- **New or worsening LUTS**
- **New or worsening sexual dysfunction**
- **Bleeding from the bowel**



The time frame in which recalled men are seen in clinic will depend on the urgency of the issue that prompted the recall. Your service will have to decide what timeframes you feel are appropriate, taking clinical need and service pressures into consideration.

Recall patient case studies are available in appendix C4.

DISCHARGE criteria



How long should men be monitored for? Audit work undertaken by staff at the Royal United Hospitals Bath NHSFT highlighted the need to develop discharge criteria. **A poster presentation on this audit is available in appendix C5.**

PSA TRACKING CLINICS in practice

When men are introduced to the care pathway, the PSA testing protocol is explained to them in detail during the workshop. This is also reiterated in an introductory clinic letter.

Men are advised:

- **Where to have their blood test**
- **When to have their blood test (usually in the first two weeks of the month in which the test is due)**
- **Not to have their test early, as monitoring is most effective if carried out at the intervals specified in the protocol**
- **When the CNS will check their results (usually in the second two weeks of the month in which the test is due)**
- **What action may be taken if their PSA rises**

PSA results appear in **"real time"** on the Patient Online Service as soon as these results have been entered on the pathology system. As such, there are instances where PSA results are reviewed by patients **prior to being reviewed by the clinical team**. Men are advised to **avoid checking their results** at times when they will not be able to reach their clinical team (i.e. on evenings and weekends).

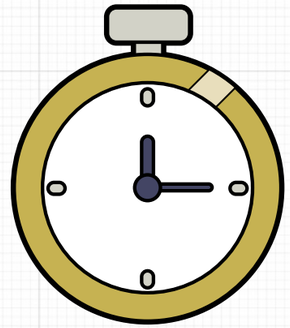
The electronic PSA tracking system lists patients in order of PSA test due date. It flags patients for review using colour coding. The CNS will work through the list of patients who are due to be reviewed. Depending on the outcome of the review, one of the following actions is taken:

- **Men whose PSA falls within normal limits are sent a normal PSA result letter, and the next PSA due date is set.**
- **Men who have not had their PSA test done by the 14th of the month are sent a PSA test reminder letter.**
- **Men who have had a PSA rise above a threshold specified in the protocol are either recalled to clinic or asked to have their next PSA test earlier than usual (typically at 6/52). On these occasions, the CNS will usually telephone a man to discuss this before sending a letter.**

Have a printer in your office, preferably near your desk. During a PSA tracking clinic, you may need to print out over 100 clinic letters. Better to find out sooner rather than later if the printer malfunctions or runs out of paper!

The CNS is responsible for ensuring the PSA tracking system is up to date and that there are no outstanding actions. In addition to reviewing new results, the CNS also uses the PSA tracking time to follow up on patients who:

- **were recalled during previous tracking clinics**
- **are suspended**
- **are still overdue from previous tracking clinics**



SUSPENDING patients

There are a number of instances where you may wish to suspend a patient from the tracker:

- **A patient is receiving treatment for a non-related condition**
- **A patient becomes terminally ill with another condition**
- **A patient has been recalled to clinic-based follow-up. (You may wish to wait for the outcome of the investigations before suspending patients, as some will have no abnormal findings and will go straight back on Supported Self-Management.)**

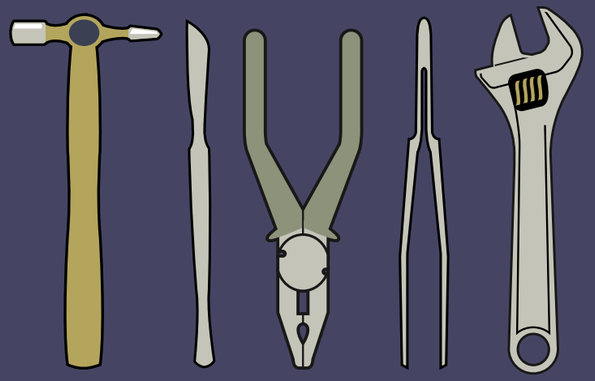
In other instances, it may be more appropriate to reset the next PSA test date. For example:

- **A man is on an extended holiday**
- **A man is being treated as an in-patient for another issue**

SECTION D THE WORKSHOPS

THE WORKSHOP FORMAT

All men are required to attend a four-hour workshop to develop the skills, knowledge and confidence required to self-manage their prostate cancer. The workshop usually consists of eight to twelve men, and is co-facilitated by a Support Worker and Clinical Nurse Specialist. It is delivered using the principles of adult learning and is facilitated in a "non-directive" manner.



The topics covered include:

- **What is Supported Self-Management?**
- **Understanding PSA monitoring**
- **How to contact your clinical team**
- **Common side effects and symptoms**
- **Emotional concerns**
- **Healthy lifestyles**
- **Moving forward and goal setting**
- **Using the Patient Online Service**

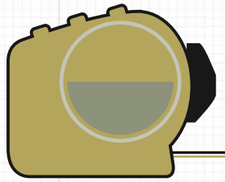
Men report that they really value the peer support element of the workshop. As such, men in each workshop can complete a "Keeping in touch form" where they can consent to (or decline) sharing their details with other men.

The following resources can be found in the appendices:

Workshop facilitators manual (D1), Workshop handouts (D2), Workshop banner and poster designs (D3, D4, D5, D6, D7), Supported Self-Management quiz (D8) and Healthy Lifestyles quiz (D9), Keeping in touch form (D10)

"The evidence base tells us it is more effective to facilitate adult learning than impose traditional teaching methods. As such, it is crucial that the facilitator uses a non-directive style for the majority of the workshop delivery, including a mixture of teaching methods - for example, discussion, videos and diagrams."

Claire Marsh, Advanced Nurse Practitioner, University Hospital Southampton NHSFT



This workshop was primarily designed to address the needs of men post-surgery, post-radiotherapy or on primary androgen deprivation therapy.

Our sites are now considering how the workshop could be adapted for men on watchful waiting and active surveillance.

MANAGING ACTIVITY and MAXIMISING UPTAKE

In our project, all men who were within three years of completing surgery or radiotherapy – or three years of commencing primary androgen deprivation therapy - were invited to the workshop. The capacity of the service to deliver workshops will determine how quickly a service can enrol men on Supported Self-Management.

Our project sites aimed to run workshops at a frequency that allowed each man to attend a workshop within twelve weeks of being enrolled on Supported Self-Management. Services aimed to book twelve men on to each workshop. Based on these criteria, if the service were to enrol six men per week onto Supported Self-Management, they needed to run fortnightly workshops. One site that recruited more than six patients per week ran fortnightly workshops and held weekly workshops to catch up when waiting times were getting too long.

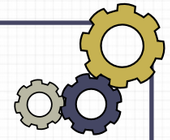
Your service will have to give consideration to who benefits most from attending a workshop – for example, a man who has been on follow-up for 6 years may not benefit from a workshop to the same extent as a man who is 8 weeks post-surgery.

Try to ensure enough members of your team are trained in workshop facilitation to provide cross cover in the event of annual leave and staff sickness.

A number of steps were taken to maximise workshop uptake:

- **Attendance at the workshop was presented in the same way as an invitation to any other clinic appointment. It was stressed that attendance at the workshop is "just as important as any other clinic appointment you are asked to attend". Some sites asked men to view this as their last clinic appointment.**
- **Feedback from other men who had initially voiced reservations about the workshop, but then really enjoyed it, was given both verbally by the Support Worker and also included on the patient information leaflets.**
- **Invitation letters (appendix D11) and reminder cards (appendix D12) were given. SMS reminders and phone call reminders were also used at some sites.**
- **Easily accessible venues were chosen, that had sufficient parking and public transport links. Some sites also chose to provide lunch and reimburse parking charges.**

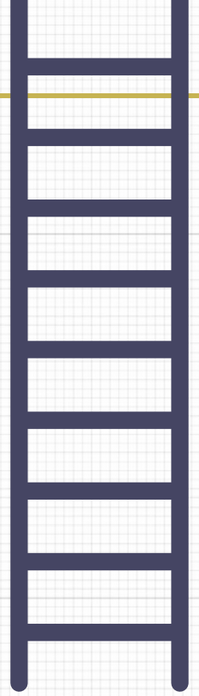
You may need to consider running the **workshops over multiple locations** if your service covers a large geographical location.



Uptake at each of the sites was generally very good. There was a small minority of men who genuinely felt very anxious and uncomfortable at the prospect of attending a workshop.

During the project, these men were not enrolled on the pathway. However, our project sites are now exploring alternative ways of presenting the workshop information (e.g. an extended face-to face appointment with the Support Worker, or video).

We recommend that your service makes a local decision as to whether men who do not attend a workshop should or should not be enrolled on Supported Self-Management.



DELIVERING high quality workshops

THE IMPORTANCE OF CONFIDENTIALITY

When men are both initially invited and then participate in the workshop, we stress the importance of respecting the confidentiality of others. Our project sites were careful that workshop sign-posting did not publicly divulge the health condition of attendees, yet was clear enough for attendees to find the venue.

TRAINING

We decided to develop a workshop-facilitation manual in order to standardise the way in which the workshops are delivered. Each of the project facilitators receive at least 8 hours face-to-face training and also undertook several hours of self-directed learning. Our project appointed a clinical psychologist to deliver facilitation skills, as we felt clinical psychologists possess the advanced communication skills required for facilitating groups in addition to having experience with working in a clinical environment.

We have included some of the training materials in appendix D13.

> Delivering workshops in this way may be a new skill for many CNSs. It important to remember that CNSs use advanced communication skills in their day-to-day work, and with training and practice can confidently adapt these skills to facilitate workshops in a non directive manner. Practice is key.
>
> **Nancy Chisholm, Macmillan Uro-Oncology Clinical Nurse Specialist, St Helens and Knowsley Teaching Hospitals NHST.**

OBSERVATION AND FEEDBACK

Each of our project sites had three workshops that were observed by external reviewers. A Quality Assurance Assessment (appendix D14) has been developed to help reviewers evaluate the workshop. This assessment can also be used by facilitators to support reflective practice.

Common observations included:

- **Facilitators giving lots of information, rather than eliciting the collective knowledge of men in the group and promoting problem solving**
- **The venue's IT setup (e.g. a poor internet connection) often made demonstrating the Patient Online Service a challenge**
- **Facilitators often felt uncomfortable having to interrupt men who spoke at length**
- **Some facilitators did not feel confident with the workshop content initially and consequently referred to the facilitators' manual frequently - rather than focussing on the group**

TOP TIP

Facilitators should learn the workshop content (facilitator's manual) inside out. This will enable facilitators to focus on key communication skills such as summary reflections, paraphrasing and active listening during the workshop delivery.

We recommend that facilitators be observed at least annually. This could be done by employing an external expert to observe or by utilising peer-to-peer observation.

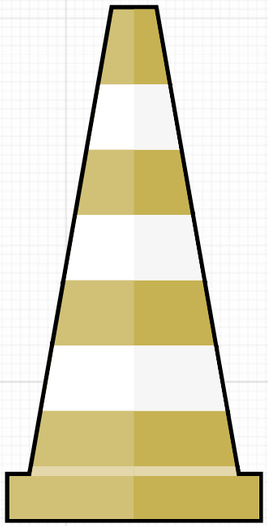
Our sites collected a great deal of feedback from men on the workshop delivery. The Support Worker asked men to feed back on their experience of the workshop during the follow-up phone call (one week after the workshop). Evaluation forms (appendix D15) were also used by some sites.

TOP TIP

Run some practice workshops with patients you know will be supportive of your learning before delivering a workshop in earnest. If possible, visit another site to see a workshop in action.

SECTION E MANAGING QUALITY AND SAFETY

MANAGING QUALITY & SAFETY



At the outset of the project, a governance protocol was developed to ensure the care pathway was delivered in a safe and effective manner.

Key components of the protocol include:

- **Leadership and decision-making**
- **Risk assessment**
- **Key Performance Indicators and Quality Standards**
- **Reporting, audit and reflective practice**

LEADERSHIP & decision-making

Each of our project sites established a working group at the project outset and had a clinical lead responsible for the implementation of the pathway. The group had a project management role (overseeing implementation of the new pathway), but also took decisions on the development of clinical guidelines and governance protocols.

The clinical lead could choose to escalate some decisions and service issues to the appropriate governance body within the organisation.

Engage Clinical Governance leads and Service Improvement leads at an early stage. Present the governance plans for the care pathway at audit and governance meetings for Urology and Oncology.

RISK assessment

In relation to delivering the new care pathway, our project site clinical teams were asked, "What could go wrong?" and "What would poor care look like?" These scenarios were then described as risks and were formulated into a risk assessment. We recommend that risk assessment be undertaken prior to implementation of the pathway and that it be updated at least annually, plus as required (e.g. in response to an incident).

Table 1 includes some of the most commonly cited risks and suggested mitigating action.

Table 1

RISK	ACTION
Men are monitored against the wrong protocol	Referring clinicians to clearly record the protocol in clinic letters. CNS to audit patient records to check monitoring protocols.
Department clinical protocols are changed incorrectly	Lead clinician to sign off all changes. Protocol documents to be managed in accordance with Trust version control policy.
Support Worker does not triage patient appropriately, resulting in the patient not receiving the care they require	Ensure adequate training and supervision is in place. Develop formal protocols and standard operating procedures where appropriate.
Manually entered clinical data is entered incorrectly	Develop standard operating procedure for manually entering data. This may involve double checking data. Use the original source of data to support clinical decision making. Audit to check clinical records are accurate.
Patient records are accidentally deleted and patients become lost to follow-up	Keep a separate register of patients enrolled on the PSA tracker. Ensure patient records are backed up on the server. Audit to ensure men have a clinical record and ensure it is accurate and up to date. Book men into "virtual clinics" on the Trust appointment system as a failsafe. Ensure men are aware of their PSA monitoring schedule.
Clinical data sent from pathology or Trust PAS is incorrect	Audit data in conjunction with IT staff.
Clinical actions are not followed up (e.g. PSAs are not reviewed, recalls are not actioned, reported symptoms are not acted upon.	Required actions to be clearly recorded in PSA tracking system. Tracking system to flag "open actions". CNS to review all "open actions" during PSA tracking clinics. Regular audit to ensure all records are accurate and actions are up to date.
Poor quality workshops resulting in misinformed patients and poor patient experience	Ensure facilitators are adequately trained. Ensure workshops are observed periodically. Capture feedback from men using evaluation forms.
Poor patient experience caused by long workshop waiting times and slow responses to phone and electronic messages	Set quality standards. Explain quality standards to patients to manage expectations. Regularly review performance, staffing and case loads.
Low activity levels threaten the financial viability and sustainability of the service	Establish Key Performance Indicators and determine the minimum level of activity required for the service to be financially viable.
The service may be inequitable if it does not take into consideration the additional needs of some groups (e.g. sensory impairment, language barrier)	Undertake an Equality Impact Assessment on the pathway. Take actions to address any issues identified by the assessment.
Men who cannot access the Patient Online Service receive a lesser standard of care	Signpost men who would like to use IT, but have IT literacy issues, to local training and support. Ensure "paper-based" procedures are still in place for men who do not have access to the Online Service.

KEY PERFORMANCE indicators and quality standards

An example list of Key Performance Indicators (KPIs) and Quality Standards are available in appendix E1. These were established to:

- **mitigate risks identified by the risk assessment;**
- **ensure men had clear expectations as to what they could expect from their follow-up care;**
- **ensure the service was adequately resourced and that processes were robust;**
- **ensure activity levels are above the minimum required level to sustain a financially viable service.**

You can see that many of the risks outlined in Table 1 have introduced a KPI or Quality Standard as part of the mitigating action.

The introduction of quality standards meant that men who were enrolled on the care pathway throughout the project were reassured that:

- **If they contacted their clinical team by telephone, their call would be returned within one working day.**
- **If they contacted their clinical team by electronic message, this would be responded to within two working days.**

At project outset, we had yet to gain an understanding of the workload generated by this pathway and of what caseloads could be realistically managed by Support Workers. As such, quality standards aimed to provide a safeguard as quality may be compromised by high activity levels that are insufficiently resourced. Examples of this may include Support Workers struggling to return phone calls on time, and CNSs not reviewing PSA results in a timely manner.

The cost-effectiveness of any pathway is affected by activity levels. For example, a service would find it hard to financially justify running workshops if only three men were attending each session.

REPORTING audit and reflective practice

It is important that performance against KPIs and quality standards are reviewed regularly. An example of a report can be found in appendix E2. We recommend an established service should be generating these reports at least quarterly. The service clinical lead should take responsibility for reviewing this report and for escalating any issues through the appropriate channels.

Basic audit can be undertaken during PSA tracking clinics to ensure all records and clinical management is up-to-date. More in depth audit may be undertaken to reflect on clinical practice. For example:

- **An audit after 12 months of the new service to review the appropriateness of the clinical protocols**
- **The service recall rate is higher than you would have expected, triggering an audit to investigate**
- **An audit to explain significant variation in practice between clinicians (e.g. some clinicians are not referring men to the care pathway)**
- **A serious incident has been reported and you want to determine if it was a one-off or is due to a more widespread problem**

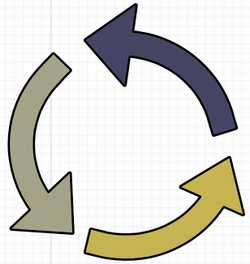
This reflective practice could align with clinical staff Continuing Professional Development requirements **(e.g. the NMC revalidation for Clinical Nurse Specialists).**

ADMINISTRATIVE processes

Robust administrative processes are required to support the delivery of a safe and effective service.
Here are some examples of administrative processes that had to be redesigned by our project sites:

- **Recording in the electronic patient record (EPR) that the patient was on Supported Self-Management, and ensuring the patient was still booked into the appointment system for the workshop and PSA tracking clinics. Not only did this support the billing process, failure to do this would make the patient appear lost to follow-up on the hospital EPR.**
- **There were a variety of approaches to ordering blood tests to support PSA tracking clinics. In some sites, GPs would accept a PSA reminder letter to perform a blood test. In other sites, the CNS had to order a blood test electronically for every PSA reminder letter sent. One of our sites gave each man three years of blood test forms when they attended the Supported Self-Management Workshop.**

SECTION F MAKING A CASE FOR CHANGE



MAKING A CASE FOR CHANGE

This section is intended to give you some of the evidence required to develop a local business case to support the implementation of the care pathway locally. Appendix F1 includes some template business cases developed in partnership with our project sites. A strong evidence base was drawn upon to design this care pathway and service evaluation activities have strengthened this evidence. Furthermore, the care pathway strongly aligns with national policy (see Table 2).

Evidence to date suggests that this method of follow up is:

- **More efficient than traditional follow-up care**
- **Highly acceptable to patients and uro-oncology clinical teams**
- **Feasible to implement in an NHS uro-oncology setting**

A controlled cohort study of the care pathway is underway and will reach its conclusion in July 2017. The study has recruited 347 men receiving usual care (comparator group) and 310 men enrolled on the new care pathway (care programme group). The study will compare these groups to determine if the care pathway has any impact on outcomes such as health-related quality of life and levels of unmet need. Barriers to implementation, factors enabling change and cost effectiveness will also be examined.

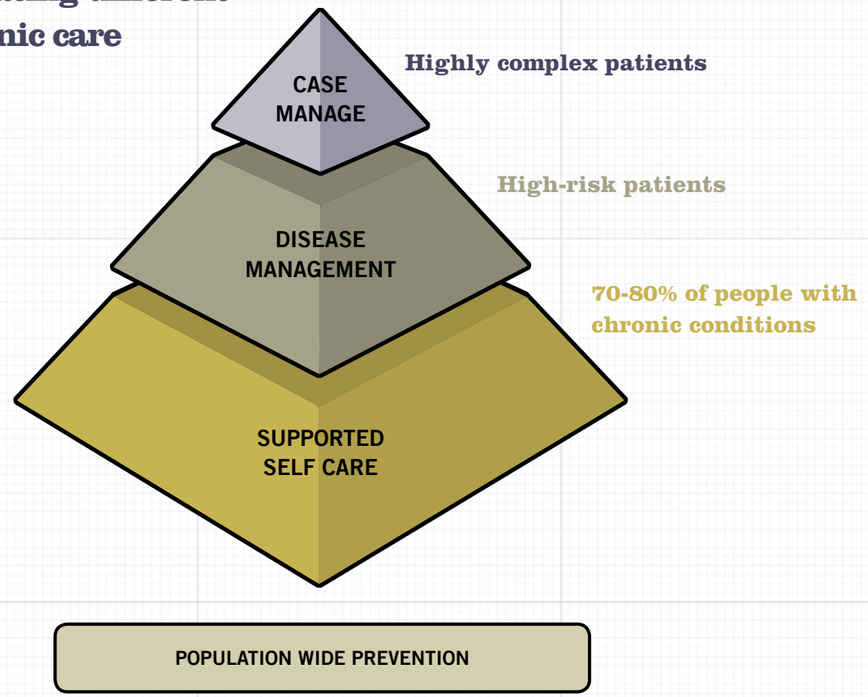
WHY DO SERVICES need to change?

The number of men living with and beyond prostate cancer is increasing Prostate cancer is the most commonly diagnosed cancer in UK men. Currently, over 330,000 men are living with and beyond prostate cancer. It is anticipated that the number of people in the UK with a diagnosis of prostate cancer, is set to increase to 620,000 by 2030 (Madaams 2012).

In the UK, approximately 90% of men diagnosed at Stage 1 or 2 live at least five more years, and 65-90% are likely to survive for at least ten more years (LSHTM 2014). This improvement in survival means that cancer services must adapt to managing prostate cancer as a long-term condition. Indeed, it is estimated that 70-80% of people living with long-term conditions can learn to be active participants in their own care with the right support (Kaiser Permanente, Figure 4). There is a growing body of literature supporting the effectiveness of self-management interventions for cancer survivors. Reviews of interventions, specifically for men with prostate cancer have shown evidence of a consistent, positive effect on distress, and sexual and urinary functioning (Cockle-Hearne & Faithfull 2010, Chambers et al. 2011). Extensive work in this area has been undertaken by the National Cancer Survivorship Initiative, which in 2013 published **Innovation to Implementation: Stratified pathways of care for people living with or beyond cancer - A "how to guide" (appendix F2)**. NHS England has committed to implementing Stratified Follow-Up pathways for breast, colorectal and prostate cancer by 2020.

Figure 4

The Kaiser Permanente model illustrating different levels of chronic care



Men with prostate cancer report high levels of unmet need

Four out of ten men with prostate cancer in the UK feel abandoned by the healthcare system once their treatment is complete (NCPES 2011). **Some unmet needs commonly reported are:**

- **29% of men with prostate cancer felt they had to wait too long to receive an appointment (NCPES 2015).**
- **More than a quarter of prostate cancer patients feel that the side effects of their treatments were not well explained, and nearly 40% report they are not offered practical advice about managing the side effects of treatment (NCPES 2015).**
- **Over half of men with prostate cancer report that they did not receive a care plan to address their ongoing needs (NCPES 2015).**
- **One in ten men with prostate cancer report they were not given the details of a named Clinical Nurse Specialist (NCPES 2015).**
- **Many prostate cancer patients suffer a loss of self-confidence after the completion of initial treatment, which may present a barrier to accessing support (Richards 2011).**
- **Generally, men with prostate cancer report they are dissatisfied with information about lifestyle changes and the availability of support to manage worries about the spread or recurrence (Morrison et al. 2012).**
- **Men are rarely invited to discuss psychosexual side effects within follow-up appointments and these men report a high level of sexuality-related unmet need (O'Brien et al. 2011).**
- **Nearly one-third report moderate or extreme levels of anxiety or depression (Ream et al. 2009).**

Services face a chronic shortage in the number of uro-oncology Clinical Nurse Specialists

It is estimated that there are only 294 urology CNSs in England (Macmillan Cancer Support 2014), whilst a further 195 are required to deliver mandated standards of care (Frontier Economics 2010). This means that men with prostate cancer are missing out on vital information and support, with only 89.1% being allocated a named CNS compared to 94.4% of breast cancer patients (NCPES 2015). Evidence shows that patients who have a named CNS have much better experiences of care (Tarrant et al 2008), so it is unsurprising, given the shortage of urology CNSs, that prostate cancer patients report poorer experiences than other patient groups (Sinfield 2009).

These issues were emphasised by a UK-wide nursing workforce survey undertaken by Prostate Cancer UK in 2014. **Of 285 Clinical Nurse Specialists who participated:**

- **49% (140) of nurses declared that they are eligible for retirement or intending to leave the profession within the next 10 years.**
- **52 nurses (18%) had a caseload of greater than 600.**
- **About 65% of respondents said they had no administrative support, or had support for clinic letters only. Of these respondents, about 86% declared that they work unpaid overtime, with about 36% declaring that they work at least four hours overtime per week.**
- **The equivalent of 58.3 full time equivalent roles were reported as frozen or vacant across the UK.**

A robust policy framework is driving this change

How does the care pathway align with national policy in England?	
Five Year Forward View NHS England 2015 (FYFV)	Supported Self Management supports the drive for further efficiency savings in the NHS care outlined in 5YFV. The "remote monitoring" aspect of this pathway introduces the largest efficiency savings: • Virtual clinic appointments brief (2 to 5 minutes), and are led by the Clinical Nurse Specialist and the Support Worker • Releases clinic appointments. Clinic-based follow up can focus on patients with more complex needs (e.g. patients receiving treatment) • Reduces pressure in terms of clinic room availability and hospital car parking spaces • Reduces patient travel and subsequently Trust carbon footprint. This model of care allows transfer of some activities from the Clinical Nurse Specialists (AfC band 7) to an AfC band 4 Support Worker. Not only is this more efficient, it also enables the Clinical Nurse Specialists to focus on patients with more complex needs. The Supported Self-Management workshop is a one-off four-hour workshop that covers a great deal of content. Many of these types of Supported Self-Management courses comprise several sessions, and are delivered over the course of weeks or even months. The Supported Self-Management pathway supports other 5YFV objectives, in particular: • Action on obesity, smoking, and alcohol consumption (Workshop) • Offering patients far greater control over their own care • Facilitating improvements in health technology, leading to a significant improvement in patients' experience of communication with the NHS and healthcare providers
NHS Outcomes Framework	This care pathway supports NHS Outcomes Framework Domains 2, 3 and 4. Domain 2 of the Framework is focused on enhancing the quality of life of people with long-term conditions, including ensuring people feel supported to manage their condition. Domain 3 indicates the necessity to help people who are recovering from ill health or injuries, including improving outcomes from planned treatments. Domain 4 relates to ensuring people have a positive experience of care, including improving people's experience of outpatient care and improving hospital responsiveness to personal needs.

Table 2 (continued overleaf)

How does the care pathway align with national policy in England?	
'Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020'	'Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020' was developed and published by an Independent Cancer Taskforce, appointed by NHS England. This 5-year plan set goals for England to be a world leader in the fight against cancer. Empowering people to take individual responsibility and self-manage their health and well-being is a strong underpinning theme in this strategy.
Implementing the taskforce recommendations: Commissioning person-centred care for people affected by cancer NHS England (2016)	This care pathway supports the key elements of this guidance: • Every person affected by cancer will have access to a recovery package, comprising essential interventions for person-centred care (Workshop, one-to-one support, holistic needs assessment and treatment summary record). • Implementation of stratified follow-up pathways (such Supported Self-Management) for breast, colorectal and prostate cancer by 2020.
'Personalised Health and Care 2020' HM Government (2015)	The HM Governments 'Personalised Health and Care 2020' calls for all patients in England to have read-write access to their entire medical record by 2018. The IT platform being used to support the PSA tracker and the Patient Online Service has the capability to enable patients read-write access to their prostate cancer care records. Access to full records is not currently active, however it is possible for the IT service provider (University Hospital Southampton NHSFT) to set this up.

Table 2

Is this method of follow up cost effective?

A detailed cost effectiveness analysis of the care pathway will be released in 2017. Some preliminary cost modelling is available in appendix F4. There is established evidence to demonstrate that the remote monitoring of stable prostate cancer is effective and costs significantly less than traditional clinic-based follow-up (Kirollos et al. 2013, Benney & McFarlane 2015). The earlier in follow-up a man is moved to remote monitoring, the higher the potential cost savings.

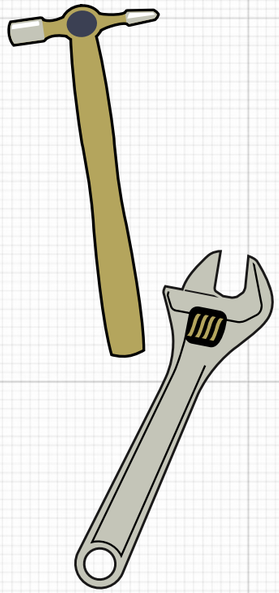
The care pathway aims to do more than remote monitoring. It aims to improve the quality of care delivered by enabling and supporting men to self-manage aspects of their condition. Investment in the workshops, the Support Worker role and the Patient Online Service should deliver this improvement in quality - however our controlled cohort study has yet to establish this. A key consideration for services will be how to balance the additional costs for the workshops, Support Worker input, and Patient Online Service with the cost savings from remote monitoring.

If implemented successfully, the care pathway should free up clinic capacity and clinical nurse specialist time. This should enable the Service to focus on patients with more complex needs, and also improve service waiting times.

Why have we introduced a band 4 Support Worker role?

Access to a named key worker significantly improves patient experience. In cancer services, this role is traditionally filled by the Clinical Nurse Specialist. Unfortunately, due to a shortage of Clinical Nurse Specialists, not all men with a diagnosis of prostate cancer have a named CNS. In 2013, Macmillan Cancer Support developed a number of new roles for the cancer workforce. One of these roles was the AfC band 4 Cancer Support Worker role. Macmillan piloted 26 Support Worker roles as part of their **One-to-One Support Project**. The evaluation highlighted positive feedback about the Support Worker roles from both patients and clinical teams. Our project incorporated a Support Worker role into the care pathway, as we felt that it is crucially important that men on the care pathway have a key point of contact within the clinical team.

What is the rationale for the workshop format?



Why workshops? There are various ways to deliver the information men need to give them the knowledge, confidence and skills to manage their prostate cancer. Examples include written information, one-to-one appointments, videos and group workshops. The care pathway incorporated all of these methods. Evidence suggests that interventions that combine psychological and educational techniques in a group setting have the most consistent impact in terms of quality of life and symptom relief (Cockle-Hearne & Faithfull 2010). Furthermore, men involved in the care pathway have given favourable feedback regarding the peer support aspects of the workshop. This reflects the findings of a review by Galdas et al. (2014, p.1230) that concluded ***"Self-management support is most likely to be successful in engaging men when it is congruent with key aspects of their masculine identity. In order to overcome barriers to access and fully engage with interventions, some men may need self-management support interventions to be delivered in an environment that offers a sense of shared understanding, connectedness, and normality, and involves and/or is facilitated by men with a shared illness experience".***

Group size: Group psychotherapy guidelines suggest group sizes of between seven and ten participants (AGPA 2007). Our project sites typically booked 12 men onto each workshop in anticipation of a small rate of non-attendance. This group size is small enough to ensure men feel they have a chance to participate and can discuss sensitive information that they may not wish to share in larger groups. There is no evidence to support the delivery of these types of interventions in large groups. On the other hand, group sizes of less than seven present a challenge in terms of the group dynamic, and having fewer experiences within the group to share.

Two facilitators: Our clinical teams preferred to deliver the workshop with two facilitators. There were a number of practical examples during the project where this approach was beneficial. If a member of the group became upset and needed a one-to-one discussion, or an invitee was lost on their way to the venue and needed directions, one facilitator could address these issues whilst the other continued to lead the group session.

Timing: A one-off four-hour approach was adopted to minimise the burden on the men and their clinical teams. Our project team felt that running longer or multiple workshops would be resource intensive and increased the risk of poor attendance rates. The timing of the workshop is important. The end of treatment has been identified as a "teachable moment" when men may be more receptive to learning about the management of their own health (Denmark-Wahnefried 2005). Hence, the Supported Self-Management workshop is delivered after treatment. It is important to note that not all patients enrolled on the care pathway attended the workshop in the immediate post-treatment stage. Some had completed treatment up to three years previously. We do not know if the workshop benefits patients who have not had recent treatment to the same extent as patients who have recently completed treatment.

Is remote monitoring safe?

There was not a single clinical incident or safety concern reported throughout the duration of the project. This reflects learning from the remote monitoring service run by Royal United Hospitals Bath NHSFT, where an audit after 11 years of service delivery that included 1,167 patients did not highlight any safety incidents (Benney and McFarlane 2015). Some clinicians within our projects' sites feel the governance arrangements for the care pathway are so robust they are now beginning to refer men on active surveillance to the pathway.

Is this method of follow up acceptable to patients?

By September 2016, 1,845 men had been enrolled on the new care pathway, and 169 workshops had been delivered. Day-to-day feedback from the men has been positive. No complaints have been raised and a number of letters of commendation have been sent to Trust executives praising the standard of care.

Initial evaluation of the workshops demonstrated a high level of acceptability to men and to clinical teams. These findings were presented at the Multinational Association of Supportive Care in Cancer conference in 2015 (see appendix F3).

> "I hate this issue of being in the dark all the time, as I said, we live from result to result, and that period in between we are left in the dark. I'm not any longer, I'm there, I'm with them, I'm up there with them. Any query, any issue, it's like going to the board meeting isn't it, where decisions are being made and I can be part of those decisions being made. I really feel I am now part of the team, if you like, and not waiting for the answers, I'm up there with them now, and that's what team work is all about, isn't it. **Man interviewed following the workshop in 2014.**"

References for this chapter along with a further reading list can be found in appendix F5.

SECTION G THE IT SYSTEM

In our project, the care pathway was supported by an IT system that was developed and delivered by University Hospital Southampton NHSFT. A patient-facing Online Service and a clinician-facing PSA tracking system form the electronic system that underpins care management. Figure 5 gives an overview of its functionality. More detailed specifications can be found in appendix G1.

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

The role of IT in Supported Self-Management

The Patient Online Service includes a Personal Health Record (PHR). The use of PHRs in the management of long-term conditions is becoming increasingly prevalent in the NHS. The HM Government's 'Personalised Health and Care 2020' calls for all patients in England to have read-write access to their entire medical record by 2018[1].

University Hospital Southampton NHS Foundation Trust has been developing its online service for patients since 2013 in several conditions, so when they became involved in the TrueNTH programme, they offered PHR IT enablement solutions to a number of the projects, including all five NHS sites involved in the TrueNTH UK Supported Self-Management project.

[1]HM Government (November 2014) Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A Framework for Action

TOP TIP

Ensure you have support from senior managers in the hospital IT department and pathology department at an early stage of implementing the care pathway.

This support would normally be required to gain business case approval.

> Self-management is only possible if the patient has access to the right information about their condition and other support tools. Enabling patients to access their own record is vital in empowering them to take more control.
>
> Kevin Hamer, Programme Manager, My Medical Record, University Hospital Southampton NHSFT

NURSE
(PSA TRACKER)

View PSA results, track when tests are due, send reminders and results to patients

Send and receive electronic messages to and from patients

Generate treatment summary records

View patient assessments and record care plans

MAN
(PATIENT ONLINE SERVICE)

View PSA results

Contact clinical team via electronic message

Complete holistic needs assessment and patient reported outcome measures

Record care plans

View online health information

Screen shots of our project IT system and an example list of patient information can be found in appendices G2 and G3.

THE TOOLKIT - TrueNTH PATHWAY IMPLEMENTATION

Considerations when choosing an IT system

Many PHRs were originally developed in the USA to support the billing process of insurance-based health services. As such, there are many on the market, but only a small number that meet the functionality requirements to support the delivery of the TrueNTH Supported Self-Management Pathway.

TrueNTH UK have developed an IT Standard which aims to help healthcare providers identify IT solutions that meet the functionality requirements. For more information on this IT Standard visit **www.prostatecanceruk.org/truenthuk/ITstandard.**

In addition to the IT Standard you should also take into consideration:

- What are the ongoing license fee costs?
- What are the ongoing support costs?
- What ongoing training and support is provided?
- Does the system meet the information governance standards required by your organisation?
- Do any of your in-house systems meet the specifications or could these systems feasibly be developed to meet the specs?
- How would the system integrate with existing hospital systems (such as the pathology systems and the patient administration system)?
- Could the system be expanded to other areas of cancer care or hospital care?
- What are the initial development costs and ongoing development costs? (For example, if you needed to add an information field for a new treatment modality to the PSA tracker, how much would it cost?)
- What do your patients and clinical teams think of the system?

Information governance

Personal Health Records have been introduced only recently by the NHS. Our project highlighted variation in levels of familiarity with PHRs among Information Governance leads.

It is important to involve Information Governance leads in procurement of the IT system. In addition to other assessments, your organisation may wish to undertake a Privacy Impact Assessment (PIA). An example PIA can be found in appendix G4.

Supporting men who do not wish to use a PHR

Low digital literacy presents a challenge when introducing PHRs, especially in the older age groups. This will become less of a challenge for future generations.

Our project ensured that paper-based methods were still in place for men who did not engage with the Patient Online Service.

Many Electronic Patient Records (EPRs) now include basic PHR functionality. The cost of developing this basic functionality to meet the needs of the care pathway may exceed the cost of procuring a separate system.

SECTION H PROJECT MANAGEMENT

PROJECT MANAGEMENT RESOURCE

Our project had a 0.6FTE National Project Manager. Each of the five project sites had local project management time. We funded each site to have 12 months of 0.2FTE nursing time dedicated to the set up and implementation of the project. Some of this time was used for the initial line management of the Support Worker and co-facilitation of the workshops. Our thinking was that, once the Support Worker role was embedded, the CNS efforts would be time-neutral. Bear in mind that our project included a great deal of design and development and also encompassed a high level of service evaluation and research.

We estimate that from the point of business case approval to the first patient being enrolled on the pathway is a period of 3 to 6 months. As a minimum, 6 months of 0.2 FTE project management working at AfC band 7 or higher is required, but ideally more resource than this should be provided. This will depend on the service context and on whether or not a CNS takes on the project management role. The CNS will need some protected time for workshops, PSA tracking clinics, supervision and the line management of the Support Worker.

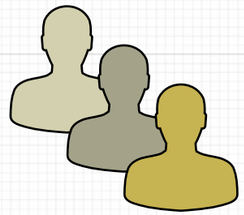
PROJECT MANAGEMENT TRAINING RESOURCES

NHS Improvement hosts a directory on their website that contains a wealth of resources for NHS project managers www.improvement.nhs.uk/resources/improvement-directory/

Prostate Cancer UK host online modules on Service Transformation at www.prostatecanceruk.org/for-health-professionals/online-learning

The NHS Handbook of Quality and Service Improvement Tools can be found in appendix H1.

KEY STAKEHOLDERS



Involving key stakeholders at the right time is a crucial part of any successful service change. Table 3 lists the key stakeholders involved in the implementation of the care pathway.

Table 3

Stakeholder	Role
Core working group: Lead clinicians, CNS, Support Worker (once they come into post), Project manager	Lead the service change. Responsible for the set up and running of the service.
Department clinicians and admin staff	To input into the design and set up of the service and clinical protocols. To be aware of their role in the delivery of the service.
Management structure: service manager, contracts managers, finance, governance groups	To be aware of the service change, and to be involved in key decisions (such as business case approval and recruitment).
IT and pathology	Responsible for setting up the IT system, and the transfer of PSA results to the PSA Tracker.
Clinical Governance and Information Governance	Involvement in the ongoing assessment of the safety of the pathway and supporting systems. Involved in the delivery of governance protocols.
Commissioners, primary care and clinical networks	To be aware of the service change. Commissioners will have a role in local funding decisions.
Patients	Should be involved in the design of the service. Patients should be informed in advance of the service change, so they are aware of their future follow-up care arrangements.

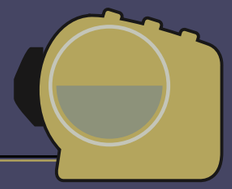
Tasks and timescales

The Gantt chart in Figure 6 outlines some of the key activities involved in project set up.
An editable version of this chart can be found in appendix H2.

Figure 6

CARE PATHWAY SET UP TIMESCALES	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12	Month 13	Month 14	Month 15	Month 16	Month 17	Month 18
BUSINESS CASE DEVELOPMENT																		
Stakeholder mapping	■																	
Form working group	■																	
Develop project plan	■																	
Map pathways (existing and new)		■																
Activity modelling (over five years)		■																
Financial modelling (over five years)		■																
Identify possible IT solutions		■																
Consultation with key stakeholders including commissioners and hospital executives			■															
Write business case				■	■													
Submit business case						■												
CARE PATHWAY SET UP																		
Commence care pathway set up							■											
Submit support worker job description and supporting documentation for review							■											
Advertise support worker role								■										
Shortlist support worker applicants								■										
Interview and appoint support worker									■									
Support worker starts										■								
Set up IT solution							■	■	■	■	■	■						
Support worker induction										■	■							
Workshop facilitation and IT training										■	■							
Scope out local services										■	■							
Prepare patient online information list										■	■							
Develop governance protocol (engaging clinical governance and information governance)							■	■										
Design printed materials							■	■										
Write PSA tracker letters							■	■										
Printed materials approvals								■	■									
Print materials										■	■							
Set workshop dates and book venues										■								
Deliver practice workshops												■	■					
Deliver real life workshops														■	■	■	■	■
Workshop peer observation and feedback												■	■					■
Start screening clinic lists											■							
Enrol men on the care pathway												■	■	■	■	■	■	■
Six month audit and service review																		■

Activity Planning, Migration Planning and Cost Modelling

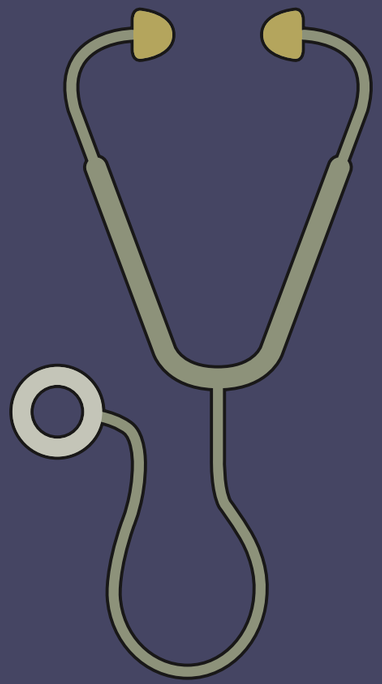


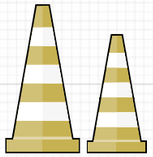
In order to support the submission of a business case, an accompanying migration plan should be developed. This is a plan that sets out the numbers of men to be "migrated" from clinic-based follow-up to Supported Self-Management, and over what time period. The plan also prioritises which clinics should be targeted first. An example of a migration plan can be found in appendix H3. Considerations include:

- Do you want to start with the clinics of the more engaged clinicians first?
- Are there any clinics where capacity issues are challenging (e.g. potentially breaching on cancer waiting time targets?)
- Are any clinicians due to retire in the near future?
- When do you normally discharge to primary care? Should this change?

Some of our project sites have undertaken an in-depth audit to understand the profile of their existing clinics and to estimate the number of men who could potentially be migrated to Supported Self-Management.

The activity and costs involved in delivering the migration plan should then be modelled over a five-year period. An example of this modelling can be found in appendix H4.





Barriers to Implementation

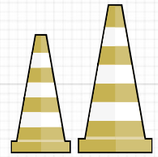


Table 4

Barrier	Action
Perverse financial incentives: Some organisations may be concerned that introducing a more efficient method of follow-up may result in a loss of income. This can present a challenge at the business case stage.	The cost to the healthcare community overall is reduced. It is important to involve commissioners early on in discussion so that mutually-agreeable billing arrangements can be put in place. Accurate cost-modelling, projected over a five-year period, should demonstrate the activity levels required to sustain income.
Poor project leadership and lack of project management. Implementation of this service requires strong leadership and dedicated project management time.	It is important to factor this resource into the business case. The clinical lead and project manager should be aware of their responsibilities before taking the role. This may be the first time the person in the project management role has managed a project. As such, it is a worthwhile investment to provide some project management training. Mentoring from someone in the organisation who has experience in managing projects is also advisable.
Lack of buy-in from clinicians	Involve them at an early stage in the design of the service and supporting protocols. Work with "the willing". You may find only two or three clinicians regularly refer to the pathway at the outset. Others will come on board once their concerns have been allayed.
Lack of understanding of components of the pathway (especially the Support Worker role and workshop format)	Awareness raising at the outset, e.g. presentations at meetings, staff intranet, staff newsletter, posters in staff areas.
Challenges implementing the IT system: There may be difficulties integrating the PSA tracker with the PAS and pathology system due to infrastructure issues and demands on staff time.	Engage the IT team at the business case development stage to ensure the IT work is adequately resourced. Establish processes to operate the PSA Tracker in the event that it is not integrated with other hospital systems. In this case there would be 100% manual data entry.
Multiple admin systems and processes	Work with key stakeholders to spend time mapping out original and new processes. Pilot and refine new processes before agreeing on final protocols.

Acknowledgements

The Authors of this toolkit would like to offer their thanks to:

The Movember Foundation for funding the TrueNTH Programme and Prostate Cancer UK for leading the UK-wide TrueNTH Initiative.

The clinical teams and IT departments from the following organisations, whose hard work and dedication has made this care pathway a reality: Dartford and Gravesham NHST; Royal Cornwall Hospitals NHST; Royal United Hospitals Bath NHSFT; St Helens and Knowsley Teaching Hospitals NHST; and the University Hospital Southampton NHSFT.

University Hospital Southampton NHSFT IT department for providing the IT solution for the care pathway.

Our Project Board for their support, oversight and advice throughout the project, and our researchers at University of Surrey and University of Southampton.

To everyone who contributed to the development of this toolkit, with special thanks to our designers Glassup & Stoski and to the TrueNTH UK Exercise and Diet project, whose resource The Manual inspired the design of this toolkit.

1st Edition, November 2016

The Toolkit

A TrueNTH project delivered by:

UNIVERSITY OF Southampton

Funded in partnership by: