TrueNTH Supported Self-Management FAQs

1. What is TrueNTH?

TrueNTH is a global initiative, led by Movember, tackling critical areas of prostate cancer care. The international network of representatives includes clinicians, academics, patients, and organisations from across the UK, Canada, Australia and other countries. Through this initiative we are working together to identify and demonstrate the best and most cost-effective models for improving prostate cancer survivorship care and support.

The TrueNTH Supported Self-Management model has been funded by Movember and delivered in partnership with Prostate Cancer UK, University of Southampton and NHS Trusts.

2. You mention that there are other similar models available? What are they and what is key to making them work?

There are several similar approaches being rolled out in Trusts across the UK. Our research shows that for a model to be successful, it requires:

- Ongoing access to a support worker, who introduces the supported self-management programme at the final clinic appointment.
  Ongoing individually tailored support as required
- Access to a supported self-management workshop
- Ongoing patient access to an online IT service that allows them to view test results, complete assessments, view information and message their clinical team.
- Ongoing remote monitoring of Prostate Specific Antigen (PSA) results using a PSA tracking system

3. When and where was the model tested?

The project ran from 2014 to 2017, and tested the model across 5 NHS Trusts. Over this time, 2675 men were enrolled on the programme and over 250 supported self-management workshops were delivered.

The trials took place at:
- University Hospital Southampton NHSFT
- Royal United Hospitals Bath NHSFT
- Royal Cornwall Hospital NHST
- Dartford and Gravesham NHST
- St Helens and Knowsley Teaching Hospitals NHST

Protocols and governance

4. What protocols are in place for effective governance?

St Helens and Knowsley Teaching Hospitals NHST were one of the original pilot sites, following on from the successful pilot, Cheshire and Merseyside Cancer Alliance have implemented the programme and have rolled it out across all trusts within the Alliance. Their protocols can be found here

5. What is used to identify the patient needs?

A health MOT (HNA) is built into the IT system (MMR) and patient portal element of the IT system and the assessment is completed by the patients and then discussed, and a care plan generated with the cancer support worker.

The workshops also provide the opportunity to empower the patient to self manage and the patient portal element of the IT system allows patients to communicate with the clinical team with the patient's queries triaged and allocated to the correct member of the clinical team.

6. How long do you continue PSFU? Do you discharge to community?

See protocol above, page 12 - 17

7. Are all men with prostate cancer eligible for this or is it just men in certain situations/certain stages of disease?

This model is designed for men who have already received primary treatment for prostate cancer, such as radiotherapy or surgery, and who are now being monitored for any recurrence of the disease.

Implementation Tips

8. Is there any funding nationally that is available for implementation?

In England funding is supported from NHS England and is written into the NHS Long Term Plan. The Cancer Alliance can evidence the work required and place in the operational plan and evidence the potential benefits.

Please see Cancer Alliance Funding Arrangements FAQ. For access to the workspace, please contact your Cancer Alliance LWBC lead via the contact details here https://www.england.nhs.uk/cancer/cancer-alliances-improving-care-locally/cancer-alliance-contacts/

Cheshire and Merseyside Cancer Alliance have produced a comprehensive suite of implementation resources, including a financial impact tool and an evaluation report on the implementation of PSFU, which can be accessed at their website https://www.cmcanceralliance.nhs.uk/our-priorities/living-and-beyond-cancer

In Wales funding is supported from NHS Performance Funds for health boards to improve follow-up backlog delays with recommendation that funding allocated towards implementing this pathway through working with the National Planned Care Programme.

Clinical Engagement

9. What are your top tips for bringing clinicians onboard with implementation of PSFU/SSM?

Facilitating peer to peer conversations and peer-reviewed publications on PSFU.

It can help to use NHS strategy/policy/planning levers such as the NHS England Outpatient Programme's work on Patient Initiated Follow-up (PIFU) – now included in the Covid-19 Phase 3 recovery planning guidance
https://www.england.nhs.uk/operational-planning-and-contracting/

The original stratified follow up 'How To' guide (2013) was endorsed by Royal Colleges and professional organisations and has advice on brining clinicians together to implement PSFU.

Several of the NICE guidance recommendations on cancer include some or all elements of PSFU.

The British Gynaecological Cancer Society has recently published Patient Initiated Follow-up (PIFU) guidance (not exactly relevant to prostate but shows clinical leadership on this issue).

The NHS Cancer Programme commissioned the South Central West CSU to deliver a qualitative evaluation study of PSFU which will be shared with Cancer Alliances in September 2020. The evaluation provides an understanding of the Cancer Alliances approach to implementation of PSFU, associated barriers and enablers, and provides recommendations for action which include stakeholder engagement.

Support Worker Role

10. **What does the support worker role involve, and why is it important?**
A new support worker role was based on early work by Macmillan Cancer Support. Whilst there was some variation across the different participating NHS Trusts as to the precise role description, key tasks included:
    - identifying and enrolling suitable patients;
    - holding an initial consultation with men to introduce them to the programme;
    - co-facilitating the support self-management workshop;
    - serving as the first point of contact for men on the programme;
    - and setting men up on the Patient Online Service and PSA Tracking System.

The introduction of the support worker role was overwhelmingly positive, providing significant support for nurse specialists, who would otherwise see an increased workload. The addition of this role allows them to concentrate on supporting men rather than administrative tasks.

11. **Is the CSW & navigator the same person?**
Yes. Nationally there are >20 titles for the same Band 4 role. One of the problems is standardising the title to educate both the workforce and patients.

Workshop/Patient Engagement

12. **What does the workshop involve, and why is it important?**
The Supported Self-Management Workshops were piloted and then rolled out as part of this project. They were co-facilitated by a nurse specialist and the support worker, lasted 4 hours, and had between 8 and 10 men in attendance.

The workshops are considered a fundamental part of the follow-up pathway. In the aim to increase patient activation levels (specifically to improve knowledge skills and confidence in the context of cancer follow-up) the following topics are covered:

- What is supported self-management?
- Understanding PSA monitoring
- Signs of disease progression and recurrence
- 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 (this is an online portal that patients can use to access test results, message their clinical team, complete assessments and access health information)

The workshops are an essential element to empower the patients to self manage, educating patients on physical ailments to be aware of and when to contact the clinical team with concerns as well as providing the opportunity for shared experiences to give men the best opportunity to learn from one another.

13. How do you manage patients who are not computer/IT literate?

Patients are offered to use the patient portal element of the IT system with training and log in details provided. If they choose to opt out of having access to the patient portal the system can still be used by the clinical team to manage the patients follow up in the same way with letters built into the system and printed instead of being sent out electronically. The patient will receive everything through the post and be contacted via telephone as opposed to the digital communication.