

# Survivorship and prostate cancer: the TrueNTH Supported Self-Management programme

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**With the rapid increase in the number of new prostate cancer diagnoses and the growing number of cancer survivors, there is a need for a new model of survivorship care to address the holistic needs of our patients. The TrueNTH initiative, launched by the Movember Foundation, is set to markedly change the survivorship experience of men with prostate cancer and has the potential to make a big impact on their lives.**



**P**rostate cancer is the most common cancer in men in the UK, with around 37 000 men being diagnosed with the disease every year.<sup>1</sup> In recent years, significant increases in incidence have been reported in many countries around the world. Much of this increase, both in the UK and worldwide, can be linked to the incidental finding of prostate cancers following transurethral resection of the prostate (TURP) and prostate-specific antigen (PSA) testing in primary care.<sup>2,3</sup> Over the last 25 years, the five-year relative survival rate for men with all stages of prostate cancer has increased, due to a combination of early detection and increasingly effective treatment of the disease, whether localised or advanced.<sup>4</sup> Within prostate cancer survivorship, there is therefore a need to ensure that those men have access to the care and support they require to adjust to life after cancer diagnosis.

## **SURVIVORSHIP**

In cancer, survivorship focuses on the holistic needs of a patient after initial

treatment, and covers the physical, psychological and social issues of cancer, beyond the diagnosis and treatment phases. Survivorship care encompasses issues such as the ability to get healthcare and follow-up treatment, the side-effects of treatment and quality of life. Family members, friends and carers are also an integral part of the survivorship experience.

The National Cancer Survivorship Initiative (NCSI), which originated from the Cancer Reform Strategy of the Department of Health in 2007, was a partnership between NHS England and Macmillan Cancer Support from 2008 to 2013. Its aim was to ensure that people living with cancer had the support and services they needed to resume as normal a life as they could following cancer treatment.<sup>5</sup> Following on from the success of the NCSI, the new Living With and Beyond Cancer (LWBC) Programme was set up in June 2014 to support healthcare commissioners to take the required actions to improve cancer survivorship outcomes.<sup>6</sup>

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**PROSTATE CANCER SURVIVORSHIP**

Clinical guidelines, from leading organisations such as NICE, for the care of men with prostate cancer focus on diagnosis and treatment, with little attention to survivorship care. Four out of ten men with prostate cancer feel abandoned once treatment is finished and a significant proportion report unmet needs.<sup>7</sup> In July 2014, the American Cancer Society (ACS) released guidelines on prostate cancer survivorship to co-ordinate this aspect of care.<sup>4</sup> The ACS guidelines list five main areas of prostate cancer survivorship care, with particular attention to the role of primary care physicians:

**1. Health promotion**

Assess information needs related to prostate cancer, including its treatment, side-effects and other health concerns, and provide survivors with the appropriate resources to meet these needs.

Advise survivors on the importance of maintaining a healthy weight, engaging in physical activity, eating a balanced diet, avoiding or reducing alcohol consumption and stopping tobacco use.

**2. Surveillance for prostate cancer recurrence**

Measure serum PSA level every 6 to 12 months for the first five years and annually thereafter. Refer patients with rising PSA levels back to the prostate cancer specialist for follow-up and further treatment and perform an annual DRE.

**3. Screening and early detection of second primary cancers**

Thoroughly evaluate prostate cancer survivors presenting with haematuria, rectal bleeding, pain or other red-flag symptoms.

**4. Physical and psychosocial assessment and management**

Assess for physical (urinary, sexual and bowel) and psychosocial effects of

Projects	Aims
TrueNTH Decision Support	Help men with localised, low-to-intermediate risk prostate cancer to make decisions about their treatment path
TrueNTH Exercise and Diet	Help patients and their families to adopt a healthy lifestyle and make changes where needed
TrueNTH Supported Self-Management	Support patients to self-manage their follow-up care once they have received initial treatment
TrueNTH Managing Incontinence	Help men access the continence products they need
TrueNTH Tackling the Late Effects of Pelvic Radiation Treatment	Help reduce the late effects of radical radiotherapy

*Table 1. TrueNTH survivorship projects*

prostate cancer and its treatment. Use validated questionnaires and tools to help identify and measure the burden of the side-effects.

**5. Care co-ordination**

Treating specialists should provide primary care physicians with a treatment summary and survivorship care plan.

**TrueNTH**

TrueNTH is a new global initiative, led by the Movember Foundation, to improve the prostate cancer survivorship experience. Its aim is 'to support men and their families through all stages of the disease – from diagnosis through to end of life'.<sup>8</sup> This novel programme was launched in September 2014 in the UK, Australia, New Zealand, the USA and Canada. In the UK, the programme is being managed by Prostate Cancer UK, with over £5 million being invested. It is a three-year pilot programme with five survivorship projects, as outlined in Table 1.

**SUPPORTED SELF-MANAGEMENT IN THE UK**

Traditional follow-up care pathways involve face-to-face clinic review at regular intervals, with limited support between appointments. With advances in

prostate cancer diagnosis and treatment, the number of prostate cancer survivors is increasing. However, very little has been done to expand existing services. Men with prostate cancer report high levels of unmet need. Factors that may play a role in this include a shortage of uro-oncology clinical nurse specialists and increasingly over-booked hospital clinics with little time available for each patient.

**Aims**

The TrueNTH Supported Self-Management initiative, launched in five NHS Trusts, aims to create a new post-treatment care pathway for men able to manage their own care. Patients can decide for themselves if there is a need for a follow-up appointment in clinic. Men eligible for this new model of care will be given the tools to self-manage and will not receive traditional outpatient follow-up.

**Methods**

Patients who are able to self-manage and meet the following eligibility criteria will be deemed suitable for the programme:

- 6 weeks after radical prostatectomy with PSA ≤0.1
- 6 weeks post-completion of radiotherapy and PSA <2

- 3 months post-commencement of primary androgen deprivation therapy with response and PSA <4
- On commencement of watchful waiting with PSA <30 and PSA doubling time of >1 year.

Patients on active surveillance will not be included in the programme.

Once recruited, patients will take part in a one-off, four-hour supported self-management introductory course, run by a cancer nurse specialist and a support worker. This will provide them with the skills and confidence to self-monitor for symptoms and signs of recurrence, and to manage lifestyle changes. They will also be given access to the TrueNTH online portal. They will then need to have regular PSA tests, as outlined by the hospital specialists; the dates for these will be available in the online PSA tracking system and through correspondence from the hospital. Blood tests may be carried out at either their local GP surgery or the hospital. Those who fail to have their PSA test will receive two reminders by post and then a phone call.

The results of the PSA test will be forwarded to the TrueNTH online portal via a secure interface that the patients are able to view from the comfort of their own homes. The results will also be checked by the patient's clinical team, and this will be acknowledged via a letter to the patient. A letter with the PSA result will be sent to both the patient and their GP. Monitoring and recall criteria may be personalised for individual patients depending on their initial treatment (Table 2). Having direct access to the PSA result will therefore eliminate the need to travel and wait to see a clinician in hospital, also freeing up clinic appointments for patients newly diagnosed with prostate cancer and other urological conditions.

The patients will be asked to complete regular assessments in the form of a

Treatment	Eligibility	Monitoring	Recall
Radical prostatectomy	6 weeks post-surgery and PSA ≤0.1	Year 1: 3-monthly PSA Years 2–5: 6-monthly PSA Years 6–10: annual PSA	1. PSA >0.1: phone patient and retest in 6 weeks 2. PSA >0.2 or 3 consecutive rises 3. New LUTS, visible haematuria, bone pain
External beam radiotherapy	6 weeks post-treatment and PSA <2	Year 1: 3-monthly PSA Years 2–5: 6-monthly PSA Years 6–10: annual PSA	1. PSA > nadir + 2 2. 3 consecutive rises 3. New LUTS, visible haematuria, rectal bleeding, new bowel symptoms, bone pain
Androgen deprivation therapy	3 months after starting treatment with response and PSA <3	6-monthly PSA, creatinine and ALP	1. PSA >4 2. New LUTS, visible haematuria, bone pain 3. Testosterone levels on recall
Watchful waiting	On starting watchful waiting with PSA <30 and doubling time >1 year	6-monthly PSA, creatinine and ALP	1. PSA >30 or DT <1 year 2. New LUTS, visible haematuria, weight loss, bone pain

Table 2. Protocol for the management of patients on the TrueNTH Supported Self-Management programme

'health MOT checklist', which can be accessed either via the TrueNTH online portal or in paper format. The checklist will provide a way of identifying any concerns or problems the patient may have in living with prostate cancer. Figure 1 shows a flow chart of the programme elements.

**Evaluation**

Evaluation of the TrueNTH Supported Self-Management programme will be undertaken using a controlled cohort design and previously tested validated measures.

It will compare the following outcomes for men in the programme with those who have received the usual follow-up care:

- Unmet needs
- Quality of life

- Anxiety and depression
- Skills for self-management
- Healthy behaviours
- Health service use
- Satisfaction with follow-up care.

The cost of the care programme will be compared with that of standard clinic-based follow-up care. The healthcare professionals' and patients' experiences of the TrueNTH programme will also be documented, as well as factors that promote or inhibit the programme's implementation.

The evaluation will compare the above-mentioned outcomes in 300–400 men receiving usual care and in a comparative number of men using the new care pathway. The results will be available in July 2017.

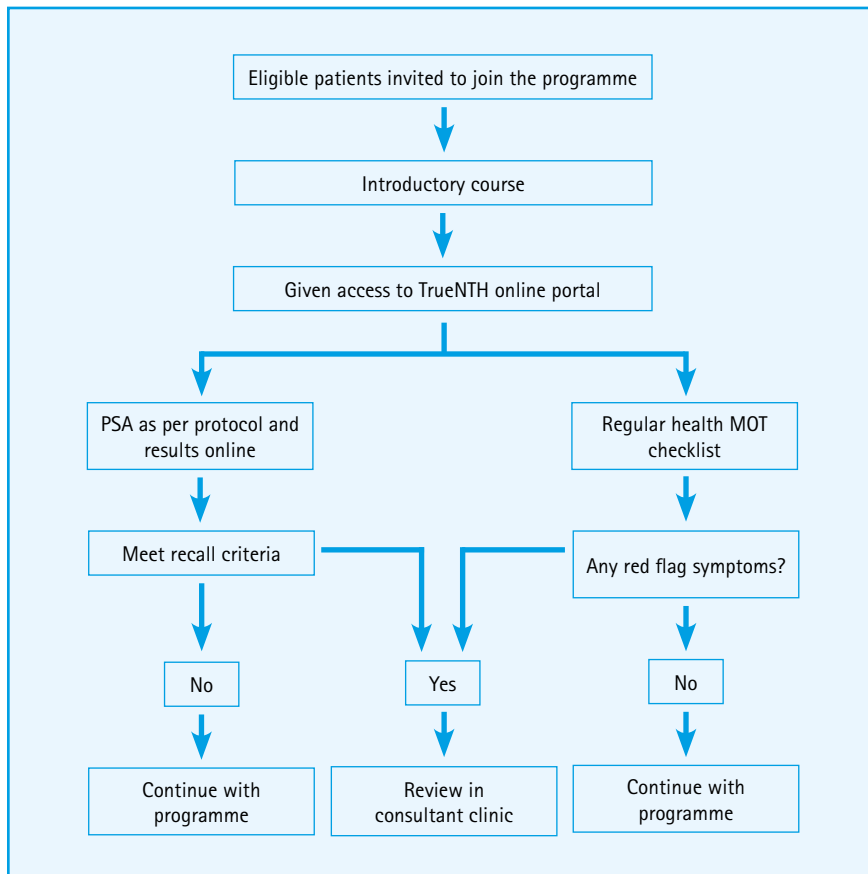


Figure 1. Flow chart for the TrueNTH Supported Self-Management programme

## CONCLUSION

With the rapid increase in the number of new cancer diagnoses and the growing number of cancer survivors, there is now a need for a new model of survivorship care to address the holistic needs of survivors. Prostate cancer survivorship in the UK is lagging behind. The recent appointment of a Prostate Cancer UK Survivorship nurse specialist in the North-East of England marks a step in the right direction. However, the TrueNTH initiative, launched by the Movember Foundation, is set to markedly change the survivorship outcomes of men with prostate cancer and has the potential to make a big impact on their lives. Not only does it aim to provide a better standard of care, but it can hopefully deliver significant savings to the NHS that can be used for other cancer management programmes.

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For further information on this programme please contact Hazel Brodie, project manager (H.Brodie@soton.ac.uk).

## REFERENCES

1. Office for National Statistics. Cancer Statistics Registrations, England (Series MB1) (<http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html>; accessed 9 December 2015).
2. Hsing AW, Tsao L, Devesa SS. International trends and patterns of prostate cancer incidence and mortality. *Int J Cancer* 2000;85:60–7.
3. Bray F, Lortet-Tieulent J, Ferlay J, et al. Prostate cancer incidence and mortality trends in 37 European countries: an overview. *Eur J Cancer* 2010;46:3040–52.
4. Skolarus TA, Wolf AM, Erb NL, et al. American Cancer Society prostate cancer survivorship care guidelines. *CA Cancer J Clin* 2014;64:225–49.
5. Department of Health. National Cancer Survivorship Initiative Vision. January 2010 (<http://www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf>; accessed 9 December 2015).
6. National Cancer Survivorship Initiative. Living with and beyond cancer: taking action to improve outcomes March 2013 ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/181054/9333-TSO-2900664-NCSI\\_Report\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf); accessed 9 December 2015).
7. Department of Health. Cancer Patient Experience Survey national report 2011–12. August 2012 ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf); accessed 9 December 2015).
8. Prostate Cancer UK. TrueNTH (<http://prostatecanceruk.org/for-health-professionals/our-projects/truenth>; accessed 9 December 2015).