

Executive Summary

TrueNTH UK supported self-management and follow-up care programme for men with prostate cancer. Evaluation report.



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Southampton

<p>E1 The number of UK men living with and beyond prostate cancer is set to double by 2030. Clinics are already struggling to cope with these increasing numbers, a problem compounded by workforce challenges. This project developed and evaluated a new model of stratified follow-up, with the majority of men supported to self-manage their condition post-treatment, freeing up resources and time in clinic for patients with more complex needs. An implementation toolkit (including detailed guidelines) has been developed to allow other healthcare providers to adopt this new model of care.</p>	<p>E6 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 key topics included understanding supported self-management; PSA monitoring; contacting the clinical team; common side effects and symptoms; emotional concerns; healthy lifestyles; moving forward; and using the patient online service.</p>	<p>E9 Key findings from the evaluation included:</p> <ul style="list-style-type: none"> – Outcomes for men in the programme group were for the most part equivalent to men in the comparator group, with very modest improvements in the programme group in relation to unmet existential need, bowel symptoms, and psychological wellbeing. – Satisfaction levels with the model of care were high. – The direct per patient cost over the 8 month follow up period was higher in the programme group compared with the comparator group (£102 vs £59). However, the overall per patient cost was lower (£289 vs £327). This is because wider health service utilisation was lower in the programme group. – The programme meets NICE cost-effectiveness criteria for recommended adoption. – Successful implementation of the programme required behavioural and cultural changes on behalf of the clinical team. These included adopting new processes, and developing trust in self-management, and the role of the support worker. – The programme was perceived, by staff at the sites, to improve the quality of care provision. – The introduction of the support worker role was seen as overwhelmingly positive, providing significant support for nurse specialists. – The workshop is considered a fundamental part of the programme. Training was needed in facilitation skills, and the less directive delivery style was initially counter-intuitive for some nursing staff. – The workshops are appropriate for men with a variety of treatment experiences. – The better the PSA Tracker was integrated into the incumbent IT systems, the more useful it was. There were workload implications when the integration was not completed, with clinical teams having to spend additional time manually inputting data into the system. – Six out of every ten men signed up to use the IT system, although not all of them used the service regularly. The remaining 4 out of ten chose not to sign up, and their follow up was managed by telephone and letter. 	<p>E10 The project identified a number of implications for a wider implementation of this new model of follow up care. They included:</p> <ul style="list-style-type: none"> – The need for flexibility to meet the needs and preferences of patients, such as alternative options for those not engaging with the workshops or with the online service. – Further development of the support worker role – The need for facilitation skills training for nurse specialists and support workers – Further development of the IT service – The importance of robust communication between staff delivering the supported self-management programme (the cancer nursing team) and a patient's urologist / oncologist. – The need to develop national tariffs and reference costs for activities such as workshops and PSA tracking clinics. – The need to develop guidelines on the frequency and duration of PSA testing in prostate cancer follow up
<p>E2 The key elements of the new model of care are:</p> <ul style="list-style-type: none"> – Ongoing access to a support worker, who introduces the supported self-management programme at the final clinic appointment. Ongoing individually tailored support as required – 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 	<p>E7 A new PSA Tracking system was designed and built as part of the project. This allowed men to access their PSA results online as soon as these results were available to clinicians. Although there were concerns from clinical teams about patients having such access before clinicians had assessed them, the project showed that men were not adversely affected by this, even if their test results were abnormal.</p>		
<p>E3 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.</p>	<p>E8 Four participating NHS sites were involved in a formal evaluation, comparing outcomes of 293 men on the programme with a pre-service change cohort of 334 men who received their hospital's usual follow up care. Patients from both groups were sent questionnaires at three time points (baseline and 4 and 8 months later) and 39 men and 32 staff members took part in semi-structured interviews. There was also an evaluation of the use of the IT service, and an economic evaluation.</p>		
<p>E4 To deliver the new model of care, three innovations were needed – the new support worker role, the supported self-management workshop, and the IT service.</p>			
<p>E5 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.</p>			<p>E11 A number of areas of further research and evaluation have been identified, including: how best to extend the programme to patients with more complex needs; and how best to embed Holistic Needs Assessment and Patient Reported Outcome Measures in a service model where patients are monitored remotely.</p>

This document is the executive summary from the report:

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To find out more about the project visit:

www.southampton.ac.uk/truenth-ssm

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TrueNTH is a global initiative funded by The Movember Foundation 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. In the UK it is delivered in partnership with Prostate Cancer UK.

The TrueNTH Supported Self-Management and Follow-Up care project was led by University of Southampton, and delivered in partnership with: Dartford and Gravesham NHST; Royal Cornwall NHST; Royal United Hospitals Bath NHSFT; St Helens and Knowsley Teaching Hospitals NHST; University Hospital Southampton NHSFT and University of Surrey.