

Self-managed care helps men with prostate cancer

TrueNTH, established by the Movember Foundation aims to significantly improve the lives and experiences of men living with prostate cancer, along with their partners, carers and family members.

One of the nine TrueNTH projects supported in the UK is [the Supported Self-Management and Follow-Up Care programme](#). Led by the University of Southampton, the programme began in January 2014. Programme Lead, Professor Alison Richardson, said: "It has been developed to really help men live after being diagnosed with and undergoing treatment for prostate cancer. The focus is on improving men's quality of life by providing them with the care, support and advice that they need."

TrueNTH is an international partnership of over 300 healthcare professionals, academics and volunteers and is delivered in this country in partnership with Prostate Cancer UK.

What has changed?

An estimated 330,000 men are living with and beyond a diagnosis of prostate cancer in the UK. Over recent decades, survival rates have improved dramatically. This means services must adapt to managing prostate cancer as a long-term condition and focus on increasing the quality of life of survivors and managing clinical demand.

Normally, men with prostate cancer receive regular clinic-based follow-up appointments for several years, but research shows for some men this follow-up care is not meeting their needs. So a new model of follow-up care based on principles of supported-self management and remote monitoring have been developed, building on work by Macmillan Cancer Support, NHS England, NHS Improvement and other partners.

Five NHS trusts have piloted this approach and initial indications suggest men participating were happy with their care. The trusts are University Hospital Southampton NHSFT, Dartford and Gravesham NHS Trust, Royal United Hospital Bath NHS Foundation Trust, Royal Cornwall Hospitals NHS Trust and St Helens and Knowsley Teaching Hospitals NHS Trust. Further results will be available when the programme evaluation is published later this year.

How the programme works

When a patient comes to the end of their active treatment (for example radiotherapy and/or surgery, although they may still be on hormone therapy), and they have a stable PSA (standard test for prostate cancer) they are considered for the programme.

Those patients selected to participate initially attend a workshop hosted by a clinical nurse specialist and support worker. Here patients get advice on things they can do to better manage their health and to support their recovery. They are also encouraged to complete a Holistic Needs Assessment to assess their health, social and well-being needs. Patients are encouraged to support one another as part of the workshop.

Following the workshop, patients are contacted by their support worker to discuss their needs and to co-produce their self-management plan.

Patients then self-manage their care using a bespoke computer system. They are monitored remotely by their specialist cancer team, who will call them back into clinic if necessary. Each patient has a dedicated support worker who they are encouraged to contact if they have questions or concerns.

The bespoke computer system used by the patient is integrated with the trust pathology system. This means patients can access their own test results and personal information. Initially clinical teams were concerned about how men would react if they accessed the system and found that their PSA level had increased. However, feedback has shown that when this happens men will contact their support worker for advice.

Impact

Patients have benefitted from having a convenient and accessible way to contact their care team and from having a dedicated support worker. Some patients also find it easier to raise issues that are worrying them through the computer system rather than face-to-face.

A prostate cancer patient described the benefits for him: "If anything is wrong, I can easily get in touch with the oncology department straight away. Or they'll probably be in touch with me if my PSA is sky high anyway... and if I have any questions to ask the oncology nurse, I can send them an instant email message through the system. ... I think it's great, you know. It's a much better system."

Clinical teams involved in the programme have also described the huge benefits of the programme.

Debbie Victor, Uro-oncology Clinical Nurse Specialist at the Royal Cornwall Hospitals NHS Trust described how almost 1,000 men at her trust took part in the programme.

Debbie said: "The convenience of not coming to clinics, getting real time results and having a dedicated contact number and messaging system through the secure portal is invaluable. Patients know if they have a problem in between regular reviews they can contact us for reassurance to book them into a clinic."

Debbie also said the system has freed up a lot of clinic time, enabling the clinical team to focus on those patients who are not as well face-to-face.

Next Steps

The programme team has received additional funding from TrueNTH translate as much of the learning from the programme as possible across the UK.

NHS England is now funding the development of workshops for both colorectal and breast cancer modelled on the Supported Self-Management and Follow Up Care Programme's workshops. These will be piloted in partnership with Wessex Cancer Alliance in 2018.