NHS England

University Hospital Southampton NHS Foundation Trust: Cancer 'Patient Triggered Follow Up' Project to enable living well beyond cancer

Context

'Achieving World-class Cancer Outcomes, A Strategy for England 2015-2020', emphasised the importance of taking a person-centred, whole pathway approach to the commissioning and provision of cancer services, and highlights the need to improve quality of life for people living with and beyond cancer.

NHS England has committed to ensuring every cancer patient receives the four interventions known as the 'recovery package', which aims to help patients live well during and after their cancer treatment. Additionally, NHS England has committed to rolling out stratified follow up pathways, which deliver aftercare services differently to better use resources and promote wellbeing, recovery and empowerment.

The NHS is committed to helping patients live well beyond cancer, and through the recovery package and stratified follow-up pathways Cancer Alliances, which help to bring together senior clinical and managerial leaders locally, will achieve this. The work at Southampton shows the innovative ways in which Trusts, Clinical Commissioning Groups (CCGs) and the cancer charitable sector can work to achieve the different aspects of the of the Cancer Alliance objectives.

The Cancer Centre at University Hospital Southampton (UHS) has been working towards the principles of these goals for years. They commenced a review of cancer follow up (aftercare) services in 2009, with project funding from Macmillan Cancer Support, in order to improve service delivery and to support cancer survivors to take an active role in their recovery.

The first phase of this work has resulted in a re-design of services for patients who have completed curative treatment for breast, colorectal and testicular cancer. These patients do not require further treatment, and are in a clinically sound position to manage their own care so they can live their life to the full. Predictably this will include approximately 70-80 per cent of breast cancer survivors, 95 per cent of testicular cancer survivors, and 50 per cent of colorectal cancer survivors. The new service commenced in December 2011. A project team was set up including a research fellow to evaluate the impact of developing Patient Triggered Follow Up. The evaluation included quality of life measurement, patient focus groups and staff education. Engagement with CCGs, GPs and community teams was integral to implementing change. Funding was also provided by Breast Cancer Care for breast cancer Moving Forward Workshops.

Since 2013/14 the Trust has been expanding this work to prostate, lymphoma and endometrial cancer through the Patient Triggered Follow Up (PTFU) initiative.

Solution

The trust is supporting six cancer sites that are running site specific programmes which has enabled re-designing and tailored aftercare for these groups of cancer survivors through the PTFU.

The aims of the PTFU are to promote self-management as a key part of the recovery package, encourage the appropriate use of health care resources, and most importantly to improve patient experience.

The PTFU supports and empowers patients to manage their own recovery. This is in response to

patients expressing the view that taking back control and being well informed is key to recovery from cancer. Routinely attending outpatient follow up clinics to be given straightforward results with the inconvenience of travel, parking and waiting to be seen has been perceived as unnecessary.

Rather than attending an outpatient appointment, the PTFU team consisting of a Band 4 Support Worker or Clinical Nurse Specialist makes contact with the patient initially either through a face to face meeting in clinic, by telephone or sending information by post or email. The patient is informed of all the information relating to the PTFU, including the contact details they need to trigger an out-patient appointment if they feel it is necessary. Supported self-management of their health and well-being is discussed with the patient (in line with the recovery package), and the patient is given an appointment to attend a health and wellbeing workshop, or a relevant 'Moving Forward' course.

One example of a workshop patients can attend is 'the Prostate Cancer and Living Well workshop' which was developed by University of Surrey, University of Southampton, Prostate cancer UK, Movember and a True North initiative. The half day course focuses on important signs and symptoms of prostate cancer, emotional impact, healthy lifestyle, PSA and the surveillance tracking system and patient stories. It is facilitated by a patient and the PTFU team.

Patients are also enrolled onto the PTFU computer system. The system allows patients to access their test results online, and the system also sends letters to the GP and patient informing them of test results and the next steps.

Once enrolled, the patient will also receive regular updates on health and wellbeing resources, which includes health promotion material that a patient can use. Patients will also be invited to attend walking sessions to promote healthy living. Patients can also use the trust's "Drop in Wellbeing" Weekly session at the local Macmillan Centre. This session is a place where patients can go to find out what services are available to them, and is funded by the hospital trust and run by one of the trust's most experienced and innovative Band 4 Support Workers.

Not only is this system to be the benefit of recovering cancer patients, but it also saves resources. There are currently 1,413 patients enrolled into PTFU, saving approximately 5,500 outpatient appointments each year, and this is increasing year on year.

Ali Keen, Head of Cancer Nursing at University Southampton Hospital Trust, said: "after diagnosis and treatment for cancer, having the information and support to focus on health and wellbeing is incredibly important to patients and their family. Getting 'back to normal' can take many months and for a number of people life will never feel the same again. Not having to constantly come back to hospital for unnecessary check-ups is a first step to recovery and independence. The second is to make sure that any ongoing symptoms are managed well and the patient understands the signs of potential recurrence so that they can be assessed only as necessary. Our Patient Triggered Follow Up service does both of these things, putting the patient firmly in control of how they manage their recovery, and at the same time giving them the support they need and deserve from the NHS, so that they can live well beyond cancer. At the same time by reducing unnecessary hospital outpatient appointments the Trust can focus these resources more effectively".

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