

<b>Institution:</b> University of Southampton		
<b>Unit of Assessment:</b> 03 Allied Health Professions, Dentistry, Nursing and Pharmacy		
<b>Title of case study:</b> 03-03 Transforming cancer care and improving the lives of cancer survivors		
<b>Period when the underpinning research was undertaken:</b> 2004 – 2019		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Claire Foster	Professor of Psychosocial Oncology; Director, Macmillan Survivorship Research Group	Jul 2004 – present
Jessica Corner	Professor of Cancer and Palliative Care	Feb 2002 – Dec 2015
Alison Richardson	Professor of Cancer Nursing/End of Life Care	Sep 2009 – present
Lynn Calman	Associate Professor	Oct 2011 – present
Chloe Grimmett	Senior Research Fellow/NIHR post doc Fellow	Feb 2012 – present
Jane Frankland	Senior Research Fellow	Sep 2005 – present
David Wright	Research Fellow / Senior Research Fellow	Nov 2002 – Jun 2008 / August 2018 – present
<b>Period when the claimed impact occurred:</b> September 2014 – December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b></p> <p>Research led by the University of Southampton (UoS) has improved the lives of cancer survivors, with people better able to understand and manage the long-term impact of cancer on their health and wellbeing. It has significantly changed healthcare policy and practice, creating personalised care systems that respond to patient need and optimise limited resources. Since 2014 the findings have influenced NHS England's cancer strategy, Health Education England's cancer workforce planning and Wessex Cancer Alliance's Five-Year Plan. They resulted in changes to NICE prostate cancer guidelines, Canadian care standards and UK prehabilitation guidance. Self-management models developed and validated by UoS have been mandated for use in all Welsh urology centres and have changed services in 38 NHS trusts in England, with implementation planned in four Scottish health boards. An online portal providing remote access to prostate cancer care has been adopted by 38 NHS trusts and a digital tool for people affected by cancer related fatigue is used nationally and in Australia. There are 2.5 million cancer survivors in the UK (Macmillan Cancer Support): UoS research has been instrumental in supporting them.</p>		
<p><b>2. Underpinning research</b></p> <p>Half the UK population will develop cancer and half of those diagnosed will live for more than 10 years (Cancer Research UK). Traditional aftercare, a one-size-fits-all approach based on routine appointments, is unsustainable and ineffective at meeting the increasing complexity of people's needs. This is recognised in the NHS Long-Term Plan, which places cost-effective personalised care as a key pillar of 'a new service model for the 21st century'. For 17 years, the Macmillan Survivorship Research Group (MSRG), led by Professor Claire Foster, has enhanced understanding of the impact of cancer and its treatment on people's lives.</p> <p>The <b>Macmillan Listening Study</b> (2004-07) [3.1], the first to involve cancer patients in the direction of research, identified two high priority questions for people living with cancer: 1) How does cancer and its treatment impact on people's daily lives? 2) How can people be supported to manage this impact? Through grants, including a total of £5.2m from Macmillan Cancer Support, MSRG has answered these questions, contributing significantly to understanding what constitutes effective personalised care:</p> <p><u>1) How does cancer/treatment impact on people's daily lives?</u></p> <p>The <b>ColoREctal Well-Being [CREW]</b> prospective cohort study (2009-18) [3.2; 3.3] involved 1,038 newly diagnosed colorectal cancer patients recruited from 29 UK cancer centres before surgery with curative intent, following them for 5 years. Little was known about the needs and</p>		

experiences of cancer survivors, and CREW, the first study of its kind, identified patient-reported cancer/treatment related problems. CREW data enabled health and well-being trajectories to be predicted; 30% of participants had poor health and well-being up to 5 years later. Clinical levels of depression and low confidence to self-manage pre-treatment were as important as disease stage for predicting long-term health and well-being recovery [3.2]. Confidence to manage illness-related problems remained unchanged over time [3.3]. Those with comorbidities limiting daily living had poorer quality of life following cancer diagnosis. MSRG recommended early and regular assessment of confidence to manage symptoms, depression and comorbidities, and the tailoring of healthcare/self-management support to individuals' needs to improve quality of life.

## 2) How can the impact of cancer/treatment on people's lives be supported?

University of Southampton researchers developed and evaluated new NHS care pathways for people with colorectal, breast, testicular [3.4] and prostate cancer [3.5], incorporating self-management support. The **Patient Triggered Follow-up [PTFU]** study (2011-14), led by Professor Jessica Corner, redesigned services for 700 patients with less complex needs at University Hospital Southampton (UHS) who had completed curative intent treatment for breast, colorectal or testicular cancer [3.4]. With around 100,000 new diagnoses of these cancers in the UK each year (Cancer Research UK), the traditional routine follow-up model was unsustainable. PTFU involved remote surveillance via an online patient portal and self-management support via a workshop. The study found PTFU to be acceptable to patients and a realistic alternative to traditional aftercare.

The **TrueNTH UK Supported Self-Management [TrueNTH UK]** study (2014-19), led by Professor Alison Richardson under the Movember Foundation's \$28m TrueNTH global initiative to tackle critical areas of prostate cancer care, extended PTFU, adapting, evaluating and scaling self-management support for men with prostate cancer [3.5]. Prostate cancer affects around 330,000 men a year in the UK (expected to double by 2030), and cost-effective care models are needed. TrueNTH UK developed a supported self-management care model in five NHS hospitals, involving 2,500 men with prostate cancer. It included a workshop for patients, support from Band 4 cancer support workers, and access to an online patient portal [MyMedicalRecord] that linked men to their care team. This provided real-time access to test results, replacing the need for expensive hospital-based follow-up appointments. Results, reported in national media, demonstrated improved bowel symptoms and psychological wellbeing for men, and fewer unmet needs compared to usual care [3.5]. It was acceptable to men and cost-effective, saving on average £39 per patient.

A third of people in CREW experienced cancer related fatigue after treatment. Many lacked confidence to manage it. Led by Foster, **RESTORE** digital support (2010-16) was created and tested: a novel resource, co-produced with patients, clinicians and Macmillan Cancer Support, to increase confidence to manage fatigue after treatment. RESTORE provides information on fatigue, supports goal setting and shares learning. A randomised controlled trial [3.6], involving 12 hospitals and 163 patients, found RESTORE improved confidence to manage fatigue.

## 3. References to the research

**3.1 Corner J, Wright D, Hopkinson J, Gunaratnam Y, McDonald J, Foster C.** (2007) The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *British Journal of Cancer*, 96: 875 – 881.

<https://doi.org/10.1038/sj.bjc.6603662>

**3.2 Foster C, Haviland J, Winter J, Chivers-Seymour K, Batehup L, Calman L, Corner J, Din A, Fenlon D, May C, Richardson A, Smith P.** (2016) Pre-surgery depression and confidence to manage problems predict recovery trajectories of health and wellbeing in the first two years following colorectal cancer: results from the CREW cohort study. *PLOS ONE*, 11(5): e0155434.

<https://doi.org/10.1371/journal.pone.0155434>

**3.3 Grimmitt C, Haviland J, Winter J, Calman L, Din A, Richardson A, Smith P, Foster C.** (2017). Colorectal cancer patient's' self-efficacy for managing illness-related problems in the first two years after diagnosis, results from the Colorectal Wellbeing (CREW) study. *Journal of Cancer Survivorship*, 11(5):634-642. <https://doi.org/10.1007/s11764-017-0636-x>

**3.4 Batehup L, Porter K, Gage H, Williams P, Simmonds P, Lowson E, Dodson L, Davies N, Wagland R, Winter J, Richardson A, Turner A, Corner, J.** (2017). Follow-up after curative

treatment for colorectal cancer: Longitudinal evaluation of patient initiated follow-up in the first 12 months. *Supportive Care in Cancer* 25(7),2063-2073. <https://doi.org/10.1007/s00520-017-3595-x>

**3.5 Frankland J, Brodie H, Cooke D, Foster C, Foster R, Gage H, Jordan J, Mesa-Eguiagaray I, Pickering R, Richardson A.** (2019) Follow-up care after treatment for prostate cancer: evaluation of a supported self-management and remote surveillance programme. *BMC Cancer* (19): 368. <https://doi.org/10.1186/s12885-019-5561-0>

**3.6 Foster C, Grimmer C, May C, Ewings S, Myall M, Hulme C, Smith P, Powers C, Calman L, Armes J, Breckons M, Corner J, Fenlon D, Batehup L, Lennan E, May C, Morris C, Neylon A, Ream E, Turner L, Yardley L, Richardson, A.** (2016) A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial. *Supportive Care in Cancer*, 24(6):2445-53. <https://doi.org/10.1007/s00520-015-3044-7>

#### 4. Details of the impact

##### Changing policy approaches towards personalised care for people with cancer

Having shaped the UK National Cancer Survivorship Initiative, a flagship programme led by the Department of Health and Macmillan Cancer Support to improve support for people recovering from cancer, the Macmillan Listening Study went on to be influential in the Movember Foundation's decision to commit \$28m to improving the lives of prostate cancer survivors. The global TrueNTH programme (2014-2017), chaired by Corner, reflected a wider policy shift in the UK and internationally to personalised cancer care that is cost-effective and responsive to patient need. CREW also provided important evidence to inform this agenda. The findings were instrumental in shaping the strategic direction of the Wessex Cancer Alliance's new personalised care agenda, as set out in its five-year plan launched in February 2020. This informed service delivery across seven hospitals serving a population of 2.8 million [5.1].

CREW significantly contributed to UK prehabilitation guidance for people with cancer published by Macmillan, NIHR and the Royal College of Anaesthetists in July 2019 [5.2]. CREW informed the guidelines' key principles, specifically the impact of poor mental health and self-efficacy on patient health and wellbeing. The guidance has been widely accessed, with clinical practitioners and trusts using the guidance to justify prehabilitation service business cases. Dr Chloe Grimmer was an invited member of the Psychology expert working group for the guidance. CREW informed quality standards for developing, implementing and measuring self-management support in Ontario, Canada (*Self-management in cancer*, November 2018) [5.3]; Foster was the only invited expert outside Canada on the steering committee.

PTFU and TrueNTH UK have contributed significantly to national policy on supported self-managed follow-up. With more than 47,000 new cases of prostate cancer in the UK each year (Cancer Research UK), adoption of the TrueNTH UK care model from 2015 has significantly impacted on service configuration, potentially saving over £1.8m a year nationally (based on £39 saving per patient). PTFU and TrueNTH UK were highlighted by NHS England (NHSE) as models of good clinical practice for meeting the objectives of its 2015-20 strategy: *Achieving World-Class Cancer Outcomes* [5.4; 5.5]. The NHSE lead for Living With and Beyond Cancer stated in 2018: '*TrueNTH research has made significant contribution to the evidence base that underpins the implementation of stratified follow up nationally... The insights from the research will influence NHSE's revision of Innovation to Implementation*' [5.5]. This guidance was published in March 2020 with a prominent citation of the cost-effectiveness of PTFU and TrueNTH UK [5.6].

TrueNTH UK findings informed new recommendations in the updated NICE guideline *Prostate cancer: diagnosis and management*, published in May 2019. Specifically, they resulted in the timeframe for initiating supported self-management to be revised from two years to six months (Rec. 1.3.46) [5.7]. In January 2020, TrueNTH UK was highlighted by NHS Digital as an important model for improving the experiences and outcomes of men with prostate cancer [5.8]. TrueNTH UK and CREW evidence have informed nursing workforce planning throughout England, in particular the creation of new Band 4 Cancer Support Worker (CSW) roles within nursing teams. Health Education England (HEE) said TrueNTH UK '*generated significant insight into the workforce required to deliver cancer follow-up – particularly in relation to the introduction of the new band 4 support worker role*', using it as a case study of best practice in its own

stakeholder engagement [5.9]. The finding that CSWs had made a '*significant contribution to cancer-related supportive care*' was cited in the Wessex Cancer Alliance's five-year plan and led directly to the creation of 11 permanent CSW posts within nursing teams for colorectal, upper gastrointestinal and other tumour groups at University Hospital Southampton (UHS) NHS Foundation Trust [5.1].

### **Changing health service delivery for the benefit of people affected by cancer**

CREW evidence has informed models of care that are stratified according to timely assessment of patient-identified need and confidence to self-manage. Macmillan Cancer Support and NHSE are committed to incorporating assessments of confidence to self-manage into updated Holistic Needs Assessments, a key component of *The Recovery Package* – a recognised set of interventions for improving the lives of cancer patients [5.10]. CREW evidence has been used by HEE and Macmillan Cancer Support to develop and deliver core competencies and learning requirements for Allied Health Professionals, nurses and the wider workforce in the UK [5.10]. Since April 2020, CREW participant data have been used by Macmillan and the Wessex Cancer Alliance to understand the impact of COVID-19, informing strategic responses to the pandemic. Macmillan commented that senior leadership, strategy and planning teams had used CREW '*to gain an understanding of the likely impact of COVID-19 at a time where few data were available. Knowing how many live alone, look after others, receive practical support from others outside the home, have access to the internet, and the proportions of people affected by cancer living with comorbidities was essential for our development of guidance and support*' [5.10].

As a result of the PTFU study, UHS introduced needs assessments into the clinical pathway from diagnosis to tailor support during treatment, with better access to the nursing team and support workers. Throughout the impact period, this has benefitted an estimated 80% of breast, 95% of testicular and 50% of colorectal cancer survivors in Southampton (where 67,500 new cases are diagnosed each year) [5.4]. Adopted by UHS in August 2014, the Trust has since extended this to include people with lymphoma, endometrial and prostate cancer (more than 60% of men with prostate cancer have received supported self-management) [5.4].

TrueNTH UK's supported self-management model [TrueNTH UK], a finalist in the Health Service Journal (HSJ) Awards in 2017, was adopted in all five study sites by Spring 2015: UHS, Royal United Hospitals Bath, Royal Cornwall Hospital, Dartford and Gravesham and St Helens and Knowsley Teaching Hospitals Trusts. Prostate Cancer UK presented TrueNTH UK findings at eight NHS webinars and events in 2017/18, encouraging wider adoption of the care model [5.11]. By 31<sup>st</sup> December 2020, 38 NHS trusts in England (25%) had adopted TrueNTH UK, with a further 10 trusts planning to do so in 2021 [5.12]. Nearly 11,200 men with prostate cancer had been supported by TrueNTH UK by 31<sup>st</sup> December 2020, and 6,900 people with breast, colorectal, haematological or gynaecological cancers had accessed the care pathway following wider replication [5.12]. TrueNTH UK informed recommendations for managing prostate cancer in the Welsh Planning Framework, 2019-22 [5.13]. In June 2019, the Welsh Government mandated implementing the model in all 14 Welsh urology departments [5.11, 5.13], serving more than 8,000 men with prostate cancer, affecting the care of around 5,300 men, and freeing up around 8,000 outpatient appointments per year. A Scottish cancer network is committed to implementing TrueNTH across its four Health Boards [5.11]. In eight hospital trusts in the Cheshire and Merseyside Cancer Alliance, more than 5,500 people with breast, colorectal and prostate cancer used the pathway between May 2015 – November 2019, saving 38,000 outpatient appointments [5.14]. A toolkit was produced by the TrueNTH UK team to provide an NHS guide for implementing the model and supporting service change across UK cancer centres. The toolkit was accessed by all NHS centres providing uro-oncology services in England (N=138) and Wales (N=14), and 10 centres in Scotland, Northern Ireland and the Republic of Ireland [5.12]. As an indication of the significance of these service changes, use of the TrueNTH UK model saves approximately 1.5 appointments per patient per year, potentially saving £14.3 million a year in the UK if all newly diagnosed patients accessed the model.

The online portal *MyMedicalRecord* (MyMR), co-developed by UoS and UHS for TrueNTH UK to provide online remote access to test results, is used across breast, colorectal, testicular, lymphoma, prostate and endometrial cancers at UHS [5.12]. The portal was winner of an HSJ technology award in 2016 with TrueNTH forming a major part of the evidence presented. There has been wide uptake of MyMR: by 31<sup>st</sup> December 2020, it was supporting remote surveillance

of men with localised prostate cancer in 38 NHS trusts in England [5.12]. In August 2020, Hampshire Hospitals Trust began using the platform to manage patients with mild COVID-19 symptoms from home. In June 2020, UHS was named as a supplier on the Crown Commercial Service's Spark Dynamic Purchasing System Framework, which gives NHS trusts easier access to the MyMR platform.

### **Improving patient outcomes through service change and better access to information**

In 2017, NHSE published a case study highlighting how Southampton's PTFU approach had benefitted patients [5.4]; this provides an indication of the wider patient benefit delivered through policy and practice changes described earlier in this section. In it, UHS' Head of Cancer Nursing wrote: *'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'* [5.4].

69% of men participating in TrueNTH UK agreed / strongly agreed that they felt reassured under the Programme, valuing the ease of contacting clinical teams, having quick access to results, not having to attend hospital, and the reassurance of talking to others at the workshop. Other patient benefits reported in Cheshire and Merseyside Cancer Alliance's adoption of the model (January 2020) include: tailored treatment plans, increased self-care skills and reduced expenses [5.14]. One CSW said that *'patients find it easy to navigate, very accessible and are so relieved they have so much more time freed up by not having to attend in-person follow-ups'* [5.14]. In 2016, Dr John McGrane, Oncology Consultant, Royal Cornwall Hospital Trust [RCHT], reiterated the patient benefit: *'We see around 400 new patients a year at RCHT with prostate cancer, which has increased around 25% in five years. Our clinics were becoming overwhelmed, with some patients having to travel great distances for follow up clinics that would at times only take about 5 minutes. The TrueNTH project allows well patients to be managed at home, allowing them to have access to their own records and to follow their own progress. It also ... helps to free up spaces within our clinics for new patients or for patients who have encountered problems'* [5.15].

Macmillan launched RESTORE in October 2019, providing the first free evidence-based digital resource for managing cancer related fatigue for patients and health professionals. The study showed 77% of users had increased confidence to self-manage fatigue after using RESTORE. The resource was promoted to UK health professionals via Macmillan's Professionals, encouraging them to refer patients to it as part of the Recovery Package [5.10]. When promoted on Macmillan's Facebook channel in October 2019, it attracted 1,300 reactions, 114 comments and 209 shares. It was highlighted online by the Patient Information Forum, Tameside & Glossop NHS Trust, South Warwickshire NHS Trust, North Wales Cancer Patient Forum and Peter MacCallum Cancer Centre, Australia. Nationally, nearly 1000 people registered to use RESTORE within a month of its launch. In February 2020, the Wessex Cancer Alliance cited RESTORE in their five-year plan as an important resource for supported self-management [5.1].

## **5. Sources to corroborate the impact**

- 5.1 Letter of support from Managing Director, Wessex Cancer Alliance.
- 5.2 <https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf>
- 5.3 <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/57371>.
- 5.4 NHSE case-study.
- 5.5 TrueNTH's impact at a national level: Letter from Becky Clack, NHSE.
- 5.6 Citation in NHSE's Personalised Stratified Follow up handbook.
- 5.7 TrueNTH's influence on NICE guideline 131: Panel member Prof Sanjeev Madaan letter.
- 5.8 TrueNTH project NHS Digital highlight.
- 5.9 Letter from Programme lead Cancer and Diagnostics, Health Education England.
- 5.10 Letter from Specialist Advisor, Macmillan Cancer Support.
- 5.11 Letter from Head of Improving Care, Prostate Cancer UK.
- 5.12 Letter from My Medical Records, UHS.
- 5.13 Uptake of TrueNTH by Welsh Government: Welsh planning framework; supporting letter.
- 5.14 TrueNTH's influence on Cheshire and Merseyside Cancer Alliance: case-study.
- 5.15 Patient benefit delivered through TrueNTH: Royal Cornwall Hospital case-study.