

Institution: University of Surrey		
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Improving follow-up care for men after prostate cancer treatment		
Period when the underpinning research was undertaken: 2004-2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Sara Faithfull	Professor of Cancer Nursing Practice	01/07/2002 – present
Dr Agnieszka Lemanska	Lecturer in Integrated Care	06/02/2012 – present
Dr Deborah Cooke	Reader in Integrated Care	01/10/2012 – present
Professor Heather Gage	Professor of Health Economics	01/09/1990 – present
Period when the claimed impact occurred: August 2013- December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words) <p>Men now live longer with and beyond prostate cancer but suffer the consequences of the disease and its treatment. Research involving men with prostate cancer at the University of Surrey has had the following impacts: (i) the development, implementation and evaluation of TrueNTH supported self-management (SSM) and follow-up care programme for men who have completed treatment for prostate cancer; and (ii) the <i>Macmillan Competency Framework for Nurses</i> and allied health professionals caring for adults living with and beyond cancer. Impact has been realised for the lives of men with prostate cancer, health professionals delivering follow-up care and healthcare efficiency within the NHS.</p>		
2. Underpinning research (indicative maximum 500 words) <p>Prostate cancer is the most common UK male cancer, with approximately 48,500 new cases each year. Incidence rates for prostate cancer are projected to rise by 12% in the UK by 2035, but with early detection and effective treatment almost 8 in 10 (77.6%) now survive their disease for ten years or more (Source: Cancer Research UK). However, whilst quantity of life has improved with time, quality has not. Men are living longer with, and beyond, prostate cancer but suffering consequences of the disease and treatment side-effects. This presents significant challenges for healthcare systems providing sustainable follow-up care.</p> <p>Research led by Professor Sara Faithfull (with Cooke, Gage, Lemanska) into the supportive care needs, treatment side-effects and consequences of men surviving prostate cancer, together with their work on workforce readiness, has uniquely positioned the University of Surrey as a core contributor to improvements in follow-up care for men with prostate cancer.</p> <p>1. Identifying the supportive care needs of men living with prostate cancer</p> <p>A pan-England survey (2004-2005) by Faithfull (in collaboration with King's College London) examined the supportive care needs of (n=741) men with prostate cancer in England. The team identified that men surveyed had specific and significant unmet supportive care needs. Areas of greatest need related to psychological distress, sexuality-related issues and management of enduring lower urinary tract symptoms [R1].</p>		

2. Late manifestation of side-effects following treatment

Faithfull and Lemanska conducted a secondary analysis of patient-reported outcomes (PROs) data reported up to 5 years after treatment by men receiving standard versus escalated conformal radiotherapy for localised prostate cancer and identified that symptoms often arise late after treatment. Specifically, men with poorer physical function and health prior to treatment reported poorer PROs at year 3. This was the first study to identify late manifestation of treatment effects [R2].

3. TrueNTH Self-Management and Follow-up Care Programme (TrueNTH SSM)

The traditional approach to cancer follow-up care - of routine clinic appointments at pre-defined intervals - has not always led to the needs of men with prostate cancer being adequately addressed (for example R1, R2, R4). Since 2015, NHS policy in England has advocated a personalised stratified follow-up (PSFU) approach for post-treatment cancer care with remote surveillance and supported self-management for those with stable disease.

Dr Deborah Cooke and Professor Heather Gage collaborated with colleagues at the University of Southampton to develop, implement and evaluate a new approach to follow-up care for men who had completed treatment for prostate cancer; the TrueNTH supported self-management and follow-up care programme (TrueNTH SSM) funded by the Movember Foundation and delivered with Prostate Cancer UK. Men on the programme have a named cancer support worker (CSW), access to online services (test results, assessments, messages from clinicians) and attend one 4-hour workshop (designed by Cooke) to develop knowledge, skills and confidence to self-manage their condition. Results show the programme is: broadly comparable to traditional follow-up care; acceptable to men; largely cost-neutral in the first eight months; and viable for scale-up [R3].

4. Post-treatment service provision: healthcare workforce readiness and confidence in managing the long-term consequences of cancer

Research led by Professor Faithfull found that lack of contact, advice and/or support from a nurse following prostate cancer treatment was a significant predictor of men's unmet supportive care needs [R4]. Faithfull further explored nurses and allied health professionals' self-reported confidence in managing all areas of care for adult cancer survivors finding: deficits in important areas of practice (i.e., medications management; long-term complex symptom management; care planning) and perceived gaps in knowledge and education. Results have been used to inform future workforce planning and the development of education and training [R5, R6]. These findings were first presented in the Macmillan Report *Evaluation of Health Workforce Readiness and Confidence in Managing the Consequences of Cancer as a Long-Term Condition* [R5], which subsequently underpinned the Macmillan Competency Framework for Nurses (MCFN) published by Macmillan in 2014 [S4].

3. References to the research (indicative maximum of six references)

Bold denotes University of Surrey affiliation. The quality of the research is evidenced by publications in leading peer-reviewed journals and a report authored by researchers and published by a major national cancer support charity.

[R1] Ream, E., Quennell, A., Fincham, L., **Faithfull, S.**, Khoo, V., Wilson-Barnett, J., & Richardson, A. (2008). Supportive care needs of men living with prostate cancer in England: a survey. *British Journal of Cancer*, 98(12), 1903–1909. DOI: [10.1038/sj.bjc.6604406](https://doi.org/10.1038/sj.bjc.6604406)

[R2] **Lemanska, A.**, Dearnaley, D., Sydes, M., & **Faithfull, S.** (2018). Older age, early symptoms and physical function are associated with the severity of late symptom clusters for men undergoing radiotherapy for prostate cancer. *Clinical Oncology*, 30(6), 334–345. DOI: [10.1016/j.clon.2018.01.016](https://doi.org/10.1016/j.clon.2018.01.016)

[R3] Frankland, J., Brodie, H., **Cooke, D.**, Foster, C., Foster, R., **Gage, H.**, **Jordan, J.**, Mesa-Eguiaagaray, 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(1), 368. DOI: [10.1186/s12885-019-5561-0](https://doi.org/10.1186/s12885-019-5561-0)

[R4] Cockle-Hearne, J., Charnay-Sonnek, F., Denis, L., Fairbanks, H., Kelly, D., Leonard, K., Van Muilekon, E., Fernandez Ortega, P., Thoft-Jense, B. & **Faithfull, S.** (2013). The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries. *British Journal of Cancer*, 109, 2121-30. DOI: [10.1038/bjc.2013.568](https://doi.org/10.1038/bjc.2013.568)

[R5] Faithfull, S. & Samuel, C. (2011). Evaluation of Health Workforce Readiness and Confidence in Managing the Consequence of Cancer as a Long-Term Condition: Final Report Part 1 for Macmillan Cancer Support. <https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-publications/research-and-evaluation-reports.html#283506>

[R6] Faithfull, S., Samuel, C., Lemanska, A., Warnock, C., Greenfield, D. (2015). Self-reported competence in long term care provision for adult cancer survivors: A cross sectional survey of nursing and allied health care professionals. *International Journal of Nursing Studies*, 53, 85-94. DOI: [10.1016/j.ijnurstu.2015.09.001](https://doi.org/10.1016/j.ijnurstu.2015.09.001)

Funding:

1. S. Faithfull (P.I), A. Lemanska. National Cancer Survivorship Initiative, Macmillan Cancer Relief and Department of Health, Grant: 3272571, 01/04/2010 - 31/12/2011 £106,522
2. S. Faithfull (P.I). Prostate Cancer Education Project, European Oncology Nursing Society, 112843, 01/02/2011 - 30/04/2012, £36,901.
3. H. Gage, D. Cooke. TrueNTH programme Supported Self-Management, Movember Foundation in partnership with Prostate Cancer UK 250-25/30/40, 03/01/2014-31/07/2017, £55,065.

4. Details of the impact (indicative maximum 750 words)

Knowledge derived from our research has translated into the development and implementation of (i) a UK-wide programme delivering personalised follow-up care (TrueNTH SSM); and (ii) the Macmillan Competency Framework for Nurses (MCFN) that is ensuring nurses and allied health professionals have the skills, knowledge and behaviours to provide effective follow-up care. Collectively, these developments have **generated impacts for public policy, lives of men with prostate cancer, health professionals delivering follow-up care, and healthcare efficiency within the NHS:**

1. Developing and implementing the TrueNTH SSM programme

1.1 Impact on public policy

The Government's target – NHS Long-Term Plan (2019) – is for all hospital trusts to deliver personalised stratified follow-up (PSFU) for prostate cancer by 2020 [currently delayed due to COVID-19]. TrueNTH SSM, underpinned by our research **[R3]**, is being implemented in men referred onto the SSM arm of PSFU; it is the only prostate-specific programme for PSFU referred to in the core policy document **[S1, p22]** guiding implementation.

1.2 Impact on lives of men living with and beyond prostate cancer

The TrueNTH SSM programme **[R3]** is being used to provide routine NHS follow-up care to men with prostate cancer stratified to SSM. Over the period 2015-2020, the TrueNTH SSM programme has been rolled out across 36 NHS Trusts in England with 10 more planning on implementing it in the near future (3 of these confirmed); this equates to around 20% of all NHS Trusts in England implementing the TrueNTH SSM programme. It is being employed in 1 of 4 Scottish Health Boards, and there is intent for it to be implemented in Wales. [Planned roll-out of TrueNTH SSM during 2020 has been significantly disrupted by the COVID-19 pandemic]. To 31 December 2020, 11,198 men with prostate cancer have been placed onto the TrueNTH programme **[S2]**.

Feedback from men referred to the TrueNTH SSM programme has been overwhelmingly positive. For example, patients using this service at Liverpool University Hospitals have cited valuing the time and money it has saved them (by not having to attend the ~12 outpatient appointments), the assurance of a named individual for support (cancer support worker), and peer-support opportunities as positive aspects of the service [S3, p.27].

1.3 Impacts on healthcare efficiencies

A key benefit of TrueNTH is that clinical time (of consultants and nurses) is released and can be redeployed for other activities, such as diagnosing more new patients and reducing waiting times; supporting more complex patients; and more clinics for elective care and procedures [S3, p.25]. For example, a Consultant Urological Surgeon at Liverpool University Hospitals NHS Foundation Trust reported: *"I am delighted that the scheme has been greatly received by patients. Our [TrueNTH] programme has significantly reduced the time spent in clinics by consultants, freeing up time for operating. I personally, am now able to perform an additional two robotic prostatectomies on alternate weeks"* [S3, p.29].

The roll-out of TrueNTH has increased hospital capacity; modelling suggests that for every 1,000 men with prostate cancer referred onto a PSFU, up to 1,900 outpatient appointments become available for redeployment over the subsequent five years [S1, p.6, 24]. This means that for the 11,198 men on the TrueNTH programme 20,113 outpatient appointments will become available over the subsequent five years. Further, TrueNTH's implementation is generating savings (having accounted for set-up, integration, and running costs) of around £118k per Trust over a 5-year period [S3, p.40].

Prostate Cancer UK's Head of Improving Care Amy Rylance has stated that TrueNTH is providing: *"a cost-effective way [to deliver follow-up care] to the growing number of men living with and beyond prostate cancer in the UK and [has] become a dominant model of follow-up care"* [S2].

2. The Macmillan Competency Framework for Nurses (MCFN)

2.1 Impact on health professionals delivering cancer care

Professor Sara Faithful was one of three key contributors to the first competence framework for UK nurses involved in the care of adults living with and beyond cancer – the *Macmillan Competency Framework for Nurses* (MCFN, 2014) [S4]. The framework builds on Faithful's earlier report *Evaluation of Health Workforce Readiness and Confidence in Managing the Consequences of Cancer as a Long-term Condition* [R5] and draws on her research [R4, R6]. The MCFN is endorsed by both the UK Oncology Nursing Society (UKONS) and Royal College of Nursing (RCN).

A revised version of the MCFN was released in March 2020 [S6] and as of November 2020 4,256 print copies have been distributed to healthcare professionals and the pdf version (freely available on Macmillan's website) has been viewed approximately 5,211 times [S7].

The MCFN has impacted on patient care through a variety of different routes including [S7]:

- Being used as a resource in the online module 'supporting people living with and beyond cancer' at Edinburgh Napier University.
- Being included in the Undergraduate nursing programme at the University of Cardiff.
- Being used by The Christie NHS Foundation Trust as a framework to develop higher-level apprenticeship roles (Clinical Nurse Specialist and Living with and Beyond Cancer Specialist).
- Being referenced by the European Oncology Nursing Society and used to inform the Survivorship chapter of the updated core curriculum.
- Has helped managers to identify the skills and knowledge needed within teams to meet the clinical needs of their particular cancer populations (person-centred care competency framework); and thereby to identify and address any skills and knowledge gaps.

- Raising awareness through dissemination in professional journals and newsletters (i.e., UK Oncology Nursing Society bulletin, 2014, 2020; Royal College of Nursing newsletter, 2014; Nursing Times, 2015).

The MCFN was designed so that individual competences can be selected to match local service requirements and development plans. It is therefore also relevant to allied health professionals and has been used to guide the recruitment and development of the Cancer Support Workers employed to deliver PSFU and remote monitoring in follow-up care **[For example see S3, S5]**.

The President of UKONS asserts that: *“A significant proportion of the nursing workforce providing follow-up care may have little cancer-specific education and the MCFN provides these nurses with a framework to map and assess their cancer-specific competences against. It is perhaps this part of the nursing workforce where the MCFN provides the greatest potential for impact”* **[S8]**.

5. Sources to corroborate the impact (indicative maximum of 10 references)

[S1] NHS England & NHS Improvement. (March 2020). *Living with and beyond cancer: Implementing Personalised Stratified Follow-up Pathways. A handbook for local health and care systems*. <https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf>

[S2] Testimonial from Prostate Cancer UK on number of UK men receiving TrueNTH; number of Trusts across England and Wales that have adopted it or are planning to; number of Scottish Health Boards that have adopted it or are planning to; and impact of TrueNTH on NHS efficiency. (PDF)

[S3] Cheshire and Merseyside Cancer Alliance. (January 2020). *Implementing personalised stratified follow up in cancer: A review*. https://www.cmcanceralliance.nhs.uk/application/files/4915/8505/7839/CMCAPSFU_Attain_report_Jan20_v3.pdf

[S4] Macmillan Cancer Support. (2014). *A competence framework for nurses: Caring for patients living with and beyond cancer*. https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf

[S5] East of England Cancer Alliance. (February 2019). *Core competency Framework: For Band 4 Support Workers Caring for Adult Patients with a Cancer* (version 1.0) <https://www.canceralliance.co.uk/documents/LWBC/East%20of%20England%20Cancer%20Alliance%20-%20Support%20Worker%20%20Core%20Competency%20Framework%20%20vs1.1%20Jan%202019.pdf>

[S6] Revised Macmillan Competency Framework for Nurses (MCFN) supporting people living with and affected by cancer: <https://www.macmillan.org.uk/healthcare-professionals/news-and-resources/guides/competency-framework-for-nurses> (November 2020)

[S7] Testimonial from Macmillan Cancer Support on the University of Surrey's contribution to the development of the Macmillan Competence Framework for Nurses (MCFN) caring for patients living with and beyond cancer and its impact. (PDF)

[S8] Testimonial from the UK Oncology Nursing Society's (UKONS') president on the impact on the cancer nursing profession of the Competence Framework for nurses caring for patients living with and beyond cancer. (PDF)