Institution: Oxford Brookes University

Unit of Assessment: 3, Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Improving the quality of life of people living with and beyond a diagnosis of cancer

Period when the underpinning research was undertaken: 2010–present

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:**
Eila Watson	Professor Supportive Cancer Care	[text removed for publication]
Jo Brett	Senior Research Fellow	
Lauren Matheson	Research Fellow	
Mary Boulton	Professor Health Sociology	

Period when the claimed impact occurred: 1 August 2013–31 July 2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

Our research has had a significant impact on improving the experiences, quality of life and health outcomes of people living with and beyond a cancer diagnosis. As more people are diagnosed and live longer with cancer, the prevalence of cancer survivors is growing rapidly, and, in the UK, will reach 4,000,000 by 2030. People living with and beyond a cancer diagnosis can experience wide-ranging impacts following diagnosis and treatment, and understanding how to maximise quality of life is increasingly important. Through a number of projects commissioned by three leading cancer charities, we have provided robust and novel evidence of the physical, psychological and social consequences of diagnosis and treatment on patients and their families, highlighting important gaps in care and support. This evidence is essential to plan the provision of appropriate monitoring and intervention, required to ensure that quality of life is maximised. Our work has (1) influenced development of national cancer policy, (2) provided key evidence to guide cancer charities in developing strategy, and (3) informed the development and delivery of supportive care services at both the local and national level, thus benefiting many cancer patients in the UK and beyond.

2. Underpinning research

The Supportive Cancer Care Research Group (SCCRG), established in 2007 and led by Professor Eila Watson, is internationally renowned in cancer survivorship research. With more people being diagnosed and living longer with cancer it is important to understand the impacts cancer diagnosis and treatment can have, both in the short and longer term, so that quality of life can be optimised for patients and their families. The SCCRG has significant expertise in generating understanding of patients' (and family members') experiences of living with and beyond a cancer diagnosis, and identifying and addressing unmet supportive care needs. This includes commissioned charity awards to undertake research characterising the experiences, health outcomes, and supportive care needs of people with (1) prostate cancer (funded by Prostate Cancer UK (PCUK)/Movember), (2) pancreatic cancer (funded by Pancreatic Cancer UK) and (3) pelvic cancers (funded by Macmillan Cancer Support). This research has resulted in 20 publications in international, peer-reviewed journals.

Prostate cancer: Watson was co-applicant on a successfully funded PCUK/Movember commissioned call: 'Life After Prostate Cancer Diagnosis (LAPCD): a national Patient Reported Outcomes Measures (PROMs) study' (totalling GBP2,120,289) [G1]. The study was designed to provide a detailed understanding of outcomes for men following diagnosis and treatment for prostate cancer to inform future policy and service development. **Watson was a key member of the multidisciplinary, multicentre programme team, actively contributing to all stages of the**

programme and jointly leading the Qualitative and User Involvement work streams. Matheson and Brett were also core members of the research team. The LAPCD research programme was unique in its scale and methods, surveying **all** men in the UK who were 18–42 months post-diagnosis. 35,823 men took part and 215 telephone interviews were conducted with men and their partners. It is the largest population-based, PROMs study to be conducted to date, and has yielded novel and important data on men's overall quality of life, side effects of treatment, psychological wellbeing, and social and financial difficulties. Key findings included: poor sexual function is very common (81.0%), regardless of cancer stage, and over half of men in the study (55.8%) received no intervention for this [Ref 1]; androgen deprivation therapy (ADT) results in diminished quality of life compared with men receiving other prostate cancer treatments (e.g. significantly higher rates of problems with lack of energy (29.4% vs 14.7%) and hot flushes (30.7% vs 5.4%)) and thus minimal utilisation of this treatment is warranted [Ref 1]; and approximately one in five men regret the treatment choice they made and greater support around treatment decision-making is required [Ref 2, 3]. These findings have been used to influence policy-makers and impact on service development.

Pancreatic cancer: In 2017, recognising our expertise in the area, **Pancreatic Cancer UK commissioned** the SCCRG (Watson (PI) and Brett (Co-I)), working in partnership with the Picker Institute Europe, to **determine the supportive care needs of people affected by pancreatic cancer** [G2]. Patients with pancreatic cancer, who generally have a poor prognosis and significant needs, making them hard to reach, are neglected in patient-reported outcomes research. However, the team successfully recruited 274 individuals to the study, the **first UK survey of this nature** with this patient group, and the findings highlighted significant unmet needs in psychological care and support for patients and their families. In addition, patients who were not eligible for surgery (and therefore had a worse prognosis) reported poorer experiences and greater unmet needs than patients who had received surgery. Overall, 29% did not receive enough information at diagnosis, and one in ten respondents felt they were not involved in decisions about their treatment but would have liked to have been [Ref 4].

Pelvic cancers: The SCCRG (Watson (PI) and Boulton (Co-I)) undertook a mixed methods study funded by **Macmillan Cancer Support to understand the long-term and late consequences of patients who had received radiotherapy treatment in the pelvic area** [G3]. This study included over 418 patients who had received treatment and was novel in that, unlike previous studies which focussed on patients closer to diagnosis and treatment, it included patients treated up to 11 years previously. The study indicated that moderate/severe problems with bowel, urinary and sexual functioning following treatment were relatively common (e.g. bowel urgency (59% women, 45% men); urine urgency (49% women, 46% men); ability to have a sexual relationship affected (24% women, 53% men)), and highlighted that problems were just as frequent in those 6–11 years post-treatment as in those 1–5 years post-treatment. Symptom severity was significantly associated with poorer overall quality of life and higher levels of depression (possible or probable depression was recorded for 13.4% of the overall sample) [Ref 5]. The findings of this commissioned study were included in an influential report published by Macmillan Cancer Support (see Section 4).

3. References to the research

Publications

1. Downing, A., Wright, P., Hounsome, L., Selby, P., Wilding, S., **Watson, E**., Wagland, R., Kind, P., Donnelly, D. W., Butcher, H., Catto, J. W. F., Cross, W., Mason, M., Sharp, L., Weller, D., Velikova, G., McCaughan, E., Mottram, R., Allen, M., ... Glaser, A. W. (2019). Quality of life in men living with advanced and localised prostate cancer in the UK a population-based study. *Lancet Oncology, 20*(3), 436-447. DOI: 10.1016/S1470-2045(18)30780-0
2. Wagland, R., Nayoan, J., **Matheson, L**., Rivas, C., **Brett, J**., Downing, A., Wilding, S., Butcher, H., Gavin, A., Glaser, AW. & **Watson, E**. (2019). 'Very difficult for an ordinary guy': Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: Findings from a UK-wide mixed methods study. *Patient Education and Counseling, 102*(4), 797-803. DOI: 10.1016/j.pec.2018.12.004
3. Wilding, S., Downing, A., Selby, P., Cross, W., Wright, P., **Watson, E**., et al. (2020). Decision regret in men living with and beyond non-metastatic prostate cancer in the UK: a population-

based patient-reported outcome study. *Psycho-Oncology, 29*(5), 886-893. DOI: 10.1002/pon.5362

4. **Watson, EK., Brett, J**., Hay, H., et al. (2019). Experiences and supportive care needs of UK patients with pancreatic cancer: a cross-sectional questionnaire survey. *BMJ Open, 9*(11):e03268. DOI: 10.1136/bmjopen-2019-032681
5. Adams, E., **Boulton, MG.**, Horne, A., Rose, PW., Durrant, L., Collingwood, M., Oskrochi, R., Davidson, S. & **Watson, E**. (2014). The Effects of Pelvic Radiotherapy on Cancer Survivors: Symptom Profile, Psychological Morbidity and Quality of Life. *Clinical Oncology, 26*(1):10-7. DOI: 10.1016/j.clon.2013.08.003

Grants

G1. PIs, Glaser A, Gavin A Co-Is, Wright P, **Watson E**, Wagland R, Downing A, Hounsome L, Selby P. Funding for the study, “Life After Prostate Cancer Diagnosis” from Prostate Cancer UK/Movember, 2014–2017: Total Grant Award GBP2,120,289
G2. PI, Watson E, Co-Is, Brett J, Tallet A, Hay H. Funding for the study, “The Supportive Care Needs of People with Pancreatic Cancer” from Pancreatic Cancer UK. 2017–2018: GBP36,552
G3. PI, Watson E, Co-Is, Boulton M, Adams E. Funding for the study, “The late effects of pelvic radiotherapy: assessing the needs of long term cancer survivors” from Macmillan Cancer Support, 2010–2011: GBP54,089

4. Details of the impact

Research conducted by the SCCRG has had a significant impact on improving the experiences, quality of life and health outcomes of people living with and beyond a cancer diagnosis locally, nationally and internationally by influencing policy, practice and service development. This is demonstrated by our work uncovering the consequences of diagnosis and treatment of prostate, pancreatic and pelvic cancers.

Improving experiences and outcomes of men living with and beyond a diagnosis of prostate cancer:

Around 48,500 men are diagnosed with prostate cancer every year in the UK and around 1 in 8 men will get a diagnosis in their lifetime. **PCUK/Movember are using the findings of our landmark LAPCD study to highlight variation and gaps in services to government and cancer alliances, and lobby for improved services to patients [S1].** For example, our work highlighted the lack of support provided for men experiencing erectile dysfunction following treatment. As described on the PCUK website, *“…These results not only highlight the importance for all men to speak out honestly about their side effects, it’s equally important for all healthcare professionals treating men for prostate cancer to incorporate support for erection problems within post-treatment follow-up plans. In a bid to tackle the problem, the Movember Foundation [has funded] an online self-management programme for people living with prostate cancer, through the global TrueNTH initiative which is available now online.*” [S1] This includes an e-resource, ‘Maximising Sexual Wellbeing’ (https://prostate.lifeguidewebsites.org). The Movember Foundation has committed over GBP5,000,000 million in the UK and over USD35,000,000 globally to change the way men live with and beyond prostate cancer.

Significantly, PCUK are also using the LAPCD findings to inform their own strategic and service developments. For example, our study highlighted the particular challenges faced by men receiving ADT and, as a result, PCUK has established projects to make sure that men receiving this type of treatment receive the support they need, and to investigate variation in the use of ADT [S2]. We also highlighted the difficulties men face with treatment decision-making and the PCUK Health Information team subsequently undertook a user-led investigation into how treatment decision-making can be better supported. PCUK nurses are also piloting a sexual support telephone service [S2].

To drive service improvements at a local level, the LAPCD study team has developed toolkits presenting NHS Trust-level patient outcomes data alongside a national comparator for each of the 111 NHS Trusts across the UK who took part in the study [S2].

Movember, the global men’s cancer charity, have used the study findings to populate an interactive, web-based tool for patients called 'Men Like Me' (c. 3000 men in the UK have used the site so far, with plans for further marketing and extended access beyond the UK). This enables men with prostate cancer to explore the outcomes seen in men with similar characteristics (e.g. age) and who have had similar treatment, to use this information to help them understand what is normal after diagnosis and treatment, and help inform treatment decision-making and help-seeking for side effects of treatment [S3]. The UK Movember website has significant reach, with 2,489,885 new users in 2019 and over 5,000,000 hits recorded.

Improving experiences and outcomes of people with Pancreatic Cancer:

Pancreatic Cancer UK cites Watson et al, 2019 (Ref 5) in its 2019 Annual Report, explaining that they are using our findings to guide their service development and expansion of support, as well as working with NHS commissioners to close gaps in care, and campaigning for improvements in earlier diagnosis and faster treatment within the NHS and across the UK, in patient services and support within the NHS [S4]. Driven by our key finding regarding the lack of psychological support for pancreatic cancer patients, Pancreatic Cancer UK have developed a training course for nurse specialists addressing the psychological impact of diagnosis. The first training course was run in March 2020 and was fully subscribed (16 attendees). The planned roll out across the UK has unfortunately been temporarily delayed due to the coronavirus disease pandemic. Nutrition was another area of unmet need highlighted by our research and, as a result, a first training day on Dietetic Management & Pancreatic Cancer was held in Leeds on 9 October 2019, which was attended by 44 dietitians and clinical nurse specialists; a second was conducted virtually in October 2020, attended by 60 health professionals [S5]. A presentation was also made to the All Party Parliamentary Group on Action against Cancer and the National Cancer Patient Experience Advisory Group, who are utilising the findings on unmet needs in some of the workstreams included in the NHS Long-Term Plan, such as health and wellbeing support and the work on early diagnosis [S6].

The main study findings were also integrated into the 2019 Pancreatic Cancer UK Clinical Pioneer Awards research funding call. This call included 'supportive care' as one of the priority topic areas for bids, with interventions to address psychological needs (unmet psychological needs was one of our main findings) and the development of a Quality of Life Metric (to build on our survey) highlighted as potential examples of projects within this topic area [S7].

Improving experiences and outcomes of patients receiving radiotherapy treatment for pelvic cancer:

The findings from our Pelvic Radiotherapy Late Effects Study which highlighted the prevalence of long term and late effects of treatment **were cited in the influential Macmillan Cancer Support 2013 report *'Cured–but at what cost? Long-term consequences of cancer and its treatment'*, which provided, for the first time, estimates on the numbers of people in the UK affected by distressing problems such as chronic fatigue and bowel and urinary problems, including incontinence, pain and sexual difficulties [S8].** As a direct result of the report, the Macmillan Consequences of Treatment (CoT) programme was established and has been a significant driver in shaping cancer survivorship policy, practice and research in England since 2013. For example, the importance of addressing the consequences of cancer treatment has been highlighted in national Cancer Strategy documents since 2013, including *Achieving Word-Class Cancer Outcomes: A strategy for England 2015–2020* (page 31); *Improving Outcomes: A Strategy for Cancer – Third Annual Report* (page 63); and *Cancer across the domains: a vision for 2020* (page 8) [S9]. A 'Consequences of Cancer Toolkit' for primary care professionals to help them identify and manage the consequences of cancer treatment, and to support patients to live well after a cancer diagnosis, is an example of many positive interventions resulting from the CoT programme [S10].

Locally, a consultant oncologist from Oxford University Hospitals (OUH) NHS Foundation Trust has described how our findings were instrumental in the establishment of a late-effects clinic for patients treated with radiotherapy to the pelvis, and the appointment of a radiographer and gastroenterologist with a focus on late effects *"..we had a very successful Pelvic radiotherapy late effects meeting in January 2016 [where our findings were presented] which […] significantly improved communication between all departments but particularly Gastroenterology. Awareness* *increased amongst the multidisciplinary team. As a result, we have had … discussions with the dietetics team to increase support for radiotherapy patients, which has now been achieved… Through the Maggie's Centre we have run a Pelvic radiotherapy support group for patients. We have also raised awareness within radiotherapy for psycho- sexual issues following cancer treatment and now have radiographers trained to offer support [...]*" [S12]. This resulted in the OUH NHS Trust appointing a Macmillan Late Effects radiographer, as well as appointing to a new gastroenterology oncology post with dedicated time for managing the effects of cancer treatment in 2019.

5. Sources to corroborate the impact

S1 Prostate Cancer UK website (i) has a dedicated page for the LAPCD study https://prostatecanceruk.org/about-us/projects-and-policies/life-after-prostate-cancer-diagnosis; (ii) News and views *Study reveals lack of support for sexual side effects of prostate cancer treatment* (02/02/19), where key findings from the LAPCD summarised and actions highlighted

S2 Prostate Cancer UK Charity, Letter of endorsement from Head of Policy, Knowledge & Impact, outlining the impact of the LAPCD study findings on service development and policy

S3 Movember /True North website, ***Men Like Me*** interactive toolkit provides information for men with prostate cancer (populated using data from our LAPCD study) https://truenth.org/men-like-me/.

S4 Pancreatic Cancer UK Annual Report 2020 cites Watson et al, 2019 (Ref 5) on page 39 and describes the impact of the findings, accessible here

S5 Pancreatic Cancer UK, Email correspondence with their Events and Project Manager (Support, Research and Influencing), confirming events that have taken place following the gaps identified in Watson et al, 2019 (Ref 5) study

S6 National Cancer Patient Experience Advisory Group, Feedback after 5 March 2019 meeting where Watson et al, 2019 (Ref 5) findings were discussed

S7 Pancreatic Cancer UK Research Funding Call (2019) identified the supportive care pathway, including psychological support, as key priority areas for research as a result of our findings. https://www.pancreaticcancer.org.uk/for-researchers/apply-for-funding/clinical-pioneer-awards/.

S8 Macmillan Cancer Support, the 2013 report *Cured – but at what cost. The long term consequences of cancer and its treatment* refers to Watson et al 2014 (Ref 6) five times (see pages 3 (fn 2), 5 (fn 20), 8 (ft 27), 10 (ft 39) and 16 (ft 56)), accessible here

S9 National Cancer Strategy document, (i) '*Achieving Word-class Cancer Outcomes: A strategy for England 2015-20',* on page 31 (accessible here) refers to commissioning guidance which highlights the importance of providing support to reduce and manage any consequences of cancer and its treatment*;* (ii) *Cancer across the Domains – A vision for 2020*, reports the All Party Parliamentary Group against Cancer's analysis of progress in cancer care, and makes policy recommendations which ensure that the consequences of treatment are routinely addressed (accessible here)

S10 Royal College of General Practitioners & Macmillan Cancer Support, *Consequences of cancer toolkit (*https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit.aspx*)*, an example of an intervention developed as a result of the Consequences of Treatment Programme of which our study (Ref 6) was a part, highlighting long term and late consequences of patients who had received radiotherapy treatment in the pelvic area

S11 Oxford University Hospitals NHS Foundation Trust, Letter from a Consultant Oncologist and co-author on Watson et al 2014 (Ref 6) outlines local service developments following publication and dissemination of study findings