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| Institution: University of Southampton |
| Unit of Assessment: 03 Allied health professions, dentistry, nursing and midwifery, and pharmacy |
| Title of case study: 03-04 Transforming care for cancer survivors |
| <p>1. Summary of the impact</p> <p>There are currently 2 million cancer survivors in the UK. This is predicted to become 6 million by 2050 - by which time more than 50% of the UK population are expected to have experienced a cancer diagnosis. Our research and expertise have been central to the creation of the Department of Health's National Cancer Survivorship Initiative (NCSI), and framing policy more widely to respond to this challenge. It has provided evidence of the wide-ranging impact of the disease following cancer treatment, and has led to new models of cancer aftercare being implemented across the UK and internationally. Our research has linked directly to policy and practice through Professor Jessica Corner's membership of the NCSI Steering Group, as co-chair of the Department of Health's Cancer Patient Experience Advisory Group, and through our partnership with Macmillan Cancer Support.</p> |
| <p>2. Underpinning research</p> <p>The Macmillan Survivorship Research Group at the University of Southampton is led by Dr Claire Foster, with Professor Jessica Corner. It plays a leading role in the national and international movement to enhance care for cancer survivors. It is the only group of its kind in the UK and is uniquely placed for national and international impact. Our research played a major role in making the case for the <u>Department of Health (DH) National Cancer Survivorship Initiative (NCSI)</u>, and in underpinning its continuing work in improving the health and well-being of cancer survivors.</p> <p>The Macmillan Survivorship Research Group focuses on advancing understanding of the health outcomes and experiences of cancer survivors. Until recently this population has been neglected and their needs poorly understood. We discovered that cancer survivors are often unprepared for the continuing impact of cancer on their lives, and health professionals are unaware of the problems they experience. We showed that healthcare services need to adapt to this rapidly growing population, and we identified and developed effective models of aftercare to enhance quality of life and make better use of healthcare resources.</p> <p>The <u>Macmillan Listening Study</u> [3.1] used ground breaking participatory research methods to work with and actively consult people affected by cancer across the UK. We collaborated with cancer service users trained as co-researchers - with a strong focus on including people from under-represented groups - to show that people with cancer ranked the wide-ranging impact of cancer on everyday life and the need for support to self-manage as their highest priorities. They ranked these higher than research into new treatments or basic scientific understanding of cancer.</p> <p>From this Dr Claire Foster and Dr Deborah Fenlon developed a model of recovery of health and well-being following primary cancer treatment [3.3]. This study also demonstrated that patients may experience low confidence following treatment and find it difficult to self-manage the impact of cancer and its treatment without support. As a result of this work, focus on recovery is now incorporated into NCSI recommendations.</p> <p>We led the analysis of national survey data comparing cancer survivors' health outcomes with healthy individuals and those with long-term conditions (initial data published in 2008; detailed analyses published 2011). To reinforce impact with continuing evidence, Professor Jessica Corner and Dr Richard Wagland have collaborated with researchers at Leeds on the design and analysis of the <u>Department of Health National Cancer Patient Reported Outcomes Surveys</u> of cancer survivors in England 1-5 years following diagnosis [3.5 and 3.6] and the 2012 national survey of all colorectal cancer patients in England. As a direct result of our research and impact on policy 21,000 colorectal cancer survivors from every NHS Trust in England have now reported their health status in the first comprehensive survey of cancer survivors' health outcomes in the world.</p> <p>Our research [3.2] showed for the first time that UK cancer survivors not only had poorer health and well-being than healthy individuals, but also had similar health profiles and levels of dependence on health services as those living with other long term conditions. This has profound implications for the organisation and delivery of health services and has informed the Department</p> |

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of Health's National Cancer Survivorship Initiative (NCSI).

Against this background, Dr Elizabeth Reed and Professor Jessica Corner conducted the first survey to map the quality of life and health outcomes of women living with metastatic breast cancer. The findings revealed high levels of unrelieved pain and need for support services for women who were leading otherwise normal lives [3.4]. This study provided data used by the Secondary Breast Cancer Taskforce to underpin its policy interventions.

3. References to the research

Publications:

- 3.1 **Corner, J.**, Wright, D., Hopkinson, J., Gunaratnam, Y., McDonald, J. W. & **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 (6): 875-881.
www.ncbi.nlm.nih.gov/pmc/articles/PMC2360101/
- 3.2 Elliott, J., Fallows, A., Staetsky, L., Smith, P. W. F., **Foster, C. L.**, Maher, E. J., **Corner, J.** (2011) The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*, 105: S11-S20.
www.ncbi.nlm.nih.gov/pmc/articles/PMC3251954/
- 3.3 **Foster, C.** & **Fenlon, D.** (2011) Recovery and self-management support following primary cancer treatment. *British Journal of Cancer*, 105: S21-S28.
www.ncbi.nlm.nih.gov/pmc/articles/PMC3251956/
- 3.4 **Reed, E.**, Simmonds, P., Haviland, J., **Corner, J.** (2012) Quality of life and experience of care in women with metastatic breast cancer: a cross sectional survey. *Journal of Pain and Symptom Management*. 43 (4): 747-758.
www.sciencedirect.com/science/article/pii/S0885392411004489
- 3.5 Glaser, A., Fraser, L., **Corner, J.**, Feltbower, R., Morris, E. J. A., Hartwell, G., Richards, M., Wagland, R. (2013). Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey. *BMJ Open*, 3: e002317
www.ncbi.nlm.nih.gov/pmc/articles/PMC3641492/
- 3.6 **Corner, J.**, Wagland, R., Glaser, A., Richards, M. (2013). Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *BMJ Open*, 3: e002316.
www.ncbi.nlm.nih.gov/pmc/articles/PMC3641435/

Grants:

1. Corner, J. 5 year funding for Macmillan Research Unit 2003-2008. £1,160,121, Macmillan Cancer Support. Awarded 2003.
2. Foster, C., Fenlon, D., Corner, J. 5 year funding for Macmillan Survivorship Research Group 2009-2014. £1,447,924, Macmillan Cancer Support. Awarded 2009.
3. Corner, J., Reed, E., Simmonds, P., Gulliford, T. A study of the experience of living with secondary breast cancer. Breast Cancer Campaign. £171,887. Awarded 2004.

4. Details of the impact

Impact on public policy

Our work has two routes to impact. First, through our relationships with the Department of Health (DH) and second, through our partnership with Macmillan Cancer Support. Our research has inspired action to reorganise cancer services through the recently established National Cancer Survivorship Initiative (NCSI). Increased awareness of the unmet needs of cancer survivors as a result of our work supports major health policy change in the UK and informed the NCSI 2010 Vision [5.5], and has influenced policy internationally promoting greater involvement of cancer survivors in developing health service priorities [5.2, 5.3]. As a result, addressing the needs of people who survive cancer has become core to public policy and is changing public perception of the disease. The NCSI has become an integral part of DH National Cancer Strategy and is an important component of the DH's *Improving Outcomes: A Strategy for Cancer*, published in

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January 2011. Further evidence of direct impact may be found in the National Cancer Research Institute Strategic Plan for 2008-2013 [5.4] which proposed actions to address 'detection, diagnosis and prognosis' and 'improving clinical outcomes and survivorship' for those living with and beyond cancer by highlighting the needs of cancer survivors to policymakers, funding bodies and service providers.

More recently, our work on the experiences of women living with metastatic breast cancer was widely cited by media and policymakers (for example the NCSI report [5.6] published in March 2013). The research, funded by Breast Cancer Campaign, drew attention to this neglected group and, for the first time, illustrated how the disease unfolds from first diagnosis to death, using new mapping techniques devised at the University of Southampton. This research received attention in Parliament [5.9] when Baroness Morgan referenced the study in the House of Lords in November 2011 during the discussion of the Health and Social Care Bill, and was widely publicised in the media [5.10, 5.11] including the Daily Mail (circulation 1.8 million). Most importantly this has led to the development of a movement in support of the 36,000 women living with secondary breast cancer in the UK [5.12].

Impact on services

More than a million people will benefit from new models of aftercare resulting directly from the NCSI. We demonstrated that cancer and the emotional and physical side effects of cancer treatment impose an on-going burden for individuals in remission that had not been previously recognised. This now underpins the NCSI and is driving a change in the approach to care following initial cancer diagnosis and after successful treatment which places greater emphasis on supporting recovery. Professor Corner chairs the self-management work stream in the NCSI and our research [3.1, 3.2, 3.3] has demonstrated cancer survivors' need for information, care and support for self-management. This has led to the DH, Macmillan Cancer Support and NHS [5.1, 5.5] focussing on the design and implementation of supported self-management care models. Data from the Macmillan Health and Wellbeing Study [3.2] underpins the 2010 *NCSI Vision* report [5.5] and studies by the Macmillan Survivorship Research Group underpin the NCSI guidance issued in *Living with and beyond cancer: taking action to improve outcomes* report [5.6].

Impact on funding bodies

The Macmillan Listening Study informed research priorities of national cancer charities Macmillan Cancer Support and Breast Cancer Campaign. It resulted directly in Macmillan Cancer Support establishing a User Led Research Grant Scheme which ran for four consecutive years. This provided funding for studies where patients, caregivers and cancer survivors have an equal voice in deciding research questions and approaches with researchers and clinicians [5.8]. The report is cited in the Breast Cancer Campaign's gap analysis [5.13] indicating the need for research to focus on the impact of cancer on everyday life.

International impact

Southampton's innovative research methods in which service users with cancer co-led the Macmillan Listening Study has been highly influential nationally [5.7] and internationally [5.2]. The methods used in the study have been adopted in palliative care (Perkins et al., 2007) and Professor Corner was a member of the advisory panel for the Australian National Framework for Consumer Involvement in Cancer Control established by the Australian Federal Government. The framework report was published in 2011 and cited the study [5.3]. In addition, Professor Corner is Chair of the Movember Foundation Survivorship Action Partnership Global Advisory Committee. Launched with funds of over \$28 million, using the model of supported self-management developed through the NCSI the Survivorship Action Partnership is a global programme to develop networks in Australia, Canada, UK and USA focussed on implementing innovation to improve the lives of men living with prostate cancer.

5. Sources to corroborate the impact

- 5.1 Letter of endorsement from Professor Sir Mike Richards, Director for Reducing Premature Mortality (Domain 1), NHS England.
- 5.2 Letter of endorsement from Susan Hanson, Australian Government Cancer Australia.
- 5.3 Cancer Australia and Cancer Voices Australia (2011). National Framework for Consumer

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- Involvement in Cancer Control. Cancer Australia, Canberra, ACT. Cites Listening study <http://canceraustralia.gov.au/publications-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer> (Listening Study cited 11 times in PDF report: pages 24, 25, 28, 29, 30, 33, 34 – reference 28 in list)
- 5.4 *National Cancer Research Institute Strategic Plan 2008-2013* (published April 2008). Cites Listening Study: see page 13; reference listed on page 55.
http://www.ncri.org.uk/includes/Publications/reports/StrategicPlan_web.pdf
- 5.5 *National Cancer Survivorship Initiative Vision* report (2010). Cites Macmillan Health and Well-being Survey 2008 (pages 12, 14, 40, 54) which became detailed Elliott et al., paper provided as reference 3.2
<http://www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf>
- 5.6 National Cancer Survivorship Initiative report (March 2013): *Living with and beyond cancer: taking action to improve outcomes*. Cites Foster & Fenlon, 2011 as Key evidence on page 91; Cites Reed et al., 2012 for Further Reading on page 112.
<https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes>
- 5.7 INVOLVE (2012) *Briefing notes for researchers: involving the public in NHS, public health and social care research*. Cites Listening Study (2 references on page 48)
<http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/>
- 5.8 Macmillan User Led Grant Competition information (A direct result of the Listening Study). See pdf document on:
http://www.southampton.ac.uk/msrq/ourresearch/completedprojects/core/macmillanlistenings_tudy.page
- 5.9 Discussion of Health and Social Care Bill in House of Lords on 28 November 2011 – reference to advanced breast cancer research
<http://www.publications.parliament.uk/pa/ld201011/ldhansrd/text/111128-0002.htm#1111291000294> The main reference to our work is stated under the following: 28 Nov 2011: Column 73, 7.15pm, Baroness Morgan of Drefelin, paragraph 3 onwards.
- 5.10 Examples of media interest in the advanced breast cancer research (Reed et al., 2011) Mail Online - <http://www.dailymail.co.uk/health/article-2064317/Women-advanced-breast-cancer-feel-neglected-healthcare-left-suffering-extreme-pain.html#comments>
- 5.11 Huffington Post - http://www.huffingtonpost.co.uk/2011/11/21/breast-cancer-sufferers-pain-drugs-medicine_n_1104864.html
- 5.12 <http://www.breastcancercare.org.uk/news/blog/shouting-about-our-spotlight-secondary-breast-cancer-campaign> References Reed's research in Appearance versus Reality paragraph.
- 5.13 Breast Cancer Campaign Gap Analysis (2013) <http://breast-cancer-research.com/content/15/5/R92>. References Listening Study [3.1] and Foster and Fenlon's conceptual framework [3.3]