

Institution: The University of Manchester
Unit of Assessment: 3
Title of case study: Improving care and support for patients and families throughout the cancer trajectory. (ICS-03)
<p>1. Summary of the impact</p> <p>Research by our group at the University of Manchester has impacted directly on policy addressing inequities in access to treatment for older women with breast cancer, affecting treatment for 10,060 older breast cancer sufferers in England each year. Our research has led to improvements in pre-operative nutrition and screening for malnutrition for nearly 100,000 patients in Greater Manchester. We have contributed directly to international guidelines on post-treatment follow up for breast cancer and management of cough in lung cancer. We have also contributed to development of national vocational rehabilitation, employer support and benefits advisors for cancer survivors, affecting 700,000 survivors across the UK. Our work has led to implementation of family carer support needs assessment in UK hospice services, to date supporting some 4,500 carers per year with wider roll out imminent.</p>
<p>2. Underpinning research</p> <p><i>See section 3 for references [1-6]; see section 5 for corroborating sources (S1-S10); UoM researchers are given in bold. In REF3a and REF5 this case study is referred to as ICS-03.</i></p> <p><u>Key researchers:</u></p> <ul style="list-style-type: none"> • Ziv Amir (Senior Research Fellow, 2003-2012) • Kinta Beaver (Research Associate, 1997-2005; Senior Research Fellow 2005-2008; Professor 2008-2010; Honorary Professor, 2010-2013) • Sorrel Burden (Research Fellow, 2006- 2013; Clinical Senior Lecturer, 2013-date) • Gunn Grande (Research Fellow, 2002-2005; Lecturer, 2005-2007; Senior Lecturer 2007-2009; Reader, 2009-2011; Professor, 2011-date) • Katrina Lavelle (Research Fellow, 2006- date) • Karen Luker (Professor, 1997-date) • Alex Molassiotis (Reader, 2003-2005; Professor, 2005-date) • Chris Todd (Professor, 2001-date) <p>Key studies</p> <p>Our research has identified key problem areas, developed and tested solutions to improve support for patients and their families throughout the cancer trajectory in the following areas:</p> <p>Inequities in access to breast cancer treatment</p> <p>We showed that older women in the UK are substantially less likely to receive standard management for operable breast cancer, compared with younger women (including triple assessment, primary surgery, axillary node surgery, test for steroid receptors), and that this disparity is not explained by differences in tumour characteristics and general health (Lavelle, Todd) [1].</p> <p>Appropriate follow up after breast cancer treatment</p> <p>We identified best practice for follow up after breast cancer treatment through a programme of work. We demonstrated cost effectiveness of telephone follow-up, which is as good as intensive follow up in terms of patient-reported outcomes and early detection of recurrence, with substantial cost savings. (Beaver, Luker [2]).</p> <p>Physical wellbeing pre- and post-treatment</p> <p>We demonstrated a substantial problem of malnutrition in pre-operative colorectal cancer patients and weight change post-treatment (Burden, Molassiotis [3]). We improved the use of a Malnutrition Universal Nutrition Screening Tool (MUST) in identifying and addressing malnutrition amongst inpatients and demonstrated that pre-operative sip-feeding reduces post-operative complications in weight losing colorectal cancer patients (Burden). We identified best evidence on managing the distressing symptoms of cough and breathlessness in lung cancer and other</p>

respiratory disease through a series of systematic reviews (**Molassiotis** [4]).

Economic impact of cancer on survivors: returning to work

We were the first to publish the UK's rate of return to work for cancer survivors (80%) and factors associated with difficulties in returning to work (duration of absence, treatment modalities, lack of advice). We demonstrated significant unmet need for assistance, lack of timely access to occupational health services, insufficient understanding by health professionals and employers, poor professional-employer communication, and severe impact of cancer on family finances (**Amir, Luker** [5]).

Support needs of family carers during end of life care

We summarised evidence on adverse impact of caring on families, demonstrated the link between lack of support and impact on carers, identified the lack of evidence-based assessments of carer needs for routine practice in end of life care, and developed, tested and implemented the Carer Support Needs Assessment Tool (CSNAT) to support those caring for a 'loved one' whilst preserving their own wellbeing (**Grande** [6]).

3. References to the research

The research underpinning this impact has been published in leading journals with strong impact factors. The research has been supported by competitively awarded grants, including from NIHR, MRC, CRUK, NCRI.

- [1] **Lavelle K, Todd C, Moran A, Howell A, Bundred N, Campbell M.** Non-standard management of breast cancer increases with age in the UK: a population based cohort of women ≥ 65 years. *British Journal of Cancer.* 2007, 96:1197-1203. doi:10.1038/sj.bjc.6603709.
- [2] **Beaver K, Tysver-Robinson D, Campbell M, Twomey M, Williamson S, Hindley A, Susnerwala S, Dunn G, Luker K.** Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial. *BMJ,* 2009;338:a3147 doi:10.1136/bmj.a3147.
- [3] **Stamataki Z., Burden S. Molassiotis A.** Weight Changes in Oncology Patients During the First Year After Diagnosis: A Qualitative Investigation of the Patients' Experiences. *Cancer Nursing.* 2011 34:401-409. doi: 10.1097/NCC.0b013e318208f2ca.
- [4] **Molassiotis A, Bailey C, Caress A, Brunton L, Smith J.** Interventions for cough in cancer. *Cochrane Database of Systematic Reviews* 2010 9. CD007881 doi: 10.1002/14651858.CD007881.pub2.
- [5] **Amir Z, Moran T, Walsh L, Iddenden R, Luker K.** Return to paid work after cancer: A British experience. *Journal of Cancer Survivorship* 2007: 1, 129-136. doi:10.1007/s11764-007-0021-2
- [6] **Ewing G, Brundle C, Payne S, Grande G.** The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end of life care at home: a validation study. *Journal of Pain and Symptom Management,* 2013 46:395-405. doi:10.1016/j.jpainsymman.2012.09.008

4. Details of the impact

1 Inequities in access to breast cancer treatment

Our findings have directly shaped policy and informed public and political debate as follows.

- a) Our work on inequalities of access to breast cancer services [1] was used as evidence in the Cancer Reform Strategy (2007p.89; S1) for the need to address age related inequality in treatment and formation of a National Cancer Equality Initiative (set up in 2008). Our work is cited as evidence of continued need in the report on progress by the National Cancer Equality Initiative (Reducing cancer inequality 2010 p76; S2) which proposes the establishment of age as a key treatment equality metric. Our work is quoted as the rationale for the National Cancer Research Intelligence Network's continued monitoring of under-treatment of older people (S3).
- b) Our research informed political and policy briefings and we contributed to breakfast events, organised by breast cancer charities, at the 2009 party political conferences. The research was cited in the joint breast cancer charities' statement to the Parliamentary Group on Cancer's inquiry into cancer inequalities.

2 Appropriate follow up after breast cancer treatment

Our trial of follow up after breast cancer [2] was cited as evidence in the updated Guidelines for Breast Cancer Follow up of the American Society of Clinical Oncology (S4). These guidelines set the standard for cancer management internationally and have had world-wide impact on management of breast cancer.

3 Physical wellbeing pre- and post treatment

- a) Our malnutrition screening alone has improved care for nearly 100,000 patients annually: “[*MUST*] was subsequently implemented in three hospitals which have nearly 100,000 inpatient admissions annually. For all admissions, nutritional screening with the *MUST* tool is undertaken and the care plan instigated”. [Letter from Central Manchester Foundation Hospital Trust (S5)].
- b) Our work on cough and respiratory symptoms has been central in shaping national clinical guidelines on management of cough in lung cancer, and specifically within “*Clinical expert guidelines for the management of cough in lung cancer: report of a UK task group on cough*” (S6). The guidelines impact on management of a distressing symptom that affects 47-85% of the >41,000 UK patients diagnosed with lung cancer each year.

4 Economic impact of cancer on survivors: returning to work

Over 700,000 people of working age live with cancer across UK. The loss in UK productivity from cancer survivors being unable to undertake work is estimated at £5.49 billion. Even modest improvement in survivors’ return to work has considerable impact. We contributed substantially to the Department of Health (DH) and Macmillan Cancer Support launch of the National Cancer Survivorship Initiative (NCSI), serving on the Secretariat and summarising existing literature.

Impact through NCSI:

- a) Our research was instrumental in developing the NCSI Vision document (S7);
- b) Based on our evidence, the NCSI Work and Finance work-stream identified its aim to ensure that people living with cancer receive information, advice and rehabilitation support;
- c) Our work was central in reviewing vocational rehabilitation services and developing a cancer vocational rehabilitation model for piloting and provided underpinning evidence for the final Discussion Paper (S8);
- d) The rehabilitation model was piloted across England (2010-2011). The report evaluating this work, recognising the Manchester contribution, reveals significant improvement in employment status and cost gains (S9).

Impacts through Macmillan Cancer Support (MCS):

- e) Based on our work MCS launched the “Working through Cancer” programme. The key document, “*The road to recovery: getting back to work*”, was substantially underpinned by our research. The programme, which is heavily dependent on our work, includes (a) vocational rehabilitation; (b) support for small and medium enterprises, where both the MCS advice for employers (S10) and a MCS scoping study to establish suitable resources for employers, heavily reference our work; (c) “*Putting fair into welfare*”, a successful campaign to oppose proposed government changes to the benefits system that would have left thousands of people living with cancer without vital financial support when they most needed it.
- f) Our evidence was instrumental in supporting MCS Benefits Adviser posts throughout the UK. Delivered out of 76 Citizens Advice Bureau (CAB) offices there are 43 MCS/CAB specialist cancer benefits advice services providing specialist advice on welfare benefits, tax credits, grants and loans and help from local authority. It is estimated that the MCS/ CAB service has helped over 39,000 people with over 19,000 issues, 78% related to welfare benefits.

5 Support needs of family carers during end of life care

The Carer Support Needs Assessment Tool (CSNAT) has been implemented in 9 palliative home care services in UK and one in Australia. The UK services alone support 4100-4600 carers per annum. 40 UK home care services are committed to implementing CSNAT in late 2013 (S11). CSNAT research findings formed a section of Help the Hospices Guidance on carer assessment, and our work informed European Association for Palliative Care guidance (S12) which formed the basis for Marie Curie Cancer Care investment in carer research.

5. Sources to corroborate the impact

Inequities in access to breast cancer treatment (Todd/ Lavelle)

Source 1: The Cancer Reform Strategy 2007, Department of Health (6.30, pp88-89 ref 38).

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006

Source 2: Reducing cancer inequality: evidence, progress and making it happen: A report by the National Cancer Equality Initiative. Department of Health 2010 (BJC referenced in this ref 43 p76)

<http://webarchive.nationalarchives.gov.uk/20130513211237/http://www.ncat.nhs.uk/sites/default/files/work-docs/NCEI%20Report%20March%202010%20for%20website.pdf>

Source 3: National Cancer Intelligence Network, 2010. Evidence to March 2010 on cancer inequalities in England. www.ncin.org.uk/equalities (ref 43, p 16)

Appropriate follow up after breast cancer treatment (Beaver/ Luker)

Source 4: American Society of Clinical Oncology (ASCO) SPECIAL ARTICLES: Khatcheressian JL, Hurley P, Bantug E, Esserman LJ, Grunfeld E, Halberg F, Hantel A et al (2012). Breast Cancer Follow-Up and Management After Primary Treatment: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology (JCO)* Mar 1, 2013:961-965; published online on November 5, 2012; DOI:10.1200/JCO.2012.45.9859.

Physical wellbeing pre- and post treatment (Burden/ Molassiotis)

Source 5: Burden S: Letter from Lisa Edwards, Central Manchester University Hospitals NHS Foundation Trust.

Source 6: Molassiotis A Smith JA Bennett MI Blackhall F Taylor D Zavery B Harle A Booton R Rankin EM Lloyd-Williams M Morice AH (2010) Clinical expert guidelines for the management of cough in lung cancer: report of a UK task group on cough. **Cough** 6:9.

<http://www.coughjournal.com/content/6/1/9>

Economic impact of cancer on survivors: returning to work(Amir)

Source 7: NHS Improvement, National Cancer Survivorship Initiative – Vision, January 2010

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_d/h/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_111477.pdf

Source 8: NCSI (Work & Finance work-stream), Vocational Rehabilitation Strategy Paper , November 2009

<http://www.ncsi.org.uk/wp-content/uploads/Vocational-Rehabilitation-Strategy-Paper1.pdf>

Source 9: Eva G, Playford D, Sach T, Barton G, Risebro H, Radford K, Burton C. Thinking positively about work. Evaluation of the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream Vocational Rehabilitation Project. Final Report 2012.

<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/NCSIVREvaluationFinalReport-SummaryFinalVersionJuly2012.pdf>.

Source 10: Managing cancer in the workplace: An employer's guide to supporting staff affected by cancer. Macmillan Cancer Support, 2011, 2nd Edition

<http://be.macmillan.org.uk/Downloads/CancerInformation/WorkAndCancer/MAC12891Managingcancerintheworkplace31712.pdf>

Support needs of family carers during end of life care (Grande)

Source 11: Implementation of Carer Support Needs Assessment Tool (CSNAT) in hospice home care: supporting letter from Sue Varvel, Chair of the National Association for Hospice at Home

Source 12: Payne S and The European Association for Palliative Care Task Force on Family Carers, 2010. White paper on improving support for family carers in palliative care: Part 1. *European Journal of Palliative Care*, 17 (5) 238-245. ISSN 1352-2779.