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HORIZONS

Welcome, introductions and the history of HORIZONS

Professor Claire Foster, PhD, CPsychol
Director of the Macmillan Survivorship Research Group,
Faculty of Health Sciences

HORIZONS: a cohort study to explore recovery of health and well-being in adults diagnosed with cancer

HORIZONS study: Understanding the impact of cancer diagnosis and treatment on everyday life

Chief Investigator: Professor Claire Foster

Co-investigators: Calman, Corner, Haviland , May, Richardson, Rogers, Smith

Macmillan Survivorship Research Group
University of Southampton

Sponsor: University Hospital Southampton NHS Foundation Trust

MSRG Programme Focus

1. Understanding recovery and self-management following primary treatment for cancer
2. Developing and testing interventions to support self management
3. User involvement and representing those typically underrepresented.

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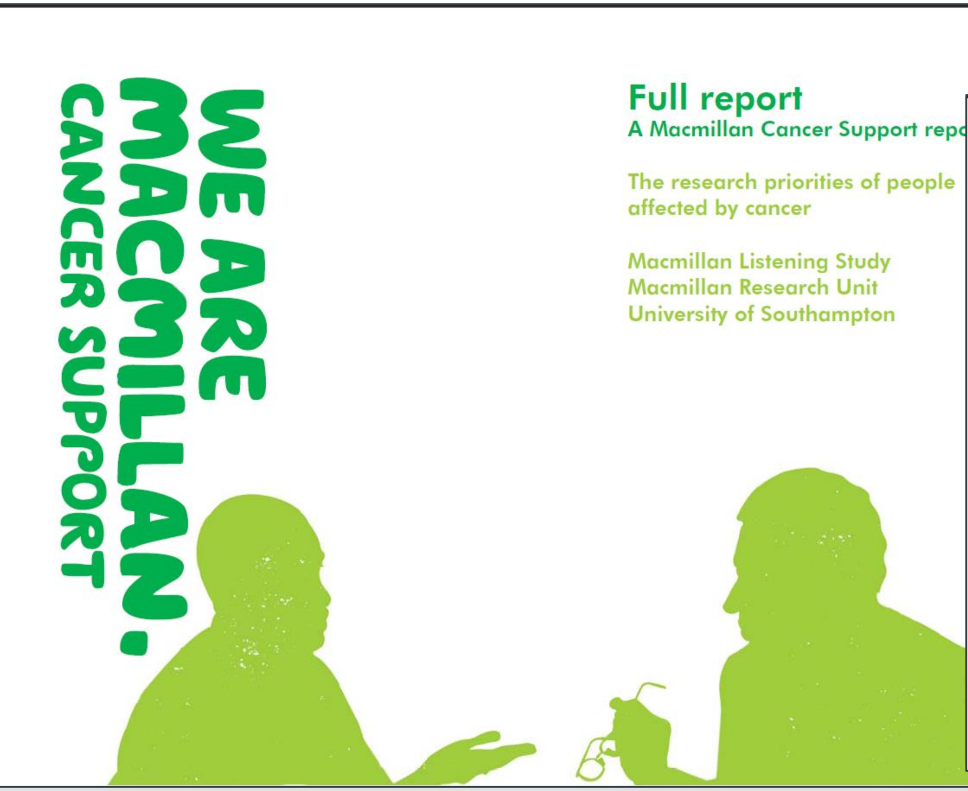
#1 priority: impact of cancer on everyday life

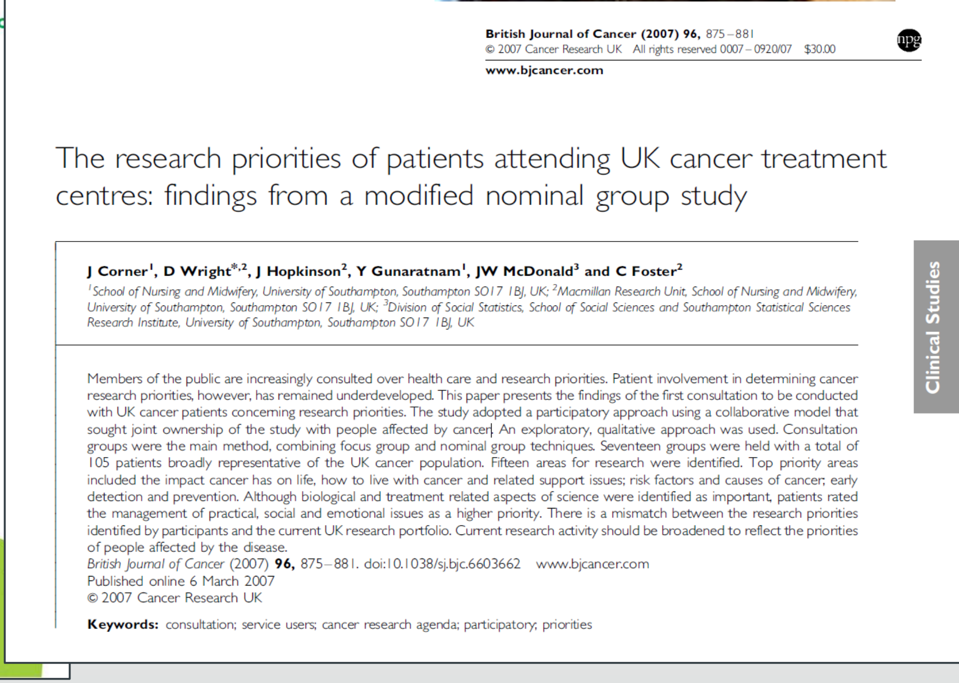


Full report

A Macmillan Cancer Support repo

The research priorities of people affected by cancer

Macmillan Listening Study
Macmillan Research Unit
University of Southampton



British Journal of Cancer (2007) 96, 875–881
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www.bjcancer.com

The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study

J Corner[1], D Wright[*,2], J Hopkinson[2], Y Gunaratnam[1], JW McDonald[3] and C Foster[2]

[1]School of Nursing and Midwifery, University of Southampton, Southampton SO17 1BJ, UK; [2]Macmillan Research Unit, School of Nursing and Midwifery, University of Southampton, Southampton SO17 1BJ, UK; [3]Division of Social Statistics, School of Social Sciences and Southampton Statistical Sciences Research Institute, University of Southampton, Southampton SO17 1BJ, UK

Members of the public are increasingly consulted over health care and research priorities. Patient involvement in determining cancer research priorities, however, has remained underdeveloped. This paper presents the findings of the first consultation to be conducted with UK cancer patients concerning research priorities. The study adopted a participatory approach using a collaborative model that sought joint ownership of the study with people affected by cancer. An exploratory, qualitative approach was used. Consultation groups were the main method, combining focus group and nominal group techniques. Seventeen groups were held with a total of 105 patients broadly representative of the UK cancer population. Fifteen areas for research were identified. Top priority areas included the impact cancer has on life, how to live with cancer and related support issues; risk factors and causes of cancer; early detection and prevention. Although biological and treatment related aspects of science were identified as important, patients rated the management of practical, social and emotional issues as a higher priority. There is a mismatch between the research priorities identified by participants and the current UK research portfolio. Current research activity should be broadened to reflect the priorities of people affected by the disease.

British Journal of Cancer (2007) **96,** 875–881. doi:10.1038/sj.bjc.6603662 www.bjcancer.com

Keywords: consultation; service users; cancer research agenda; participatory; priorities

Why so important?

- Rising numbers
- 50% adult cancer patients predicted to survive ≥10 years
- Living with consequences
- Unmet needs
- Living with comorbidities

Increased recognition

- Needs of people living with and beyond cancer

At the end of it you just ***feel kind of left out at sea****. You are a bit kind of 'OK what happens now?' And it's* ***like a security blanket has been taken away*** *in some ways.* ***You kind of miss it!*** *It's the worst thing you'd ever go through, you miss having it there and* ***the routine of it*** *there.*

- Evidence needed to inform design and delivery of effective services & interventions that support self-management

Limited evidence

- **Recovery of health and well-being:** Very little known about patterns of recovery from cancer – how long it takes, what it is like, who is likely to experience problems, how can these be managed.
- **Supporting recovery and self-management:** Limited evidence to support people to self-manage the impact of cancer and its consequences on everyday life

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CREW

Understanding the recovery and wellbeing of those affected by colorectal cancer

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Fenlon, D.R., Richardson, A., Addington-Hall, J.M., Smith, P., Corner, J.L., Winter, J. & Foster, C. (2012) **A cohort study of the recovery of health and wellbeing following colorectal cancer (CREW study); protocol paper.** *BioMedCentral Health Services Research*, 12:90 doi:10.1186/1472-6963-12-90

Areas of assessment

- Clinical aspects
- Socio-demographic aspects
- Physical & psychological symptoms & functioning
- Quality of life
- Personal attributes & perceptions
- Health service use; social support

- 1350 eligible people attended clinics in 29 cancer centres [Nov 2010 - Mar 2012]
- 91% of these approached
- N=1,055 (78%) gave consent
- Baseline questionnaire before surgery
- Follow-up: 3, 9, 15, 24, 36, 48, 60 months

Foster, C. & Fenlon, D. (2011) Recovery and self-management support following primary cancer treatment. *British Journal of Cancer,* 105, S21-S28.

NCRN

NCRI
National
Cancer
Research
Institute

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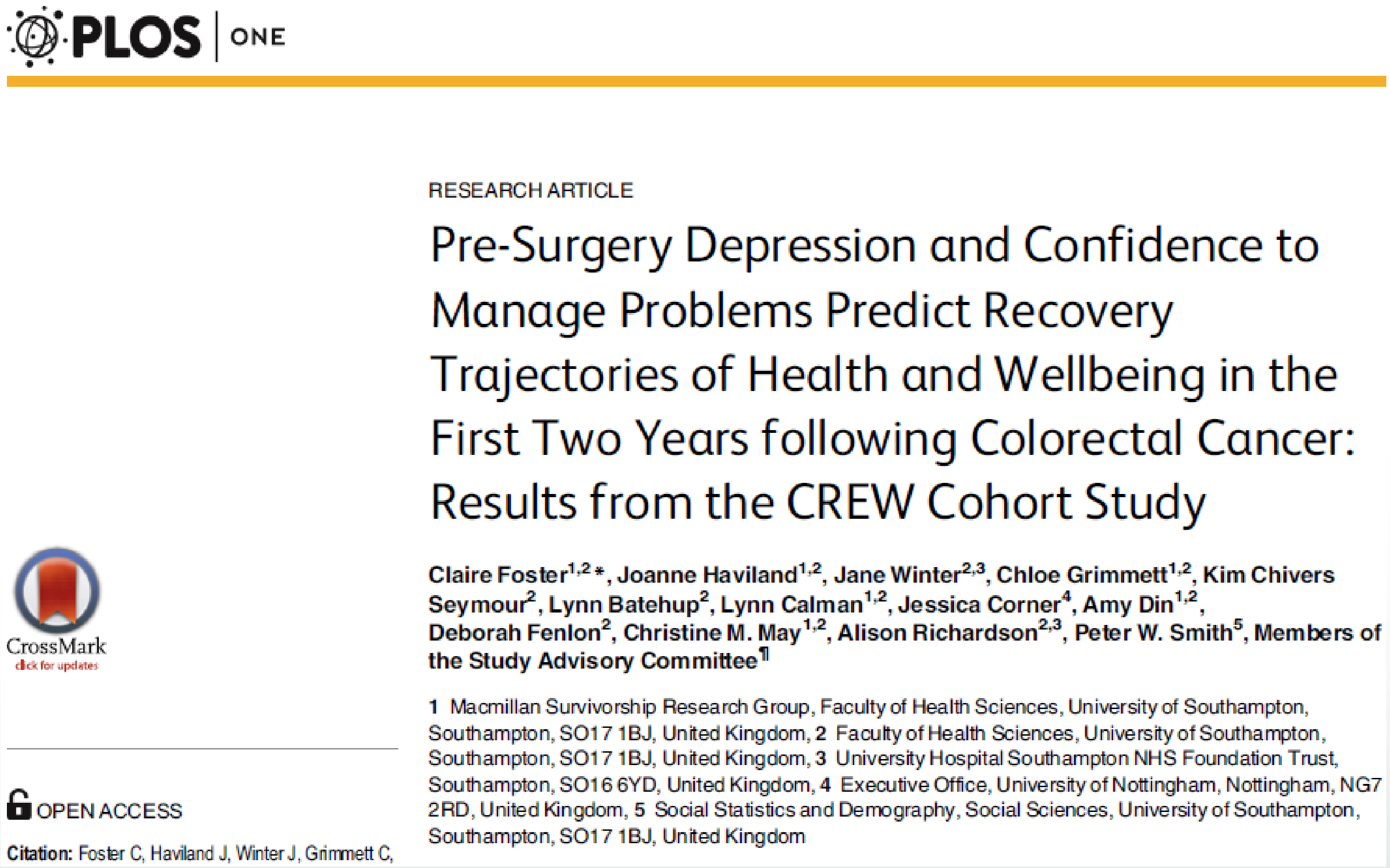

PLOS | ONE

RESEARCH ARTICLE

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

Claire Foster[1,2]*, Joanne Haviland[1,2], Jane Winter[2,3], Chloe Grimmett[1,2], Kim Chivers Seymour[2], Lynn Batehup[2], Lynn Calman[1,2], Jessica Corner[4], Amy Din[1,2], Deborah Fenlon[2], Christine M. May[1,2], Alison Richardson[2,3], Peter W. Smith[5], Members of the Study Advisory Committee[¶]

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OPEN ACCESS

Citation: Foster C, Haviland J, Winter J, Grimmett C,

Foster, C. et al. (2016) PLoS ONE 11(5): e0155434. doi:10.1371/journal.pone.0155434

- Establish the HORIZONS Programme of **additional 3,000** cancer patients to capture their health outcomes and experiences from **before they begin active treatment** and regularly **over their life-course**

- Maintain and develop the HORIZONS Programme as a **national and international resource** to explore consequences of cancer treatment from the individual perspective across the life-course

The Macmillan HORIZONS Programme sets out to improve the lives of people affected by cancer by building understanding of the cancer survivorship population and providing a depth of evidence not available through other research.

It will

- Adopt a longitudinal cohort approach
- Reveal how the consequences of cancer treatment affect people's lives
- Lead the way in understanding complex survivorship experiences and health outcomes
- Provide novel and detailed evidence to inform the national and global movement to transform care for cancer survivors

HORIZONS data will:

- Improve understanding of the consequences & characteristics that increase risk of poor recovery, ability to self-manage
- Enable us to predict who is most likely to need support and when
- Help to prepare future patients for likely consequences and how long these might last
- Help health professionals provide more personalized care tailored to patients' needs and to support people to live as healthy and active a life as possible.

I mean psychologically I guess I am a ***fairly optimistic sort of person*** *[…] as I said,* ***what is it, what can we do about it, how long will it last?*** *and if I know the answers to those three questions* ***I don't worry about it and just get on****.*

To achieve this and best support those living with and beyond cancer we need the evidence from HORIZONS

Is this worthwhile?

Don't talk yourselves down. Most carers and probably most patients could tell you everything you have said today BUT we have neither the voice or the authority to express it. By doing these studies, publishing the results and talking about them you are taking a huge burden from our shoulders. This changes our lives. You are astonishing people.

(NCRI conference patient representative participant, anon)

Introductions

University Hospital Southampton NHS
NHS Foundation Trust

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- Funders
- Participants
- Participating Centres
- Research Partners
- Research Team
- Strategic & Scientific Advisors

Macmillan Survivorship Research Group

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