

# Southampton

Wishing you a very Merry Christmas and a Happy New Year, From the Macmillan Survivorship Research Group



**Hello and Seasons Greetings!** We are sending you an update on the CREW Cohort Study (funded by Macmillan Cancer Support). We have lots of news to share. CREW is closing at the end of the year now that we have collected data from participants up to 5 years post-surgery. We will continue to analyse the enormous amount of data generated by CREW and expect to publish lots more papers and reports in the next few months.

**Establishing CREW:** Between November 2010 and April 2012, participants were recruited into the CREW study. Your efforts paid off and we had a sample of 1055 participants. The CREW study involves people with colorectal cancer from the point of diagnosis and before they had surgery with curative intent. The original plan was to follow up participants for 24 months, but Macmillan Cancer Support, recognising the value of the data being generated, agreed to continue funding annual follow-up questionnaires up to 5 years post-surgery.

We really appreciate the recruitment efforts of the CREW centres and we have been delighted by the commitment of the participants. Response rates over time for CREW have been one of its successes. The chart on the following page shows the response rates for eligible participants at each follow-up point.



# Southampton

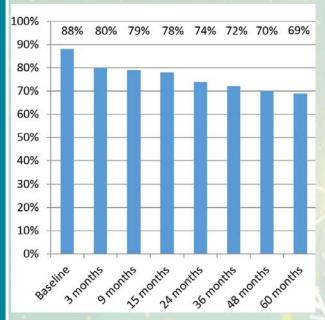


CREW findings: We now have a rich dataset detailing what life is like for people in the first 5 years following a diagnosis of colorectal cancer.

Our aim is that CREW findings and forthcoming results will help to shape and improve future support services for individuals with cancer and other long-term conditions.

We have already published some papers in academic journals, and have many more in the pipeline. Keep an eye on our webpage (www.southampton.ac.uk/msrg) or follow us

on Twitter (@macmillanuos) to find out when papers are published, and do get in touch if you would like us to send you our papers. Here is a brief summary of some of our findings so far.



Flavia Bellotto Trigo:

Baseline clinical factors are not the most important predictors in the recovery of health and wellbeing. Instead, we found that pre-surgery psychosocial factors, such as confidence to manage illness related problems (self-efficacy) and depression, predict quality of life, health status and wellbeing. For example, those who, at baseline, reported higher levels of depression and lower self-efficacy experienced poorer quality of life.

There is little change in self-efficacy in the first two years and around 40% of the CREW participants had suboptimal levels of confidence to manage illnessrelated problems. This suggests that it is important to identify people with low self-efficacy at diagnosis and start early intervention to help build skills and confidence to self-manage and improve health-related quality of life.

Along with self-efficacy, another important factor

which impacts recovery for colorectal cancer patients is whether they have other conditions as well (comorbidities). Many people with colorectal cancer have co-morbidities but what is most relevant is how much those conditions affect their everyday life. Those individuals whose conditions impact their daily activities may need more support during their recovery.

Our findings also underline the importance of the support offered by family and friends from the time of diagnosis throughout recovery. Around 30% of our sample felt that this support reduced over time, even though the actual number of family members and close friends did not change. Those people who felt they were lacking in social support had worse quality of life and higher levels of anxiety and depression.

#### The Macmillan Survivorship Research Group (MSRG): a growing team

**Administrator** 

The MSRG has grown in size since the early days of CREW. We are now a team of 22 research and administrative staff. We would like to welcome the following new team members, whose profiles can be found

**Nicole Tipler:** 

on the MSRG website: **Trial Administrator Helen Clegg: Trial Administrator** 

**Debbie Ellis:** Data-manager Dr Becky Foster: Research Fellow

Fabia Le Moignan: Trial co-ordinator Dr Jane Frankland: Senior Research Fellow

**Richard Brooks:** Senior Research Fellow Trial co-ordinator Dr Sally Wheelwright:

1. Foster, C. et al (2016) 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. PLOS ONE, 11(5):e0155434. DOI: 10.1371/journal.pone.0155434

2. Grimmett, C. et al (2017) Colorectal cancer patient's self-efficacy for managing illness-related problems in the first two years after surgery, results from the ColoREctal Wellbeing (CREW) study. Journal of Cancer Survivorship

3. Haviland, J. et al (2016) The impact of co-morbidities on recovery from colorectal cancer within first 2 years after surgery: Result from the UK Colorectal Wellbeing (CREW) cohort study. Paper presented at National Cancer Research Institute Conference, 6-9 November 2016. Liverpool, UK. Oral presentation.

4. Haviland, J. et al. (2017) Social support following diagnosis and treatment for colorectal cancer and associations with healthrelated quality of life: results from the UK ColoREctal Wellbeing (CREW) cohort study. Psycho-Oncology. 26(12):2276-2284

### Newsletter Issue 11



# Southampton

#### **MSRG Announcements!**



### Research undertaken by the Macmillan Survivorship Research Group (MSRG)

Our largest new study is **HORIZONS**, funded by **Macmillan Cancer Support**, which will explore the recovery experiences of 3000 people diagnosed with either non-Hodgkin's lymphoma, breast cancer (<50 years) or a gynaecological cancer. HORIZONS already has 55 sites open across England, Wales, Scotland and Northern Ireland.

We have just started collecting data for the **TrueNTH Global Registry-Prostate Cancer Outcomes Study**, funded by **Movember Foundation**. This is an international project which will systematically collect clinical and outcome data to compare patient relevant

outcomes in men with localised prostate cancer. The aim of the study is to identify new approaches to improve care and outcomes.

The **National Cancer Quality of Life Metric** Project has also just got underway, funded by **NHS England**. This study was set up by NHS England to improve the long term care of cancer patients. In Southampton, colorectal and prostate cancer patients will be asked to complete a short questionnaire about their health and wellbeing after treatment and again 12 months later.

We are very proud that our colleague Dr Chloe Grimmett has gained a prestigious five year NIHR post-doctoral fellowship. She will develop a conceptual model of physical activity behaviour change in cancer survivors, and then an intervention to promote sustained long-term physical activity.

We have recently completed two studies. **Roy Castle Lung Cancer Foundation** funded a project to find out whether it is possible to involve **lung cancer patients treated with radiotherapy** over time in a cohort study similar to CREW. This study provided evidence that it is possible to involve people who have treatable but not necessarily curable cancer and will inform new work looking at self-management in this group.

We have recently completed the, **Breast Cancer Choices** study, funded by **Breast Cancer Now**, to develop a web-based decision aid to help younger women with breast cancer decide whether to have a genetic test or not.

### Macmillan Survivorship Research Group Online and on Social Media

For full details of MSRG updates please visit the MSRG website, www.southampton.ac.uk/msrg or follow us on twitter @macmillanuos. If you would like to get in touch please contact us on MSRG@soton.ac.uk.

Finally, we would like to express our sincere thanks for all of the effort and continued commitment that you have given to CREW. Without you, CREW would not have been possible. We look forward to working with you again soon.

Wishing you all a very Merry Christmas and all the best for 2018

The Macmillan Survivorship Research Group

### FAQs

	The second secon
Q	Will the CREW Cohort study collect anymore data?
$\boldsymbol{A}$	Currently we have no plans to continue collecting data from the CREW participants.
Q	How can I get involved in other MSRG research projects?
A	We usually put out expressions of interest at the start of our studies. All MSRG research projects are listed on our website (www.southampton.ac.uk/msrg). If you would like to get involved in other MSRG research projects please email MSRG@soton.ac.uk
Q	How can I hear about MSRG publications?
A	We regularly update the MSRG website and the MSRG Twitter page with all of our news, including publications,

#### **Contact details:**

MSRG, Faculty of Health Sciences, Building 67, University of Southampton, SO17 1BJ

MSRG@soton.ac.uk

Professor Claire Foster Email: C.L.Foster@soton.ac.uk

Tel: 023 80596885 Extension: 26885

Amy Din Email: A.E.Din@soton.ac.uk

Tel: 023 80596885 Extension: 27879