UNIVERSITY OF
Southampton

Personalising care for people with bowel cancer

Key findings from the Colorectal Wellbeing (CREW) study

Macmillan Survivorship Research Group

CREW
Understanding the recovery and wellbeing of those affected by colorectal cancer

Funded by
MACMILLAN CANCER SUPPORT

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CREW study participants

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THE COLORECTAL WELLBEING (CREW) STUDY
IN A NUTSHELL

1000
participants
with bowel cancer

From
across
the **UK**

65%
had colon
cancer

35%
had rectal
cancer

70%
recovered well

40%
had low confidence
to self-manage

15%
had a questionnaire score
suggestive of depression
5 years after surgery

27%
had co-morbidities
which impacted
everyday life

25%
had unmet
needs

30%
said support
from others
declines

Pain

Frequent urination

Diarrhoea

Most frequent troublesome symptoms in the 5 years following surgery

Contents

Welcome to the Colorectal Wellbeing (CREW) study

CREW was informed by patients who told us that research needed to focus on understanding the impact of cancer on people's everyday lives and developing ways to help manage this impact. Since CREW began in 2010, our understanding of how colorectal cancer can affect people's lives has increased significantly and the information gained is changing the way people diagnosed with colorectal cancer are cared for and supported.

Professor Claire Foster
Director of the Macmillan Survivorship Research Group (MSRG)

The contribution of CREW findings to the NHS

The findings from CREW are of high relevance to the strategic direction of the Wessex Cancer Alliance, particularly relating to the personalised care agenda. CREW findings have informed personalised care activities across 7 hospitals serving a population of around 2.8 million.

I would like to highlight the importance of CREW findings for the Improving Access to Cancer Nurse Specialist and Key Workers evaluation, completed in 2019. The evaluation reported that the introduction of Cancer Support Workers has made a significant contribution to cancer-related supportive care, findings that were cited in Our Cancer Plan for Wessex, 2019-2024, launched in February 2020. The evidence provided by CREW on the impact of colorectal cancer on people's health and wellbeing was instrumental in informing the commissioning and delivery of this impactful workforce intervention.

Sally Rickard
Managing Director, Wessex Cancer Alliance, NHS England

The contribution of CREW findings to Macmillan Cancer Support

Findings from CREW are of high relevance to Macmillan Cancer Support and have helped inform our strategic thinking on how personalised care can be best supported. Recommendations from the five-year CREW data have informed our guidance on pre-habilitation for people with cancer (published in July 2019), and our ongoing work on delivering effective Holistic Needs Assessment (HNA) as part of the Recovery Package. In particular, the need to identify confidence to self-manage from the point of diagnosis is valuable in ensuring HNAs remain fit-for-purpose and of benefit to people living with and beyond cancer. Presentations of CREW findings to Macmillan teams since the study's initiation have ensured we have robust evidence to inform the delivery of our services and our policy and influencing work. Presentations to Macmillan Allied Health Professionals in July 2019, for example, have helped justify the importance of key workers in supporting patient-identified issues as well as the need to address psychological problems and comorbidities from the point of diagnosis.

Dany Bell
Treatment, Medicines and Genomics Strategic Advisor,
Macmillan Cancer Support

ColoREctal Wellbeing (CREW) study

How do people treated with curative intent surgery for bowel cancer recover in the five years following surgery and who is most at risk of poor outcomes?

Introduction

Bowel cancer, also known as colorectal cancer (CRC), is the most common cancer to affect both men and women. Nearly everyone survives bowel cancer if it is diagnosed at the earliest stage. There are about 268,000 people in the UK today who have been diagnosed with bowel cancer, a figure that is predicted to rise to 630,000 by 2040[1]. Almost 42,000 people are diagnosed in the UK every year.

The usual treatment for curable bowel cancer is surgery. Some people may also have chemotherapy and/or radiotherapy before surgery (neoadjuvant treatment), while others may have chemotherapy after surgery (adjuvant treatment).

Although survival rates for bowel cancer have been improving, relatively little was previously known about how people recover: how long it takes; what it is like; who is likely to experience problems, and how these can be managed. There was also limited evidence to inform interventions and support people to self-manage the impact of bowel cancer and its consequences on everyday life.

People affected by cancer told us that research needed to focus on understanding the impact of cancer and treatment on people's everyday lives and finding ways to help them to manage this impact[2,3]. This was the starting point for the ColoREctal Wellbeing (CREW) study.

With CREW, we set out to explore how people recover their health and wellbeing after being treated for bowel cancer.

Our three main objectives were to:

1. Plot the usual pattern of recovery of health and wellbeing following treatment for primary bowel cancer.
2. Investigate whether and how health needs change over this period.
3. Explore factors that influence the restoration of health and wellbeing and determine who is most at risk of poor or protracted recovery.

The CREW study followed people diagnosed with bowel cancer from before they had surgery for the next five years. This report summarises its findings to date and should:

1. Improve understanding of the consequences of cancer and its treatment
2. Enable us to predict who is most likely to be at risk of poor recovery and so need more support and when.
3. Help prepare people diagnosed with bowel cancer in the future for likely consequences and how long these might last, and so support self-management.
4. Help health professionals provide more personalised care that is tailored to individuals' needs and support people to live as healthy and active a life as possible.

The CREW study: How we did it

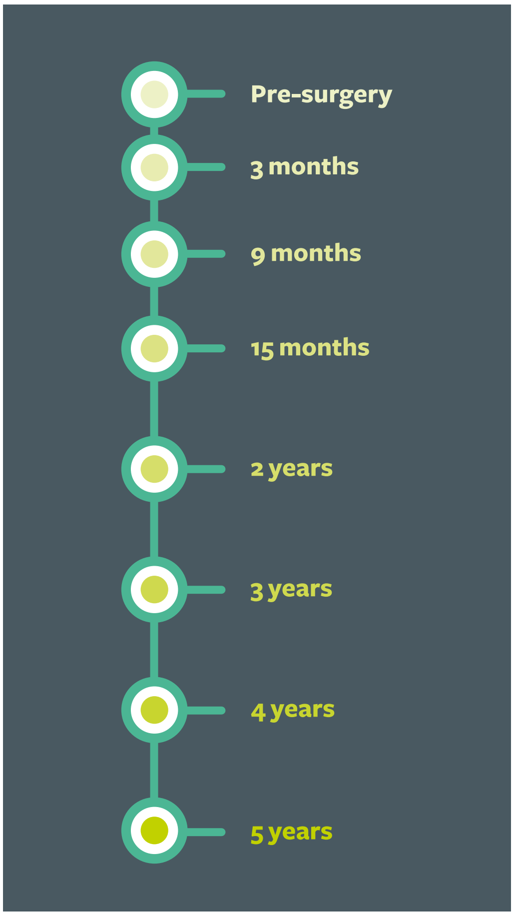


Figure 1: Time since surgery when questionnaires were sent to participants

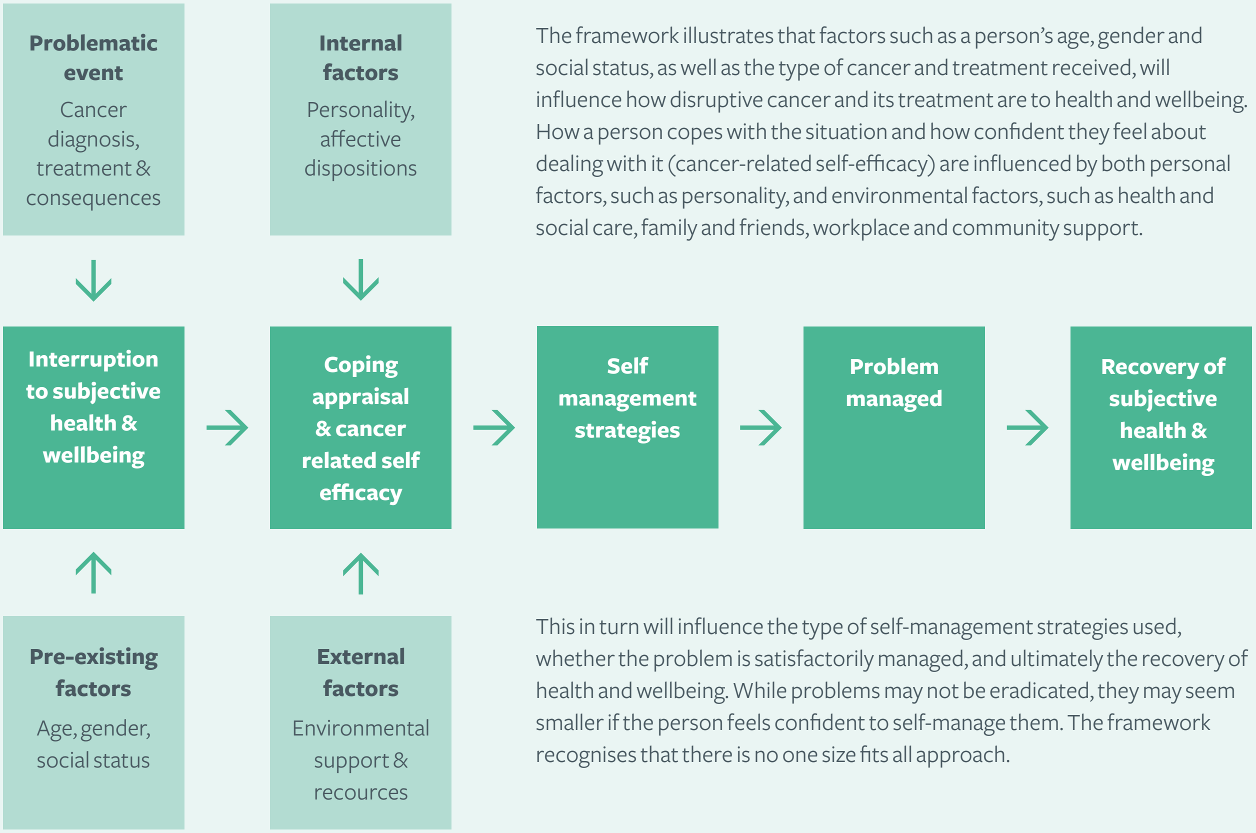
People who were diagnosed with bowel cancer were at the heart of the CREW project. As well as taking part as research participants, people who had been affected by bowel cancer advised us on the kind of information we should collect and how we should go about doing it.

People were invited to take part in CREW if they had a newly confirmed diagnosis of non-metastatic bowel cancer (cancer that has not spread to other parts of the body) and were waiting for surgery to remove the cancer, and hopefully cure them of the disease[4]. Participants also had to be aged 18 years or over and be able to complete the questionnaires (translation facilities were available for those that did not speak English).

CREW participants were invited to complete questionnaires at eight time points over a period of five years (see Figure 1). Before questionnaires were sent out, we checked with each participant's GP to make sure this was appropriate. The questionnaires provided a wealth of information about how participants were doing in terms of their health, wellbeing and quality of life, how confident they were to manage their health, what their needs were, how supported they felt, and what use they made of health services. As we followed the same people over time, we were able to see how things changed and what stayed the same.

The questions included in the CREW questionnaires were based on our framework of recovery[5], shown below.

A list of the measures used is provided in Appendix 1. Further details on these, and all the findings presented here, are available from the published papers listed at the end of the report.



The framework illustrates that factors such as a person's age, gender and social status, as well as the type of cancer and treatment received, will influence how disruptive cancer and its treatment are to health and wellbeing. How a person copes with the situation and how confident they feel about dealing with it (cancer-related self-efficacy) are influenced by both personal factors, such as personality, and environmental factors, such as health and social care, family and friends, workplace and community support.

This in turn will influence the type of self-management strategies used, whether the problem is satisfactorily managed, and ultimately the recovery of health and wellbeing. While problems may not be eradicated, they may seem smaller if the person feels confident to self-manage them. The framework recognises that there is no one size fits all approach.

Figure 2: Framework of recovery

Location of CREW sites

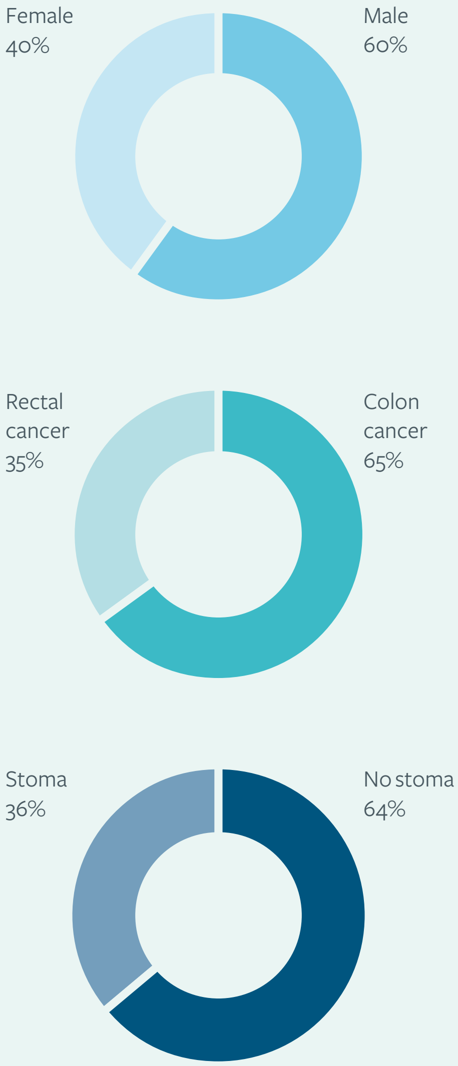


Figure 3: CREW participants at baseline

Along with the questionnaires, we also collected information about diagnostic details, treatment and recurrence from medical notes during the first two years post-diagnosis. Some people who were invited to take part in CREW did not want to fill out questionnaires but agreed that we could collect information from their medical notes.

Who did and did not take part in CREW?

People recently diagnosed with colorectal cancer at 29 sites across the UK were invited to participate from November 2010 – March 2012.

A total of 1,017 people joined the CREW study, 85% of all those who were invited to do so, a very high proportion for this kind of project. Most of the CREW participants were from England (85.6%), with 10.9% from Wales and 3.5% from Scotland. Figure 3 shows some baseline characteristics of CREW participants. Participants ranged in age from 26 to 95 years and the average age was 68 years.

With permission, we collected information from the people who chose not to participate including their age, gender, ethnicity, whether they lived alone or with others, and what their employment status was. We also asked if they were happy to give a reason for not taking part. The people who chose not to take part were similar to those who participated in terms of the ratio of males to females, ethnicity, and whether they lived alone or with others. Overall, they were a little older (average age 72 years) than the people who agreed to participate (average age 68 years). The most common reasons for not taking part included: anxiety about treatment; not wanting to be followed-up for a long period; feeling too ill to complete questionnaires; or already taking part in a different study.

Of the 1,017 participants, 872 agreed to complete questionnaires. The remaining 145 gave permission for their medical notes to be checked. The 145 people who did not want to complete questionnaires were slightly older (average age of 73 years) than those who did (average age of 68 years). This was the only statistically significant difference between the two groups.

We compared the CREW participants with data from the National Bowel Cancer Audit (NBOCA) and found that the only difference was that many more CREW participants received neo-adjuvant radiotherapy for rectal cancer than was usual at that time (48% in CREW compared with 11% in NBOCA). This could be due to a clinical trial of short course radiotherapy[6], which was recruiting at the same time as CREW.

Overall, we are confident that the people who took part in CREW are representative of people diagnosed with bowel cancer who had surgery with the aim of curing their cancer. This is important because it means that the CREW findings are likely to have general relevance and apply to other people living with and beyond bowel cancer.

As always happens in studies which run over a number of years, some participants decided they no longer wanted to take part. Also, very sadly, some of the CREW participants died. Nevertheless, even at five years, 71% of the participants who were sent a questionnaire returned it. This is a high proportion, especially as originally CREW had been planned as a two-year study. When asked what was the best thing about taking part in CREW, a number of participants commented on their satisfaction at being able to help

others. Responses included: "*Being able to return a small part of the support I have been given*"; "*Doing something useful*," and, "*knowing that you are doing something positive after being diagnosed which may help other people in the future.*"

Others felt that it had been a useful exercise that had helped them personally. One participant remarked: "*it's been a useful periodic self-check. A moment to consider the state of things. And bring into focus one's otherwise dissipated feelings on the situation.*" Another said, "*It has been useful in making me reflect on not only my illness and how it affected me, but on how it could have changed my life even more.*"

> *"I actually enjoy these questionnaires as they make me realise I'm not alone! Thank you!"*
>
> **CREW participant**

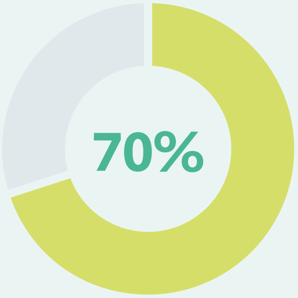


Figure 4: 70% CREW participants recovered well overall

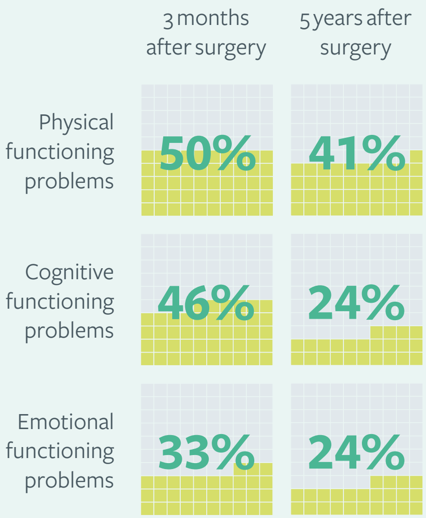


Figure 5 : Percent of participants with top 3 clinically relevant functioning problems

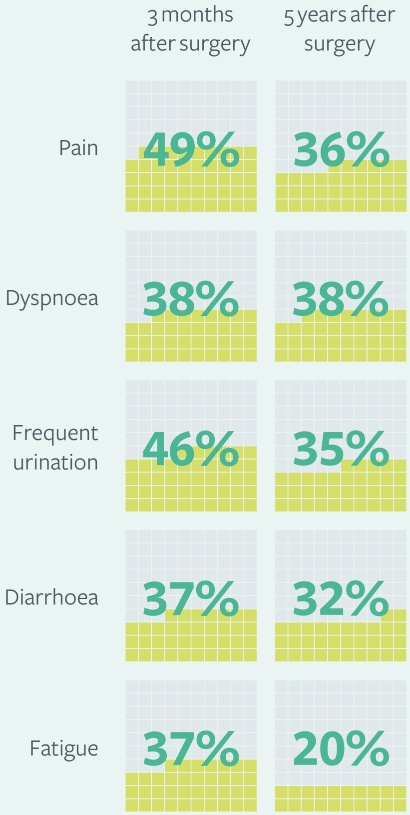


Figure 6 : Percent of participants with the top 5 most common symptoms experienced over the 5 years of CREW

The results: What has CREW found out?

1. Recovery of health and wellbeing following bowel cancer treatment

Around seven out of ten people (70%) were doing well after treatment for bowel cancer in terms of their overall health and wellbeing. However, around three out of ten (30%) did less well and this was still the case five years after surgery. The study showed that psychosocial factors before treatment, particularly depression and a lack of confidence to manage illness-related problems (low self-efficacy), were as important as stage of disease for predicting people's long-term recovery of health and wellbeing[7].

2. Health needs during recovery from bowel cancer treatment

a) Symptoms and functioning

Although the majority of people recovered well in terms of overall health and wellbeing, many people experienced ongoing symptoms and levels of functioning which had a negative impact on their lives. Even though in general there was some reduction in the proportion of people reporting problems during follow up, there were still large numbers of people experiencing the more common problems at five years. For example, three months after surgery, 50% of CREW participants had problems with physical functioning, affecting activities such as having a walk and self-care. Five years after surgery, 41% still had problems. Poor cognitive functioning, specifically being able to concentrate on things and remember things, and emotional functioning problems, such as feeling tense, worried, irritable and/or depressed, were also common, persistent problems (see Figure 5).

The five most common symptoms for the CREW participants over the five years were pain, dyspnoea (being short of breath), frequent urination, diarrhoea and fatigue (see Figure 6). For example, nearly half of CREW participants reported pain three months post-surgery. At five years, more than a third were still experiencing significant pain.

There were also some additional common problems identified specifically in people with rectal cancer. For those without a stoma, frequent bowel movements, flatulence and insomnia were relatively frequent problems. For those with a stoma, common problems were nausea/vomiting, poor body image, embarrassment because of their stoma, worry about future health and insomnia. Reduced social functioning, meaning their condition interfered with family life and social activities, and reduced role functioning, meaning their condition interfered with daily and leisure time activities, were also common problems for people with rectal cancer who had a stoma.

While many of the problems reported here are not unique to people who have had bowel cancer, they can have a persistent negative impact on everyday life and support for people who have had bowel cancer could be targeted at these problems.

b) Sexual functioning

The vast majority of women, over 90% at most time points, reported a lack of sexual interest. For men, around 70% had low sexual interest three months following surgery, reducing slightly to 62% by five years. Impotence was a very common problem for men, with an average 50% affected over the five years.

c) Mental health

CREW highlighted that mental health is a concern for people with bowel cancer. To be diagnosed with a mental health condition, an individual's distress

level must impair daily functioning and be experienced over time. We used standard questionnaire measures to assess levels of depression and anxiety in CREW participants. These questionnaires have cut-off scores which are associated with clinically significant levels of depression and anxiety. However, it is important to note that someone can only be diagnosed with depression or anxiety by a qualified professional. Nevertheless, if someone is reporting a lot of symptoms associated with depression or anxiety, they may require extra support, even if they do not receive a diagnosis.

The standard questionnaires suggested that, compared with best estimates for the general population, mental health problems were more common among CREW participants. Before surgery, 21% of CREW participants – more than one in five people – scored above the cut-off indicating a high level of depression. Although there was some reduction in this number over follow up, at five years the proportion remained high at 15%. Around 3% of people in the general population are estimated to have clinical depression.

Even more CREW participants had high levels of anxiety. At baseline, while waiting for surgery, 39% scored above the cut-off indicating high levels of anxiety. High levels of anxiety at baseline may not be surprising, but at five years the figure was still 20%. This compares with 6% in the general population who are estimated to have clinical anxiety.

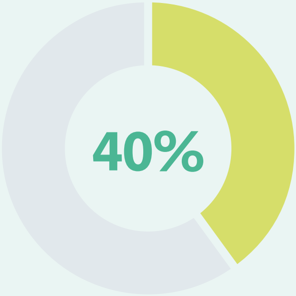
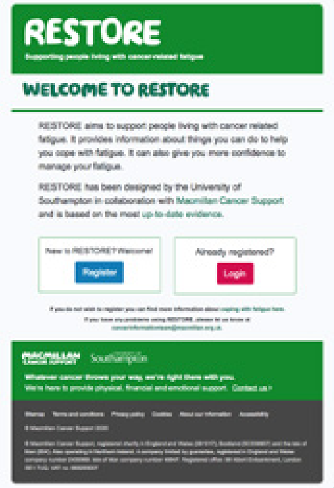


Figure 7: The percent of people with low levels of confidence to self-manage remained at 40%

3. What factors influence the restoration of health and wellbeing and who is most at risk of poor or protracted recovery?

a) Self-confidence

Throughout the five years of CREW, around 40% of participants reported low levels of confidence to manage their illness-related problems (especially symptoms)[8]. We know that people who are not confident about managing problems are more likely to have worse health and wellbeing outcomes. This is why resources like RESTORE, that are designed to improve confidence, are so important.



RESTORE

Supporting people living with cancer-related fatigue

WELCOME TO RESTORE

RESTORE aims to support people living with cancer related fatigue. It provides information about things you can do to help you cope with fatigue. It can also give you more confidence to manage your fatigue.

RESTORE has been designed by the University of Southampton in collaboration with Macmillan Cancer Support and is based on the most up-to-date evidence.

New to RESTORE? Welcome!

Already registered?

Whatever cancer throws your way, we're right there with you.
We're here to provide physical, financial and emotional support. Contact us ›

RESTORE is a web-based resource, developed by the Macmillan Survivorship Research Group in collaboration with patients, clinicians and academics[9]. RESTORE is evidence-based and has been successfully evaluated in a trial[10]. It provides clinical information about cancer-related fatigue (CRF), examples of how others manage, and support in managing the impact of CRF in everyday life. RESTORE supports the self-management of CRF through self-monitoring levels of fatigue, goal setting, patient stories, and a fatigue diary. It is divided into five sessions designed to be completed at weekly intervals. Sessions one and two cover an introduction to CRF, causes and effects, and the concept of goal setting. Users then have a choice of areas to focus on: diet, sleep, exercise, home life, work; managing thoughts and feelings about fatigue; or talking to others about fatigue.

RESTORE is freely available, without the need for referral at www.macmillanrestore.org.uk

b) Social support and unmet needs

CREW also investigated the impact of social support and having unmet care-related needs on health and wellbeing outcomes and found that these were important factors. 30% of CREW participants reported that social support declined in the first two years following surgery[11]. Examples of social support include having someone dependable who will listen in times of need, help with daily chores, provide love and affection, and be good company. Despite

> *"I am surprised that my overall level of confidence has diminished over time - I thought the opposite would happen as I became more knowledgeable about the disease and more "experienced" in knowing what to do. With time my confidence seems to have been progressively eroded."*
>
> **CREW participant**

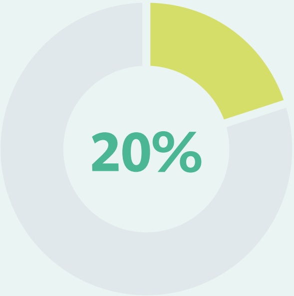


Figure 8 : A quarter of CREW participants had unmet needs when treatment had finished

having the same number of friends and family around them, nearly a third of participants felt less supported as time went on. Low and declining social support was associated with poor mental health and low quality of life. It was particularly important to have someone around to share positive social interactions with.

A quarter of participants reported at least one moderate or severe problem that had not been addressed by professionals after treatment had been completed (15 months after surgery) and this was still the case at 24 months[12]. The three most common unmet needs, each affecting about 1 in 10 people were: anxiety around fear of cancer spreading; not being able to do the things that were previously possible; and a lack of energy/tiredness. Having unmet needs, particularly if those needs were physical or daily living, was associated with worse quality of life.

c) Impact of other chronic conditions

Around 72% of CREW participants had other chronic conditions in addition to their cancer but having a comorbidity in itself did not lead to worse outcomes[13]. What was really important was whether the comorbidity had an adverse effect on everyday life. This was the case for 27% of CREW participants, putting them at risk of experiencing worse quality of life, lower functioning and worse symptoms following their cancer treatment. Arthritis was one of the most common chronic conditions affecting everyday life, while having a diagnosis of anxiety or depression had the most significant impact on health and wellbeing.

Summary of risk factors for poor recovery following bowel cancer treatment

Taking all these findings together provides a clear picture of the risk factors for poor health and wellbeing outcomes. These are:

- → Depression
- → Low confidence to manage illness-related problems
- → Insufficient social support
- → Unmet needs
- → Comorbidities that impair everyday life

Recommendations for people diagnosed with bowel cancer, family and friends

Most people recover well after treatment for bowel cancer, but this is less likely to happen for those who do not feel confident about managing their condition. If you, or your family, need some support or advice, it may be helpful to talk to your Clinical Nurse Specialist (CNS), Cancer Support Worker (CSW), GP or another member of the clinical or social care team and look at the resources at the end of the report.

If you think you could be experiencing depression consider speaking to your GP or a member of the clinical or social care team as it can be treated. Depression is a long lasting (two weeks or more) low mood disorder, which affects everyday life. Symptoms can include feeling miserable, having a sense of hopelessness, taking no pleasure or interest in anything, and experiencing physical symptoms like poor sleep or a change in appetite.

If you are experiencing fatigue, RESTORE may help (see page 11). This web-based resource is free and easy to use and does not require a referral. If you are experiencing other symptoms, try speaking to a member of your clinical or social care team, or your GP, about how to manage these problems. It may be helpful to talk about the things you need help with, whether this is related to everyday life, mental health or healthcare.

Living with cancer and other conditions e.g. arthritis, depression, can make life more challenging. Mentioning any additional health problems to your health or social care team will allow them to help you manage them during your cancer treatment and follow-up.

Unmet needs may have an impact on the lives of family and friends, as well as the person diagnosed with cancer. Friends and family can also ask a member of the clinical or social care team for help and use the resources at the end of this report.

Family and friends can be supportive by being available to talk, offering practical support for everyday life and being affectionate. Most importantly, do enjoyable things with your friend or relative who is living with cancer.

Improving treatment and care – how healthcare professionals, commissioners and policymakers can use CREW findings

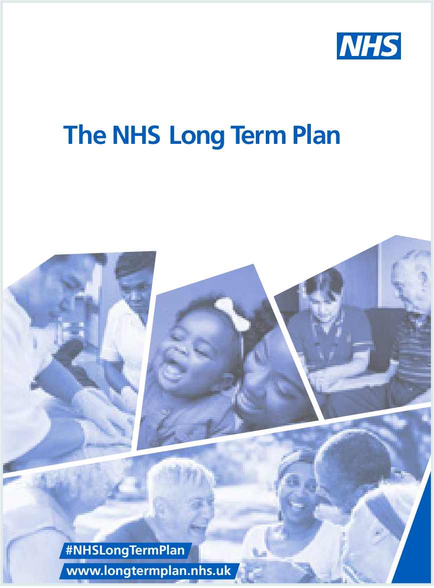
The CREW study provides evidence to support current NHS objectives in England, Wales and Scotland. For example, the 2019 **NHS Long Term Plan** states that:

By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Patients will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.

Tying in with these objectives, findings from CREW can help tailor the information and support required for people with bowel cancer, in order to more accurately match their needs. This complements the NHS Long Term plan's concept of Universal Personalised Care.

In addition, the 2004 *Supportive and Palliative Care guidelines* (NICE CSG4) recommend that commissioners should ensure that all patients receive psychological assessments with access to appropriate psychological support (5.16). They suggest a network-wide approach be adopted to delivering psychosocial support, with skilled professionals providing a range of psychological interventions.

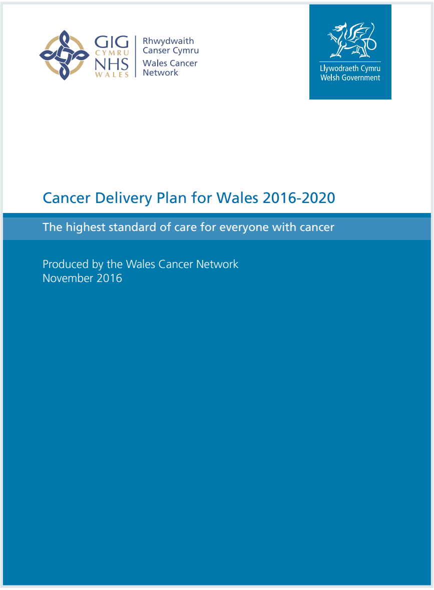
Based on current policy and guidelines, we make the following recommendations informed by CREW findings. Some of these recommendations will support what is already in place in some organisations, providing reassurance that current practice is supported by robust evidence, whilst others will be new.



NHS

The NHS Long Term Plan

#NHSLongTermPlan
www.longtermplan.nhs.uk



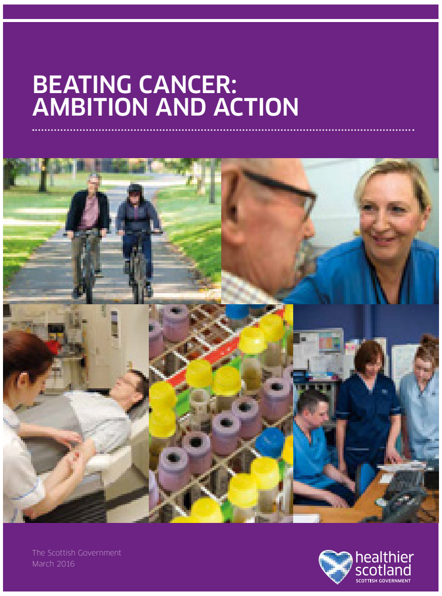
GIG CYMRU NHS WALES
Rhwydwaith Canser Cymru
Wales Cancer Network

Llywodraeth Cymru
Welsh Government

Cancer Delivery Plan for Wales 2016-2020

The highest standard of care for everyone with cancer

Produced by the Wales Cancer Network
November 2016



BEATING CANCER:
AMBITION AND ACTION

The Scottish Government
March 2016

healthier scotland
SCOTTISH GOVERNMENT

“I also have high blood pressure and arterial fibrillation but the biggest nuisance is arthritis.”

CREW participant

CREW Recommendations

1. Improving personalised care

- → Supportive clinical conversations, including a holistic needs assessment (HNA), should be conducted at or soon after diagnosis, throughout treatment and during recovery by the health and social care team to enhance the quality and personalised nature of support. With the right training, cancer support workers (CSWs) could carry out HNAs.
- → HNAs should include assessment of confidence to manage illness-related problems, screening for depression, an assessment of whether comorbidities limit daily activities and the individual’s confidence to manage multiple conditions.
- → HNAs should contribute to the development of care plans. Care plans should be reviewed regularly to check implementation and to revise if necessary, in line with updated HNAs.
- → The health and social care team should signpost and refer people with bowel cancer to appropriate support services within acute and community settings, and within secondary care in response to their HNAs. They should also signpost to relevant self-management tools, such as RESTORE.
- → The health and social care team should recognise the importance of social support during recovery and signpost to sources of support when necessary. They should also recognise that family and friends may need guidance about how to support the person with bowel cancer and be ready to signpost to sources of support for family and friends.
- → All health and social care professionals should be able to recognise the psychosocial needs of people with bowel cancer and should support the use of HNAs.

2. Supporting people living with chronic conditions (comorbidities)

- → The health and social care team should work with the person with bowel cancer to co-develop a tailored care plan that is responsive to complex needs. The health and social care team should liaise with psychological and other services, ensuring the complex needs of the individual are met.
- → Cross-specialty clinics for people with comorbidities could enable multi-professional management, with targeted interventions, support services, tailored assessment and follow-up to aid recovery of health and wellbeing. Such integrated care requires a platform where professionals can work across primary care, community services and secondary care, and where physical, mental health and social care services are brought together in one clinic. The ‘GOLD’ Geriatric Oncology service provided at Guy’s Hospital, where cancer and other co-existing medical conditions are managed, is one example (https://tinyurl.com/y3stywg4).

3. The wider picture: Planning for and meeting demand

The CREW findings also lead to recommendations for steps that will require a greater strategic overview, with input from commissioners and policymakers.

- → Workforce development should be supported through changes to competencies and curricula of Royal Colleges and other professional organisations, ensuring the psychosocial implications of cancer survival, supported self-management and comorbidities are included.
- → Results from the NHS England Quality of Life Metric could be used to assess how HNA completion affects outcomes. The Quality of Life Metric

is a questionnaire that all people diagnosed with cancer in England will be invited to complete 12-24 months after diagnosis.

- Commissioners must ensure psychological, social support, supported self-management and other services are commissioned with suitable capacity to meet increased demand. A mapping exercise to identify gaps between need and service provision should be carried out. Mapping exercises should be conducted through Cancer Alliances, as part of Sustainability and Transformation Plans (STP) activity, NHS England Transformation Funding, or funded through other means. Psychological and other support services should be remapped periodically, as business as usual, to ensure service provision continues to reflect need. A suite of resources to help system leaders and commissioners examine and develop their current psychosocial support services for adults affected by cancer, as well as their families and carers is available at www.healthylondon.org/resource/psychosocial-support
- Data generated through HNAs should be used by STPs, Cancer Alliances and Clinical Commissioning Groups (CCGs) to understand cancer recovery and inform mapping activities of care provision.

How CREW findings are supporting personalised supportive care in clinical practice

CREW findings are being used to change practice in the Wessex region. One example, is a project funded by NHS England[14]. The project involved introducing full-time cancer support workers (CSWs) into the cancer health and social care team to support stratified supportive care from around the point of diagnosis. The idea was that people with more complex needs could receive enhanced input from clinical nurse specialists, while people with less complex needs could be predominantly supported by CSWs. The project team acknowledged it was CREW findings that highlighted how important it is to identify people with additional supportive care needs at an early stage, around diagnosis. CREW findings were also used to help define complexity, through recognition of the importance of factors such as depression, social isolation, and comorbid conditions that impair everyday life.

How CREW contributes to current research priorities

In December 2018, the National Cancer Research Institute (NCRI) published its top ten research priorities for people living with and beyond cancer. Findings from the CREW study actively support many of these priorities, in particular:

UK Top 10 living with and beyond cancer research priorities

1. What are the best **models for delivering long-term cancer care** including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?
2. How can patients and carers be **appropriately informed** of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?
3. How can care be better co-ordinated for people living with and beyond cancer who have **complex needs** (with more than one health problem or receiving care from more than one specialty)?
4. What causes **fatigue** in people living with and beyond cancer and what are the best ways to manage it?
5. What are the short-term and long-term **psychological impacts** of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?
6. How can the **short-term, long-term and late effects** of cancer treatments be (a) prevented, and/or (b) best treated/ managed?
7. What are the biological bases of side-effects of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?
8. What are the best ways to manage **persistent pain** caused by cancer or cancer treatments?
9. What specific **lifestyle changes** (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?
10. How can we **predict** which people living with and beyond cancer will experience **long-term side-effects** (side-effects which last for years after treatment) and which people will experience **late effects** (side-effects which do not appear until years after treatment)?

NCRI research priority 1: What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?

CREW shows that: The best models need to reflect that one size does not fit all: care needs to be tailored around factors such as confidence to self-manage, comorbidities and what support is available. Those who are likely to struggle to manage long-term side effects can be identified soon after diagnosis, which means that earlier interventions can be introduced.

NCRI research priority 2: How can patients and carers be appropriately informed of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?

CREW provides robust evidence of recovery following surgery for bowel cancer. People diagnosed with bowel cancer and carers receiving this information will be better prepared for what to expect.

NCRI research priority 3: How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?

CREW shows that there should be particular focus on the comorbid conditions that limit daily activities.

NCRI research priority 5: What are the short-term and long-term psychological impacts of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?

CREW shows that depression and anxiety are more common in people with bowel cancer than the general population, even five years after surgery. To provide greater support, early (around the time of diagnosis) and ongoing assessment and intervention is required.

NCRI research priority 6: How can the short-term, long-term and late effects of cancer treatments be prevented, and/or best treated/managed?

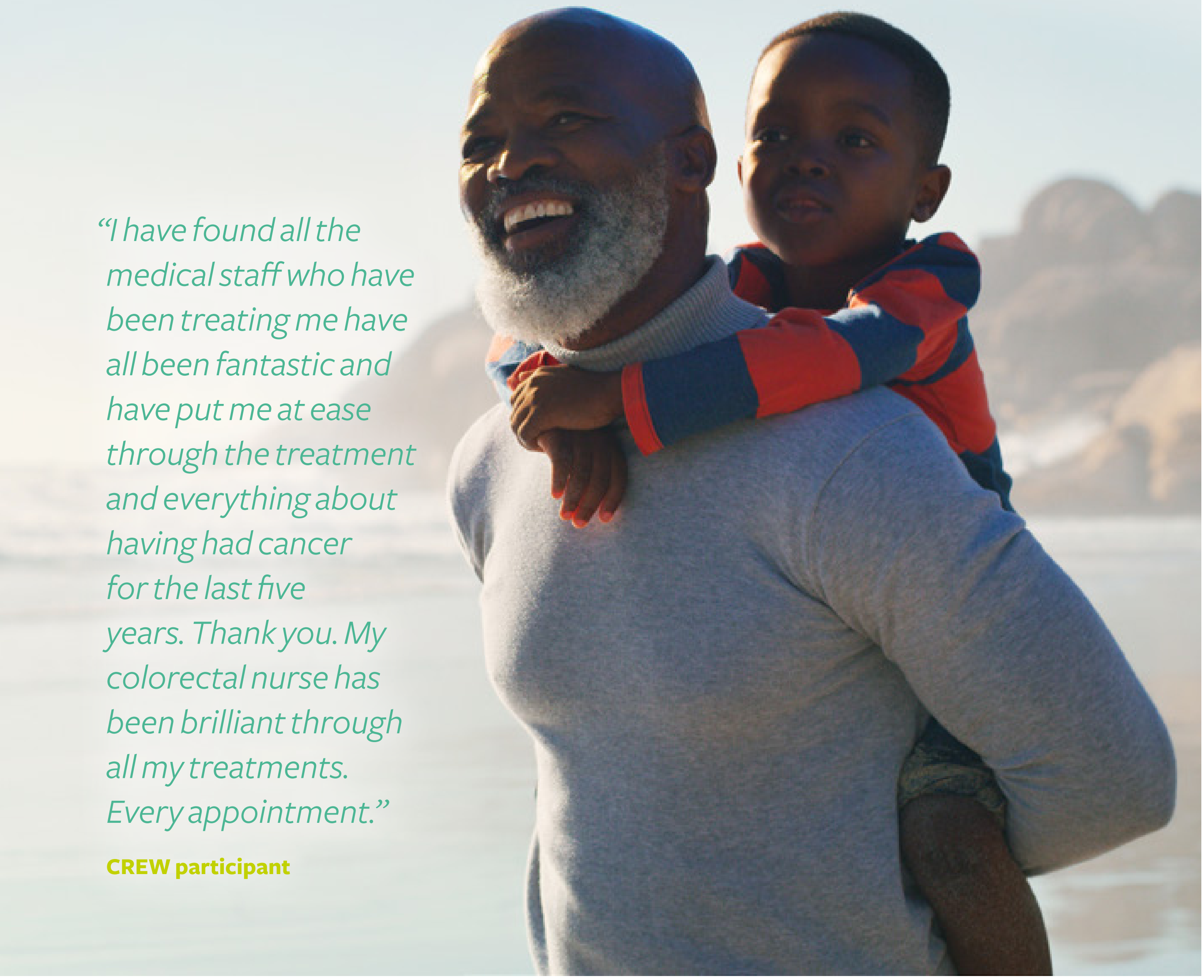
CREW shows that support to improve confidence to self-manage problems should be offered to those who need it from the time of diagnosis onwards.

Conclusion:
What have we learned from CREW?

The CREW study has enabled us to assess how people recover health and wellbeing following treatment for bowel cancer over a five-year period and investigate whether and how health needs change over this period. We explored factors that influence the restoration of health and wellbeing and saw that psychosocial factors rather than the stage of disease at diagnosis governed people's long-term recovery. This demonstrates the importance of personalising care to meet the needs of each individual's circumstances.

We know that to improve the treatment and care of people affected by cancer, we must ensure that it better reflects the needs of each individual and demonstrably improves quality of life. This can only really be achieved by putting people rather than process at the heart of any treatment and care plans. By asking individuals affected, CREW identifies those issues that are important to people with bowel cancer: confidence to manage cancer-related problems; depression; comorbidities and persistent symptoms that affect everyday life; unmet needs and social support. Building on these findings, asking individuals affected by cancer about these issues at the outset and assessing and intervening from diagnosis onwards, will further personalise and therefore improve treatment and care.

CREW confirmed the importance of confidence to manage treatment and care. In order to have this confidence, people need timely access to clear and relevant information, which will also help them to have more helpful, better-informed conversations with those who treat and care for them.



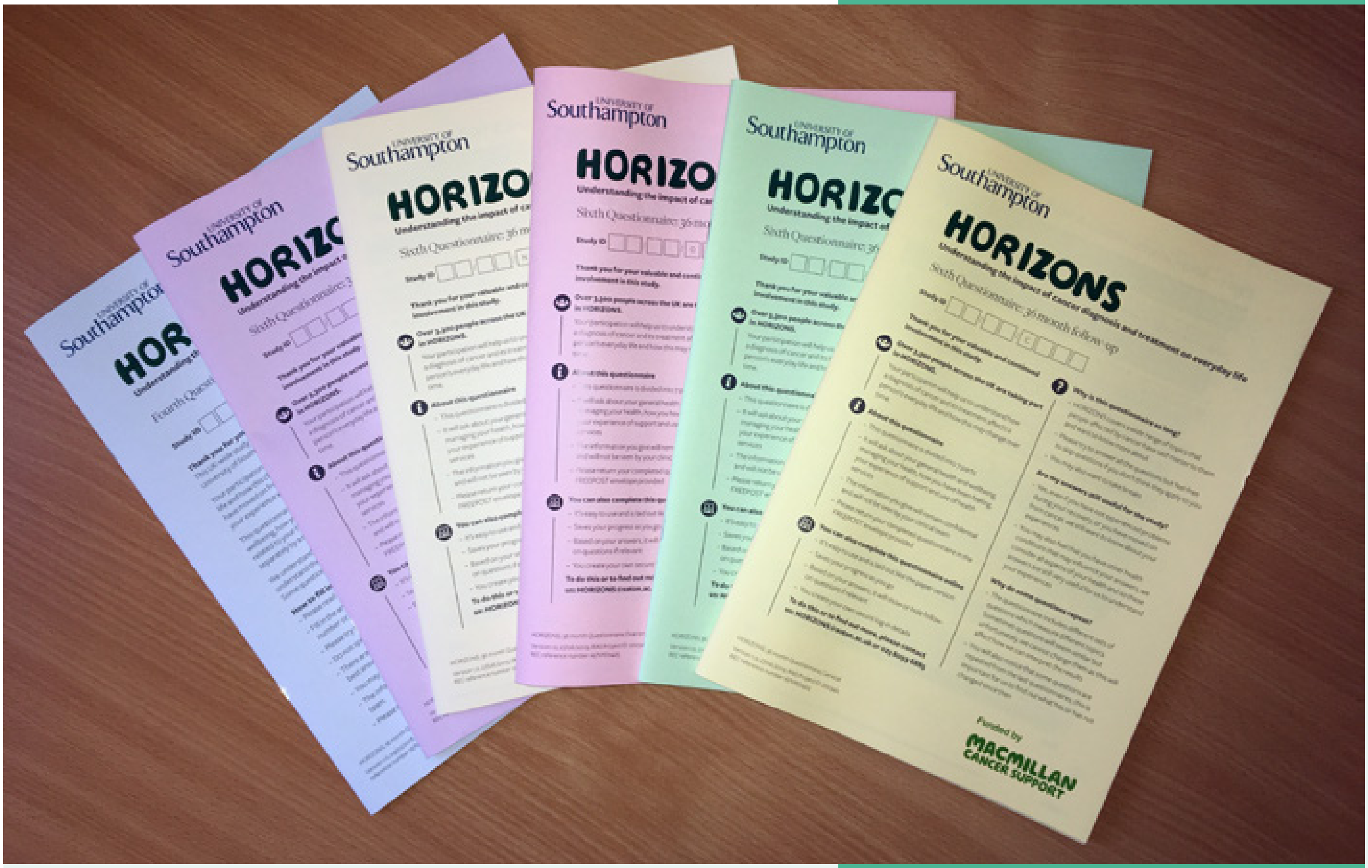
> *"I have found all the medical staff who have been treating me have all been fantastic and have put me at ease through the treatment and everything about having had cancer for the last five years. Thank you. My colorectal nurse has been brilliant through all my treatments. Every appointment."*
>
> **CREW participant**

> *"I feel extremely fortunate that this cancer has not had a serious impact on my quality of life. After my initial surgery and recovery period I have been able to do everything I could before."*
>
> **CREW participant**

To help provide information, we are planning a CREW dashboard. This dashboard will be a web-based resource that will let people explore what they can expect in terms of symptoms and functioning while recovering from bowel cancer surgery, and therefore increase their preparedness for any likely consequences. By having information about what to expect, and for how long, they can be better placed and more empowered to make informed decisions. When people affected by cancer are better informed about what to expect, and the people treating them know which factors are most important for recovery, conversations between the two will be more productive. This will help health professionals provide more personalised care tailored to individuals' needs and support people to live as well as possible.

Ongoing research:

The CREW study focussed on one of the most common cancers. In HORIZONS, we are exploring the recovery of health and wellbeing in people experiencing a variety of treatment and recovery pathways, less common cancers, under-researched groups and groups with particular survivorship concerns[15]. HORIZONS includes three groups of participants: i) younger women (<50 years) with breast cancer; ii) people with non-Hodgkin's lymphoma; iii) women with a gynaecological cancer (endometrial, cervical, ovarian and vulval). Over 3,000 participants have consented to take part in the HORIZONS study and will be followed up for a minimum of two years. You can find out more about HORIZONS and follow the progress of the study at www.horizons-hub.org.uk



Accessing Data

The CREW cohort dataset is representative, with relatively low attrition rates, and includes longitudinal patient-reported data from pre-treatment through to five years post-surgery. It is therefore a valuable resource for exploring recovery of health and wellbeing following curative intent treatment for bowel cancer. We welcome requests from researchers and others for access to both CREW and HORIZONS data. See www.horizons-hub.org.uk/access_data.html for details.

Useful Resources

www.macmillan.org.uk

www.bowelcanceruk.org.uk

www.cancercaremap.org

> *"I don't honestly believe anyone gets over cancer completely. Even if the physical stuff goes away/cured there will never be any let up of the fear and mental distress caused."*
>
> **CREW participant**

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Appendix: What was assessed in CREW

Framework domain	Measure
Problems experienced	EORTC QLQ-C30[16] and QLQ-CR29[17] Supportive care needs survey (SCNS-SF34)[18] Disease and treatment details (self-reported and medical details)
Health and wellbeing	Quality of life in adult cancer survivors, (QLACS)[19] Personal wellbeing index-adult (PWI-A)[20] EQ-5D[21]
Pre-existing factors	Socio-demographic details – e.g. age, sex, work status Co-morbidities List of threatening experiences[22]
Personal factors	Illness perception questionnaire (revised), IPQ-R[23] Self-efficacy for managing chronic disease, SEMCD[24] Cancer survivor self-efficacy scale, CS-SES[25] PANAS scale, PANAS[26] State trait anxiety index, STAI[27] Centre for epidemiological studies depression, CES-D[28]
Environmental factors	Medical outcomes study social support survey, MOS-SSS[29]
Coping and self-management	Brief cope inventory, COPE[30]

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