MSRG

UNIVERSITY OF Southampton

The MSRG programme and Wessex Cancer Alliance: working in partnership

Prof Claire Foster

Professor of Psychosocial Oncology
Director of the MSRG

Macmillan Survivorship Research Group

Funded by MACMILLAN CANCER SUPPORT

MSRG Programme

ENABLE
UNDERSTANDING THE IMPORTANCE OF SELF-MANAGEMENT SUPPORT IN PEOPLE LIVING WITH CANCER

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

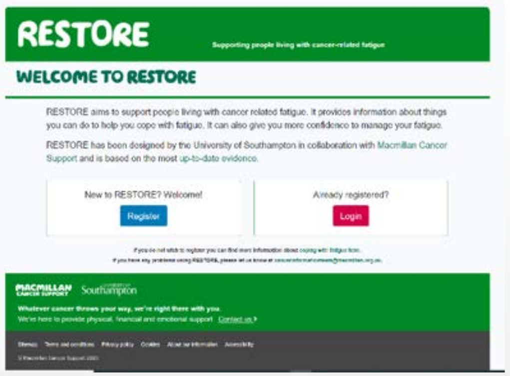
HORIZONS
Understanding the impact of cancer diagnosis and treatment on everyday life

WE ARE MACMILLAN.
CANCER SUPPORT

Full report
A Macmillan Cancer Support repo

The research priorities of people affected by cancer

Macmillan Listening Study
Macmillan Research Unit
University of Southampton



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

Research Programme Focus

1. Understanding impact of cancer and treatment on everyday lives
2. Co-creating and testing self-management support to manage the impact of cancer/treatment

Underpinned by user involvement and representation from those typically underrepresented in research

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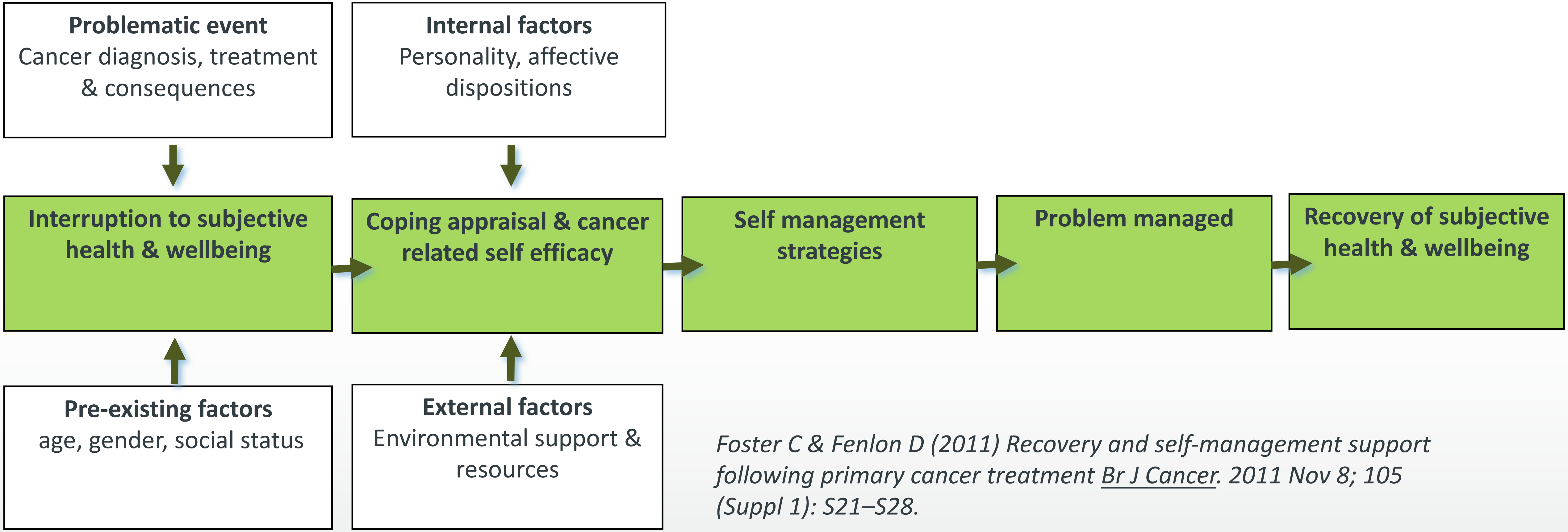
Theoretical framework



Problematic event
Cancer diagnosis, treatment & consequences

Internal factors
Personality, affective dispositions

Interruption to subjective health & wellbeing

Coping appraisal & cancer related self efficacy

Self management strategies

Problem managed

Recovery of subjective health & wellbeing

Pre-existing factors
age, gender, social status

External factors
Environmental support & resources

Foster C & Fenlon D (2011) Recovery and self-management support following primary cancer treatment Br J Cancer. 2011 Nov 8; 105 (Suppl 1): S21–S28.

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Working together

Impact of COVID-19 sub-study

Research Question: What is the impact of the COVID-19 pandemic on patients and carers living with cancer that is treatable but not curable?

Method: Phone interviews (March-May 2020) using a topic guide, with an opportunistic sub-sample, recorded and transcribed

Participants: 12 Patients (10 male) diagnosed with myeloma, prostate cancer and ovarian cancer, all advised to shield. 9 carers (8 female), Patients and carers aged 40-78

https://www.southampton.ac.uk/msrg/ourresearch/macmillan-supported-self-management-study.page

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'It feels it's wasting whatever time I've got left': Living with treatable but not curable cancer during the COVID-19 pandemic

ENABLE
UNDERSTANDING THE IMPORTANCE OF SELF-MANAGEMENT SUPPORT IN PEOPLE LIVING WITH CANCER

NHS The Christie NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust NHS
UNIVERSITY OF PLYMOUTH
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www.southampton.ac.uk/msrg

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@HORIZONS_MSRG

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

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

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Identifying patient needs at diagnosis which impact long term health and well-being: findings from CREW and HORIZONS

Dr Lynn Calman

Associate Professor, Deputy Director of the MSRG

Macmillan Survivorship Research Group

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

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ColoREctal Wellbeing (CREW) Study Objectives

Prof Claire Foster (CI)

1. Plot natural history of recovery of health & well-being
2. Investigate whether/how health needs change over time
3. Explore what influences recovery of health & well-being & determine who is most at risk of poor/protracted recovery

https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page


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Personalising care for people with bowel cancer

Key findings from the Colorectal Wellbeing (CREW) study

Macmillan Survivorship Research Group

CREW

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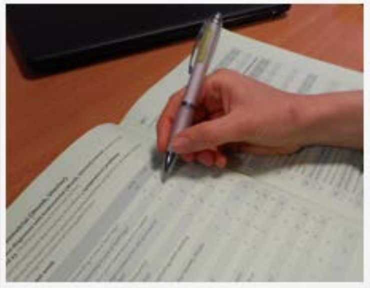
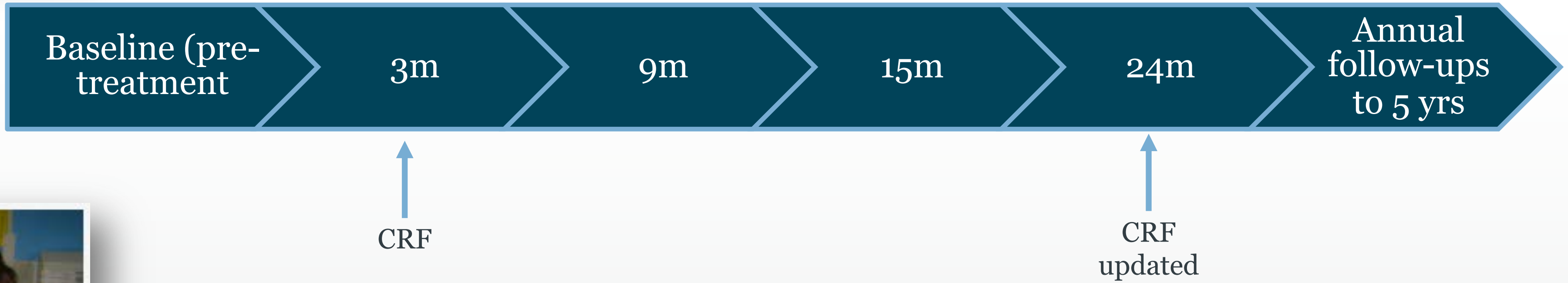
Data collection



Questionnaires: validated Patient Reported Outcome Measures (PROMs), sociodemographic and socioeconomic questions, and open-ended questions



Baseline (pre-treatment → 3m → 9m → 15m → 24m → Annual follow-ups to 5 yrs

3m: CRF

24m: CRF updated

Case Report Forms (CRFs): clinical information from medical records including diagnosis, treatment, recurrence

Fenlon et al. (2012). *BMC Health Serv Res*, **12**: 90

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Study design and sample

Prospective, longitudinal cohort study of 1,000 CRC patients

29 hospitals across England, Wales, Scotland

Questionnaire response rate 71-88%

Mean age 67 yrs (range 32-95). 57% male

Awaiting primary curative intent surgery (Dukes' stage A-C)

Recruitment Nov 2010-March 2012

Minimum dataset on 91% of all eligible people

65% colon; 35% rectal. 36% had a stoma (most temporary)

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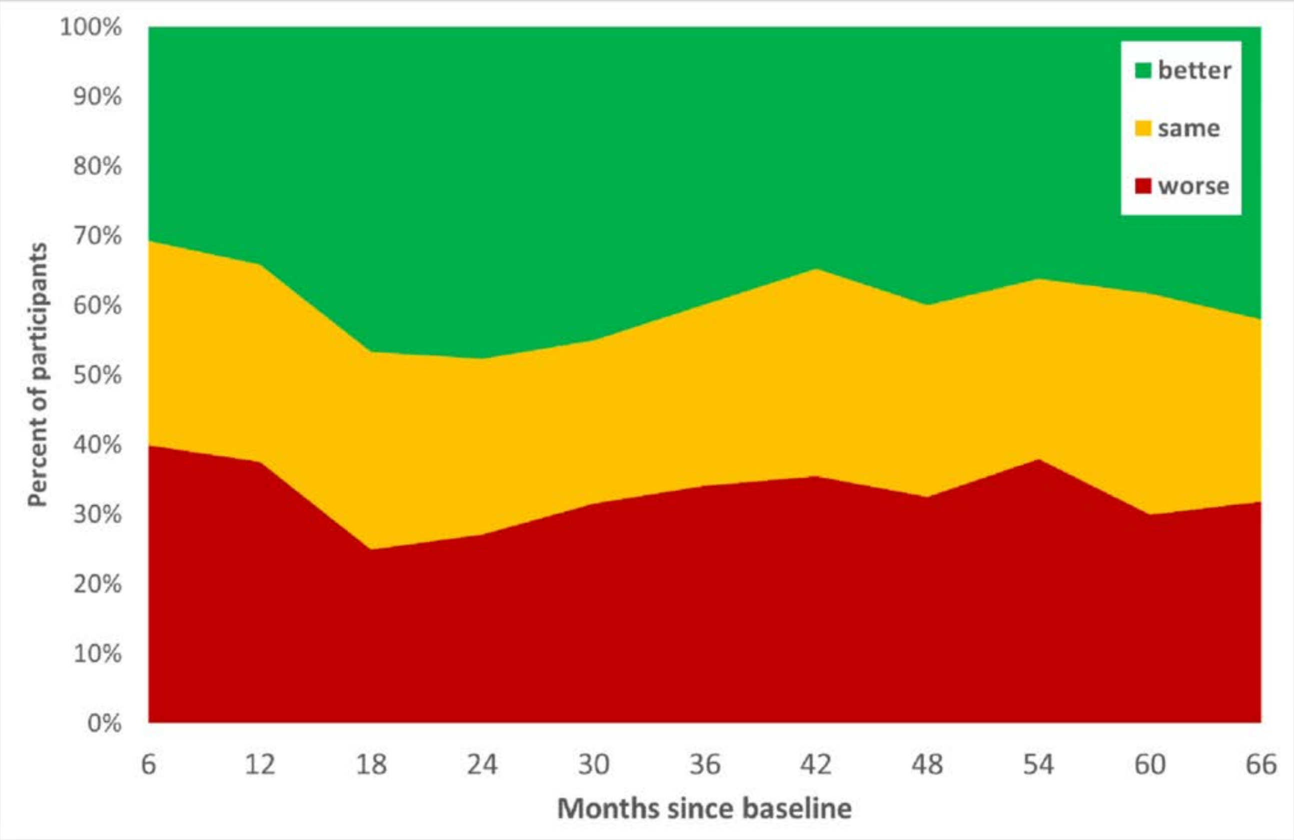
Recovery of health and wellbeing

- Around 70% recover well. Around 30% do less well, and this is still the case 5 years after surgery
- **Psychosocial factors** as important as stage at diagnosis for long-term recovery of health and wellbeing
- **Depression** and **low self-efficacy** (confidence to self-manage) **at diagnosis** were the most consistent predictors of poor health & wellbeing outcomes



Changes in quality of life (QLACS-GSS) compared to baseline

Wheelwright et al. (2020). *Plos One*, **15** (4)

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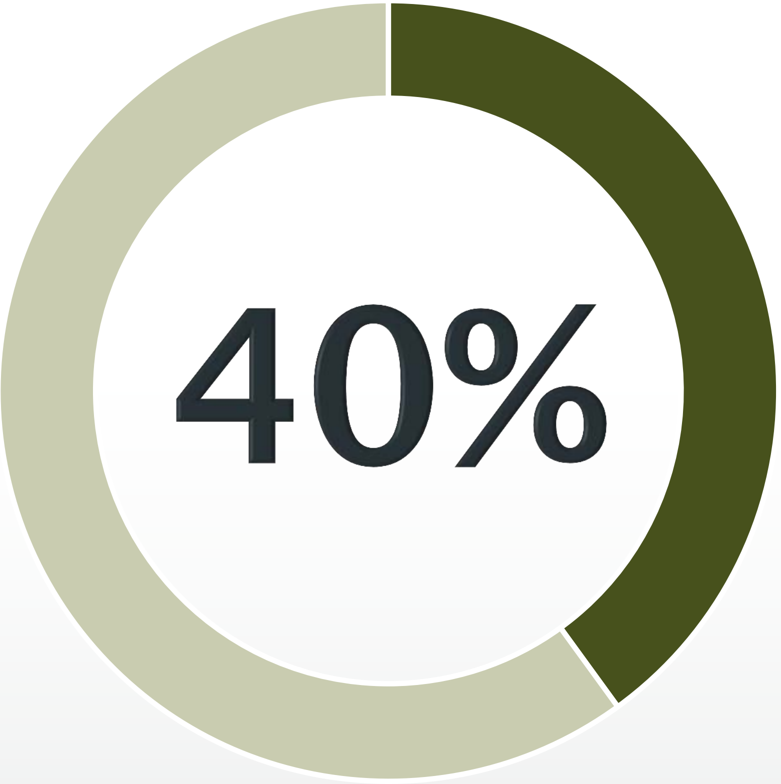
Self-efficacy



Percent with low self-efficacy

‘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

Grimmett et al. (2017). *Journal of Cancer Survivorship*, **11** **(5)**: 634-642.

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www.macmillanrestore.org.uk

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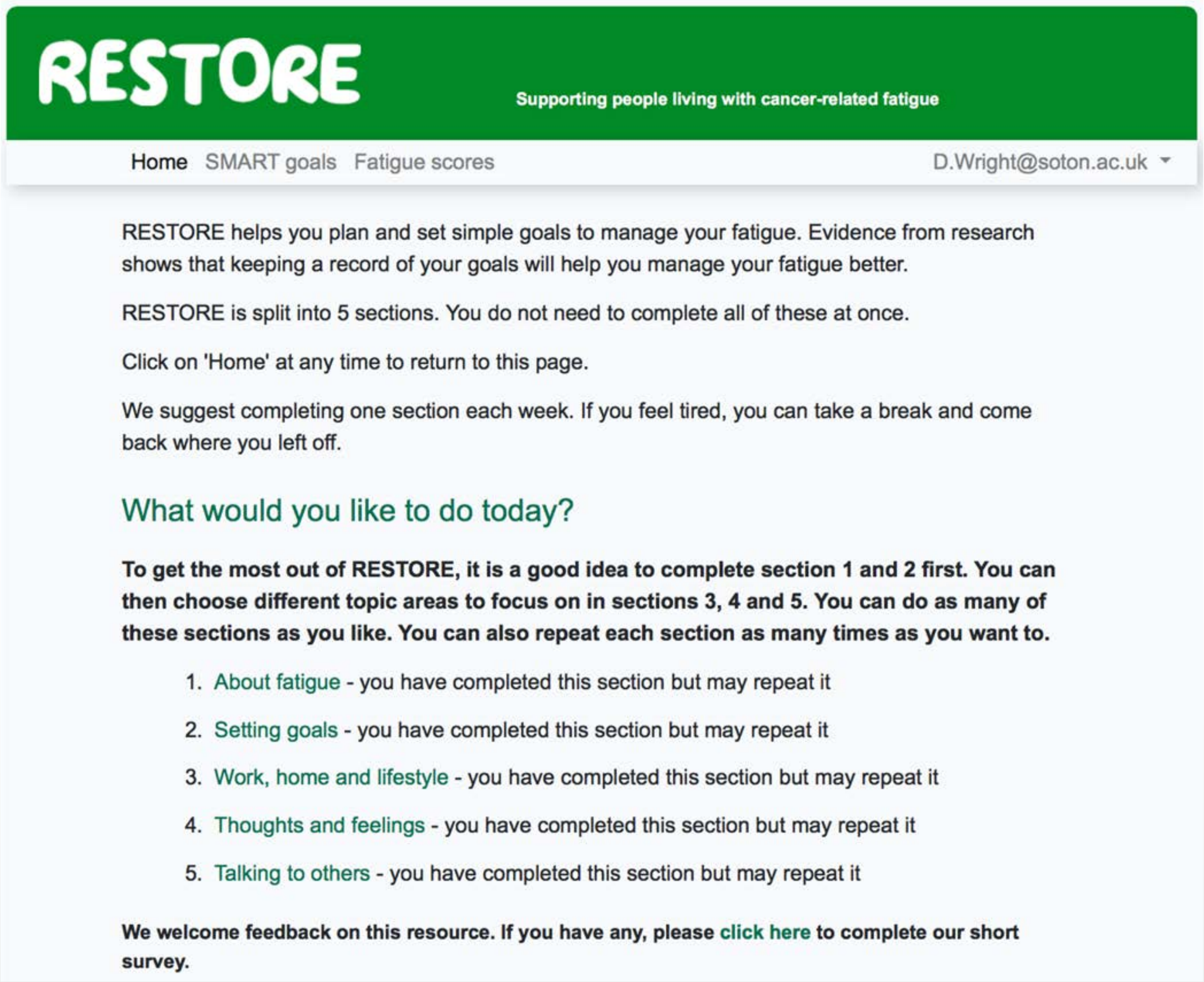

RESTORE helps you plan and set simple goals to manage your fatigue. Evidence from research shows that keeping a record of your goals will help you manage your fatigue better.

RESTORE is split into 5 sections. You do not need to complete all of these at once.

Click on 'Home' at any time to return to this page.

We suggest completing one section each week. If you feel tired, you can take a break and come back where you left off.

What would you like to do today?

To get the most out of RESTORE, it is a good idea to complete section 1 and 2 first. You can then choose different topic areas to focus on in sections 3, 4 and 5. You can do as many of these sections as you like. You can also repeat each section as many times as you want to.

1. About fatigue - you have completed this section but may repeat it
2. Setting goals - you have completed this section but may repeat it
3. Work, home and lifestyle - you have completed this section but may repeat it
4. Thoughts and feelings - you have completed this section but may repeat it
5. Talking to others - you have completed this section but may repeat it

We welcome feedback on this resource. If you have any, please click here to complete our short survey.

Macmillan Survivorship Research Group

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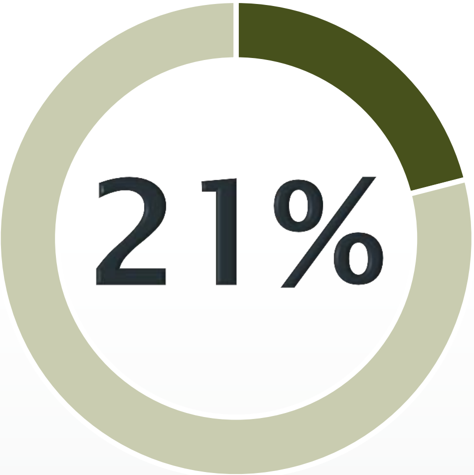
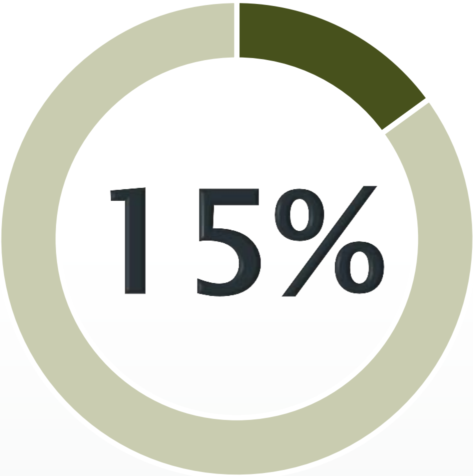
Depression

Percent scoring above cut-off for clinically significant levels of depression on the CES-D

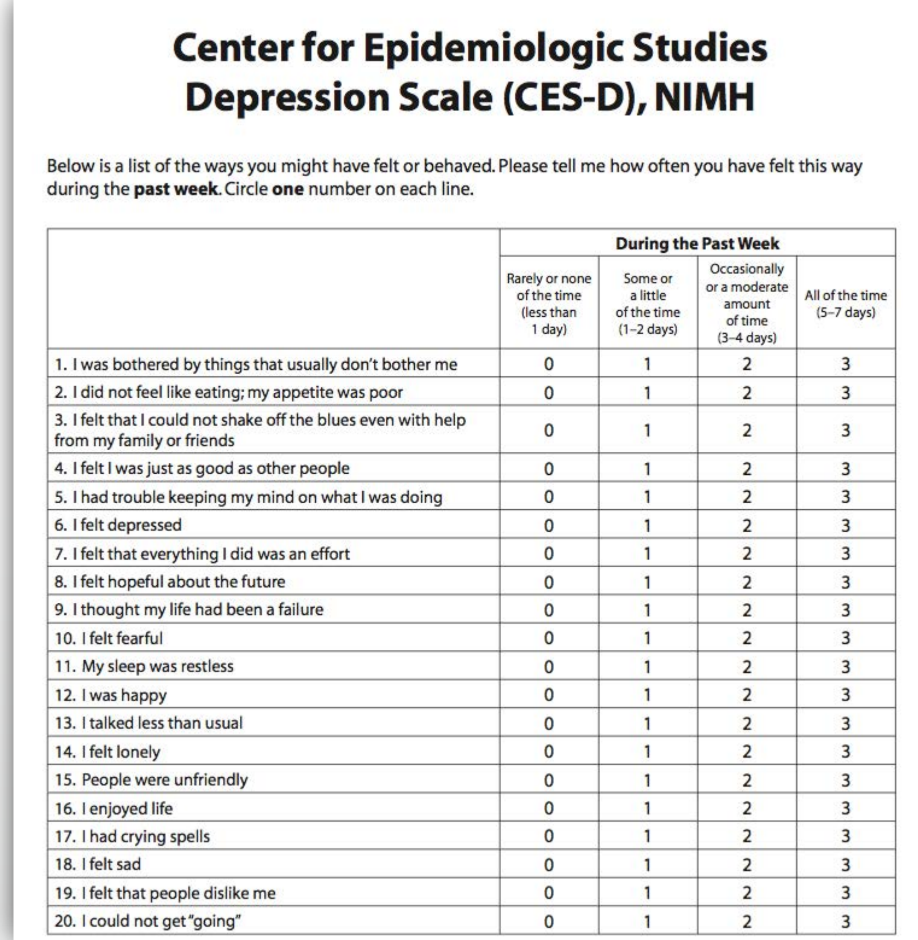


At diagnosis



At 5 years

Compared with 3% in general population (best estimate)



Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the **past week**. Circle **one** number on each line.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1–2 days)	Occasionally or a moderate amount of time (3–4 days)	All of the time (5–7 days)
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating; my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends	0	1	2	3
4. I felt I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3
13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3
18. I felt sad	0	1	2	3
19. I felt that people dislike me	0	1	2	3
20. I could not get "going"	0	1	2	3

Calman et al. Manuscript in preparation

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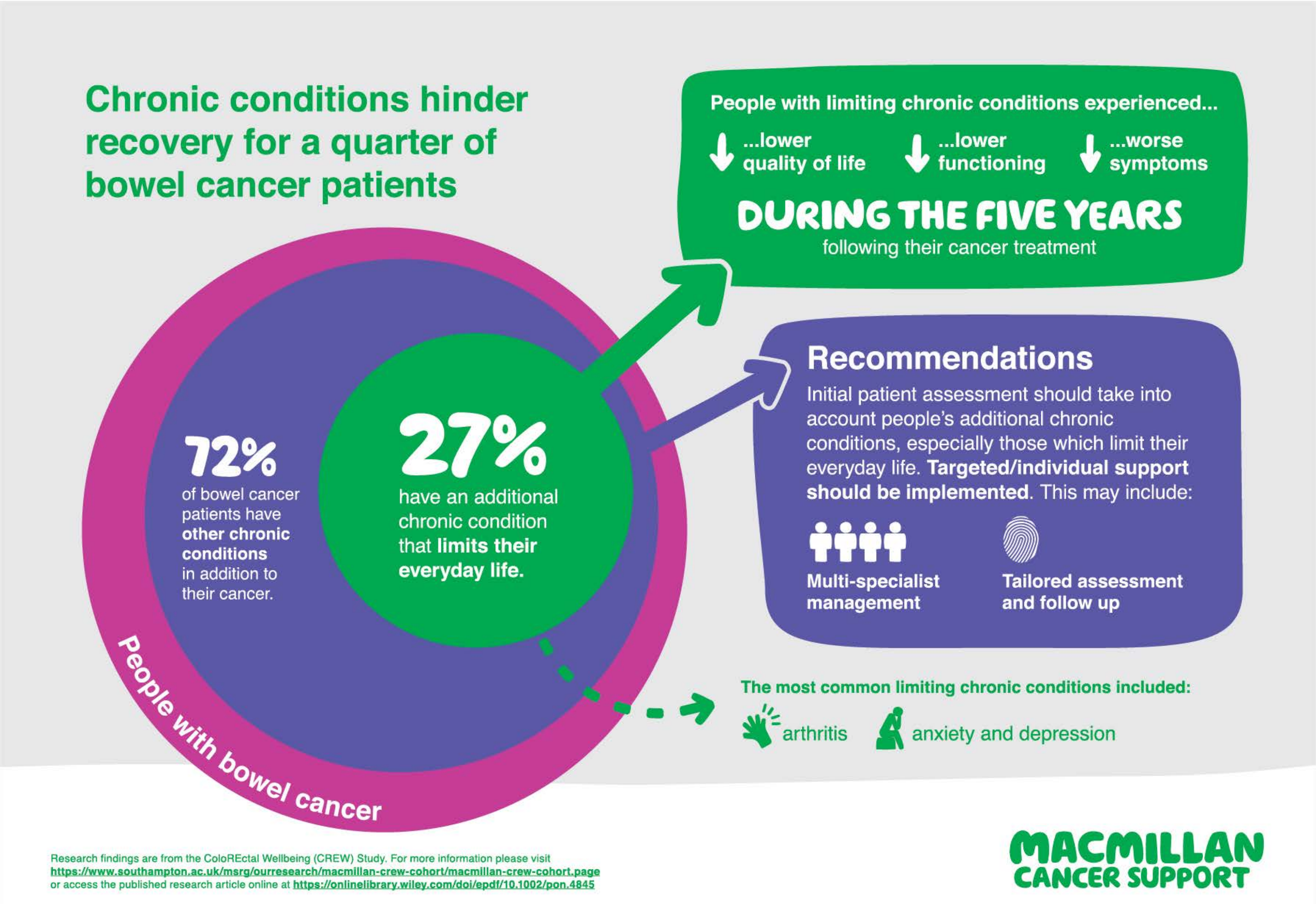

Chronic conditions hinder recovery for a quarter of bowel cancer patients

72% of bowel cancer patients have **other chronic conditions** in addition to their cancer.

27% have an additional chronic condition that **limits their everyday life.**

People with bowel cancer

People with limiting chronic conditions experienced...

- ...lower quality of life
- ...lower functioning
- ...worse symptoms

DURING THE FIVE YEARS
following their cancer treatment

Recommendations

Initial patient assessment should take into account people's additional chronic conditions, especially those which limit their everyday life. **Targeted/individual support should be implemented**. This may include:

- **Multi-specialist management**
- **Tailored assessment and follow up**

The most common limiting chronic conditions included:

- arthritis
- anxiety and depression

Research findings are from the ColoREctal Wellbeing (CREW) Study. For more information please visit **https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page** or access the published research article online at **https://onlinelibrary.wiley.com/doi/epdf/10.1002/pon.4845**

Cummings et al. (2018). *Psycho-oncology*, **27** (10): 2427-2435

Co-morbidities

- 72% had a co-morbidity
- 27% had a co-morbidity which impaired everyday life & resulted in lower QOL
- Mental health co-morbidities had most negative impact.

Social support

Low & declining social support associated with poor mental health & low QOL

Perceived social support declined in 30% of participants

Haviland et al. (2017). *Psycho-oncology*, **26** (12): 2276-2284

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Unmet needs

25% of CREW participants reported at least one moderate/severe unmet need 15 months and 2 years after surgery

Unmet needs most commonly physical (e.g. pain) or psychological (e.g. anxiety)

Unmet needs associated with poorer QoL

Sodergren et al. (2019). *Journal of Cancer Survivorship*, available online

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Who is at risk of poor outcomes and is therefore most in need of support? People with…

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

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Conclusions and recommendations

1. People who are at risk of poor health and wellbeing outcomes can be identified pre-treatment
2. Psychosocial factors are as important as disease stage for personalised **care** and should inform stratified pathways of care
3. Holistic needs assessments (HNAs) should be carried out from diagnosis onwards & used to develop care plans which are regularly reviewed
4. HNAs should assess confidence to manage illness-related problems, include screening for depression and an assessment of whether comorbidities impact daily life
5. Continue to review needs over time & signpost to resources to support self-management

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Study Questions

CI: Prof Claire Foster

1. What impact does cancer and its treatment have on people diagnosed with cancer in the short, medium and long term?
2. What are the health outcomes, experiences and self-management activities over the life-course and what influences these?
3. How do people connect with and mobilise resources that help them self-manage consequences of cancer and its treatment?

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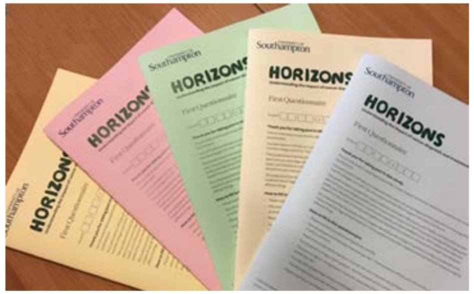
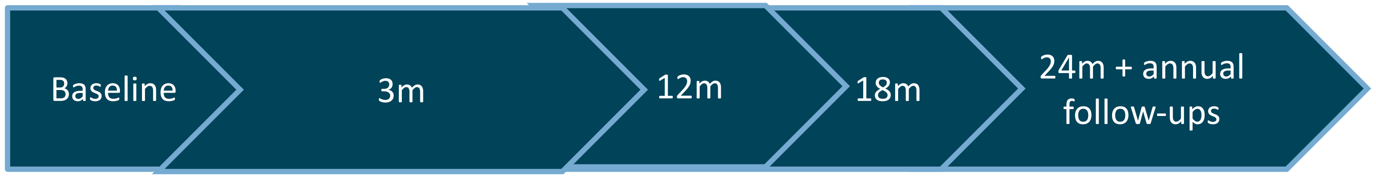
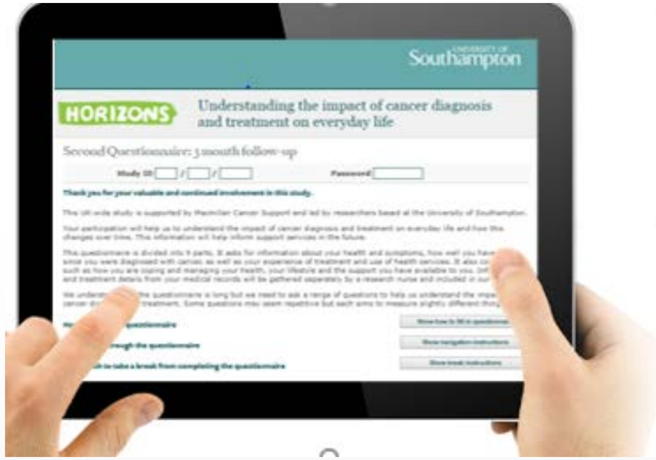
Data collection

- **Questionnaires:** validated Patient Reported Outcome Measures (PROMs), sociodemographic and socioeconomic questions, and open-ended questions





Baseline → 3m → 12m → 18m → 24m + annual follow-ups



Southampton

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

Second Questionnaire: 3 month follow-up

Study ID: ☐ / ☐ / ☐ Password: ☐

Thank you for your valuable and continued involvement in this study.

- **Case Report Forms (CRFs):** Clinical information from medical records including diagnosis, treatment, recurrence, co-morbidities, etc

Baseline → 6m → 12m → 24m + annual follow-ups

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HORIZONS Participants

3,442
people from
across the UK

1,434
Breast cancer patients
<50 years

719
Non-Hodgkin's
Lymphoma patients

1,289
Gynaecological
cancers patients

- Experiencing a variety of treatment and recovery pathways.
- Have various important, specific concerns e.g. future fertility, impact on work, body image.
- Giving a voice to people with less common cancers

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Emerging baseline findings

- HORIZONS cohorts report worse quality of life than CREW participants
- More HORIZONS participants report high levels of anxiety and/or depression (pre COVID-19)
- NHL and gynaecological cohorts are particularly vulnerable in terms of quality of life, anxiety and depression
- More HORIZONS participants report lower confidence to self-manage than CREW participants

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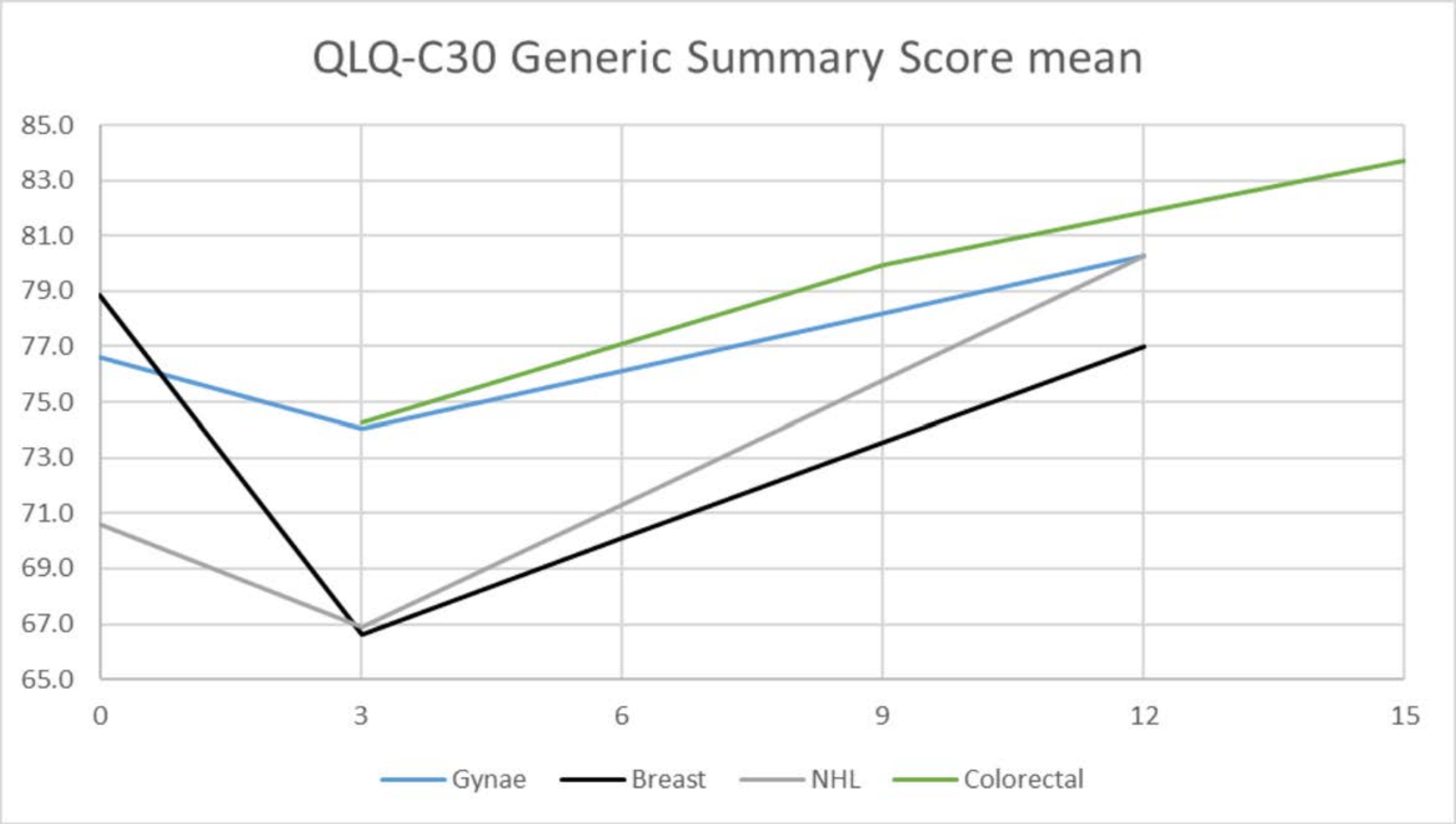
HORIZONS: mean summary scores for QLQ-C30 over time



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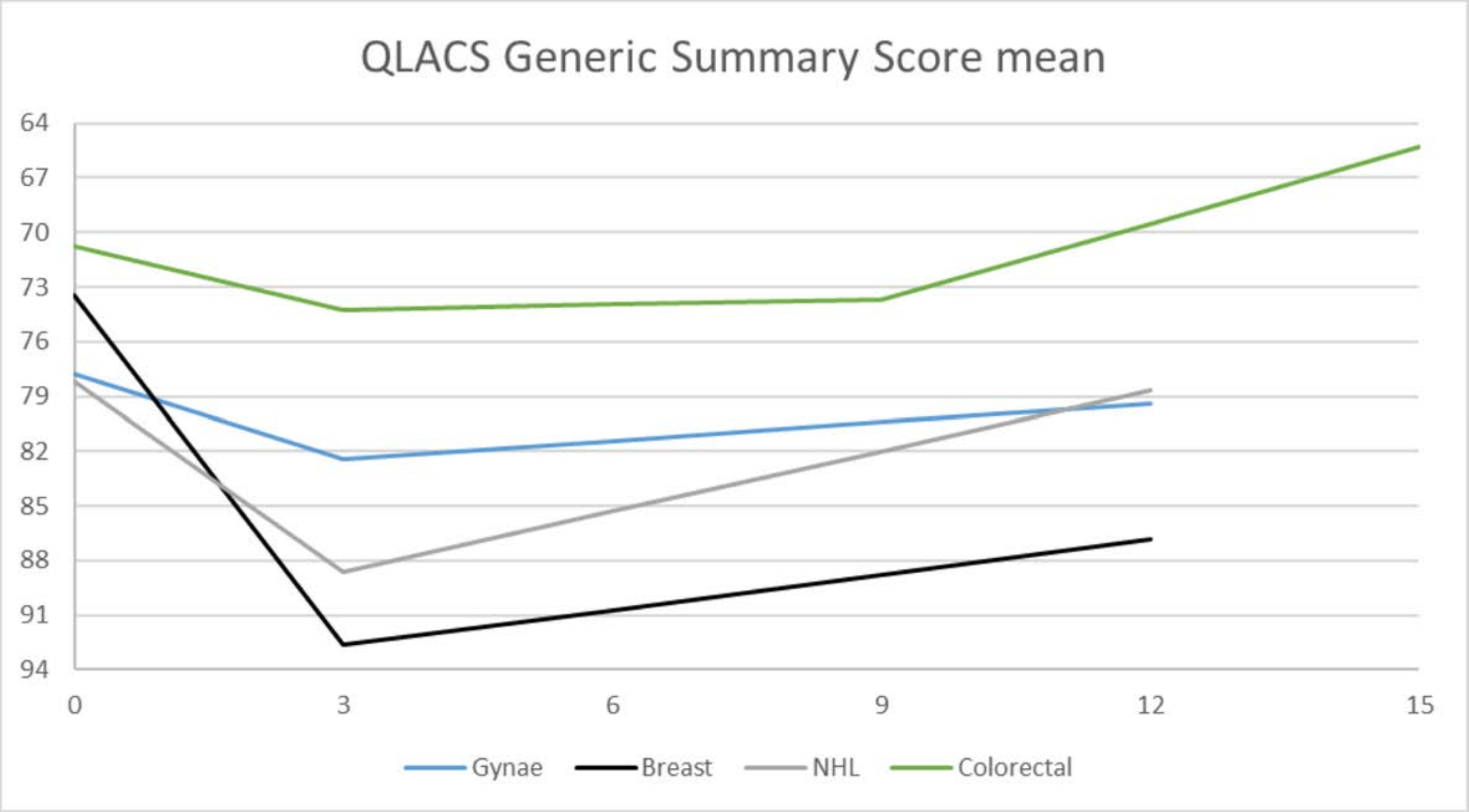
HORIZONS: mean summary scores for QLACS over time



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Data Access

We welcome requests for access to the CREW database from researchers and others. For details, see **www.horizons-hub.org.uk/access_data.html**

Acknowledgements

With thanks to the participants, participating sites, members of our Strategic Advisory Groups, Research Partners, colleagues at the Macmillan Survivorship Research Group and our funder, Macmillan Cancer Support

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🌐 www.southampton.ac.uk/msrg

🌐 www.HORIZONS-Hub.org.uk

@MacmillanUoS
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Delivering integrated personalised care and workforce development: key findings from WCA evaluations

Dr David Wright

Senior Research Fellow

Macmillan Survivorship Research Group

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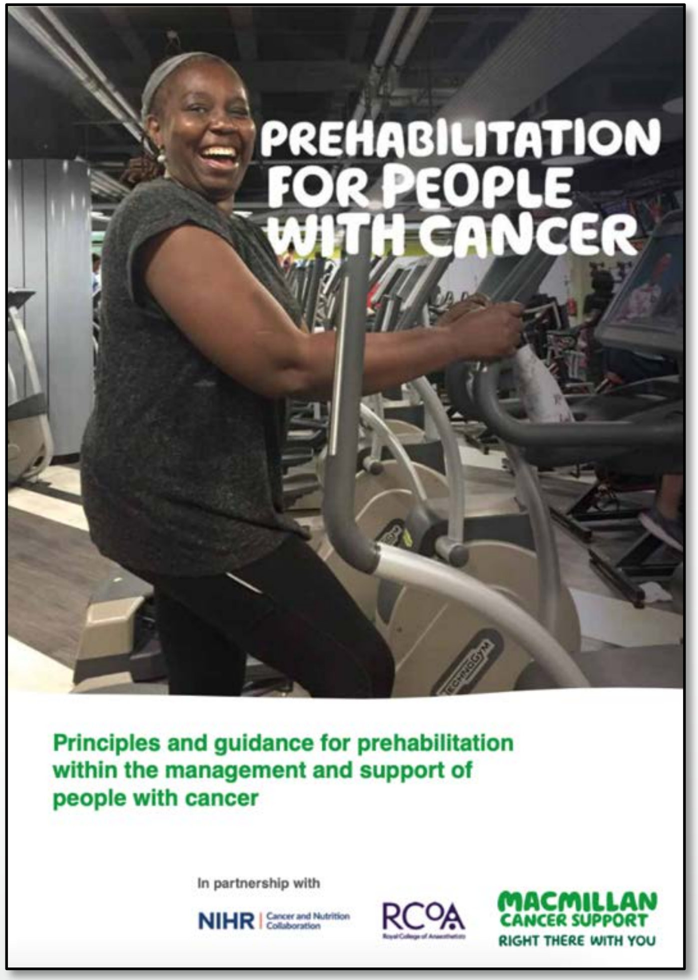
Uptake of MSRG findings



PREHABILITATION FOR PEOPLE WITH CANCER

Principles and guidance for prehabilitation within the management and support of people with cancer

In partnership with

NIHR | Cancer and Nutrition Collaboration

RCoA

MACMILLAN CANCER SUPPORT
RIGHT THERE WITH YOU

Cancer Care Ontario

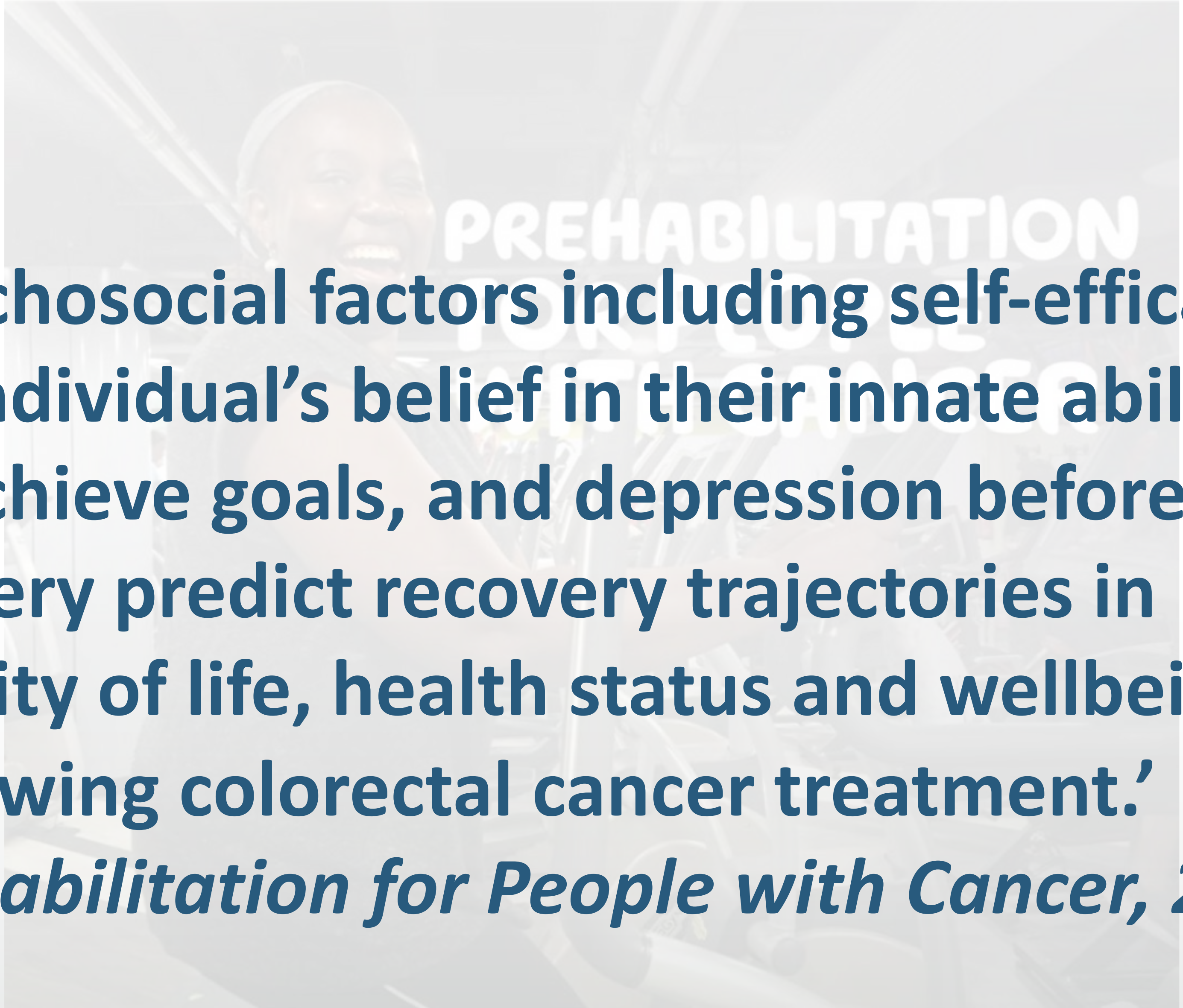
November 2018

Self-Management in Cancer | Quality Standards

PATIENT EDUCATION PROGRAM, CANCER CARE ONTARIO

For information or questions about this report, please contact the Patient Education Program at: patienteducation@cancercare.on.ca

Ontario
Cancer Care Ontario



> **‘Psychosocial factors including self-efficacy, an individual’s belief in their innate ability to achieve goals, and depression before surgery predict recovery trajectories in quality of life, health status and wellbeing following colorectal cancer treatment.’**
>
> ***Prehabilitation for People with Cancer, 2019***

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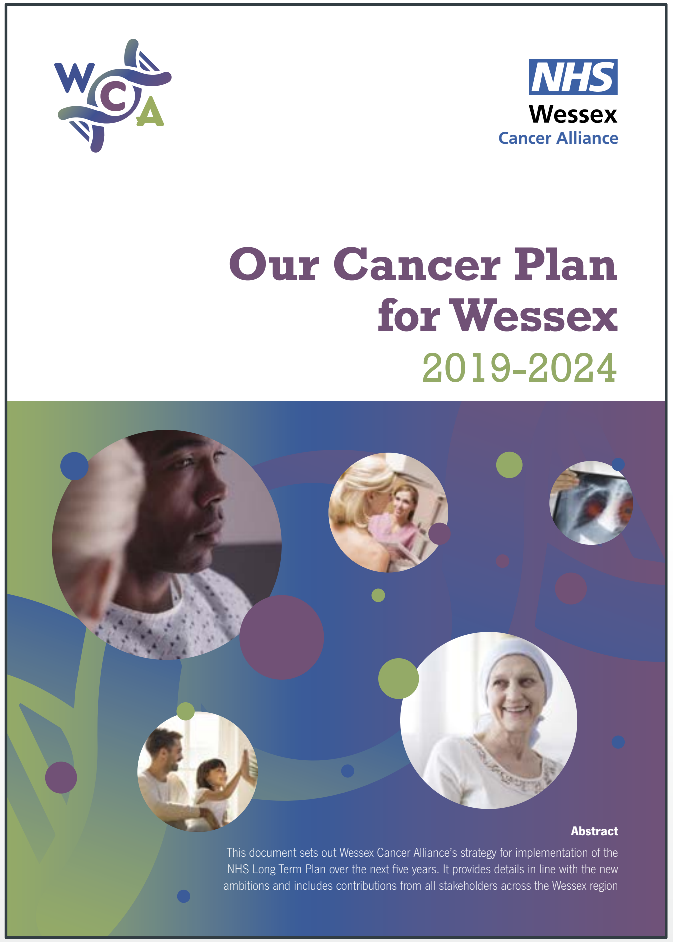
Wessex Cancer Alliance

Committed to:

- personalised treatment and care
- effective health service
- developing workforce
- a firm evidence-base to service innovation



NHS
Wessex
Cancer Alliance

Our Cancer Plan
for Wessex
2019-2024

Abstract

This document sets out Wessex Cancer Alliance's strategy for implementation of the NHS Long Term Plan over the next five years. It provides details in line with the new ambitions and includes contributions from all stakeholders across the Wessex region

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Evaluation Programme

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Improving Access to CNSs + Key Workers

Cancer Nursing Across Boundaries

Patient Activation Measure

Right by You Wessex

Patient Activation Measure II

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Improving Access to CNSs and Key Workers

Context

- National shortage of CNSs
- Greater complexity of CNS role, high demand on time
- New service models recommended

Intervention

- Incorporating CSWs into specialist nursing teams.
- 2 Band 4 CSWs introduced to GI cancer nursing team at University Hospital Southampton

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Improving Access to CNSs and Key Workers

Findings

- Introducing CSWs resulted in a positive impact on access to
  - assessment and care planning
  - community support services
  - practical and financial support
  - health and wellbeing advice and support
- Following the introduction of CSW, patients more likely to report
  - being given contact details of a key worker
  - the wider healthcare team worked well together

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Improving Access to CNSs and Key Workers

However

- Introducing roles is a carefully managed process, requiring support to nursing teams to establish clear roles and responsibilities
- CSW roles cannot fully mitigate the impact of CNS vacancies, due to the differing nature of roles

Impact

- Led directly to the creation of 11 permanent CSW posts at UHS

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Cancer Nursing Across Boundaries

Project aim

- To deliver personalised care for people living with and beyond cancer through effective, integrated primary and secondary care

Intervention

- Boundary spanning postholder:
  - 0.8 FTE to work with 11 general practices
  - Training and development
  - Specialist advice and support
  - Liaison between primary and acute care

NHS
Health Education England

WCA

UNIVERSITY OF Southampton

Service delivery model

Primary Care Engagement

Suite of Options

Training Needs Analysis

ID learning needs practice nurses/Cancer CNS

Single point of contact for cancer queries

Building relationships Acute/Primary care

PDSA cycles areas of improvement pathways

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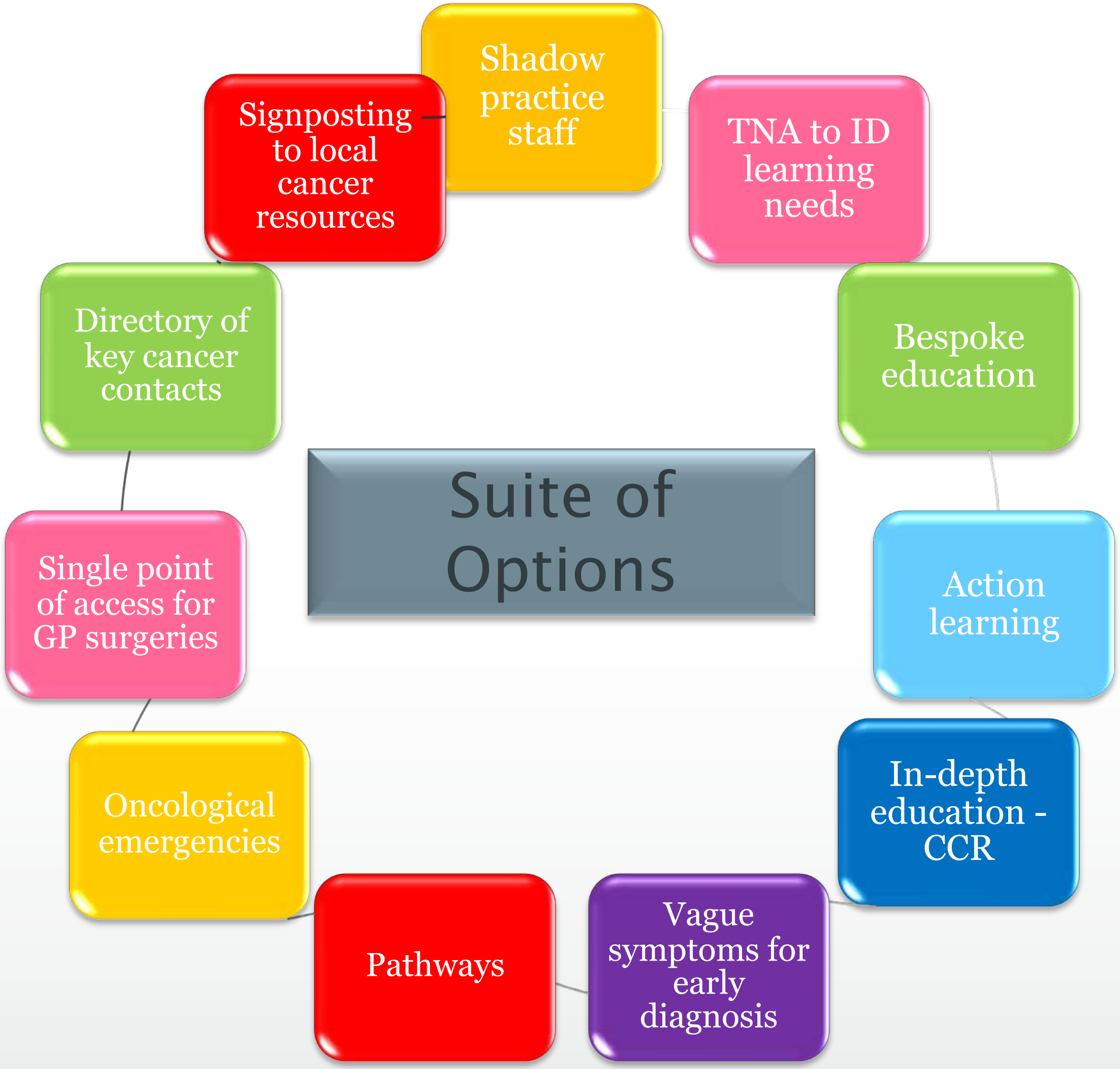

Suite of Options

- Shadow practice staff
- TNA to ID learning needs
- Bespoke education
- Action learning
- In-depth education - CCR
- Vague symptoms for early diagnosis
- Pathways
- Oncological emergencies
- Single point of access for GP surgeries
- Directory of key cancer contacts
- Signposting to local cancer resources

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Emerging Findings

Example of integrated care

- Practice nurse contacted CNS, concerned about a newly diagnosed patient. CNS facilitated financial support and counselling at Macmillan Centre

Results through relationships

- *'My role built relationships with practice nurses. I made secondary cancer care accessible to them. They taught me about what practice nurses do and long term condition management… In exchange, I talked about cancer care in a non-threatening way… It was a real exchange of knowledge about each other's roles with the patient at the centre.'*

Funded by MACMILLAN CANCER SUPPORT

Post COVID 3 month project pause

Online learning scoping

- Reviewing online & e-learning modules/courses related to project
- Grouping in accredited & CPD certified platforms
- Reviewing course content and applicability for primary care TNAs
- Reviewing own module resources and launching online e-learning

Creating e-learning content

- Agree content with stakeholders
- Develop course content
- Plan delivery and administration

Provide e-learning content

- Free hour long webinars delivered by Teams to ALL staff
- Slides and recordings circulated
- Document of attendance

Right by You Wessex

Intervention aim:

- to develop an integrated personalised care model that maximises patient outcomes, experience, health and wellbeing
- boundary spanning CNSs and CSWs core to the model

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Intervention

- A supported conversation to be held as close to the point of diagnosis as possible in the secondary, primary or community setting, and then as often as required, using Chat & Plan.
- A holistic needs assessment to be completed if appropriate
- Development of a personalised care plan, co-created with the individual
- Navigation to the right support for the individual, helping people access the services and support they need
- Sharing appropriate information with the person living with cancer

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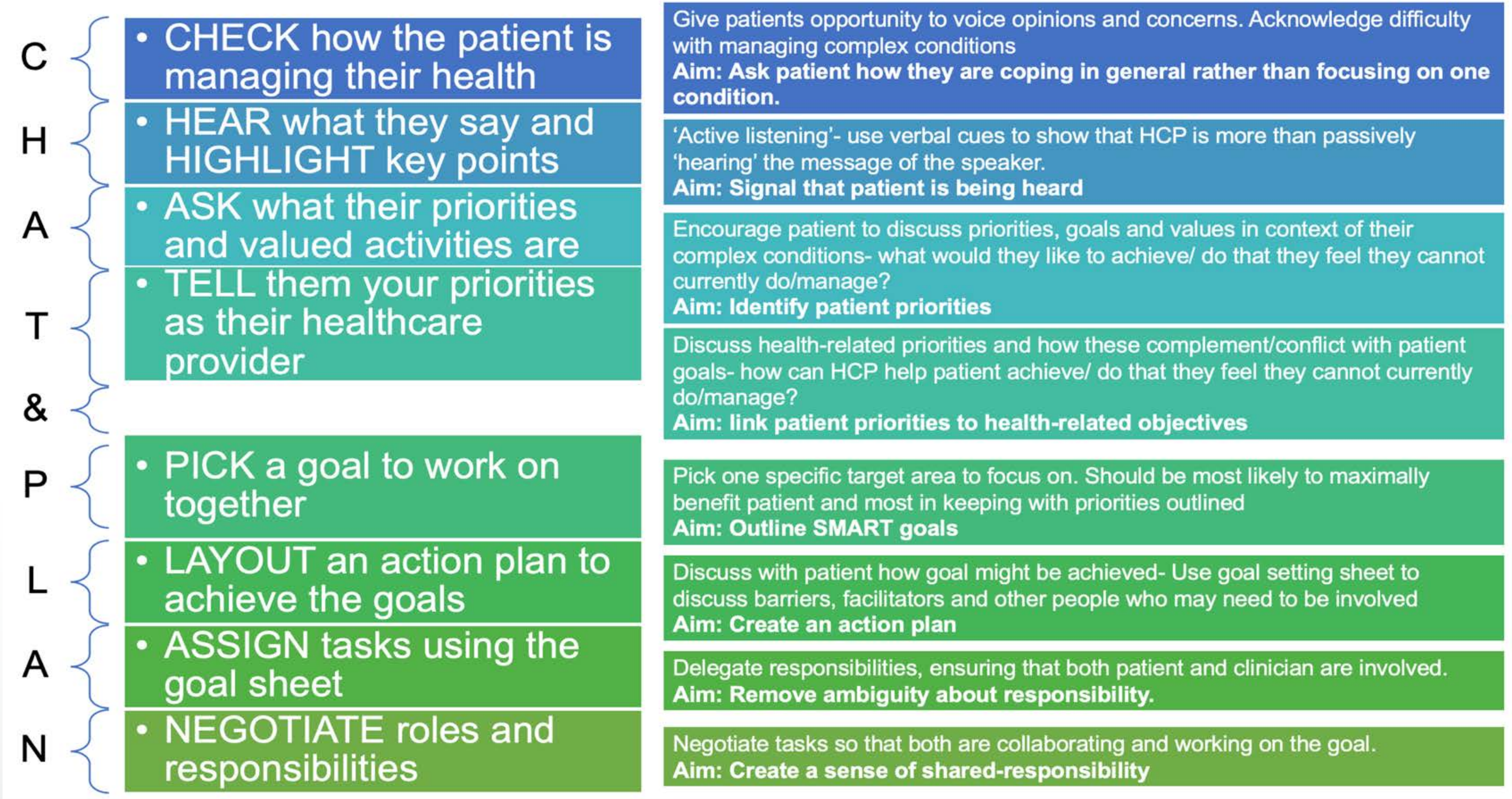

C	CHECK how the patient is managing their health	Give patients opportunity to voice opinions and concerns. Acknowledge difficulty with managing complex conditions **Aim: Ask patient how they are coping in general rather than focusing on one condition.**
H	HEAR what they say and HIGHLIGHT key points	'Active listening'- use verbal cues to show that HCP is more than passively 'hearing' the message of the speaker. **Aim: Signal that patient is being heard**
A	ASK what their priorities and valued activities are	Encourage patient to discuss priorities, goals and values in context of their complex conditions- what would they like to achieve/ do that they feel they cannot currently do/manage? **Aim: Identify patient priorities**
T	TELL them your priorities as their healthcare provider	Discuss health-related priorities and how these complement/conflict with patient goals- how can HCP help patient achieve/ do that they feel they cannot currently do/manage? **Aim: link patient priorities to health-related objectives**
&		
P	PICK a goal to work on together	Pick one specific target area to focus on. Should be most likely to maximally benefit patient and most in keeping with priorities outlined **Aim: Outline SMART goals**
L	LAYOUT an action plan to achieve the goals	Discuss with patient how goal might be achieved- Use goal setting sheet to discuss barriers, facilitators and other people who may need to be involved **Aim: Create an action plan**
A	ASSIGN tasks using the goal sheet	Delegate responsibilities, ensuring that both patient and clinician are involved. **Aim: Remove ambiguity about responsibility.**
N	NEGOTIATE roles and responsibilities	Negotiate tasks so that both are collaborating and working on the goal. **Aim: Create a sense of shared-responsibility**

Corbett TK, Cummings A, Lee K, et al. Planning and optimising CHAT&PLAN: A conversation-based intervention to promote person-centred care for older people living with multimorbidity. PLoS One. 2020 Oct 16;15(10):e0240516.

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Right by You Wessex Evaluation aims

- What is the impact of RbY Wessex on patient experience and outcomes?
- How is RbY Wessex's approach to integrated, personalised care designed and delivered?
- Does RbY Wessex deliver effective integrated working between primary, secondary and community care?
- What is the impact of RbY Wessex on health professional experience and outcomes?
- What is the impact of RbY Wessex on health service delivery?

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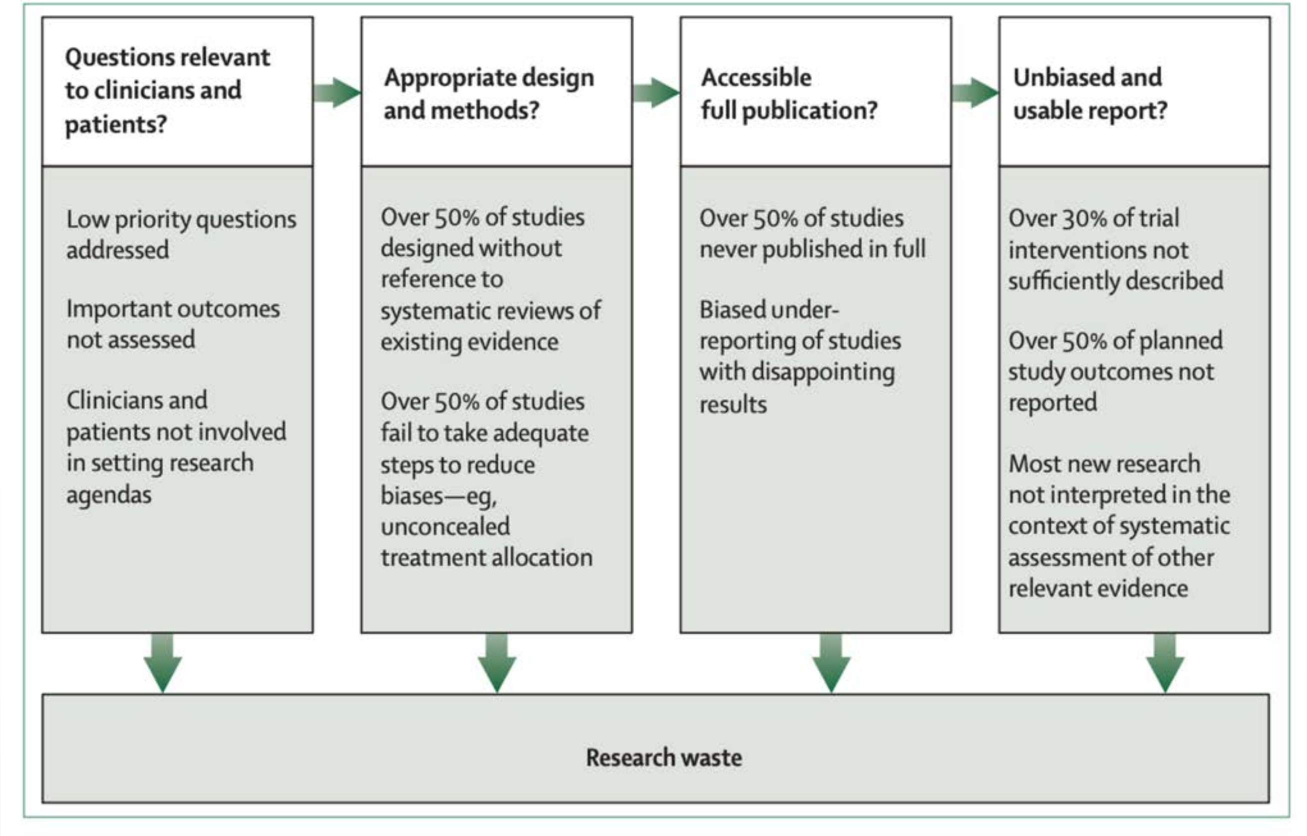
Avoiding research waste



Questions relevant to clinicians and patients?

Low priority questions addressed

Important outcomes not assessed

Clinicians and patients not involved in setting research agendas

Appropriate design and methods?

Over 50% of studies designed without reference to systematic reviews of existing evidence

Over 50% of studies fail to take adequate steps to reduce biases—eg, unconcealed treatment allocation

Accessible full publication?

Over 50% of studies never published in full

Biased under-reporting of studies with disappointing results

Unbiased and usable report?

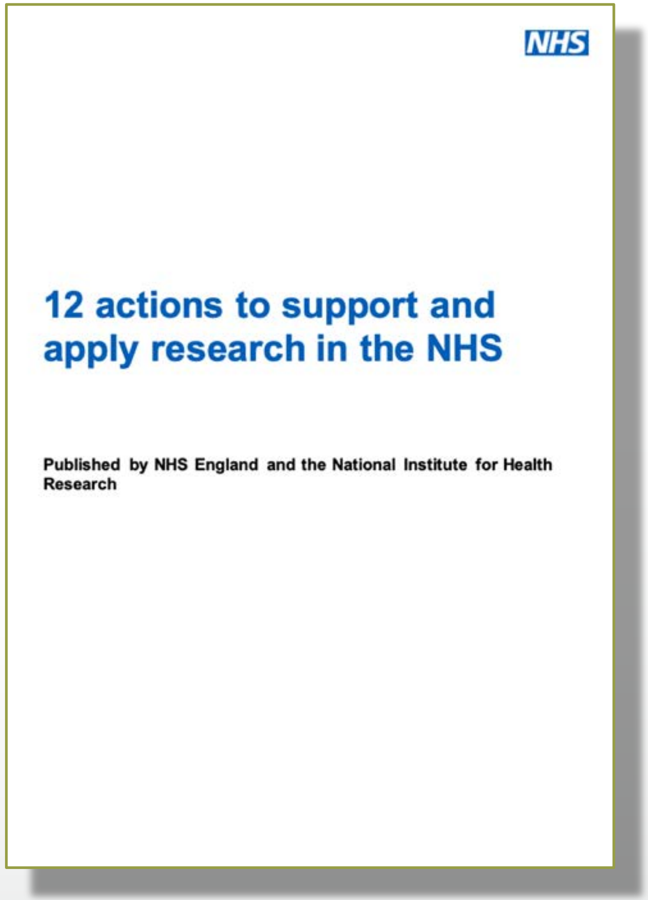
Over 30% of trial interventions not sufficiently described

Over 50% of planned study outcomes not reported

Most new research not interpreted in the context of systematic assessment of other relevant evidence

Research waste

Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet. 2009 Jul 4;374(9683):86-9.



NHS

12 actions to support and apply research in the NHS

Published by NHS England and the National Institute for Health Research

In Conclusion

- Partnership working yield many benefits, including:
  - Minimising research waste
  - Commissioning for impact
  - Timely uptake of findings to inform policy and practice, to the benefit of people living with cancer
  - Rigorous evidence-base to inform development, design and delivery of innovative services
  - Workforce development underpinned by rigorous, current evidence
  - Facilitating replicability of innovation

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