Macmillan HORIZONS Programme:
Establishing a UK-wide prospective cohort to understand the impact of cancer and its treatment on everyday lives

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Macmillan Survivorship Research Group
Living with and beyond cancer: A changing landscape

- Experiences and outcomes of cancer treatment and care are changing.
- More people experience cancer as life-changing and as a long-term condition.
- Understanding survivorship is important to inform design & delivery of cost effective interventions.
#1 priority: impact of cancer on everyday life

What are the impacts of cancer and its treatment?

How can the impact be managed?

Corner et al. (2007). *British Journal of Cancer, 96*: 875-881
Macmillan Survivorship Research Group

HORIZONS

RESTORE

CREW

Listening Study

2019

2002

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Data collection (N=1,017)

29 centres across England, Scotland & Wales

Eligibility criteria:
- Diagnosis of CRC (Duke’s A-C)
- Awaiting primary curative intent surgery
- >18 years
- Ability to complete questionnaires

Medical Details

Update

Surgery
Theoretical framework

Problematic event
Cancer diagnosis, treatment & consequences

Interruption to subjective health & wellbeing

Internal factors
Personality, affective dispositions

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

Some learning from CREW

• Resource intense – funding, people, space
• Stakeholder engagement - design, delivery, dissemination, impact
• NCRI adoption – research nurse support, devolved nations
• Site engagement – responsive, informative
• In house trial administration support
• Real time data entry and checks
• Reporting and pathways to impact

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Understanding the impact of cancer diagnosis and treatment on everyday life

• What **impact** does cancer & its treatment have on people diagnosed with cancer in the short, medium & long term?

• What are **health outcomes, experiences & self-management activities** over the life-course across different cancer types & what influences these?

• How do people **connect with & mobilise resources** which enable them to self-manage consequences of cancer & its treatment?

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Study Design

• Three cohorts

• Patients awaiting curative intent treatment

• Longitudinal study

• Recruitment at NHS treatment centres

• All eligible patients to be approached
Our three initial cohorts

Breast cancer
Women aged <50 years old

non-Hodgkin lymphoma (NHL)
Diffuse large B cell NHL

Gynaecological cancers
Ovarian cancer
Endometrial cancer
Cervical cancer
Vulval cancer

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HORIZONS sites

- 78 sites recruited patients
- Sites located in all UK nations
- 110 hospitals

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Data collection

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

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

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Qualitative study

• Face-to-face interviews with a sub-sample of around 30 HORIZONS participants, 12 to 18 months out from treatment start

• Aims to explore how people connect with and use supportive services and resources to help their recovery following cancer treatment
Site engagement

- Site initiation meetings
- Best practice document
- Teleconferences
- Quarterly newsletters
- Dissemination events: Site Update Days, Webinars
Stakeholder engagement

Study advisors

• User Reference Group and research partners
• Clinical experts
• Programme Management Group
• Scientific Advisory Board

Pilot phase
Participant feedback
Site feedback

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Participant engagement
Recruitment update

5,451 patients approached

3,328
Consented participants

1,396 Breast cancer
700 NHL
1,232 Gynaecological cancers

815 Endometrial
166 Ovarian
212 Cervical
39 Vulval

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Ingredients for success in setting up and running a longitudinal cohort study...?

- Robust science
- **Sufficient funding** to support stakeholder engagement activities (design, delivery, dissemination, impact)
- **Expertise** and capacity of coordinating team – research, clinical, trial coordination, data management, statistics etc; support development
- **Meaningful engagement** with a range of stakeholders as early as possible and throughout (design, delivery, dissemination, impact)
- **Meaningful engagement** with staff at recruiting sites
  - Establish and maintain good communication links with each site
  - Provide opportunities for site staff to meet the Co-ordinating team and other site staff
  - Respond to feedback from site staff
- **Learn from** the experiences of others; **Regular review** of processes, procedures etc
- **Be flexible and open** to changing procedures, e.g. feedback from stakeholders
- **Engage with participants** to maintain interest and promote retention in the study wherever possible
- **Collaboration**
Please contact us for further information

Twitter

If you are active on Twitter, please follow us:

@HORIZONS_MSRG

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