

Macmillan HORIZONS Programme

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Background

Experiences and outcomes of cancer treatment and care are changing. A growing number of people are experiencing cancer not as a life-limiting disease, but as a life-changing and long-term condition. There is a growing imperative to understand the changing landscape of cancer and its consequences: as we do so, we will be better able to inform the design and delivery of cost effective interventions that make possible supported self-management, as well as service organization and delivery. The Macmillan HORIZONS Programme hosted by the University of Southampton will provide the robust and comprehensive data that the patient, clinical, and policy communities need to transform care for people living with and beyond cancer.

Aims and objectives

The aims of the HORIZONS Programme are to build a centre of excellence by:

- Establishing the Macmillan HORIZONS Programme of cohorts of cancer patients to capture their health outcomes and experiences from before they begin active treatment and regularly over their life-course
- Maintaining and developing the HORIZONS Programme as a national and international resource to explore consequences of different cancer diagnoses and treatments from the individual perspective across the life-course

The objectives are to:

- Establish a series of representative cohorts including thousands of adults diagnosed with a range of cancers across the UK before their treatment begins
- Map health outcomes, experiences and self-management over the life-course and what influences these
- Map the impact of cancer and its consequences on people diagnosed with cancer before and after treatment and over their lifetime
- Inform policy and practice based innovative solutions to minimise the health burden and maximise support available to them over their life-course
- Identify, systematically engage, and support, people affected by cancer and Macmillan as partners in our research

Programme Themes

Theme 1

Recovery from cancer treatment

- Determinants of recovery
- Detailed examination of elements of recovery following primary cancer treatment

Theme 2

Self-managing the consequences of cancer

- Determinants of self-management
- Detailed examination of self-management following primary cancer treatment

Initial cohorts

- Breast cancer patients diagnosed ≤ 50 years
- Non-Hodgkin's Lymphoma (NHL) patients (Follicular lymphoma & Diffuse large B cell lymphoma subtypes)
- Gynaecological cancer (e.g. ovarian, cervical & uterine)
- We will continue to follow-up colorectal cancer patients in CREW cohort



Cohort study methods

HORIZONS is a series of prospective cohort studies of adults treated for non-metastatic cancer. Patients will be recruited from NHS treatment centres across the UK. Questionnaires will be administered **before** treatment (baseline), and followed up at regular intervals.

Nested qualitative work will examine the themes in detail through a variety of methodologies, to explore the real life and everyday experiences of cancer survivors and their perspectives on the complex processes underlying recovery. For example, barriers to recovery, disruption of cancer and its consequences to people's lives and perceived burden of this.

Primary outcome measures

Recovery of health and well-being: The primary outcome measure of recovery of health and well-being will be the Quality of Life in Adult Cancer Survivors scale measuring various aspects of survivorship in generic and cancer specific domains.

Self-management: The primary outcome measure of self-management will be the Self-efficacy for managing chronic disease scale which assesses confidence to manage illness related problems.

Other validated measures (generic and tumour specific) used will be informed by the conceptual framework and some study specific questions will be developed. These will be agreed during the set up period of HORIZONS.

Data will also be collected from routinely collected health data and nested qualitative studies with sub-groups of participants in the HORIZONS Programme.

Key Horizons outcomes

By carefully capturing evidence prospectively and over the time about cancer survivors' life histories we will be in a position to understand what consequences are faced, when and what can be done to improve the lives of people living with and beyond cancer.

The Macmillan HORIZONS evidence will:

- Improve understanding of the consequences of different cancers and treatments, impact of co-morbidities, impact of recurrence and late effects, characteristics that lead to increased risk of poor recovery, ability to self-manage and what helps or hinders this
- Enable us to predict who is most likely to need support, what form this should take and when it should be available.
- Help to prepare future patients for likely consequences and how long these might last following treatment so that they know what to look out for and when to seek support and to support decision making where appropriate
- Support the transformation of care for people living with and beyond cancer. Better information, on short and long term outcomes and experiences across cancer types and treatments, will enable health professionals to provide more personalized care to their patients tailored to their needs and to support people to live as healthy and active a life as possible.
- Inform the development of risk stratification models, such as likely proportion of patients in different follow-up pathways across cancer/treatment type
- Identify areas for service innovation and other solutions to support cancer survivors to manage the consequences of cancer and its treatment across all aspects of their lives.
- Be an important vehicle for the development of further important clinical/research questions and development of theoretical models.