

HORIZONS: a new study to explore the short, medium and long term consequences of a cancer diagnosis and cancer treatment

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Background

- Advances in early detection and treatment have resulted in a growing number of cancer survivors worldwide[1] and many will face challenges following primary treatment that can impact all aspects of their daily life
- Improving our understanding of the consequences of cancer and its treatment will enable health professionals to better prepare future patients for the likely impact of a cancer diagnosis and to tailor care to patients' needs during recovery to support their self-management
- The Macmillan HORIZONS Programme, based at 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

The HORIZONS Programme aims to answer the following questions:

- What impact does cancer and its treatment have on people diagnosed with cancer in the short, medium and long term?
- What are the health outcomes, experiences and self-management activities over the life-course across different cancer types and what influences these?
- How do people connect with and mobilise resources which enable them to self-manage consequences of cancer and its treatment?

Research Themes

- The HORIZONS programme is underpinned by Foster and Fenlon's conceptual framework which has self-management of cancer / treatment consequences as a core component of recovery[2]
- HORIZONS is structured around two linked research themes (Fig 1):



Figure 1: Research Themes

Progress to date

As of the 6th March 2017:

- HORIZONS has opened in 9 sites with 11 hospitals recruiting (Fig 2)
- 215 eligible patients have been identified (Fig 3)
- 130 have given consent to complete questionnaires and for data from their patient records to be analysed (full consent)
- 108 baseline (pre-treatment) questionnaires have been completed and returned so far
- The first 3 month follow-up questionnaire was sent in December 2016, 36 have been returned so far

Conclusions

- Results from this large study will add to the body of knowledge about cancer survivors' outcomes and experiences, including those with less common cancers
- The data gathered has the potential to provide detailed evidence to inform and transform care for people living with and beyond cancer

Methods

- Prospective, longitudinal cohorts of adults (>16 years) treated for non-metastatic cancer
- 3,000 patients will be recruited from NHS treatment centres across the UK
- The study was piloted in late 2016 in 6 sites and will open in over 50 sites
- Recruitment is expected to continue until Spring 2019
- Nested qualitative studies are planned

Initial cohorts

- Breast cancer patients aged <50 years
- Non-Hodgkin Lymphoma (NHL) patients: Diffuse large B cell lymphoma subtype
- Gynaecological cancer patients: cervical, endometrial and ovarian

Data collection

- Participants will complete questionnaires before treatment begins (baseline), 3, 9, 12, 15, 24 months and annually
- Data will cover domains such as symptoms, quality of life, recovery, wellbeing, self-efficacy, self-management, social support, social networks and lifestyle factors
- The primary outcome measure is the Quality of Life in Adult Cancer Survivors (QLACS)[3]
- Clinical information from medical records will be collected via case report forms (CRFs)
- CRFs will be collected prospectively



Figure 2: Opened study sites

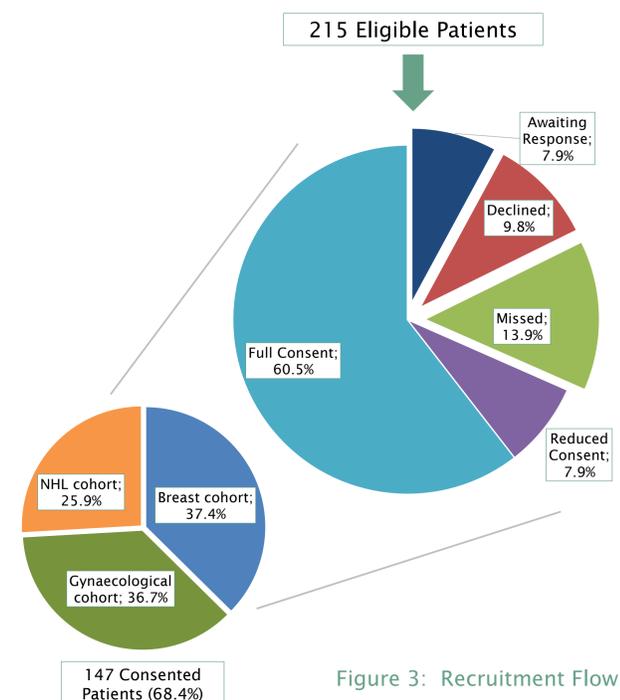


Figure 3: Recruitment Flow

References

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