

Cohort profiles at baseline in the Macmillan HORIZONS Programme

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Background

A growing number of people are experiencing cancer not as a life-limiting disease, but as a life-changing and long-term condition. This means services and care management will need to adapt to meet demand with greater emphasis on **self-management**. Evidence generated by assessing the impact of cancer and its treatment on people's everyday lives will help prepare both people **recovering from cancer** and health care professionals for what to expect. We will be better able to inform the design and delivery of cost effective interventions that support self-management, as well as service organization and delivery.

HORIZONS study design

A prospective, longitudinal cohort study exploring recovery of health and well-being of adults treated for non-metastatic cancer.

Questionnaires: socio-demographics, validated Patient Reported Outcome Measures (PROMs) and open-ended questions – self-reported by participants

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

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

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

HORIZONS cohorts

- ❖ **Breast cancer:** women diagnosed at age 50 or younger
- ❖ **Non-Hodgkins Lymphoma (NHL):** patients with Diffuse large B cell lymphoma
- ❖ **Gynaecological cancer:** Cervical, Endometrial, Ovarian, Vulval

These cohorts were selected because they have different treatment pathways, particular survivorship concerns (e.g. fertility) and are under-researched.

Map of sites

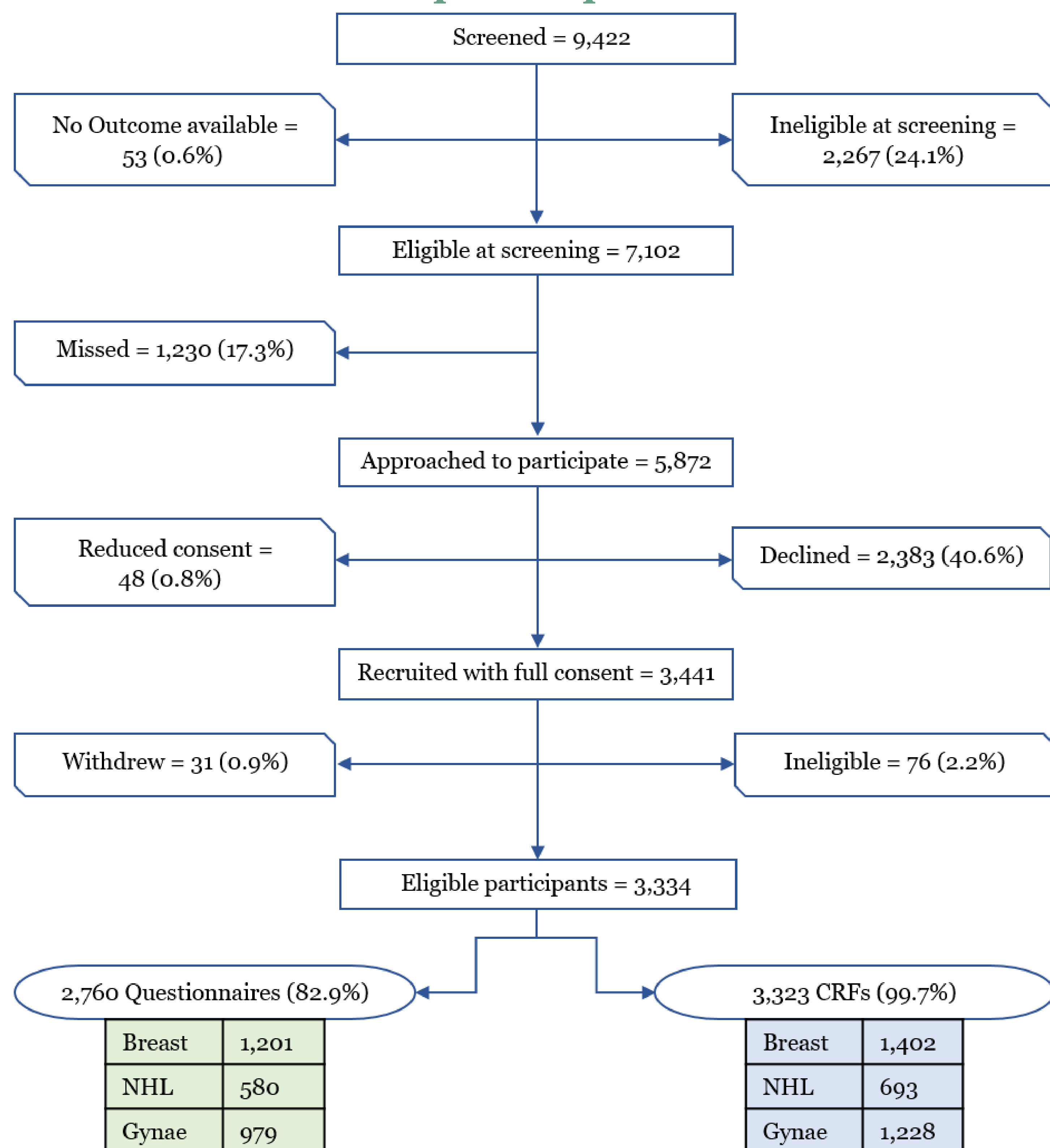


Recruitment

- ✓ The target sample size was 3,000.
- ✓ Sample size calculations were based on the primary outcome measure (Quality of Life in Adult Cancer Survivors).
- ✓ Recruitment from **110** NHS treatment centres across the UK between September 2016 and March 2019.
- ✓ All newly diagnosed patients due to have curative intent treatment were invited to participate; sites provided aggregate data on decliners.
- ✓ Pre-treatment (baseline) clinical and self-reported information was collected from the sites and full consenters.
- ✓ Planned follow-up: up to 5 years.

Full information on sample inclusion/exclusion criteria, conceptual framework and data collected in the Macmillan HORIZONS programme can be found in the published protocol Foster *et al* (2019) BMJ Open.

Recruitment & participation at baseline



Descriptive results at baseline

- ✓ The target sample size was met with 3,334 eligible participants recruited.
- ✓ Baseline data (questionnaire and/or CRF) were received for 3,330 patients.
- ✓ High response rates: almost 100% for CRFs and 83% for questionnaires.

Socio-demographic characteristics (Questionnaire-based)	Breast (N=1201)	NHL (N=580)	Gynae (N=979)
Mean age at diagnosis [range]	43 [24-50]	66 [23-94]	62 [22-90]
Male	n/a	329 (57%)	n/a
White British	1032 (86%)	522 (90%)	906 (93%)
Married/cohabiting	915 (76%)	416 (72%)	667 (68%)
Living alone	85 (7%)	108 (19%)	198 (20%)
Caring for children <18 years	705 (59%)	57 (10%)	119 (12%)
Own accommodation	867 (72%)	459 (79%)	751 (77%)
Above compulsory education	1004 (84%)	394 (68%)	644 (66%)
In full-time employment	576 (48%)	107 (18%)	201 (21%)

Clinical and health characteristics (CRF-based)	Breast (N=1402)	NHL (N=693)	Gynae (N=1228)
Any comorbidity	475 (34%)	447 (64%)	765 (62%)
ECOG 0-1 (no/little symptoms)	1346 (96%)	606 (87%)	1135 (93%)
Bulky disease	n/a	132 (19%)	n/a
Letter stage B	n/a	231 (33%)	n/a
Tumour grade 2	606 (43%)	n/a	276 (22%)
Tumour grade 3	584 (42%)	n/a	299 (24%)

Conclusion

The Macmillan HORIZONS Programme at the University of Southampton will provide robust and comprehensive data that the patient, clinical, and policy communities can use to transform care for people living with and beyond cancer.

Collaborate and use the data

We encourage collaboration and facilitate data sharing by researchers from all disciplines. Our Data Access Policy and application forms are available at: www.horizons-hub.org.uk/access_data.html

References

Foster C, Calman L, Richardson A. *et al* (2019) HORIZONS protocol: a UK prospective cohort study to explore recovery of health and well-being in adults diagnosed with cancer. *BMJ Open*. 9:e029662. doi: 10.1136/bmjopen-2019-029662

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