

HORIZONS: a prospective cohort study exploring the consequences of a cancer diagnosis and its treatment from before treatment begins. *Progress during the first 22 months of recruitment.*

Claire Foster^{1,2*}, Lynn Calman^{1,2}, Joshua Turner^{1,2}, Rebecca Foster^{1,2}, Amanda Cummings^{1,2}, Sophia Taylor^{1,2}, Carl May³, Alison Richardson^{2,4}, Anne Rogers², Peter. W. Smith⁵

¹ Macmillan Survivorship Research Group, Health Sciences, University of Southampton, ² Health Sciences, University of Southampton, ³ Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, ⁴ University Hospital Southampton NHS Foundation Trust, ⁵ Social Statistics and Demography, Social Sciences, University of Southampton.

*Contact: C.L.Foster@soton.ac.uk

Background

Understanding the impact of cancer and its treatment on everyday life is increasingly important as the number of people living with and beyond cancer rises^[1]. This knowledge can enable health professionals to better prepare future patients and tailor care to survivors' needs during recovery.

Aim

The HORIZONS programme aims to recruit people about to start primary cancer treatment and follow them over time to examine a range of clinical and psychosocial outcomes and experiences.

Methods

- A multi-centre, prospective cohort study of adults (≥ 16 years) with cancer treated with curative-intent.
- 3,000 patients will be recruited from over 70 NHS treatment centres across the UK.
- Participants complete questionnaires before treatment (baseline), then at 3, 12, 18, 24 months and annually. Questionnaires capture socio-demographic and economic characteristics and cover a range of assessments including quality of life (EORTC QLQ-C30, QLACS), health status (EQ-5D), psychological wellbeing (HADS), self-efficacy, social support (MOS-SSS), social networks and lifestyle.
- Clinical outcomes are collected prospectively through Case Report Forms (CRFs) at the start of treatment, 6 months and annually.
- Nested qualitative work is planned and will commence in 2019.

Results

- Between 9 September 2016 and 30 June 2018, 3,648 eligible patients were approached at 78 sites (109 hospitals). Of which 2,114 consented to participate: 827 breast, 859 gynaecological cancers and 428 NHL.
- From those who consented, 1,719 (81%) baseline questionnaires were returned and 2,039 (96%) CRFs were completed (Fig 1). We present data from 1,636 baseline questionnaires and associated CRFs.
- 83% of participants were recruited from hospital sites in England, 9% from Wales, 7% from Scotland, and 1% from Northern Ireland.

Clinical characteristics

- Overall, the distribution of stage at diagnosis for each cancer type closely aligns with national Cancer Research UK (CRUK) data^[2-7]. A high proportion of breast, cervical, vulval and endometrial cancer participants are diagnosed with stage 1 or 2, whilst more NHL participants are diagnosed with stage 3 or 4 disease but this may also reflect our inclusion criteria (Fig 2).
- ECOG Performance status describes a patient's level of functioning; status 0 (fully active) to 4 (completely disabled)^[9]. Over 90% of participants are categorised as status 0 or 1. Recruitment of patients classed as status 4 has been difficult possibly due to the requirements of completing a questionnaire and recruiting prior to treatment when patients may be too unwell to consent.

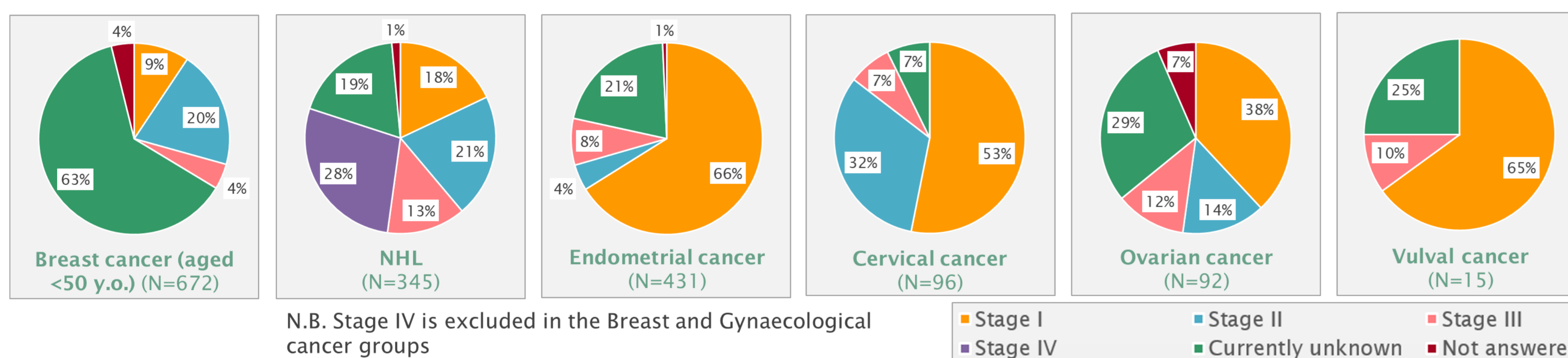


Figure 2. Stage at diagnosis by cancer type (collected at the start of treatment)

Demographic characteristics

- Overall, most age profiles closely match data reported by CRUK^[2,3,5] except vulval cancer participants are younger (*Median age* = 59) and cervical cancer participants are older (*Median age* = 45) when compared to national statistics^[4,7]
- The gender split in NHL is comparable to the national average^[2] with slightly more males (56%) recruited than females (44%).
- White ethnicity is the largest ethnic group recruited (96%) and whilst this is higher than the national average (87%)^[9] it may reflect incidence rates of the HORIZONS cancer types which are observed to be lower in Black and Asian ethnicities in the UK^[10]

Acknowledgements

The HORIZONS programme is funded by Macmillan Cancer Support. We would like to thank all HORIZONS participants, staff at our study sites, our HORIZONS Study Advisory Board, Tumour Specific Expert Panels, User Reference Group, and members of the Macmillan Survivorship Research Group.

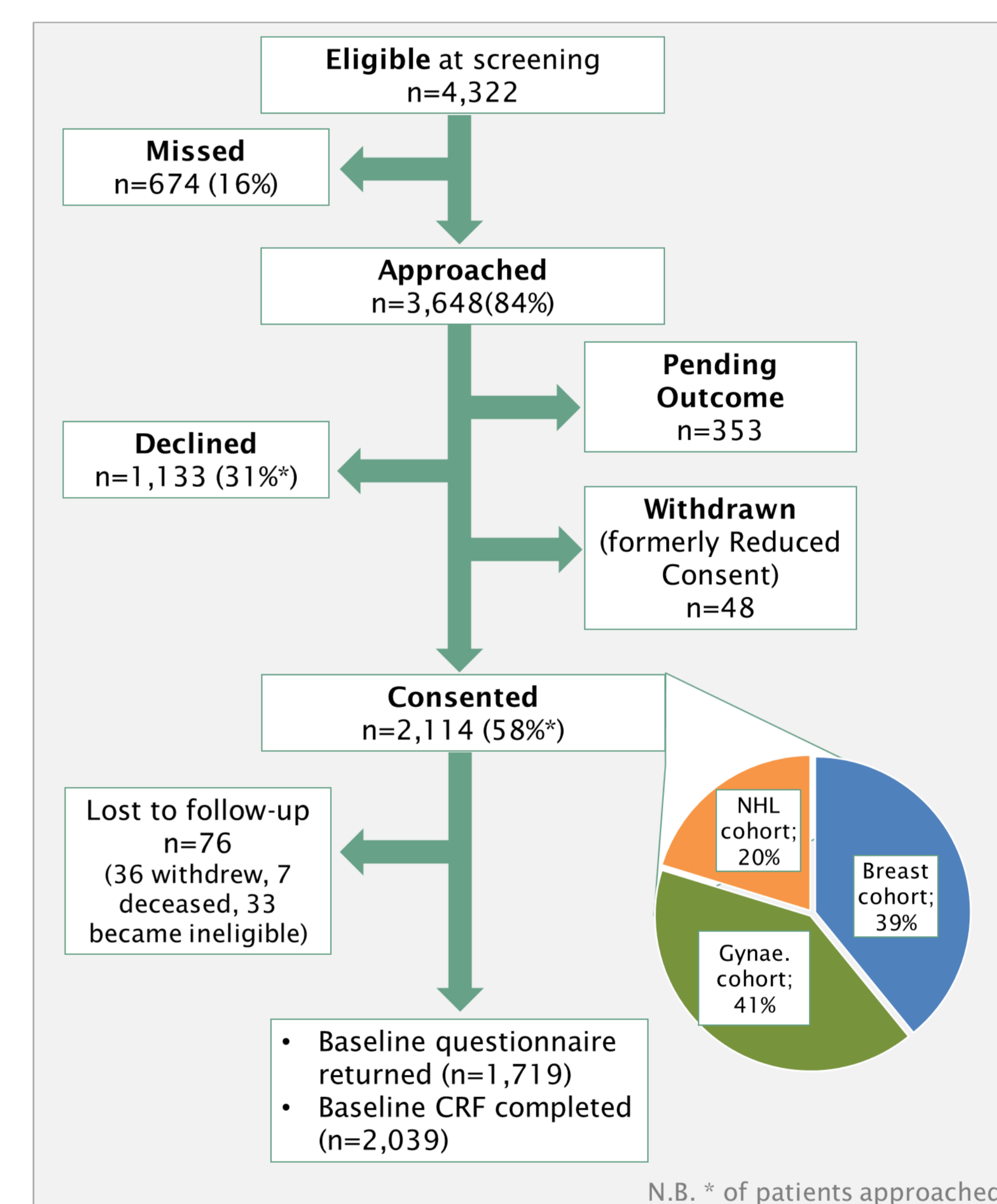
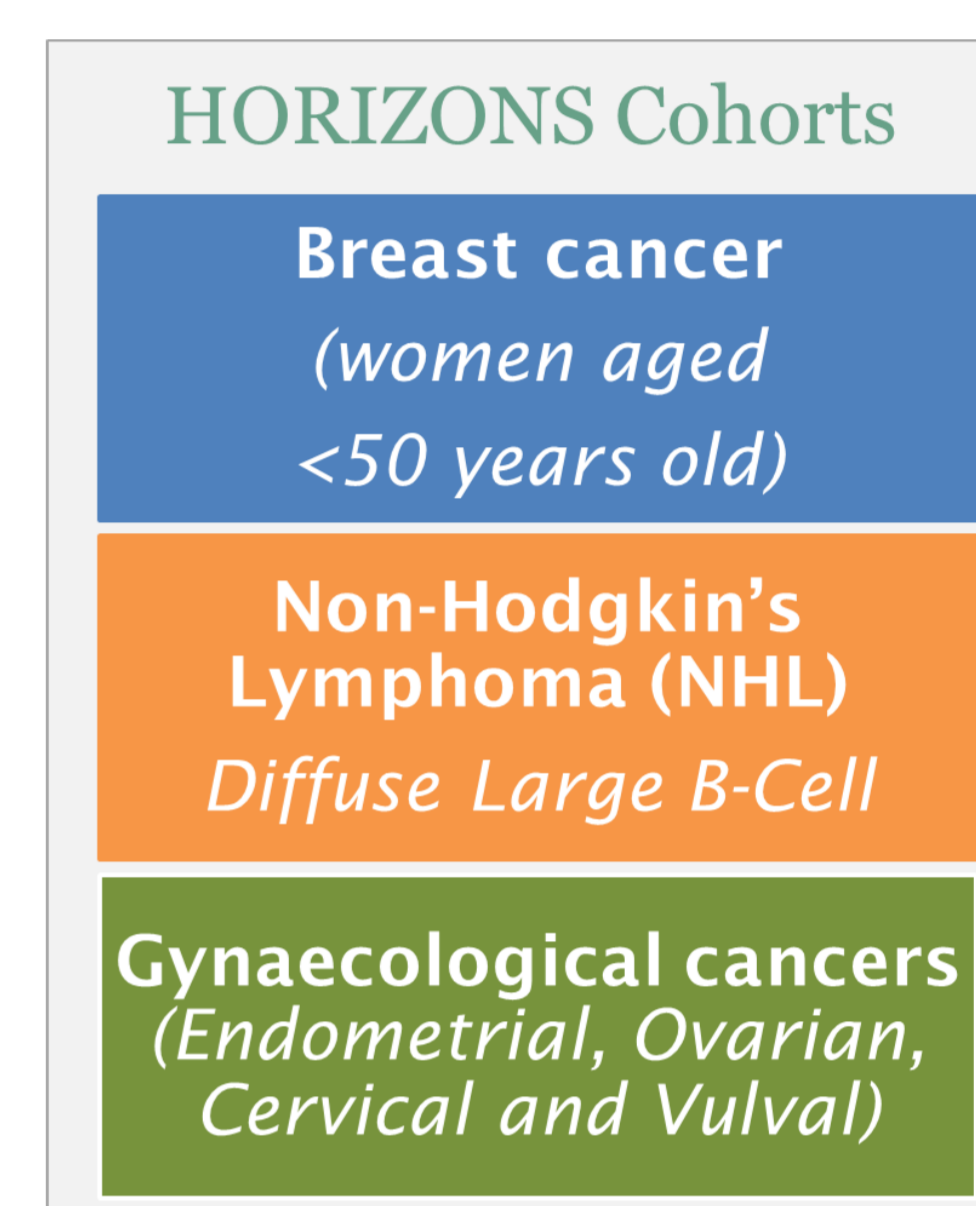


Figure 1. Recruitment flow diagram (up to Baseline timepoint)

Conclusions

- Recruitment to HORIZONS is ongoing and expected to continue until Spring 2019.
- Early findings indicate our sample hold characteristics broadly in line with national cancer and demographic statistics.
- Close monitoring of these data, along with expert advice, will be used to carefully develop our study processes to ensure a representative cohort of cancer survivors is established and can be followed over their life-course.

References

1. Mladimans, J., Uitley, M. and Muller, H. (2012). Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*, 107(7), 1195–1202.
2. Cancer Research UK (2018). Non-Hodgkin's Lymphoma statistics. Available Online [Date accessed: 01/10/2018]
3. Cancer Research UK (2018). Ovarian cancer statistics. Available from <https://www.cancerresearchuk.org> [Accessed: 01/10/2018]
4. Cancer Research UK (2018). Cervical cancer statistics. Available from <https://www.cancerresearchuk.org> [Accessed: 01/10/2018]
5. Cancer Research UK (2018). Uterine cancer statistics. Available from <https://www.cancerresearchuk.org> [Accessed: 01/10/2018]
6. Cancer Research UK (2018). Breast cancer statistics. Available from <https://www.cancerresearchuk.org> [Accessed: 01/10/2018]
7. Cancer Research UK (2018). Vulval cancer statistics. Available from <https://www.cancerresearchuk.org> [Accessed: 01/10/2018]
8. Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T. E., McFadden, E. T., & Carbone, P. P. (1982). Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*, 5(6), 649–656.
9. Office for National Statistics (2012). *Ethnicity and National Identity in England and Wales: 2011*. Office for National Statistics: Newport, UK.
10. National Cancer Intelligence Network (2009). *Cancer incidence and survival by major ethnic group, England, 2002–2006*. National Cancer Intelligence Network: London, UK

